

Will my taking part be confidential?

Yes. All data collected will be held on secure, password protected systems and will be kept confidential. Researchers will **not** receive your personal information (eg. name, address, postcode, date of birth, NHS number) when they receive samples.

What will happen to the results of the research study?

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 Bank 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 organising and funding the biobank?

This is a project run by NHS Wales and supported and paid for by the Welsh Government, Cancer Research Wales, Velindre NHS Trust and Cancer Research UK.

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.

You may be interested in other activity that is taking place in Wales to help health and social research (please note this will not necessarily be cancer related), such as Healthwise Wales (<https://www.healthwisewales.gov.wales/landingPage.php>). If you are happy to be contacted by researchers, please indicate this on the consent form and include an email address. Your name and email address will be the only information that we will share with these researchers.

Contact for Further Information

If you would like further information you can either

- ask the person who has provided this leaflet to you
- phone the central office on **02920 743243**
- write to:

**Wales Cancer Bank
Cardiff University
A2 Corridor
2 Floor
UHW Main building
Heath Park
Cardiff CF14 4XN**

- If you have access to the internet you can visit the project website **www.walescancerbank.com**

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



PATIENT INFORMATION SHEET

**Wales Cancer Bank
Banc Canser Cymru**

A2 corridor, 2 Floor, UHW
Cardiff, CF14 4XN
Tel: 029 20743243

Director/Cyfarwyddwr
Dr Richard Adams
Principal Scientist/Prif Wyddonydd
Professor Gerry Thomas
Manager/Rheolwr
Dr Alison Parry-Jones

We are inviting you to take part in research by donating samples to a biobank, called the Wales Cancer Bank.

Before you decide whether to take part, it is important for you to know why the biobank has been set up and 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 Bank 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 research.

Why have I been chosen?

Patients in Wales who are having, or have had tissue removed during surgery or a biopsy procedure, may be invited to take part. The bank would like to collect both normal tissue and cancer tissue from patients and so your tissue, blood and other samples will be useful for cancer 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. If you decide to take part, you are still free to change your mind at any time and without giving a reason. However, if you change your mind a long time after your operation, some of your samples may already have been used for research but we will destroy any samples we may still have in storage. 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?

You are about to have, or have had, some tests for your illness, including for example, blood tests, an operation or biopsy procedure. These procedures often involve the removal of fluids, pieces of tissue or even a whole organ. These samples are sent to a laboratory to be tested by scientists and doctors. This can help them diagnose your medical condition. All of the tissue and/or fluids may not be needed for a full and accurate diagnosis – this may leave some that could be used for research that under normal circumstances would be thrown away. If you agree to donate to the biobank, any tissue or fluid that is not needed for your diagnosis can be stored 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 operation you can still take part in this research by giving us permission to ask the pathologist 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, your hospital doctor will normally 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. These blood samples may provide other helpful information needed for the research. If you have specific questions about this, please ask the person taking your consent.

After your current treatment your hospital doctor may invite you back for further visits and this may involve other samples being taken. 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. The 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.

Any information related to your diagnosis and treatment will be treated in the strictest confidence. Wales Cancer Bank staff will need to look at your personal medical information. Researchers using samples will not receive any personal information such as your name, telephone number or address. We will not disclose any information about you to any third party, such as insurance companies. Under the Data Protection Act you are entitled to see what is recorded about you by applying to the Wales Cancer Bank, Cardiff University, Cardiff.

What do I have to do?

You will need to give your written 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.

What are the advantages and disadvantages of taking part?

Blood, tissue and fluid samples are taken as part of your operation and your routine treatment and care. The tissue samples taken for the biobank will only be taken after all of the necessary clinical tests have been carried out on them. Therefore, taking part in this project will have no disadvantages.

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 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.

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 Bank is a not-for-profit organisation, but a fee may be charged to researchers using the samples to help recover some of the administrative costs involved in maintaining the biobank. However, your tissue or blood samples may be used for research that may lead to the development of new drugs or treatments. The research may be carried out in Academic Institutions, the NHS or commercial companies involved in cancer research in the UK or abroad.

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 information and samples collected from it will become the responsibility of the NHS Wales.