

PaRIS PATIENT SURVEY

The PaRIS survey and your personal data

Your general practitioner is inviting you to take part in this research on behalf of Sciensano and the NIHDI. The research is part of an international study that will help us compare and improve patient care across different countries or regions.

The information below explains who we are, the personal data we collect, how we use it, who we share it with, and what your legal rights are.

Who is running the survey?

Sciensano is a research centre and the National Institute of Public Health in Belgium. For more information visit <https://www.sciensano.be/en>.

Symeta Hybrid SA is administering the survey on behalf of Sciensano and your general practitioner. For more information visit <https://www.symeta.com/symeta/static/about-us.shtml>.

Which other organisations are involved?

The survey is being developed by the international PaRIS-SUR consortium and the Organisation for Economic Co-operation and Development (OECD), in close collaboration with Sciensano.

For more information about the consortium visit their website at: www.paris-sur.org.

There is more information about the OECD, the PaRIS Survey and their privacy statement on their website at: www.oecd.org.

What is your legal basis for processing my personal data?

Sciensano need a legal basis to process your personal data.

The legal basis for processing this data is the law of 30 July 2018 on the protection of individuals with regard to the processing of personal data ('framework law') and the General Data Protection Regulation (GDPR).

How did you get my contact details?

Symeta Hybrid SA is contacting you on behalf of your primary care provider. Names were chosen at random from all people who are aged 45 or over and who have had a contact in the last six months. Your primary care provider has shared a limited amount of information so that Sciensano can invite you to take part in this research. This information includes:

- Your name, address and mobile phone number
- Your gender and month and year of birth

They have only been given your name and address to allow them to contact you to take part in the survey. Information about your age and gender will only be used to make sure that the anonymised survey data matches the profile of the practice population as closely as possible.

Symeta Hybrid SA will keep this information confidential and will only use your contact information to invite you to take part in this survey. Once the survey is finished, Symeta Hybrid SA will securely destroy your contact details.

Have you got access to my health data?

No, apart from having had an appointment with a general practitioner in the last six months, no other information about your health has been shared with Symeta Hybrid SA or Sciensano.

Who are my contact details shared with?

Symeta Hybrid SA will keep your contact details in the strictest confidence in accordance with this Privacy Policy, and use them solely for this research. He is fully approved and compliant with the norms ISO 27001 and ISO 9001 and the General Data Protection Regulation (GDPR).

Your contact details are not directly shared with the research team of Sciensano to ensure the confidentiality of your participation.

Do I have to take part?

Participation in this survey is voluntary and free of all constraints. The decision to participate in the PaRIS survey will not affect the quality of care you receive. There are no costs associated with your participation in the survey.

You can withdraw your consent at any time. Please see the section below covering 'Your rights'.

What will I be asked to do?

We are asking you to complete a questionnaire about your health and your experience with your general practitioner.

The information requested in the questionnaire are self-reported, i.e. you fill in the questionnaire. You do not need to make an appointment with your doctor to complete it. No data will be requested or provided by your doctor or any other database.

What happens to my answers?

Sciensano and Ipsos MORI will keep your answers to the questions in strict confidence in accordance with this Privacy Policy.

Your answers will be put together with the answers from other people and are not linked to contact details. They will be pseudonymised, this means that they will be linked to your unique survey number instead of your name so that we cannot identify you.

They will not be shared with your primary care provider.

Ipsos MORI will be responsible for collecting your answers using an online survey. Your answers will be put together with the answers from everyone else in your country. This dataset will not include your name or contact details. It will be analysed by the international consortium on behalf of OECD and Sciensano.

After the project is completed, the OECD will receive and store an anonymous dataset on their secure server and publish the results of the survey in various reports for policy-makers and healthcare professionals. Some scientific articles will be published by the international consortium. All published results will be fully anonymised, which means that it will not be possible to identify anyone.

How will you ensure that my personal information is secure?

Sciensano and the international consortium take their information security responsibilities very seriously. They take precautions to ensure your information is protected from loss, theft or misuse. Security precautions include appropriate physical security of offices and controlled and limited access to computer systems. Strict measures are taken to ensure personal information is securely stored and seen only by the personnel directly involved in the project.

Both Sciensano and Ipsos MORI have regular audits of their information security system and are accredited to the International Standard for Information Security, ISO 27001. All staff adhere to all aspects and terms of the law of 30 July 2018 and the General Data Protection Regulation (GDPR).

Does this online survey use cookies or similar code?

Some online surveys collect information through the use of 'cookies'. These are small files stored on your computer. We only use these files for quality control and validation. They also allow us to see which survey numbers have completed the questionnaire (which means we do not need to send you a reminder), and allow you to re-enter if you do not complete it in one sitting. It is possible for you to delete 'cookies' or to prevent their use by changing the browser settings on your computer.

We also automatically capture information about your operating system, display settings and browser type, including IP address, in order to ensure that the survey questionnaire is delivered in a form suited to the software your computer is using. We do not capture any other information from your computer.

How long will you hold onto my personal data and identifiable responses?

Symeta Hybrid SA will only hold onto your personal data in a way that can identify you for as long as is necessary to support the research project and findings. In practice, this means that once we have reported the anonymous findings, we will securely remove your personal, identifying data from our systems and those of our suppliers.

For this study, we will securely remove your personal data from our systems by 31/07/2022.

Where will your personal data be held and processed?

- Your personal contact data used to invite you to take part in this survey will be stored by Symeta Hybrid SA in data centres and servers within Belgium.
- All pseudonymised online survey data will be collected by Ipsos MORI and stored in a data centre and server within the EEA.
- Pseudonymised data for each country will be stored by the PaRIS Survey consortium and OECD in data centres and servers within the EEA.

Has the survey been approved by an ethical committee?

This study has received formal ethical approval from the Ethics Committee Erasme Hospital (references: P2021/385).

Your rights

- You have the right to access your personal data within the limited period Symeta Hybrid SA holds it, i.e. until the contact information is destroyed.

- Taking part in this survey is voluntary and is done so with your consent. You have the right to withdraw your consent to our processing of your personal data at any time. However, once the data are analysed it is not possible to withdraw your data from the anonymised outputs.
- You also have the right to rectify any incorrect or out-of-date personal data about you which we may hold.
- If you want to exercise your rights, please contact us at the address below.
- We must generally respond to requests in relation to your rights within one month, although there are some exceptions to this.
- You have the right to lodge a complaint with the Data Protection Officer of Sciensano if you have concerns on how we have processed your personal data. You can contact the Data Protection Officer at dpo@sciensano.be or via the contact form on the website <https://www.sciensano.be/en/privacy-notice-sciensano>.

How can I contact Sciensano about this survey and/or my personal data?

Data Protection Officer at:

Email: dpo@sciensano.be
Post: Rue Juliette Wytzman 14 – 1050 Ixelles
Tel.: +32 2 642 51 11