

# PaRIS

Patient Reported Indicator Surveys

## Frequently Asked Questions

PaRIS International Survey of People Living with Chronic Conditions



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with Chronic Conditions



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## 1.1. What is the PaRIS Survey of people living with chronic conditions?

The PaRIS Survey is an international survey of people living with chronic conditions who are managed in primary care, or other ambulatory health care settings. This survey is carried out in countries across the world and yields internationally comparable data.

A general description of this survey can be found in the [PaRIS Brochure](#).

## 1.2. Why a new survey of people living with chronic conditions?

Populations around the world are ageing and people with chronic conditions form the most rapidly growing group of health care users. In many OECD countries, around two-thirds of the population aged 45 and older live with at least one chronic condition. Most of these people receive routine follow-up care in primary care or other ambulatory care settings. **For this group of people, we are currently unable to properly assess the extent to which the care they receive makes a difference to their wellbeing.** Assessing their outcomes and experiences through a survey sheds light on whether the care people are receiving contributes to better health outcomes—being more functional and more active with less pain—and to a better experience of care— that the care they receive is seamless and tailored to their needs.

## 1.3. Why is this done by the OECD?

The OECD is an international organisation committed to building better policies for better lives. Together with governments, policy makers and citizens, the OECD generates evidence-based international standards by providing a forum and knowledge hub for the collection, reporting and benchmarking of indicators of health system performance and healthcare quality. International collaboration helps countries exchange experiences, share best practices, advice on policies and set international standards. The OECD is experienced in developing new surveys to benchmark international performance in different policy areas.

In their [Ministerial Statement](#) in 2017, Health Ministers from over 40 countries called on the OECD to invest in better cross-country comparative measures of patients' own experiences of medical care and health care outcomes, and to further engage in the analysis and development of such comparative measures.

#### 1.4. What are the benefits of the PaRIS survey for health policy?

The survey provides insight into what health care really delivers to people. This information is essential to help **policy makers** better understand how their health systems are performing and how they could be improved. The survey sheds light on how successful health systems, particularly primary care or other ambulatory care systems, are in responding to people's needs. It depicts what is working well in these countries and identifies the areas requiring policy attention.

The survey facilitates international learning and identifies best practices for strengthening health systems, and making them more responsive to the needs of the people who use them.

#### 1.5. How do healthcare providers benefit from the survey?

**Healthcare providers** who participate in the PaRIS survey receive data as feedback. This aggregated information shows them the outcomes and experiences of their patient populations and how these results compare to those of their peers. This type of feedback information has proven to be a powerful tool for improving the quality of care. Healthcare providers may also discuss the results with peers to learn from each other.

PaRIS primarily aims to develop tools for quality improvement, and **not for** use in public benchmarking, accountability or pay-for-performance schemes.

#### 1.6. How do patients benefit from this survey?

Generating systematic data on outcomes and experiences is only a means to an end: helping health systems become more people-centred. The main purpose of the PaRIS initiative is to help make health systems better tailored to people's needs. This is why **patients** benefit most of this initiative. Patients are involved in every step of the development of the survey. An international Patient Advisory Panel advises the OECD and the PaRIS international consortium.

For more information on how different stakeholders are engaged in the PaRIS survey, read our technical paper [here](#).

#### 1.7. What will the PaRIS survey measure?

The PaRIS survey is **the survey of outcomes and experiences of people living with one or more chronic conditions**. The survey includes both Patient Reported Outcome Measures (PROMs) and Patient Reported

Experience Measures (PREMs) for people with chronic conditions. Examples of PROMs are ratings of peoples' pain, physical functioning and psychological well-being. Examples of PREMs are peoples' experiences with healthcare, such as experienced waiting times and communication with healthcare providers. In addition to PROMs and PREMs, some background characteristics such as age, gender and the type of conditions will be collected to be used in data analysis.

For more information, read the protocol article of the PaRIS survey [here](#).

### **1.8. How were the survey instrument (questions) developed?**

The PaRIS questionnaires consist of a patient questionnaire and a healthcare provider questionnaire. The PaRIS conceptual framework, developed through a systematic, replicable, iterative, and inclusive process, provides the basis for the questionnaires. To develop the questionnaires, a comprehensive approach—including systematic reviews, engagement with international stakeholders ([PaRIS Patient Advisory Panel](#), [Technical Advisory Community](#) and [National Project Managers](#))—was conducted to identify appropriate scales and items. A modified Delphi procedure was conducted to select a core instrument for each domain and additional relevant scales/items. A similar approach was used to develop the provider questionnaire to collect information about the characteristics of primary care settings.

For more information on how different stakeholders were engaged in the development of the PaRIS questionnaires, read our technical paper [here](#).

### **1.9. How is robustness and international comparability of the survey results ensured?**

Rather than starting from scratch, most of the items in the PaRIS questionnaires were selected from previously validated and tested survey instruments used in international contexts. In addition, the development of the survey went through many steps, including cognitive testing in each participating country, psychometric analysis and cross-cultural validation, in collaboration with world-leading experts in the field of patient-reported measures. To ensure that the survey is applicable in all participating countries, stakeholders and experts from participating countries were actively involved in its development and translation.

For more information, read the protocol article of the PaRIS survey [here](#).

### 1.10. How is the privacy of participants to the survey protected?

The PaRIS Survey is designed to protect the privacy of survey participants, including both patients and care providers. All Consortium partners involved and the OECD Secretariat will ensure that the conduct of the survey continues to comply with all applicable data protection laws and meets the highest regulatory standards for the protection of sensitive personal health data, including OECD data protection requirements. The Consortium and the OECD Secretariat assist countries with documentation to fulfil national requirements for regulatory and ethical approvals, privacy impact assessments and privacy notices. The survey is being conducted with the informed consent of survey participants, and only pseudonymised data are provided to the Consortium and the OECD Secretariat. The survey data centre (IT platform) and any necessary transfers of survey data will adhere to the highest standards for data security. When the survey is completed, the OECD will impose controls and safeguards to provide secure access to the international pseudonymised survey data to approved persons. Countries will manage access to national pseudonymised survey data in accordance with local requirements. The OECD has several other large-scale international data collections where microdata are collected, while meeting the highest standards for data privacy and data protection. Where necessary, adaptations have been made for countries to comply with national legislation in addition to international standards.

Read more about [data protection and privacy](#).

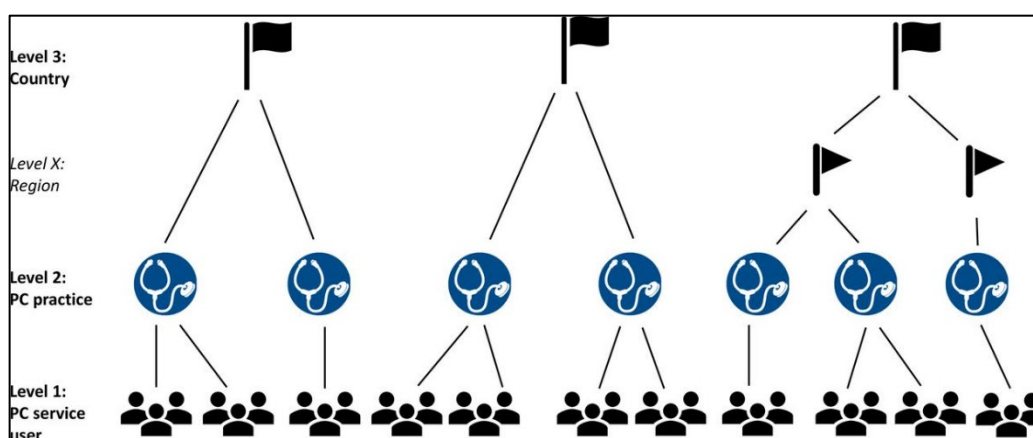
### 1.11. What is the timeline for the survey?

The PaRIS Survey is being developed and implemented in three phases: 1) Design and development phase (2017-2019), 2) Field Trial phase (2020-2022), and 3) Main Survey phase (2023-2024). In the design and development phase, survey design and materials such as the questionnaires and the implementation guidelines were developed by the OECD Secretariat, in collaboration with an international consortium (see 1.15 for more information). In the Field Trial phase, participating countries tested the PaRIS survey design and instruments in their respective countries. In the Main Survey phase, the PaRIS survey is fully implemented in the countries and data collection takes place.

### 1.12. What is the sample size of the survey in terms of numbers of patients and providers?

The sample size of the PaRIS survey was determined based on the basis of two criteria: 1) First, the numbers should be large enough to ensure the reliable assessment of the most important outcomes. 2) The numbers should be large enough to enable answering the main research questions of the PaRIS survey. Based on the Field Trial evaluation, the following minimum numbers of participating primary care (PC) practices and patients have been established: **For countries with more than 1000 eligible primary care practices : 100 primary care practices and 75 patients per practice.** For countries with fewer than 1000 eligible practices: 75 primary care practices and 75 patients per practice. If there are fewer than 75 eligible practices in a country, the country should strive to include all primary care practices.

PaRIS survey has a multilevel design. In the first step, a primary care provider is sampled from each primary care facility, then patients of this primary care provider are sampled. On provider level, the unit of data collection is a primary care facility. Figure 1 shows the sampling design of the PaRIS survey.



**Figure 1. Multilevel design of the International Survey of People Living with Chronic Conditions (PaRIS survey).** PC, primary care. ([de Boer. et al, 2022](#))

### 1.13. What is the advantage of organising this survey internationally?

International benchmarking helps policy makers understand how their health systems are performing, and where improvements and efficiencies can be made. Organising the survey internationally allows for the creation of robust and comparable information that can be used to determine





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Survey of People Living with Chronic Conditions; WP-PaRIS, Working Party for PaRIS. ([de Boer. et al, 2022](#))

### **1.15. Who is the PaRIS Consortium and what is its role?**

A consortium of five highly qualified and experienced international partners: NIVEL, Ipsos MORI, University of Exeter, Avedis Donabedian Institute and Optimedis A.G was selected through a tendering process to assist the Secretariat and the countries with the development and implementation of the PaRIS survey. NIVEL is the consortium leader and Contractor for the project.

More information about the PaRIS-SUR Consortium can be found [here](#).

### **1.16. How is the survey financed?**

The financing of the international costs of the PaRIS survey comes from a mix of resources such as the regular budget of the OECD Health Committee, contributions from countries and grants from the European Commission).

### **1.17. Which countries participate in the PaRIS survey? What can my country participate in the PaRIS survey?**

In 2023, 20 countries implemented the first cycle of the PaRIS survey. These countries are Australia, Belgium, Canada, Czech Republic, France, Greece, Iceland, Israel, Italy, Luxembourg, Netherlands, Norway, Portugal, Romania, Saudi Arabia, Slovenia, Spain, Switzerland, USA, Wales (UK). Please contact the [OECD Secretariat](#) to get more information about how to participate in future cycles.

### **1.18. I am a health care professional, how can I participate in the PaRIS survey?**

Eligible healthcare providers from participating countries (who signed an agreement to join the PaRIS survey) can participate in the PaRIS survey as respondents. Following a random sampling approach, healthcare providers included in the sample receive an invitation to respond to the survey. By responding to this invitation, you can participate in the PaRIS survey.

Although healthcare professionals who are not sampled or professionals from non-participating countries cannot respond to the PaRIS survey, they are encouraged to contact the [OECD Secretariat](#) for any questions or comments.

### 1.19. I am a patient, how can I participate in the PaRIS survey?

Eligible patients from participating countries (who signed an agreement to join the PaRIS survey) can participate in the PaRIS survey as respondents. Following a random sampling approach, patients included in the sample receive an invitation to respond to the survey. By responding to this invitation, you can participate in the PaRIS survey.

Although patients who are not sampled or patients from non-participating countries cannot respond to the PaRIS survey, they are encouraged to contact the [OECD Secretariat](#) for any questions or comments.

### 1.20. I am a researcher, how can I access to the PaRIS questionnaires and other survey materials?

PaRIS survey materials and questionnaires are only available to participating countries and their appointed partners to implement the PaRIS survey. These materials are currently not publicly available.

If you are working in a governmental organisation or affiliated institution and you would like to get more information about the PaRIS survey, please contact the [OECD Secretariat](#) to be liaised with your National Project Managers.

Individual researchers cannot use PaRIS questionnaires or other survey materials for their own projects. Nevertheless, the PaRIS team welcomes exchanges about related projects and the link with the PaRIS survey. Please contact the [OECD Secretariat](#) for more information. In future, PaRIS data will be available for individual researchers. Please contact the [OECD Secretariat](#) for more information.