



### **With our thanks**

This publication was produced under the overall management of Jeremiah Mwangi (Policy and External Affairs Director, IAPO), Jo Groves (CEO, IAPO) and Professor Jonathan Tritter (International Centre for Governance and Public Management, Warwick Business School) provided guidance in the development of the review.

IAPO would especially like to thank Yasemin Dil for her excellent research, writing and commitment to this project. The production of this review has been made possible thanks to an educational grant from Novo Nordisk.



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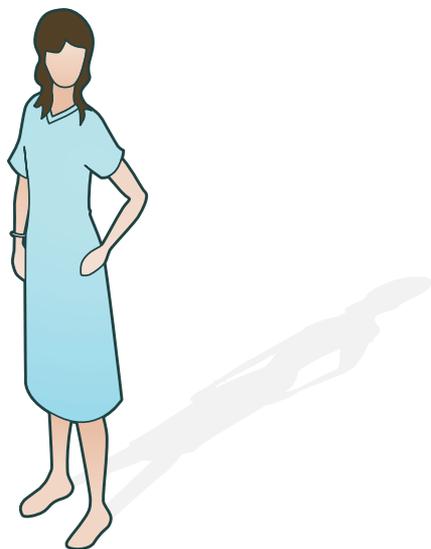
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In order for organizations to practice patient-centred healthcare they need to understand what it is, why it is important and how to do it. This understanding will lead to better health outcomes as healthcare is provided in a way that better meets the needs of patients.

Indicators of patient-centredness relevant to activities, organizations and countries can support the necessary development to promote patient-centred healthcare. The generation of evidence and examples of good practice can enable a shift in the culture, organization and delivery of healthcare to maximize patient benefit.

This review is part of a wider project being undertaken by the International Alliance of Patients' Organizations (IAPO) to develop a set of process and outcome indicators of patient-centredness that can be applied by relevant stakeholders to measure the extent and quality of their work towards operational patient-centredness. This project will help to provide a shared understanding and baseline for patient-centredness among stakeholders enabling them to benchmark their work, and improve their approach and accountability. In the long-term IAPO will encourage and support stakeholders to examine their work against these indicators.

To achieve patient-centred healthcare, the IAPO Declaration on Patient-Centred Healthcare (PCH)<sup>1</sup> states that healthcare must be based on the following five principles, and these are being used as the basis for evaluating current practice and developing new patient-centred indicators:

**1. Respect** – Patients and carers have a fundamental right to patient-centred healthcare that respects their unique needs, preferences and values, as well as their autonomy and independence.

**2. Choice and empowerment** – Patients have a right and responsibility to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. This requires a responsive health service which provides suitable choices in treatment and management options that fit in with patients' needs, and encouragement and support for patients and carers that direct and manage care to achieve the best possible quality of life. Patients' organizations must be empowered to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choices.

**3. Patient involvement in health policy** – Patients and patients' organizations deserve to share the responsibility of healthcare policy-making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to healthcare policy but include, for example, social policy that will ultimately impact on patients' lives.

**4. Access and support** – Patients must have access to the healthcare services warranted by their condition. This includes access to safe, quality and appropriate services, treatments, preventive care and health promotion activities. Provision should be made to ensure that *all* patients can access necessary services, regardless of their condition or socio-economic status. For patients to achieve the best possible quality of life, healthcare must support patients' emotional requirements, and consider non-health factors such as education, employment and family issues which impact on their approach to healthcare choices and management.

**5. Information** – Accurate, relevant and comprehensive information is essential to enable patients and carers to make informed decisions about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual's condition, language, age, understanding, abilities and culture.

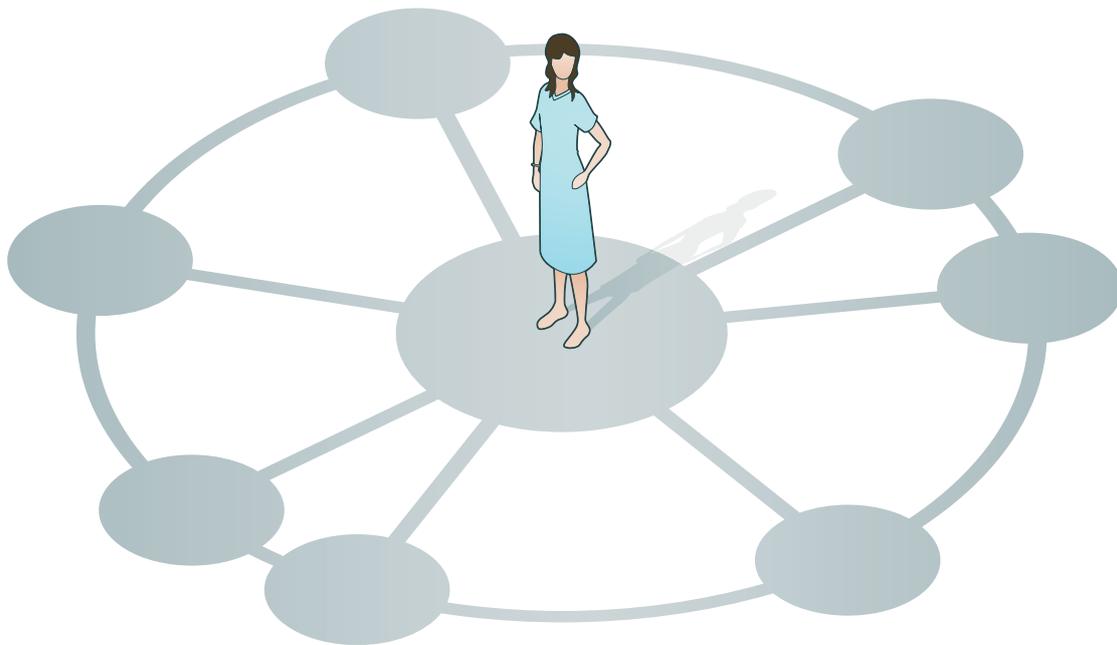
As part of the initial phase of the Patient-Centred Healthcare Indicators Project, this paper identifies and reviews current initiatives and indicators which aim to measure the patient-centredness of activities, organizations, countries and any other relevant stakeholders.

# Methods

Published scientific literature was identified by using searches of PubMed, Web of Science and Google Scholar. General internet searches were conducted to identify any country, government or organisational technical reports and documents, or assessment tools. A search of internet sites of organizations and associations who endorse patient-centred healthcare such as the Picker Institute, Planetree and Institute for Patient- and Family-Centred Medicine was also conducted.

A range of search terms were used which attempted to incorporate the many synonyms for patient-centred healthcare used across the world such as 'people-centred care' and 'patient-centred medicine', with the addition of terms such as 'indicators', 'measures', 'evaluation' and 'quality'. For the purpose of this review we use the term indicator as defined by Mainz (2003). Mainz broadly explains that indicators "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>2</sup>

To be included, all documents had to describe current or potential recommended measures and indicators of patient-centred healthcare. The term measure was defined very broadly as something which aims to ascertain the size, amount or quality of patient-centredness either as a certain aspect of healthcare or healthcare as a whole. Search terms were kept as broad as possible to identify all possible literature including both system level and disease specific measures and indicators. There was no date restriction for the documents. All literature was reviewed to determine applicability and, if included, the different elements of each were mapped. It must be acknowledged that this review only includes initiatives or indicators which directly attempt to measure patient-centredness. A large number of proxy indicators, which may include some of the aspects of patient-centred healthcare, could also have been identified. This, however, was not the aim of this paper.





A number of different types of measures and indicators were identified from the literature review. These included system level indicators, disease/condition specific indicators, self-assessment tools and patient experience measures.

## System level indicators

This section presents system level indicators for patient-centred healthcare starting with those that have developed quite specific indicators for either the whole system, or for hospital or primary care settings, to more general recommendations and suggestions for indicators.

## People-Centred Healthcare Initiative National Indicators Project, WHO Western Pacific Region, 2010<sup>3</sup>

In 2007 the World Health Organization (WHO) Western Pacific Region set out a policy framework for people-centred healthcare.<sup>4</sup> WHO define people-centred healthcare as “a balanced consideration of the values, needs, expectations, preferences, capacities, and health and well-being of all the constituents and stakeholders of the health care system”.<sup>5</sup> The people-centred approach encompasses the whole health system and appreciates that people become patients.

WHO identified four domains of people-centred healthcare for policy action; individuals, families and communities, health practitioners, health care organizations and health systems, and the policy framework called for an effective monitoring and evaluation system to be created. The first phase of the National Indicators Project sought to review current people-centred healthcare indicators used around the world, assess these indicators and develop a framework, and create a target set of indicators, through consultation with experts in the field. Indicators from the Commonwealth Fund, Picker Institute, National Committee for Quality Assurance and the Agency for Healthcare Research and Quality amongst others were identified for the four domains.

Phase II of the National Indicators Project aimed to re-define the people-centred healthcare framework to ensure that the set of indicators represented a clear set of indicators for a people-centred health system as a whole, and identify any additional or different sources of indicators. This included changing the scope of the first domain to individuals, patients and communities, and identifying policy measures for each of the domains:

- For *Individuals, Patients and Communities* six policy measures regarding health literacy, communication, self-management, voluntary sector involvement, social infrastructure for community participation and community leaders for advocacy were developed.
- For *Health Practitioners* there were two policy measures for holistic and compassionate care and commitment to safe and quality services.
- For *Health Care Organizations* seven policy measures for environment of care, coordination of care, multidisciplinary care teams, patient education and family involvement, standards and incentives for safe, quality and ethical services, models of care, leadership capacity were developed.
- For *Health Systems* nine policy measures with commitment to primary care, financing, evidence base for improving care, rational technology use, monitoring professional standards, public accountability measures, monitor patient and community concerns, ensure protection of patient information were developed.

Thus an expanded list of indicators was identified, although for some policy measures indicators are not currently available and suggestions are being sought from experts. These are under review by healthcare professionals and consultants to determine their applicability, validity, reliability and feasibility. Table 1 shows an example policy measure and indicator for each of the domains.

Table 1

Domain	Policy Measure	Indicator
Individuals, Families and Communities	Provide communication and negotiation skills that lead to meaningful participation in decision-making	Appropriate information is available to enable all consumers and carers where appropriate to choose to share in the decision-making about their care (Victorian Department of Health, Australia)
Health Practitioners	Enhance commitment to quality, safe and ethical services	Guidelines are present on how to identify needs for groups of patients (e.g. asthma patients, diabetes patients, surgery, rehabilitations) (International Network of Health Promoting Hospitals and Health Services)
Health Care Organizations	Strengthen the integration of patient-education, family involvement, self-management and counselling into health care	Proportion of children whose parents routinely received all aspects of family centred care (Child and Adolescent Health Measurement Initiative)
Health Systems	Put in place financial incentives that induce positive provider behaviour and improve access and financial risk protection for the whole population	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)

### Pan-Canadian Primary Health Care Indicators, by Canadian Institute for Health Information, 2006<sup>6</sup>

105 primary health care (PHC) indicators were developed by the Canadian Institute for Health Information. These were developed in order to produce reliable and comparable data to measure and improve primary health care across the country. These indicators were measured as a percentage and were grouped into eight domains, one of which is patient-centred primary health care and another focuses around providing whole-person care to ensure the emotional, physical and social aspects of healthcare are acknowledged. However, a large number of indicators in other domains were identified as indicators of patient-centred care, if evaluated against IAPO's five principles of patient-centred healthcare. The report describes indicators for access to primary health care, information, and patient involvement in both policy-making, and treatment and management. Some examples are shown in Table 2.

### Is the NHS Becoming More Patient-Centred? Trends from the national surveys of NHS patients in England 2002–2007 by Nick Richards and Angela Coulter from the Picker Institute, 2007<sup>7</sup>

This paper presents the results of 26 national patient experience surveys taken by nearly 1.5 million National Health Service (NHS) users created by the Picker Institute Europe. The Picker Institute which includes the Picker Institute Europe is a non-profit organization which is dedicated to creating and using evidence to promote patient-centred care.<sup>8</sup> The Picker Institute Europe undertakes surveys for a range of healthcare providers. They have developed a range of indicators to measure patients' actual experiences and what patients identify as key issues.<sup>9</sup> These indicators are based on the Picker Institute's eight domains of patient-centred healthcare. The eight domains are; fast access to reliable health advice, effective treatment delivered by trusted professionals, involvement in

Table 2

Indicator Label	Indicator Measure
Community input for PHC planning	% of PHC organizations who currently have processes to involve community input for planning the organization's services (e.g. advisory committees, focus groups)
Client/patient participation in PHC treatment planning	% 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
Time with PHC provider	% 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

In terms of IAPO's five principles of patient-centred healthcare, the largest proportion of indicators fell into the *access and support* category, and few were present in the *respect* category.

The indicators were developed using a number of strategies including: a review of national and international documents on PHC indicators and frameworks to produce preliminary indicators, consensus conferences to review the preliminary indicators which included policy-makers, providers, researchers and system managers, working groups to define the indicators and develop technical specifications, and a three-round Delphi process in order to establish the importance of the indicators.

decisions and respect for preferences, clear, comprehensible information and support for self-care, attention to physical and environmental needs, emotional support, empathy and respect, involvement of, and support for, family and carers, and continuity of care and smooth transitions.<sup>10</sup>

The Picker Institute Europe has been working in collaboration with the NHS for some time, providing and co-ordinating surveys for the national NHS programme, individual hospital trusts and other organizations. The report included indicators for access to healthcare, respect for the patient, information and patient involvement in decision-making amongst others at both primary care and hospital levels as shown in Table 3.

Table 3

Domain	Indicator	
	Primary Care	Hospital
Emotional support, empathy and respect	% of primary care patients who said that the doctor always treated them with respect and dignity	% of inpatients who said they were always treated with respect and dignity while in hospital
Clear, comprehensible information and support for self-care	% of primary care patients prescribed new medicines by a GP or nurse practitioner who felt they had been given enough information about its purpose	% of hospital patients taking medicines home after discharge who were told completely about the purposes of the medicine in a way they could understand
Involvement in decisions and respect for preferences	% of primary care patients prescribed new medicines who said they had 'definitely' been involved as much as they wanted to be in decisions about which medicines would be best for them	% of hospital patients who said they had been sufficiently involved in decisions about their care as much as they wanted to be

In terms of IAPO's five principles, the largest number of indicators fall into the information category, with a relatively equal spread of indicators across the respect, choice and empowerment, and access and support categories. However, there were no indicators for patient involvement in health policy, apart from a more general indicator regarding whether patients were asked to give their views on the quality of care they received whilst in hospital.

### The NHS Indicators for Quality Improvement by the NHS Information Centre, 2009<sup>11</sup>

The NHS Indicators for Quality Improvement were developed to provide insight into and improve the delivery of care throughout the NHS. They deliberately cover a wide range of healthcare aspects in order to help local clinical teams select the most relevant and appropriate indicators for local quality improvement and allow them to benchmark and measure quality. These include acute care, children's health, end of life care, learning disabilities, long-term conditions, maternity and newborn, mental health, planned care, staying healthy, and other. Within each of these healthcare aspects, there are indicators for safety, effectiveness and experience. The indicators relevant to patient-centred healthcare come under the patient experience section under the other and planned healthcare aspects. The indicators are almost identical to those used by Picker in the example above. These include:

- Score for patients who overall felt they were treated with respect and dignity while in hospital.
- Score for patients who reported that staff explained the purpose of the medicines they were to take at home in a way they could understand.
- Score for patients who reported they were involved as much as they wanted to be in decisions about their care and treatment.

These indicators were developed through input from clinicians and NHS professionals through the NHS Information Centre's Clinical Quality Indicators Survey.<sup>12</sup>

### Person-Centred Care Index DRAFT by International College for Person-Centred Medicine and WHO, Department of Health System Governance and Service Delivery, 2012<sup>13</sup>

The Person-Centred Index (PCI) (DRAFT) contains 34 indicators of person-centred care, and is being developed jointly by the International College for Person-Centred Medicine (ICPCM) and WHO in order to measure and assess person-centred care in health systems. The indicators are rated on a scale of level of presence in any given health system, from not present to very present. These are split into eight domains that they have identified to be key to person-centred care. An example for an indicator in each of the domains is presented in Table 4.

The ICPCM is a non-profit research and advocacy organization working towards re-assessing medicine and healthcare in order to achieve person-centred care. On the ICPCM website they explain that person-centred care medicine is "dedicated to the promotion of health as a state of physical, mental, social and spiritual wellbeing as well as to the reduction of disease, and founded on mutual respect for the dignity and responsibility of each individual person".<sup>14</sup> The indicators were developed through a literature review, identification and delineation of key concepts of development of health systems in becoming person-centred, a consultation group which included key informants from different specialities, and patients and families to identify key person-centred factors and their importance. This project is still ongoing and the indicators are to be further reviewed.

### North West London Strategic Health Authority Patients' Parliament, Patient Centred Standards for Access to Primary Health Care Services DRAFT by Health Link, England 2005<sup>15</sup>

This is a short set of standards and indicators developed in order for general practitioners (GP) (family doctors) to understand what is important to their patients, with the aim that GP practices provide patient-centred services. An example of an indicator for each of the standards/domains is presented in Table 5.

Table 4

Domain	Indicator
Ethical Framework	Attending to the patient's personal values, choices and needs
Cultural Sensitivity	Attending to the patient's language needs and preferences
Holistic Approach	Utilizing a bio-psycho-socio-cultural-spiritual framework
Relational Focus	Cultivating trust during clinical communication and the care process
Organization and Implementation of Person-centred Care	Conducting a diagnosis that takes account of the whole person
People-centred Organization of Services	People's participation in the planning of health services
Person-centred Education, Training and Research	The health system promotes person-centred health professional training

Table 5

Domain/Standard	Indicator
Access	Clear policies are in place on how services are offered to patients
Flexibility	Patients are able to obtain their prescription by any reasonable means
Competent and courteous staff	Reception staff are fully trained and are welcoming, courteous and efficient in all their dealings with patients
Equitable services	Patients with special needs associated with their disability or illness are given care and support if necessary in co-operation with other agencies to cover their needs over a 24-hour, 7-day week period when required, in consultation with the patient and the carer
Patient feedback	Regular surveys of patient experiences are conducted
Confidentiality	Patient health and contact details are kept confidential at all times
Clean environment	GP practices should be clean, welcoming, comfortably furnished and adequately heated and ventilated

**Potential Indicators of patient-centred care for the Ministry of Health, Saskatchewan, Canada by Steven Lewis, Health Policy Consultant, 2009<sup>16</sup>**

This is a discussion paper by Steven Lewis which provides some broad, illustrative potential patient-centred care indicators. These indicators span across the entire healthcare system and aim to assess both the patients and health service providers. They can be split into four domains which are shown in Table 6, with a suggested example indicator for each.

Table 6

Domain	Indicator
Access	Time to third next available appointment to see a primary care provider
Periodic patient surveys	Patient experiences and perceptions of responsiveness to desire to self-manage and otherwise be a partner in care
Periodic provider surveys	Provider surveys to measure mechanisms by which they obtain patient feedback
Survey/audits of boards of healthcare providers	Surveys or audits of boards to track perceived barriers to higher patient-centred care performance
Reviews of health education organizations	Surveys or audits to assess how patient-centred care is incorporated into the formal curriculum

The author explains that periodic patient surveys are essential in measuring patient experiences of, for example, respectfulness and clarity of communication, respect and empathy, encouragement in ownership of own health and in self-management, and convenience of services, amongst others. Additionally, the paper suggests that surveys of healthcare providers must be carried out regularly in order to assess provider attitudes towards engaging patients as partners in their own health, how they organize their teams, encourage and promote patient-centred care and how they obtain patient feedback.

**The Healthcare Quality Strategy for NHS Scotland, 2010<sup>17</sup>**

On the basis of a series of commitments made to improve the health and quality of health of all those in Scotland,<sup>18</sup> the Scottish Government have created three quality ambitions which are based upon peoples own wants and needs, and the Institute of Medicine’s six dimensions of healthcare quality,<sup>19</sup> one of which is person-centred care. The Institute

of Medicine is a non-profit, non-governmental American organization that provides information and advice regarding health and healthcare to the public and decision-makers.

The quality ambitions were translated into a Quality Measurement Framework which described 12 Potential National Quality Outcome Measures: healthcare experience, staff experience, staff attendance, healthcare associated infections, emergency admissions, adverse effects, hospital standardised mortality rate, proportion of people who

live beyond 75 years, patient reported outcomes, patient experience of access, self-assessed general health, and percentage of last 12 months of life spent in a preferred place of care. A number of these measures are related to patient-centred healthcare and reflect an understanding of the importance of patients’ views and experiences in patient-centredness. Specific indicators, however, have not yet been developed.

**Disease/condition specific indicators**

A number of disease/condition specific papers were identified where authors sought to develop, in most cases, valid and reliable patient-centred indicators for that specific condition. Only studies that developed indicators or quality measures specifically for patient-centred healthcare were included. Those that developed general quality indicators were excluded.

### Development of Generic Quality Indicators for Patient-Centered Cancer Care by Using a RAND Modified Delphi Method (Uphoff *et al*, 2012 from the Netherlands)<sup>20</sup>

In this study 17 indicators were developed which were grouped into five domains. The five domains are shown in Table 7, with an example of an indicator for each of the domains.

Similar to the study by Uphoff *et al* (2001), detailed above, indicators were developed through the identification of evidence-based guidelines and recommendations for management of patients with all types of cancer.<sup>20</sup> These recommendations were rated by patients with head and neck cancer and seven patient representatives during interviews, and then translated into 56 indicators. The indicators were

Table 7

Domain	Indicator
Communication	If no curative options are available, the health care provider should emphasize that the patient will receive optimal palliative care and that the health care provider will not leave the patient to his/her fate
Physical support	The health care provider should make an inventory of complaints and problems that hinder the patient, search for causes, educate the patient on this subject, and start medical or nonmedical treatment with use of relevant medical disciplines
Psychosocial care	The health care provider should gather information on the psychosocial and emotional health status of the patient on important moments in the process of care and adequately refer to specialists, depending on the diagnosed problems
After-care	The health care provider should inform the patient on the most important complaints that can occur after primary treatment has finished and that can be a sign of progression of the disease
Organization of patient-centred care	One health care provider should be installed as coordinator of care, to guarantee continuity of care for the patient

These indicators were developed through an initial identification of 92 key evidence-based recommendations from guidelines for patient-centred cancer care identified through a literature review of national and international, and medical organization guidelines. This was followed by rating and prioritization of the recommendations by a multidisciplinary panel of patient representatives and medical professionals, and a consensus meeting to finalise the set of indicators.

tested on 132 cancer patients across six hospitals in the form of a questionnaire with a four-point scale to determine their psychometric characteristics; room for quality improvement, applicability, and discriminating capacity and reliability. Twenty-six indicators had good psychometric properties.

### Development of indicators for patient-centred cancer care (Ouwens *et al*, 2010 from the Netherlands)<sup>21</sup>

The authors of this paper developed 56 indicators of patient-centred cancer care which were grouped into eight domains of patient-centred healthcare. Table 8 shows the eight domains, with an example of an indicator for each.

### Measuring patient-centredness, the neglected outcome in fertility care: a random multicentre validation study (Nelen *et al*, 2010 from the Netherlands)<sup>22</sup>

In this paper a patient-centredness questionnaire-infertility (PCQ-infertility) of 46 items was developed with the aim to measure patient-centredness in fertility care, and discriminate between the patient-centredness of different fertility clinics. The items were grouped into the Picker Institute's eight domains of patient-centred care and indicator examples are shown in Table 9.

Table 8

Domain	Indicator
Access	Patient starts his/her treatment within 35 days after his first visit to the specialist
Follow-up	Patient knows which side effects to be aware of at home
Communication and respect	Specialist shows interest in the patient as a person
After-care	The health care provider should inform the patient on the most important complaints that can occur after primary treatment has finished and that can be a sign of progression of the disease
Patient and family involvement	Family and friends have opportunities to ask the specialists questions
Information	Patient receives written information on all applicable items
Coordination of:	
— Specialists	Patient knows how to reach the specialists
— Oncology nurses	An oncology nurse was present during the bad news consultation
Physical support	Patient gets support to control physical complaints such as pain, suffocation, nausea, blood coughs, tingling, weight loss and insomnia
Emotional support	Specialist asks the patient about possible fear and mental state

Table 9

Domain	Indicator
Accessibility	Accessibility of the team for questions (by email or phone)
Information	Sound instructions on how to inject hormones
Communication	Specialist shows interest in the patient as a person
Patient involvement	Honesty and clarity on what to expect of the fertility services
Respect for patient's values	Physician had empathy with your emotions and actual situation
Continuity and transition	One caregiver as central point for problems or questions
Competence	Staff used difficult words without explaining them
Care organization	Waiting time between first visit and receiving treatment plan

The authors conducted focus groups with 24 couples and six additional women to understand patient-centredness within the infertility context and to produce questionnaire items that were moderated using the Picker Institute's eight domains of patient-centred care.<sup>9</sup> A total of 729 relevant quotes were extracted from the transcripts and grouped into 81 care aspects. Of these, 53 most common aspects were chosen for the pilot version of the questionnaire. The questionnaire was piloted in 30 fertility clinics across the Netherlands and consisted of 127 items to test for psychometric properties, namely appropriateness of item, internal consistency, construct validity, quality for improvement, discriminative power. 46 items had good psychometric properties.

### Self-assessment tools

A range of self-assessment tools for hospital and healthcare providers were identified during the literature review. These included tools by organizations that promote patient-centred healthcare and tools for accreditation. Together these suggest a potential set of indicators which could be used to identify the essential structures and systems that need to be in place for a provider to deliver patient-centred healthcare. Unless stated in the text the process of development of these tools is unknown.

### Self-assessment tool for organizations by Planetree and Picker Institute (2008)<sup>24</sup>

This tool was developed by Planetree and the Picker Institute in order to help health provider organizations assess their patient-centredness and prioritize improvement. It is part of the Patient-Centred Care Improvement Guide.<sup>25</sup> Planetree is a non-profit organization founded in 1978 by a patient that promotes and encourages patient-centred healthcare through coaching and consultation services, partnering with healthcare providers and quality evaluation and research.<sup>26</sup>

The tool is divided into 11 sections and an example indicator for each section is provided in Table 10.

### Tools by the Institute for Patient- and Family-Centred Care

The Institute for Patient- and Family-Centred Care (IPFCC) is a non-profit organization founded in 1992 which aims to provide direction in advancing the understanding and practice of patient- and family-centred care through education, consultation and technical assistance, development of materials and information and partnership with different stakeholders.<sup>27</sup> The IPFCC has developed a large number of tools including *Advancing the practice of patient- and family-centred care in hospitals: How to*

Table 10

Domain/Section	Indicators
Setting the stage, strengthening the foundation	The organization's commitment to patient-centred care is formally and consistently communicated with patients, families, staff, leadership and medical staff
Communicating with patients and families	Patients are made aware of how to raise a concern related to patient safety and/or their care while they are hospitalized
Personalization of care	Patients are able to make requests for when meals will be served to accommodate their personal schedule and routine
Continuity of care	Tools are provided to patients to help them manage their medications, medical appointments and other healthcare needs
Access to information	Patients and families have access to a consumer health library.
Family involvement	'Family' is defined by the patient
Spirituality	Space is available for both quiet contemplation and communal worship
Environment of care	Hospital spaces create a first impression of 'welcome', 'comfort' and 'healing'
Integrative medicine	Complementary and integrative therapies are available based on patient interest and community utilization patterns
Caring for the community	Space is made available within the facility for community groups to meet
Care for the caregiver	Staff's stress-reduction and well needs are addressed



get started,<sup>28</sup> which offers an initial assessment of patient-centredness of hospitals. This tool looks at issues such as organizational culture and philosophy of care, patient participation in advisory roles, patterns of care, access to information, education and training programmes, research and human resource policies.

In 2004 IPFCC and the American Hospital Association developed the *Strategies for Leadership, Patient- and Family-Centred Care, A Hospital Self-Assessment Inventory*.<sup>29</sup> This tool was distributed to the chief executive officer of every US hospital and describes indicators divided into ten sections. Evidence to support the indicators is assessed on a sliding scale of 1–5, with 1 being low and 5 being high. Examples of indicators for each section are shown in Table 11.

**Table 11**

Domain/Section	Indicator
Leadership	Leaders of the organization, through words and actions, consistently convey that the patient's and family's experience of care matters, that it is important to quality, safety and the best outcomes
Mission and definition of quality	The organization has defined how patient care will be provided and what is expected relative to the experience of care
Patients and families as advisors	There is a paid position(s) for a patient or family leader to facilitate the development of patient- and family-centred initiatives
Patterns of care	Families can remain with the patient during nurse change of shift, in accordance with patient preference
Information/education for patients and families	Written information is provided in primary languages of patients and families served by the hospital
Charting and documentation	Patients, and families in accordance with patient preference, have easy access to the medical record/chart
Patient and family support	Employee/medical staff ask patients to identify family members or other support people who will participate in care
Quality improvement	Patients and families are involved in quality improvement initiatives
Personnel	There are rewards and recognition for patient- and family-centred practice
Environment and design	There is a comfortable sleep space for a family member in the patient's room

The Institute for Healthcare Improvement and the National Initiative of Children's Healthcare Quality developed a Patient- and Family-Centred Care Organizational Self-Assessment Tool, in partnership with IPFCC.<sup>30</sup> This is another tool for hospitals and its content is almost identical to *A Hospital Self-Assessment Inventory* described above.

### The Council on Quality and Leadership key factors and success indicators in person-centred supports<sup>31</sup>

The Council on Quality and Leadership (CQL) is an American organization founded in 1969 which is involved in defining, measuring and improving the quality of life for people with mental illness, disabilities and older people, and improving person-centred care. They have a CQL accreditation programme which promotes and helps to improve patient-centredness of organizations.<sup>32</sup> CQL developed eight key factors and 34 success indicators aimed to be quality of life indicators for people with disabilities, mental illness and older adults. These are intended for organizations to use as part of their internal quality improvement agendas. Table 12 gives an example of an indicator for each key factor.

The indicators were developed based on commissioned research and content reports by external experts, an international Delphi survey, advisory groups, focus groups with key stakeholders and pilot tests in the United States and Canada.

**Table 12**

Domain/key factor	Indicator
Patient-centred assessment and discovery	People have the authority to plan and pursue their own vision
Person-centred planning	Planning is responsive to changing priorities, opportunities and needs
Supports and services	Supports are available in an emergency or a crisis
Community connection	Community membership facilitates personal opportunities, resources and relationships
Workforce	Personnel have the flexibility and autonomy to support people
Governance	People and practices play meaningful leadership roles
Quality and accountability	Participants, families and advocates evaluate supports and providers
Emerging practices in individual budgets	People control their budget allocations

### National Committee for Quality Assurance Patient-Centred Medical Home Program 2011<sup>33</sup>

The National Committee for Quality Assurance (NCQA) is an American non-profit organization which is devoted to improving the quality of healthcare founded in 1990. NCQA works with different stakeholders in the healthcare arena including patients to determine what is important, how it should be measured and how to do this.<sup>34</sup> The NCQA has developed a set of six standards for organizations to improve their primary care and patient-centredness. The six standards are: enhance access/continuity; identify/manage patient populations; plan/manage care; provide self-care support/community resources; track/coordinate care; and measure/improve performance.

Applying the standards scheme permits primary care organizations to be recognised as patient-centred medical homes through a three level scoring scale, with each level having six essential components. Strange *et al*, (2010)<sup>35</sup> explain that for many practices meeting these standards will most likely happen in stages.

The standards were developed through extensive research, input from a multi-stakeholder advisory committee including representatives of consumer organizations, the results of an open public comment period and in-depth interviews with NCQA recognized practices.

### Patient-centred care organizational status checklist by Dr Karen Luxford (2010)<sup>36</sup>

This checklist is located in a discussion paper Patient-Centred Care: Improving Quality and Safety by Focusing Care on Patients and Consumers published by the Australian Commission on Safety and Quality in Health Care.<sup>36</sup> The paper contains an extensive literature review discussing definitions of patient-centred care and international approaches and initiatives and concludes by making a number of policy and organizational level recommendations for health service executives and managers in order to achieve and measure patient-centred care. The checklist includes questions regarding the collection and use of patient experience data, governance, organizational commitment to patient-centred care and committees and plans for patient involvement, for example:

- Is there a 'dashboard' of performance metrics monitored by the organization which includes patient experience indicators?
- Have staff training activities included communication skill training or patient-centred values?

- Are patients and families considered 'partners' in care?
- Is the culture of the organization supportive to change? Open to learning?

### Patient experience surveys

An area where patient-centred indicators are being used is in the construction of patient experience surveys. An integral part of good patient-centred healthcare is about understanding the views and perspectives of patients in the management of their health and healthcare. These patient experience surveys are used to explore and identify patient views and opinions regarding their health and healthcare. They are utilized by governments, and private healthcare providers and organizations. In Table 13 a range of examples of patient experience surveys and tools are presented.

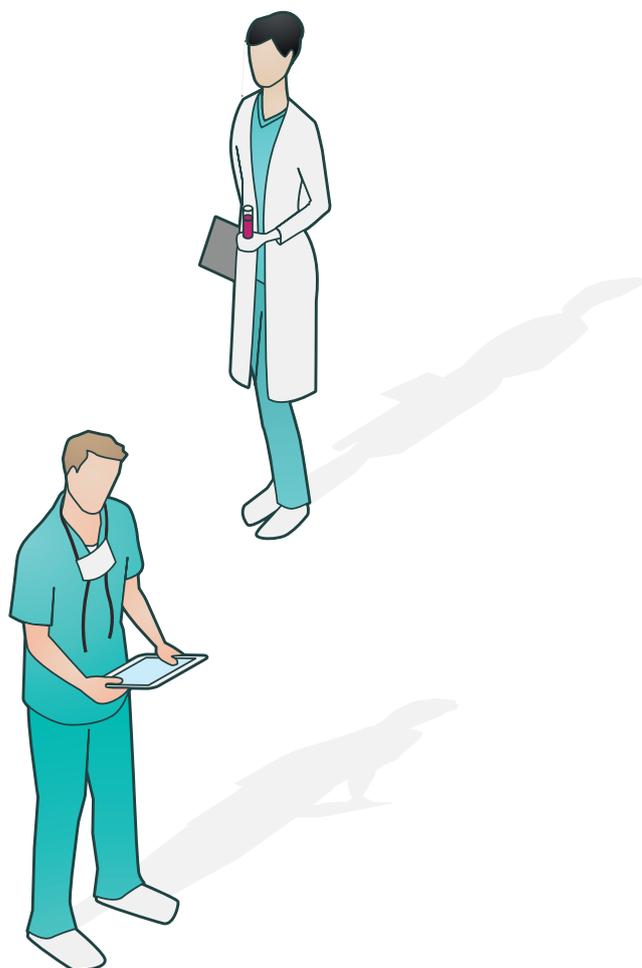


Table 13

Survey/Tool	Created by	What it is and how it is used
<b>General</b>		
Consumer Assessment of Healthcare Providers and Systems (CAHPS) 1990 and Hospital-based Consumer Assessment of Healthcare Providers and Systems (H-CAHPS)	US Department of Health, Agency for Healthcare Research and Quality (AHRQ), 1990s	<p>Standardised family of surveys to evaluate the way care is provided from the consumer/patient perspectives which try to focus on what is important for the patient/consumer, and what the consumer/patient can best assess such as communication or access to care. There are surveys for both ambulatory and institutional settings.</p> <p>The CAHPS Health Plan Survey for ambulatory settings is widely used by insurance companies across the US, including commercial, Medicaid, State Children's health Insurance programme and Medicare plans. The H-CAHPS pays attention to the experiences of adult inpatients in hospitals. The AHRQ reports that hospitals across the US are using this survey and voluntarily reported the data to Medicaid and Medicare.</p> <p>The surveys are updated regularly, with the aim to improve and create new surveys for different populations and settings by the CAHPS Consortium, a group of public and private research organizations.<sup>37-38</sup></p>
Primary Care Assessment Tools (PCAT)	Johns Hopkins School of Public Health	A set of tools consisting of consumer/patient surveys for adults and children, facility surveys and provider surveys in order to assess the quality of primary care services. To do this, however, primary care services were translated into a theoretical framework of assessable concepts: first contact care, person-focused care over time, comprehensive and coordinated care, and community orientation, family-centredness and cultural competence. The surveys provide information on whether the structures and processes of primary care are in place. <sup>39</sup>
Patient Activation Measure (PAM)	J Hibbard <i>et al</i> , 2004 University of Oregon	<p>Designed in order to measure the knowledge, skills and confidence of patients, in order that they may manage their own health and healthcare. There are four levels of patient activation; the first is patients as passive recipients of care, the second is the building of knowledge and confidence, the third is taking action when individuals feel they are acquiring new knowledge and skills and the fourth is maintaining behaviours where patient has adopted new behaviours and feels more confident and in charge of their own health and healthcare.</p> <p>This measure was developed with consultation with patients and experts and has been tested for validity and reliability. The authors explain that patient activation could be used as an indicator for quality assessment.<sup>40</sup></p>
Measure of Processes of Care (MPOC)	King <i>et al</i> , 1995 CanChild Centre for Childhood Disability Research, McMaster University, Ontario, Canada	<p>Developed to measure parents of children with chronic conditions perceptions of the care they receive from children's rehabilitation treatment centres and how much it is family-centred. The MPOC has been translated into Arabic, Danish, French, Hebrew, Japanese, Latvian, Portuguese, Spanish and Chinese.<sup>41-42</sup></p> <p>There is also the MPOC for Service Providers (MPOC-SP) developed in 1998 which is a self-assessment tool for paediatric service providers to assess their family-centredness. This has been translated into Arabic, Danish, Hebrew, Portuguese and Japanese.<sup>43</sup></p>
Patient Assessment of Chronic Illness Care (PACIC)	MacColl Centre for Health Care Innovation, 2004	PACIC was developed to evaluate the quality of care for chronic illness from the patient perspective. <sup>44</sup> This validated survey aims to assess for the care that patients with chronic illnesses matches the Chronic Care Model. The Chronic Care Model identifies the community, health system, self-management support, delivery system design, decision support clinical information systems, and patient-centred care as essential for good chronic illness care. <sup>45</sup>
Patient Experience Measuring Survey Tool	NHS Scotland, Patient Experience Programme	Patient experience surveys for inpatient care, primary care and care for those with long-term conditions. Results of the surveys are used to improve healthcare services and planning throughout Scotland. <sup>46</sup>
<b>Disease/condition specific</b>		
Diabetes Patient Experience Survey Tool	NHS Diabetes and NHS Information Centre, 2008-2009	Developed by the Picker Institute Europe to assess patient involvement in their own diabetes care, the extent to which NHS staff are encouraging and empowering them to manage their own condition. Different survey response methods were assessed including postal and electronic methods and were tested in a range of NHS Trusts. Postal surveys were found to be the most effective method for collecting data. <sup>47</sup>
QUOTE questionnaires	Netherlands Institute for Health Services Research (NIVEL), 1990s	<p>QUOTE (Quality of Care Through the Patients Eyes) questionnaires are a set of questionnaires to identify patients' experiences of the healthcare they receive and used to evaluate or improve quality of care. There are currently questionnaires for HIV, asthma, cancer, rheumatoid disease and physical limitations.</p> <p>These were developed on the basis of what is important to patients through focus groups and individual interviews with patients.<sup>48</sup></p>
Measure of Activity Limitations (MAL) for rheumatoid arthritis	Goodacre <i>et al</i> , 2007	This patient-centred questionnaire was developed in order to understand patients' experiences of activity limitation in rheumatoid arthritis. This questionnaire addresses the impact of symptoms of rheumatoid arthritis on patient activity, global function and task performance. <sup>49</sup>
Dementia Care Mapping (DCM)	Bradford Dementia Group, University of Bradford	<p>Developed as a clinical tool to assess quality of care from the perspective of those with dementia, and based on patient-centred care. This tool involves systematic observation and scoring of the wellbeing.</p> <p>DCM is used in hospitals, care homes and day care settings. It is being used internationally, with people from 24 countries being trained in the DCM method.<sup>50</sup></p>

### Other stakeholders involved in healthcare

This review identified a number of stakeholders in healthcare delivery such as health professional associations and the healthcare industry e.g. pharmaceutical, health insurance and medical device companies, which have shown some internally driven efforts towards patient-centredness. These stakeholders have a significant impact on healthcare systems, and there have been a number of calls for more of a patient-centred approach from them. An article by Ellen Hoenig Carlson in 2009 describes five key factors for pharmaceutical companies to become more patient-centred. These are:<sup>51</sup>

1. Put the patient at the centre of every decision right from the beginning of commercialization.
2. Translate clinical benefits to real-world health gains.
3. Drive a more collaborative relationship between doctor and patient versus simply focusing on patient behaviours and outcomes.
4. Improve patient and carer experience through the treatment pathway, along all touches.
5. Take nothing for granted (all small details can be meaningful to patients and their families).

Although there is little academic or published literature regarding how these other stakeholders are measuring and evaluating their patient-centred approach, some companies such as UCB, who aspire to be a “patient-centric global biopharmaceutical leader”,<sup>52</sup> are making efforts to become more patient-centred.

Patient View, an independent research organization, conducted a survey of 500 patient groups regarding

patients’ views and opinions of the pharmaceutical industry.<sup>53</sup> This survey used six indicators in order to rate company performance:

1. Whether the company have an effective patient-centred strategy.
2. The quality of the information that the company provides to patients.
3. The company’s record on patient safety.
4. The usefulness to patients of the company’s products.
5. The company’s record on transparency with external stakeholders.
6. Whether the company acts with integrity.

There is also some evidence that insurance companies are attempting to adopt a more patient-centred vision. As mentioned in the previous section, the H-CAPHS survey is being used by Medicaid and Medicare in the US to assess patient views.

Furthermore, The American Academy of Family Physicians (AAFP) has developed a set of guidelines; Principles for the Development and Management of Patient-Centred Formularies to be used by physicians and health providers, and the health insurance plans with which they work, to ensure patients’ best interests.<sup>54</sup> These guidelines state that formularies should be developed collaboratively by physicians, pharmacists and patients, and that they should be fiscally responsible and evidence-based.





This literature review identifies current efforts to measure the patient-centredness of healthcare providers, organizations, and national health systems. The key point of reference was the five principles of IAPO's Declaration on Patient-Centred Healthcare. We found a number of health system level indicators, some disease/condition specific indicators, a number of organizational self-assessment tools and a range of patient-experience surveys incorporating aspects of patient-centredness.

Few well-defined and coherent system level or governmental indicators were identified in the literature review. Within those that were identified there was an uneven spread of indicators across the five principles in IAPO's Declaration on Patient-Centred Healthcare with the emphasis on indicators of access and support and information, with fewer indicators relating to patient choice, empowerment and respect. Indicators for patient involvement in planning and policy-making was only identified in the Pan-Canadian Primary Healthcare Indicators and the DRAFT Person-Centred Care Index by the International College for Person-Centred Medicine and WHO.<sup>6, 13</sup>

Of the actual system level indicators that were identified, most were focused upon either hospital care and/or primary care, as opposed to the health system as a whole. However, WHO WPRO People-Centred Healthcare Initiative National Indicators Project is currently in the process of developing indicators to measure the people-centredness of an entire health system as opposed to specific parts of it.<sup>3</sup> They are generating specific indicators for four levels of healthcare: individuals, patients and communities, health practitioners, health care organizations and health systems, allowing people-centredness to be measured coherently across the entire health system. The DRAFT Person-Centred Index by International College for Person-Centred Medicine and WHO is also developing indicators to assess the person-centredness of a health system, although they have not described specific indicators for different levels of the health system. Furthermore, Steven Lewis' discussion paper for the Saskatchewan Ministry of Health provides examples of broad indicators for patient-centred healthcare across an entire health system including patients and service providers. His approach also includes suggestions on evaluating how organizations and boards create and assess policies regarding patient-centred care.<sup>16</sup>

Overall, the evidence from the majority of indicators identified in this literature review failed to demonstrate any involvement of patients in their development. IAPO

would assert that patient involvement in the development of measures of patient-centredness should be fundamental. The exception was the disease/condition specific measures where the indicators for patient-centred healthcare tended to be generated through the use of established guidelines and recommendations, interviews and focus groups with patients and patient representatives as well as experts and health professionals.

Contrasting the views of health professionals and patients provides an opportunity to develop indicators that incorporate different forms of evidence. For example Uphoff *et al*, 2012 reported a disagreement between patients and the project's expert panel on indicators in the communication domain. Discussion between the two groups ultimately led to the development of two new indicators for good communication and informed consent.<sup>20</sup> There is evidence that including patients in the development of indicators leads to the identification of issues that may not have been considered previously.<sup>20-21, 55</sup>

For some of the self-assessment tools it could not be ascertained how they were developed, however the Picker Institute do develop their surveys through patient involvement. It is also important to note that patient preferences and issues will vary in different contexts. Development of indicators and self-assessment tools should involve patients familiar with the setting where the indicators will be utilised.

There are vast amounts of resources available to promote and improve the patient-centredness of healthcare providers. Although self-assessment tools for organizations, hospitals and governments are an important starting point in ascertaining patient-centredness, most of these emphasize improving these bodies, rather than assessing the degree of patient-centredness. Nevertheless, such an approach that emphasizes ticking boxes rather than promoting debate and reflection may miss the essence of being patient-centred. Furthermore, the linking of particular forms of patient-centred measurement to accreditation programmes, such as NCQA Patient-Centred Medical Home Program and Council for Quality and Leadership<sup>32-33</sup> may lead to confusion for patients as they emphasize different aspects of patient-centredness and frame the evaluation from the perspective of health service providers rather than patients.

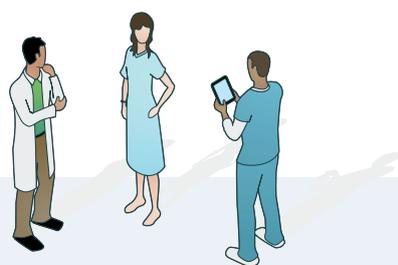
The notion of ticking boxes to achieve patient-centredness is perhaps reflected in the sheer number of patient experience surveys available around the world. There seems

to be a significant emphasis on the collection of patient views and opinions; acknowledging patient views are an essential element of a patient-centred approach but do not in themselves constitute a patient-centred system. For many health service providers and organizations, gathering information on patients' views and opinions of their healthcare is used as a substitute to deliver patient-centred services.

The uneven spread of indicators seen in the results of this literature review is in part a consequence of the lack of clarity regarding the definition of patient-centred healthcare; what it is and how to practice it. For instance, the WHO National Indicators Project is focused on person-centred healthcare which, although similar to patient-

centred healthcare, differs in certain ways. Such approaches are also compromised by a lack of patient involvement in the development of indicators, and the prominence of self-assessment tools and patient experience surveys perhaps signifies that patient-centred healthcare is not being seen as a change to the very foundations of healthcare provision. Although many countries such as England, Canada and the US have announced their commitment to patient-centred healthcare, without a clear and coherent vision of what it is and how to measure it, it is unlikely that there will be significant progress. Patient-centred healthcare should be an integral element of the philosophy of organizations, governments and healthcare providers and is a key part of a cultural shift in the prioritization, organization and delivery of healthcare.

## The way forward



This literature review highlights the need for a coherent and robust set of indicators to measure patient-centredness across whole health systems as well as healthcare provider organizations. One approach to achieve this is to measure patient-centredness from a different angle. Patients' needs can be framed and broken down by looking at the 'patient journey', as described in IAPO's Background Paper for the Policy Statement on Patient Information.<sup>51</sup>

The 'patient journey' is comprised of all the different points of healthcare contact relating to an individual patient, from the moment they suspect something might be wrong with their health, to the point where a condition or disease is treated or managed on an ongoing basis. The 'patient journey' can provide a framework for understanding and measuring patient-centred healthcare and developing indicators as it allows the focus of measurement to be narrowed to different stages along the journey, while still ensuring that patient-centredness as a whole can be assessed.

Many of the indicators presented in this paper use a general domain such as access and support, within which there are a number of different indicators for different points in the delivery of healthcare to a patient. A clearer picture of patient-centredness would be possible however

if these different domains, and indicators were measured individually at each stage of a 'patient journey'.

We need to move away from only attempting to quantify patient-centredness which, in itself, does not truly demonstrate the quality of the interaction of a patient with a healthcare provider or health system. The indicators and self-assessment tools currently available may still be important in identifying the necessary prerequisites, or minimum requirements for patient-centredness, which could be the first stage in a three-tiered approach to achieving patient-centred healthcare.

The latter stages of becoming patient-centred could potentially use evidence-based qualitative indicators such as patient narratives or testimonials, whereby certain testimonials and narratives could be used as exemplars, providing a deeper insight into patient needs, perspectives and interactions with healthcare providers and the health system. Additionally, although there are initiatives that have developed indicators to assess patient-centredness, these are not currently being evaluated. Thus, further research needs to be carried out in the development of both optimal indicators for patient-centredness and a systematic way to evaluate them.

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