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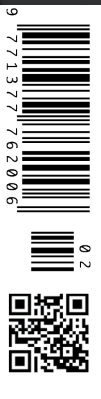
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# Shared Journey Towards People-Centred Health Systems

## From narrative to action

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The one and only reason that health systems exist, is to make a positive contribution to the lives of people using them. Surprisingly, we still cannot tell to what extent they succeed in this mission. There is strong interest among patients, healthcare providers and policymakers to transform our health systems, with the objective of putting people at their centre and continuously improving their lives. We have talked enough and it is time for action.

### Key Points

- Economies in the OECD are spending 10% on average on healthcare, but we know little about what exactly we get back for this large investment.
- Although there are massive amounts of data on healthcare, few of these data tell us to what extent health systems make peoples' lives better.
- The relevance of getting systematic insight in the outcomes of healthcare as reported by patients is widely acknowledged.
- Countries across the globe are now joining forces and working together to make the step towards a new generation of health statistics: patient-reported outcomes and patient-reported experiences.
- The systematic measurement of patient-reported indicators is an essential step towards people-centred health systems.

### What Do Health Systems Deliver?

Countries across the OECD spend close to 10% of their Gross Domestic Products on health. Looking at both the demographical and epidemiological projections, and the emergent health needs such as the threat of pandemics, this percentage will continue to rise in the coming years. 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, one pivotal aspect is often painfully absent: the perspective of the patient.

Healthcare activities generate a lot of data: 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 and should be used fully. However, as comprehensive as they are, none of these data touches on the very essence of healthcare: *does it make patients' lives better? 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 mobilisation 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, academia, healthcare providers and patients are joining forces to make health systems more people-centred. 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.

### Patient-Reported Data in Policy and Practice

The use of Patient-Reported Outcome Measures (PROMs) is no novelty 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 capitalise on existing data collections has been limited so far, for several reasons.

that providers may be judged based on unfair comparisons, resulting from flawed or insufficiently standardised data, and that 'getting the figures right' may become a goal in itself, with the risk of manipulation. In such cases, the debate may quickly move away from ways of providing the best care for patients towards a discussion about money, reputational damage, or an everlasting methodological discussion.

### International Effort

The world-famous Parisian Victor Hugo said that nothing is more powerful than an idea whose time has come. Indeed, policymakers, patients, healthcare providers across the globe agree that health systems need to change; from health systems that are centred on supply and 'curing illness' to health systems that are centred on people's individual needs and well-being. The question is not so much 'if' but *how* this should materialise. 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 (OECD 2017). Today, countries inside and outside the OECD have joined forces in this international effort called the Patient-Reported Indicator Surveys initiative ([PaRIS](#)), and first data collection will commence in 2021.

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## Healthcare activities generate a lot of data. However, none of these data touches on the very essence of healthcare: *does it make patients' lives better?*

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First, the variety of tools and initiatives has created a situation of 'many flowers blooming'. Even within the same country measurement practices vary, and internationally the ability to compare is limited.

Second, PROMs are mostly used in hospital settings and typically apply to curative, episodic situations with a clear 'before and after' the intervention. Hip and knee replacements are typical examples. 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.

Third, as soon as the collection of patient-reported measures becomes a national undertaking, focussed on public benchmarking or accountability, the interest of healthcare providers may be reduced. Common concerns are

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. To overcome the challenges as mentioned above, two key principles are leading in the PaRIS initiative: inclusive development and alignment with national directions.

### Inclusive Development

A continuous dialogue between governments, patient groups, health professionals, payers and other key stakeholders in the industry is essential to move forward. This is complex and time-consuming. However, there are no short cuts; all these perspectives are necessary and change requires joint work. To illustrate this with two examples: although patient involvement in the development of patient-reported measures may seem obvious, studies have



shown that many such instruments were developed without any patient involvement or with minimal involvement of patients. The OECD has established an international panel of patient organisations, including international umbrella organisations such as the NCD Alliance and the European Patients' Forum, to advise on crucial steps and ensure that PaRIS data will truly reflect elements that matter to patients.

Moreover, most healthcare providers are keen to know more about the outcomes and experiences of their patients, because they want to improve their quality of care. Excluding providers from the development process would have been a missed opportunity, and they would see little value in receiving a tool developed without their inputs. Therefore, the OECD consults provider organisations and international networks of providers in the development process of PaRIS. This guarantees that PaRIS will generate information that helps providers improve healthcare. PaRIS will enable providers to compare aggregated results with those of their peers, in an anonymous format, and identify ways to continue improving their practice.

### Alignment with National Directions

Health systems are organised in different ways across countries. Some are more centralised whereas others have regionalised structures. Some have primary care providers as gatekeepers for secondary care whereas other systems offer more direct access. Maybe even more important is that many countries have already ongoing initiatives, in which patient-reported measures are collected, through national or local surveys, clinical registries, or other initiatives.

Although this may pose a challenge for the development of international standards, the PaRIS initiative actually benefits from the richness of national and local expertise. The development of the flagship project of the PaRIS initiative, the International Survey of People Living with Chronic conditions, already includes 17 countries. This survey focusses on people with chronic conditions who live in the community and whose conditions are mainly managed in primary care settings. The development and implementation is 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.

One of the driving forces of PaRIS is that rather than imposing a new standard, countries work together to find the common ground in the collection of patient-reported measures for specific conditions and discuss how best to align their data collections to facilitate international learning. In addition to the survey of patients with chronic conditions, international condition-specific working

groups are hard at work, such as the breast cancer working group, with nearly 100 participants representing countries and clinical registries. Similarly, the working group for hip and knee replacements includes 16 countries and international networks such as the International Society of Arthroplasty Registries (ISAR) and the World Confederation for Physical Therapy (WCPT).

### Next Steps Towards More People-Centred Health Systems

One of the most important sayings in organisation theory is that if you can't measure it, you can't improve it. The international collection of patient-reported measures is a necessary step to take on our shared journey towards more people-centred healthcare systems; health systems that are organised 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 no '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.

### Conflict of Interest

The authors declare that they have no competing interests. ■

### REFERENCES

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