

LAST UPDATE: 08-06-2023

BUDIYU PRIVACY POLICY

PatientSolutions BV ("PatientSolutions" or "we") with its office at the Torenallee 3, 5616 BA in Eindhoven, wants you to be familiar with how we protect your privacy. This privacy policy describes how we handle personal information collected through the Budiyu application. In this privacy policy, the word "personal information" refers to all personal medical and health-related data you insert into the app together with data generated from using the app by you. Furthermore, the words "you" and "user" refer to the person that has installed the app on its device and has created an account within the app.

1. ABOUT THE BUDIYU APP

The App is built with the intention to improve the quality of life for patients living with a chronic disease. It has been developed by experienced doctors from PatientSolutions with the help of patients (organizations). The current version offers support to parents of patients with an MC4R gene defect, but in the future the Budiyu app can be expanded to support other patient groups as well.

This Privacy Policy also applies to new versions of the Budiyu App as soon as they are introduced.

Please read the privacy information below to learn more about how your personal information is processed and for what purposes.

2. PROCESSING OF PERSONAL INFORMATION

We process personal information with your consent on the basis of the consent form that you signed. We have put appropriate safeguards in place and put strict limitations on the processing of those data to protect your privacy rights.

2.1 Personal Information processed to provide the functionality of the Budiyu app

In order to make the best use of the functionalities of the Budiyu app, the Budiyu app will process your personal information as well as that of patients suffering from MC4R gene defect that legally fall within your care. You can manually insert this information into the Budiyu app.

The following personal information of you is stored on the Budiyu server:

- Unique identification code
- First and last name
- Date of birth and country of residence
- email address and password
- scan/photo as avatar
- journal entries of the quality of life questions

The following personal information of the child is stored:

- first and last name
- date of birth

- scan/ photo as avatar
- journal entries of the quality of life questions
- weight
- hunger score
- medication use

You can also manage the personal information of others in the app based on your role. In this first version of the Budiyu app there is only the role of a parent for a child for whom you want to manage the personal information. You can add the child yourself or you can be invited by another adult to manage the child's personal information together.

In the future, the roles will be able to be expanded upon which this privacy statement will be updated. This always concerns the management of (part of) the personal information as mentioned above.

PatientSolutions takes great care in protecting your privacy. The personal information is stored on the Budiyu server in an encrypted manner. Encryption is a security measure that aims to make the data unreadable for any person accessing the data wrongfully unless having the data encryption key. We dive further into the security measures concerning your personal information later in this document.

2.2 Personal Information processed for other purposes

We collect the personal information for two other purposes described below: i) analytics (in anonymized form) to improve the Budiyu app; ii) future research (in pseudonymized form) into quality of care.

2.2.1 Use of anonymous personal information for analytical purposes

We solely use anonymised data such as (non-exhaustive) functions used, device type, amount of time on a screen, and time of use of the app. For this purpose we use Google Firebase Analytics software in the configuration of anonymous collection so that we will not collect any personally identifiable information for this purpose.

These anonymous data will be stored on our secure DataLab server.

The anonymous data will only be used in aggregated form for two purposes only:

- By PatientSolutions to gain insight into the use of the Budiyu app and to adapt it accordingly
- By Rhythm Pharmaceuticals to gain insight into the use of the Budiyu app

2.2.2 Option to process pseudonymised information for future research

On day 3 after the installation of the Budiyu app and then on day 7, month 1 and at various times in the following months, the Budiyu app asks if you want to give consent to share your personal information securely with PatientSolutions for future research into the quality of care.

You will receive extensive information about this optional request in the Budiyu app on which you can make an informed choice.

- If you give consent:
 - You confirm that this consent is freely given, specific, informed and unambiguous by pressing the “yes” button in the chat. This consent is shown in the settings section under “Permissions”
 - From that moment onwards, your personal information will be collected and stored in our separate secure DataLab server.
 - you will receive a new notification after 2 years with the question whether you still support this choice. This is to prevent your consent from being valid indefinitely.
- If you withdraw your consent:
 - you can also withdraw your consent at any time via the Settings in the Budiyu app. From the moment onwards, no more personal information will be collected and stored in our secure DataLab server.
 - The previously collected and stored personal information in our secure DataLab server will be retained. How you can have this personal information removed, you can read further down under “YOUR RIGHTS”.

We pseudonymise personal information by automatically removing all identifiable personal information (except for your year of birth) and by replacing your unique Budiyu identifier with a unique Datalab identifier.

The pseudonymized DataLab server is not accessible to third parties, except for authorized employees of PatientSolutions for data quality control (e.g. preventing duplications or incorrect data) and generating anonymized aggregated reports for analytical purposes. Logging of access to the DataLab is done.

We only provide the analyses in aggregate form to third parties. Under no circumstances will these results contain personal information and PatientSolutions will under no circumstances provide the underlying data to third parties. For example, the analytical insights can be shared with health insurers, pharmaceutical companies and (academic) hospitals to further contribute to the improvement of patient care.

3. LEGAL BASIS

- The Budiyu app processes your personal information, as this is necessary for the functionalities of the app. The processing is therefore based on contractual necessity (Article 6.1(b) of the GDPR).
- Because this information qualifies as medical and health-related information, the Budiyu app will ask for your explicit consent to process your personal information (Article 6.1(a) and 9.2(a) of the GDPR).
- The Budiyu app will transfer your personal information to the secure DataLab server for analysis only with your explicit consent (Article 6.1(a) of the GDPR). You can withdraw this consent at any time via the settings of the Budiyu app.

4. SECURITY OF YOUR INFORMATION

Please note that your information is stored on our servers in a coded (i.e. encrypted) format, which means that even if someone unlawfully accesses your information, the information will not be readable by them. The information in the Budiyu app is not accessible to others. When setting up the Budiyu app, you first create a Budiyu account by registering with a working email address and creating a password. You will then receive an email containing a link to confirm your Budiyu account. You then have to log in once with your email address and password, after which you will receive a 6-digit code by email as extra security. You must enter this in the Budiyu app to continue the installation of Budiyu. The app will then ask you to set a 5-digit passcode to ensure that unauthorized persons cannot access the Budiyu app and the information stored in it, even if you lose your device. The app doesn't allow you to set a simple password that can be easily guessed by others, such as 00000 or 12345.

When you get a new phone on which you want to use the Budiyu app again, you can immediately log in to your Budiyu account with your email address and password during installation, with which all your previously saved data will immediately be visible again in the app.

Your information is also always encrypted when it is transferred or in transit and the information is stored encrypted on our servers. The server on which this data is managed meets the latest security requirements and all information is stored encrypted so that it is not visible to anyone.

We take appropriate security measures to protect your personal data and also require this from parties that process personal data on our behalf. The (sub)processors we engage meet strict security standards and are in possession of mandatory ISO and NEN certifications when appropriate (e.g. ISO27001, ISO9001 and NEN7510). For example, we ensure that only persons have access to your data who must necessarily have access to it and that access to your personal data is protected. All our employees are bound by confidentiality agreements.

To further protect your security, we have ensured that the information is only processed within the European Economic Area (**EEA**).

5. PERSONAL DATA SHARING AND PROCESSORS

We do not share your personal data with others, unless we are required to do so by law or in case we ask companies to help us provide our services like developing the app or hosting the app on servers. We call such companies 'processors'. Where we ourselves are data-controllers, these companies are "sub-processors". We conclude so-called processor agreements with these (sub) processors. In it we agree that they may only use your personal data on our instruction and for the provision of the services mentioned above. They are not allowed to use your personal data for their own purposes.

We use the following types of (sub-)processors or outsource the following data processing activities:

- Storage of personal information on servers, backend database to which the Budiyu app is connected for management and maintenance;

- analytical software to improve our application (including privacy-friendly Google Analytics GA4), and;
- hosting provider(s) for the Budiyu app;

6. RETENTION PERIOD

The pseudonymized personal information will be processed for quality care analysis on the secure DataLab server as long as PatientSolutions manages the Budiyu app and carries out its legal objective of improving patient care. Your personal information for which you gave consent, will be kept indefinitely, unless you request its deletion. A request for deletion of your personal information can be done via helpdesk@budiyu.com

Every 2 years we will ask for your explicit consent to continue processing your information for these purposes.

When no new personal information is collected via the Budiyu app due to the following circumstances:

- the Budiyu app is deleted from the telephone without withdrawing consent;
- the Budiyu app is still on the telephone but the user does not use it anymore;

Then, we will automatically delete the personal information from our servers after a period of 2 years (i.e. retention period).

7. USE OF BUDIYU APP BY MINORS

The Budiyu app is not intended for anyone under the age of sixteen (16).

8. YOUR RIGHTS WITH REGARDS TO THE PERSONAL INFORMATION PROCESSED IN THE APP

Privacy legislation gives you certain rights with regard to the processing of personal information. The rights we describe below are not absolute rights. We will always consider whether we can reasonably comply with your request. If this is not possible, or if it would be at the expense of the privacy of others, for example, we can refuse your request. If we refuse a request, we will let you know with reasons.

8.1 Right to withdraw consent

The personal information processed through and for using the Budiyu app will be processed, unless you would withdraw consent altogether.

If you withdraw consent for collection of pseudonymized data:

- you can also withdraw your consent at any time via the Settings in the Budiyu app. From the moment onwards, no more personal information will be collected and stored in our secure DataLab server.
- The previously collected and stored personal information in our secure DataLab server will be retained. How you can have this personal information removed, you can read further below.

8.2 Right of access

You have the right to request which personal information we process from you or the child. You can also ask us to provide insight into the processing purposes, the categories of personal

information involved, the (categories of) recipients of personal information, the retention period, the source of the personal information and whether or not we use automated decision-making.

You may also request a copy of your or the child's personal information processed by us. Do you want additional copies? Then we can charge a reasonable fee for this.

8.3 Right to rectification

If the personal information processed by us about you is incorrect or incomplete, you can request us to adjust or supplement the personal information. If we grant your request, we will, if not requiring disproportionate efforts, inform the parties to whom we provide data.

8.4 Right to portability

At your request, we can transfer the personal information that we process to you or another party to be designated by you. You can make such a request at reasonable intervals.

8.5 Right to erasure of data

Do you no longer want us to process certain personal information? Then you can request that we erase certain (or all) personal information about you or the child. You may exercise this right when:

- The personal information is no longer necessary for the purposes for which it was collected or processed;
- You withdraw your consent to the processing of personal information and there is no other legal ground for the processing;
- You object to the processing of your personal information and there are no overriding legitimate grounds for the processing;
- Your personal information has been unlawfully processed;
- Your personal information has to be erased for us to comply with a legal obligation.

If the holding of the data is necessary for the handling of legal proceedings or a (legal) dispute, we will delete personal information only after the procedure or dispute has ended.

If we grant your request, we will inform the parties whom we provide data about this.

You can send a request for access, correction, deletion, data transfer of personal data or objection to the processing of personal information to helpdesk@budiyu.com. We will then contact you to try to grant this request after we have established your identity (first on the basis of verification questions such as date of birth and otherwise via a shielded ID).

We aim to process your request, complaint or objection within one month. If it is not possible to make a decision within one month, we will notify you of the reasons for the delay and when the decision is expected to be provided (not later than 3 months after receipt).

9. RESTRICTION OF PROCESSING

If you dispute the correctness of personal data processed by us, if you believe that we have processed personal data unlawfully, if we no longer need the data or if you have objected to the processing, you can also request that we restrict personal data. For example, during the time that we need to assess your dispute or objection, or if it is already clear that there is no (any longer) legal basis for further processing of that personal data, but you still have an interest in us not yet erasing the personal data. If we restrict the processing of personal data at your request, we may still use that data to handle legal proceedings or a (legal) dispute.

10. AUTOMATED INDIVIDUAL DECISION MAKING

We do not make decisions based solely on automated processing.

11. UPDATES TO THIS PRIVACY POLICY

This Privacy Policy is subject to change. The "LATEST UPDATE" legend at the top of this Privacy Policy indicates the date when this Privacy Policy was last revised. All changes will become effective as of the date of revision.

12. TO CONTACT US

PatientSolutions BV, is the company responsible for the collection and use of personal information under this privacy policy and is therefore the data-controller.

If you have any questions about this privacy policy, please contact our Data Protection Officer Mark van Kuijk at mark@budiyu.com or the address listed above.

Because email communications are not always secure, please do not include sensitive information in your emails to us.

When you send us an email, we process your email address and the data you send us for as long as necessary to handle the question and for a maximum of 6 months after the last contact moment. The basis for this processing is our legitimate interest to be able to respond to contact requests.

You can also submit a complaint to the Dutch Data Protection Authority (AP). Go to www.autoriteitpersoonsgegevens.nl for more information. You can also contact an EU/EEA data protection authority for your country or region of residence.