OECD PaRIS survey

FAQ on Data Protection

General

**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 care providers. The OECD Secretariat and international consortium will ensure that the conduct of the survey meets the highest regulatory standards for the legal and safe processing of sensitive personal health data, including [OECD data protection requirements](https://www.oecd.org/gov/privacy/OECD-DPR-Draft-Framework.pdf), the General Data Protection Regulation (GDPR), and any applicable national legislation.

Ipsos MORI, who will be directly handling the personal data collected, work 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.

In addition, Nivel, the lead contractor, 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. Within each country, National Project Managers (NPMs) and their teams will manage the sampling and survey invitations, and the international consortium will manage the data collection and processing.

- National Project Managers will be provided with a unique set of ID numbers, allowing them to directly invite patients and providers to take part without sharing any contact information across international borders.
The online survey will be centrally managed and hosted by Ipsos MORI. By using unique ID numbers, the information collected from patients and providers who consent to take part will be pseudonymous.

When the survey is completed, international pseudonymised survey data will only be shared with approved persons. National Project Managers will manage access to national pseudonymised survey data in accordance with local information governance requirements.

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 sections below on sampling, data collection, reporting and ethics answer additional questions that countries may have about managing this process.

**Sampling**

**What information will countries need to provide to the OECD and the international consortium to invite people to take part in the survey?**

National project teams will be responsible for inviting patients and providers to take part in the survey. No contact information is shared with the OECD or the international consortium at any stage.

The consortium will help participating National Project Managers decide on the best method of inviting patients and 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, national project teams will need to access contact details and a limited amount of demographic information from patient registration records (gender and age) to help check 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 needed. National Project Managers will be supported in seeking relevant information governance and ethical approvals.

**What information governance approvals will be needed?**

National information governance approvals will be needed to allow access to the sample information. In each country, the international consortium will work with the National Project Manager to understand the detail of these approvals. A first step will be understanding the appropriate legal basis for the research 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 contact information?**

Only national project teams implementing the PaRIS survey will have access to patient contact information, including any suppliers they use in order 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, it will need to be securely destroyed.

**How will patient contact information be shared? Will it cross international borders?**

Patient contact information will need to be securely shared with national project teams and their suppliers. The exact method of transfer will vary by country but guidelines for transfer will be provided to ensure that the data is protected to the highest standards, including the General Data Protection Regulation and International Standard for Information Security, ISO 27001.

Patient contact information will not cross international borders; it will be stored and managed locally, and only seen by the team directly involved in the project within each country.

**Where will patient contact information be stored and processed?**

Patient contact information will be securely stored and processed by national project teams, and will not be shared outside the country.

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**Data collection**

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

The survey among patients with chronic conditions will include questions about:

- Patient Reported Outcome Measures (PROMS) – for example, ratings of pain, physical functioning and psychological well-being.
- Patient Reported Experience Measures (PREMS) – for example, waiting times and communication with healthcare providers.
- Background characteristics – such as age, sex and the type of conditions (collected for data analysis).

Ambulatory care providers will also be asked some questions to establish the key characteristics of the clinic/primary healthcare professional, to understand how these may relate to the outcomes and experiences of patients with chronic conditions.

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

**How will patients and providers be invited to take part in the survey?**
This will depend on agreed research methodology in each country but is likely to be a combination of letter, text message and/or email, depending on the national context and contact information available.

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

Again, this will depend on the agreed research methodology in each country, but is likely to be primarily collected online combined with other appropriate modes (postal, telephone or face-to-face) to ensure that the research is as inclusive and cost-effective as possible.

The online surveys (of patients and providers) will be securely hosted in Ipsos MORI’s data centre (accredited to the international Information Security Standard ISO 27001).

Ipsos MORI applies various precautions to ensure information is protected from loss, theft or misuse. Security precautions include appropriate physical security of offices and controlled and limited access to computer systems. Stringent measures are taken to ensure personal information is securely stored and seen only by the personnel directly involved in the project.

Data collected via other modes (postal, face-to-face or telephone) will be managed locally. Guidance will be provided on working with suppliers to ensure this information remains secure.

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

After the survey has been completed, providers will have access to aggregated anonymised, statistical results, but will not be able to see data collected from individual patients.

**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 will be provided for those who do not want to take part indicating how they can opt out.

**Will the information collected cross international borders?**

Responses from individual patients will cross international boundaries. However, this information will be pseudonymous, i.e. there will be no direct link between these data and the sample with identifying information (which will be managed locally).

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

All data collected for this survey will be stored by Ipsos MORI in data centres and servers within the United Kingdom/Romania (depending on arrangements following the UK’s exit from the EU). These data centres are fully accredited to the International Standard for Information Security, ISO 27001.

**Can patients access their own information? And can they request that their data are deleted?**

Patients will:

- have the right to access any personal data (both contact information and survey responses) until the point at which the sample is deleted (this will be around three months after publication of the results) – this will need to be dealt with by national project teams and Ipsos MORI.
• be able to withdraw their consent and object to the processing of their personal data or any survey answers they provide at any time before the data is processed for reporting – for online data collection this will be dealt with by Ipsos MORI.

These requests must generally be dealt with within one month.

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.

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 National Project Managers 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?

To some extent, this will depend on the legal basis for the research in each country, but in all countries patients and providers will need to consent to take part. When invited to take part in the survey, all participants will be provided with information about what taking part involves, including how long the survey will last and how their data will be stored and handled. This information will be provided in clear language using a range of different formats (e.g. letters, posters, online).

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 information from their own patients and look at how they compare with other providers.
- The findings will be used to help health systems becoming more people-centred benefiting patients.
- The anonymised data will be made publicly available and can for instance be used for academic research.

**Will individual answers be kept confidential?**

Yes. Individual answers to the questions will not be linked to names, addresses or any other personal identifier. The international consortium will treat individual answers as confidential and adhere to all aspects and provisions of the General Data Protection Regulation and all other relevant legislation, including requirements for secure storage.

**Will countries be able to do analysis with their own data?**

Yes. Each country will be provided with pseudonymised datasets that contain individual level responses for patients and providers.

**Will part of the data be publicly available?**

Yes, the OECD publishes a wide variety of health-related data. Public data will be anonymised and aggregated. See the database *OECD Health Statistics* at [https://oe.cd/ds/health-statistics](https://oe.cd/ds/health-statistics) and [https://data.oecd.org/health.htm](https://data.oecd.org/health.htm) to find out how this is done for other indicators. Data will also be reported in OECD and other publications.