



*Inspiring responsible and
ethical research capacity
in and for Africa*

PRIVACY POLICY ON PROTECTION OF PERSONAL INFORMATION

In terms of the Protection of Personal Information Act 4 of 2013

(The Protection of Personal Information Act (or POPI Act) is South Africa's equivalent of the EU GDPR. It sets some conditions for responsible parties (called controllers in other jurisdictions) to lawfully process the personal information of data subjects (both natural and juristic persons)).

INDEX

1. Introduction
2. Purpose of Privacy Policy
3. The Information EthiXPERT collects
4. What is personal information
5. What is meant by "Processing of Personal Information"?
6. When will EthiXPERT process personal information?
7. What is "Special Personal Information"?

8. When will Special Personal Information be processed?
9. When and how will we process special personal information of children?
10. Your consent
11. Collection of personal information
12. How and why we use your personal information
13. How we use your personal information for direct marketing
14. Necessary communication
15. Disclosure
16. Safeguarding your personal information
17. When will we share your information with other countries?
18. Retention
19. Your privacy rights and responsibilities
20. Cookie Policy
21. This Privacy Policy does not apply to
22. Changes to this Policy
23. Handling of complaints
24. Important contact information

1. INTRODUCTION

EthiXPERT aims to build responsible and ethical research capacity in and for Africa. Research Ethics is fundamental for health, quality of life and social development. To this end, EthiXPERT is devoted to build capacity in responsible conduct of research by providing training and developing relevant tools to facilitate knowledge and skills development to health and social research stakeholders in Africa, including research institutions, institutions of higher learning, researchers, research integrity officers, research ethics committees and research administrators, among others. We acknowledge that research is dynamic, expensive and competitive. As such, no single individual, organisation or government can single-handedly realize the desired optimal health standards, quality of life and social

development without the support of other institutions and the society at large. EthiXPERT therefore wishes to partner with relevant role players including decision-makers, research institutions, implementing agencies and funding organisations to identify important research gaps and to develop and deliver sustainable and culturally acceptable evidence-based solutions.

2. PURPOSE OF THE POLICY

The purpose of this Privacy Policy is to explain how EthiXPERT use Personal Information.

EthiXPERT commits to:

1. the use of Personal Information in a way that is fair, honest and responsible;
2. provide clear details about how we use Personal Information
3. promptly resolve concerns around the use of Personal Information; and
4. take reasonable steps to protect Personal Information from misuse and to keep it secure.

We will comply with all Applicable Laws when dealing with your Personal Information. For the purposes of this Privacy Policy, “Applicable Laws” shall include but not be limited to the Protection of Personal Information Act, 2013 (“POPIA”) and other data processing legislation.

3. THE INFORMATION ETHIXPERT COLLECTS

“Personal Information” means information that is gathered through:

- networks
- users of the RHInnO Ethics platform
- website
- social media platforms
- stakeholder engagement
- services providers
- partners
- consortium members
- funders

We collect and process Personal Information to provide information on or to access our services and products, to help us improve our offerings to you, auditing our products and services, to comply with Applicable Laws, and other specified and lawful purposes. We collect Personal Information provided to us by users of our website, other social media platforms, course attendees and users of the RHInnO Ethics platform. We may collect or receive Personal Information from other sources, where permitted or required, or if consent has been given by you for that information to be shared. This may include information from commercially available sources, such as public databases.

Website usage information is collected using “cookies” which allow us to collect standard internet visitor usage information and preferences. This may include information on your location and IP address(es).

4. WHAT IS PERSONAL INFORMATION?

Personal Information refers to any information that identifies you or specifically relates to you. Personal Information includes, but is not limited to, the following information about you:

- a. information relating to your race, gender, sex, pregnancy, marital status, national, ethnic or social origin, colour, sexual orientation, age, physical or mental health, well-being, disability, religion, conscience, belief, culture, language and birth;
- b. information relating to your education or your medical, financial, criminal or employment history;
- c. any identifying number, symbol, e-mail address, physical address, telephone number, location information, online identifier or other particular identifying detail;
- d. your biometric information;
- e. your personal opinions, views or preferences;
- f. correspondence sent by you that is implicitly or explicitly of a private or confidential nature or further correspondence that would reveal the contents of the original correspondence;
- g. the views or opinions of another individual about you; and
- h. your name if it appears with other Personal Information relating to you or if the disclosure of the name itself would reveal information about you.
- i. Personal information includes Special Personal Information, as explained below.

5. WHAT IS MEANT BY “PROCESSING OF PERSONAL INFORMATION”?

When used in this Privacy Policy, ‘Process or processing’ means any operation or activity or any set of operations, whether or not by automatic means, concerning personal information, including—

- a. the collection, receipt, recording, organisation, collation, storage, updating or modification, retrieval, alteration, consultation or use;
- b. dissemination by means of transmission, distribution or making available in any other form;
- c. merging, linking, as well as restriction, degradation, erasure or destruction of information.

6. WHEN WILL ETHIXPERT PROCESS PERSONAL INFORMATION?

Personal Information will only be processed if:

- a. you have consented thereto; and/or
- b. a person legally authorised by you, the law or a court, has consented thereto; and/or
- c. it is necessary to conclude or perform under a contract, we have with you; and/or
- d. the law requires or permits it; and/or
- e. it is required to protect or pursue your, our or a third party's legitimate interest; and/or
- f. a competent person (like a parent or guardian) has consented to the processing of your information if you are a minor person.

7. WHAT IS SPECIAL PERSONAL INFORMATION?

Special Personal Information is Personal Information about or related to your:

- a. religious beliefs;
- b. philosophical beliefs;
- c. race;
- d. ethnic origin;
- e. trade union membership;
- f. political beliefs;
- g. health or sex life;
- h. biometric information; and/or
- i. criminal behaviour and alleged commission of an offence and any proceedings in respect thereof.

8. WHEN WILL SPECIAL PERSONAL INFORMATION BE PROCESSED?

We may process your Special Personal Information if:

- a. you have consented to the processing;
- b. the processing is needed to create, use or protect a right or obligation in law;
- c. the processing is for statistical or research purposes and all legal conditions are met;
- d. the Special Personal Information was made public by you;
- e. the processing is required by law;
- f. processing is for historical, statistical or research purposes to the extent that the purpose serves a public interest and processing is necessary for that purpose concerned or it appears to be impossible or would involve disproportionate effort to request consent and sufficient guarantees are provided to ensure the processing does not adversely affect your privacy to a disproportionate extent;
- g. information has been deliberately made public by you;
- h. racial information is processed, and the processing is required (i) to comply with laws and other measures designed to protect or advance persons, or categories of persons,

disadvantaged by unfair discrimination; or (ii) for identification purposes where it is essential for that purpose;

- i. health information is processed, and the processing is to determine your liability risk, or to comply with a liability insurance or to enforce a liability insurance right or obligation; and/or
- j. processing biometric information is carried out and we have obtained that biometric information in accordance with the Applicable Law or if such processing is necessary to supplement the processing of information on criminal behaviour or biometric information which is permitted under POPIA or other Applicable Laws.

9. WHEN AND HOW WILL WE PROCESS PERSONAL INFORMATION OF CHILDREN?

A child is a natural person under the age of 18 years who is not legally competent, without the assistance of a competent person, to take any action or decision in respect of any matter concerning him or herself. We process Personal Information of children if the law permits.

We will only process the Personal Information of children if any one or more of the following applies:

- a. a person who can legally agree has consented to the processing, being a parent or guardian;
- b. the processing is needed to create, use or protect a right or obligation in law;
- c. the processing is for statistical or research purposes and all legal conditions are met; or
- d. the child's Personal Information was made public by the child, with the consent of a person who can legally agree thereto.

10. YOUR CONSENT

We will not process Personal Information without your consent save as permitted by Applicable Laws. We may ask for additional consent if we need to use your Personal Information for purposes not covered by this Privacy Policy. You are not obliged to provide such consent but if you decide not to then your participation in certain activities may be restricted. If you provide additional consent, the terms of that consent shall prevail in the event of any conflict with the terms of this Privacy Policy.

By using our website, social media platforms, by registering for courses and through entering into agreements of whatsoever nature, you are consenting to the processing of your Personal Information by EthiXPRT.

If you do not agree to the processing of your Personal Information in this way, you are advised not to:

- a. use our websites and social media platforms as your Personal Information will be processed by them as described in this Privacy Policy, or
- b. otherwise provide EthiXPRT directly with your Personal Information.

11. COLLECTION OF PERSONAL INFORMATION

We collect Personal Information from you directly and from third parties such as stakeholders, service providers, funders and from public sources and from third parties we interact with for the purposes of conducting our business (including but not limited to government departments, Higher Education Institutions, Research Administrators, Research Ethics Review Committees, Research Ethics Committees, Research Ethics Committee Administrators and Researchers). If the law requires us to do so, we will ask for your consent before collecting Personal Information about you from third parties. We also collect Personal Information about you based on your use of our training events, digital on-line platform (RHInnO Ethics) our website and social media platforms.

We collect Personal Information about you based on how you engage or interact with us such as on social media, e-mails, letters, telephone calls or surveys.

The third parties from whom we may collect your Personal Information include, but are not limited to, the following:

- a. colleagues
- b. consortium members
- c. project coordinators
- d. funders
- e. people you have authorised to share your Personal Information, like a medical practitioner or our service providers;
- f. stakeholders
- g. payment processing service providers, merchants, banks and other persons that assist with the processing of your payment instructions and card scheme providers (like VISA or MasterCard);
- h. insurers, reinsurers, brokers, other financial institutions or other organisations that assist with insurance and assurance underwriting, the providing of insurance and assurance policies and products, the assessment of insurance and assurance claims and other related purposes;
- i. law enforcement and fraud prevention agencies and other persons tasked with the prevention and prosecution of crime;
- j. regulatory authorities, industry ombudsman, governmental departments, local and international tax authorities;
- k. credit bureaux;
- l. trustees, Executors or Curators appointed by a court of law;
- m. verification service providers;
- n. our service providers, agents and sub-contractors like Accountancy firms and other persons we use to offer training events and RHInnO Ethics to you;
- o. courts of law or tribunals;
- p. our joint venture partners if applicable; and/or
- q. marketing list providers.

12. HOW AND WHY WE USE YOUR PERSONAL INFORMATION

We will process your Personal Information only for the purposes for which it was collected or agreed to by you and:

- a. to provide you with RHInno Ethics support, training opportunities and consultancy services;
- b. to market RHInno Ethics, training events and consultancy services to you, where permitted;
- c. to respond to your enquiries and complaints;
- d. to comply with legislative, regulatory, risk and compliance requirements (including directives, sanctions and rules), voluntary and involuntary codes of conduct and industry agreements;
- e. to conduct verification and fraud prevention checks and sharing information relating to the purpose with South African Fraud Prevention Services;
- f. to confirm and verify your identity or to verify that you are an authorised user for security purposes;
- g. for operational purposes and where applicable, credibility management;
- h. fulfil reporting requirements and information requests in connection with our reporting obligations in terms of Applicable Laws;
- i. to detect, prevent and report theft, fraud, money laundering and other crimes. This may include the processing of Special Personal Information, like alleged criminal behaviour or like the supply of false, misleading or dishonest information when entering into an agreement with us or avoiding liability by way of deception;
- j. to open, manage and maintain your relationship with us;
- k. to enforce and collect on any agreement when you are in default or breach of the agreement terms and conditions, like tracing you or to institute legal proceedings against you;
- l. for audit and record keeping purposes;
- m. to conduct market and behavioural research, including scoring and analysis to determine if you qualify for RHInno Ethics subscription;
- n. to develop, test and improve our RHInno Ethics platform and other services for you;

- o. for historical, statistical and research purposes, like market segmentation;
- p. to maintain your information for quality, risk, vendor management purposes;
- q. to process payment instructions;
- r. to analyse the effectiveness of our advertisements, competitiveness and promotions;
- s. to enable us to deliver goods, documents or notices to you;
- t. for security, identity verification and to check the accuracy of your Personal Information;
- u. to communicate with you and carry out your instructions and requests;
- v. for customer satisfaction surveys and promotions;
- w. to inform you of our RHInnO Ethics platform and appropriate training, you may be interested in to enable you to take part in and make use of;
- x. for legitimate business purposes, including but not limited to when required for the purposes of raising funding;
- y. to share information with EthiXPERT our stakeholders and trusted third parties we work with. These trusted third parties include our partners, funders, consortium members and RHInnO Ethics Users.
- z. to transmit such information to other countries, when necessary. Where such countries do not have specific data privacy laws EthiXPERT will take appropriate steps to ensure your information is safeguarded; or
- aa. to enable our systems to access, scan, and transport your Personal Information within EthiXPERT or to a hosted third-party site. EthiXPERT may also transmit your Personal Information across a closed network, in various media, and modify or change the format (but not the content) of your Personal Information to comply with technical requirements of connecting networks or devices or computers.

13. HOW WE USE YOUR PERSONAL INFORMATION FOR DIRECT MARKETING

We may use your Personal Information to:

- a. suggest products or services (including those of relevant third parties) which we think may be of interest to you; or
- b. offer you the opportunity to take part in webinars and promotions.

We will do this in person, by post, telephone or electronic channels such as SMS or e-mail. If you are not a client, or in any other instances where the law requires, we will only market to you by electronic communications with your consent.

You can opt out of receiving direct marketing from us.

14. NECESSARY COMMUNICATION

We may use your Personal Information to contact you when contractually or legally required to do so and in connection with:

- a. information, projects, RHInnO Ethics, partnerships or training that you have requested; or
- b. complaints, queries or comments received from you.

15. DISCLOSURE

If we share your Personal Information with a third party, we shall use our best efforts to ensure that they keep your information secure, take all reasonable steps to protect it from misuse and only use it in a manner consistent with this Privacy Policy and Applicable Laws.

In general, we will only share your Personal Information if any one or more of the following apply:

- a. you have consented to this;
- b. it is necessary to conclude or perform under a contract, we have with you;
- c. the law requires it; and/or
- d. it is necessary to protect or pursue your, our or a third party's legitimate interest.

16. SAFEGUARDING YOUR PERSONAL INFORMATION

We take all reasonable precautions in line with generally accepted information security practices to keep your Personal Information secure and require any third parties that handle or process your Personal Information on our behalf to adhere to appropriate standards. We are legally obliged to provide adequate protection for the Personal Information we hold and to implement measures to prevent unauthorised access and use of Personal Information. We will, on an ongoing basis, continue to review our security controls and related processes to ensure that your Personal Information is secure.

We will take appropriate and reasonable technical and organisational steps to protect your Personal Information, including the following:

- a. keeping our systems secure (like monitoring access and usage);
- b. storing our records securely;
- c. controlling access to our premises, systems and/or records; and
- d. safely destroying or deleting records.

We may need to transfer your Personal Information to another country for processing or storage. We will ensure that anyone with whom we have an agreement for the storage and/or processing of your Personal Information agrees to treat your Personal Information with the same level of protection as we are obliged to do.

17. WHEN WILL WE SHARE YOUR INFORMATION WITH OTHER COUNTRIES?

We will only transfer your Personal Information to third parties in any other country if:

- a. your Personal Information will be adequately protected under the other country's laws or an agreement with the third-party recipient;
- b. the transfer is necessary to enter into or perform under a contract with you, or a contract with a third party that is in your interest;
- c. you have consented to the transfer; or
- d. the transfer is in your interest.
- e. if the head office of EthiXPRT is moving across the borders

This transfer will happen within the requirements and safeguards of the Applicable Laws.

18. RETENTION

We will keep your Personal Information for as long as:

- a. applicable Laws require us to keep it;
- b. a contract between you and us requires us to keep it;
- c. you have consented for us keeping it;
- d. we are required to keep it to achieve the purposes for which it was provided;
- e. we require it for statistical or research purposes provided that we have established appropriate safeguards against the records being used for any other purpose;
- f. required by a code of conduct or Applicable Laws;
- g. required for lawful business purposes.

To the extent that we are no longer authorised to retain the record of your personal information, we shall as soon as reasonably practicable (to the extent technically and possible and practicable and provided that we are not obligated to retain such record by Applicable Law), delete, destroy or de-identify the record of your personal information and use its reasonable endeavours to ensure that anyone to whom such information was supplied delete, destroy or de-identify the record of your personal information.

19. YOUR PRIVACY RIGHTS AND RESPONSIBILITIES

You must provide proof of identity when enforcing your information privacy rights. You must inform us when your Personal Information changes.

Our manual in terms of the Promotion of Access to Information Act 2 of 2000 (PAIA), provides further information on how you can give effect to the rights listed below. The manual is available from the EthixPERT website, www.ethixpert.org.za

You may opt out of marketing communications or other circulars. If you are a RHInnO Ethics User, then we may continue communicating with you in respect of your existing products and services.

You have the right to request access to your Personal Information in our possession by contacting us. This includes requesting:

- a. confirmation that we hold your Personal Information;
- b. a copy or description of the record containing your Personal Information; and
- c. the categories of third parties who have had access to your Personal Information.

We will attend to requests for access to Personal Information within a reasonable timeframe. You may be required to pay a reasonable fee to receive copies or descriptions of records, or information about third parties. We will inform you of the fee before attending to your request.

Please note that the Promotion of Access to Information Act 2 of 2000 may limit your right to access information.

You have the right to request us to correct the Personal Information we have about you if it is inaccurate, irrelevant, excessive, out of date, incomplete or misleading. If information was obtained unlawfully and we are no longer authorised to keep it, you may request us to delete it. You must inform us of your request in writing. Please refer to our PAIA Manual for further information in this regard, which sets out the process you should follow to give effect to this right. It may take up to 15 business days for the change to reflect on our systems. We may request documents from you to verify the change in Personal Information.

If you have any specific agreement with us, that relationship may determine how you must change your Personal Information. We will inform you of the requirements to update your information. Please adhere to these requirements. If the law requires or entitles us to keep a record of any information, we may decline to delete it. The deletion of certain Personal Information could lead to the termination of your business relationship with us. You may object on reasonable grounds to the processing of your Personal Information. We will not be able to give effect to your objection if the processing of your Personal Information was and is permitted by law or you have provided consent to the processing and our processing is done according to your consent or if the processing is necessary to conclude or perform under a contract with you.

You must inform us of any objection in writing. Please refer to our PAIA and POPIA Manual for further information in this regard, which sets out the process you should follow to give effect to this right.

Where you have provided your consent for the processing of your Personal Information, you may withdraw your consent. If you withdraw your consent, we will explain the consequences to you. We may proceed to process your Personal Information even if you have withdrawn your consent if the law permits or requires it. It may take up to 15 business days for the change to reflect on our systems, during this time we may still process your Personal Information.

You have a right to file a complaint with us or any Regulator with jurisdiction about an alleged contravention of the protection of your Personal Information by us. We will address your complaint as far as possible.

20. COOKIE POLICY

A cookie is a small piece of data sent from our website to your computer or device hard drive or Internet browser where it is saved. The cookie contained information to personalize your experience on our website or applications and may improve your experience on the website or applications. The cookie will also identify your device, like the computer or smart phone. By using our website or application you agree that cookies may be forwarded from the relevant website or application to your computer or device. The cookie will enable us to know that you have visited the website before and will identify you. We may also use the cookie for marketing purposes or to prevent or respond to fraudulent behaviour.

21. THIS PRIVACY POLICY DOES NOT APPLY TO:

- a. information collected by third party websites, platforms and/or applications (“Third Party Sites”) which we do not control;
- b. Third Party Sites which you access via links on the EthixPERT website; and
- c. marketing of any nature on Third Party Sites that we may sponsor or participate in.

Third-Party Sites may have their own privacy policies and terms and conditions. We encourage you to read them before using those Third-Party Sites.

22. CHANGES TO THIS POLICY

This Privacy Policy may be amended and replaced from time to time by posting the updated version on the EthixPERT website (www.ethixpert.com) with no prior notice.

23. HANDLING OF COMPLAINTS

Complaints in respect of the processing of Personal Information may be submitted to EthixPERT by email to informationofficer@ethixpert.org or may be communicated directly to the Information Regulator.

24. IMPORTANT CONTACT INFORMATION

Head Office Address

34 Stanger Avenue
Eldoraigne X18
Pretoria

Information Officer :

Tel: +32 (00) 485 83 6421
Email: informationofficer@ethixpert.org

Compliance Officer :

Tel: +27 (0) 82 374 2390
Email: corline@ethixpert.org

The Information Regulator :

Name: The Information Regulator (South Africa)
Postal Address: P.O Box 31533 Braamfontein, Johannesburg, 2017
Tel: (010) 023 5207
Email: infoereg@justice.gov.za

Drafted June 2021

Author: Corline van Rooyen

Acknowledgements: SA HomeLoans, Human Science Research Council and National Research Foundation