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UKCRC Tissue Directory and Coordination Centre

The UK Clinical Research Collaboration (UKCRC) Tissue Directory and Coordination Centre (the Centre) aims to coordinate Biobanking activities in the UK. The Centre represents a first step in integrating national biobanking infrastructure to support research activity. You can read more about the project and how to get involved at <https://www.biobankinguk.org>.

A joint vision

Biomedical researchers rely on human tissue samples for a multitude of research projects; cancer is of particular note as it such a heterogeneous disease. Given the development of precision medicine and the need for more reliable disease models in other fields, the demand for high quality samples and associated data will increase over time. Until now, there has been no coordinated effort to catalogue or coordinate human biosample acquisition and storage. The Centre was established in 2014 by the UK Clinical Research Collaboration (UKCRC) Experimental Medicine Funders Group in order to achieve their Vision for Human Tissue Resources.

The funder's vision

"Funders aim to maximise the value of human tissue samples and resources while minimising duplication of effort. This requires better characterisation of tissue samples, asking for generic consent, and increased linkage to accurate clinical data. Sample collections must then be made more easily discoverable and accessible for use in high quality, ethical research."

The Centre has therefore been established to promote best practice, harmonisation and standardisation, and increase sample visibility in the hope that this will lead to increased sharing of samples, creating a more efficient research environment in the UK.

The UKCRC Tissue Directory

Launched in 2016, the UK-wide Tissue Directory, is a first step in promoting access to samples for research. The directory contains the details of biological samples and data held across >80 biobanks in the UK. The directory aims to facilitate communication between researchers and biobanks, providing a quick and efficient route for researchers to access appropriate samples and data to match their research needs.

Researchers can search the online directory and locate appropriate tissue samples held by a specific biobank, based on the associated datasets

giving age and gender of donors, and sample type. It is possible to search the directory using the specific disease term by viewing the list of diseases or the A-Z of Biobanks.

The Centre does not facilitate sample access; it acts as a platform for promoting visibility of existing resources.

An ethical duty to share

The UK Ethics Committee Authority (UKECA) has now made registration in the UKCRC Tissue Directory a condition of the Research Ethics Committee (REC) favourable opinion for research tissue banks (RTB). Patients gift their samples, under the impression that they will be used for scientific medical research. This change in the terms of REC favourable opinion should lead to a shift in the culture of research. Dr Philip Quinlan has said: "It is fantastic that the UKCRC Tissue Directory and Coordination Centre has been recognised as the best centre to do this work; tissue banks will have an ethical obligation to ensure their sample collections are visible to the community and we hope this will lead to better coordination between biobanks ensuring more samples are contributing directly to medical progress." Indeed, this is the first ever defined expectation for researchers to register the existence of the samples they hold.

Award winning engagement

The Centre actively engages with all stakeholders through events, campaigns and communications to ensure the development of the project provides plenty of information. The centre works with people and organisations to promote best practice, governance and public engagement.

The Centre has run a number of successful road-shows at institutions around the country to promote its work and encourage feedback. The Centre's most recent annual meeting was held on the 16th November at the Oval in London. UK Biobanking Showcase was a unique opportunity to bring together all stakeholders in the field and featured debates, give talks and award the prestigious "Biobank of the Year".

2016 saw the centre in parliament at a Biobanking event: "The Biobanking time-bomb; maintaining public trust in medical research". The aim of this event was to address the future risks to biobanking if certain issues were not addressed. These risks include the reducing contributions from Research grants to Biobanks, cost recovery being insufficient to recover financial deficits, particularly due to the increasing cost of running

biobanks. Reward mechanisms and access to clinical data are also important issues that were discussed. Find out more about the event on our website.

As well as engaging with Biobanks and policy makers, The Centre has an active public engagement programme. Project and Engagement manager, Jessica Sims, has developed a Board game to explain biobanking to the public. This innovative approach to a complex and sensitive issue has won public engagement awards in the past. Ms Sims says “public understanding is vital to tissue donation. I wanted to develop a way of really engaging with people in a format they can understand”. Contact Ms Sims at j.sims@ucl.ac.uk to learn more about the game,

BBMRI.uk

The Biobanking and BioMolecular Resources Research Infrastructure (BBMRI) – European Research Infrastructure Consortium (ERIC; BBMRI-ERIC) – is one of the largest research infrastructures for health in Europe today. It provides services and expertise for its members, including expert centres, events, and a European sample locator. They have also coordinated a number of research projects within Europe and beyond.

The Centre represents the UK and engages with this network on ethical, legal and societal issues (ELSI), IT and Quality common service groups. It has also contributed to the drafting of sample quality standards along with BBMRI-ERIC. Visit their website or get in touch to find out more about getting involved with this network.

To get involved

The Centre in the UK relies on the research community to shape our work; it is therefore keen to engage with pathologists, particularly those involved in biobanking on how you can help (contact email at head of paper). You can register your samples online at <https://directory.biobankinguk.org/>. There are more resources including the latest biobanking news and advice at <https://www.biobankinguk.org/>. Finally, you can also Sign up to The Centre's Newsletter for all the latest news and events.



Awarding the prestigious “Biobank of the Year”.



Playing the game.



Newcastle Roadshow