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### The Patient-reported Indicator Surveys: measuring what matters to patients

#### Abstract

Although health systems across the OECD spend around 9% of their GDP on health, we still do not know to what extent health systems are truly delivering what people need. Until the returns on investments in health can be stated more clearly in terms of outcomes, policymakers will be flying with little guidance to direct decisions on the mobilization and use of resources. Slowly but surely, a paradigm shift is taking place in the way we think about healthcare, with a focus on the people who use it. Policymakers, academics, healthcare providers and patients are joining forces to make health systems more people-centered. The use of Patient-Reported Outcome Measures (PROMs) has become common in the past years, particularly in clinical settings. There is a rich variety of tools and initiatives, but opportunities for international learning are limited because of this variety within and across countries. Moreover, PROMS are mainly used in hospital settings, and for specific conditions, whereas a growing group of healthcare users lives with multiple conditions and is mainly treated in primary care settings.

During their Health Ministerial meeting in 2017, health ministers called on the OECD to lead the development of a new generation of health performance measures and to support countries in implementing them. This was the start of the Patient-Reported Indicator Surveys (PaRIS) initiative. Country officials, academics, patient organizations and providers have joined forces in this first-ever international survey on patient-reported measures of this scale. This international collection of patient-reported measures is a necessary step to take on our shared journey towards more people-centered healthcare systems.

### **What are health systems delivering to people using them?**

Health systems collect massive amounts of data on inputs, spending and activities. There are international standards for the recording and calculation for healthcare costs, diagnoses, hospital admissions, prescriptions, mortality and many others. Such information is essential intelligence for policymakers, funders, and providers of care. However, as comprehensive as they are, none of these data touches on the very essence of healthcare: does it make patients' lives better?

Although health systems across the OECD spend around 9% of their GDP on health, it is shocking how little we know about whether health systems are truly delivering what people need<sup>1 2</sup>. This puts emphasis on one question: what exactly are health systems delivering to people using them? In the past two decades, the body of literature on health systems performance, the number of performance indicators and the amount of benchmarking exercises has grown in most OECD countries. Despite the useful insights that these approaches generate, the perspective of the patient is painfully absent. Does healthcare improve what really matters to patients? How do patients experience the care they receive? Do they feel ready and empowered to manage their conditions and take good care of their health?

The inability to answer such vital questions is problematic: until the returns on investments in health can be stated more clearly, policymakers will be flying with little guidance to direct decisions on the mobilization and use of resources. In addition to massive human suffering and loss of lives, the COVID-19 pandemic has laid bare many vulnerabilities of health systems. Older people and people living with chronic conditions are impacted most, but their health systems know very little whether they have what they need to better manage their health needs.

Slowly but surely, a paradigm shift is taking place in the way we think about healthcare, with a focus on the people who use it. Policymakers, academics, healthcare providers and patients are joining forces to make health systems more people-centered. The willingness is there, now it is time to walk the talk, and the COVID-19 pandemic has only made this effort even more urgent. Making this a shared effort is the only way forward.

### **Populations are changing**

The populations in most countries have changed dramatically: we all have aging populations, and this goes hand in hand with a continuous increase of chronic conditions. In the age group above 65, 6 out of 10 people live with two or more chronic conditions. In the overall population, this share concerns 1 out of 3 people. They are not going to be cured, but they rely on healthcare to manage their conditions, to provide regular care, prescribe medication, provide lifestyle counselling, etc. The purpose of health systems is not only to cure diseases, and to lengthen life, it is about the quality of life, supporting people in what matters to them.

This cannot be measured in clinical outcome measures, You can only get this information by asking patients about the outcomes and experiences with care. Next to physical health, mental health plays an important role. And here we should not just think about disorders or mental diseases, but also about the

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<sup>1</sup> OECD (2019), Health at a Glance 2019: OECD Indicators, OECD Publishing, Paris, <https://doi.org/10.1787/4dd50c09-en>.

<sup>2</sup> Gurria A and Porter M, Putting People at the Centre of Healthcare, Huffington Post, January 2017 [https://www.huffpost.com/entry/putting-people-at-the-cen\\_b\\_14247824](https://www.huffpost.com/entry/putting-people-at-the-cen_b_14247824)

quality of life in general. Are people able to do their work, can they engage in social activities, or are they hampered by pain, concerns, fatigue, limitations in mobility, sleeping problems, etc.?

### **Measuring outcomes and experiences**

The use of Patient-Reported Outcome Measures (PROMs) has become common in clinical settings. There is an abundance of available instruments to measure PROMs, and their use has become increasingly common. Healthcare providers are intrinsically interested in how their patients are doing. PROMs tools can help fostering a constructive dialogue between patient and provider, and help tailoring care to their needs. Moreover, providers can learn from each other by comparing results. Examples of patient-reported outcomes that hugely impact people's lives are levels of pain, mobility, the ability to participate in social activities, and anxiety. However, the ability for policymakers to capitalize on existing data collections has been limited so far, for several reasons.

First, there is a large variety of tools and initiatives across and even within countries. Opportunities for international comparing and learning are therefore limited.

Second, PROMs are mostly used in hospital settings and typically apply to curative, episodic situations with a clear 'before and after' the intervention. However, there is a large, and growing, group of healthcare users who live with chronic conditions and receive healthcare in primary care settings for years or even decades. In such cases, there is no 'before and after'; their healthcare is a continuous process.

### **International effort**

Policymakers, patients, healthcare providers across the globe agree that health systems need to change; from health systems that are centered on supply and 'curing illness' to health systems that are centered on people's individual needs and well-being. The question is not so much 'if' but how this should materialize. This fundamental change has important implications for how we measure health system performance.

During their Health Ministerial meeting in 2017, health ministers called on the OECD to lead the development of a new generation of health performance measures and to support countries in implementing them<sup>3</sup>. Today, countries inside and outside the OECD have joined forces in this international effort called the Patient-Reported Indicator Surveys initiative ([PaRIS](https://www.oecd.org/health/paris/)), and first data collection will commence in 2021<sup>4</sup>.

In the past years, the OECD has had intensive dialogues with leading experts across the globe to make a feasible plan for this ambitious undertaking. Together with an international expert Taskforce seven key principles were formulated that are leading in the PaRIS initiative.

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<sup>3</sup> OECD (2017) The Next Generation of Health Reforms. OECD Health Ministerial meeting, Ministerial Statement. 17 January 2017. <https://www.oecd.org/health/ministerial-statement-2017.pdf>

<sup>4</sup> <http://www.oecd.org/health/paris/>

## Seven key principles of the PaRIS initiative

- 1. Inclusive development:** Stakeholders and countries are developing the PaRIS survey together. By making this a shared undertaking, policy makers, patients and health care providers are involved to ensure that instruments and indicators are relevant for them. PaRIS has an international Patient Panel of patient organizations and a Technical Advisory Community. The work is overseen by an international Working Party in which all participating countries are represented.
- 2. Supporting people-centered health systems:** Data collection is only a means to a goal. The survey will provide 'actionable' information that helps policy makers improve care.
- 3. Alignment with national directions and initiatives:** The survey will create synergy with initiatives already going on in countries. Where possible, PaRIS should be implemented in a way that it strengthens national strategies. Based on the international standards, a country-specific plan is developed to ensure a smooth implementation.
- 4. Multi-level approach:** The survey will combine information on the levels of patients, health care providers and health care systems to get the full picture. The different layers of information will help policy makers identify priorities on the right level.
- 5. Phased approach:** The development of PaRIS will go through three phases: a development phase, a field trial and the implementation of the main survey. Countries commit to the project phase by phase.
- 6. Future-proof data collection:** The survey will use state-of-the-art innovative methods for data collection and data sharing that are safe, privacy-respectful, and user-friendly.
- 7. Protection of data privacy and security:** The survey design and the practices of data processors fully protect the privacy of survey participants, both patients and health care providers.

At the time of writing, a majority of the OECD member states has joined the PaRIS initiative. The development and implementation are supported by an international consortium of academics and one of the industry leads in international survey research. This will be the first-ever international survey on patient-reported measures of this scale.

In 2021, the field trial phase of PaRIS commences. This phase will take 1.5 years and during this period, questionnaires will be translated and tested. The survey will be implemented on a small scale. After evaluation of the results, the main survey will be implemented in the second half of 2022.

## Next Steps Towards More People-Centered Health Systems

If you cannot measure it, you cannot improve it. The international collection of patient-reported measures is a necessary step to take on our shared journey towards more people-centered healthcare systems; health systems that are organized to support people in those aspects that matter most to them. There is no other purpose of health systems than serving patients. Patient-reported measures are not 'soft data'; they must be measured in a valid, rigorous way and developed together with all stakeholders at the table. It is not about fees, it is not about bar charts and league tables, it is about the lives and well-being of patients.