

GMG Privacy Policy for Genetic Testing

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Purpose

This document describes the regulations and measures in place to protect the privacy and private information of patients for clinical services of the Garvan Molecular Genetics facility.

Terms and Abbreviations

Term	Explanation
GMG	Garvan Molecular Genetics
GIMR	Garvan Institute of Medical Research
OAIC	Office of the Australian Information Commissioner

Introduction

As part of Australian legislation including the Australian Privacy Principles set out in the *Privacy Act 1988* and in accordance with Garvan Institute of Medical Research's (GIMR) general privacy regulations, GMG is committed to ensure and enforce the maintenance of patient's privacy at all times. The following policy details GMG's privacy policy.

GMG Privacy Policy

1. GMG, a service of the GIMR, appreciates that privacy is important to you. GMG is committed to handling personal information (including health information and other sensitive information) in accordance with applicable privacy laws, including the Australian Privacy Principles set out in the *Privacy Act 1988 (Cth)*.
2. GMG is a specialist provider of clinical genetic services. GMG uses specialised genetic sequencing technology for confirmatory screening of genetic disease. Our services are only available on request from your treating specialist.
3. This document sets out our policies for handling your personal information. In this policy 'we' and 'us' refers to GMG and 'you' refers to any individual about whom we receive personal information.
4. This policy applies only to personal information received and stored by GMG. The general privacy policy applicable to the GIMR is available at <https://www.garvan.org.au/about-us/policies/privacy-policy>.

Privacy Summary

1. We may receive and store personal information about you (including information about your health) from your treating specialist, to provide you with clinical genetic services. Scientific personnel working with GMG use your personal information to generate a technical genetic report (confirmatory technical report **ONLY**) which is provided to your treating specialist. We may disclose your personal information to reputable service providers who provide us with scientific and technical services necessary to provide you with the services your treating specialist has requested.
2. Your personal information is held securely in accordance with this privacy policy and privacy laws and is treated with respect and care. You have the right to contact us to access or correct your personal information. We encourage you to contact us if you have questions or concerns about your privacy or how your personal information is handled by GMG.

What information does GMG receive and store about you and why?

1. We may receive and store personal information necessary to provide the clinical genetic services requested by your treating specialist. When we receive a request for a technical genetic report, an electronic record is made containing your personal information such as your name, date of birth, address and other contact details. The information we receive in a request will typically include information about your health including:
 - a. your medical history;
 - b. results of previous tests and investigations;
 - c. your family medical history;
 - d. your genetic information;
 - e. medications you may be taking or treatments you are undergoing;
 - f. details about your treating doctors and other health professionals involved in your care; and
 - g. other information which may be relevant to your care.

How does GMG receive and use your personal information?

1. We will receive your personal information from your treating specialist. We use your personal information to provide the services requested by your treating specialist and to provide your specialist with a technical genetic report.
2. We will only receive and store your personal information with your consent.
3. We will not use your personal information for direct marketing without your consent.

How does GMG hold your personal information?

1. We hold personal information in paper based and electronic records and systems. Personal information may be received in paper-based documents (such as request forms) and converted to electronic form for storage (with the original paper-based documents either archived or securely destroyed).
2. GMG uses physical security and other measures to ensure that personal information is protected from misuse, interference and loss; and from unauthorised access, modification and disclosure. Personal information held in paper-based form is generally securely stored at our facilities in Sydney, or in the case of archived records, at an external storage facility in Australia.
3. Personal information held in electronic form is held in GMG computer systems and is accessible to scientific personnel working at GMG. All our staff are bound by a formal code of conduct. We educate and supervise staff to ensure information is handled in accordance with this privacy policy and privacy laws, and with respect and care.
4. We maintain computer and network security by using firewalls, user identifiers and passwords to control access to our computer system.

How does GMG disclose your personal information?

1. We will disclose your personal information, typically in the form of a technical genetic report, to your treating specialist.
2. We work with reputable contractors and service providers (such as organisations who provide us with scientific and technical services) and IT services providers to provide our services. We will disclose your personal information to these third party service providers only to the extent necessary to provide you with clinical genetic services. We require our service providers to comply with GMG's Privacy Policy and Australian privacy laws.
3. GMG uses highly-advanced technology to provide its services. In order to utilise that technology safely and effectively, our technology suppliers' technicians may have incidental access to your personal information in the course of providing calibration, maintenance and support services.

4. We may also use or disclose your personal information for the administration, management and operation of GMG including safety and quality assurance activities; accreditation activities; testing and maintenance of information technology systems; risk management and management of legal liabilities and claims (for example, liaising with our insurers); responding to complaints or inquiries; and responding to subpoenas or other legal orders and obligations.
5. We may also disclose your personal information to third parties where you have consented or we are required or entitled to do so by law.

Will your personal information be sent overseas?

1. GMG does not typically or routinely disclose personal information to overseas recipients.
2. Unless we have your consent, or an exception under the Australian Privacy Principles applies, we will only disclose your personal information to overseas recipients where we have taken reasonable steps to ensure that the overseas recipient does not breach the Australian Privacy Principles in relation to your personal information.

How can you access or seek correction of your personal information?

1. If you would like further information or do not understand any aspect of the clinical genetic services you have received from GMG, we would encourage you to speak to your treating specialist so that information can be explained.
2. However, you have a right to request to access the personal information that we hold about you using the contact details provided in the "How to contact us" section below. In limited circumstances, access to your personal information may be declined in accordance with privacy laws. In those circumstances, we may give you access through a mutually agreed intermediary (for example, an appropriate health professional). We will provide you with access free of charge.
3. We endeavour to ensure that your personal information is accurate, complete and up-to-date whenever we use it. You can assist us with this by letting us know if your details change or if you notice errors or discrepancies in information we hold about you. If you consider any personal information we hold about you is not accurate, or is incomplete or out-of-date, you may request we amend our records. Please note that it is generally not possible to make changes to clinical information, however, you may be entitled to request that we associate a statement with your record.

What should you do if you have a complaint about the handling of your personal information?

1. If you have any questions or concerns about this Privacy Policy or how your personal information has been handled by GMG, please contact us using the details in the "How to contact us" section below.
2. You may make a complaint about privacy to the Privacy Officer using our contact details. The Privacy Officer will first consider your complaint to determine whether there are simple or immediate steps which can be taken to resolve the complaint. We will generally respond to your complaint within two weeks.
3. If your complaint requires more detailed consideration, we will acknowledge receipt of your complaint within two weeks and endeavour to respond to your complaint promptly. We may ask you to provide further information about your complaint and the outcome you are seeking.
4. In most cases, we will consider and respond to a complaint within 30 days. If the matter is complex and we require more time to consider and respond to your complaint, we will let you know.
5. If you are not satisfied with our response, or you consider that we may have breached the Australian Privacy Principles or the *Privacy Act 1988*, you are entitled to make a complaint to the Office of the Australian Information Commissioner (OAIC). The OAIC can be contacted by telephone on 1300 363 992 or full contact details can be found online at <https://www.oaic.gov.au/about-us/contact-us>

How are changes to this Privacy Policy made?

1. GMG may amend this Privacy Policy from time to time, with or without notice to you. We recommend that you visit www.garvan.org.au/gmg regularly to keep up to date with any changes.

How to contact us

In writing: Garvan Molecular Genetics

Garvan Institute of Medical Research
384 Victoria Street, Darlinghurst, NSW 2010

Telephone: + 61 (0)2 9295 8384

Email: gmg@garvan.org.au

References

1. Privacy Act 1988, No119, 1988, compilation 68 (path: http://www.austlii.edu.au/cgi-bin/download.cgi/au/legis/cth/consol_act/pa1988108)
2. Australian Privacy Principles (path: <https://www.oaic.gov.au/privacy/australian-privacy-principles>)
3. GIMR Privacy Policy (path: <https://www.garvan.org.au/about-us/policies/privacy-policy>)
4. GIMR Research Policy (path: <https://www.garvan.org.au/about-us/policies/research-policy>)