



Putting people
at the centre
of health care

PaRIS survey of Patients
with Chronic Conditions



“Asking patients to assess the results of their care is perhaps the most important single step we can take to improve health care.”

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OECD provides leadership on measuring how health systems respond to **patients' needs**

Health systems collect massive amounts of data on inputs, spending and activities, such as for instance on how many patients are treated, what services are delivered, whether clinicians follow guidelines, and how much is spent.

However, 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.

The outcomes achieved for patients and how they experience care are rarely measured in a systematic and rigorous way. It is difficult to improve what is not been measured. The PaRIS (Patient-Reported Indicators Surveys) initiative addresses this major gap.

PaRIS benchmarks outcomes and experiences of **health care that matter to people**

With a mandate from OECD Health Ministers, the OECD launched in 2017 an innovative initiative of Patient-Reported Indicators Surveys (PaRIS) to make health systems more people-centred. At the core of making health systems more people-centred is our ability to systematically collect data on what matters most to patients. PaRIS will help policy makers do so in two ways:

- First, PaRIS helps to accelerate and standardise the international monitoring of patient-reported indicators in areas where such indicators of health care quality and outcomes are already used. Countries within and beyond the OECD are collaborating to develop patient-reported indicators, with three working

groups currently focusing on hip and knee replacements, breast cancer, and mental health care.

- Second, PaRIS is developing a new international survey of outcomes and experiences for patients with chronic conditions who are treated in primary health care or other ambulatory health care settings, where little is being measured at present.

This brochure focuses on the international survey of patients with chronic conditions.

“While primary health care is asked to modernise and address rising needs of populations, little information and data is available on its outcomes and performance.”

The PaRIS survey for Patients with Chronic Conditions fills in an information gap in health systems...

Outcome measures available today focus on mortality, and incidence and prevalence of disease, usually recorded by health care professionals in administrative datasets. Little information is available about how users of health services experience care and to what extent it adds value to their lives.

As populations age, and more people suffer from chronic conditions, additional pressure is placed on primary, community and ambulatory health care services, which typically are the first points of contact with the health system. These services manage and treat people with chronic conditions, support self-management of their health and advise on health pathways. Because patients with chronic conditions often receive fragmented care from multiple health care providers, they are at risk of complications and errors. For health systems, this adds to cost.

While primary health care is asked to modernise and address rising needs of populations, many countries struggle to measure what happens within primary health care, with little information and data available on outcomes for patients and performance of health systems.

The PaRIS survey of Patients with Chronic Conditions fills in this critical information gap in primary health care, focusing on:

- Patient-Reported Experience Measures (PREMS), which measure how patients experience health care and refers to practical aspects of care, such as care co-ordination, waiting times and provider-patient communication.
- Patient-Reported Outcome Measures (PROMS), which measure how patients assess the results of the care they receive. PROMS contain information about outcomes such as quality of life, pain, physical functioning and psychological well-being.



“PaRIS will provide information about the outcomes of care that matter most to patients and how users of health services experience care.”

... and it helps policy makers understand how health systems address the needs of chronic patients

Key questions that PaRIS will help shed light with include for example:

- Are diabetes programmes in my country making people actually feel better?
- How do people who were diagnosed with cancer in the past five years fare and does this differ from similar patients in other countries?
- How well is care organised around the needs of patients?
- Are patients with chronic heart conditions better off in some parts of the country than in others?
- How does the effectiveness of pain management vary across patient groups and geographic areas in my country?
- How well can people with multiple chronic conditions perform daily life activities?

The PaRIS survey facilitates international learning:

The PaRIS survey of Patients with Chronic Conditions will be the first international survey of patient-reported health outcomes and experiences of adults with one or more chronic conditions who are treated in primary or ambulatory health care settings.

Results from the survey will show how key outcomes and experiences vary across and within countries. This will allow countries to benchmark and learn from each other's approaches. It will also foster a dialogue with service providers about how to further improve the performance and people-centredness of primary health care services.

Developing the survey on an international level rather than a national level has two main benefits:

- It offers opportunities for international learning about effective strategies for supporting people-centred care and measuring progress;
- It brings efficiencies and cost-savings by sharing the costs of developing, testing and validating the tools to measure patient-reported outcomes and experiences.

The survey is guided by seven key principles

Principles guiding the development of the PaRIS Survey



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.

2. **Supporting people-centred 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.

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.

Both patients and health care providers will be surveyed

The survey will provide perspectives from both patients and their health care providers:

- *Patients surveyed:* People aged 45 and older who have visited primary/ambulatory health care at least once in the six months preceding the survey. To identify patients with chronic conditions, a validated list of the most common conditions will be used.
- *Primary/ambulatory health care providers surveyed:* Single-handed practitioners and practitioners working in an ambulatory/primary health care clinic or health centre.

The sampling will take place in stages:

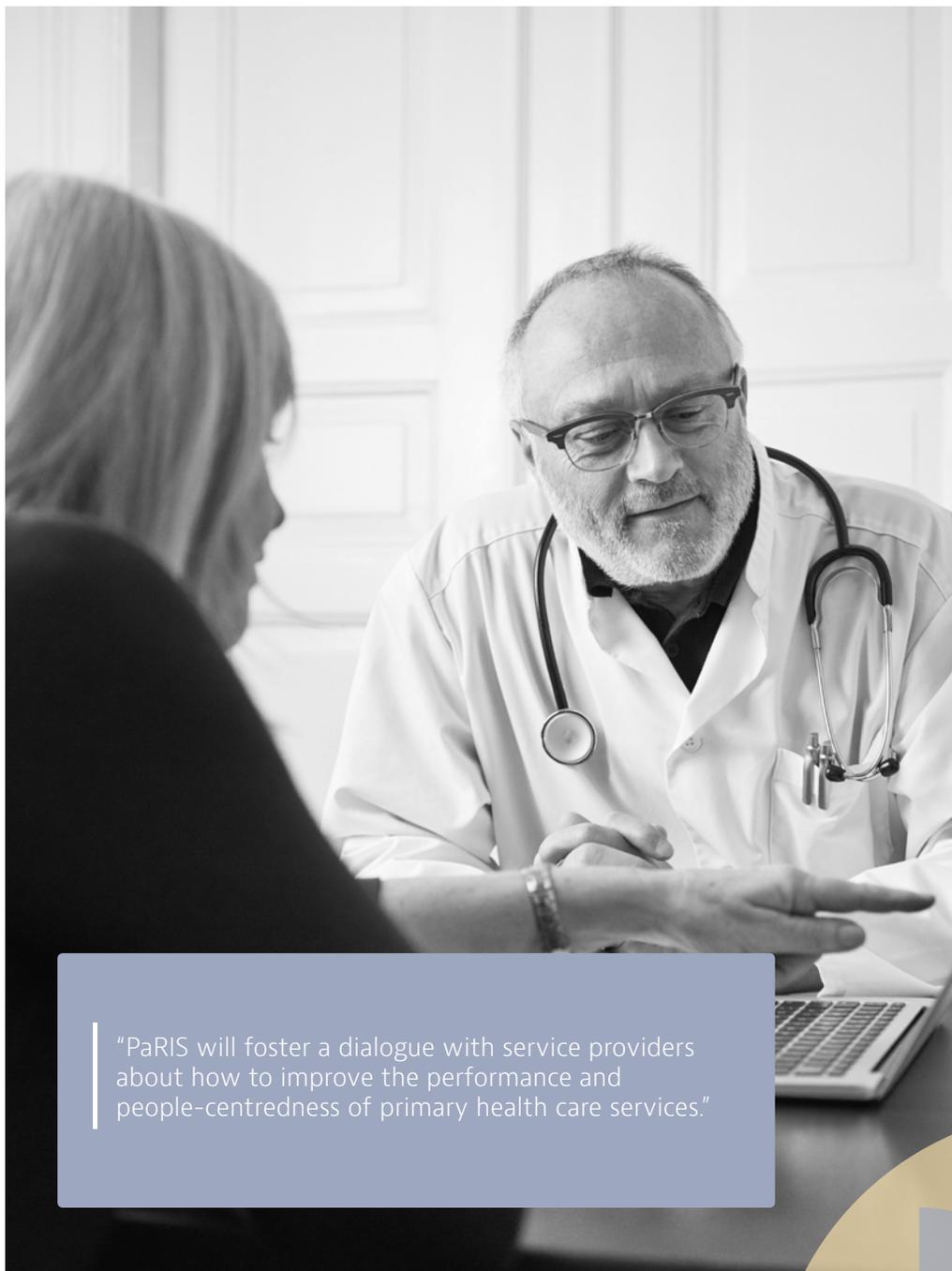
- *Stage 1:* Selection of geographical areas or communities. In the first stage, a representative sample of areas within participating countries will be identified.
- *Stage 2:* Selection of primary/ambulatory health care providers. Eligible primary/ambulatory health care providers will be sampled from the selected areas/communities. In some countries, both patients and providers may be sampled from health registries.
- *Stage 3:* Selection of patients receiving ambulatory/primary health care. Eligible patients will be drawn from the population cared for by the primary/ambulatory health care providers selected in stage 2.

Two survey questionnaires are planned:

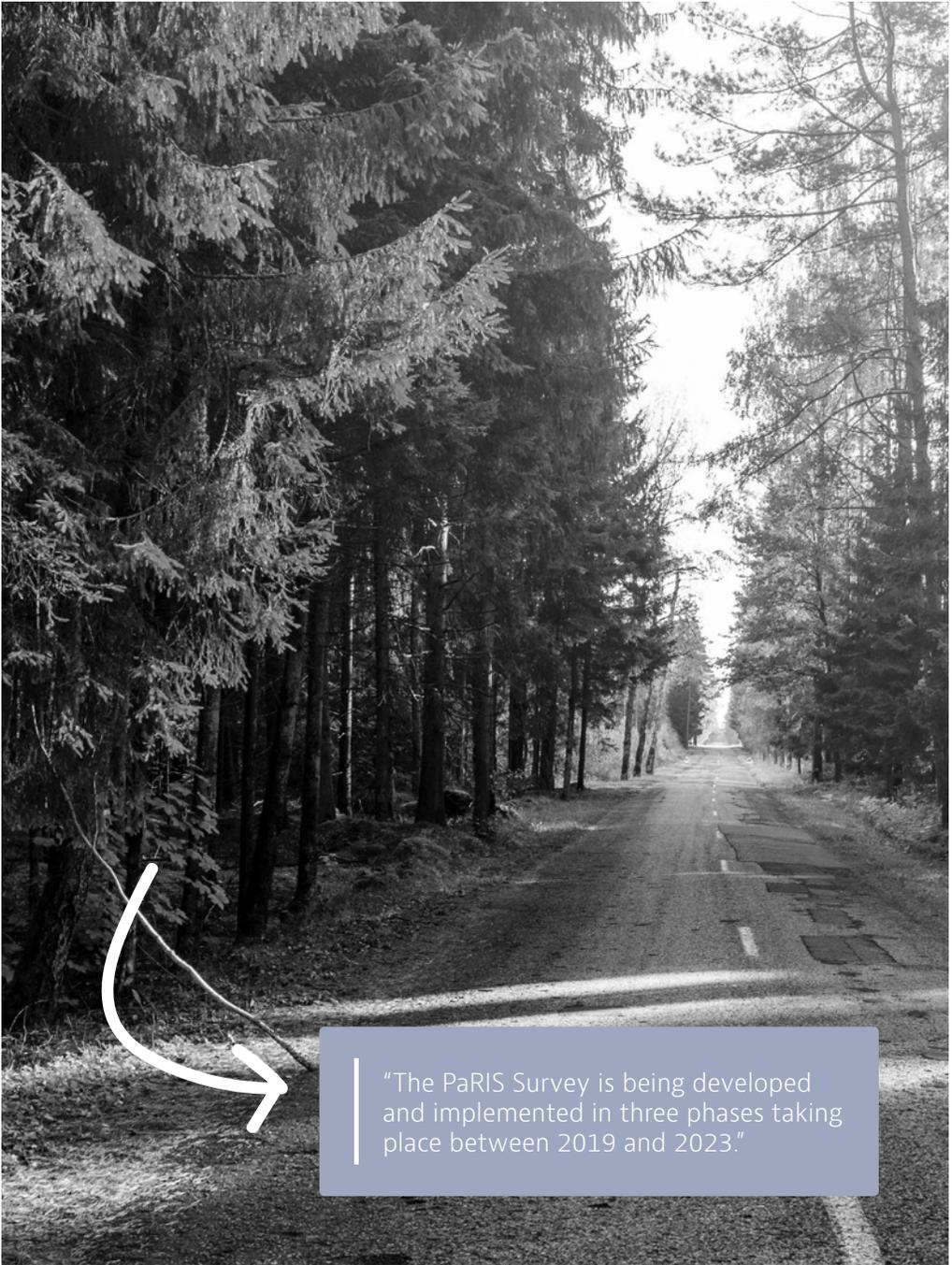
- *The patient questionnaire* contains information about patients' characteristics such as age and gender, health care experiences and health care outcomes. No patient clinical data from patient records are requested or provided by clinicians. It should take about twenty to thirty minutes to complete the questionnaire.
- *The provider questionnaire* contains information about the structural characteristics of their practice/clinic. This will be a short questionnaire taking approximately ten minutes to fill out.

The questionnaires will be developed during the first phase of the PaRIS Survey and will draw to the extent possible from existing instruments.

Data collection and processing will take place under applicable national legislative and regulatory requirements for data protection.

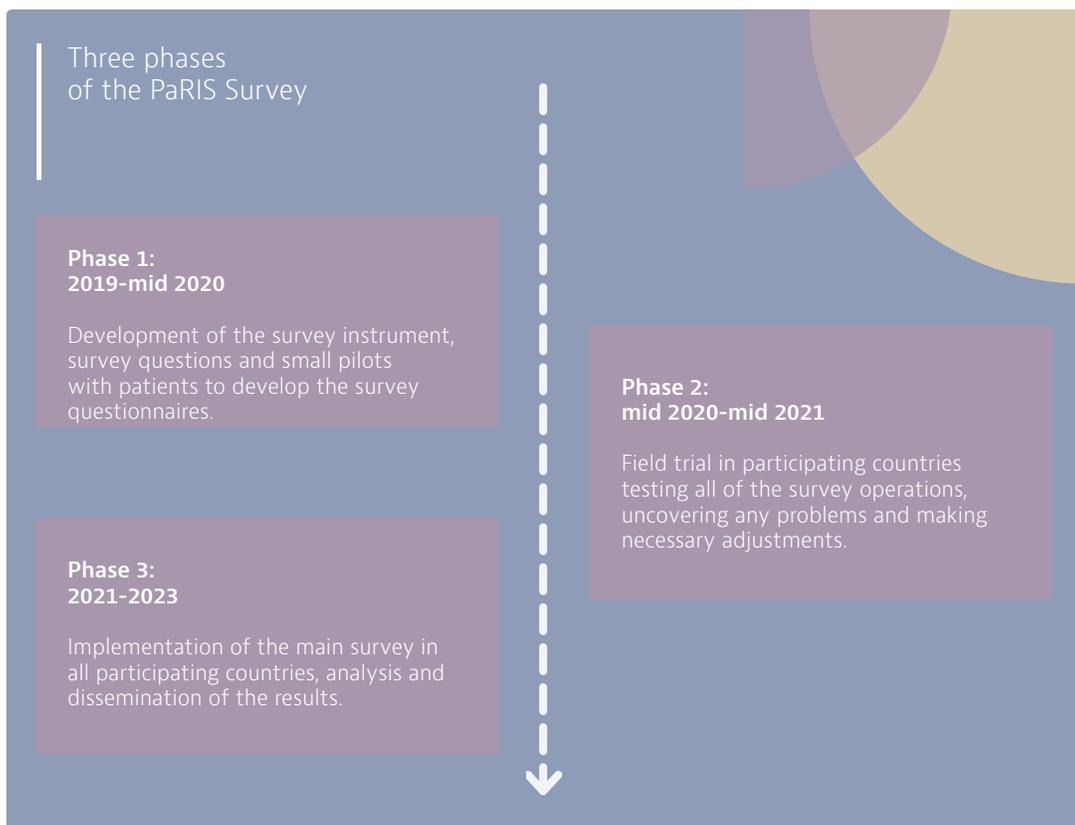


“PaRIS will foster a dialogue with service providers about how to improve the performance and people-centredness of primary health care services.”



“The PaRIS Survey is being developed and implemented in three phases taking place between 2019 and 2023.”

The survey will be developed and implemented in three phases



OECD countries oversee the survey

The OECD Health Committee and the Working Party for PaRIS oversee the PaRIS survey of Patients with Chronic Conditions. Survey development is also guided by advisory bodies including health care providers, patients and technical experts. An OECD international contractor provides survey management. Countries appoint National Project Managers who are responsible for the practical implementation of the survey, following the guidelines provided by the OECD Secretariat.

The financing of PaRIS includes contributions from countries and grants (e.g., by the European Commission).

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