

7 July 2022



PaRIS Survey Privacy Policy for Patients

Survey of people living with chronic conditions

This survey and your personal data

WentWest is inviting you to take part in this survey on behalf of the Australian Commission on Safety and Quality in Health Care and the Australian Government Department of Health. The survey is part of an international study led by the Organisation for Economic Co-operation and Development (OECD), on people living with chronic conditions (called the PaRIS survey – PaRIS-SUR). The survey will help us compare and improve patient care across different countries or regions. For more information visit <http://www.oecd.org/health/paris/>

The information below explains who we are, what data we collect about you, how we use the data, who the data are shared with, and what your legal rights are.

Who is running the survey?

The survey is being carried out by WentWest and ORIMA Research on behalf of the Australian Commission on Safety and Quality in Health Care and the Australian Government Department of Health.

Which other organisations are involved?

The Organisation for Economic Co-operation and Development (OECD) has appointed an international consortium (the PaRIS-SUR consortium) to develop and conduct the survey on its behalf, in close collaboration with the Australian Commission on Safety and Quality in Health Care and the Australian Government Department of Health.

One member of the international consortium is Ipsos MORI. Ipsos MORI will provide the technical support and survey tool for the survey with WentWest.

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: [Privacy Policy - OECD](#).

How did you get my contact details?

WentWest is contacting you because your GP's practice is participating in this survey. Names were chosen at random from all patients at your GP's practice who are aged 45 or over and have visited the practice in the last six months. Your GP practice has shared a limited amount of information so that WentWest can invite you to take part in this survey. This information includes:

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

WentWest will use your name, address, and mobile phone number information to invite you to take part in the survey. Your gender and age information will only be used to make sure you are eligible to participate in the survey.

WentWest 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, WentWest will securely destroy your contact details.

Have you got access to my health data?

No, apart from having had an appointment with your GP in the last six months, no other information about your health has been shared with WentWest.

Who are my contact details shared with?

WentWest will keep your contact details secure in accordance with the Privacy Act and will use them solely for this survey. WentWest is working with an organisation called ORIMA Research to help run this survey. More information about ORIMA Research and its privacy policy can be found at <https://orima.com.au/>

Do I have to take part?

Taking part in the survey is voluntary and will not affect the care you receive now or in the future. If you take part, you can withdraw your consent at any time.

What happens to my answers?

Your answers will be collected using an online survey. Your answers will be put together with the answers from other people surveyed in Australia. This dataset will not include your name or any other contact details.

The data will be analysed by the international consortium on behalf of OECD, the Australian Commission on Safety and Quality in Health Care and the Australian Government Department of Health. Your answers will be linked by the international consortium with the answers that your GP practice gives on a separate GP practice survey. This will be done using the deidentified code given to you as your survey identification number and the deidentified code given to your GP practice as their survey identification number.

Any published results will be aggregated and fully anonymised, which means that it will not be possible to identify anyone.

Your answers will not be shared with your GP practice in any identifiable form.

How will you ensure that my personal information is secure?

WentWest, ORIMA Research and Ipsos MORI take their information security responsibilities very seriously. They will 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 any personal information is securely stored and seen only by the personnel directly involved in the project. Regular audits are conducted of information security, in line with the International Standard for Information Security ISO 27001.

Does this online survey use cookies or similar code?

Some online surveys collect information using '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 ID 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 to ensure that the survey questionnaire is delivered in a form suited to the software your computer is using, this information includes: your IP address, display settings, and browser type.

How long will you hold onto my personal data?

WentWest will only hold onto your personal data for as long as is necessary to support the project and findings. In practice, this means that once we have reported the anonymous findings, we will securely remove your personal data from our systems and those of our suppliers.

For this survey, we will securely remove your personal data from our systems by July 2025.

Where will your personal data be held and processed?

- Contact data used to invite you to take part in this survey will be stored by WentWest in data centres and servers within Australia.
- All anonymised online survey data will be collected by Ipsos MORI and stored in a data centre and server within the UK.
- Anonymised data for each country will be stored by the PaRIS Survey consortium and OECD in data centres and servers within the UK/European Union.
- The Australian Commission on Safety and Quality in Health Care, the Australian Government Department of Health, WentWest and ORIMA Research will have access to the aggregated anonymised results of the survey and will store these data in data centres and servers within Australia.

Has the survey been approved by an ethics committee?

This survey is a quality improvement initiative and not considered research. Ethics approval is not required for quality improvement initiatives in Australia and the survey therefore does not require formal ethical approval.

Your rights under the Privacy Act

- You have the right to access your personal data within the limited period that WentWest holds it, i.e. until the contact information is destroyed.
- Taking part in this survey is entirely 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 this 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 WentWest at PaRIS@wentwest.com.au
- 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 Office of the Australian Information Commissioner if you have concerns on how we have processed the data. You can contact them at enquiries@oaic.gov.au

Under what legislation is my data protected?

In Australia, the collection of personal data (information about an identifiable, living person) is protected by the Privacy Act 1988 (the Privacy Act).

The Privacy Act is the principal piece of Australian legislation protecting the handling of personal information about individuals. This includes the collection, use, storage and disclosure of personal information in the federal public sector and in the private sector.

Your rights under the Australian Privacy Principles contained in the Privacy Act will be respected. When your data are collected, it will be deidentified and will be handled according to this legislation.

All personal information is held securely. Personal information will not be disclosed to other organisations not identified in this document unless it is required under Australian law or a tribunal/court order.

Once your de-identified data are captured by Ipsos MORI, it will be kept private under the EU General Data Protection Regulation, because Ipsos MORI is based in Europe. This regulation applies to data processing activities in Europe, where the international consortium and the OECD are based. The General Data Protection Legislation is a European Union law that governs the way in which countries in Europe can use, process, and store personal data.

How can I contact the Australian Commission on Safety and Quality in Health Care about this survey and/or the data collected by it?

Australian Commission on Safety and Quality in Health Care

Email: parisinitiative@health.gov.au

Post: Australian Commission on Safety and Quality in Health Care GPO Box 5480 Sydney NSW 2001