

Daisy Tumour Bank Privacy Notice

This Notice is for people who have donated or have been invited to donate human tissue to the Daisy Tumour Bank (DTB). You should read this Notice alongside the patient information sheet provided to you by DTB staff at the University of Hull (UoH) or your NHS clinical team at Hull University Teaching Hospitals NHS Trust.

Questions

If you have any questions or concerns about donating to the DTB and how your data will be collected and managed for the purpose of cancer research, please contact the DTB using the details in the patient information sheet.

If you have any other questions or concerns about UoH's processing of information for research purposes and the content of this privacy notice, please contact the **UoH Data Protection Officer (DPO)**:

Email: dataprotection@hull.ac.uk

Telephone: 01482 466594

Address: University of Hull, Cottingham Road, Hull HU6 7RX

About this notice

As a result of your participation, UoH will hold your "personal data", i.e. information in a form that identifies you as individual [often referred to as "data" in this Notice].

UoH is the data controller of the information it collects and processes as described in this Notice. This means that it has the core legal responsibility to safeguard the information and ensure it is processed lawfully. The law is set out in the EU General Data Protection Regulation (called "GDPR") and a new UK law, the Data Protection Act 2018.

Your rights as a data subject and how to exercise them

Under the data protection laws, you have a number of rights in relation to our processing of your data. In summary these are:

- Right to request access to your data as processed by UoH and information about that processing
- Right to rectify any inaccuracies in your data,
- Right to request erasure of your data from our systems and files
- Right to place restrictions on our processing of your data
- Right to object to our processing of your data
- Right to data portability: where we are processing data that you have provided to us, on the basis of consent or as necessary for the performance of a contract between us, you have the right to ask us to provide your data in an appropriate format to you or to another controller.

Exceptions: Most of these rights are subject to some exceptions or exemptions. In particular, there are limits on your right to restrict our processing or erase your data where this would impact

adversely on the integrity and value of the research, although as explained above, we will usually agree to withdraw your data from studies where this is possible.

If you would like to exercise any of your rights as outlined above, you can contact the DPO as above or visit the Data Protection page on our website

<https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx>

We will always aim to respond clearly and fully to any concerns you have about our processing and requests to exercise the rights set out above. However, as a data subject, if you have concerns about our data processing or consider that we have failed to comply with the data protection legislation, then you have the right to lodge a complaint with the data protection regulator, the Information Commissioner:

Online reporting: <https://ico.org.uk/concerns/>

Email: casework@ico.org.uk

Tel: 0303 123 1113

Post: Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

Legal basis for processing your data

The law states that we can only process your personal data if the processing meets one of the conditions of processing in Article 6 GDPR. If we are processing your special category data for our activities, we must meet one of the conditions in Article 9 GDPR. Special Category data includes personal data which relates to your ethnicity, sex life or sexual orientation, health or disability, biometric or genetic data, religious or philosophical beliefs, political opinions or trade union membership. Under the data protection legislation we need to explain the legal basis for holding your data, i.e. which of these conditions apply.

In general, where we are collecting and processing your personal data for the purposes of cancer research the following conditions apply:

- Article 6.1(e) of the GDPR, i.e. our processing is necessary for the performance of a task carried out in the public interest. Research is a task that UoH performs in the public interest, as part of our core function as a university;
- Article 9.2(j) of the GDPR, i.e. our processing is necessary for research purposes or statistical purposes. This condition applies as long as we are applying appropriate protections to keep your data secure and safeguard your interests.

Consent is not generally the legal basis under the data protection legislation for use of your personal data for research. This is because we can only rely on your consent as the basis for processing data if we would always be able to act on a withdrawal of consent, by removing your data from our research project and outputs. Often we would not be able to do this in the context of research, as this could affect the validity and integrity of the research process and/or the outputs from the research.