Will I be contacted again?
Once you have signed the consent form, your samples will be collected during routine procedures and you will not be approached again.

How will I know if my samples are being used in the future?
You will not be contacted when your samples are used, however you can obtain information on future research conducted on samples stored in the HSA Biobank via the Lowy Biorepository website:
www.biorepository.unsw.edu.au

Research findings will be published in peer-reviewed journals and presented at conferences and professional forums. In each case, information will be provided in such a way that you cannot be identified.

Will drug or biotechnology companies be able to use my samples for profit?
There is the possibility that research involving your blood or tissue samples may result in commercially viable technology or treatments. You will not be able to claim financial benefit from any discovery arising from the use of your samples.

What happens if I suffer injury or complications as a result of the HSA Biobank?
There is no physical risk in collecting tissue for the HSA Biobank beyond that already present in your operation. The collection of blood sample may occasionally cause bruising. If you suffer any injuries or complications as a result of the negligence of any of the parties involved in HSA Biobank you may be entitled to compensation; the cost of your treatment would have to be paid out of such compensation.

How can I get further information?
If you have any questions about the HSA Biobank, please contact us at:
HSA Biobank
Lowy Biorepository Manager
The University of New South Wales
Sydney NSW 2052
E: biorepository@unsw.edu.au
T: +61 2 9385 1493

Further information about the HSA Biobank, including a full version of the participant information sheet, can be found at www.tcrn.unsw.edu.au/HSA.
At your request we will print this information sheet for you.

Thank you for taking the time to consider participating in the HSA Biobank. If you wish to become involved, please sign the associated consent form.

This information brochure is for you to keep.

The HSA Biobank
Banking today for improved cancer outcomes

The HSA 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 HSA Biobank should contact the Research Support Office on: 02 9382 3587, or email: ethicsnhn@sesi.ahs.health.nsw.gov.au and quote reference number 11/160.

Version 1.0, November 2012
What is the HSA Biobank?

A biobank is a collection of human biological samples linked to patient information that is stored for long periods of time and is made available to be used repeatedly and by a variety of research groups for research, now and into the future.

The Health Science Alliance (HSA) Biobank is an initiative of the Translational Cancer Research Network, and the result of a forward-looking collaboration between the University of NSW and NSW Health. It will provide a substantial resource for cancer research, increase our understanding of cancer, and enable quality research that produces better outcomes for cancer patients.

The HSA Biobank is housed at the Lowy Biorepository, University of NSW, and aims to collect and store biospecimens and associated information from every new cancer patient that consents to participate at your hospital.

Requesting your participation

We ask you to consider giving your permission for the collection of your biospecimens and associated clinical data for storage in the HSA Biobank. Your biospecimens will be stored for possible use in future research.

The information provided in this brochure details what you need to know as a potential participant in the HSA Biobank. PLEASE READ IT CAREFULLY. Feel free to ask questions about any information in the brochure, or to discuss the project with a relative, friend or your local health care worker.

Once you agree to take part in the HSA Biobank, you will be asked to sign a consent form. By signing the consent form, you are indicating that you understand the information and that you give your consent to participate in the HSA Biobank.

Do I have to participate in the HSA Biobank?

Participation in the HSA Biobank is voluntary. You may withdraw your consent at anytime by contacting the HSA Biobank and requesting that your samples and linked data be destroyed. Your decision not to participate in the HSA Biobank or to withdraw consent will not affect any dealings you have with Medicare Australia, or any medical treatment or care you receive, now or in the future.

What will my participation involve?

If you agree to participate, we will collect:

- A small sample of tissue and/or fluid from your already removed specimen.
- A blood sample of approximately 10mL (two teaspoons), which is taken during routine blood collections.
- If we are unable to obtain a blood sample we may ask you for a spit sample or mouth swab instead.

We will also request access to information from the following medical records relating to you, your operation and diagnosis:

- Hospital, pathology, emergency department records.
- State databases, including the Admitted Patients Data Collection; Registry of Births, Deaths and Marriages; ABS Mortality Data; the NSW Cancer Registry and The 45 and Up Study.
- Medicare Benefits Scheme records (your visits to health professionals) and the Pharmaceutical Benefits Scheme (your use of prescription medicines).

What will happen to my samples and data?

Your samples and health data will be stored in the Lowy Biorepository until they are required for research. Future research will focus on cancer and may include its prevention, diagnosis, treatment, genetics, demographics and clinical trials.

Any research proposal requesting access to your samples and health data will only be considered if it has been approved by a Human Research Ethics Committee.

Will the samples be identifiable as mine after they are stored?

Your samples are given a unique identification code and this code is used to maintain your confidentiality.

For how long will my samples be stored?

Your samples will be stored until they are required for use in research.

Only the HSA Biobank owner, the Biobank manager, the consenting nurse and the person collecting your specimens will have access to your identifiable data.

Senior medical researchers may be provided with your identifying data if it is relevant to their research and only if a Human Research Ethics Committee has granted approval.

For how long will my samples be stored?

Your samples will be stored until they are required for use in research.