

Frequently Asked Questions

PaRIS International Survey for People Living with
Chronic Conditions



Frequently Asked Questions for Country Participants

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1.1. What is PaRIS survey of people living with chronic conditions?

PaRIS is the OECD's Patient-Reported Indicator Surveys initiative. Within the PaRIS initiative, countries work together on developing, standardising and implementing a new generation of indicators that measure the outcomes and experiences of health care that matter to people.

An important part of the PaRIS initiative is the development of a new survey of people living with chronic conditions who are managed in primary care, or other ambulatory health care settings. This survey will be carried out in countries across the world and will yield 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 aging and people with chronic conditions form the most rapidly growing group of health care users. In many OECD countries, around 2/3 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. Many receive care from different providers and face fragmented, un-coordinated care and, as a result, are at risk of receiving substandard care. **For this group of people, we are currently unable to properly assess to what extent the care they receive makes a difference for them.** Assessing the outcomes and experiences amongst them will shed light on whether the care people receive contributes to better health results – they are more functional, more active, with less pain – and to a better experience of care – the care they receive is more seamless, and more tailored to their needs. More information can be found in the [PaRIS Brochure](#).

1.3. Why is this done by the OECD?

The OECD is an international organisation committed to build better policies for better lives. In collaboration with governments, policy makers and citizens, OECD works on creation of evidence-based international standards by providing a forum and knowledge hub for collecting, reporting and benchmarking health system performance and health care quality indicators. International collaboration helps countries to exchange experiences, share best practices, advice on policies and set international standards. The OECD is experienced in developing new surveys to benchmark international performance across diverse 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 experience 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 care really delivers to people. This information is essential to help **policy makers** better understand how their health systems are performing and how this could be improved. The survey will shed light on how successful health systems are and in particular, how primary care, or other ambulatory care systems are

responding to the needs of people. It will tell what is working well in these countries and identify the areas that require policy attention.

The survey will facilitate international learning and identify best practices that will help strengthening health systems, and making health system better organised around the needs of people using them.

1.5. How will healthcare providers benefit from the survey?

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

PaRIS aims to develop tools for quality improvement in the first place and not for public benchmarking, accountability or pay-for-performance schemes.

1.6. How will patients benefit from this survey?

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

1.7. What will the PaRIS survey measure?

The PaRIS survey will be a survey of the outcomes and experiences of people with one or more chronic conditions. The survey will include both Patient Reported Outcome Measures (PROMS) and Patient Reported Experience Measures (PREMS) for patients 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. On top of the PROMS and PREMS, some background characteristics such as age, sex and the type of conditions will be collected to be used in data analysis. More information can be found in the [PaRIS Brochure](#).

Next to a patient questionnaire, there will be a short provider questionnaire to collect some practice and provider characteristics.

1.8. How will the survey instrument (questions) be prepared and can countries add national level questions?

Questions will be drawn from existing instruments and are coordinated with national or international partners who have extensive experience with measuring patient-reported outcomes and experiences. Countries will have the opportunity to provide feedback on the survey draft instrument.

Countries will have the option to add country-specific questions to the survey. Additional questions are permitted as long as they are not found to be detrimental to the survey, such as adversely affecting response rates or the psychometric properties of survey scales. At this time, it is estimated that countries may be able to add between 5 and 10 additional questions to the main survey, if desired.

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

The questionnaire will ask concrete experiences and facts such as “are you able to walk 100 metres?” instead of “how satisfied are you with your mobility?” Moreover, together with world-leading experts in the field of patient-reported measurements, the development of the survey will undergo many steps such as cognitive testing and cross-cultural validation to ensure robustness and international comparison. To ensure that the survey is applicable in all participating countries, countries will be actively involved in the development.

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

The PaRIS survey is designed to protect the privacy of the survey participants, both patients and care providers. All Consortium partners involved and the OECD Secretariat will ensure that the conduct of the survey complies 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 will assist countries with documentation to fulfil national requirements for regulatory and ethical approvals, privacy impact assessments and privacy notices. The survey will be conducted with the informed consent of survey participants, and only pseudonymised data will be 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 and it meets the highest standards for data privacy and data protection. Where necessary, adaption will be made for countries to comply with national legislation.

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. The first phase is the development of the instrument, survey questions and small pilots with people to develop the survey questionnaires. This will take place in 2020. The second phase will proceed from 2021 to mid-2022. In this phase there will be a field trial for participating countries, testing all the survey operations. It is envisaged that reports from the field trial operations be published. The third phase, from mid-2022 to 2023, will consist of the main survey implementation in all participating countries, data analysis and survey results publication.

1.12. What will be the sample size of the survey in terms of numbers of patients and providers?

The PaRIS Consortium will make a statistical power analysis in order to determine the minimal sample size. At this stage, it is not possible to carry out such an analysis, because it requires parameters that can only be estimated when it is known which instrument will be used. However, as initial assumption if that 50 (providers) * 50 (patients) = 2500 patients will be a minimum for most countries. Countries will have a say in sample size and will be able to choose to oversample to increase statistical reliability of their data and create more opportunities for subgroup or subnational analyses.

1.13. What is the advantage of organising such as 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 performance at all levels of the health system, and to make comparisons across countries.

A second consideration is economies of scale. The PaRIS survey will make available a fully developed and specified survey tool and survey protocol that can be implemented at a much smaller cost than if each country was developing their own individual PROMs and PREMs tools and infrastructure for assessing the quality of primary care, or other ambulatory health care services. This allows countries to access a state-of-the-art survey platform for a fraction of the costs.

1.14. How is the PaRIS survey governed?

The PaRIS survey is led by the countries. The OECD Working Party for PaRIS guides the development of the work on the new patient reported indicator survey. All participating OECD countries are represented in the Working Party, which reports to the Health Committee. The OECD Secretariat works with all parties involved in the development of the PaRIS survey and provides the support that is need to run the Working Party and the Health Committee. The Secretariat conducts the policy and data analysis and publications of results, based on the indicators developed. Publications are released under the responsibility of the OECD Secretary General, as is practice with other reports produced by the Health Committee.

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 Optimedix A.G has been identified 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 is the Contractor of the project.

- Nivel is an Independent non-profit research institute with strong roots in primary care, patient experience measurements and health system performance assessment. Nivel's mission is to carry out high quality research which has a demonstrable impact upon society.

- Ipsos MORI is part of the third largest market research and public opinion polling company globally, operating in over 90 markets and with over 18,000 staff. Ipsos MORI is also an industry leader in patient surveying.
- Avedis Donabedian Research Institute- UAB (FAD) is a non-profit organisation associated to the Autonomous University of Barcelona. Its mission is to support governments, health and social care organisations and professionals to improve quality and safety of care.
- University of Exeter Medical School's (Exeter, UK) Health Services and Policy Research Group (HSPRG) strengths are in the use of Patient Reported Measures of Outcome and Experiences of health care (PROMs and PREMs), research on models of care for p with multi-morbidity, and Patient Safety in General Practice.
- OptiMedis AG is a private management and data science company with the key aim to set up, implement, manage and evaluate integrated health care networks in order to generate social impact.

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 other grants (e.g., by the European Commission).

1.17. Which countries participate in the PaRIS survey?

By the end of 2020, countries will decide whether they will participate in the data collection that will commence in 2021. Currently, around 20 countries are preparing for the survey, including a number of non-OECD members.

Based on expressed interest, the OECD expects that the majority of these countries will participate in the data collection. If you have any questions about individual country participation, please reach out to the Secretariat at paris_survey@oecd.org.

1.18. What is the first step I need to take if my country wants to participate in Phases 2 and 3 of the survey?

Please contact the Secretariat at paris_survey@oecd.org.

1.19. Who are the PaRIS Points of Contact?

For items related to PaRIS, the best point of contact is the OECD team, who can be reached at paris_survey@oecd.org.