

The present information is intended to Long COVID Companion users.

DESCRIPTION OF LONG COVID Companion app

The Long COVID Companion app has been co-designed by the Luxembourg Institute of Health (LIH), with people affected by Long COVID and healthcare professionals to ensure to meet the needs from people living with Long COVID. Patient partners of the #ApresJ20 association were also involved throughout the development process. This application is intended to provide day-to-day support for adult people with COVID Long, to help them manage their symptoms more effectively, visualize how they are progressing, and support discussions with the healthcare professionals who care for them. It is in no way intended as a medical diagnostic tool, personal medical advice or treatment aid. Under no circumstances does it replace the opinion, diagnosis or recommendations of a healthcare professional.

All the app's features are present, and can be used optionally and at the rhythm you want.

On the "Profile" page, you can enter information such as :

- Socio-demographic data (e.g. month and year of birth, gender, country of residence)
- Information on your COVID-19 infections and Long COVID (dates of infection, diagnosis, medical treatment, etc.).

You can complete your profile at any time, whenever you like.

You can choose an Avatar to accompany you throughout your use of the application.

On the app's homepage, which is updated everyday, you'll have access to various functionalities displayed on a scrolling page. In particular, you can :

- enter your state of health for the day (your general state of health on a scale of 0 to 10, and your detailed symptoms with their intensity as you feel them),
- add events to your medical diary (appointments, treatments, milestones, etc.),
- add life events (food intake, physical activity, sleep, other...)
- record by voice how you're feeling, and anything else you'd like to keep in your diary. You can access this voice diary at any time to retrieve the information you have entered. This is an additional tool to monitor your overall health.

In addition, you can complete standardized questionnaires on your symptoms and quality of life. The results of these questionnaires will be communicated to you in the application in the form of a numerical score, together with the interpretation of this score, depending on the type of questionnaire. Please note that this does not constitute a medical diagnosis, but is provided for information purposes only.

You can visualize the evolution of your symptom intensity using graphs, and download a visual report which you can then share with anyone you choose.

Finally, a "Resources" page provides useful links to validated information sites on Long COVID, specialized care networks and patient associations.

The application also gives you access to the #ELISA COVID LONG FRANCE CHATBOT. This chatbot will answer your questions about Long COVID, providing useful information validated by healthcare professionals. We invite you to read the information notice located in the "Privacy Policy" section of this tool before using it.

Why do we process your personal data?

The LIH will need to collect, store and process some of your personal data to enable you to use the Long COVID Companion application, and, if you consent, to contact you by email to send you newsletters with information and research results linked to Long COVID and to inform you about research studies related to Long COVID you could be interested in.

In addition, in order to help the LIH and other Luxembourg and international research teams to advance biomedical research, your anonymized data, i.e. data that no longer allows you to be identified, may be used for research on digital health, for a better understanding of the Long Covid, or to analyze the impact of the Long Covid on the evolution of vocal parameters, as a reflection of your physical and mental health (vocal biomarkers and emotion analysis). These data will never be linked to your personal data (please refer to the "data retention" section for more information).

LIH is responsible for the collection, storage, and more generally the processing of your personal data and ensures their protection, in accordance with the General Data Protection Regulation (EU) 2016/679 of April 27, 2016 (**GDPR**) and any subsequent texts replacing or supplementing this text, in particular the Luxembourg law of August 1, 2018 organizing the National Commission for Data Protection and implementing the GDPR (together the **Data Protection Law**).

Which data are collected?

The use of the web app "Long COVID Companion" implies the collection of personal data about you to the extent that they are necessary for the proper functioning and your use of the application.

We will collect the following data directly from you through the Long COVID Companion app:

When creating your Long COVID Companion account: your email address, password, first and last name. This data will be stored separately from the data specified below.

1/ Data collected using questionnaires integrated into the app:

- Data about your health: weight, height, COVID-19 infections, type of medical care you receive, symptoms, past or future medical appointments, significant medical events, quality of life, impact of Long Covid on your daily life.
- data related to your personal characteristics: month/year of birth, gender,
- other categories of data processed: level of physical and intellectual activity, presence of stressful events, food intake, level of education, etc.
- Technical data: dates and times of connection

2/ Free voice recording of the vocal diary. Please note that the app will ask you for permission to access the microphone of the device on which you are using the application, so that you can make the recordings. Voice recordings will only take place during the recording sessions you choose to make.

Your data will not be used for any fully automated decision-making or profiling. The Long COVID Companion application does not use cookies and does not collect any geolocation information via your IP address.

Data collected via the Long COVID Companion application is limited to the information you voluntarily enter in the application. No additional data will be collected on the type of device or server you use to access the application.

From time to time, you will be asked to complete satisfaction and application evaluation questionnaires, the results of which will be processed anonymously.

On which legal basis do we process your data?

The use of your personal data is based on explicit consent (art. 6.1a and art. 9.2a of the GDPR).

You can also opt-in or opt-out of receiving newsletters containing information about possible research studies that may be of interest to you.

Who can access your data?

Data collected for the proper operation of the Long COVID Companion Web App are not transferred to other entities and **access to them is restricted to LIH IT administrators** who manage the Web App.

Your data (e.g. health and voice data) may be shared with LIH researchers or external research partners, only after anonymization.

In some cases, data collected for the purpose of enabling your use of the Long COVID Companion Web App may be disclosed to:

- law enforcement or other governmental and regulatory bodies or agencies, upon request and to the extent permitted by law.
- some regulated professionals such as lawyers.

Any questions you may ask the Chatbot #ELISA COVID Long France will be stored anonymously by Kyomed in accordance with the privacy policy accessible directly in the Chatbot.

What are your rights?

You have the right to access and amend your personal data. In accordance with the conditions set out by the law, you also have the right to object to the way in which your data is being used, to request the deletion of your data, to request the restriction of certain aspects of the processing of your data, and to retrieve your data so that you can send it to a third party (right to data portability).

Lastly, you have the right to lodge a complaint with Luxembourg's National Commission for Data Protection (CNPD) in relation to the processing of your personal data.

If you wish to exercise your rights, or if you have any queries concerning the processing of your personal data by LIH, you can contact the LIH Data Protection Officer by e-mail at dpo@lih.lu or by post at :

LUXEMBOURG INSTITUTE OF HEALTH
Protection des données
1A-B, rue Thomas Edison
L-1445 Strassen
LUXEMBOURG

How do we protect your personal data?

The LIH takes appropriate security measures, based on the sensitivity of the data concerned, to protect your data from the risk of unauthorized access, loss, fraudulent use, disclosure, alteration or destruction. Your data will be treated as strictly confidential. They will be pseudonymized, i.e. a confidential reference code will be used instead of your name. This code alone cannot be used to identify you directly, and will only be used to process your data for the correct operation of the application. The correspondence table establishing the link between the reference code and your name will be kept by LIH in a confidential and secure manner, separate from other application data. Only a limited number of people have access to it (see "Who has access to your data" below).

In addition :

- Access to the Long COVID Companion web app is via an authentication system ensuring separation between your credentials and other information you provide in the app.
- Access to your user account is reserved for IT staff only.
- Data transfers are encrypted/encrypted via HTTPS.
- Data encryption (in transit and at rest), pseudonymization, access control and monitoring (unauthorized traffic or unauthorized access to the system) are in place to prevent unauthorized access and data loss.
- To guarantee the integrity and confidentiality of your data, the identification information (provided for the purposes of creating the Long COVID Companion account) is stored separately from the information provided in the questionnaires (different databases on separate servers).
- Data sets are backed up regularly. Backups are tested with restore tests. Data quality management is handled outside the Long COVID Companion web app.

Data storage

Your account data and all other data collected via the application will be stored in compliance with the law.

Your data will be anonymized if one of the following 3 cases occurs:

- 1/ You delete your Long COVID Companion account.
- 2/ Account inactivity for more than one year
- 3/ Withdrawal of your consent.

Anonymization consists of deleting data that could identify you (surname, first name, e-mail address). You will also no longer receive e-mails from us.

Transfers of data outside the European Union

Your personal data will not be transferred outside the European Union.

For more detailed information on the appropriate measures implemented by LIH, you may send a written request to the LIH Data Protection Officer by e-mail to dpo@lih.lu.

For any other questions relating to the Long COVID Companion application, please contact us by e-mail at longcovidcompanion@lih.lu.

I confirm that I am over 18 and I consent to the collection, storage and processing of my personal data by LIH as described above in connection with the use of the Long COVID Companion web application.

I agree to be contacted by email by LIH (information about Long Covid, newsletters or information about research studies that may be of interest to me).