

How **PRIVACY** and **ACCESS** to your **PATHOLOGY RESULTS** is managed in New Zealand

Pathology laboratories take your **privacy** and healthcare **rights** very seriously. There are **laws** they must follow about how and when to collect, record, store, use and share your **personal and health information**.

The **New Zealand Information Privacy Principles (Privacy Act 1993)**, **Health Information Privacy Code** and the **Health Act 1956** outline how **government and private organisations** providing health services to you must handle, use, manage, disclose and store your **personal information**. Under the Privacy Act, **personal information** means “information about an identifiable individual” and includes details about your health as well as predictive genetic information collected before, in the course of or incidental to the provision of any health service. (PA s 2(1), HIPC s 4(1))

The principles of the **Treaty of Waitangi** underpin the delivery of health services to Māori, to enable Māori to participate in the delivery of health services.

This is how pathology laboratories manage your right to **PRIVACY for your pathology results**

Pathology laboratories collect, use and disclose your personal information to:

make sure you have the right tests produce pathology results and deliver them to the right health service providers determine trends or significant changes to your pathology results over time enable billing and payments to happen fulfil regulatory and public health requirements assure quality and improved processes assist with education and research (which usually requires your consent, unless the information is anonymised and can longer be used to identify you) general administration of management of the laboratory (together, the **Purposes**). (RCPA 1)

Tip: *The Royal College of Pathologists of Australasia (RCPA) recommends that **laboratories develop their own Privacy Policy and Information** for patients and referring doctors. (RCPA 1) Contact the relevant laboratory or look at their website to find this information.*

Collection of your personal information directly from you

Your pathology laboratory will only **collect your personal information**:

- in connection with one or more of the **Purposes**; and
- **directly from you.**

If reasonably practical in the circumstances, your pathology laboratory will advise you why the information is needed, who else will see it and where it will be stored. This information is usually contained in the laboratory's **own Privacy Policy**.

There are certain circumstances in which your pathology laboratory may collect your personal information from **someone else**. These circumstances include the following:

- where you authorise collection of your personal information from someone else;
- to avoid prejudice to your interest;
- to avoid prejudice to your or someone else's safety;
- where collection is for the purpose of assembling a family/whānau or genetic history of an individual to whom you are genetically related and the information is collected directly from that individual;
- where it is not reasonably practicable in the circumstances to collect information directly from you; or

- where the information is publicly available.

Tip: If you are in **doubt** about why your information is being collected, always ask **why** they want or need it, **how** it is going to be used, and **who** it will be disclosed to. (IPP Principle 3, HIPC Rule 3)

Identifying you is critically important

Accurately identifying you by collecting your personal information is **critically important to protect you**, and to make sure **your samples are labelled correctly**. For example, a person can be transfused with the wrong blood type if they are not identified properly. (DOH1, LTO1, RCPA 5)

Your pathology results must be delivered securely

Most pathology results are **transmitted electronically** to your treating practitioners, but they must be **encrypted** during the transmission. (MH 24/6/16) *Encrypted means being sent using a code to prevent unauthorised access to the information. (DICT 1)* They may also be delivered by **phone, fax or as paper** copies. The treating practitioner can also download your pathology results **from secure internet sites** or access results **online** using a **unique password and login**. (RCPA 3, MH 24/6/16)

Tip: International Accreditation New Zealand (IANZ) **accredited laboratories** must have systems in place to ensure the **privacy and confidentiality of patients** is maintained at all times, including during the transfer of pathology results by any electronic system. Their system access controls must also protect the laboratory's information, including pathology results, from being improperly disclosed, modified, deleted or rendered unavailable. Accredited laboratories will have the **RCPA/IANZ logo or endorsement certificate** clearly displayed, or ask the pathology laboratory staff if they have IANZ/RCPA certification. (IANZ, RCPA 5)

There are rules that protect your pathology results when you are in hospital

Hospitals and their medical staff and employees are subject to **privacy and confidentiality obligations**. This means medical staff and employees who have access to your personal and health information are required to understand and comply with their **obligations and responsibilities** to maintain and protect your privacy. They are usually required to sign a **privacy agreement** as part of their **employment contract**. In addition, medical staff are subject to **legal and professional obligations** to respect your **right to confidentiality and privacy**. (GMP 22, HDC Right 1(2)) When you leave hospital, a **discharge summary** that will include your pathology results is prepared for you by your medical team and sent to your treating practitioner/s to ensure continuity of care. (GMP 50, HDC Right 4(5))

Your rights are protected after you die

When you die, your pathology results won't be released to any other party unless they have the **legal authority** to access them, such as an executor of your estate. (MH, 31/5/16, HIPC, R11(1)(a)(ii)) However there may be cases where it is not desirable or practicable to obtain authorisation from your legal representative prior to disclosing your personal and health information. These circumstances include where the disclosure of the information is **necessary to prevent or lessen a serious threat to public health or public safety or the life of a person**. In such cases, it may be necessary for genetic test results that impact on other family/whānau members to be disclosed if the health care practitioner considers that disclosure is **necessary to prevent or lessen a serious threat** to the individual's health or life (HIPC, Rule 11(2)(d)).

Tip: Rule 11 "Disclosure" in the Health Information Privacy Code applies to both health information about living and deceased individuals.

This is how pathology laboratories manage ACCESS to your pathology results

You can access your own pathology results

Pathology results are considered **health information**, and if you want to see them then they must be provided to you in a secure way. (MH, 31/5/16) You may be asked to pay a fee to cover administrative costs such as photocopying, printing and staff time to comply with your privacy request. (RCPA 1, PA, s 35)

Tip: *Even if arrangements have been made for you to receive a written copy of your pathology results, the laboratory **won't release them to you verbally over the phone** as well. This is to protect your information because it can be difficult to positively identify the caller. (RCPA 3, MH, 31/5/16)*

You don't own your pathology results

Your pathology results stay with the **pathology practice** and the **treating practitioner** who requested your pathology test/s. However, you have **legal rights** with respect to **your personal information**, except in some situations. (RCPA 1, MH 24/6/16) An example is when an organisation is satisfied, after consultation undertaken with an individual's treating practitioner, that giving access to certain information would **prejudice the individual's physical or mental health**. (HA, s 22F; HIPC, Rule 11(4)(a))

There are laws governing who else can access your pathology results

Your pathology results are confidential, and pathology laboratories are bound by **privacy laws** regarding the use and release of your personal information. There is usually only **two groups who can access your pathology results**: your treating practitioner/s and health care team, and those who must be notified by law of your results.

Results won't be provided to potentially interested parties such as your employer or a relative (unless you are a child, in which case the results will be provided to your parent or legal guardian) **without your written consent**. Even a **relative who is a doctor** cannot access your pathology results unless they are in a **treating relationship** with you. (MH, 31/5/16, RCPA 2, 3, HIPC, Rule 11)

Tip: *The multi-disciplinary team approach to health care is very common in New Zealand. This means **treating practitioners, including pathologists, work together and share necessary information**, usually according to **codes of practice**, to make sure they deliver optimum patient care. (GMP)*

Your pathology results can be shared without your consent

This occurs when the pathology practice is **ordered by a court of law** to release your results, or when they are **required by law** to notify the Ministry of Health of a "Notifiable Disease". However, in most cases the notification of the relevant "Notifiable Disease" will be done without disclosing any identifying personal information, unless disclosure of identifying personal information is **necessary to respond effectively to a public health risk** (HA, s 74AA)

There are rules about how long your pathology results are kept

The **general minimum amount of time** the pathology laboratory will keep your pathology results is **10 years** (HRHI, reg 5). **The exception is genetic test results**, which must be kept for **100 years**. (NPAAC 1)

Tip: *Your pathology report is a part of your **medical record** and may be kept in, or remain accessible from, the laboratory information system. The laboratory may also need to maintain a number of records that verify the validity of the tests used to produce your results. (NPAAC 1)*

This is how pathology laboratories manage PRIVACY and ACCESS to GENETIC TEST RESULTS

Genetic test results are just like the results of any other pathology test when they are requested by your treating practitioner, **with one main difference**. (NHMRC 2) **You share your DNA with your family/whānua**. A treating practitioner may be authorised under **New Zealand privacy laws** to release information directly to at-risk relatives about a familial disorder in **exceptional circumstances**. (RCPA 4, HIPC, Rule 10(1))

Exceptional circumstances include where the treating practitioner believes on reasonable grounds that the disclosure and use of the information for a purpose not connected with the purpose for which the personal information was initially collected is **necessary to prevent or lessen a serious threat to public health or public safety or the life or health of the individual concerned or another individual**. In these cases, the treating practitioner may consider it necessary to use and disclose your genetic test results (which was originally obtained for the purpose of treating you) to your at-risk relative (for the purpose of preventing or lessening a serious threat to his or her health) (HIPC, Rule 10(1)(d)).

Purchasing a genetic test without the involvement of a medical professional is known as a **direct-to-consumer (DTC) genetic test**. A third party will hold your DNA sample and the results of their analysis. If the service is **based overseas, you will no longer be protected by New Zealand privacy laws**. (NHMRC 1)

***Tip:** Some DTC testing policies allow genetic test results to be **sold to third parties** such as pharmaceutical companies. You should always **examine the privacy policies and terms and conditions** of your chosen DTC testing company to **make sure your privacy rights are protected**. (NHMRC 1)*

If you wish to learn more about your privacy rights, visit the website of the Office of the Privacy Commissioner: <https://www.privacy.org.nz/>.

If you think your privacy has been breached, you can make a complaint by:

- writing to your pathology laboratory; or
- writing to the Privacy Commissioner:

Office of the Privacy Commissioner
PO Box 10094
Wellington 6143

These are other reliable sources of information you may like to use

These are other reliable sources of information you may like to use

- Royal College of Pathologists of Australasia - <https://www.rcpa.edu.au>
- Lab Tests Online - <http://www.labtestsonline.org.au>
- Australian Government Department of Health - <http://www.health.gov.au>
- Office of the Australian Information Commissioner - <https://www.oaic.gov.au>

New References:PA: Privacy Act 1993 -

<http://www.legislation.govt.nz/act/public/1993/0028/latest/DLM297095.html>

IPP: Information Privacy Principles:

<http://www.legislation.govt.nz/act/public/1993/0028/latest/DLM297037.html>

IANZ: <file:///C:/Users/TL/Downloads/SpecificCriteriaMedicalTesting.pdf>

GMP: Good Medical Practice, Medical Council of New Zealand (December 2016) - <https://www.mcnz.org.nz/assets/News-and-Publications/good-medical-practice.pdf>

HDC: Code of Health and Disability Services Consumers' Rights – <https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/>

HIPC: Health Information Privacy Code: <https://www.privacy.org.nz/assets/Files/Codes-of-Practice-materials/Consolidated-HIPC-current-as-of-28-Sept-17.pdf>

HA: Health Act 1956 – <http://www.legislation.govt.nz/act/public/1956/0065/latest/DLM306662.html>

HRHI: Health (Retention of Health Information) Regulations 1996 -
http://www.legislation.govt.nz/regulation/public/1996/0343/latest/DLM225616.html?search=ts_act%40bill%40regulation%40deemedreg_retention_resele_25_a&p=1

NPAAC 1: National Pathology Accreditation Advisory Council *Requirements for the Retention of Laboratory Records and Diagnostic Material* -
[http://www.health.gov.au/internet/main/publishing.nsf/Content/B8562E2C3D131ED8CA257BF0019153C/\\$File/20180612%20-%20Final%20-%20Retention.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/B8562E2C3D131ED8CA257BF0019153C/$File/20180612%20-%20Final%20-%20Retention.pdf)