What is the HSA Biobank?

Universal patient consent to, and collection of:

1. A sample of resected tissue
2. Blood/buccal swab
3. Clinical information
4. Medicare Australia data
5. State-based linked datasets

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What is different about the HSA Biobank?

- **All** patients having surgery for a known or suspected cancer can be given the opportunity to participate.

- Processes for consent and collection are being integrated within **routine** hospital pathways.

- Resulting biobank is open to **any researcher** with appropriate approvals.

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Timeline

Jan 2012 | Apr 2012 | Dec 2012 | May 2013 | Sep 2013 | Jan 2014 | Jun 2014 | Nov 2014

SESLHD HREC approval

Patient consent and tissue collection starts

SESLHD official consent form approved

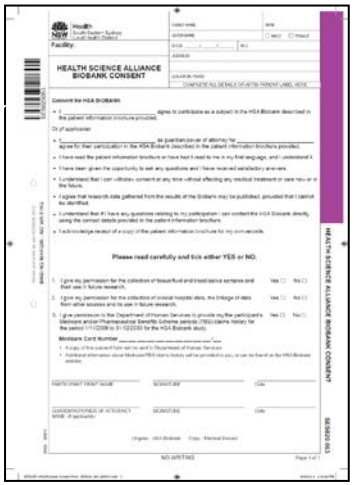
Pre-op consent model piloted Breast/CRC POWH/RHW

Consent pilot #2 UpperGI /Urology POWH

STGH roll-out

Consent pilot #3 STG Peritonect-omy/Gynae

Albury-Wodonga Health joins


HEALTH SCIENCE ALLIANCE BIOBANK CONSENT

Please read carefully and tick either YES or NO.

Oct 2013
1000 consents reached!

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HSA Biobank projects

1. Routine tumour collection
   – SEALS Anatomical Pathology

2. Integrated IT projects

3. Consent projects

4. Linked data projects

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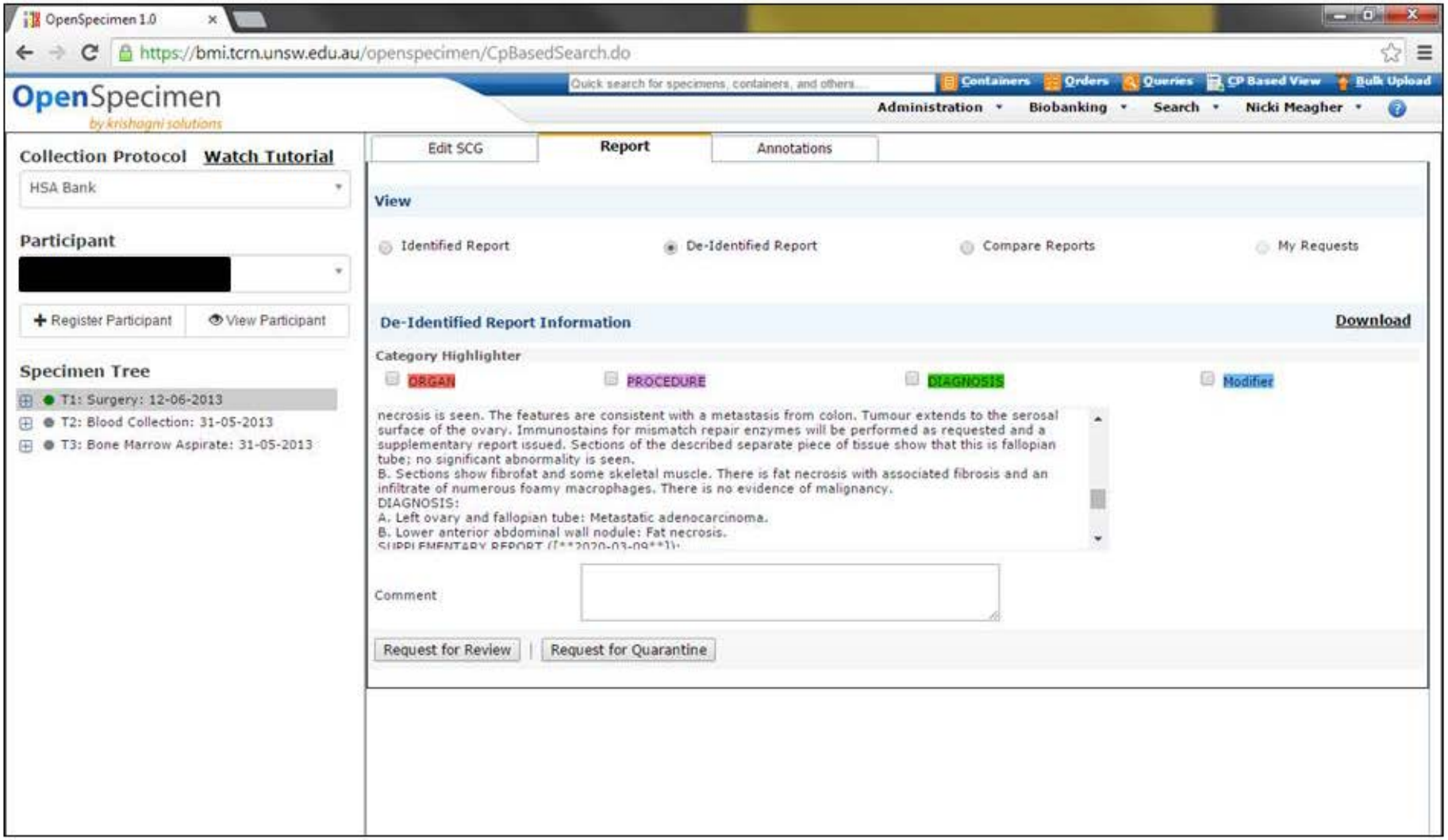
Integrated tumour banking

Systematic tissue collection through SEALS Pathology

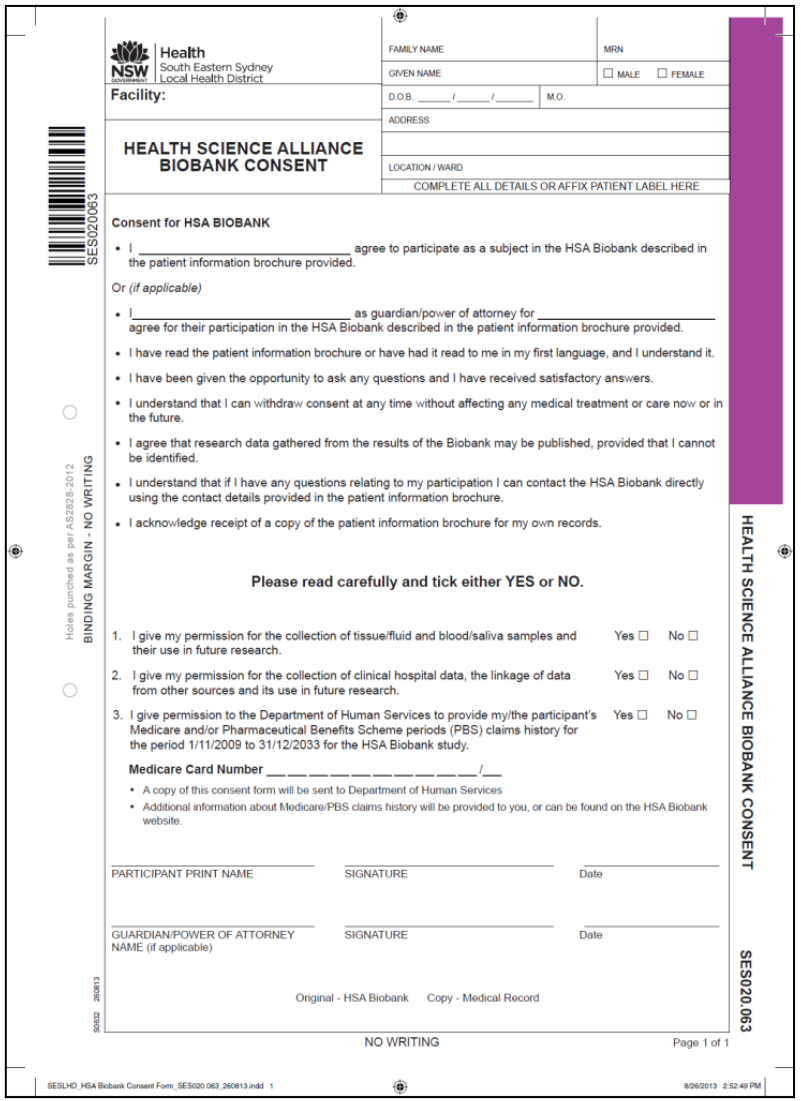
- Randwick AP technician now funded by NSW Health Pathology
- Routine fresh and paraffin-embedded tumour biobank allocation
- Routine nomination of reserve tumour block for biobanking at SEALS St George

OmniLab biorepository module

= pathology report delivery into biobank database



Consent materials



Health
South Eastern Sydney
Local Health District

Facility:

FAMILY NAME | MRN
GIVEN NAME | ☐ MALE ☐ FEMALE
D.O.B. ____/____/____ | M.O.
ADDRESS
LOCATION / WARD
COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

HEALTH SCIENCE ALLIANCE BIOBANK CONSENT

SES020.063

Consent for HSA BIOBANK

- I _____ agree to participate as a subject in the HSA Biobank described in the patient information brochure provided.

Or *(if applicable)*

- I_____ as guardian/power of attorney for _____ agree for their participation in the HSA Biobank described in the patient information brochure provided.
- I have read the patient information brochure or have had it read to me in my first language, and I understand it.
- I have been given the opportunity to ask any questions and I have received satisfactory answers.
- I understand that I can withdraw consent at any time without affecting any medical treatment or care now or in the future.
- I agree that research data gathered from the results of the Biobank may be published, provided that I cannot be identified.
- I understand that if I have any questions relating to my participation I can contact the HSA Biobank directly using the contact details provided in the patient information brochure.
- I acknowledge receipt of a copy of the patient information brochure for my own records.

Please read carefully and tick either YES or NO.

1. I give my permission for the collection of tissue/fluid and blood/saliva samples and their use in future research. Yes ☐ No ☐
2. I give my permission for the collection of clinical hospital data, the linkage of data from other sources and its use in future research. Yes ☐ No ☐
3. I give permission to the Department of Human Services to provide my/the participant's Medicare and/or Pharmaceutical Benefits Scheme periods (PBS) claims history for the period 1/11/2009 to 31/12/2033 for the HSA Biobank study. Yes ☐ No ☐

Medicare Card Number ___ ___ ___ ___ ___ ___ ___ ___ ___ ___/___

- A copy of this consent form will be sent to Department of Human Services
- Additional information about Medicare/PBS claims history will be provided to you, or can be found on the HSA Biobank website.

PARTICIPANT PRINT NAME | SIGNATURE | Date

GUARDIAN/POWER OF ATTORNEY NAME (if applicable) | SIGNATURE | Date

Original - HSA Biobank Copy - Medical Record

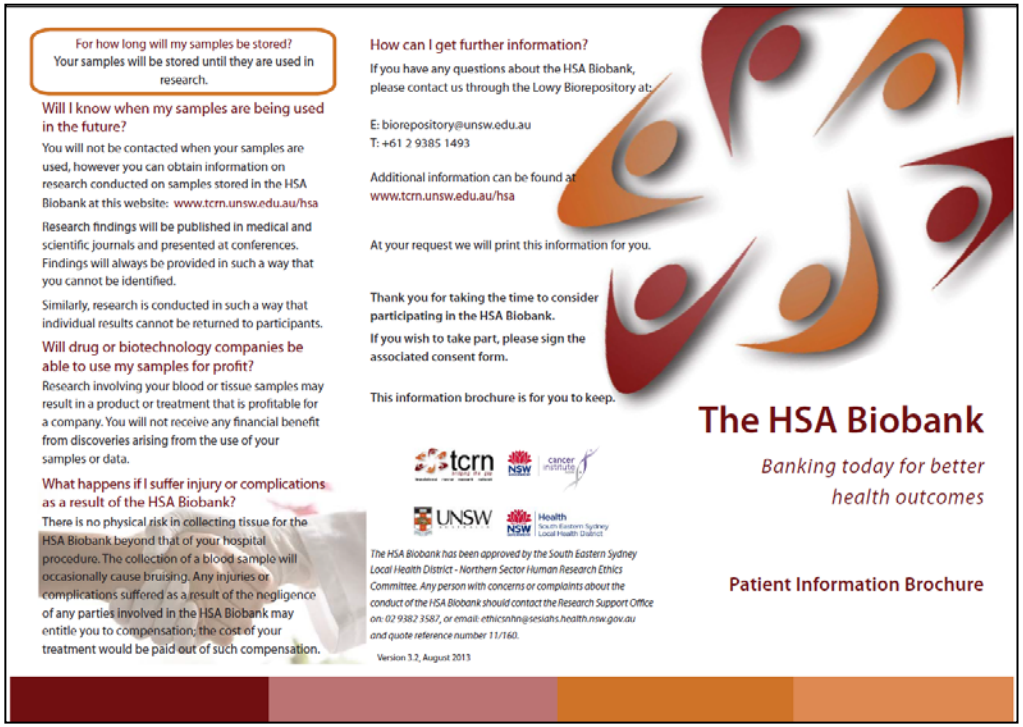
NO WRITING

Page 1 of 1

HEALTH SCIENCE ALLIANCE BIOBANK CONSENT SES020.063

Holes punched as per AS2828-2012 BINDING MARGIN - NO WRITING

SESLHD_HSA Biobank Consent Form_SES020.063_260813.indd 1 8/26/2013 2:52:49 PM



For how long will my samples be stored?
Your samples will be stored until they are used in research.

Will I know when my samples are being used in the future?

You will not be contacted when your samples are used, however you can obtain information on research conducted on samples stored in the HSA Biobank at this website: www.tcrn.unsw.edu.au/hsa

Research findings will be published in medical and scientific journals and presented at conferences. Findings will always be provided in such a way that you cannot be identified.

Similarly, research is conducted in such a way that individual results cannot be returned to participants.

Will drug or biotechnology companies be able to use my samples for profit?

Research involving your blood or tissue samples 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.

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 of your hospital procedure. The collection of a blood sample will occasionally cause bruising. Any injuries or complications suffered as a result of the negligence of any parties involved in the HSA Biobank may entitle you to compensation; the cost of your treatment would be paid out of such compensation.

How can I get further information?

If you have any questions about the HSA Biobank, please contact us through the Lowy Biorepository at:

E: biorepository@unsw.edu.au
T: +61 2 9385 1493

Additional information can be found at www.tcrn.unsw.edu.au/hsa

At your request we will print this information for you.

Thank you for taking the time to consider participating in the HSA Biobank.

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

This information brochure is for you to keep.

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: ethicsnhh@seslahs.health.nsw.gov.au and quote reference number 11/160.

Version 3.2, August 2013

The HSA Biobank

Banking today for better health outcomes

Patient Information Brochure

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Consent projects

- Phase 1 (2012-13)
  - Develop materials and systems for pre-op consent, and pilot in breast and CRC.

- Phase 2 (from 2013-14)
  - Refine processes, pilot in urology, upper GI
  - Pilot at St George Hospital – peritonectomy + gynaecological oncology

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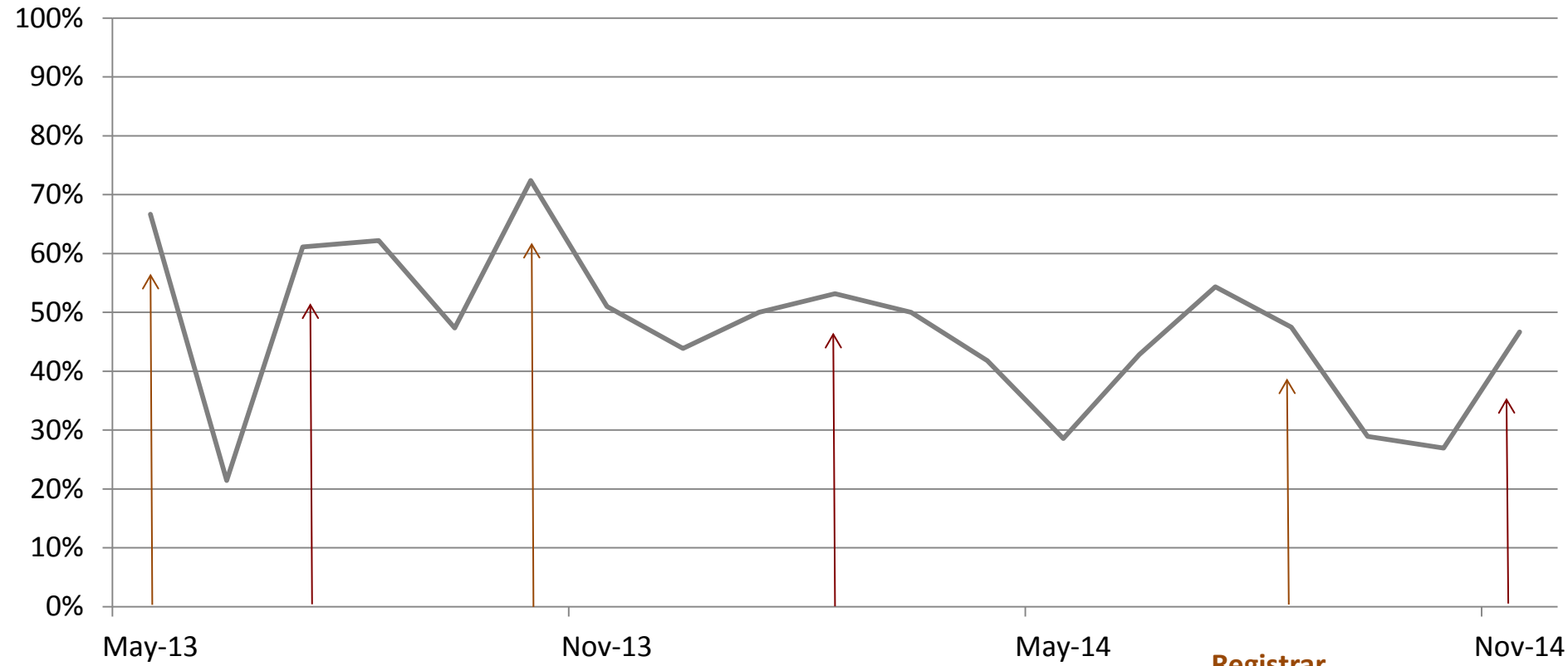
Malignant cases offered consent POWH/RHW/STG*



Consent pilot #1 (6th May - 23rd June 13)

Post-pilot evaluation and registrar change-over

Height of consent pilot#2 (16th Sept-3rd Dec 13)

Registrar change-over Feb 14

Registrar change-over Aug 14

Prompt added to theatre lists Oct 14

*Based on 11 tumours streams joining at different times

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HSA Biobank – consents and teams

Consent	1506
Partial consent	98
Refused	104
Withdrawn	5

Participating tumour streams

Breast
Colorectal
UpperGI
Sarcoma
Gynae
Haematology
STG Peritonectomy
Urology
Other general surgery

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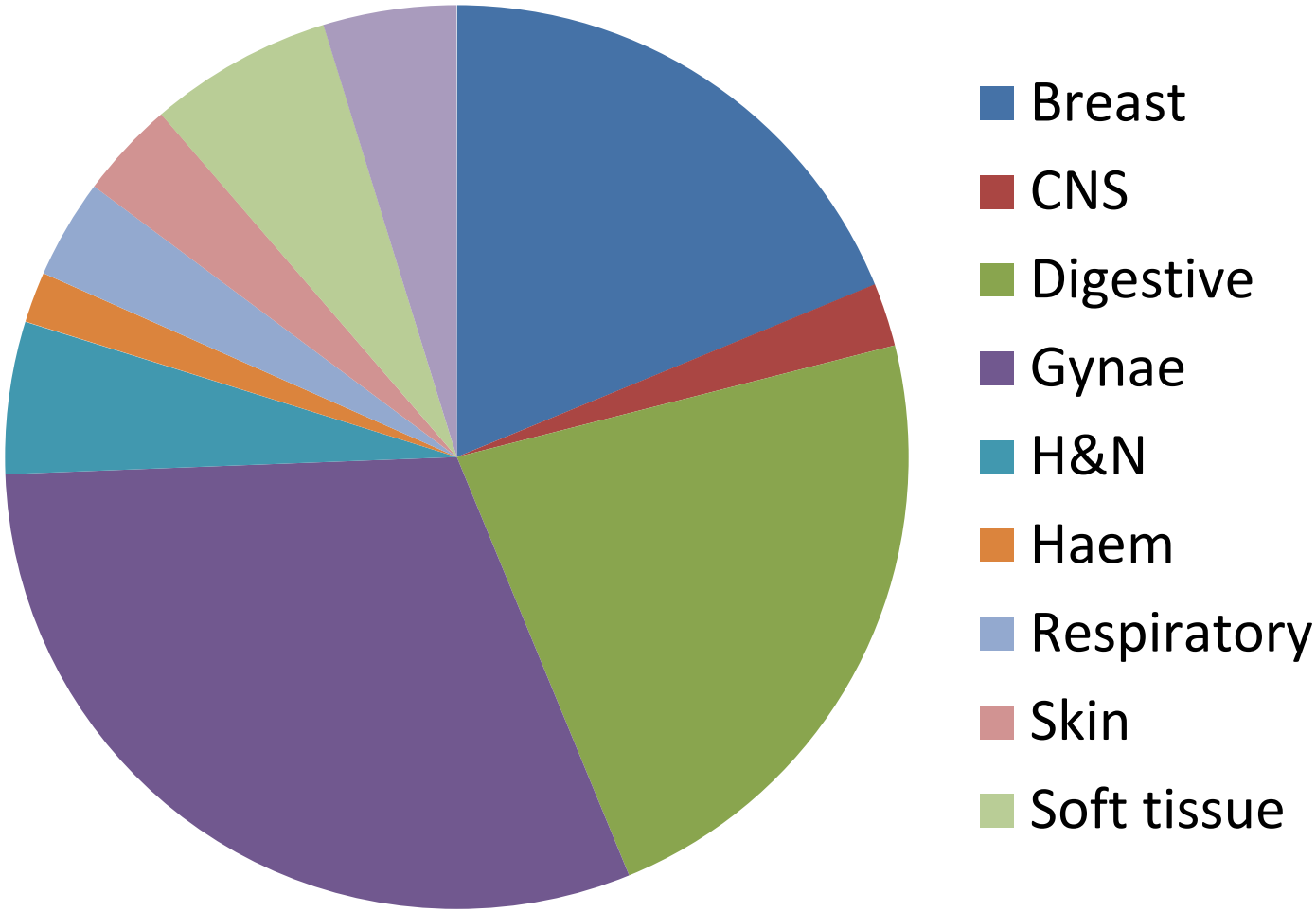
Snapshot - tumour tissue sites



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