

PRIVACY POLICY

This policy explains how your data is used by the C19-YRS online system (the system), and the C19-YRS.com and C19-YRS.me websites (the websites).

The system refers to the clinician web portal, and the patient app, which can be accessed on Android and iOS mobile devices or through a web browser. The websites refer to the publicly available support resource website, and the product information website, which are separate from the system.

Who is responsible for the system

The system and website are managed by ELAROS 24/7 LIMITED (ELAROS) a company registered in England and Wales under No. 07469411 and whose registered office is at Electric Works, Sheffield Digital Campus, Sheffield, S1 2BJ.

ELAROS respects personal privacy and is committed to protecting personal data and fully complying with its legal obligations under the GDPR and the Data Protection Act 2018.

ELAROS is a 'data processor' for data gathered through the system, which means that we only process personal data as instructed by our customers. Our typical customers are either clinical organisations that provide care and treatment, or trusted research organisations, such as Universities, who are using the system to support a research study.

ELAROS is a data controller for any data gathered through the websites, which do not gather any personally identifying or sensitive data.

Contacting ELAROS

You can contact ELAROS by writing to us at the above address, or by emailing us at support@elaros.com or by calling us on 0114 286 6200.

Who is responsible for the management of data protection at ELAROS?

We have appointed a data protection officer to support the management of data protection at ELAROS and for dealing with any questions you may have in relation to this privacy policy. You may contact ELAROS using the contact details given above, or directly at dpo@elaros.com.

ELAROS hosts the system and cloud-based software through a third-party hosting provider, **PNP Digital** (<https://pnp.digital/>). For more information on PNP's storage policies for data collected via the system, visit <https://pnp.digital/policies/>

What sort of personal data do we hold and collect?

The system needs to process your name and other details so that staff who are supporting you (the data controllers) know who you are. This information may include:

- Name (First Name and Last Name)
- Address (optional)
- Postcode (optional)
- National Health ID Number, such as NHS number in England, or CHI number in Scotland
- Date of Birth
- Clinical centre you are being seen at
- City, town, borough or district you have been referred from
- Gender
- Email address (optional for referred patients, required for self-registering patients)
- Telephone number (optional, required for self-registering patients)
- Your primary language

The system will also collect and process data about your health, relevant medical history and symptoms if unwell, in particular information about symptoms relating to your health condition if the clinical organisations providing you with care require it. We process this sensitive data so that the clinical teams using the system can access up-to-date information that can inform patient care.

Some additional information may be requested, including but not limited to:

- Information about your health status (including height and weight)
- Information about your medical history/pre-existing conditions
- Number of days in hospital and intensive care due to your health conditions
- Racial or ethnic origin data
- Smoker status
- Any medication you take and what for

Questionnaires in the system may also ask questions on other sensitive topics, such as:

- Thoughts of self-harm (Depression)
- Unpleasant dreams (PTSD screening)
- General thoughts and feelings from family members
- Whether you care for another individual (social role)
- Weight loss and nutritional health (optional)
- Employment status (optional)

The websites do not gather any personally identifying information but they do record technical information about you and how you interact with our website, such as the pages you visit, the links you click, the region you are in, and the time and date of your visits.

Who is your data shared with?

To process your data through the system, ELAROS requires the support of another company called PNP Digital Ltd. PNP Digital are a UK-based software development company composed of app developers, cloud software engineers, web designers and business experts, focused on delivering bespoke digital app and cloud software solutions. PNP Digital host the system

on behalf of ELAROS but are not permitted to process the data collected within it other than as instructed by the relevant data controllers. For more information on PNP Digital's storage policies for data collected via the system, visit <https://pnp.digital/policies/>

ELAROS only acts upon the instructions of our customers and data from the system will only be shared with other bodies with their authorisation (unless exceptional circumstances apply and we are required to share data by law).

Non-identifiable, technical data gathered through the websites may be shared with third parties by ELAROS for purposes such as service improvement and evaluation.

The system and websites are intended for our customers' purposes, so we will never share personal or sensitive personal data with any third party for marketing or commercial purposes.

Will my data be used to support research?

The clinical bodies that are providing users of the system with care may elect to support non-commercial research and the system provided by ELAROS can support this if we are instructed to do so by our customers. Where this is the case, these clinical bodies will have data-sharing agreements with their research partners. Possible reasons for supporting research include:

- To better understand the long-term impact of your condition
- To advance scientific research and potential treatment pathways
- To support ongoing demographic research - exploring the impact of, for example, ethnic origin or smoker status on the trajectory of different health conditions

Prior to instructing ELAROS to provide data about you to a University or other research organisation, our clinical customers will seek your consent and capture your response within the system. None of your data can lawfully be shared by ELAROS with any organisation(s) other than the clinical bodies that are providing you with care without your consent, and in any case no data will be shared in a form that can identify who you are.

What are your data protection rights?

You have several rights under data protection law, including the right to see what data is held about you, have it corrected if it is inaccurate and even to have data removed from the system in some circumstances. If you wish to understand more about your rights or to exert them, you must contact the body providing you with care as ELAROS can only act when instructed by them. We will of course do all we can to assist you.

ELAROS keeps its privacy policy under regular review and places any updates on its home web page. This privacy policy was last updated on 22 July 2024.

Contacting the regulator to make a complaint

You have the right to make a complaint at any time to the Information Commissioner's Office (ICO), the UK supervisory authority in relation to data protection issues (www.ico.org.uk). If you feel that your data has not been handled correctly, or are unhappy with our response to any requests made to us regarding our use of your personal data, you have the right to lodge a complaint with the Information Commissioner's Office. We would, however, appreciate the chance to deal with any such concerns before you approach the ICO so please contact us in the first instance.

The ICO can be contacted by calling 0303 123 1113 or by going online at www.ico.org.uk/concerns.

If a data subject is based outside the UK, you have the right to lodge a complaint with the relevant data protection regulator in your country of residence.

Further information

Questions, comments and requests regarding this privacy policy are welcomed and should be addressed to dpo@elaros.com.