

# Privacy notice Epione – Website and Application

## Document version 2

Version diffusion: 14 of October 2020

This privacy notice refers to Epione Platform v1.X.X

## New in this version

- Update of the intended use of the Epione Platform
- Clarification of personal data in article 2
- Clarification of Lawfulness of processing and legitimate interest in article 3
- Information related to personal data not transferred outside the European economic area added
- Clarification related to the right to file a complaint

For further questions, If you have any questions about how your Personal Data are processed, you can contact the data protection officer of Epione at [privacy@epione.care](mailto:privacy@epione.care).

## Article 1 – GENERAL TERMS

**1.1** Epione BV, with registered offices in Belgium, Groeneweg 35A, 3090 Overijse, and company number 0671.531.790, (hereinafter “**Epione**”) processes your Personal Data gathered through the Epione platform (the “**Epione Platform**”) and takes responsibility for the processing of your personal data on the Application and Website as a “**data controller**”.

**1.2** Epione is a software platform on advice, intended for patients and healthcare professionals to monitor the patient’s chronic neurological disorders. The Epione Platform consists of two Epione Applications and an **Epione Dashboard**. Together with the Epione Dashboard, each Epione Application is specific for a particular chronic neurological disorder:

- The **Epione Application Helpilepsy** and the Epione Dashboard are specifically intended for patients and healthcare professionals to monitor the patients’ epilepsy
- The **Epione Application MigraineManager** and the Epione Dashboard are specifically intended for patients and healthcare professionals to monitor the patients’ migraine.

Optionally, your healthcare professional can access the tracked data through the Epione web application to help in monitoring the disease and its evolution.

**1.3** Your privacy is very important to us. This Privacy Notice (hereinafter "Privacy Notice") is created to inform you about how we treat your personal data, and how you can exercise control over that data. It defines your legal rights and obligations towards Epione.

Our Privacy Notice can be subject to future amendment and modification. In this event we will notify you with an invite to take a look at these changes, whom we will clearly indicate in the Privacy Notice.

**1.4** The collection and processing of personal data is governed by strict conditions, enforced by the law. Epione acts in accordance with:

- i. the Belgian Privacy Law of 30 July 2018 on privacy protection in relation to the processing of personal data; and/or
- ii. the EU Regulation of 2016 concerning the protection of individuals with regards to the processing of personal data, regarding the free movement of such data and repealing Directive 95/46/EC;
- iii. and/or (iii) all (future) Belgian laws regarding the implementation of this Regulation; and/or
- iv. the Code of Conduct for mobile health applications.

**1.5** This Privacy Notice is applicable, inter alia, to how we handle your personal data through our “**Services**” being the services offered, following and linked to our “**Website**”

<https://helpilepsy.com/> and <https://migrainemanager.care/> and the “**Application**”, being the designated definition in this Privacy Notice for the following as a whole:

- i. The Epione Dashboard for Patient and Physician;
- ii. The Epione Application Helpilepsy ; and
- iii. The Epione Application MigraineManager.

**1.6** In case of use of Epione for someone under the legal age of consent, you need to have the authorisation of the tutor/parent before using Epione. To be able to provide you our Services, we will first need your express consent (opt-in) of this Privacy Notice. This means you consent to the processing of the personal data that you provide when using our services.

You are not obliged to provide us with your personal data, however you must understand that we are not able to deliver you the Services in case you refuse to provide us with certain personal data.

Please note that you are also not obliged to install the Application. A Patients' refusal to install the Application will not have any impact on the quality of the treatment by their physician.

## Article 2 – COLLECTED PERSONAL DATA

### 2.1 Data you communicate to us:

- **Category 1 – Your user details:**

- information concerning your Epione user account
- your contact information, and
- if you contacted Epione via social media: social media information

This includes: Email address, first Name & Last Name, phone Number, birthday\*, gender, physical Address\*, preferred language, timezone, e-mail validated, neurologist name, neurologist email, hospital of neurologist.

- **Category 2 – Your communications through our Services**

- information about the communication you had with Epione, or through the Application and/or Services.

This includes: Firebase Cloud Messaging ID\*, account creation date, last action date, conversations through support systems, engagement with mobile app (scrolls, clicks...), engagement with emails (opening, clicking...), engagement with website (visits...), engagement with web app (scrolls, clicks...), appointment answers (prep & feedback)\*.

- **Category 3 – Your health data (only for Epione Platform)\*:**

- information about your health conditions, and other health related information; and
- health information from third party devices such.

This includes: Explicit consent given, data from 3rd party devices, video of seizure (only for Helpilepsy) begin data of disease, approximate frequency of disease, current, past and future treatments in use, past seizures (with all details), past side effects, past and future

appointments with physicians, past and future disease-related events, hours of treatments taken, mood, sleep, seizure detected from other devices (only for Helpilepsy), past headaches & headache types (only for MigraineManager).

▪ **Category 4 – Your usage of our Services:**

- your usage data obtained by placing cookies (see our Cookie Policy)
- information relating to more “technical” aspects of your use of the Application and/or Services.

This includes: Mobile app version\* and IP address.

\* only personal data from Helpilepsy and MigraineManager applications.

**2.2 Epione can obtain personal data through different means:**

- a. during your registration and use of our Application and/or Services;
- b. via your Patient, who referred you as their Physician
- c. by filling out questionnaires (for instance when you give us feedback, or when you use our Support function);
- d. via social media (for instance when you like, or contact us on Facebook)
- e. upon the connection of third-party devices or services to Epione, such as Google Fit or Apple Health (but only when you have explicitly and preliminary gave consent).
- f. by placing cookies (see our [Cookie policy](#))

**2.3 Data minimization**

To minimize the data collected, a lot of data fields are optional, leaving the choice to you to fill them in. If you decide not to fill certain fields, you might not experience the full Epione product.

**Article 3 – PURPOSES OF THE PROCESSING OF DATA**

We want to highlight that Epione collects and processes your personal information for one overarching goal, i.e. to offer you a safe, comfortable and personalized Epione-experience.

Legitimate interest means that the interest of Epione prevails over your interest, because the processing of your Personal Data shall not create a risk to your fundamental rights and freedoms.

The processing of your Personal Data might be necessary for the performance of the agreement between you and Epione. Epione will not be able to comply with certain of its obligations if you refuse to provide or the processing of your Personal Data. For example, the processing of your Personal Data might be necessary to provide you access to the Platform or respond to your questions.

When you provide consent, this consent is always free, and you have the right to withdraw this consent at any time. When you withdraw your consent, Epione will no longer process your Personal Data, unless that processing is based on legitimate interest or the performance of the agreement.

The purposes that are listed here may not be complete and Epione may process your Personal Data for another legitimate reason. When this is the case Epione will notify you as soon as possible of this new purpose.

That being said, your personal data will only be processed for the following purposes:

**3.1. General purposes (all categories 1 to 4):**

- To maintain the safety of our Application and/or Services and improve them, as well as to create statistics based on the “legitimate interest” of Epione to improve the Application and/or Services;
- In order to manage your account on the Application and to make sure you can enjoy the Application and the services related to the Application fully, based on the execution of the agreement which you requested;
- In order to properly and easily address or notify you, or to be addressed by you. Also, to be able to follow up on your communication to us – all based on the execution of the agreement, which you requested;
- Health-related information (**Category 3**) will be processed by Epione, so you are able to use the Application and/or Services, based on the execution of our agreement; or in case the information was retrieved from third-party devices and services, upon your (explicit and preliminary) consent.

Before you connect a third-party device and service to the Epione platform, we suggest you take a look at their settings. Tools might be present to enable you to specify what kind of data Epione could access.

**3.2. Scientific research and statistical purposes**

Additionally, some of your personal data - including health-related information (categories 1 to 4), will be upon collection added to a special database.

Before we do this:

- Only for internal (scientific and statistical) further use: the data will be anonymized (= in no way you can be linked to the data ever again), or pseudonymized (= only with extra information can you be linked to the data again), depending on what is possible, or desirable – the latter taken from your perspective.

This database will not contain any personally identifiable data, and if we provide this data to third parties, Epione will make sure it is anonymized (e.g. the data must be sufficiently aggregated). This means that in no way you can ever be linked to this transferred data.

You can request that your anonymized data (= data that in no way can be linked back to you) shall not be used for these scientific or statistical purposes. To request this, you can send an email to [privacy@epione.care](mailto:privacy@epione.care).

### **3.3. Direct marketing:**

Your personal data (**category 1 to 4**); will only be used for direct marketing purposes if you give your explicit and preliminary consent (“opt-in”).

In case you have given your consent and you are added to Epione’s direct mailing list, Epione may use your personal data to send you marketing material as well as other material relating to Epione, her products and/or services.

Epione can also transfer some of your personal data to her partners, for direct marketing purposes relating to Epione, her products and/or services.

### **3.4. Transfer to sub-processors:**

In order to process your personal data, we provide access to your personal data **to some of our trusted employees**.

Epione will also appeal to **sub-processors** in executing the agreement, to provide the requested service

- In order to communicate with you and provide you the means to communicate with your Patient/Physician
- In order to capture your opinion on our Application and/or Services
- In order to optimize your experience with our Application and/or Services
- In order to be easily addressed we work with social media channels
- In order to provide your medical institution with the data relating to the treatment you are receiving

Epione won’t sell, let, hand out your personal data nor place them at disposal of third parties, except in the situations provided for in this Notice, or unless your explicit and preliminary consent (**also, see art. 3.2 and 3.3**).

Epione has taken all legal and technical precautions to prevent unauthorized access and use.

We guarantee a similar level of protection by imposing contractual obligations to these sub-processors that are similar to this Privacy Notice and guarantee that the medical secrecy rules that protect patient medical data will at all times be respected.

If you are directed to another application, platform or website through the Epione Platform, other terms and conditions and other privacy and cookie policies may apply. You should take into account and read these terms and conditions and privacy and cookie policies of the other applications, platforms and websites you visit.

In case of whole or partial reorganization or cession of Epione's activities, whereby Epione reorganizes, transfers, ceases her business activity or in case Epione goes bankrupt, your personal data may be transferred to new entities or third parties.

In that case, Epione shall inform you beforehand of the fact that your personal data will be transferred to a third person.

### **3.5. Legal requirements:**

In extraordinary circumstances it may occur that Epione is obliged to transfer your personal data following a court order, or in order to comply with imperative laws and/or regulations. Epione will, if reasonably possible, try to inform you beforehand, unless revealing this information is subject to legal constraints.

### **3.6. Personal Data is not transferred outside the European Economic Area:**

Epione collects your personal data and stores then in Europe in Frankfurt, Germany. No transfer of personal data is realized.

## **Article 4 – DURATION OF THE PROCESSING**

We will store and process your personal data for the period we're legally obliged to do so, or for as long as this is essential for the purposes of the processing, or the contractual relationship between you and Epione.

Therefore, we keep a record of your data for as long as your account is active, or if your personal data is necessary to offer you a particular service. Additionally, in certain circumstances we might retain a limited amount of information for the period it would be of vital importance to maintain the security of our Services.

You may at all times cease to

- use the Application and/or;
- uninstall it and/or;
- delete your account (in your settings).

If you delete your account, you will be given the choice whether you also wish us to delete any data that you asked us to back up. If you do wish us to delete your data, this means you are pursuing your right to erasure (**see art. 5.2**). Even when your account is deleted, Epione might still process and disclose your Personal Data to third parties after your Personal Data has been anonymized. Some of your Personal Data might however still be used by Epione when the processing is based on legitimate interest of Epione.

If you do not delete your account, Epione will keep the data you have backed up, as it contains medical information that could be important for you in the future. In that way, you can benefit from a back-

up service, whilst not being an active user of other Epione Services – including but not limited to the Services as we defined above.

However, if you aren't using Epione anymore, we will contact you occasionally (= at least once every 3 years) to ask if you wish us to retain the data. If after 15 years, you haven't done any action in our platform, your personal identifiable data will be deleted.

Should Epione cease to be able to keep your data, it will be sent to you in an electronic and commonly-used format.

## **Article 5 – YOUR RIGHTS**

### **5.1. Right of access and right to obtain a copy**

You have the right to freely obtain at any moment access to your personal data, as well as to be informed about the purpose of the processing by Epione. We would like to invite you to check our Terms of Use for some extra information on this topic.

### **5.2. Right to rectification, erasure or restriction**

You have the choice to share your personal data with Epione.

You also have the right to request Epione to rectify your personal data. Please note that you can change your account information in the Application at any time on the "Settings-Account" page.

You can also request the processing of your personal data to be restricted, if you think your data is inaccurate and you subsequently notified us about this.

Additionally, you have the right to request Epione to erase your data in as far we were not able to anonymize it.

Yet, with regard to certain personal data provided by you, Epione is bound by certain legal obligations, pursuant to which Epione is not allowed to delete the information.

Also, if Epione cannot access, change or delete your data - e.g. because it is stored on your device – you should understand that we do not really have the time to come and stop by, so it will be up to you to undertake these actions yourself.

Furthermore, you acknowledge that a refusal to share data or a request to erase these data will make the delivery of several Epione services impossible.

### **5.3. Right to object**

You have the right to object to the processing of your personal data when you have serious and legitimate reasons to do so.

You also have the right to object to the use of your personal data for purposes of direct marketing. In such case specific reasoning will not be requested.

### **5.4. Right to data portability**



You have the right to obtain your personal data, which is processed by Epione in a structured, commonly used format and/or to transfer this data to another data controller.

#### **5.5. Right to withdraw consent**

When the processing is based on prior consent you have the right to withdraw this consent.

#### **5.6. Right to request not to be subject to automated decisions and profiling**

You have the right to request us not to be subject to a decision based solely on automated processing, including profiling, which produces legal effects concerning you or similarly significantly affects you.

#### **5.7. Exercising your rights**

You are not required to pay any charge for exercising your rights. If you make a request, we will answer in a reasonable time frame.

Please contact us at [privacy@epione.care](mailto:privacy@epione.care) if you wish to make a request.

#### **5.8. Right to file a complaint**

If you have any concerns about our use of your personal information, you can make a complaint to us at either through e-mail at [privacy@epione.care](mailto:privacy@epione.care);

or by mail to, Epione BV, Groeneweg 35A, 3090 Overijse, Belgium

In case you're not satisfied of our handling of your complaint, you have the right to file a complaint with the Belgian Data Protection Authority, which is the Lead Supervisory Authority of Epione:

Belgian Data Protection Authority

Drukpersstraat 35, 1000 Brussels,

Tel +32 (0)2 274 48 00, Fax +32 (0)2 274 48 35,

e-mail: [contact@apd-gba.be](mailto:contact@apd-gba.be)

However, you are always free to contact your own European ~~or EU-vested authority thereto.~~

This does not affect a procedure before the civil court.

If you have suffered damages caused by the processing of your personal data, you can file a claim for damages.

## **Article 6 – SAFETY AND CONFIDENTIALITY**

6.1. We have adopted safety measures which are suited on both a technical and an organisational level to avoid the destruction, the loss, the forgery, the adjustment, the non-authorized access or the notification of the personal data by accident to a third party, as well as the non-authorized processing of these data. Nevertheless, if these events would occur and would affect your personal data, Epione will inform you of the breach without undue delay, including a summary description of the potential impact and a recommendation on measures to mitigate the possible adverse effects of the breach.

Epione has made sure to encrypt all communications concerning your health-related data. Also, the information on the Epione servers, in Frankfurt, Germany, with Amazon Web Services (AWS), can only be read by Epione and/or her team members and/or her employees in possession of the right key. The outside world cannot access this information. This is ensured through a Data Processing Agreement between Epione and AWS.

6.2. Please note that the automatic transfer of data to the Physician is only possible after the Patient has correctly made the link to the Physician through their mobile device. Doing this correctly, is the Patients' sole responsibility.

6.3. At the same time, you also share responsibility for maintaining the privacy and security of the Application and/or Services, for example: by not allowing any third party to use your personal Epione account on the Application and/or Services and avoiding all other non- authorised access to your login and access code. You are solely responsible for the use of the Application and/or Services on your devices, IP-address and identification data, as well as for its confidentiality.

6.4. In any case, you need to immediately notify Epione of any unauthorized use of your personal Account by sending an e-mail to [privacy@epione.care](mailto:privacy@epione.care).

## **Article 7 – APPLICABLE LAW AND JURISDICTION**

This Privacy Notice is managed, interpreted and executed in accordance with Belgian law which exclusively applies to every potential dispute.

The courts and tribunals of Brussels have exclusive jurisdiction to settle any dispute arising out of or in connection to the interpretation or execution of the present Privacy Notice.