

# BMJ Open 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 (PCC) 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 PCC.

**Methods** Design: scoping review. Data Sources: studies were identified through searching seven electronic databases and the grey literature. Search terms included quality improvement, quality indicators, healthcare quality and PCC. Eligibility Criteria: articles were included if they mentioned development and/or implementation of PC-QIs. Data Extraction and Synthesis: extracted data included study characteristics (country, year of publication and type of study/article), patients' inclusion in the development of indicators and type of patient populations and point of care if applicable (eg, in-patient, out-patient and primary care).

**Results** A total 184 full-text peer-reviewed articles were assessed for eligibility for inclusion; of these, 9 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 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.

## 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*.<sup>1</sup> PCC is an approach that has become central to policies and programming to improve healthcare efficiencies and address patient safety issues.<sup>2</sup>

## Strengths and limitation of this study

- Transparent and rigorous search strategy.
- Involvement of patient partner in the study.
- Study informed by a previously published protocol.
- Search strategy using only English terms.
- We did not assess the quality of the measures and/or indicators identified.

PCC is a model in which healthcare providers are encouraged to partner with patients and families to design and deliver individualised care. PCC models have been linked to positive patient experiences and improved outcomes, such as increased adherence to care and treatment.<sup>3–5</sup> In the literature, a PCC approach has been found to benefit patients and healthcare organisations in reducing costs, for instance through decreasing the length of hospital stays and readmission rates.<sup>6,7</sup> However, PCC is conceptualised differently among different stakeholders, impacting effective implementation in care settings.<sup>8</sup> 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.<sup>9</sup>

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.<sup>10</sup> 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).<sup>11</sup> While various quality indicators have been developed to measure healthcare safety, effectiveness and access,<sup>12</sup> 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 synthesise existing literature on quality indicators used in the evaluation of PCC. 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 PCC 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,<sup>13</sup> using methodology based on Arksey and O’Malley’s scoping review framework<sup>14</sup> and Levac *et al*’s methodological enhancement.<sup>15</sup> 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 PCC. For this scoping review, the AHRQ<sup>16</sup> definition of a quality indicator was adapted to incorporate a patient and family focus. Specifically, a PC-QI was defined as the unit of measurement of healthcare system, organisational or individual performance, that quantifies patients’ and families’ experiences with the care received and 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 PCC, search strategies were developed that combined terms from two concepts: PCC and PC-QIs (online supplementary 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 organisations 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.<sup>17</sup> 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 (eg, validation). The title and abstract of each citation identified was screened for eligibility independently by two reviewers (M-JS and 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 (online supplementary file 2). Extracted data included study characteristics (country, year of publication and type of study/article), patients’ inclusion in the development of indicators and type of patient populations and point of care if applicable (eg, in-patient, out-patient and primary care).

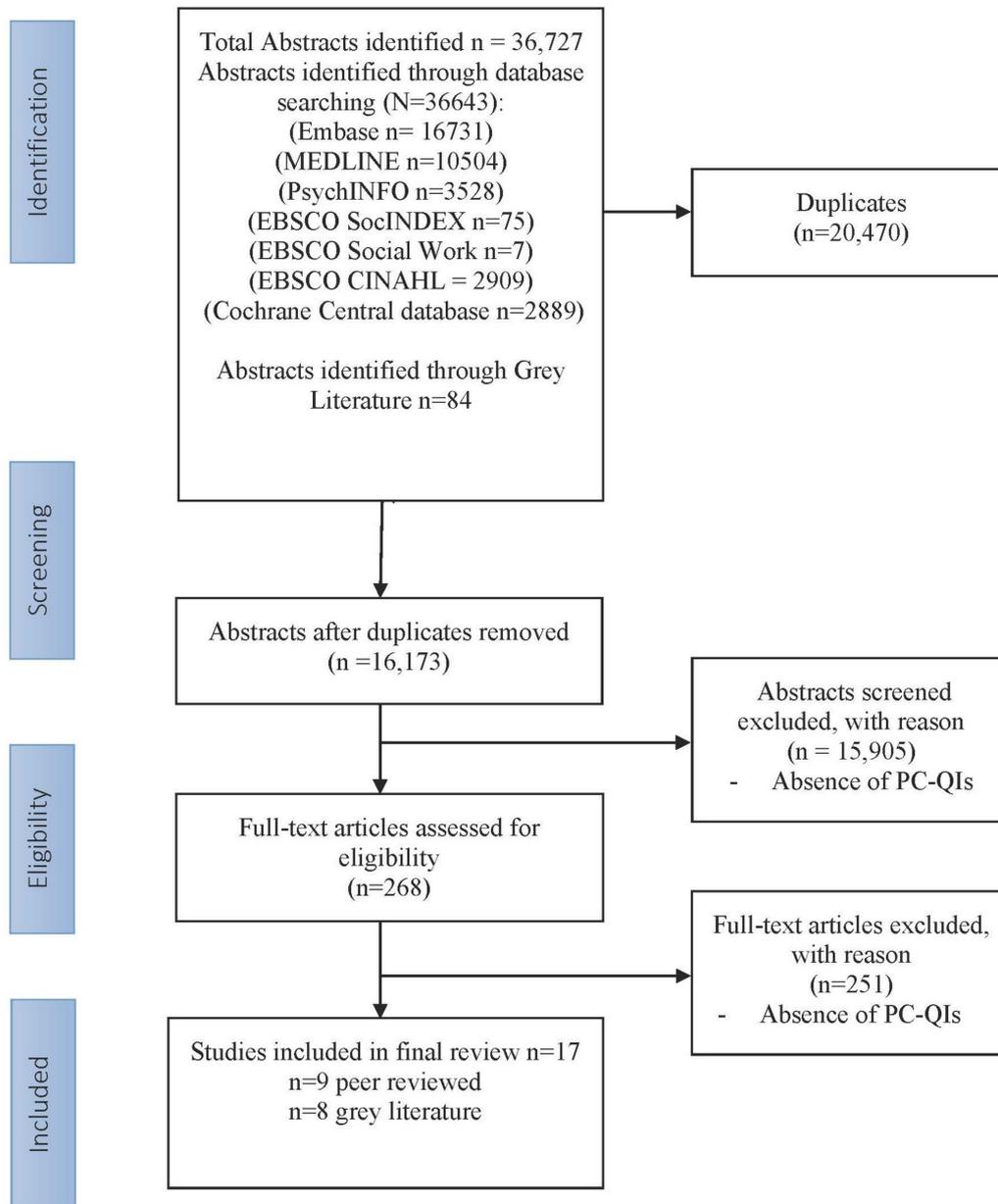
All extracted indicators were classified collaboratively by two authors (M-JS and SA) according to a person-centred care framework<sup>18</sup> developed by the team and guided by the Donabedian model of quality of care.<sup>19</sup> This framework provides a roadmap for healthcare systems to implement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

### Patient involvement

Levac *et al* recommend the involvement of stakeholders in the scoping review methodology.<sup>15</sup> 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.<sup>15</sup>

## RESULTS

A total of 36 643 citations were retrieved, and on 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, 9 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



**Figure 1** Flow diagram for study inclusion. PC-QIs, patient-centred quality indicators.

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), USA (n=2), Canada (n=3), UK (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 (eg, cancer, fertility care and home parenteral nutrition, HPN) 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

**Table 1** Characteristics of articles on patient-centred quality indicators

Study identifier (first author)	Country	Year	Study type	Population	Patients involved	Number of indicators and ways to measure PCC
Peer-reviewed literature (n=9)						
den Bresej <i>et al</i> <sup>42</sup>	The Netherlands	2013	Focus groups/interviews/consensus meetings	Fertility care	Yes	34
Dreesen <i>et al</i> <sup>29</sup>	Belgium	2014	Focus groups/interviews/consensus meetings	Home parenteral nutrition (HPN) patients	Yes	33
Ouwens <i>et al</i> <sup>30</sup>	The Netherlands	2010	Focus groups/interviews/consensus meetings	Cancer: non-small-cell lung carcinoma	Yes	54
Sewitch <i>et al</i> <sup>43</sup>	Canada	2013	Focus groups/interviews/consensus meetings; surveys	Colonoscopy patients-adult	Yes	20
Uphoff <i>et al</i> <sup>31</sup>	The Netherlands	2012	Focus groups/interviews/consensus meetings	Cancer	Yes	21
Wensing <i>et al</i> <sup>20</sup>	The Netherlands	1996	Focus groups/interviews/consensus meetings; surveys	Chronically ill patients (chronic obstructive pulmonary disease, diabetes, cardiovascular disease, migraine and chronic disease of locomotor system)	Yes	41
Zimmerman <i>et al</i> <sup>32</sup>	USA	2014	Focus groups/interviews/consensus meetings	Community-based, assisted living support patients	Yes	43
Cox and Gray <sup>44</sup>	UK	2014	Guest editorial	-	-	4
Carinci <i>et al</i> <sup>28</sup>	UK	2015	Modified Delphi approach/consensus meeting	-	-	12
Non-peer-reviewed literature (n=8)						
Lewis <sup>26</sup>	Canada	2009	Discussion paper	-	-	6
RNAO <sup>25</sup>	Canada	2002	Guidelines document/report	-	-	18
Silow-Carroll <i>et al</i> <sup>45</sup>	USA	2006	Report	-	-	6
Kelley and Hurst (OECD) <sup>24</sup>	-	2006	Working papers	-	Yes	7
OECD <sup>27</sup>	-	2006	OECD website	-	Yes	8
Essence of care – patient focused benchmarks for clinical governance (NHS) <sup>22</sup>	UK	2003	Report	-	Yes	116
Davies <i>et al</i> <sup>23</sup>	UK	2009	Report	-	-	10
IAPO <sup>21</sup>	-	2012	Literature review	-	-	69

IAPO, International Alliance of Patients' Organizations; NHS, National Health Service; OECD, Organization for Economic Co-operation and Development; PCC, patient-centred care; RNAO, Registered Nurses Association Ontario.

**Table 2** Examples of patient-centred care (PCC) measurement classified according to the person-centred care framework<sup>18</sup>

PCC measure classification	Domain	Example of ways to measure PCC
Structure (n=80)	Supporting a workforce committed to PCC.	<ul style="list-style-type: none"> <li>▶ The development needs of healthcare personnel are met by ongoing review through supervision, appraisal and individual development plans.<sup>22</sup></li> <li>▶ All staff and volunteers can articulate person-centred principles and practices applicable to their role(s) and demonstrate their implementation.<sup>32</sup></li> </ul>
	Providing a supportive and accommodating PCC environment.	<ul style="list-style-type: none"> <li>▶ Residents have a choice of a private room.<sup>32</sup></li> <li>▶ Patient satisfaction survey translated into Spanish.<sup>44</sup></li> </ul>
Process (n=343)	Cultivating communication.	<ul style="list-style-type: none"> <li>▶ (Regular) doctor involving patients in decisions about care or treatment.<sup>27</sup></li> <li>▶ Making use of open-ended questions in a conversation with the patient.<sup>31</sup></li> <li>▶ Patient had the knowledge and support to make decisions.<sup>30</sup></li> <li>▶ Regular doctor providing easy-to-understand explanations.<sup>28</sup></li> </ul>
	Respectful and compassionate care.	<ul style="list-style-type: none"> <li>▶ Patient received emotional support from nurses if needed.<sup>30</sup></li> <li>▶ Giving confidence to the patient.<sup>29</sup></li> <li>▶ Does the general practitioner pay attention to patients' needs?<sup>20</sup></li> </ul>
Outcome (n=79)	Patient-reported outcomes.	<ul style="list-style-type: none"> <li>▶ Measures are in place to assess and provide feedback on the interpersonal skills of healthcare personnel.<sup>22</sup></li> <li>▶ Regarding infertility treatment, patients would like to see all members of the infertility treatment team following the same policy.<sup>42</sup></li> </ul>

to patients' needs?<sup>20</sup> Actual indicators were presented as percentages and proportions, and identified from six grey literature sources.<sup>21–26</sup> 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'.<sup>25</sup>

Study populations included cancer patients (n=2), colonoscopy patients (n=1), HPN patients (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, 7 studies used focus groups, interviews and/or consensus meetings, 10 studies included patients and family caregivers in the development of PCC measures and 1 article developed measures through the authors' clinical and research work. Two sources developed ways to measure PCC from patient-reported experience surveys,<sup>24 27</sup> and two studies used a framework.<sup>25 28</sup>

Some studies grouped ways to measure PCC according to domains of PCC that were based on previously defined frameworks or through consensus (eg, access to care, communication and information). Domains identified from the person-centred care framework are categorised according to structure, process and outcome.<sup>18</sup> Here table 2 presents examples of measuring PCC classified according to the person-centred care framework,<sup>18</sup> and table 3 presents the actual indicators classified according to the same framework.<sup>18</sup>

#### How are PC-QIs 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).<sup>23 29–31</sup> Of those four sources where the definition of a PC-QI was clear, two included actual indicators.<sup>21 23</sup> The National Health Service report described indicators as 'items that patients, carers and professionals believed were important in achieving the benchmarks of best practice'.<sup>22</sup>

Have the existing PC-QIs been implemented and evaluated across various points-of-care settings, processes of care and at the system level to measure PCC?

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.<sup>28 30</sup> The study by Ouwens *et al* assessed guidelines for psychometric characteristics and only 26 out of 56 guidelines were found to be reliable.<sup>30</sup> The study by Carinci *et al* used a modified Delphi approach with expert Organization for Economic Co-operation and Development members to rate the PCC measures, using validity, reliability, relevance, actionability, international feasibility and international comparability as the criteria.<sup>28</sup> Uphoff *et al* recommended using the Gol and Grimshaw model for evaluating indicators,<sup>31</sup> while a future direction for Zimmerman *et al* was the evaluation of the indicators.<sup>32</sup> The working paper by Kelley and Hurst presented criteria that can be used to select indicators.<sup>24</sup> These included the importance of what is being measured (which includes

**Table 3** Identified PC-QIs from the literature classified according to the person-centred care framework as actual indicators<sup>18</sup>

Type of indicator	Domain	PCC indicators (n=25)
Structure	Creating a PCC culture	<ul style="list-style-type: none"> <li>▶ An induction programme is in place which promotes the philosophy of care.<sup>22</sup></li> <li>▶ % of PHC organisations who currently have processes to involve community input for planning the organisation's services (eg, advisory committees and focus groups).<sup>21</sup></li> <li>▶ Clear policies are in place on how services are offered to patients.<sup>21</sup></li> </ul>
	Supporting a workforce committed to PCC	<ul style="list-style-type: none"> <li>▶ Percent of nurses attending education sessions (orientation and organisation professional development opportunities) on client-centred care.<sup>25</sup></li> <li>▶ Percent of non-nursing staff attending education sessions (orientation and organisation professional development opportunities) on client-centred care.<sup>25</sup></li> </ul>
Process	Cultivating communication	<ul style="list-style-type: none"> <li>▶ Percent of patients with access to an online HER (a) by region and (b) by practice.<sup>26</sup></li> <li>▶ Proportion of service users who stated that the district nurse provided health advice or information about his/her condition.<sup>23</sup></li> <li>▶ Proportion of service users who stated that they were involved as much as they wanted to be in decisions about their care and treatment.<sup>23</sup></li> </ul>
	Respectful and compassionate care	<ul style="list-style-type: none"> <li>▶ Proportion of service users who stated that their district nurse treated them with respect and dignity.<sup>23</sup></li> <li>▶ Percent of inpatients who said they were always treated with respect and dignity while in hospital/primary care.<sup>21</sup></li> </ul>
	Engaging patients in managing their care	<ul style="list-style-type: none"> <li>▶ Percent of PHC clients/patients, 18 years and older, with a chronic condition(s), who actively participated in the development of a treatment plan with their PHC provider over the past 12 months.<sup>21</sup></li> <li>▶ Percent of hospital patients who said they had been sufficiently involved in decisions about their care as much as they wanted to be.<sup>21</sup></li> <li>▶ 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 healthcare team, discharge teaching guided by the client's goals for managing their care at home.<sup>25</sup></li> </ul>
	Integration of care	<ul style="list-style-type: none"> <li>▶ Percent of hospital patients taking medicines home after discharge who were told completely about the purposes of the medicine in a way they could understand.<sup>21</sup></li> </ul>
	Access to care	<ul style="list-style-type: none"> <li>▶ Percentage 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).<sup>26</sup></li> <li>▶ Percentage of out-patients seen within 13 weeks of GP referral.<sup>24</sup></li> <li>▶ Percentage of those on waiting list waiting 12 months or more.<sup>24</sup></li> <li>▶ Proportion of service users who were able to contact a district nurse when needed, including outside of normal working hours.<sup>23</sup></li> <li>▶ The percentage of patients who, in the appropriate national survey, indicate that they were able to obtain a consultation with a GP or appropriate healthcare professional within two working days (NHS Confederation, UK).<sup>21</sup></li> <li>▶ Percentage of PHC clients/patients, 18 years and older, 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.<sup>21</sup></li> </ul>

Continued

**Table 3** Continued

Type of indicator	Domain	PCC indicators (n=25)
Outcome	Patient-reported experiences	<ul style="list-style-type: none"> <li>▶ Proportion of service users who stated that the district nurse had all the necessary information about the service user and his/her health needs.<sup>23</sup></li> <li>▶ Proportion of service users who stated that the district nurse had all the equipment and dressings needed.<sup>23</sup></li> <li>▶ Proportion of service users who stated that the district nurse was knowledgeable and competent.<sup>23</sup></li> <li>▶ Proportion of service users who rated the district nurse service as very good or excellent.<sup>23</sup></li> <li>▶ Proportion of children whose parents routinely received all aspects of family-centred care (child and adolescent health measurement initiative).<sup>21</sup></li> </ul>

GP, general practitioner; HER, health electronic record; NHS, National Health Service; PCC, patient-centred care; PC-QIs, patient-centred quality indicators; PHC, primary healthcare.

policy importance), scientific soundness and feasibility of the measure.<sup>24</sup>

## DISCUSSION

This review specifically examined existing PC-QIs in the academic and grey literature. PCC has been increasingly adopted by many jurisdictions; however, this review revealed there to be gaps in the conceptualisation 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 AHRQ.<sup>16</sup>

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

**Table 4** Definition of quality indicator used by authors

Study identifier (first author, year)	Definition of quality indicator used
den Breejen <i>et al</i> (2013), <sup>42</sup> Sewitch <i>et al</i> (2013), <sup>43</sup> Uphoff <i>et al</i> (2012), <sup>31</sup> Zimmerman <i>et al</i> (2014), <sup>32</sup> Cox and Gray (2015), <sup>44</sup> Lewis (2009), <sup>26</sup> RNAO (2002), <sup>25</sup> Silow-Carroll <i>et al</i> (2006), <sup>45</sup> Kelley and Hurst (2006), <sup>24</sup> OECD website (2006) <sup>27</sup> and Carinci <i>et al</i> (2015) <sup>28</sup>	Definition not included.
Dreesen <i>et al</i> (2014) <sup>29</sup>	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. <sup>46</sup>
Ouwens <i>et al</i> (2010) <sup>30</sup> and Uphoff <i>et al</i> (2012) <sup>31</sup>	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’. <sup>47</sup>
Davies <i>et al</i> (2011) <sup>23</sup>	An explicit measurable statement of the quality of care given. Relates to a single outcome or process of medical care. Clearly defined and unambiguous. <sup>47 48</sup>
NHS (2003) <sup>22</sup>	Items that patients, caregivers and professionals believed were important in achieving the benchmarks of best practice. <sup>22</sup>
IAPO (2012) <sup>21</sup>	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. <sup>49</sup>

IAPO, International Alliance of Patients’ Organizations; NHS, National Health Service; OECD, Organization for Economic Cooperation and Development.

Institute of Medicine,<sup>1</sup> PCC continues to be operationalised and measured differently.<sup>33</sup> 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.<sup>34</sup> The absence of a standard definition of PC-QIs poses concerns for standardised measurement of PCC, and for implementation of PC-QIs in healthcare settings.

In compliance with quality improvement agencies, quality councils and organisations such as the AHRQ, quality indicators should be presented as a unit of measurement—as a percentage or proportion.<sup>16</sup> 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.<sup>35</sup> 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 does not 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 standardised 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.<sup>36</sup> 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 PCC.

Additionally, this review found large variances for domains to categorise approaches to measuring PCC. In an attempt to organise our findings and understand the ways of measuring PCC, we used a previously published person-centred care framework<sup>18</sup> 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 (eg, cultivating communication). These findings are consistent with the current measurement landscape, for instance trauma indicators,<sup>37</sup> and AHRQ PC-QIs<sup>38</sup> which mainly assess processes and outcomes. For PCC, structures, such as policies and education programmes can provide an important basis to improve PCC practice.<sup>18 39</sup> 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.<sup>18</sup> 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 Service) reveal a more generic approach to measurement (Family and Friend Test).<sup>40</sup> In order to create a standardised set of PC-QIs, indicators must be developed across the continuum of care. Santana and Stelfox also found a lack of implementation of indicators in care settings in their review.<sup>37</sup> 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 organisations, 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.<sup>41</sup> 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 PC-QIs provide directions for future research. First, there needs to be consensus on a standard definition of PC-QI to guide future measurement of PCC. 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. Finally, 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,<sup>13</sup> 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.<sup>41</sup>

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