

## BIORESOURCE PAPER

# The UK Clinical Research Collaboration (UKCRC) Tissue Directory and Coordination Centre: The UK's Centre for facilitating the Usage of Human Samples for Medical Research

Philip R. Quinlan<sup>1,2</sup>, Emma Lawrence<sup>4</sup>, Amir Pourabdolla<sup>1,2</sup>, Jessica Mai Sims<sup>4</sup>, Amir Gander<sup>4,5</sup>, Barry Fuller<sup>4,5</sup>, Brian J. Thomson<sup>3</sup>, Jonathan M. Garibaldi<sup>1,2</sup> and Brian Davidson<sup>4,5</sup>

<sup>1</sup> School of Computer Science, University of Nottingham, Nottingham, UK

<sup>2</sup> Advanced Data Analysis Centre, The University of Nottingham, Nottingham, UK

<sup>3</sup> School of Medicine, The University of Nottingham, Nottingham, UK

<sup>4</sup> Division of Surgery and Interventional science, Royal Free Campus, UCL, London, UK

<sup>5</sup> Tissue Access for Patient Benefit, UCL, London, UK

Corresponding author: Dr. Philip Quinlan  
([Philip.Quinlan@nottingham.ac.uk](mailto:Philip.Quinlan@nottingham.ac.uk))

The UKCRC Tissue Directory and Coordination Centre was established to improve access to and utilisation of UK human tissue samples for medical research. The key output of the Centre is the creation of the UK's first pan-disease Tissue Directory (<https://directory.biobankinguk.org/>). Any researcher can search the Directory based on a series of simple key words including disease classification, age, sex, sample type, preservation details, quality indicators and datasets available. The Directory as of April 2017 contains 100 Bioresources. Researchers seeking fresh samples can also search for facilities that offer bespoke collection services. Future work of the Centre will be to explore greater standardisation of biobanking activities across the UK and to facilitate an inter-connected research infrastructure related to the use of human biosamples.

**Keywords:** Directory; UKCRC; tissue; biobank; virtual resource; sharing

**Funding statement:** The Centre is funded by a consortium, the UK Clinical Research Collaboration, and administered by the Medical Research Council, grant number: MR/M501748/1.

## (1) Bioresource Overview

### Project description

The UKCRC Tissue Directory and Coordination Centre was founded in 2014 in response to the UKCRC's Funders Vision for Human Tissue Resources which is to "maximise the value of human tissue samples and resources while minimising duplication of [sample collection] effort. This requires better characterisation of tissue samples, asking for generic [research] 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" [1].

The primary aim of the project is to minimise sample collection duplication and avoid wastage of sample collections through better description of existing collections and improving their discoverability for use in multiple research initiatives. The Centre is achieving this through

community engagement, development of sample quality standards and the establishment of a web-based Tissue Directory. The Centre does not hold any tissue samples and is not affiliated with any specific collection or biobank. As such, the Centre is able to bring together different resources from an unbiased perspective. The Centre also acts as the UK node of the Europe wide-BBMRI-ERIC network [2], representing the UK internationally. BBMRI-ERIC is a European wide network of biobanks and biomolecular resources which provides expertise and services and facilitates access to collections of partner biobanks and biomolecular resources.

The UKCRC Tissue Directory was created to increase visibility of existing tissue collections in the UK. The Directory acts as a match-making service: providing knowledge and expertise to match researcher needs with existing infrastructure and resources. By putting researchers in touch

with existing resources, the Directory prevents duplication of collections thereby saving valuable research time and money. Researchers can search for samples based on disease classification and are then presented with meta-data on the samples to help them locate the most relevant resource. The UKCRC Tissue Directory will feed registered biobanks into the Europe-wide BBMRI-ERIC Bioresource directory [3].

### Classification (1)

Human.

### Species

Homo sapiens.

### Classification (2)

Biological samples and associated data.

### Context

#### *Spatial coverage*

The UKCRC Tissue Directory and Coordination Centre is coordinated from University College London, London (Latitude: N 51 33', 11.1996" Longitude: -0, 9', 55.821") and the Tissue Directory is managed and hosted at The University of Nottingham, Nottingham (Latitude: N52, 53',19.6722" Longitude: -1,12',11.9046"). Registered Human tissue samples are from the UK only, but searches can be performed from around the world.

#### *Temporal coverage*

01/01/2016 – ongoing.

#### *Temporal coverage for accessibility*

The Centre is an active project and the tissue Directory is live and guaranteed to be available until 2020, and it is anticipated to be sustainable beyond this. Once researchers have identified appropriate human tissue collections access to the samples and associated clinical data is at the discretion of each individual bio-resource.

## (2) Methods

### Steps

The Centre was setup at the end of 2014 with the purpose of providing a mechanism for researchers to discover and access standardised, existing tissue collections in the UK. A full stakeholder review was undertaken to understand the capabilities, needs and desires of the community. This review drove the development of the first versions of the web based Directory, which launched to tissue custodians in early 2016. Those who had samples and data were invited to register their tissue collections. Those that had registered within the National Cancer Research Institute (NCRI) Biosample Directory, run by the Confederation of Cancer Biobanks [4], were automatically transferred. Institutions with major biobanking facilities were visited and workshops coordinated to increase use and interaction with the UKCRC Directory. The Centre staff provide support to researchers and biobanking personnel wishing to register or access tissue collections. Online resources to help communicate and engage with the community, including explanatory videos can be found on the Centre's website

[5]. Tissue custodians are continually being engaged with to promote registration. Policy development with institutions, funders and governing bodies are being developed as one mechanism to drive registrations. In 2016 the UK Ethics Committee Authority (UKECA) made registration in the directory a condition of the Research Ethics Committee (REC) favorable opinion for research tissue banks (RTB). This means that all samples collected under a research tissue bank will require registration with the directory in the future, leading to more comprehensive coverage. The development of the Centre website and Directory is being managed through an agile development process allowing updates and improvements as the needs of users change.

### Stabilization/preservation

This information is available by contacting the resources directly via the links in the Tissue Directory.

### Type of long-term preservation

This is not collected but is reflected in the storage temperature and material type filters.

### Storage temperature

The full range of storage temperatures can be found by adjusting the 'Preservation Type' filter.

### Shipping temperature from patient/source to preservation or research use

This information is only available by contacting the resources directly.

### Shipping temperature from storage to research use

This information is only available by contacting the resources directly.

### Quality assurance measures

The availability of quality assurance measures can be found by adjusting the 'Associated data' filter. Further details of what quality assurance were performed can then be requested from the resources.

### Source of associated data

Availability of clinical records, follow-up records, genealogical records, imaging data, national registry data, pathology records, primary care records, psychological data, survey data and treatment records can be found by adjusting the 'Associated Data' filter. Further details on the source of this information can then be requested from the resources.

## (3) Bioresource description

### Object name

Meta-data on UK Human Tissue Samples.

### Bioresource name

The UKCRC Tissue Directory and Coordination Centre.

### Bioresource location

UKCRC Tissue Directory and Coordination Centre is based at University College London, 9th Floor South, Royal Free Hospital, Pond St, London NW3 2QG and The School of

Computer Science, Advanced Data Analysis Centre, Jubilee Campus, The University of Nottingham, Nottingham, NG8 1BB.

**Bioresource contact**

contact@biobankinguk.org.

**Bioresource URL**

<https://www.biobankinguk.org/>.

**Identifier used**

N/A.

**Bioresource type**

National Coordinating Centre/BBMRI national node.

**Type of sampling**

Tissue taken from a variety of studies including: population, family, disease based, longitudinal cohort; sampled in clinical care; sampled in a research protocol, are registered in the Directory.

**Anatomical site**

Various.

**Disease status of patients/source**

Various, SNOWMED-CT coding is used for disease classification, at the time of writing over 100 disease types are listed.

**Clinical characteristics of patients/source**

Various. Age, gender, disease classification and other clinical information is collected during registration and displayed in search results.

**Size of the bioresource**

At the time of writing, 100 Bioresources are registered in the directory covering over 100 disease types. This is indicative of approximately 6 registrations a month.

**Vital state of patients/source**

A full range of vital states (for example during and post diagnosis, or postmortem) are captured and can be found by adjusting the 'Collection Point' filter.

**Clinical diagnosis of patients/source**

SNOMED-CT is used for disease classifications; searches can start with the disease details.

**Pathology diagnosis**

The details of the pathology diagnosis are not recorded directly, but we ask the bioresource leads to indicate if they have access to the pathology records. This can be found under the 'Associated Data' filter.

**Control samples**

Control samples are indicated by the 'non-affected' option in the 'Macroscopic Assessment' filter. Samples from healthy or un-diagnosed can be found by using the SNOMED-CT term 'Fit and Well' or 'No abnormality seen'.

**Biospecimen type**

The full range of biospecimen types (including tissue, blood, plasma, tissue and DNA) can be found by adjusting the 'Material Type' filter.

**Size of the bioresource**

At the time of writing over 100 Bioresources constituting a wide diversity of collections are registered.

**Release date**

This resource went live to tissue custodian registrants in Spring 2016 and to researchers in August 2016.

**Access criteria**

The Directory is open access and, as such, anyone is able to search for samples fulfilling their criteria. Contact information for the resources are included in the search results so that researchers can begin requesting samples and services. The Directory therefore facilitates contact between the parties and does not facilitate direct access.

**(4) Reuse potential**

The Centre was established on exactly this premise – to help facilitate the sharing and reuse of existing samples and data. In addition to this, the Centre facilitates the optimal use and reuse of existing samples by working with our funder partners. The sharing of samples listed on this Directory has the potential to save time and money in scientific research. The Centre is also working towards a system to give confidence that samples reach a certain level of quality control to further facilitate sharing.

**Ethics Statement**

No personal identifiable information is listed in the Directory. Tissue custodians can specify the consent restrictions for each tissue collection individually. It remains the responsibility of each registered Bioresource to ensure the required ethics and governance permissions are in place. In 2016 the UK Ethics Committee Authority (UKECA) made registration in the directory a condition of the Research Ethics Committee (REC) favorable opinion for research tissue banks (RTB).

**Constraints**

There are no constraints to using the UKCRC Tissue Directory. Individual bioresources may have constraints on sample usage and this can be established by contacting the resource directly via links provided in the Directory.

**Acknowledgements**

The Authors would like to acknowledge the contribution of Anne Carter, the original Director who retired in 2016, the NCRI Confederation of Cancer Biobanks and the Project Steering Committee, past and present.

Present Steering Committee: Mrs Amanda Gibbon, Professor Brian Davidson, Professor Jane Kaye, Dr Claire Newland, Ms Jenni MacDougall, Professor Andy Hall, Professor Seth Love, Dr Tim Peakman, Dr Kirstin Goldring and Dr Alison Parry-Jones.

**Competing Interests**

The authors have no competing interests to declare.

**Author Roles**

Director: Dr Phillip Quinlan

Principal Investigator: Professor Brian Davidson

Bioresource project manager: Ms Jessica Sims

**References**

1. **UK Clinical Research Collaboration (UKCRC), Experimental Medicine Funders Group and The NCRI's Board Sub-group on Clinical and Translational Research.** UK Funders' Vision for Human Tissue Resources. <http://www.ukcrc.org/>: UK Clinical Research Collaboration; 2011 01/09/2011.
2. **Mayrhofer, M T, Holub, P, Wutte, A, and Litton, J E** BBMRI-ERIC: the novel gateway to biobanks. From humans to humans. *Bundesgesundheitsblatt, Gesundheitsforschung, Gesundheitsschutz.* 2016; 59(3): 379–84. DOI: <https://doi.org/10.1007/s00103-015-2301-8>
3. **Holub, P, Swertz, M, Reihls, R, van Enckevort, D, Muller, H and Litton, J E** BBMRI-ERIC Directory: 515 Biobanks with Over 60 Million Biological Samples. *Biopreservation and biobanking.* 2016; 14(6): 559–62. DOI: <https://doi.org/10.1089/bio.2016.0088>
4. **Confederation of Cancer Biobanks.** NCRI Confederation of Cancer Biobanks. Available from: <http://ccb.ncri.org.uk/>.
5. **Quinlan, P** UKCRC Tissue Directory <https://www.biobankinguk.org/directory/2016> [cited 2016 22/12/2016]. Available from: <https://www.biobankinguk.org/directory/>.

**How to cite this article:** Quinlan, P R, Lawrence, E, Pourabdolla, A, Sims, J M, Gander, A, Fuller, B, Thompson, B J, Garibaldi, J M and Davidson, B 2017 The UK Clinical Research Collaboration (UKCRC) Tissue Directory and Coordination Centre: The UK's Centre for facilitating the Usage of Human Samples for Medical Research. *Open Journal of Bioresources* 4: 6, DOI: <https://doi.org/10.5334/ojb.31>

**Published:** 18 May 2017

**Copyright:** © 2017 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CC-BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by/4.0/>.