

You won't be told what research studies your samples are used for.

We will not be able to tell you when or where researchers use your sample for a research study. Research projects that use donated samples and health and personal information (data) will be listed on the Health Precincts Biobank website:

www.analytical.unsw.edu.au/facilities/biorepository/health-precincts-biobank

Research findings will be published in scientific journals and presented at conferences. Findings will always be presented in such a way that you cannot be identified. Similarly, research is conducted in such a way that individual results generally cannot be returned to participants.

Use of samples by drug or biotechnology companies.

Research involving your samples and data may result in a product or treatment that is profitable for a company. You will not receive any financial benefit from discoveries arising from the use of your samples or data.

Injury or complications as a result of participation in the Health Precincts Biobank.

There is no physical risk in collecting tissue for the Health Precincts Biobank beyond that of your hospital procedure. The collection of a blood sample may occasionally cause bruising. Any injuries or complications suffered as a result of the negligence of any parties involved in the Health Precincts Biobank may entitle you to compensation; the cost of your treatment would be paid out of such compensation.

Your samples could be held forever or until you choose to stop taking part.

In summary, you are being asked to give your consent to:

- Donate samples to the UNSW Health Precincts Biobank for ethically approved health and medical research
- Have your sample linked to health and personal information (data) held by the NSW and Commonwealth governments
- Have your sample and health and personal information (data) stored securely and used for ethically approved health and medical research now and into the future

If you wish to take part, please sign the associated consent form.

Thank you for taking the time to consider participating in the Health Precincts Biobank. Your donation will help medical research and the treatment of patients for years to come.

This brochure is for you to keep.

Further Information

You can contact the Health Precincts Biobank at:

E: HealthPrecinctsBiobank@unsw.edu.au

T: +61 2 9065 5665

W: www.analytical.unsw.edu.au/facilities/biorepository/health-precincts-biobank

The Health Precincts Biobank has been approved by the South Eastern Sydney Local Health District - Northern Sector Human Research Ethics Committee. Any person with concerns or complaints about the conduct of the Health Precincts Biobank should contact the Research Support Office on: 02 9382 3587, or email seslhd-rso@health.nsw.gov.au and quote reference number 11/160. Version 4.0, December 2021



UNSW
SYDNEY

UNSW RESEARCH INFRASTRUCTURE

Mark Wainwright Analytical Centre

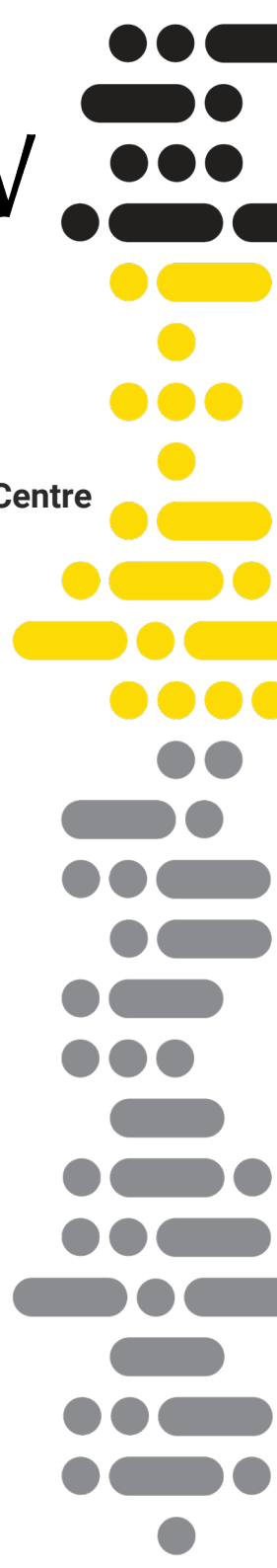
Health Precincts Biobank

(Formerly the HSA Biobank)

PATIENT INFORMATION BROCHURE

Contact:

02 9065 5665



The Health Precincts Biobank

A biobank is a collection of human samples such as tissue and blood, linked to patient information, which can be made available to researchers, now and into the future.

The Health Precincts Biobank (previously known as the Health Science Alliance (HSA) Biobank) provides a valuable resource to researchers so that they can increase our knowledge and understanding of disease, and enabling high quality medical research and education, leading to better health outcomes for all.

The Health Precincts Biobank is an initiative of UNSW Biospecimen Services and is a collaboration between UNSW Sydney and NSW Health Pathology.

Please read this Patient Information Brochure carefully. Feel free to ask questions and to discuss the Health Precincts Biobank with a relative, friend or your local health care worker.

Once you understand what the Health Precincts Biobank is about and you agree to take part, you will be asked to sign a consent form.

You are being asked to donate a sample to support health and medical research.

We are asking for you to consent to allow your samples (e.g. blood, tissue, urine), and personal and health information (including non-identifiable scans) to be collected by the Health Precincts Biobank for use in research and education. Your samples, or a portion of them, may be used immediately as part of an ongoing project, or they may be stored until they are used in future research.

It is your choice to donate or not.

Participation is voluntary. You can talk to your healthcare team, family, or friends before you decide. If you decide to take part you are still free to change your mind at any time and without giving a reason. If you change your mind, some of your sample and health information may already have been used for research but we will destroy any samples we still have in storage. Your decision to say no or to withdraw consent will not affect your medical treatment nor your dealings with Medicare Australia.

If you give your consent, the following will be collected:

- A small piece of tissue and/or fluid from the sample removed during your procedure
- A blood sample or a mouth swab/saliva sample

If you have had a prior operation or biopsy that relates to this procedure, we may also access this tissue. If you have another operation in the future within this Local Health District, signing the Health Precincts Biobank consent form will also allow us to collect a sample from that procedure.

Your samples will be linked with your health and personal information (data).

The Health Precincts Biobank will also request access to relevant health information about you from the following sources:

- Hospital, pathology, emergency department records

- State and national databases such as: Admitted Patients Data Collection; Registry of Births, Death and Marriages; and the NSW Cancer Registries
- Medicare Benefits Schedule records (your visits to health professionals) and the Pharmaceutical Benefits Scheme (your use of prescription medicines)

Your samples, and health and personal information (data), might be used for a range of different health or medical research studies, now and in the future.

Your samples and health data will be stored within Biospecimen Services at UNSW Sydney, until they are requested for research or education. Future research will examine causes of disease, prevention, diagnosis, treatment and genetics. Future education uses will involve teaching medical, science and nursing students.

Like a bank, samples and personal and health information are kept under secure and tightly controlled conditions. If a breach of privacy happens it will be dealt with in line with privacy laws and guidelines. All research and education projects must be approved by a Human Research Ethics Committee before access to your samples or data can be granted.

Your name and address are removed from your samples.

Your samples and other information will be given a unique code used by researchers. Your name and identifying details will be in a separate file that is not available to others. This maintains your confidentiality. All information is stored securely.

