

OECD PaRIS survey

FAQ on Data Protection and Governance

General

What is PaRIS?

PaRIS is the OECD's Patient-Reported Indicator Survey of People Living with Chronic Conditions. It is the first international survey to assess the outcomes and experiences of patients who are treated within primary and ambulatory care settings across countries.

In each participating country, the PaRIS survey will be administered to a random sample of primary and ambulatory care clinics, with a survey questionnaire to collect clinic characteristics; and to a random sample of patients aged 45 and older who are cared for by the selected clinics, with a survey questionnaire.

Patients and health care providers selected to participate in this survey will consent to participate and will participate voluntarily. Information will be provided to ensure that consent is informed.

Who will collect the PaRIS data?

The OECD is conducting the PaRIS survey and has contracted an International Consortium to provide survey management. The International Consortium is led by the Netherlands Institute for Health Services Research (NIVEL) and includes Ipsos MORI.

Ipsos MORI will manage the data collection and processing in all countries, except those electing to manage data collection and processing nationally for legal or operational reasons.

Each participating country will appoint a National Project Manager (NPM) who will be responsible for survey operations within their country and will work closely with the International Consortium.

What data protection standards will be in place for the PaRIS survey?

The PaRIS survey is designed to protect the privacy of survey participants, both patients and health care providers.

It will meet the highest regulatory standards for the legal and safe processing of sensitive personal health data, including [OECD Data Protection Rules](#) and any applicable national legislation, including the European Union *General Data Protection Regulation (GDPR)*.

Ipsos MORI, who will be directly handling the personal data collected, works to the highest industry standards, which will inform the full survey design process:

- **ISO 20252:** the international market research standard covering all stages of a market research project.
- **ISO 9001:** the international general company standard with a focus on continual improvement through quality management systems
- **ISO 27001:** International standard for information security designed to ensure the selection of adequate and proportionate security controls

Ipsos MORI is also an ESOMAR member and complies fully with the ICC/ESOMAR International Code on Market and Social Research, which was developed jointly with the ICC (International Chamber of Commerce) – participation will be voluntary, consent to taking part will be informed, the research will avoid any harm to data subjects, and all data used or collected during the research process will remain confidential.

Nivel, the head of the International Consortium, has a quality management system that complies with ISO 9001, the Code of Conduct for Medical Research of the Foundation Federation of Dutch Medical Scientific Societies, the Netherlands Code of Conduct for Research Integrity 2018.

How will the data for the PaRIS survey be shared?

Personal contact information will not leave countries. NPMs will manage the sampling and survey invitations in their country and NPMs will not share any personal information that identifies survey respondents with Ipsos MORI or the OECD.

- Ipsos MORI will provide each NPM with a unique set of survey-specific code numbers.
- The NPM will provide each survey participant with a survey-specific code number.
- Survey participants will enter their code number within a secure on-line portal; will provide informed consent; and, subject to their consent, will complete the survey on-line and the de-identified data will be saved in the survey data centre.
- Where NPMs collect data directly from survey respondents, NPMs will de-identify the data by removing all personal contact information and attaching a survey-specific code number to each case before securely transferring the data to the survey data centre.

Ipsos MORI regularly runs multi-country surveys, including handling personal data shared by national authorities, and advises on approaches that are in line with local regulatory and ethical frameworks. For PaRIS, this will include understanding the correct legal basis for the research and the data controller and processor relationship, which may vary by country. The International Consortium will also help countries with the documentation needed to achieve national regulatory and ethical approvals, complete privacy impact assessments and provide guidance on ensuring privacy notices are clear and transparent.

The OECD will establish a process for researchers to be granted access to the de-identified international survey data to analyse them for research and statistical purposes. Access will be subject to a data sharing agreement that specifies rules for data security and privacy protection. Countries will manage access to national de-identified survey data in accordance with local requirements.

Sampling

What information will countries need to provide to the OECD and the International Consortium to invite people to take part in the survey?

None. No contact information is shared with the OECD or the International Consortium at any stage. NPMs will be responsible for inviting patients and health care providers to take part in the survey.

The International Consortium will help participating NPMs decide on the best method of inviting patients and health care providers, based on the contact information available.

Will countries need to access confidential health information from patient medical records?

In order to invite patients to take part in the survey, NPMs will need to access contact details and a limited amount of demographic information from patient registration records (gender and age) to help check that the survey is representative. In addition, to ensure the survey is relevant, if possible, the sample source should identify whether a patient has had an appointment in the last six months.

No other confidential clinical data (such as any medical conditions, prescriptions or care received) will be accessed.

What information governance approvals will be needed?

National information governance approvals will be needed to authorise the national data collection and allow access to the sample information. In each country, the International Consortium will work with the NPM to understand the requirements of these approvals. A first step will be understanding the appropriate legal basis for the survey and completing a data privacy impact assessment. Guidance will also be provided on the required supporting documentation, including the content of privacy notices and the wording of advance materials.

In most countries ethical approvals will also be needed – see below for more detail.

Who will have access to patient and clinic contact information?

No contact information is shared with the OECD or the International Consortium at any stage. Only NPMs implementing the PaRIS survey will have access to patient contact information, including any suppliers they use to invite people to take part in the survey. For example, suppliers that may be contracted for sending emails, text messages or printing letters.

This contact information will only be used for the PaRIS survey. Once the survey is finished, NPMs will securely destroy the contact information. Some countries may elect to ask survey respondents' consent to securely store keys to re-identify the survey data for approved research projects and subject to safeguards.

How will patient and health care provider contact information be shared? Will it cross international borders?

Patient contact information will not cross international borders; it will be stored and managed locally.

Patient and clinic contact information will be securely shared within countries with NPMs' staff and suppliers who are contacting survey respondents in their country. The exact method of transfer will vary by country, but the International Consortium will provide guidelines to ensure that the data is protected to the highest standards during transfers, adhering to requirements of applicable legislation and the International Standard for Information Security, ISO 27001.

Where will patient and health care provider contact information be stored and processed?

Patient and health care provider contact information will be securely stored and processed by national project teams and will not be shared with the OECD, the International Consortium or any other party outside the country.

Data collection

What type of data will be collected from patients and health care providers?

The patient survey will include questions about:

- Patient Reported Outcome Measures (PROMS) – for example, self-reported ratings of pain, physical functioning and psychological well-being.
- Patient Reported Experience Measures (PREMS) – self-reported opinions about health care experiences, for example, waiting times.
- Background characteristics – such as age, sex and self-reported chronic conditions.

The clinic survey will include questions about key characteristics of the health care provider to understand how these may relate to the outcomes and experiences of patients with chronic conditions. No confidential clinical data about patient survey respondents (such as any medical conditions, prescriptions or care received) will be collected.

More information can be found in the [PaRIS Brochure](#).

How will patients and health care providers be invited to take part in the survey?

This will vary by country depending on the national context and contact information available. The method used will be agreed between the country and the International Consortium and is likely to be a combination of letter, text message and/or email to sampled patients and health care providers from NPMs.

How will information be collected from patients and health care providers, and how will this be protected?

The survey method used will be agreed between each country and the International Consortium. In most countries, the survey will be primarily collected online combined with other appropriate modes (postal, face-to-face or telephone) to ensure that the research is as inclusive and cost-effective as possible.

Participants invited to the centralised online survey will each be given their own survey-specific code by the NPM. Survey participants will enter their code within a secure on-line portal; will provide

informed consent; and, subject to their consent, will complete the survey online and the de-identified data will be saved in the Ipsos MORI secure survey data centre (accredited to the international Information Security Standard ISO 27001) in a European Union country.

In countries where the survey and data are managed locally, participants will be invited by the NPM to an online, postal, face-to-face or telephone survey conducted by the NPM. The International Consortium will provide guidance to the NPM to ensure the data remains secure. The NPM will de-identify the data and attach a survey-specific code to each case before securely transferring the data to the Ipsos MORI secure survey data centre.

The de-identified data will be securely transferred to and stored by the OECD on a server at its offices in Paris, France. Once the first results from the survey have been published, the survey data will be deleted from the Ipsos MORI secure survey data centre.

Will health care providers be able to see the data collected from patients?

No, health care providers participating in the survey will not be able to see data collected from individual patients. After the survey has been completed, health care providers will have access to aggregated, anonymised, statistical results that will provide them with a better understanding of how to improve the quality of the care they provide.

Will taking part be voluntary?

Yes. Taking part in the survey will be voluntary and any answers will be given with the individual's consent. Clear information about all aspects of the survey will be provided to ensure that consent is informed.

Will the information collected cross international borders?

Personal contact information will not leave countries; they will be stored and managed locally. Answers to survey questions from patients and clinics will contribute to a de-identified international dataset for statistics and research.

During data collection, the de-identified data will be securely stored in an Ipsos MORI data centre (accredited to the International Standard for Information Security, ISO 27001).

The de-identified data will be securely transferred to and stored by the OECD on a server at its offices in Paris, France. Once the first results from the survey have been published, the survey data will be deleted from the Ipsos MORI secure survey data centre.

Where will the data collected from patients and health care providers be stored and processed?

Data collected for this survey will be securely transferred to and stored in an Ipsos MORI data centre (accredited to the International Standard for Information Security, ISO 27001) in a European Union country.

The de-identified data will be securely transferred to and stored by the OECD on a server at its offices in Paris, France. Once the first results from the survey have been published, the survey data will be deleted from the Ipsos MORI secure survey data centre.

Can patients and health care providers access their own information? And can they request that their data are deleted?

Patients and health care providers:

- Have the right to access any personal data (both contact information and survey responses). The Access Request can be honoured by the NPM until the date when the sample and any re-identification keys held by NPM are destroyed. This may be as soon as 3 months after data collection ends.
- Can withdraw their consent and object to the processing of their personal data or any survey answers they provide at any time before the data are processed for reporting. This request can be honoured by the NPM who will delete data they have collected and coordinate with Ipsos MORI to delete data held within the Ipsos MORI data centre.

How long will countries need to retain personal contact information?

Countries will only need to hold onto personal contact information for as long as it is necessary to support the research project and findings. In practice, this means that once the anonymous research findings have been published, all personal, identifying data can be securely deleted by the NPM.

Some countries may elect to ask survey respondents' permission to securely store keys to re-identify the survey data for future approved research projects. In this case, the time limit for key retention will be according to local data governance laws and requirements.

Ethics

Has the study undergone ethical approval?

Ethical approval will be needed in each country where this is a general requirement when seeking access to the survey sample or contacting patients for research. The International Consortium will support NPMs in preparing answers for submission to local ethics boards, including providing other supporting documentation such as draft survey materials that will be shared with participants.

The study will also be reviewed by Ipsos MORI's internal ethical review panel at an early stage to help inform and support the direction of the research. This will offer additional reassurance on the robustness of the approach to countries who do have an ethical review process in place.

How will informed consent be collected?

The OECD and the International Consortium require that sampled patients and health care providers consent to participate in this voluntary survey and that clear information about all aspects of the survey, including data processing, storage and uses, is provided to inform their consent decision. This information will be provided in clear language using a range of different formats (e.g. letters, posters, online). National data governance requirements for obtaining consent will be respected.

Reporting

How will the data collected be used?

The survey data will be used at different levels:

- The data will be used to help **policy makers** better understand how their health systems are performing and how this could be improved.
- **Health care providers** who take part will be able to see anonymised, aggregated indicators of their own results and compare them with indicators for their country and other countries.
- The findings will be used to help health systems become more people-centred benefiting **patients**.

The de-identified data will also contribute to research. The OECD will establish a process for researchers to be granted access to the de-identified international survey data to analyse them for research and statistical purposes. Access will be subject to a data sharing agreement that specifies rules for data security and privacy protection.

Will individual answers be kept confidential?

Yes. Individual answers to the questions will not be linked to names, addresses or any other personal identifiers. The International Consortium will treat individual answers as confidential and adhere to all aspects and provisions of the European Union *General Data Protection Regulation* and all other relevant national legislations, including requirements for secure storage.

Will countries be able to analyse their own data?

Yes. Each country will be provided with de-identified datasets that contain individual level responses for patients and health care providers that can be analysed for research and statistical purposes. Countries may opt to produce a national report of survey results to be released at the same time or after the OECD publishes a first report of international survey results.

Some countries may ask survey respondents for their consent to a linkage of their survey data with other national health or health care datasets. In this case, the country will securely store survey data re-identification keys for the purpose of enabling a dataset linkage.

Will the data be publicly available?

Yes, the OECD will publish indicators from the survey. Public data will be anonymised and aggregated. See the database *OECD Health Statistics* at <https://oe.cd/ds/health-statistics> and <https://data.oecd.org/health.htm> to find out how this is done for other indicators. Indicators will also be reported in OECD and other publications.