

## How PRIVACY and ACCESS to your PATHOLOGY RESULTS is managed in Australia

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

The **Australian Privacy Principles** outline how a number of **government and private organisations** must handle, use and manage your **personal information**. This includes details about your health as well as predictive genetic information. (OAIC 5,6)

A number of **privacy acts** also protect your **personal information, govern how it is handled** and give you **greater control** over your information. (OAIC 1) The Act that applies to you **depends on which state or territory you live in**, and on whether your pathology tests are being processed in a **public or private laboratory or at a hospital laboratory**. (OAIC 3) You can find more information about these privacy acts on the *Office of the Australian Information Commissioner's* website.

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

#### ***Pathology laboratories collect, use or disclose your personal information to:***

- make sure you have the right tests
- produce pathology results and deliver them to the right health 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). (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.

#### ***When your consent isn't needed***

A pathology laboratory can sometimes **collect your personal information without your consent**. For example, when:

- There are **rules** requiring collection.
- There is a serious or imminent **threat to life**.
- The information is required for **management, research or statistical purposes** relevant to **public health or public safety**, or for the **management, funding or monitoring of a health service** where it **isn't practical to gain consent** and **de-identified information isn't sufficient**. (RCPA 1)

***Tip:*** **De-identified information** means **removing information that can identify you** such as your name, address and date-of-birth. It also means removing or altering other information that could identify you. (OAIC 12)

#### ***Identifying you is critically important***

Accurately identifying you by collecting 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)

**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. (OAIC 1)

### **Your pathology results must be delivered securely**

Most pathology results are **transmitted electronically** to 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:** National Association of Testing Authorities (NATA)/RCPA **accredited laboratories** must have systems in place to ensure the **privacy and confidentiality of patients** is maintained at all times. 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 **NATA/RCPA logos or endorsement certificates** clearly displayed, or ask the pathology laboratory staff if they have NATA/RCPA certification. (NPAAC 2,3, RCPA 5)

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

Hospitals are subject to **privacy, confidentiality and security legislation**. This means staff who have access to your sensitive health information are required to understand their **obligations and responsibilities** to maintain your privacy, and are usually required to sign a **privacy agreement** as part of their **employment contract**. (MH, 31/5/16) 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. (MH, 31/5/16)

### **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) **Genetic test results** impact other family members so they **may be released** if the genetic information is deemed necessary **to prevent a serious threat to the life, health or safety of related parties**. (OAIC 7, MH 24/6/16)

**Tip:** While the Privacy Act doesn't generally protect the personal information of people who have died, **individual State and Territory privacy legislation addresses this issue** including providing the opportunity to **allow decisions** to be made on behalf of the person who has died. (ALRC 2)

## **This is how pathology laboratories manage ACCESS to your pathology results**

### **You can access your own pathology results**

Pathology results are considered **sensitive information**, and if you want to see them 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. (RCPA 1)

**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 reside with the **pathology practice** and the **treating practitioner** who requested your pathology test/s. You are **legally entitled** to the information contained in them except in some situations. (RCPA 1, MH 24/6/16, OAIC 11) An example is when an organisation reasonably believes that giving access to this information would pose a serious threat to any individual, or to public health and safety. (OAIC 11)

### ***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 they are a 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)

***Tip:** The multi-disciplinary team approach to health care is very common in Australia. 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. (RCPA 1)*

### ***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 send results to **Cancer Registries** or to **health authorities**. (RCPA 3) For example, if you are diagnosed with a **notifiable disease** such as influenza or hepatitis B, your result will be forwarded to the **relevant health authority** along with your contact phone number and the contact details of the treating practitioner who requested your test. This information is required in case the health authority needs to follow up your test result, and to make sure their records are accurate. (MH, 31/5/16)

### ***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 **seven years** for adults, and seven years from the age of majority for minors (which is currently 25 years of age). **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**. A treating practitioner may be authorised under **Australian privacy laws** to release information directly to at-risk relatives about a familial disorder in **exceptional circumstances**. (RCPA 4, OAIC 7) These include when:

- Your treating practitioner obtains your genetic information while they are **providing a health service** to you.

- Your treating practitioner reasonably believes there is a **serious threat to the life, health or safety** of your genetic relatives.
- Providing your genetic information to your genetic relatives is necessary to **reduce or prevent these threats**.
- Your treating practitioner complies with the **Privacy Act**.
- The person who receives the information is your **genetic relative**. (OAIC 9)

**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 Australia's 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)*

#### 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:

OAIC 11 - <https://www.oaic.gov.au/agencies-and-organisations/app-guidelines/chapter-12-app-12-access-to-personal-information#refusing-to-give-access-under-app-12-agencies>

OAIC 12 - <https://www.oaic.gov.au/agencies-and-organisations/business-resources/privacy-business-resource-4-de-identification-of-data-and-information#what-is-de-identification>

DICT 1 - <https://en.oxforddictionaries.com/definition/encrypt>