

# EAU Research Foundation Privacy Policy

The EAU Research Foundation (EAU RF) respects your privacy and is committed to protecting the confidentiality of your personal information. This document explains how the EAU RF collects and uses personal data, and how the EAU RF protects your privacy. It also explains how you can manage your own personal information.

## Personal Information

The EAU RF is an independent non-commercial foundation. The mission of the EAU RF is to promote, facilitate and stimulate clinical and basic research in European urology. During the conduct of clinical studies and registries personal data is being collected from the following subjects:

### *1. Patients participating in EAU RF clinical studies and registries*

Health related data, as well as, if relevant, geographical information, gender, race, ethnicity and age, as specified in the study/registry protocol and approved by authorities/ethical committee(s) as required by applicable law is collected by the EAU RF. Consistent with GCP, patients names and other direct identifiers are not collected. Patients are only identified by a code. Only local investigators, research staff and authorized personnel, including EAU RF employees, may access named subject records at source. In cases where local law allows, the EAU RF may also collect full date of birth.

### *2. Local investigators and research staff, (potentially) involved in EAU RF clinical research / registry projects*

The EAU RF will collect information in relation to the involvement and performance of investigators and research staff as required by law, guidance or regulatory authority for the conduct of clinical studies and registries.

The EAU RF will also process financial information of investigators to support payment for services.

The EAU RF will use available contact information from prior feasibilities, including email addresses, for the purpose of inviting potential investigators to apply to participate in research.

The EAU RF may also use available contact information from EAU members to invite potential investigators.

### *3. Employees of third parties (e.g. CRO's), involved in EAU RF clinical research / registry projects*

The EAU RF will collect information in relation to the involvement and performance of third party employees as required by law, guidance or regulatory authority for the conduct of clinical studies and registries.

### *4. EAU RF employees*

The EAU RF collects and processes CV's and training documentation of its employees, as required by law, guidance or regulatory authority for the conduct of clinical studies and registries.

In addition information on staff for human resource, performance, payroll and tax purposes is collected. Handling of this type of personal information is described in an internal EAU policy and employees are informed by the EAU HR department.

### *5. Investigators joining the EAU RF trial network*

The EAU RF also has a trial network for which investigators who are interested in clinical research or basic science can sign up. Whenever a trial, which matches the area of expertise and preferences of the investigator, is launched, the EAU RF can contact the concerned investigator. Within this trial network the following personal data is collected: Name, work contact details (address, fax and phone number) and email address.

## Lawfulness of processing

### *1. Patients participating in EAU RF clinical studies and registries*

Data on patients participating in clinical studies or registries will be processed by EAU RF following collection of signed informed consent by the local investigator, as required by applicable law or guidance.

### *2. Local investigators and research staff, involved in EAU RF clinical research / registry projects*

The process of obtaining consent from local investigators and research staff, allowing their personal data to be processed by the EAU RF, is part of the protocol agreement which will be put in place between the EAU RF and the local investigational institution.

During feasibility consent will be obtained from the respondents, allowing the EAU RF to use available contact information for the purpose of inviting potential investigators to apply to participate in research.

### *3. Employees of third parties (e.g. CRO's), involved in EAU RF clinical research / registry projects*

The process of obtaining consent from third party employees, allowing their personal data to be processed by the EAU RF, is part of the contractual agreement which will be put in place between the EAU RF and the third party.

### *4. EAU RF employees*

EAU RF employees have provided written consent for the processing of their personal data in relation to the conduct of clinical studies and registries.

### *5. Investigators joining the EAU RF trial network*

When signing up for the EAU RF trial network the investigator will be asked to consent for the use of his/her personal data (More information on <http://uroweb.org/research/become-an-investigator>’.)

## Retention of personal information

Personal information is retained as long as is required by law, guidance or regulatory requirements for the conduct of clinical studies and registries.

Personal data collected within the EAU RF trial network will be retained for a period of 15 years.

## Disclosure of personal information

The EAU RF complies with European Union (EU) regulation and is registered under the laws of The Netherlands, and takes all reasonable care to prevent any unauthorised access to your personal data. The EAU RF staff and contractors have a responsibility to keep your information confidential.

Access to databases and folders containing personal information is restricted to appropriate staff.

The EAU RF may share personal information with sponsors or funding parties based on a contractual agreement. The EAU RF will make sure such an agreement will comprise proper data privacy safeguards in accordance with the applicable law.

The EAU RF may share personal information from local investigators, research staff and EAU RF employees for the following purposes:

- a. the conduct and interpretation of the Clinical Trial/Registry;
- b. review by governmental or regulatory agencies, Sponsor, and its agents, affiliates and collaborators;
- c. satisfying legal or regulatory requirements;
- d. publication on [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and other websites and databases that serve a comparable purpose;
- e. upon request of individual patients and doctors provision to individual patients and doctors who may be interested in participating in a clinical trial at Institution;
- f. storage in EAU RF's databases for use in selecting sites in future clinical trials.

Companies working as vendors of EAU RF are required to sign “processor” and/or confidentiality agreements whereby they will commit to only process personal information consistent with contracted purposes and apply appropriate organizational and technical security safeguards.

Personal data from investigators who have joined the EAU RF trial network will not be shared with others.

The EAU RF does not sell, trade, or rent out your personal information to others.

### International Transfers of personal information

The EAU RF is a European organisation and may share information across international borders. Transfer of personal data to a third country, including without limitation the United States, even though data protection may not exist or be as developed in those countries as in The Netherlands, may take place. In such cases the EAU RF will ensure that appropriate safeguards are provided.

### Privacy rights related to your personal information

You have the right to access, correct, delete, transfer, or object to the processing of your data. If you want to know exactly what personal information the EAU RF keeps on file, you can obtain such information. If it appears that the information is inaccurate, or you wish to oppose its use in future, the EAU RF will make the necessary amendments and confirm that these have been made. Please contact EAU RF at [researchfoundation@uroweb.org](mailto:researchfoundation@uroweb.org).

If you are a patient participating in an EAU RF clinical trial or registry, you should contact the Doctor who is treating you at the clinical trial site to exercise your privacy rights. Your identity will not be known to the EAU RF, as your Doctor has provided only encoded data about you. Only your Doctor will be able to make the necessary link to your identity.

Not all requests may be fulfilled to the satisfaction of Data Subjects. As EAU RF operates in a highly regulated environment, it is bound by many laws/regulations. As an example, under the right to be forgotten, EAU RF may not be able to erase all Data related to a Data Subject due to other laws/regulations that require Personal Data is maintained (e.g. – Adverse Event Reporting).

Investigators who have joined the EAU RF trial network will be able to access and modify their personal data via the My-EAU account/ a personal login.

## Data Security

The EAU RF takes organizational, technical and physical measures to protect the collected personal information against unauthorized access or loss. As required by the GDPR EAU RF has a policy in place how to deal with possible personal data breaches, including making any necessary notifications to individuals or governmental authorities.

## Your Comments

If you have any further questions about the EAU RF Privacy Policy or its implementation, or if at any time you believe that the EAU RF has not adhered to the principles stated in this Policy, please contact us at [researchfoundation@uroweb.org](mailto:researchfoundation@uroweb.org).

Within the EU, individuals have the right in law to complain about how their information is handled to a supervisory authority that is responsible for regulating compliance with the Regulation. A list of all EU supervisory authorities is available on the European Commission website: [http://ec.europa.eu/justice/data-protection/article-29/structure/data-protection-authorities/index\\_en.htm](http://ec.europa.eu/justice/data-protection/article-29/structure/data-protection-authorities/index_en.htm).

This privacy policy may be amended following internal review or in case of new or modified legislation. The most recent version of this policy will be available on [www.uroweb.org/research](http://www.uroweb.org/research).