

Privacy Policy

March 2019 | Version 1.0

1. Introduction

We respect your privacy and take it very seriously. We are the Africa Health Research Institute (also known as AHRI) and this is our plan of action for the protection of your personal information in terms of relevant data protection laws. It describes how we **collect**, **use**, **disclose**, and **store** your personal information.

- 1.1. **What are data protection laws?** Data protection laws are legal rules that regulate how organisations can process personal information.
- 1.2. **What are relevant data protection laws?** They are data protection laws that apply to our processing by virtue of various factors, such as the:
- *Protection of Personal Information Act 4 of 2013 (POPIA)* – to the extent that we process personal information in South Africa; and
 - *General Data Protection Regulation (GDPR)* – to the extent that we process the personal information of EU residents.

2. Application

This policy applies to you when you interact with our organisation, because we collect information about you when you do so.

- 2.1. **What is personal information?** Your personal information is any information that relates to you as an identifiable living human being or existing juristic person (to the extent that applicable law allows). You are identifiable where someone could identify you for example, by reference to your name, identification number or other identifier. Personal information can include your:
- **demographic information** – 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 or birth;
 - **historical information** – information relating to your education, medical, financial, criminal or employment history;
 - **identifying information** – identifying symbol, number, email address, physical address, phone number, location information, online or other identifier;
 - **biometric information** – information related to unique physical or other biological traits about your body, such as your fingerprint or eye colour pattern;
 - **self-opinional information** – personal opinions, views or preferences;
 - **external opinional information** – assessments in terms of other peoples' views or opinions about you; and
 - **name (under certain circumstances)** – name, if it appears with the other personal information relating to you or if the disclosure of the name itself would reveal information about you;

and includes information we collect:

- automatically when you visit our website;
 - automatically as our employee, contractor or affiliate;
 - accept on registration or submission;
 - get through a research study; or
 - you provide voluntarily; but
 - excludes anonymous, de-identified, statistical, and public information.
- 2.2. **If you are our employee, contractor or affiliate.** This policy applies to you as our current or prospective employee, contractor or affiliate if:
- you are someone who works for or with us at the present time; or
 - you are someone who we anticipate might work for or with us at some point in the future;
 - in exchange for compensation under an employment contract or independent contractor agreement; or
 - on some other basis as an affiliated researcher, medical professional or other affiliate.
- 2.3. **When you start and stop being our current employee or contractor.** You start being our current employee or contractor when you sign an employment contract or independent contractor agreement

with us. You stop being our current employee or contractor when our employment contract or independent contractor agreement with you terminates or is cancelled.

- 2.4. **When you start and stop being our prospective employee or contractor.** You start being our prospective employee or contractor when we start engaging with you for the purposes of considering you for employment or contracting with us, such as when you apply for a job or respond to a request for proposal with us (or we otherwise receive your CV or proposal). You stop being our prospective employee when you sign an employment contract or independent contractor agreement with us or we inform you that we are no longer considering you for employment or contracting with us.
- 2.5. **Your obligations** You may only send us your own personal information or someone else's personal information if you have their permission to do so.

3. Acceptance and changes

- 3.1. **Acceptance.** We may decide not to let you participate or limit your participation in a research study or partake of any of our other services if you do not accept this policy or any changes to it, to the extent that applicable law allows.

- 3.2. **Acceptance as our employee, contractor or affiliate.** You may not continue to:

- work: (i) for us as our current employee or contractor; or (ii) with us as our current affiliate; or
- engage with us for the purpose of: (i) considering your employment or contracting as our prospective employee or contractor; or (ii) involvement as our prospective affiliate;

if you do not accept this policy or any changes to it.

- 3.3. **Changes.** We may change this policy at any time and will notify you of the changes on our website or by email. The changed policy applies to you if you continue:

- using our website or our services following the notification; or
- to work: (i) for us as our current employee or contractor; or (ii) with us as our current affiliate;
- to engage with us for the purpose of considering: (i) your employment or contracting as our prospective employee or contractor; or (ii) involvement as our prospective affiliate;

following the notification. We have posted a version number on this page to make sure that you know when we've made a change to any wording on it.

4. Collection

- 4.1. **Why do we collect personal information?** We need to collect your personal information to complete the following and other related tasks:

- **research participation** – allow you to participate in our research studies;
- **medical research** – gather medical information for research purposes;
- **medical dissemination** – disseminate your medical information to health or related professionals (should you require linkage to health or related care);
- **research statistics and results** – compile statistics and results from research studies and related programs;
- **employment** – employ you and maintain an employment relationship with you;
- **contracting** – receive goods or services from you;
- **payment approval** – obtain payment approval (including credit approvals or other financial approval for payment);
- **provide goods or services** – provide you with the goods and services you request or require; or
- **legal compliance** – to comply with the law.

- 4.2. **What main types of personal information do we process?** We mainly process your personal information related to your:

- medical history and information;
- age;
- demographic information;
- birth date;

- identity number;
- passport number;
- occupational information;
- personal and work email and other contact details; and
- certain financial information relating to references and payment information;

depending on the reason that you engage with us.

4.3. How do we collect personal information? We will only collect your personal information for the stated and agreed purpose, and in the following manner:

- directly from you;
- from a representative who may act on your behalf;
- from service providers that provided you with services previously;
- from financial institutions, credit bureaus or similar;
- from our own records relating to our previous interactions;
- from automated services that were used; or
- from other relevant parties;

to the extent that applicable law allows.

4.4. Automatically through website. When you visit our website, we automatically collect your **Internet usage information** (including your IP address, browser details and usage information) through your browser, which we may use to display our website correctly, track your activities on it, or for other necessary purposes.

4.5. Automatically as our employee, contractor or affiliate. We collect some of your personal information automatically as our employee, contractor or affiliate when you use our:

- **IT equipment** – including computers, printers, and any other hardware necessary to do your work or work with us;
- **IT infrastructure** – the entire organised system of IT structures, facilities, and components necessary for the operation of our organisation, including data, computer networks, and software; and
- **employee, contractor or affiliate portal** – any website where we interact with current or prospective employees, contractors or affiliates.

4.6. On registration or submission. We may ask you to provide us with certain **identifying information** (including your first name, surname and email address) when you register on or otherwise submit information through our website for the first time.

4.7. Through a research study. We ask you to provide us certain **services information** when you participate in a research study otherwise partake of our other services.

4.8. Voluntarily. We may ask you to provide us certain **optional information** on a voluntary basis.

4.9. Consent to collection. We will get your consent to collect your personal information in accordance with applicable law when you provide us with it where consent is the basis for our processing.

4.10. Purpose for collection. We may process your information that you provide to us for the purposes that you indicated when you agreed to provide it to us. Processing includes gathering your personal information, disclosing it, and combining it with other personal information.

4.11. Direct and indirect. We generally collect personal information from you directly wherever possible, but we may sometimes collect it indirectly through third parties. We will comply with the relevant laws for indirect collection where we do so, which means that we may not need to ask your permission before doing so and may collect it without your knowledge and consent in those circumstances. We will do our best to ensure that those third parties have the right to give your personal information to us where we use them to provide us with your personal information.

5. Use

5.1. **How do we use your personal information?** We will only use your personal information in a manner consistent with the purpose for which we collected it.

5.2. **Processing.** We may process your personal information to fulfil our obligations to you. Processing means doing anything with personal information, including gathering it, disclosing it or combining it with other information. We generally process the following types on the indicated basis according to the following table:

Purpose	Data	Basis
Enquiring about our organisation and its work	Name, email, message and phone number	Legitimate interest - it is necessary for us to read and store your message so that we can respond in the way that you would expect.
Subscribing to email updates about our work	Name and email	Consent - you have given your active consent.
Signing up, and participating as a research subject	Medical history and information, age, demographical information, birth dates, identity numbers, passport numbers, occupation information, email and contact details or other information specific to the study	Consent - you have given informed consent and signed a consent form.
Applying for, or taking up employment with us	Age, demographical information, birth dates, identity numbers, passport numbers, occupation information, personal and work email and contact details and bank accounts.	Contract - you have entered into a contractual relationship with us; or consent - you have given your active consent.
Collaborating with us	Demographical information, birth dates, identity numbers, passport numbers, personal and work email and contact details.	Contract - you have entered into a contractual relationship with us; or consent - you have given your active consent.
Conducting business with us as a supplier	Work email and contact details, certain financial information relating to references, bank accounts and credit cards.	Contract - you have entered a contractual relationship with us.
Website functionality	Website activity collected through cookies	Legitimate interest - it is necessary for us to store a small amount of information, usually through cookies, to deliver functionality that you would expect.

5.3. **How do we process personal information in terms of research studies** An ethics committee, accredited with the National Health Research Ethics Council, must approve all research studies before we start collecting your personal data. They check the purpose of the research study and whether we are seeking adequate informed consent from the participants before giving us their approval to start it.

5.4. **Cookies.** We may place small text files on your device when you visit our website that allow us to provide you with a personalised experience by associating your personal information with your device. They let us remember your preferences, allow third parties to provide services to you, and otherwise serve useful purposes for you. Your internet browser generally accepts them automatically, but you can often change this setting or delete them manually. However, we won't be able to provide you with access to certain aspects of our website where cookies are necessary if you do so. We have no access to or control over any cookies that our business partners use on our website and they have their own privacy policies that govern them.

5.5. **Messages.** We may use your identifying information to send you administrative and update messages about our website.

6. Disclosure

We will only disclose your personal information to a third party where:

- you have provided your consent;
- the data have been de-identified;
- we are using a third party purely for the purposes of processing data on our behalf and we have in place a data processing agreement with that third party that fulfils our legal obligations in relation to the use of third party data processors; or
- we are required to share your personal information by law.

6.1. **Sharing.** We may share your personal information with third parties for the purposes of fulfilling our obligations to you, including with:

- our employees;
- medical professionals and researchers;
- other companies or divisions within our group;
- our other contractors who help us meet our obligations to you, including those that help us understand your personal information;
- third parties related to the purpose or who are sources of your personal information;
- third parties outside of South Africa where your personal information must be sent; or
- third parties as required by applicable law.

6.2. **Honour this policy.** We will require anyone that we share your personal information with to honour this policy whenever possible in terms of applicable law.

6.3. **Mandatory disclosure.** We may disclose personal information to third parties if required for legal reasons, such as:

- to regulators as law or governmental audit requires;
- law enforcement as subpoena or court order requires; or
- third parties as applicable law requires.

6.4. **Marketing purposes.** We may disclose aggregate statistical information that we have derived from your and other people's personal information to our advertisers or business partners.

6.5. **Personnel.** We may need to disclose personal information to our personnel to do their jobs, but will not do so unnecessarily.

6.6. **Change of ownership.** We may assign our rights to the personal information we process to our new owners if our ownership changes for any reason.

7. Consent

7.1. **What is consent?** Consent is a:

- freely given;
- specific, informed and unambiguous;
- indication of wishes;
- by clear affirmative statement;
- that gives permission.

7.2. **Acceptable forms of consent.** We will accept the following forms of consent:

- **direct consent** – direct written or verbal consent by you or your guardian;
- **implied consent** – should you fail to advise us that you do not agree with this document and you wish to exclude all or some of the provisions of it;
- **indirect consent** – should you directly or indirectly through a representative acting on your behalf, provide us with your personal information;

however, we will not accept indirect consent for research studies and will always set out to get informed consent for specific research studies.

7.3. Consent to collection, use, disclosure, and storage. You consent to us collecting, using, disclosing, and storing your personal information for the purposes provided for in this policy and any other purposes set out or implied when you provide the relevant personal information to us to the extent that applicable law allows, unless you inform us otherwise.

7.4. Broad consent to process genetic information. Your genetic information means personal information relating to your genetic characteristics from analysis of your DNA, RNA or other biological samples or similar analysis. We may ask for broad consent to process your genetic information from time to time for the purposes of adding it to biobanks or for similar research practices. This broad consent may not be completely specific, but we will do our best to make it as specific as possible in the circumstances. We may also process your genetic information without your consent in certain circumstances in terms of applicable laws.

7.5. Generally not required. We are not generally required to get your consent to collect, use, disclose, or store your personal information – except in the case of research studies or other circumstances where the law requires it. The law sometimes allows or requires us to collect, use, or disclose your personal information without your knowledge or consent under certain circumstances. However, we will ask you for your consent whenever the law requires it.

8. Storage

8.1. Accuracy. We will do our best to keep your personal information that we collect accurate, complete, and up to date.

8.2. Participation. We may ask you to update your personal information from time to time, but will take steps to verify your identity to prevent unauthorised access when doing so.

8.3. Retention. Where we collect or process your personal information for historical, statistical or research purposes, we may keep it beyond the purpose for which we collected or processed it in terms of relevant laws. We will have appropriate safeguards to prevent those records from being used for other purposes, as required. Otherwise, we will only keep your personal information for as long as is necessary in terms of the purpose for which we collected it, unless you have given us permission to keep it longer or we are otherwise legally allowed to do so.

8.4. Transfer. We may transfer your personal information outside of the country in which it was collected to a foreign country. You consent to us processing your personal information in a foreign country with less stringent data protection laws than the country in which it was collected.

9. Your rights

9.1. Personal information rights. You have a range of rights over your personal information, which include:

- **revocable consent** – where your consent is required for us to collect, use, or disclose your personal information, you may withdraw your consent at any time, subject to legal or contractual restrictions and reasonable notice - although we will make it as easy as possible for you to do this;
- **rectification or deletion** – you have the right to ask for rectification or deletion of your information;
- **access** – you have the right of access to your personal information;
- **complain to supervisory authority** – you have the right to lodge a complaint with the relevant supervisory authority if you feel your rights have been infringed.

9.2. Accommodation of rights. Please note that relying on some of these rights, such as the right to delete your personal information, will make it impossible for us to continue to deliver some services to you. However, where possible we will always try to allow the maximum compliance with your rights while continuing to deliver as many services to you as possible.

9.3. Consent not always required. We draw to your attention that in terms relevant data protection and other laws, there are instances where your express consent is not necessary to permit the processing of your personal information, which may be related to police investigations, litigation or when we legally process your personal information on some other basis.

10. Requesting access and lodging of complaints

- 10.1. **Access requests.** Please submit any requests for access to your personal information in writing to our's Information Officer at 3rd Floor, K-RITH Tower Building, 719 Umbilo Road, 4013.
- 10.2. **Sufficient detail.** Please provide sufficient detail regarding the information you require to allow us to identify what information you are seeking access to.
- 10.3. **Verify identity.** With any request for access to your personal information, we will require you to provide personal information to verify your identification and therefore your right to access the information.
- 10.4. **Reasonable charge.** There may be a reasonable charge for providing you with copies of the information you are requesting.
- 10.5. **Directing requests or complaints.** Please direct any request for access to your personal information or complaints regarding this document or any aspect thereof or any of the procedures we use to process information, to the Information Officer.
- 10.6. **Escalation.** Should you feel that we have not dealt with any complaint you have filed to your satisfaction or you wish to report a complaint to the relevant supervisory authority, you have the right to contact them.

11. General

- 11.1. **Limitation.** We are not responsible for anyone else's privacy policies or practices.
- 11.2. **Enquiries.** Please contact our Information Officer if you have any questions about this privacy policy or how we handle your personal information:
 - Name: Dr Kobus Herbst
 - Designation: Chief Information Officer
 - Postal Address: Private Bag X7, Congella, Durban 4013
 - Physical Address: 3rd Floor, K-RITH Tower Building, 719 Umbilo Road, Durban, KZN, South Africa
 - phone Number: 035 550 7503
 - Fax Number: N/A
 - E-mail: Kobus.Herbst@ahri.org