



International Alliance of
Patients' Organizations

A global voice for patients

Patient-Centred Healthcare Indicators Review

Consultation report





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Introduction

In March 2012 the International Alliance of Patients' Organizations (IAPO) launched its Patient-Centred Healthcare Indicators Review at the IAPO 5th Global Patients Congress.* Following its launch, the review was opened for consultation to all IAPO members and stakeholders involved in delivering healthcare.

IAPO received a total of 42 responses from a wide range of patients' organizations and stakeholders involved in healthcare from across the world (see Figures 1 and 2 for a breakdown of respondents by type and region). These responses provided detailed comments on the report and are an essential part of the development of patient-centred healthcare indicators. This report will provide a brief summary of the responses to the review, highlighting common issues, gaps in the review, suggestions and any additional resources identified by respondents. This report accompanies an updated version of the Patient-Centred Healthcare Indicators Review which includes additional resources suggested by the consultation respondents. Although a large number of resources were suggested, only those matching the initial criteria used for the review are included in the updated version. Please see Table 1 for suggested resources.

Key gaps and issues

When considering the Patient-Centred Healthcare Indicators Review, IAPO encouraged respondents to think about whether there were any gaps, if any crucial initiatives had been missed and what the key issues with the review were.

Language

One of the gaps mentioned by a number of patients' organizations from different world regions was that only English language initiatives or indicators to measure patient-centredness were included. It was pointed out that by excluding indicators in other languages, important initiatives and information regarding different healthcare environments was being lost, and thus the analysis of the current situation limited. IAPO is aware that it is extremely important to extend the review to other countries across the world, however, due to time, language and capacity constraints, was only able to include English language studies and initiatives.

A global set of indicators

A frequently mentioned reflection by patients' organizations, industry representatives, academics and other stakeholders was whether creating one global set of indicators for patient-centred healthcare is realistic and achievable. The most commonly cited reason for this concern was that, despite efforts to define patient-centred healthcare globally such as IAPO's five principles,¹ an internationally accepted definition does not exist.

Furthermore, due to large economic, political and cultural differences across the world, the way in which patient-centred healthcare is defined and implemented will vary greatly from country to country. Even health systems in developed countries differ greatly in their structure and services.

"I guess for me comes the logical questions of whether or not it is practical or realistic to come up with one set of patient-centred healthcare indicators that could possibly reflect all areas of health care and globally or internationally – can we have only one set of patient-centred healthcare indicators that would be comprehensive and applicable globally or internationally?"

Patients' organization representative, Canada

"With any set of indicators there will need to be some flexibility to provide for differences between healthcare systems, both in terms of their structure and also the sophistication of policy and patient engagement that may already exist."

Pharmaceutical industry representative, International

* Read more about IAPO's 5th Global Patients Congress at: www.patientsorganizations.org/congress

“More research needs to be done on what constitutes patient-centred healthcare, a uniform definition could assist health systems in low and middle income countries to make a meaningful contribution towards motivating the health systems to recognize and take patient centred healthcare models seriously.”

Patients’ organization representative, South Africa

Global disparities

Respondents also pointed out that the majority of indicators to measure patient-centred healthcare included in the review came from developed countries. These indicators would not necessarily be applicable to low and middle income countries, where the priorities, structure and capabilities of the health system will be very different.

“The reality of patient-centred healthcare in the Kingdom of Swaziland is so far removed from the literature review that it makes it extremely difficult for me to even comment at all.”

Patients’ organization representative, Swaziland

The variability between low, middle income, and developed countries also presents problems in terms of data collection for the indicators and analysis. Any data that is collected would have to be quite broad which may present problems when actually trying to implement changes. Furthermore, as mentioned by one patients’ organization, in order to be comparable across countries, the data that is collected

would have to be weighted during analysis which can often be a lengthy and difficult process.

The continuum of care

Healthcare systems often provide care at different levels and one patients’ organization representative from Canada explained that:

“There must also be consideration for the different types of healthcare across the continuum from primary health care, acute, chronic, long-term and palliative care. Indicators would likely be different for each type of setting or care delivery, as measured by patients, care providers, administrators/decision makers, and analysts.”

Thus, it is important to consider how to develop indicators which represent different healthcare settings and levels of care provision, while still providing an accurate measurement of patient-centred healthcare within the health system as a whole.

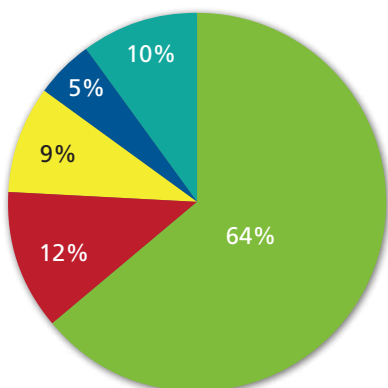
Suggested resources

Table 1 shows additional resources and initiatives suggested by respondents which are relevant to the Patient-Centred Healthcare Indicators Review. As mentioned previously, not all these resources will be applicable for inclusion in the review. The resources highlighted in the table in italics are included in the updated version of the review.

Table 1: Suggested additional resources

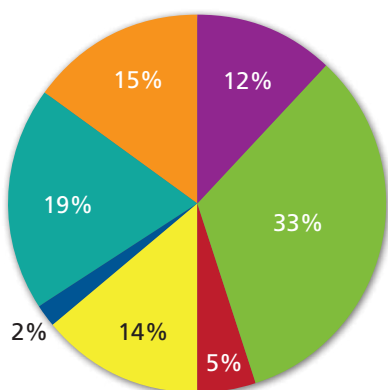
Resource	Created by	What it is
International Charter of Rights and Responsibilities for people with Diabetes	International Diabetes Federation	Charter which sets out the fundamental rights of people with diabetes, split into three domains; the right to care, the right to education and information, the right to social justice, and responsibilities. ²
<i>Community Pharmacy Patient Questionnaire</i>	<i>Royal Pharmaceutical Society, UK</i>	<i>An obligatory annual patient questionnaire allowing patients to express their opinions and provide feedback.³</i>
<i>Euro Health Consumer Index</i>	<i>Health Consumer Powerhouse, 2012</i>	<i>A user-focused, performance related assessment of 34 national healthcare systems. Measured by 42 indicators in five groups; patient rights and information, accessibility, outcomes, preventions, range and reach of services, and pharmaceuticals.⁴</i>
Human Rights Indicators	United Nations Office of the High Commissioner for Human Rights	A set of structural, process and outcome indicators in order for states to promote and monitor the implementation of human rights. ⁵
Law on Patients’ Rights, Obligations and Responsibilities	The Croatian Association for Promotion of Patients’ Rights, 2002	Law which aims to ensure respect of human dignity, physical and psychological integrity, personality and the right to self-determination for all patients within the Croatian health system. ⁶
<i>National Safety and Quality Health Service Standards</i>	<i>Australian Commission of Safety and Quality in Healthcare, 2011</i>	<i>A set of ten standards intended to provide reliable and uniform measures of safety and quality across a wide variety of healthcare services.⁷</i>
<i>NICE Clinical Guidelines for Patient experience in adult NHS Services</i>	<i>National Clinical Guidance Centre, 2012</i>	<i>A set of guidelines and 14 quality standards to promote good patient experience within the NHS and help promote a cultural shift towards a patient-centred service. The NICE guidance is grouped into 5 sections: knowing the patient as an individual; essential requirements of care; tailoring healthcare services for each patient; continuity of care and relationships; and enabling patients to actively participate in their care.⁸</i>
<i>NHS Outcomes Framework 2011/2012</i>	<i>National Health Service, UK Department of Health, 2011</i>	<i>A framework of 51 indicators grouped into five domains: preventing people from dying prematurely; enhancing quality of life for people with long-term conditions; helping people to recover from episodes of ill health or following injury; ensuring that people have a positive experience of care; and treating and caring for people in a safe environment and protecting them from avoidable harm.⁹</i>

Figure 1: Breakdown of consultation respondents



- Patients' organization / non-profit organization representative
- Healthcare industry representative
- Healthcare professional
- Academic
- Other

Figure 2: Breakdown of respondents by region



- Africa
- Europe
- Latin America
- North America
- South East Asia
- Western Pacific
- International

The 'patient journey' as a framework for measuring patient-centred healthcare

IAPO asked respondents to consider whether measuring patient-centred healthcare along different points of the 'patient journey' is appropriate. Most patients' organizations, academics and healthcare professionals, as well as industry representatives, agreed that the 'patient journey' provided a clear and logical framework for

measuring patient-centred healthcare. They agreed that this framework allows the focus to be narrowed down to specific points along the journey, so that patients' experiences can be measured at points of interaction with different levels of the health system along their journey.

"This review supports the position that utilizing the patient journey as a framework appears to be the most logical way of mapping patient centredness throughout the lifespan. Indeed it would seem impossible to have a 'one size fits all' approach to patient-centred healthcare as each patient's journey will vary considerably."

Patients' organization representative, Australia

Some patients' organizations and academics suggested that we need to develop a common framework of indicators, using certain diseases or conditions as models. An international healthcare professional association representative explained:

"Another point to consider is the interest of developing indicators which are common for all healthcare settings/ healthcare professionals, as the journey may lead to the same end (hopefully cure) but using different paths (or healthcare professionals)."

There was also discussion regarding whether the development of indicators for each of IAPO's five principles of patient-centred healthcare: respect; choice and empowerment; patient involvement in health policy; access and support; and information, as detailed in IAPO's Declaration on Patient-Centred Healthcare, was a logical way forward.¹ The indicators for the five principles could then be measured at different points along the 'patient journey', providing both a broad and detailed view of patient-centredness within the healthcare system.

Using qualitative indicators

Respondents widely agreed that developing qualitative indicators such as patient narratives and testimonials was very important. Using patient narratives and testimonials as exemplars of good and bad practice, as well as quantitative indicators, would give a fuller picture of patients' needs, perspectives and interaction with the health system.

"We agree that consumer-centredness cannot always be quantified and that the quality of a consumer's interaction with a healthcare provider or health system is not always reflected in quantitative indicators."

Patients' organization representative, Australia

Once again, a number of important issues were brought to light by patients' organizations and other stakeholders. Some explained that the quality of the patient narrative or testimonial will be dependent on the level of patient activation i.e. the level of knowledge and confidence of the patient regarding their disease/condition.

"Patient narratives are useful indicators for patient-centred healthcare, as part of the overall quality of patient-doctor communication. As such narratives rely on the perception of patients on their physicians, such perception was estimated to be higher when patients are well-informed regarding their own condition and have an overall good health education and lower in cases where patients are not aware of their health condition."

Health professional association representative, Europe

Some patients' organizations highlighted issues around practicalities, such as in what format and language the narratives will be collected, and who will record the narrative; will it be the patient, a doctor or a nurse? They commented that who the narrative is recorded by, and how, will influence both the quality and comparability of the qualitative data, and a form of standardisation must be developed if these indicators are to be useful. Furthermore, how the data will be analysed must also be taken into consideration.

Potential next steps for IAPO

A number of consultation respondents provided recommendations and ideas regarding IAPO's next steps in the development of indicators.

Suggested indicators

A number of respondents identified areas of healthcare for which indicators should be developed:

- Develop indicators for the duties and responsibilities of patients, including self-management. This could include indicators for how well a health system promotes and enables self-management and education.
- Indicators to measure the extent to which patients are provided clear and accessible information regarding all aspects of their illness, and regarding their rights as a patient.
- Explore indicators for patient access to healthcare. Although the review identified a number of indicators for 'access' to healthcare, it is an extremely broad category that should be explored in further detail. For

example, indicators for availability of services, does not necessarily reflect if, and how, patients are using them.

Recommendations to support the development of indicators

- Undertake research to determine the critical drivers for patient-centred, holistic healthcare and which models and approaches have been the most successful in achieving patient-centred healthcare.
- Explore and identify barriers to adopting a patient-centred approach to healthcare provision.
- Develop practical, clear and global operational definitions for each of IAPO's five principles of patient-centred healthcare that can be translated into indicators.
- Investigate different categories of indicators, and develop different classifications/models of indicators, for example by who collects the data (e.g. health professionals, patients etc), or how it is collected (e.g. via patients, assessment by an independent body or self-assessment etc).
- Identify and assess patient-centred healthcare initiatives solely in low and middle income countries, in various languages, to obtain a clearer picture of the global situation.
- Broaden the search of literature and current indicators to include those that have not directly been developed for the measurement of patient-centred healthcare, i.e. proxy indicators, which could provide useful information regarding healthcare. It is important to see what data is currently being collected.
- Develop of a set of principles for indicators to measure patient-centred healthcare. These principles would ensure that the indicators developed are actually measurable, achievable and have an impact. The principles would highlight the importance of patient involvement in every step of development, consider how often data is collected and how it will be analysed.

Conclusion

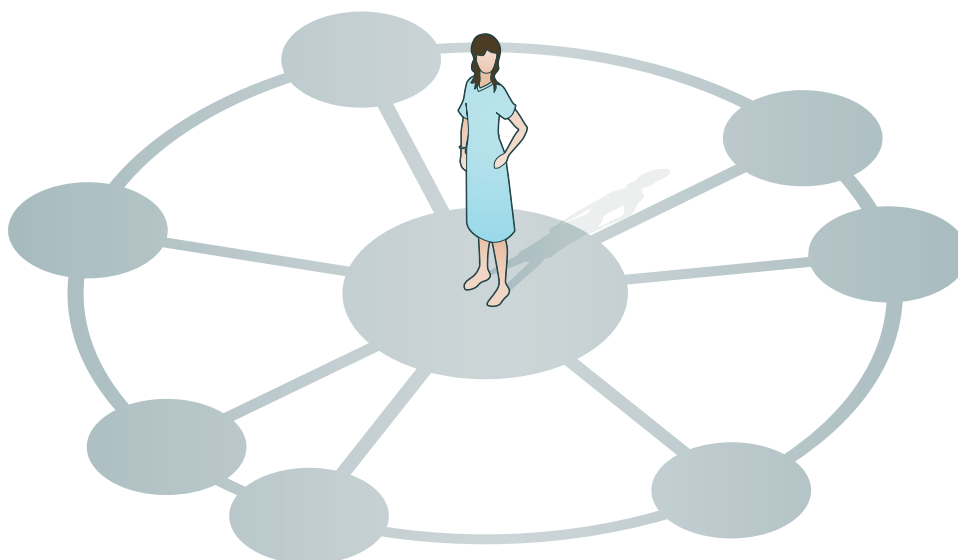
The feedback from the consultation regarding the Patient-Centred Healthcare Indicators Review was positive and constructive. There was consensus amongst respondents in relation to the themes and issues drawn out of the review. Importantly, patients' organizations, academics, healthcare professionals and industry representatives who responded

to the consultation all agreed that patient involvement in every step of the development of these indicators is crucial. When discussing the indicators at a wider level, it was stressed that although the development and use of indicators are key to identifying changes that need to be made, it is essential that these changes are actually implemented and evaluated in order to improve patient-centred healthcare. This is an important reflection which IAPO will consider in the next stages in the development of patient-centred indicators.

In light of the comments and resources detailed above, IAPO will consider how it can continue to lead the development of a set of patient-centred healthcare indicators. Finally, IAPO would like to thank everybody for their valuable input into this consultation.

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