paRIS

Patient Reported Indicator Surveys

Frequently Asked Questions on Data Protection

OECD

OECD PaRIS survey

FAQ on Data Protection

General

What is PaRIS survey of People Living with Chronic Conditions?

The PaRIS Survey of People Living with Chronic Conditions is an OECD initiative. 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 is administered to a random sample of primary and ambulatory care practices, with a survey questionnaire to collect practice characteristics and to a random sample of patients aged 45 years and older who are seen by the selected practices, with a questionnaire.

Patients and healthcare providers selected to participate in this survey participate voluntarily after giving their informed consent. See for more information about the survey the FAQ.

Who will collect the PaRIS data?

The OECD has contracted an International Consortium to assist with the survey management. The International Consortium is led by the Netherlands Institute for Health Services Research (NIVEL) and includes Ipsos, one of the world's largest market research and opinion polling companies.

Ipsos manages the data collection and processing in all countries, except those that choose to manage the data collection and processing nationally.

Each participating country has a National Project Manager (NPM) who is responsible for the survey operations in their country and who works closely with the International Consortium. In some cases, NPM's may outsource tasks such as mailings

to third parties.

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

The PaRIS data collection follows the principle of '*privacy by design*'. In addition to conventional data protection measures, such as encryption and password protection, contact information of individuals and their survey responses are physically separated throughout the process.

The OECD and its International Consortium meet the highest regulatory standards for the lawful and secure processing of sensitive personal health data, including OECD data protection requirements and the European Union's *General Data Protection Regulation (GDPR),* and respect all applicable national laws.

Ipsos, who directly handles the personal data collected, operates to the highest industry standards, which are incorporated throughout the 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**: the international standard for information security designed to ensure the selection of adequate and proportionate security controls

Ipsos 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 is 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 leader 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 countries and NPMs never share any personal information that identifies survey respondents with Ipsos or the OECD.

- Ipsos provides each NPM with a unique set of survey-specific artificial identifiers (the survey-ID).
- The NPM provides each survey participant with a survey-ID.
- Survey participants will enter their survey-ID 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 (for example on paper), NPMs will de-identify the data by removing all personal contact information and attaching a survey-ID to each case before securely transferring the data to the survey data centre.

Ipsos regularly conducts multi-country surveys, including handling personal data shared by national authorities, and advises on approaches that are consistent with local regulatory and ethical frameworks. For PaRIS, this includes understanding the correct legal basis for the research and the relationship between data controller and processor, which may vary from country to country. The International Consortium assists countries with the documentation needed to obtain national regulatory and ethical approvals, conducts privacy impact assessments and provides guidance on how to ensure that 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 for research and statistical purposes. Access will be subject to a data sharing agreement that sets out the rules for data security and privacy protection.

Countries will manage access to national de-identified survey data in accordance with local requirements.

Sampling

Do countries need to provide the OECD or the International Consortium with information on individual patients or healthcare providers to invite them to take part in the survey?

No. NPMs are responsible for inviting patients and healthcare providers to take part in the survey. No contact information is being shared with the OECD or the International Consortium at any stage.

The International Consortium will help participating NPMs decide on the best way to invite patients and healthcare providers, based on the contact information available.

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

To invite patients to participate in the survey, NPMs need contact details and a limited amount of demographic information from patient registration records (gender and age) to check that the survey is representative. In addition, to ensure that the survey is relevant, the source of the sample should, where possible, indicate

whether a patient has had an appointment in the last six months.

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

Who has access to patients' contact details?

Only NPMs conducting the PaRIS survey will have access to patient contact information, including any suppliers they use to invite people to participate in the survey. For example, suppliers who may be contracted to send emails, text messages or print letters.

This contact information will only be used for the PaRIS survey. Once the survey is completed, NPMs will securely destroy the contact information. Some countries may choose to ask respondents to agree to the secure storage of keys to re-identify the survey data for approved research projects and subject to safeguards.

Patient contact information does not cross international borders; it is stored and managed locally.

Data collection

What kind of data is being collected from patients and healthcare providers?

The patient survey includes questions on:

- 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 healthcare experiences, such as waiting times and communication.
- Use of health services
- Health behaviour
- Background characteristics – such as age, gender and self-reported chronic conditions.

The provider survey includes questions on key characteristics of the healthcare setting to understand how these may relate to the outcomes and experiences of patients with chronic conditions. The provider survey does not include items on individual characteristics such as age and gender of providers.

A detailed description of data included in the survey can be found in the PaRIS protocol article.

How are patients and healthcare providers invited to participate in the survey?

This varies from country to 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 a letter, text message and/or email to sampled patients and healthcare providers from the NPMs.

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

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

Participants invited to the centralised online survey receive their personal survey-ID from the NPM. Survey participants enter their code within a secure on-line portal; provide informed consent; and, subject to their consent, will complete the survey online. The de- identified data will be saved in the Ipsos secure survey data centre (accredited to the international Information Security Standard ISO 27001).

In countries where the survey and data are managed locally, participants are invited by the NPM to an online, postal, face-to-face or telephone survey. The International Consortium provides guidance to the NPM to ensure the data remain secure. The NPM de- identifies the data and attaches 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 healthcare providers be able to see the data collected from patients?

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

Will the information collected, cross international borders?

Personal contact information will not leave countries and will be stored and managed locally. Survey responses 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 data centre (accredited to the International Standard for Information Security, ISO 27001) in the United Kingdom.

The de-identified data will be securely transferred to the OECD and stored on a server at their offices in Paris, France. The survey data will be deleted from the

Ipsos' secure survey data centre after the first results of the survey have been published.

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

The data collected for this survey will be securely transferred to and stored in an Ipsos data centre (accredited to the International Standard for Information Security, ISO 27001) in the United Kingdom.
Although this is outside the European Union, the GDPR rules still apply to the UK. On 28 June 2021, the European Commission adopted two adequacy decisions for the transfer of personal data to the United Kingdom, under the GDPR and the Law Enforcement Directive (LED).

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

Can patients and healthcare providers access their own information? And can they ask for their data to be deleted?

Patients and healthcare providers:

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

How long will countries need to retain personal contact information?

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

Some countries may choose 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 in accordance with local data

governance laws and requirements.

Ethics

Has the study undergone ethical approval?

Ethical approval was acquired in accordance with the legal requirements in each participating country.

The study has also been reviewed by Ipsos' 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 was informed consent obtained?

The OECD and the International Consortium require that sampled patients and healthcare providers agree to participate in this voluntary survey and that they are provided with clear information about all aspects of the survey, including data processing, storage and use, to help them make the decision to consent. This information is provided in plain language using a range of different formats (e.g., letters, posters, online). National data governance requirements for obtaining consent are always respected.

Reporting

How will the data collected be used?

The survey data will be used at several levels:

- The data will be used to help **policy makers** better understand how their health systems are performing and how they could be improved.
- Participating **Healthcare providers** will be able to see anonymized, 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, to the benefit of **patients.**

The de-identified data will also be used for scientific 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, which will specifies rules for data security and privacy protection.

Will countries be able to analyse their own data?

Yes, they will. Each country will be provided with de-identified datasets containing individual level responses for patients and healthcare providers that can be analysed for research and statistical purposes.

Countries may choose to produce a national report on the survey results, which will be published at the same time as or after the OECD publishes a first report on the international survey results.

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

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.