

Will my taking part be confidential?

Yes. All data collected will be held on secure, password protected systems and will be kept confidential.



Cardiff University is responsible for this project (the Wales Cancer Biobank) based in the United Kingdom. We will be using information from you and/or your medical records in order to undertake this project and will act as the data controller for this project. This means that we are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 15 years after the project has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the project, we will keep the information about you that we have already obtained.

To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research studies?

Research studies usually take several years to complete. The results from the studies using the donated samples will be used to improve treatment and care of patients in the future. Results will be published as appropriate in the scientific papers and magazines and

regular updates of research in progress, research results and other relevant information will be published on the biobank's website (www.walescancerbank.com). In the future we would like to make the results of the scientific tests carried out on all of our donors' samples available to researchers through a website. Access to this information will be secure and only researchers who have permission from the Wales Cancer Biobank will be allowed access to this website. All information will be anonymised and therefore you will not be identified in any publication or from information available through the website.

If you wish to receive newsletters and biobank updates electronically, please provide your email address in the space on the consent form.

Who is funding the biobank?

This is a project run in collaboration with NHS Wales and supported and paid for by Health and Care Research Wales and Velindre Charitable funds, and in partnership with Cancer Research Wales.

Who has approved/reviewed the biobank?

The Wales Research Ethics Committee 3 has approved and will regularly review the biobank (Wales REC 3, Castlebridge 4, 15-19 Cowbridge Road East, Cardiff, CF11 9AB).

The Wales Cancer Bank is licensed by the Human Tissue Authority (licence 12107) under the UK Human Tissue Act (2004) to store human samples for research purposes.

Other research

If, as a result of studies performed on your biological samples you are eligible for a research study that might be beneficial to you, your doctor may contact you with more information. These studies will be unrelated to the biobank and may, for example, be a clinical trial. You do not have to take part in any of the studies if you do not wish to, and your medical treatment will be unaffected by your decision.

Contact for further information

If you would like further information or if you have any concerns or complaints, you can either

- Write to:
**Wales Cancer Bank
Cardiff University
A2 Corridor, 2 Floor
UHW Main building
Heath Park
Cardiff CF14 4XN**
- Talk to the person who has provided this leaflet to you
- Phone the central office on **02921 843243**
- Email walescancerbank@cf.ac.uk
- Visit the website (www.walescancerbank.com)

If you have access to the internet you can visit the project website (www.walescancerbank.com).

You can find out more about how we use your information on the WCB's website (data privacy notice page) or by contacting Cardiff University's Data Protection Officer, who can be contacted at inforequest@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain about how your personal data has been handled, can be found at www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection.

Thank you very much for taking the time to read this information. Should you agree to take part in this project, your generosity is very much appreciated.



**WALES CANCER BIOBANK
BIOFANC CANCER CYMRU**

Patient Information Sheet

Wales Cancer Bank Banc Canser Cymru

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We are inviting you to take part in research by donating samples to a biobank, called the Wales Cancer Biobank. Before you decide whether to take part, it is important for you to know what taking part will involve for you. Please take time to read the following information carefully and discuss it with your family, friends or your GP, if you wish.

What is a Biobank?

A biobank is an organisation that collects and stores biological samples (tissue, blood, urine etc) and data and makes them available to researchers to learn more about how conditions and diseases start, develop and how to treat them. The Wales Cancer Biobank is a biobank that collects such samples from patients throughout Wales. The biobank supports research into cancer by making samples available to scientists involved in cancer related research.

Why have I been chosen?

Patients in Wales who are having, or have had, samples removed during cancer screening, a surgical or biopsy procedure for possible cancer diagnosis, treatment or risk reduction, may be invited to take part. The biobank would like to collect both normal or non-cancer tissue and cancer tissue from patients and so your tissue, blood and other samples will be useful for cancer related research whether or not you have cancer.

Do I have to take part?

No. The choice to allow us to collect samples and data from you for this project is up to you. If you decide to take part, you can keep this information sheet and you will also be asked to sign a consent form. You are still free to change your mind at any time and without giving a reason. If you change your mind a while after your consent, some of your samples may already have been used for research but we will destroy any samples we may still have in storage. However, we will keep any information we have collected so that researchers who have already used your samples can complete their research. Whatever your decision, it will not affect any part of your treatment or other care you will receive, now or in the future.

What will happen to me if I take part?

When you have samples taken as part of cancer screening or have a procedure to reduce your risk of cancer or diagnose your illness, these samples are sent to a laboratory for testing.

All the tissue and/or fluids may not be needed and this may leave some that could be used for research that under normal circumstances might be thrown away. If you agree to donate to the biobank, any tissue or fluid that is not needed by the laboratory for your diagnosis and care can be stored by the biobank and used for research. If you are having a biopsy procedure, two or three extra samples may be taken for the biobank which may mean the procedure will take a few extra minutes. If you have already had your procedure

you can still take part in this research by giving us permission to ask the laboratory for a small amount of tissue originally used for your diagnosis. In either case the utmost care will be taken to ensure that any material provided would not affect your future health or care.

As part of your treatment or investigations, your hospital doctor may take a routine blood sample from you. We would like your consent to take an additional amount (approximately 4-8 teaspoons, or 20-40ml) that will be used for research. If you have specific questions about this, please ask the person taking your consent. We may also ask if you would give other samples, such as saliva or urine if there is a current project needing such samples. If you are having treatment for cancer your hospital doctor may invite you back for further visits and this may involve other samples being taken as part of your routine treatment. If, at a later stage, you have tissue samples taken as part of your further care we may wish to access left over samples and take a small amount of additional blood. These optional additional blood samples may be requested at a time when you would not be having blood taken for clinical purposes. This will allow researchers to make potentially helpful comparisons with your original samples.

Under data protection law we have to specify the legal basis that we are relying on to process your personal data. In providing your personal data for this research we will process it on the basis that doing so is necessary for our public task for scientific and historical research purposes in accordance with the necessary safeguards and is in the public

interest. Cardiff University, specifically Wales Cancer Biobank staff, will collect information about you for the biobank records from your NHS medical records.

This information will include your name/ NHS number/ contact details/ date of birth and health information, which is regarded as a special category of information. We will use your personal information (name, address, NHS number, date of birth) to make sure we are matching the correct medical record to the correct donated samples. Any information related to your diagnosis and treatment will be treated in the strictest confidence.

Researchers receiving samples and data from the Wales Cancer Biobank will NOT receive your personal information (eg. name, address or date of birth).

What do I have to do?

You will need to give your consent to donate your samples and allow us access to data by signing a simple form.

This may be a paper form or an electronic form on a computer tablet device if we see you in person, or we may contact you via telephone, after you have discussed this with your doctor, to discuss donating to the biobank.

What are the advantages and disadvantages of taking part?

The tissue samples taken for the biobank will only be taken after all the necessary clinical tests have been carried out. The blood and other fluid samples may be taken as extra, research only samples so it may take a little more of your time.

You may not benefit personally from the research but the results of the research using your samples, and those from others, may benefit cancer patients in the future. For example, DNA from your samples may be used by researchers for genetic testing which could help to identify factors that influence the development and treatment of cancer. Your tissue or blood samples may be used for research that may lead to the development of new drugs or treatments and samples may be released for public health emergency research that is relevant to cancer patients. The research may be carried out in Academic Institutions, the NHS or commercial companies involved in cancer related research in the UK or abroad. Your tissue will not be used for research that involves reproductive cloning. Research studies accessing samples will be approved and monitored by a review panel of experts. Researchers sign an agreement to limit the use of your donated samples only to the research approved by the panel. Products of that research may be used in later, different research that is in line with the consent you have given.

You are asked to donate your samples to the biobank for research and will not receive a financial reward either now or

in the future. The medical team involved in your treatment and care will receive no payment because of your involvement in this study. The Wales Cancer Biobank is a not-for-profit organisation, but a fee may be charged to researchers using the samples to help recover some of the costs involved in maintaining the biobank.

What if new information becomes available as a result of the research?

Results for individual patients from research studies will not normally be relayed back to you or your doctor. Very occasionally, some research projects could identify genetic changes that may indicate an inherited disease that may affect you or your family members. For more detailed information please see the website at www.walescancerbank.com/for-patients. Your hospital doctor will be notified if any information that becomes known as a result of the research may affect you or your family's future care. We are unable to contact you directly regarding research results.

What happens if the biobank closes?

Should the biobank close, the anonymised information and samples collected will either be transferred to another suitable biobank to continue to make the samples and data available for research or they will become the responsibility of the NHS in Wales.