

## DATA PRIVACY POLICY

**Updated 09/04/2021**

The ECRIN Marketplace has been created to search for similar clinical trial questions to collaborate with, and to share protocol synopses to get in touch with clinical researchers in the same domain. The ECRIN Marketplace is part of the ECRIN website, a central resource for information about the ECRIN organisation, its services, tools, projects, news, events, and publications as well as other resources related to clinical trials. This privacy policy statement is meant to explain to you the way in which we process and protect your personal data on the ECRIN Marketplace.

Our policy on protection of individuals with regard to the processing of personal data is based on the principles set out by the Regulation (eu) 2018/1725 of the European parliament and of the Council of 23 October 2018 on the protection of natural persons with regard to the processing of personal data (the GDPR) as well as the relevant French law, as applicable.

### **1. WHAT IS THE SCOPE OF THIS DATA PRIVACY POLICY?**

This policy covers ECRIN's data processing on our Marketplace (marketplace.ecrin.org).

Please be aware that ECRIN has developed a specific data privacy policy for the ECRIN website.

Also please note that the ECRIN Marketplace may provide links to third-party sites (e.g. YouTube, ECRIN partner websites). When you click on links to visit third-party websites, you may need to accept their specific terms and conditions and cookie policies as ECRIN has no control over their privacy policies.

### **2. WHAT PERSONAL DATA DO WE COLLECT ABOUT YOU?**

The following personal data might be required when you submit a clinical trial question to the Marketplace:

Name investigator, institute, city, country, email address, and the clinical trial outlines: Title, objective, patient population, intervention, comparator, outcome, rationale, additional file.

### **3. FOR WHAT PURPOSE DO WE COLLECT YOUR DATA?**

Any collection and processing of personal data on our website is for one of the following defined purposes:

1. To measure the effectiveness and efficiency of our website.
2. To gather your feedback on the ECRIN Marketplace services collected via the ECRIN contact form

3. For the correct functioning of searching or submitting clinical trial questions to the ECRIN Marketplace, and to contribute to the reduction of research waste by the sharing of clinical research questions and linking researchers interested in similar questions.

#### **4. DOES ECRIN PUBLISH YOUR DATA ON THE MARKETPLACE?**

ECRIN does not publish any of your personal data on the ECRIN Marketplace. When you submit a clinical trial question to the ECRIN Marketplace, the information will be shown as part of the search results in the ECRIN Marketplace.

#### **5. ON WHAT GROUNDS DO WE PROCESS YOUR DATA?**

As a general rule, we process your personal data on the basis of your CONSENT to ECRIN's processing of your personal data for the use of the ECRIN Marketplace.

#### **6. WHERE DO WE STORE YOUR DATA?**

All information provided by you is gathered securely through the SSL (SecureSockets Layer). An SSL is a protocol that encrypts your information into codes so that your information is kept secure while being transmitted via the Internet.

#### **7. WHO HAS ACCESS TO YOUR DATA?**

ECRIN's relevant internal parties, Akabia which is the contracted service and hosting provider in charge of the development of Marketplace, as well the researchers interested in similar questions if you agree to be contacted.

For instance, ECRIN's Project Managers have access to the data that you provide via the ECRIN Marketplace, to approve or dis-activate your clinical trial question. Relevant internal parties have access to the data that you provide via the contact form.

#### **8. HOW LONG WILL ECRIN RETAIN YOUR PERSONAL DATA?**

ECRIN will retain and process your personal data for as long as it deems relevant, and subject to applicable law, to fulfil the purpose(s) for which the data were collected. After such time, ECRIN will delete your personal data.

#### **9. WHO IS RESPONSIBLE FOR THE PROCESSING OF YOUR DATA ON OUR WEBSITE?**

ECRIN acts as the data controller of the processing of your personal data for the purposes stated above. In case ECRIN acts as a joint controller or a data processor, we will inform you via the information notice or other adequate means. The data processor for the Marketplace is the internet agency Akabia / MDCP Communication.

DATA CONTROLLER: EUROPEAN CLINICAL RESEARCH INFRASTRUCTURE NETWORK (ECRIN), 5 rue Watt, 75013 Paris, France. Registration number: 801 933 235

MARKET PLACE DATA PROCESSOR: MDCP Communication, 53 rue Cuvelle, 59100 ROUBAIX, France. SIRET n°521 713 354 0020

## **SPECIFIC INFORMATION FOR EACH OF THE ABOVE PURPOSES IS DETAILED BELOW**

### **PURPOSE 1: To measure the effectiveness and efficiency of our website**

ECRIN uses cookies to enhance users' experience and to measure the effectiveness and efficiency of the ECRIN Marketplace.

Cookies help us to improve your experience and interaction with the ECRIN Marketplace. The information gathered enables the ECRIN Marketplace to remember your actions and preferences for a certain period of time, so you do not have to re-enter this information on future visits.

### **What are cookies?**

Cookies are small text files that are placed on your computer / device by websites that you visit. They collect standard information such as browser type, browser language, your Internet Protocol (IP) address, and your interaction with the website.

### **What cookies and how does ECRIN use on the ECRIN Marketplace?**

We use Google Analytics cookies.

ECRIN collects standard information and details of visitor behaviour such as time spent on the ECRIN Marketplace. This is achieved by checking for the unique identifier in a cookie left there on a previous visit. This information is collected in a way that does not identify anyone and makes no attempt to identify the individuals visiting the ECRIN Marketplace. ECRIN will not associate any data gathered from the ECRIN Marketplace with any personally identifying information from any source.

All of our cookies are anonymous and session based and we hold no personal information in any of our cookies.

### **On what legal basis do we use cookies?**

Your consent. You can accept or reject the cookies on the ECRIN Marketplace. To accept, click on the 'Accept' button that pops up when you first visit the ECRIN Marketplace. If you do not click on Accept, and close the pop-up window, you are rejecting the cookies. You can also disable cookies directly in your browser settings.

### **Who has access to your data contained in cookies?**

The Communications Officer (and other relevant staff members, as appropriate) have access to this data.

**PURPOSE 2: To gather your feedback on the ECRIN Marketplace services collected via the contact form**

The form is intended to collect your requests or inquiries, or your feedback on the ECRIN Marketplace.

**What types of personal data do we process?**

First name, last name, function, and contact information.

**On what legal basis do we process your personal data?**

Your consent. Once you have carefully read the feedback form ([marketplace.ecriin.org/en/form/contact](https://marketplace.ecriin.org/en/form/contact)), as well as our privacy policy, and you decide to submit the form, you are providing us with your consent to process your personal data for the purpose of submitting your feedback.

**Who has access to your personal data?**

Your data may be shared within ECRIN's organisation. We never pass on, sell or swap your data for marketing purposes to third parties outside ECRIN.

**How long do we save your data for this purpose?**

ECRIN will retain and process your personal data for as long as it deems relevant, and subject to applicable law, to fulfil the purpose(s) for which the data were collected. After such time, ECRIN will delete your personal data. You may also contact ECRIN directly to delete your feedback form submission data at [contact@ecrin.org](mailto:contact@ecrin.org).

**PURPOSE 3 - For the correct functioning of searching or submitting clinical trial questions to the ECRIN Marketplace, and to contribute to the reduction of research waste by the sharing of clinical research questions and linking researchers interested in similar questions.**

The ECRIN Marketplace contributes to the reduction of research waste by the sharing of clinical research questions and linking researchers interested in similar questions. The submit form is intended to submit your clinical trial question to the ECRIN Marketplace.

**What types of personal data do we process?**

To submit a clinical trial question to the ECRIN Marketplace, the following personal information is required together with the clinical trial outlines: Name investigator, institute, city, country, email address.

“The clinical trial outlines” refers to Title, objective, categories of patient population, intervention, comparator, outcome, rationale, additional file and should not include any personal information.

## **On what legal basis do we process your personal data?**

Your consent. Once you have carefully read the submit form (marketplace.ecriin.org/en/clinical\_trial/add), as well as our privacy policy, and you decide to submit the form, you are actively providing us with your consent to process your personal data for the purpose of submitting your feedback or a clinical trial question.

## **10. WHAT ARE YOUR RIGHTS?**

ECRIN will ensure that you can exercise your rights pertaining to your personal data. To that end, ECRIN informs you that you are entitled:

- a) to have access, upon simple request, to your personal data – in which case you may receive a copy of such data (if requested)
- b) to obtain a rectification of your personal data should your personal data be inaccurate, incomplete or obsolete ("right to rectification")
- c) to obtain the deletion of your personal data ("right to be forgotten");
- d) to withdraw your consent to the data processing (where your personal data has been collected and processed on the basis of your consent);
- e) to request a limitation of the data processing in the situations set forth by applicable law ("right to restrict processing");
- f) to receive your personal data (data which you provided to ECRIN) in a structured, commonly used and machine-readable format and to transmit those data to another controller ("data portability right" allowed only where the processing is based on your consent and the processing is carried out by automated means)
- g) to file a complaint to the French supervisory authority, CNIL (French data protection authority), located at: 3 Place de Fontenoy - TSA 80715 - 75334 PARIS CEDEX 07 . You can also check the CNIL website: <https://www.cnil.fr/fr/cnil-direct/question/adresser-une-reclamation-plainte-la-cnil-queelles-conditions-et-comment>

I understand and agree that ECRIN's website and Marketplace can be seen throughout the world, and not just in the European Union where the data protection regulation (i.e. the GDPR) applies. ECRIN and Akabia have developed their own standing Data Protection Policy, for ECRIN [<https://ecrin.org/data-privacy-policy>] and for Akabia [<https://akabia.fr/politique-de-confidentialite>].

In case we are processing your data on a different legal ground, we will inform you about your data protection rights by adequate means. If you have any questions about how your personal data is being processed within this context or if you would like to exercise your data subject rights, please email your request to [contact@ecrin.org](mailto:contact@ecrin.org) and we will refer you to our Legal manager.