

# EVICR.net Eye Platform Privacy Policy

## What is EVICR.net Eye Platform?

EVICR.net Eye Platform is a platform to gather high quality ophthalmology data generated in Europe and allow the secondary use of data in performing large data analysis and foster clinical research.

With Eye Platform, EVICR.net aims to provide technological solutions that allow overcoming privacy and regulation issues associated with the sharing of data from different institutions/countries, in a secure, easy to use manner and compliant with legal and applicable requirements.

With EVICR.net Eye Platform, the Members Sites or other interested parties have the opportunity to participate in clinical research with secondary use data analysis; Authorship of publications and presentations of Results; the opportunity to propose new analysis to answer key research questions; and increase overall visibility and stature as researchers.

Data is stored in the Eye Platform at Microsoft Azure Data Centre located in Western Europe and protected using a second factor authentication protocol.

The EVICR.net respects your right to privacy and complies with its obligations under the General Data Protection Regulation (GDPR). The goal of this privacy policy is to help you understand how EVICR.net deals with any personal data you provide through the Eye Platform. By using the EVICR.net Eye Platform you are accepting the terms of this Privacy Policy.

## What types of information do we collect?

- Personal data from a Data Provider: such as name, country, EVICR.net Member/Centre; contact, email.
- Personal data from a Data Requester: such as name, positions and qualifications, Institution, contacts address, phone and email, country, EVICR.net Member Centre N°; Curriculum Vitae.
- Other technical information: such as IP address, which browser you used, date and time of access, among others, is also recorded in application logs and used for technical problem solving.

Patients' anonymised health data (e.g eye disease ophthalmologic images, other tabular data) from patients that prior consent to use their data for the

specific study and/or future research, that are uploaded to the Eye Platform by the Data Providers.

### **What do we use your information for?**

The law requires that there be a legal basis for EVICR.net to process Data Provider and Data Requester personal data. In general, this will be one, or a combination, of the following:

- processing is necessary for the performance of a contract to which the data subject is part: a Data Transfer and Sharing Agreement is signed.
- your consent;
- the processing is necessary for the performance of credentials and to contact with you if data is not uploaded and/or recorded correctly during the validation process;
- compliance by EVICR.net with a legal obligation to which it is subject;
- the pursuit of the legitimate interest of EVICR.net, except where such interests are overridden by your interests or your fundamental rights and freedoms.
- EVICR.net can also process your personal data in the rare event that it is necessary in order to protect your, or another person's, vital interests or in the performance of a task being carried out by the EVICR.net in the public interest.

The law requires that there be a legal basis for EVICR.net to process specific study coded patients' data. In general, this will be one, or a combination, of the following:

- prior consent of the data subject (patients) for their data to be used for research (e.g. Consent for the specific study and/or consent for future research);
- the data kept in the Eye Platform is anonymized data, no correlation to the subject is possible.
- compliance by EVICR.net with a legal obligation to which it is subject.
- the pursuit of the legitimate interest of EVICR.net, except where such interests are overridden by data subjects (patients') interests or fundamental rights and freedoms.

- EVICR.net can also process personal data in the execution of a task being carried out by the EVICR.net for public interest (e.g. research on ophthalmic diseases, to improve prevention and treatment).

In practical terms, the information EVICR.net and Eye Platform collects from may be used in one or more of the following ways:

**Data Providers:**

**1) To process Data Sharing and Transfer Agreement**

We will use your data in order to contact you for sharing/transferring the data requested after a Data Transfer and Sharing Agreement is signed and applicable payment is confirmed.

**2) To give access to the Data Provider cloud-based computing environment**

We will use your information to generate the credentials you will need to have access to the Data Provider cloud-based computing environment provided by the Eye Platform.

**3) To process validation upload/submission process**

We will use your information to contact you during the Eye Platform central validation during the submission period in case of non-conform data.

**Data Requesters:**

**1) To give access to the Data Request area**

We will use your information to generate the credentials you will need to have access to the Data Request dashboard.

**2) To process a Data Access Request**

We will use your information to contact you, if needed, during the Eye Platform central validation and approval of your data access request.

**3) To process Data Sharing and Transfer Agreement**

We will use your data in order to contact you for sharing/transferring the data requested after a Data Transfer and Sharing Agreement is signed and applicable payment is confirmed.

**How do we protect your information?**

EVICR.net and EVICR.net Eye Platform takes, and will continue to take, all reasonable steps (which includes relevant technical and organizational measures) to guarantee the safety of the data you provide and we will only use the data for the intended purpose.

When you interact with the Eye Platform, we use a variety of security measures to securely process and keep your personal information safe. We use a secure server so that all supplied sensitive information is transmitted via Secure Socket Layer (SSL) technology and then encrypted into the database.

However, the nature of the internet is such that we cannot guarantee or warrant the security of any information you transmit to us via the Internet will be 100% secure.

Furthermore, we guarantee that:

- All data communication and transmission to and from the web application is over https / TLS 1.2 (Azure Web App Service).
- Data communication between storage and web application is done using https / TLS 1.2 (Azure Storage REST API).
- Data stored in storage accounts encrypted at rest (containers within the storage account).
- Storage account is not accessible outside the infrastructure and resource group (only direct access from web app is configured and file sharing is disabled).
- User authentication is based on Azure Active Directory (passwords are not stored anywhere on the infrastructure).
- User authorization and data access is application defined and enforced. Different tenants on the application have access to distinct containers on the storage accounts and access is not shared or overlaid.

### **Do we use cookies?**

Yes. For more information read Eye Platform Cookies Policy available at the Eye Platform page.

### **What are the Terms and Conditions for Use of EVICR.net Eye Platform**

This information is detailed in the Data Sharing and Transfer Agreement signed between EVICR.net and the Data Provider or the Data Requester for secondary data analysis and foster clinical research.

### **Do we disclose any information to outside parties?**

We do not disclose your personal data to outside parties except as set out in this policy.

We rely on third-party service providers to perform a variety of services on our behalf, such as data research, website hosting, electronic message delivery, payment processing. Your information will only be shared with selected third-party service

providers, contracted by EVICR.net, to the extent necessary for the purpose of providing our services to you and for the completion of contracts.

We also reserve the right to enforce our policies to protect our rights and the rights of other individuals in a manner that is safe and compliant with the law.

Non-personally identifiable information may be provided to other parties for marketing, advertising, or other uses.

### **Do we transfer data outside the EEA?**

We do not disclose your personal data to outside parties except as set out in this policy.

Transfers of personal data to these suppliers are protected by appropriate safeguards, namely the EU-US Privacy Shield or by the use in contracts of standard data protection clauses adopted and approved by the European Commission.

### **Do we retain data indefinitely?**

Our policy is to keep Data Provider personal information only for as long as is required to manager EVICR.net Eye Platform in an effective manner and to comply with our various statutory obligations.

Regarding coded study patients' datasets: The Eye Platform allows the re-use of anonymized data to foster clinical research and improve the understanding of disease progression and finally to contribute to the improvement of patient care in ophthalmology. Therefore, data will be kept for the necessary period for the purpose of clinical research.

### **Your rights under the GDPR**

#### **As Data Provider and as Data Requester:**

You have rights under the GDPR. In particular, you may object to the processing of your personal data by the Eye Platform. When you want to exercise one of these data subject rights – and you are eligible to – EVICR.net will respond according to the GDPR.

1. **The right of access:** you have the right to know whether EVICR.net is processing data about you and, if so, you can request access to it.
2. **The right to rectification:** if your personal data is inaccurate, EVICR.net will facilitate its correction once it becomes aware of the inaccuracy.
3. **The right to erasure or right to be forgotten:** you are able to ask us to delete your personal data if you no longer want it to be processed and there is no legitimate reason for EVICR.net to keep it.

4. **The right to restriction of processing:** you have the right to limit the processing of your personal data.
5. **The right to withdraw consent:** you have the right to withdraw consent where we have relied upon your consent to process your personal data.
6. **The right to be informed:** you have the right to clear and understandable information about who is processing your data, what they are processing and why they are processing it.
7. **The right to data portability:** you have the right to ask us to transfer your personal data to another service provider.
8. **The right to object:** you can say if you don't want processing of your data to be undertaken.
9. **The right not to be subject to a decision based solely on automated processing:** This includes profiling, which produces legal effects or significantly affects you.

If you wish to exercise any of the above rights, please send a written request to:  
compliance.evicrnet@aibili.pt

Alternatively, you may also post your request to: EVICR.net, Edifício Prof. Doutor José Cunha-Vaz; AIBILI, Azinhaga de Santa Comba, Celas, 3000-548 Coimbra, Portugal

#### **- Anonymized study patients' datasets:**

The patient data stored in the Central Database of the Eye Platform is anonymized, guaranteeing the confidentiality of the patient. For data kept in an anonymized format, the exercise of rights is not applicable.

The Data Provider acts as the "Data Controller" of the patient's data collected for a study. For any questions regarding your study data you may contact the data protection officer of the Data Provider.

#### **Changes to our privacy policy**

Please note that the content of this Privacy Policy may be updated from time to time. Therefore, we advise you to visit the page of this Website Privacy Policy regularly to verify any updates.

#### **Contacting us**

If you have any questions regarding this privacy policy, you may contact us using the contacts mentioned above.