

## PRIVACY POLICY

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

The C19-YRS online system (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 C19-YRS.com and C19-YRS.me websites (the websites) are separate, publicly accessible websites.

### 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 C19-YRS online system, which means that we only process personal data as instructed by our customers, i.e. the clinical bodies that provide you with care and treatment.

ELAROS is a data controller for any data gathered through the C19-YRS.com and C19-YRS.me 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 [hello@elaros.com](mailto:hello@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](mailto:dpo@elaros.com).

ELAROS hosts the **C19-YRS** system and cloud-based software through a third-party hosting provider, **PNP Digital** (<https://pnp.digital/>). For more information on Pipe and Piper's storage policies for data collected on C19-YRS, visit <https://pnp.digital/policies/>

### What sort of personal data do we hold and collect?

The C19-YRS system needs to process your name and other contact details so that those who are treating you know who you are. These include:

- Name (First Name and Last Name)
- Address (optional)
- Postcode (optional)
- NHS number
- Date of Birth
- Medical centre being seen at
- City, town, borough or district you have been referred from
- Sex at birth
- Email address (optional)
- 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 short and long-term COVID. We process this sensitive data so that the clinical teams using the system can access up-to-date information to help treat you.

Some additional information may be requested, but providing this information is optional:

- Information about your health status (including height and weight)
- Information about your medical history/pre-existing conditions
- Your COVID-19 test data (date, type and result)
- Number of days in hospital and intensive care due to COVID-19 care data
- Racial or ethnic origin data
- Smoker status
- Any medication you take and what for

Questionnaires in the C19-YRS 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 C19-YRS.com and C19-YRS.me websites do not gather any personally identifying information, but 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 deliver care and treatment through the C19-YRS system, ELAROS requires the support of another company called Pipe and Piper Ltd. Pipe and Piper 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. Pipe and Piper Ltd host the system on our behalf but are not permitted to process the data collected within it other than as instructed by the relevant data controllers. For more information on Pipe and Piper's storage policies for data collected on C19-YRS, visit <https://pnp.digital/policies/>

ELAROS only acts upon the instructions of our customers and data from the C19-YRS 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 C19-YRS website may be shared with third parties by ELAROS for purposes such as service improvement and evaluation.

The C19-YRS system and website are intended for our customers' purposes, so we will never share your 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 C19-YRS system with care may elect to support non-commercial research into Long COVID 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 symptoms of Long COVID
- To advance the scientific research on Long COVID and its treatment pathways
- To support the ongoing demographic research surrounding Long COVID - exploring the impact of, for example, ethnic origin or smoker status

Prior to instructing ELAROS to provide data about you to a University or other non-commercial organisations interested in health research, our clinical customers will seek your consent and capture your response within the C19-YRS 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 if you do not 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 05 February 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](http://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](http://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](mailto:dpo@elaros.com).