

Thank you for considering the information in this leaflet.

If you wish to donate samples you will be asked to agree to the statements below in the presence of a member of our staff. A parent/guardian may provide consent for children under 16 and a consultee may be asked to make a declaration on behalf of adults without capacity to consent for themselves.

1. I confirm that I have had opportunity to consider the information provided, ask questions and have had these questions answered satisfactorily.
2. I agree to donate samples and data available during my routine clinical care to the RD&E Tissue Bank and I give permission for NHS staff to obtain information from my medical record for the purposes of research.
3. I understand that my samples and hospital data will be stored securely at the Royal Devon & Exeter NHS Foundation Trust Tissue Bank in Exeter.
4. I understand that genetic material may be extracted from my samples and used for future research into the causes of disease.
5. I understand that my agreement is voluntary and that I am free to withdraw my samples and associated data any time without giving any reason and without my medical care or legal rights being affected.
6. I understand that with the agreement of a steering committee the tissue bank will provide my anonymised data and samples to researchers for the purpose of understanding disease and improving healthcare.

Optional Statements

I give permission for researchers to feedback information to my referring hospital doctor that might be relevant to a) my current condition b) other conditions c) conditions that might affect my blood relatives. My clinician will make a decision as to whether further tests are needed on the basis of this information and may invite me for further consultations.

How can I find out more information?

This project is managed by NIHR Exeter Clinical Research Facility under the direction of Consultant Surgeon Mr Malcolm Crundwell. It is funded by the National Institute for Health Research, which is part of the NHS.

For independent advice about participation in research you may contact RD&E Patient Advice and Liaison Service on 01392 402093. For further information about the Tissue Bank please email us (rde-tr.tissuebanks@nhs.net) or call us on 01392 408178. If you would like to discuss your specific donation further with a clinician please contact: [] on [].

RD&E

Tissue Bank

Name of
Collection

5YE V2 11/04/16

NHS

National Institute for
Health Research

Help us improve healthcare



by donating your spare
medical samples for research

Everyone can help

- We are inviting you to donate samples or tissues that are being taken during your **routine hospital care**.
- Most of these samples would normally be destroyed, but may be used by scientists to help understand more about disease and thus may help to improve treatment in the future.
- Your name will be removed before samples are shared with researchers and identifiable clinical information will be held securely within the NHS.



What is the purpose of the RD&E Tissue Bank?

The RD&E Tissue Bank aims to help scientists understand disease by collecting, storing and distributing samples and body tissues that are taken during routine hospital visits from patients being diagnosed or treated within the Royal Devon & Exeter NHS Foundation Trust or other NHS institution working together with the RD&E.



What will happen to my samples and data?

Samples will be kept in conditions to make sure that they are of use for future research. They will be given a code which marries together your sample, your consent form and your medical data. Everything is then stored securely in the RD&E Tissue Bank meaning that only a small designated NHS team will be able to link your samples and data to you as an individual. Genetic material (DNA) may be extracted from your samples and used in research to understand the causes of disease. Coded data and samples (without your name) will be provided to researchers upon the approval of a Steering Committee made up of professional and lay people. The committee makes sure that samples are only used for well-designed, ethically appropriate studies aiming to improve understanding, treatment and diagnosis of human medical conditions. As a donor you may have your say on a web-based system about which projects can use samples donated to the tissue bank and find out about the results of our research.

Samples are mainly collected for use in local research however they may also be used in partnerships in the UK or overseas including partnerships with researchers within commercial companies. Samples and data will:

- Not be sold for profit
- Not be used in animal research
- Not be used in research into termination of pregnancy or human cloning
- Not be shared with non-research organisations such as the police

In the future, designated staff from the RD&E Tissue Bank may re-examine your medical record, but no-one from outside of the NHS will see your hospital records.

[This section will be made bespoke for each type of collection]

Which samples would you like me to donate?

[specific details of which samples are being asked for]

What will they be used for?

[details of the project that samples are being proactively collected for as well as broad categories of future uses]

Picture representing collection

What are the risks and benefits of taking part?

There are no additional risks involved in the collection of these samples. Your clinician will not allow samples to be taken if they cause risk to you or affect accurate diagnosis of your condition. Donation of samples is unlikely to benefit your health directly, but your donation may help scientists to improve treatment and diagnosis of your condition in the future.

What happens if researchers find something relevant to my clinical care?

Your samples may not be analysed immediately and there is no guarantee that researchers will find anything relevant to your clinical care. However it is possible that in the future research uncovers information that might be clinically relevant to your health or that of your blood relatives. With your consent, we will provide the hospital doctor who referred you to the Tissue Bank with research results, so that they could make a decision to inform you of information relevant to your current condition, other conditions that might affect you or genetic conditions that might affect your family. You may change your mind about the feedback you wish to receive at any point.

Do I have to take part?

No. Participation is entirely voluntary. It is up to you to decide whether to become a donor. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This will not affect the standard of care you receive from the NHS.