

Privacy policy for the PARI Connect app

Last updated: 25 October 2024

PLEASE READ OUR PRIVACY POLICY CAREFULLY BEFORE USING OUR APP.

1 General information

We, PARI Pharma GmbH ('PARI'), based in Starnberg, are part of the PARI Group. We are passionate about shaping a world in which everyone can breathe freely. To achieve this, we develop innovative, high quality and scientifically tested products for the treatment of respiratory diseases.

The PARI Connect App ("**App**") has been specially developed for patients with chronic lung disease and can only be used in conjunction with an eTrack Controller. The aim is to accompany patients and carers on their treatment journey and to provide them with a treatment management tool.

This privacy policy applies to our mobile iOS and Android apps. We store and process your health data only with your consent. In this privacy policy, we explain the nature, purpose and scope of data collection in the context of use of the app. We would like to point out that online data transfer may be vulnerable to security breaches. Data cannot be completely protected against access by third parties.

We are aware of our responsibility towards you and your data. We will handle your data with the greatest of care at all times and in compliance with the applicable data protection regulations.

2 Controller

The '**controller**' for processing your '**personal data**' under the data protection regulations is ourselves,

PARI Pharma GmbH
Moosstrasse 3
82319 Starnberg, Germany
Germany

3 Data protection officer

You can reach our data protection officer as follows:

PARI Pharma GmbH
Data protection officer
Moosstrasse 3
82319 Starnberg, Germany

Tel. +49 (0)8151 279279

or

dataprotection@pari.com.

4 Data processing in the context of registration

What categories of personal data do we process under this data processing activity?

PARI Pharma GmbH shall create a user account for you. We require an email address, a password and a nickname to do so.

Please create a nickname that does not allow any conclusions to be drawn about your name. Also with respect to the email address you enter, you may use an address that does not allow any conclusions to be drawn about your name. This allows you to protect your identity too.

Once you have successfully registered, we shall send you a confirmation email to the email address you entered.

What do we process your personal data for when you register?

Data processing is carried out to provide your user account. An eTrack controller is required to use the app.

What is the legal basis for this data processing activity?

The legal basis for this is the performance of a contract with you concerning use of the app as per Art. 6(1)(1)(b) GDPR/UK GDPR).

Who do we share your personal data with during this data processing activity?

We will not share your data with third parties unless you explicitly enable this in the app to give your doctor access. More information about this can be found under the section on data recipients and the 'Share data' function (see below).

5 Multi-factor authentication

What categories of personal data do we process under this data processing activity?

Multi-factor authentication can be set up to additionally restrict access to the app. A mobile phone number is used for this. Ideally, this should be a different mobile phone number to the one for your device where you install the app. The mobile phone number stored in your user account is also saved for this purpose. You then receive an additional PIN as an SMS to log into the app.

What is the legal basis for this data processing activity?

You provide your personal data on a voluntary basis. Data processing is based on your consent as per Art. 6(1)(1)(a) GDPR/UK GDPR. You may revoke this consent at any time with effect for the future. The lawfulness of processing carried out based on consent up until revocation of the same is not affected by such revocation, however. You may send your revocation to dataprotection@pari.com at any time.

Who do we share your personal data with during this data processing activity?

We do not disclose your data to third parties. More information about this can be found under the section on data recipients (see below).

6 Data processing in the context of app functions, data storage and data management

What do we process your personal data for during these data processing activities?

We store data in the app so you can view and retrieve it at any time.

- To use the app, you must either connect the app to your eTrack controller (blue or grey device) and, if applicable, additionally your mySpiroSense via Bluetooth or enter the invitation code you received from your doctor. The app then transfers and stores the inhalation data and, if necessary, the lung function measurements. The grey eTrack controller allows you to automatically transfer your inhalation data via Wi-Fi. Simply register the WiFi name and the password in the app and on the eTrack Controller.
- The app includes a treatment plan that you can enter all your treatments and activate individual reminders in. You can also enter what medication you have already taken. You can also answer questions about your current quality of life, fill out quality of life questionnaires (cystic fibrosis questionnaire – revised application ('CFQ-R')) and enter your current health data (e.g. oxygen saturation or weight). All the values and all the medication taken can be viewed in the Analysis section and sent to third parties as a report. You can also record how intense your coughing was on a coughing scale. There is also a diary function where you can save comments. By providing this feature, we want to give you an overview of your treatment.
- The app tracks some of your entries, such as the time you last took medication, to document the same.
- The app is connected to a PARI back-end where the user and treatment data is stored, managed and analysed. Central data storage means that data cannot be lost and you can switch to another mobile phone without having to create a backup first.
- The PARI back-end sends you push notifications that remind you of certain actions in your treatment process, including synchronisation with the eTrack controller, the end of treatment breaks, or reports that you can send to third parties if you have activated this function previously.
- Report function: If you'd like to send your reports to yourself or to a third party, please note that the reports are sent by email and that this may not be a secure means of communication unless end-to-end encryption is used.
- 'Share data' function: If your doctor uses the PARItrack Dashboard and invites you to share your data with them, you can enable this function in the app. You enter the code that your doctor has to give you for this in the 'Share data' section or when you first register in the app and instruct us to make the data available to the doctor. This shares your data with your doctor in the 'PARItrack Dashboard' (encrypted web portal), so they can view your treatment plan, your treatment performance, your wellbeing, your cough data and the answers to and results of the completed CFQ-R questionnaires and your vital parameters. Your doctor will not have access to your diary entries. Your doctor can enable permissions for additional practice staff to access the PARItrack Dashboard. **You can disable this at any time in the app in the 'Share data' section.** Your doctor will then no longer be able to see any of your data (neither from the past, nor from the future).
- In the UK you can also share your inhalation data with the Cystic Fibrosis Health Hub (CFHealthHub) if you have your eTrack Controller registered in the CFHealthHub platform. To do that you can select to share your data with the CFHealthHub within the share data function in the more section. Your inhalation data only will then be transferred to the CFHH platform. **You can disable this at any time in the app in the 'Share data' section.**

Please refer to the detailed data protection information of CFHealthHub for further information about data processing within the CFHealthHub.

- “Buddy System” function: This feature allows you to invite someone to support your treatment journey (“Therapy buddy”) or someone who is automatically informed if your therapy adherence drops, who can then remind you about your therapy (“Reminder”). These people have selected access or information about the entries in the app and your therapy. You can stop sharing at any time. If you change your access rights, your buddy is only shown the functions you have selected at that time.
- “Cough detection” function: Here, you can record the frequency of your nightly coughing on the microphone of your smartphone and see the results. If you use this function, the app will request the following information from you: Age range, biological sex, sleeping arrangements. The app also has to be authorised to gain access to the microphone of your device. The microphone has to be switched on. If you have activated this function, audio recordings are made when the App recognises a coughing sound. These short audio recordings are saved locally on your device, and are deleted again as soon as the number of coughs is determined. Nobody has access to the temporary, locally saved audio recordings. The function is based on a clinically validated algorithm, which analyses and evaluates the data you have entered for the coughing function and the audio recording. The cough monitoring does not work in large spaces or outdoors, if you share your bedroom with someone of the same sex or with children.

The following additional data can be specified for the app’s above functions:

Height, date of birth, manual information about treatment performance, appointments, medication, activities, and vital parameters such as weight, oxygen saturation, lung function and blood sugar.

What are the legal bases for these data processing activities?

You provide your personal data and health data on a voluntary basis. Processing of this data is based on your consent as per Art. 6(1)(1)(a) and on Art. 9(2)(a) GDPR/UK GDPR for your health data. You may revoke this consent at any time with effect for the future. The lawfulness of processing carried out based on consent up until revocation of the same is not affected by such revocation, however. You may send your revocation to dataprotection@pari.com at any time. Please note that the processing of this personal data is necessary to guarantee all of the app’s functionalities.

Who do we share your data with during this data processing activity?

Your data will not be disclosed to third parties as long as you do not actively give your doctor access to your data using the ‘Share data’ function or your therapy buddy using the ‘Buddy system’. More information about this can be found under the section on data recipients (see below).

7 Data processing for the purpose of anonymisation

What do we process your personal data for during these data processing activities?

The data collected when the app is in use may be anonymised by PARI, to remove any reference to you. The anonymised data is no longer personal data. What characterises anonymised data is the fact that it lacks any references to specific individuals, and also this information can no longer be recovered following the anonymisation process. We use the anonymised data, among other things, for scientific research and statistical purposes, and particularly for the

purpose of evaluating, communicating and (if necessary) proving the effect, use and benefits of the app.

What are the legal bases for these data processing activities?

The anonymisation process is based on Art. 9(2)(j) GDPR/UK-GDPR.

Who do we share your data with during this data processing activity?

The data is not disclosed to third parties for the anonymisation process.

8 Cookies

The app itself does not use cookies. However, in some country versions we have integrated important information and content from our website within the app for you. Only technically necessary cookies are used if you use these functions. No advertising or statistical tracking takes place. The legal basis is our legitimate interest as per Art. 6(1)(f) GDPR/UK GDPR. Our interest is to provide user-friendly presentations in the app.

Information about data processing can be found on our website at: <https://www.pari.com/de/datenschutz/datenschutzerklaerung-internet/?disableOptIn=1>

9 What we do to protect your data

Our app transfers the data you enter in the app to a PARI-managed server in the AWS cloud for secure storage and to provide you with the desired app features. For transfer, the data is encrypted for security reasons and to protect the transfer of confidential content. This encryption prevents the data you transfer from being read by unauthorised third parties. The data is also stored in encrypted form on the server.

10 Processor

We work with Amazon Web Services EMEA SARL, 38 Avenue John F. Kennedy, L-1855 Luxembourg ('AWS') and "Google Analytics Firebase" (Google Ireland Limited based in Gordon House, Borrow Street, Dublin 4, Ireland) as partners for the technical implementation and management of the app. We have concluded appropriate contracts (especially processing contracts) with the service providers that ensure that your personal data is processed in accordance with the legal requirements. Processors are not third parties. For the potential transfer to third countries, see paragraph 18.

11 Data recipients

Your data may be viewed by the following recipients. Some of them only have access to pseudonymised data.

- Processors such as AWS and Google Analytics Firebase
- Employees and external staff working for the PARI Group who require the data to carry out their tasks, e.g. app support
- People that you send your reports to in the context of the report function
- Your doctor and their staff and/or the CFHealthHub personnel, if you have shared your data with them using the 'Share data' function
- People that you have invited as therapy buddy

12 Minors

Minors may only use our app before the age of 16 with the consent of a parent or guardian. Use of the app is prohibited if a parent or guardian does not consent to the processing of the

minor's personal data. You therefore confirm to us that you are at least 16 years old during the registration process or that your parents have agreed to the use.

13 The app's access rights

We require the access rights listed below to provide our services through the app: (i) Bluetooth; (ii) if the transfer is via WiFi, access rights to this are required; and (iii) if cough detection is used, the microphone of your smartphone.

For Android devices, the Bluetooth function permits access to location data. We have no influence over that. In the context of the app, we do not store or use the location data.

14 Requests sent to us

If you contact us (e.g. using the contact form within the app, or by email, phone or fax), we shall store and process your request, including all personal data resulting from the same (e.g. name, request), for the purpose of processing your request. The legal basis for processing is our legitimate interest in responding to your request.

15 Use of analytics tools

Google Analytics Firebase

In the Android version of the app, we use Google Analytics Firebase (hereinafter referred to as 'Google Firebase') to analyse app crashes (Firebase Crashlytics) and to send push notifications. The provider is Google Inc., Google Ireland Limited, based at Gordon House, Barrow Street, Dublin 4, Ireland.

Google Firebase stores information for these purposes, including the number and duration of sessions, operating systems, device models and region.

The use of Google Firebase may require that your personal data be transferred to the USA. The storage period for the data thus recorded is a maximum of 14 months.

The use of Google Firebase to send push notifications is based on the fulfilment of the contract with you regarding the use of the app as per Art. 6(1)(1)(a) GDPR/UK GDPR.

Data processing for analysing crash reports is based on your consent to data processing as per Art. 6(1)(1)(a) and Art. 9(2)(a) of the GDPR/UK GDPR, and appropriate national laws.

More information about Google Firebase can be found at:

<https://firebase.google.com>

<https://www.firebase.com/terms/privacy-policy.html>

During transfer to Google Analytics Firebase, your data is encrypted using the HyperText Transfer Protocol Secure (HTTPS) and transferred over logically separate network infrastructures. More information about the above-mentioned protection measures can be found at <https://firebase.google.com/support/privacy>. Alternatively, you are welcome to contact us by email on the above-mentioned contact address.

Developer reports on iOS

If you have activated the sharing of iPhone analysis data with Apple Inc. and its subsidiaries in your iPhone settings, we may also be given the opportunity to access anonymised crash reports from Apple Inc. The crash reports contain anonymised information on operating system specifications as well as performance and usage statistics, but no personal data.

16 Internal analyses for product improvement purposes

We analyse your data in pseudonymised form in the context of product improvement. This is a legitimate interest as per Art. 6(1)(f) of the GDPR/UK-GDPR. If you use our app, your behaviour and the app's usage behaviour may be statistically evaluated and analysed to improve our products. These analyses take place internally. Your pseudonymised data is not disclosed to third parties.

17 Storage of your data on AWS servers

All data processed with the app is processed on servers belonging to Amazon Web Services EMEA SARL, 38 Avenue John F. Kennedy, 1855 Luxembourg, Luxembourg (**'AWS'**). Data processing takes place within the EU.

18 Transfer to third countries

PARI will not transfer your data to third countries.

When you use AWS, data are sent to AWS and, under certain circumstances, sent to the USA to Amazon Inc. Amazon Inc. may process the transferred data to create anonymised user profiles for statistical purposes. We essentially have no influence on this data processing. AWS is therefore responsible for this data processing.

AWS has implemented compliance measures for international data transfers. These apply to all world-wide activities in which AWS processes personal data from natural persons in the EU and in the UK. Data transfer to the USA is based on the Standard Contractual Clauses (SCC). Details are available here: <https://aws.amazon.com/de/blogs/security/aws-gdpr-data-processing-addendum/>.

AWS is also an active participant in the EU-US Data Privacy Framework, including the UK Extension, which governs the correct and secure data transfer of personal data from EU and UK citizens to the USA. AWS undertakes to comply with the European level of data protection when processing your relevant data, through the EU-US Data Privacy Framework including the UK Extension and through the SCC, even if the data is stored, processed and managed in the USA.

More information on the handling of user data is available in the AWS data protection policy at https://aws.amazon.com/de/privacy/?nc1=f_pr.

Google may also send your data to the USA. Google is an active participant in the EU-US Data Privacy Frameworks, including the UK Extension, which governs the correct and secure transfer of personal data from EU and UK citizens to the USA. Google also uses Standard Contractual Clauses (SCC). Google undertakes to comply with the European level of data protection when processing your relevant data through the EU-US Data Privacy Framework including the UK Extension and through the SCC, even if the data is stored, processed and managed in the USA. More information is available at <https://policies.google.com/privacy>.

19 Storage period and deletion in the event of inactivity

Unless expressly otherwise stated in this privacy policy, data stored in association with this app will be deleted as soon as it is no longer required for its intended purpose and providing

the deletion does not conflict with any statutory retention obligations, e.g. in the case of data that must be retained for commercial or tax law. National legal provisions set out in commercial and tax law may require a retention period of up to 10 years.

You have the right to withdraw your consent to the processing of your data at any time and to apply for the deletion of your data or to object to the processing of your data. If we are not obliged by law to retain your data, we will delete all of your data.

20 Your rights

You have the right at any time to request that we grant you **access** to the data stored about you (Art. 15 of the GDPR / UK GDPR). This also applies to the recipients or categories of recipients that the data is disclosed to, and the purpose and duration of storage.

You also have the right to request **rectification** under the conditions set out in Art. 16 of the GDPR/UK GDPR), the right to request **erasure** under the conditions set out in Art. 17 of the GDPR/UK GDPR), and the right to request **restriction of processing** under the conditions set out in Art. 18 of the GDPR/UK GDPR).

If personal data is processed for the performance of tasks carried out in the public interest (Art. 6(1)(1)(e) of the GDPR/UK GDPR) or to safeguard legitimate interests (Art. 6(1)(1)(f) of the GDPR/UK GDPR), you can object to the processing of your personal data at any time with effect for the future. If you file an **objection**, we must refrain from any further processing of your data for the aforementioned purposes, unless we can demonstrate compelling and legitimate grounds for processing that outweigh your interests, rights and freedoms, or processing is necessary for the establishment, exercise or defence of legal claims.

Under the conditions set out in Art. 21(1) of the GDPR/UK GDPR), data processing may be objected to on grounds relating to the data subject's particular situation.

Furthermore, you may request a **data transfer** at any time under the conditions set out in Art. 20 of the GDPR/UK GDPR.

Please contact dataprotection@pari.com to exercise these rights.

You have the right to lodge a complaint with a data protection supervisory authority without prejudice to any other administrative or judicial remedy. You may contact the data protection supervisory authority in your usual place of residence or our company headquarters for this purpose.

21 Using the app within studies

If you are using the app in the context of a study, it is possible that within the scope of the study personal data is also partly processed jointly with the person responsible for the study in accordance with Art. 26 GDPR/UK GDPR. If you have any questions, please contact the person responsible for the study. Please refer to the detailed patient information and data protection information concerning participation in studies for further information about data processing within the study, which the person responsible for the study will give you. The person responsible for the study is also the point of contact for your enquiries.

22 Modifications

We reserve the right to modify our security and data protection measures if this becomes necessary due to technical developments. In such cases, we shall also adapt our privacy policy

accordingly. Please, therefore, ensure that you have accessed the latest version of our privacy policy in each case.

The current version of our privacy policy can be found in the app under 'More'.