



Tissue Directory and  
Coordination Centre

# Registering in The UKCRC Tissue Directory

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User Guide November 2017

[www.biobankinguk.org](http://www.biobankinguk.org)

*contact@biobankinguk.org*



# Advance Information

If you are preparing to register, it's worth bearing in mind there are **4 steps** (you can watch the process on our demo [videos](#)). These can be done at any time.

- 1. Create account** (we'll send you a link to confirm your account) - Please note it is currently only possible to associate one email address to one profile.
- 2. Complete Profile information** - add general information about your resource.
- 3. Add Collections** - These are defined by disease, timeframe, consent and associated data.
- 4. Add Sample sets** - These are defined by sex, age, material and preservation type.

# Advance Information

There are some fields that are mandatory. It is worth reading through this guide or watching our videos before collating your information.

## **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



# Disease Status

Collections are categorised by disease status in the Tissue Directory. We are using SNOMED-CT coding for this.

[Find out more about SNOMED-CT](#)

If you are unsure what term to use for your disease please refer to [our list of diseases](#).

**Disease not listed?** Email [contact@biobankinguk.org](mailto:contact@biobankinguk.org) and we will add it for you.

# 1. Create Account



- Visit: <https://directory.biobankinguk.org/Register/Biobank>.
- Add the name of your resource (e.g. Trial Tissue Collection).
- Add the name of the account manager.
- Add an email for the account manager (Please note it is currently only possible to associate one email address to one profile.) This does not need to be the email address that is advertised for contacting.
- Wait for the validation link to be emailed to you.
- Click on the link to validate your account!

[Watch here](#)

# 2. Profile Information



## Complete the general information about your resource

**Edit biobank details**

**Name**

**Description**  ⓘ Use this for information that is not captured elsewhere

**URL**

**Contact email**  ⓘ The email address that researchers will use to contact you

**Logo**

No Logo

**Address**

**City**

**Country**

**Postcode**

Governing Body

# 2. Profile Information

A screenshot of a web browser showing the 'Edit biobank details' form on the UKCRC Tissue Directory website. The browser's address bar shows the URL 'https://directory.biobankinguk.org/Biobank/Edit'. The form is organized into several sections: 'City' (with a dropdown menu), 'Country' (with a dropdown menu set to 'UK'), 'Postcode' (with a text input field), 'Governing Body' (with a dropdown menu set to 'University of Emma'), and 'School / Department' (with a text input field). Below these is the 'Services' section, which contains a list of checkboxes: 'Ability to recontact' (checked), 'Access to the full pathology archive' (checked), 'Cell culture' (unchecked), 'Data analytics' (unchecked), 'Digital imaging' (unchecked), 'Immunohistochemistry - scoring' (checked), 'Immunohistochemistry - staining' (unchecked), 'Nucleic acid extraction' (unchecked), and 'Tissue micro array creation' (checked). At the bottom of the form is the 'Data sharing settings' section, which includes a checkbox for 'Opt out of sharing data with other directories' (unchecked). At the very bottom of the form are two buttons: 'Cancel' and 'Update details'.

# 3. Collection Information



Complete information about your collection, based on disease, consent and time.

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**

**HTA status**  Finished before the Human Tissue Acts  
 Begun before the Human Tissue Acts  
 Begun after the Human Tissue Acts  
 Not applicable

**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

**Collection status**  Not-started

[Watch here](#)



# 3. Collection Information



UKCRC Tissue Directory - Add collection - Google Chrome  
https://directory.biobankinguk.org/Biobank/AddCollection

**Collection status**

- Not-started
- In progress
- Completed

**Collection point**

- Pre-diagnosis
- During diagnosis
- Post-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

# 3. Collection Information



UKCRC Tissue Directory - Add collection - Google Chrome  
https://directory.biobankinguk.org/Biobank/AddCollection

Data type	Provision time (months)
<b>Quality Data</b>	
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<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"/> 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

# 3. Sample set Information



Add sample sets within your collection, based on gender, age, size and preservation details.

The screenshot shows the 'Add sample set' form in the Tissue Directory. At the top, there is a breadcrumb trail: 'Home / Collections / Collection / Add sample set'. Below this is a light blue header bar with an information icon, a 'Get in touch' button, and a 'Give feedback' button. A yellow warning banner below the header states: 'Your biobank is currently suspended, so your public profile and search results will be inaccessible. Please contact ADAC via directory@biobankinguk.org for more information.' The main form area is titled 'Add sample set'. It contains two sections of radio button options: 'Gender' with options for Male, Female, Transgender (M-F), Transgender (F-M), and Data not recorded; and 'Age range' with options for Fetus, Neonate (0 - 1 month), Infant (1 month - 2 years), Young child (2 - 6 years), Child (6 - 12 years), Adolescent (12 - 18 years), Young adult (18 - 40 years), Adult (> 40 years), and Data not recorded. Below these is a 'Number of donors' slider set to a range of 501 - 1000. The 'Material preservation details' section has an 'Add details' button. A light blue information banner at the bottom of the form says: 'There are no material preservation details in this sample set yet. Add material preservation details now.' At the very bottom of the form are 'Cancel' and 'Create sample set' buttons.

# 3. Sample set Information

A screenshot of a web application interface. A modal dialog box titled 'Add material preservation detail' is open in the center. The dialog has a close button (X) in the top right corner. It contains several sections with radio button options and a slider. The background is a blurred view of the application's main page, which includes a navigation bar with 'about the centre' and 'Biobank', and a main content area with 'Sample set' and 'Material' sections. At the bottom of the main page, there are 'Cancel' and 'Create sample set' buttons. The dialog box has 'Cancel' and 'Add' buttons at its bottom right.

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about the centre Biobank

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biobank is currently suspended, s

Sample set

Ge

Age r

Number of do

Material

add details

There

Cancel Create sample set

### Add material preservation detail

**Material type**

- cDNA/mRNA
- Core biopsy
- Embryo
- microRNA
- Peripheral blood cells
- PM tissue
- Saliva
- Tissue
- Whole blood
- Cell lines
- DNA
- Faeces
- Pathogen
- Plasma
- RNA
- Serum
- Urine

**Preservation type**

- Room temperature
- 2 °C to 10 °C
- 18 °C to -35 °C
- 60 °C to -85 °C
- Liquid nitrogen
- Paraffin

**Percentage**

0 - 10%

**Macroscopic assessment**

- Affected
- Non-affected
- Not applicable

Cancel Add



# Copy/paste function

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- To save adding sample sets again and again, there is a copy function.
- Add one set completely.
- Click “Copy” once it has been duplicated.
- Edit the details accordingly.

[Watch here](#)



# Any problems?

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## **We're here to help!**

Please email [contact@biobankinguk.org](mailto:contact@biobankinguk.org) if you encounter any problems.

There is more information including answers to [frequently asked questions](#) on our [website](#).

## **Feedback**

Is there anything missing from this guide? Please [let us know](#) so we can improve.