

User Guide to:

# UKCRC TISSUE DIRECTORY REGISTRATION

## INTRODUCTION

The UKCRC Tissue Directory is the UK's platform for discovering existing human sample resources. By connecting sample resources to researchers, it enables collections to be publicly visible and used to their full potential.

## HOW TO REGISTER

This guide has been designed to assist you in the registration process. We have included both an overview of what to expect during the process and more detailed information for different stages in the process. Please get in touch if you require more assistance.

## OVERVIEW

### STEP 1

#### CREATE ACCOUNT

Register a sample resource.

We'll send you a link once your request is approved

### STEP 2

#### COMPLETE PROFILE

Add general information about your resource.

### STEP 3

#### ADD COLLECTIONS OR, CAPABILITIES

These are defined by disease, timeframe, consent and associated data.

### STEP 4

#### ADD SAMPLE SETS

These are defined by sex, age, material and preservation type.

### \* MANDATORY FIELDS

Some fields in the registration process are mandatory. You may want to collate this information before beginning the registration process.

#### COLLECTION

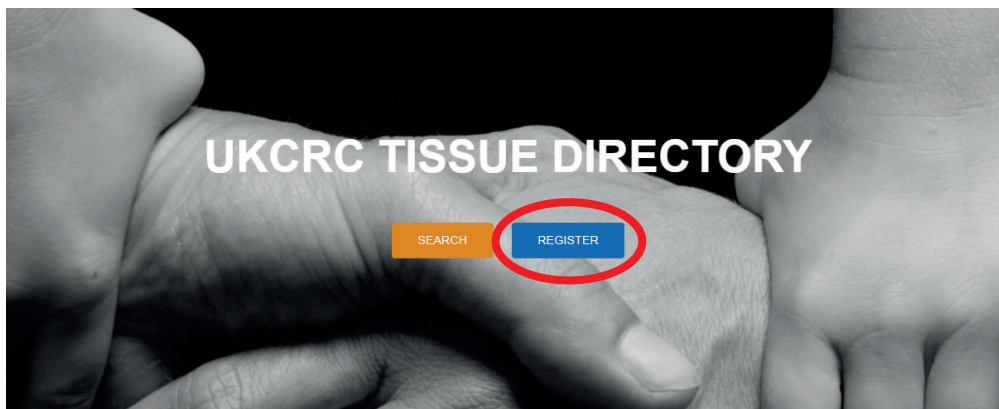
Disease status (see next page)  
Description (of resource)  
Year started  
Access conditions  
Collection type  
Collection status  
Collection point

#### SAMPLE SET

Gender  
Age range  
Material type  
Preservation type  
Macroscopic assessment

# STEP ONE: CREATE AN ACCOUNT

- Visit: <https://directory.biobankinguk.org>
- Click: Register



- Choose to either register a single resource, or a network of resources.

<p><b>Registering a sample resource</b></p> <p>A sample resource is any infrastructure that holds or can collect and distribute human samples and data (e.g. biobanks, biosources, biorepositories, cohorts and clinical trials).</p> <p>For more information</p> <p>We have developed some resources to help you register:</p> <ul style="list-style-type: none"><li>• <a href="#">View our help pages</a></li><li>• <a href="#">View our videos</a></li></ul> <p><a href="#">REGISTER A NEW SAMPLE RESOURCE</a></p>	<p><b>Registering a network</b></p> <p>A network is a group of sample resources that have come together with some common objective or agreed standard. An example is the <a href="#">Confederation of Cancer Biobanks</a>.</p> <p>Sample resource or Network?</p> <p>If you are unsure about whether to register a resource or network then <a href="#">please get in touch</a>.</p> <p><a href="#">REGISTER A NEW NETWORK OF RESOURCES</a></p>
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**Register a new sample resource**

If you have a collection of tissue samples or the ability to collect samples for researchers then you can add an overview to our database by registering below.

Sample resource name \*

Admin name \*

Admin email \*

[Register](#)

- Add the name of your resource, or the name of your network of resources.
- Add the name of the person who will be responsible for administering the resource's or network's profile information.
- Add an email for that person. This is the email address that will be used for future logins, and so you will need to have access to this account.
- Please note, it is only possible to associate one email address to one profile for the purposes of registration. However, you may advertise a different email address as your contact email address.
- Wait for the validation link to be emailed to you.
- Click on the link to validate your account!

## STEP TWO: COMPLETE PROFILE

Complete general information about your resource. Mandatory information is indicated by a red asterisk.

Home / Sample resource details / Edit sample resource details

### Edit sample resource details

**Name \***

**Description \***

**URL**

**Contact email \***

**Logo**

No Logo

**Address Details**

**Address \***

**City \***

**County \***

**Country \***

**Postcode \***

**Governance Compliance**

**Institution \***

**School / Department**

**Ethics Registration**

**HTA Licence**

**Services**

- Ability to recontact
- Access to the full pathology archive
- Cell culture
- Data analytics
- Digital imaging
- Human functional tissue assays
- Immunohistochemistry - scoring
- Immunohistochemistry - staining
- iPSC reprogramming services
- Tissue micro array creation
- Nucleic acid extraction

**Data sharing settings**

Opt out of sharing data with other directories

# STEP THREE: ADD COLLECTIONS

Complete information about your existing sample collection, based on:

- disease,
- access conditions,
- collection information,
- consent,
- the type of associated data available; and
- the amount of time necessary to provide that data.

Home / Collections / Add collection

## Add collection

**⚠ We expect you to ensure that this information can be shared in the public domain.**

**Disease status**

**Title**

**Description**

**Year started**

**Year finished**

**Access condition**

Open to applicants  Data access only

Open in response to specific calls  Access restricted at present

Open only through collaboration  Closed to access

**Collection type**

Disease specific  Longitudinal

Birth cohort  Population-based

Case-control  Quality control

Cohort  Twin-study

Cross-sectional  Clinical Trial

**Collection status**

Not-started

In progress

Completed

**Collection point**

Pre-diagnosis  Post-diagnosis

During diagnosis  Multiple points in patient pathway

**Consent restriction**

Commercial restriction

DNA restriction

Other animal work

Outside EU access

Xenograft

**Associated data**

Data type	Provision time (months)
<b>Quality Data</b>	
<input type="checkbox"/> Quality indicators	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Cold ischemic time	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Warm ischemic time	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Freezer temperature logs	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<b>Research Data</b>	
<input type="checkbox"/> Biomarker datasets	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Genomic datasets	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<b>Annotation Data</b>	
<input type="checkbox"/> Clinical records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Donor Ethnicity	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Followup records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Genealogical records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Imaging data	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> National registries	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Pathology records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Physiological/biochemical measurements	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Primary care records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Psychological data	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Survey data	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Treatment records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6

## STEP THREE, Cont.:

# ADD CAPABILITIES

Complete information about your ability to prospectively collect samples, based on:

- disease,
- consent,
- how many donors you expect a year,
- the type of associated data; and
- the amount of time necessary to provide that data.

Add capability

Disease status ⓘ

Protocols ⓘ  Bespoke consent form  
 Bespoke SOP

Annual donor expectation ⓘ

Associated data ⓘ

Data type	Provision time (months)
Quality Data	
<input type="checkbox"/> Quality indicators	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Cold ischemic time	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Warm ischemic time	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Freezer temperature logs	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
Research Data	
<input type="checkbox"/> Biomarker datasets	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Genomic datasets	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
Annotation Data	
<input type="checkbox"/> Clinical records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Donor Ethnicity	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Followup records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Genealogical records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Imaging data	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> National registries	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Pathology records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Physiological/biochemical measurements	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Primary care records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Psychological data	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Survey data	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6
<input type="checkbox"/> Treatment records	<input type="radio"/> Immediately <input type="radio"/> 0 - 3 <input type="radio"/> 3 - 6 <input type="radio"/> > 6

# STEP FOUR: ADD SAMPLE SETS

Add sample sets within your collection, based on:

- gender,
- age range,
- donor size; and
- preservation details.

Preservation details include:

- material type,
- preservation type,
- percentage of samples; and
- macroscopic assessment.

Use the copy button to duplicate your sample set. Then, edit the appropriate details.

Sample set details		Material preservation details			
Gender	Age range	Material type	Preservation type	Collection percentage	Macroscopic assessment
Female	Child (6 - 12 years)	DNA	-60 °C to -85 °C	11 - 25%	Affected

# REFERENCE GUIDE TO: FIELD DESCRIPTIONS

SAMPLE RESOURCE DETAILS	ADDITIONAL INFORMATION	EXAMPLE
Name	<p>What is the name of the resource you are registering? It is up to you how you present your resource in the directory.</p> <p>Find out about registering a network of Resources.</p>	Cancer Biobank
Description	Use this for general information and information that is not captured in other fields. You can use as much space as needed.	A collection of cancer samples from throughout the clinical pathway.
URL	If your resource has a website or page you can include it here.	www.biobank.com
Contact Email	The email address that researchers will use to contact you.	contact@biobank.com
Address	Use the address where access to the samples is based rather than where they are stored.	Pond Road, Manchester.
County	List the county associated with the location.	Greater Manchester
Country	List the UK country associated with the location.	England
Institution	The organisation where your governance is managed.	The University of Manchester
Ethics Registration	e.g. IRAS number	XXXXXXXX
HTA Licence	HTA licence number	XXXXXXXX
Services <ul style="list-style-type: none"> <li>• Ability to recontact</li> <li>• Access to the full pathology archive</li> <li>• Cell culture</li> <li>• Data analytics</li> <li>• Digital imaging</li> <li>• Human functional tissue assays</li> <li>• Immunohistochemistry - scoring</li> <li>• Immunohistochemistry - staining</li> <li>• iPSC reprogramming services</li> <li>• Tissue micro array creation</li> <li>• Nucleic acid extraction</li> </ul>	Does your resource offer any extra services? If so indicate that here.	
Data sharing settings	Some data will be shared with other platforms, such as the BBMRI-ERIC Directory. You can opt-out of this via the tick box. Contact us to find out more about our current data sharing arrangements.	

# REFERENCE GUIDE TO: FIELD DESCRIPTIONS

ADD COLLECTION	ADDITIONAL INFORMATION	EXAMPLE
Disease status	We are seeking to harmonise the terms used to describe diseases and we are adopting SNOMED-CT in this effort. We are seeking to discuss with the domain experts what terms are most relevant for certain diseases. Therefore, if you do not see a relevant term there, please get in contact. If you are collecting from healthy volunteers, please use the term 'Fit and Well'.	Benign neoplasm of bladder
Title	This is an optional field for when your collection has a specific title.	Control arm of Trial Beta
Description	Open text field where you can describe the collection.	Samples from control participants of Trial xyz.
Year started	The first year samples were collected.	2010
Year finished	If this collection is on-going, you can leave this blank.	2017
Access conditions	How is access to the samples managed?	Open only through collaboration
Collection type	Select a category that best describes your collection. If you feel that one is missing please contact us.	Cohort
Collection status	At which point in the process of collecting are you?	In progress
Collection point	Select a category that best describes the point in the diagnosis pathway that your samples were collected.	Post-diagnosis
Consent restriction	Please highlight any areas of research you do not have consent for.	Commercial restriction



# REFERENCE GUIDE TO: FIELD DESCRIPTIONS

ASSOCIATED DATA	We want to show what data you have for the sample and how long it would take you to provide it. If you can't get any of the data listed don't tick anything. It doesn't matter how long it takes, it's just to make the researcher aware.
Quality indicators	If you keep any records that would indicate the quality of the sample or that a QMS system is followed, tick this field. For example, this could be following an ISO protocol or checking a random sample for yield.
Cold ischemic time	Data indicating the time between the chilling the sample after its blood supply has been reduced or cut off and the time it is warmed by having its blood supply restored.
Warm ischemic time	Data indicating the amount of time that the sample remained at body temperature after its blood supply had been stopped or reduced.
Freezer temperature logs	Records of freezer temperatures over time.
Biomarker datasets	Results of an assay of anything that can be used as an indicator of a particular disease state or some other physiological state.
Genomic datasets	Results of any genome analysis.
Clinical records	Data obtained from accessing clinical records.
Follow-up records	Data recorded about a patient after the sample was taken.
Genealogical records	Data about the lines of family descent.
Imaging data	Access to images or data recorded from images.
National registries	Data obtained from national registries such as NCRAS.
Pathology records	Data obtained from pathology records.
Physiological /biochemical measurements	Assay results.
Primary care records	Data obtained from accessing primary care records.
Psychological data	Data obtained from accessing psychological records.
Survey data	Results from any surveys the participants were involved in.
Treatment records	Data obtained from accessing treatment records.

# REFERENCE GUIDE TO: FIELD DESCRIPTIONS

ADD SAMPLE SET	DESCRIPTION	EXAMPLE
Gender	Choose appropriate gender category based on the options provided.	Female
Age range	Select the age category that best reflects the sample set.	Young child (2-6 years)
Number of donors	Select the approx. range of donor numbers in the sample set. Examples of ranges are: 1- 10, 11-100, 101-500, 201-1000, 1001-3000, 3001 – 5000, 5001-10,000 etc.	201-1000

ADD MATERIAL PRESERVATION DETAIL	DESCRIPTION
Material type	Divide your sample set into what different materials you have sampled. If there is something missing please contact us.
Preservation type	Select how the samples are currently stored. If there is something missing please contact us.
Percentage	<p>This is to give the researcher an idea if the samples you are describing are available on all, or just a sub-set of the participants within the collection.</p> <p>The percentage is an approximation; we want to reflect whether this sample is always collected or is it rarely collected for every patient.</p>
Macroscopic assessment	What percentage of the tissue sample is affected by the disease, for example 90% of the tissue is malignant or infected.

ADD CAPABILITY	DESCRIPTION
Disease status	We are seeking to harmonise the terms used to describe diseases and we are adopting SNOMED-CT in this effort. We are seeking to discuss with the domain experts what terms are most relevant for certain diseases. Therefore, if you do not see a relevant term there, please get in contact. If you are collecting from healthy volunteers, please use the term 'Fit and Well'.
Protocols	Select these if you can offer custom-made SOPs and consent procedures.
Annual donor expectation	Number of donors per year