

African Genetic Counsellors Association (AGCA)



Privacy Policy

Last Updated: 7 September 2025

1. Introduction

The African Genetic Counsellors Association is a non-profit organisation that supports and promotes the professional practice of genetic counselling across Africa. We are committed to protecting the privacy of all visitors to our website (<https://africangcassociation.org/>) and ensuring that your personal information is processed in compliance with the **Protection of Personal Information Act, 4 of 2013 (POPIA)**, applicable African privacy laws, and relevant international standards such as the **EU General Data Protection Regulation (GDPR)** where applicable.

This Privacy Policy explains how we collect, use, store, and protect your personal information, and outlines your rights.

2. Definitions

- **“Personal Information”**: Information that identifies or can reasonably identify you, such as your name, contact details, professional credentials, and other details you provide.
- **“Special Personal Information”**: Sensitive categories of data as defined under POPIA, including health information, genetic data, and information about children.
- **“Processing”**: Any operation concerning personal information, whether automated or manual.
- **“You” / “Your”**: Any website visitor, member, donor, volunteer, or service user.

3. Information We Collect

3.1 Information You Provide Voluntarily:

- Name, surname, and contact details.
- Professional qualifications, registration details, and areas of expertise (if applying for membership or listing).
- Payment details (for donations, membership fees, or event registrations).

- Health or genetic information (only where necessary and with explicit consent).
- Consent forms and research participation agreements.

3.2 Information Collected Automatically:

- IP address, browser type, device type, and operating system.

3.3 Information from Third Parties:

- Publicly available professional registers or partner organisations (for verification purposes).

4. Purpose of Processing

We process your personal information to:

- Provide information, services, and resources relating to genetic counselling.
- Process membership applications, donations, and payments.
- Communicate updates, newsletters, and event invitations (with opt-out options).
- Maintain a voluntary member directory.
- Conduct ethically approved research and training.
- Comply with legal and regulatory obligations.
- Improve our website, services, and outreach activities.

5. Special Personal Information & Consent

Where we collect **special personal information** (such as genetic or health data), we will:

- Obtain your **explicit consent** before processing.
- Use it **only for the specified purpose** for which it was collected.
- Apply enhanced security safeguards.
- De-identify or anonymise data wherever possible.
- You may withdraw your consent at any time by contacting us (see Section 16).

6. Children's Privacy

We do not knowingly collect personal information from persons under the age of 18 without the consent of a parent or legal guardian. If such information is inadvertently collected, we will delete it promptly upon becoming aware.

7. Research Participation

If you participate in research projects facilitated or supported by us:

- Participation is **voluntary**.
- Any identifiable data will only be used with **your informed consent** and **ethical clearance** from a recognised review board.
- Data will be anonymised wherever possible for reporting or publication.

8. Legal Basis for Processing

We process personal information on one or more of the following legal grounds:

- Your consent.
- Performance of a contract with you.
- Compliance with a legal obligation.
- Legitimate interests aligned with our non-profit mission.

9. Third-Party Links

Our website may contain links to third-party websites. We are not responsible for the privacy practices or content of those sites. We encourage you to review their privacy policies before sharing any personal information.

10. Disclosure of Information

We may share your personal information with:

- Service providers (e.g., IT hosting, payment processors).
- Partner organisations (only with your consent).
- Regulatory or statutory bodies as required by law.
- We do not sell or rent personal information.

11. Cross-Border Transfers

If we transfer your personal information outside South Africa, we will ensure that adequate safeguards are in place as required by **Section 72 of POPIA**, such as contractual clauses or transfers to jurisdictions with adequate data protection laws.

12. Data Storage & Localisation

Your personal information may be stored on secure servers located within South Africa or in other jurisdictions (such as the EU or the US). Where data is stored outside South Africa, we ensure that the hosting provider offers **comparable legal protection**.

13. Data Security

We employ appropriate organisational, physical, and technical measures to protect personal information against loss, theft, unauthorised access, disclosure, alteration, or destruction.

14. Data Retention

We retain personal information only as long as necessary for the purposes for which it was collected, or as required by law.

15. Data Breach Notification

If a security compromise occurs that affects your personal information, we will:

- Notify you and the Information Regulator **as soon as reasonably possible**.
- Provide details of the breach, potential impact, and remedial measures.

16. Your Rights

You have the right to:

- Access your personal information.
- Request correction, deletion, or restriction of processing.
- Object to processing.
- Withdraw consent (where applicable).
- Lodge a complaint with the Information Regulator.

17. Contact Information

- **Information Officer:** Nakita Laing
Email: info@africangcassociation.org

18. Complaints

- If you believe we have not handled your personal information in accordance with this Privacy Policy, you may lodge a complaint with:
- **Information Regulator (South Africa)**
- Website: <https://infoeregulator.org.za>
- Email: complaints.IR@justice.gov.za

19. Changes to this Privacy Policy

We may amend this policy from time to time. The updated version will be posted on our website with the revised effective date.