Photo: FIND/Katie G.Nelson

REGISTRATION GUIDE

FIND VIRTUAL BIOBANK DIRECTORY

CONTACT US: vbd@finddx.org VBD WEBSITE: https://vbd.finddx.org FIND WEBSITE: http://finddx.org

INTRODUCTION

The Foundation for Innovative New Diagnostics (FIND) Virtual Biobank Directory (VBD) aims to give visibility to specimen collections hosted by other organizations or networks worldwide. This is to encourage and support commercial and academic researchers in the development and evaluation of new and existing diagnostic tests for infectious diseases in low-middle-income countries.

HOW TO REGISTER:

This guide has been designed to assist you in how to register for the VBD. We have included both an overview of what to expect during the process and more detailed information for the different stages in the process. If you need more assistance, don't hesitate to contact us at vbd@finddx.org

OVERVIEW:

1

CHOOSE TO REGISTER AS:

A new biobank OR a new network of resources

(1) What's the difference?

2

FILL IN THE PRELIMINARY INFORMATION:

Biobank/Network name, Admin name

Admin email

You will receive a confirmation email

3

CONFIRM REGISTRATION:

Use this link in the confirmation email to complete your registration and create the profile of your biobank/network

4

EDIT BIOBANK OR NETWORK GENERAL DETAILS:

- Description
- Contact email
- Address details
- Institution
- Services offered
- The admins
- Funders
- Collections and the sample set details
- Capabilities for prospective collections
- Network acceptance
- Annual stats

*(1) A **biobank** is any infrastructure that holds or can collect and distribute human samples and data (e.g. biobanks, bioresources, biorepositories, cohorts and clinical trials).*
*A **network** is a group of biobanks that have come together with some common objective or agreed standard. If you are unsure about whether to register as a biobank or network, please contact us.*

MANDATORY FIELDS

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

BIOBANK DETAILS

Name
Description
Contact email
Address
Institution

COLLECTION

Disease status
Year started
Access condition
Collection status
Collection point
Consent restriction

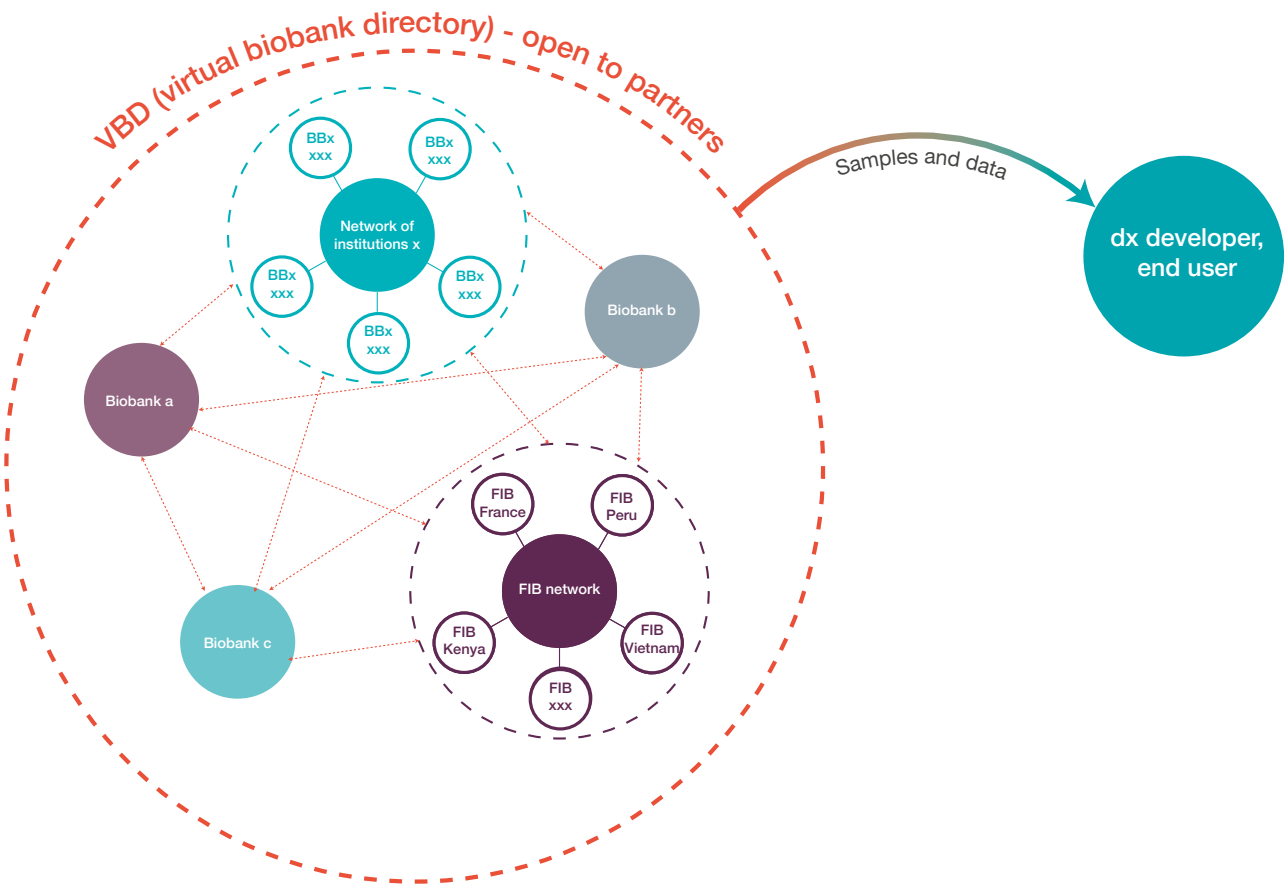
SAMPLE SET

Sex
Age range
Number of donors

MATERIAL PRESERVATION DETAILS

Material type
Storage temperature
Microscopic assessment

VIRTUAL BIOBANK DIRECTORY INFRASTRUCTURE:

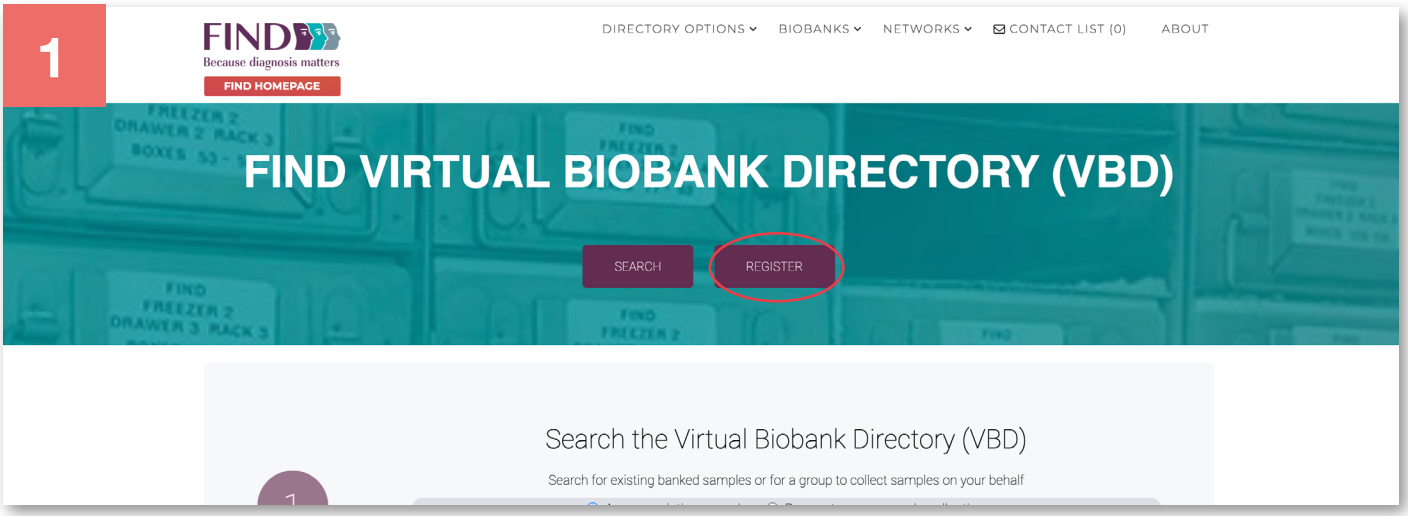


STEP ONE:

CREATE AN ACCOUNT

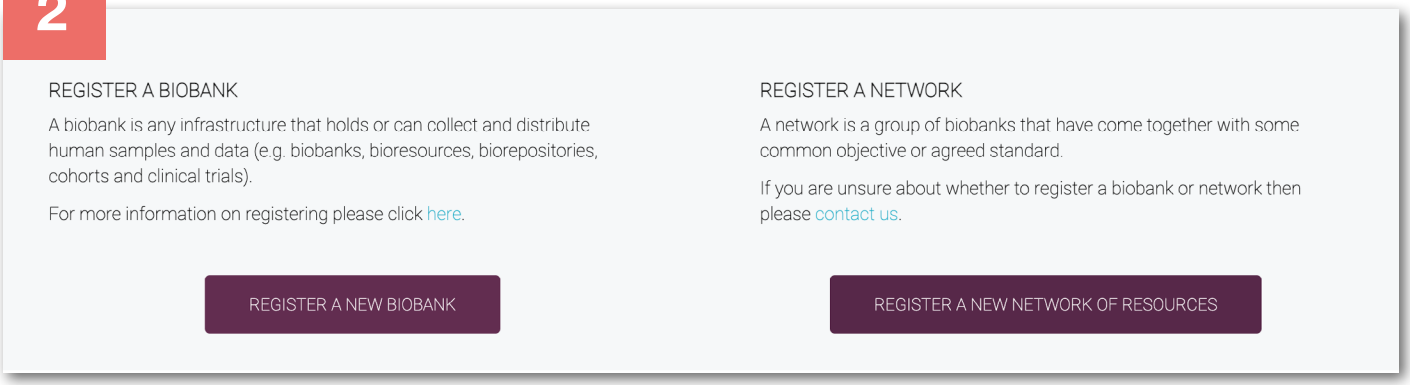
Visit: https://vbd.finddx.org/
Click: Register

1

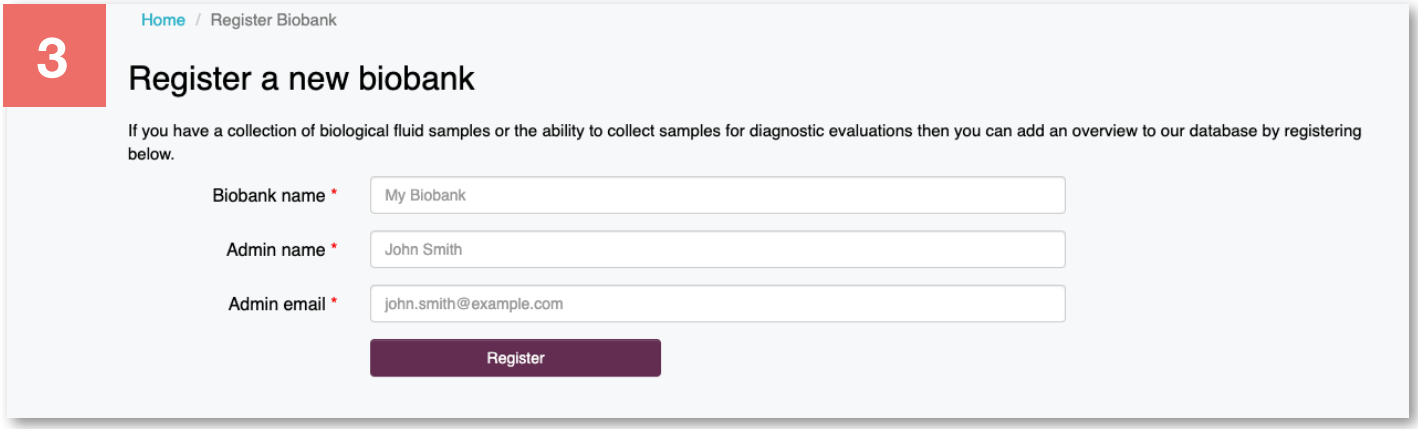


- You can register as a biobank or a network by clicking on the corresponding item.

2



- You will be redirected to a new page to fill in preliminary information.

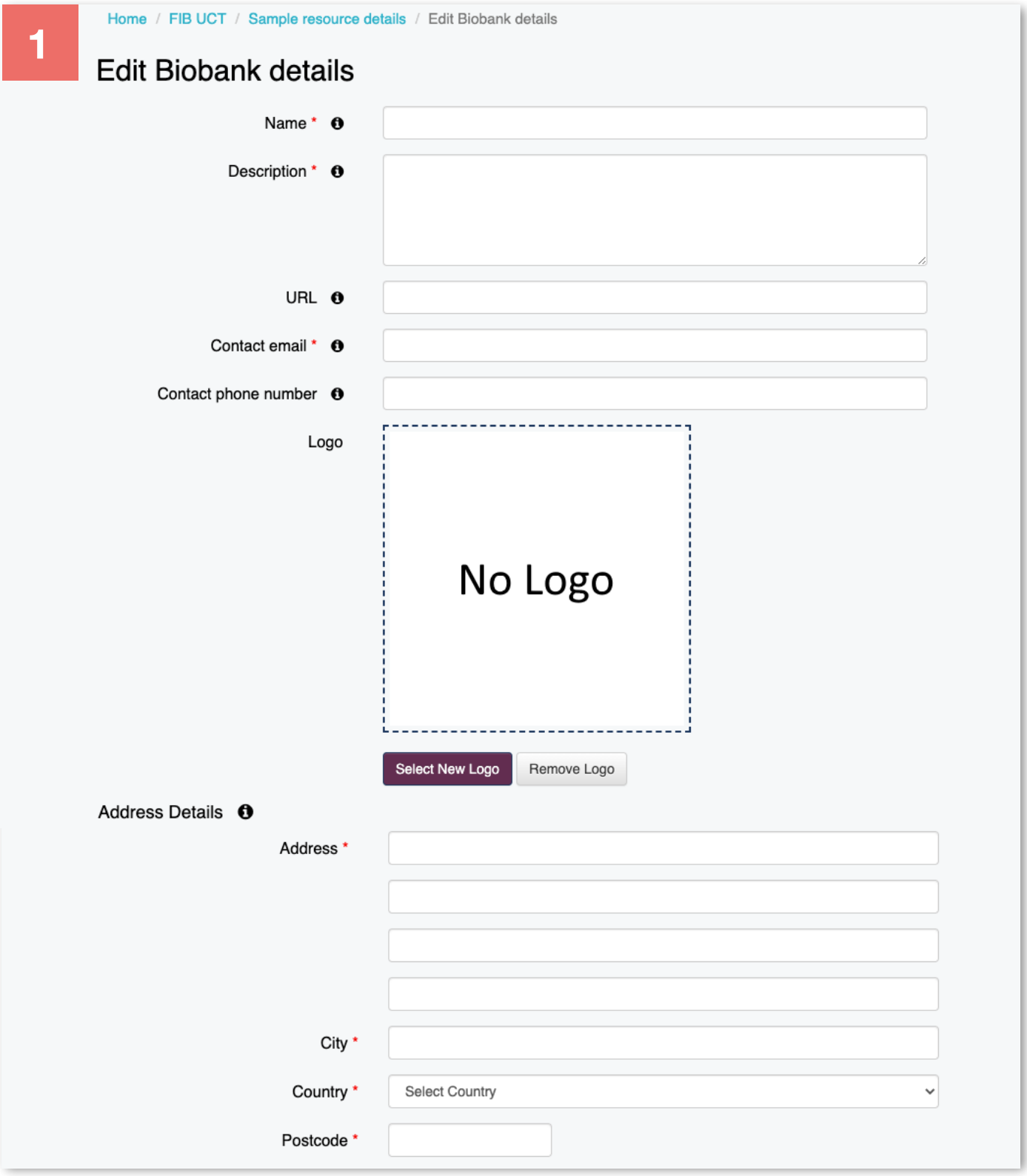


- Add the name of your biobank or network.
- Add the admin name. This is the person responsible for managing the biobank/network information.
- Add an email for the admin. It is essential that you have a direct access to this email account as it will be used for further registration steps and login to the FIND VBD.
- Later in the registration process you will have the possibility to add additional email addresses associated with your biobank/network.
- A validation link will be emailed to you.
- Click on the link to validate your account.

STEP TWO:

CREATE A PROFILE

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



Governance Compliance

Institution *

School / Department

Ethics Committee Approval

Services

- [ ] Infectious strain isolation
- [ ] Ability to recontact
- [ ] Access to the full pathology archive
- [ ] Cell culture
- [ ] Data analytics
- [ ] Digital imaging
- [ ] Molecular Extractions
- [ ] Immunohistochemistry - scoring
- [ ] Immunohistochemistry - staining
- [ ] Nucleic acid extraction

Services

- [ ] Infectious strain isolation
- [ ] Ability to recontact
- [ ] Access to the full pathology archive
- [ ] Cell culture
- [ ] Data analytics
- [ ] Digital imaging
- [ ] Molecular Extractions
- [ ] Immunohistochemistry - scoring
- [ ] Immunohistochemistry - staining
- [ ] Nucleic acid extraction

Data sharing settings

- [ ] Opt out of sharing data with other directories

Reasons for Registering

- [ ] Condition for local ethics approval
- [ ] Condition for funding
- [ ] Requirement set by host institution
- [ ] Desire to make sample collections visible
- [ ] Desire to make collection service visible

Other

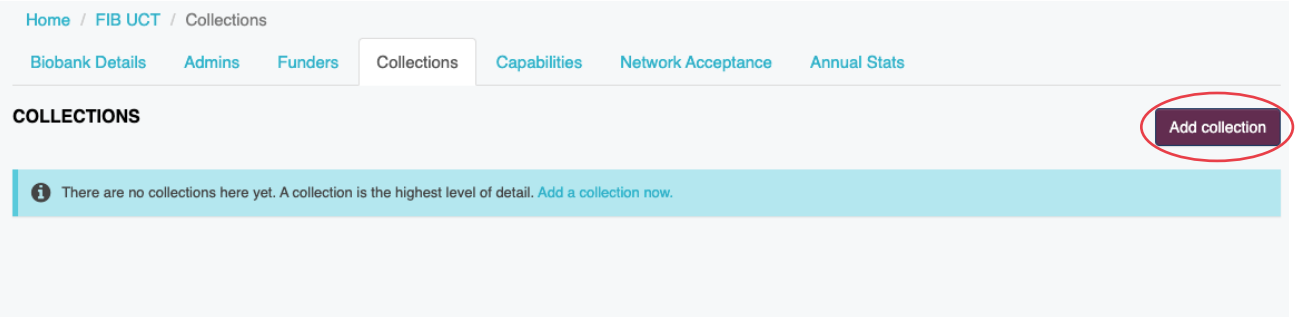
Cancel | Update details

STEP THREE :

ADD COLLECTIONS

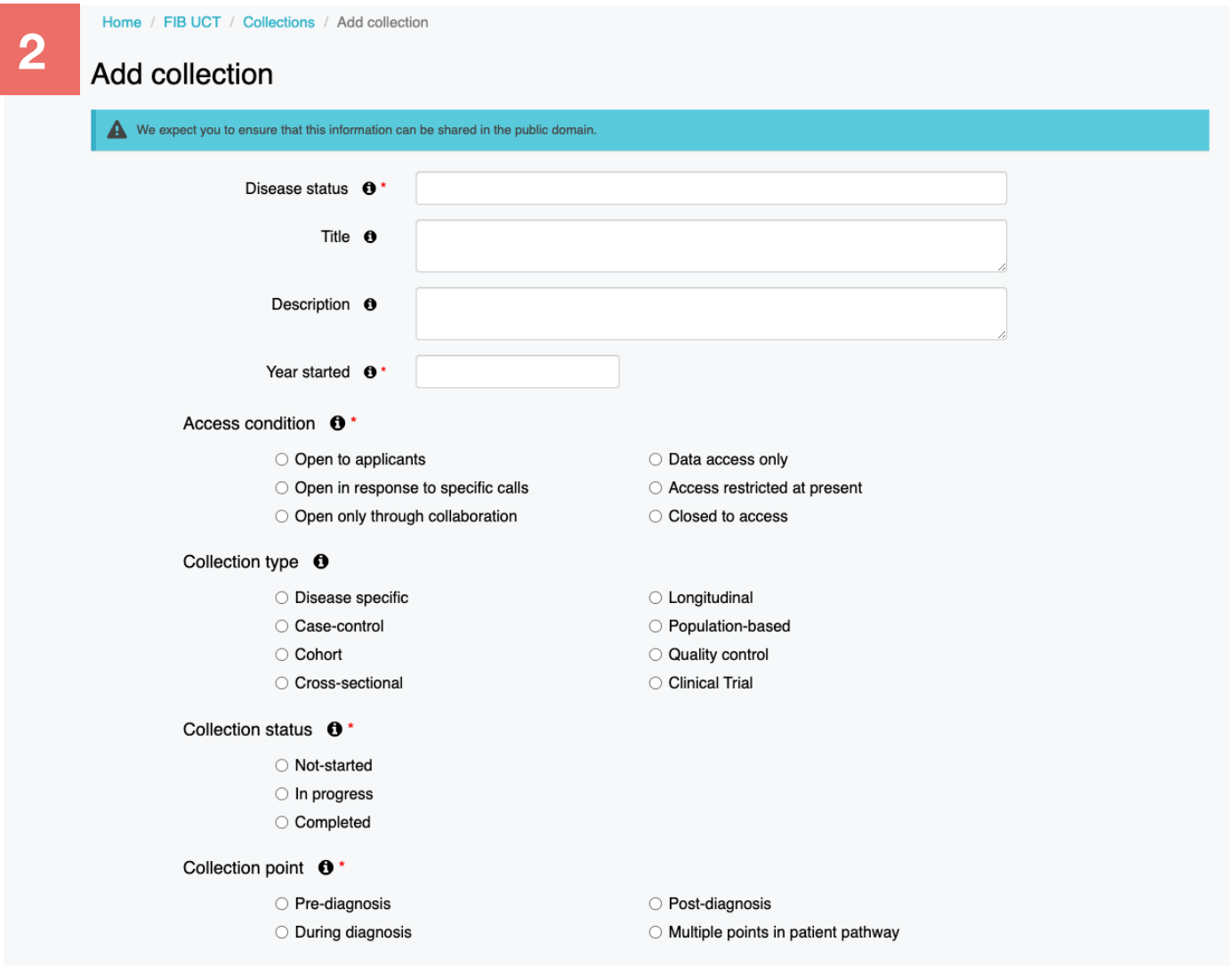
You can add several collections to your biobank/network. For each collection added, complete the corresponding information as shown below.

1



➤ Click on “add collection”

2



Consent restriction *

- [ ] Genetic analysis restriction
- [ ] Human genetic analysis restriction
- [ ] Scope of use restriction
- [ ] Export restriction
- [ ] Disease area restriction
- [ ] Project specific restriction
- [ ] Commercial restriction

Associated data

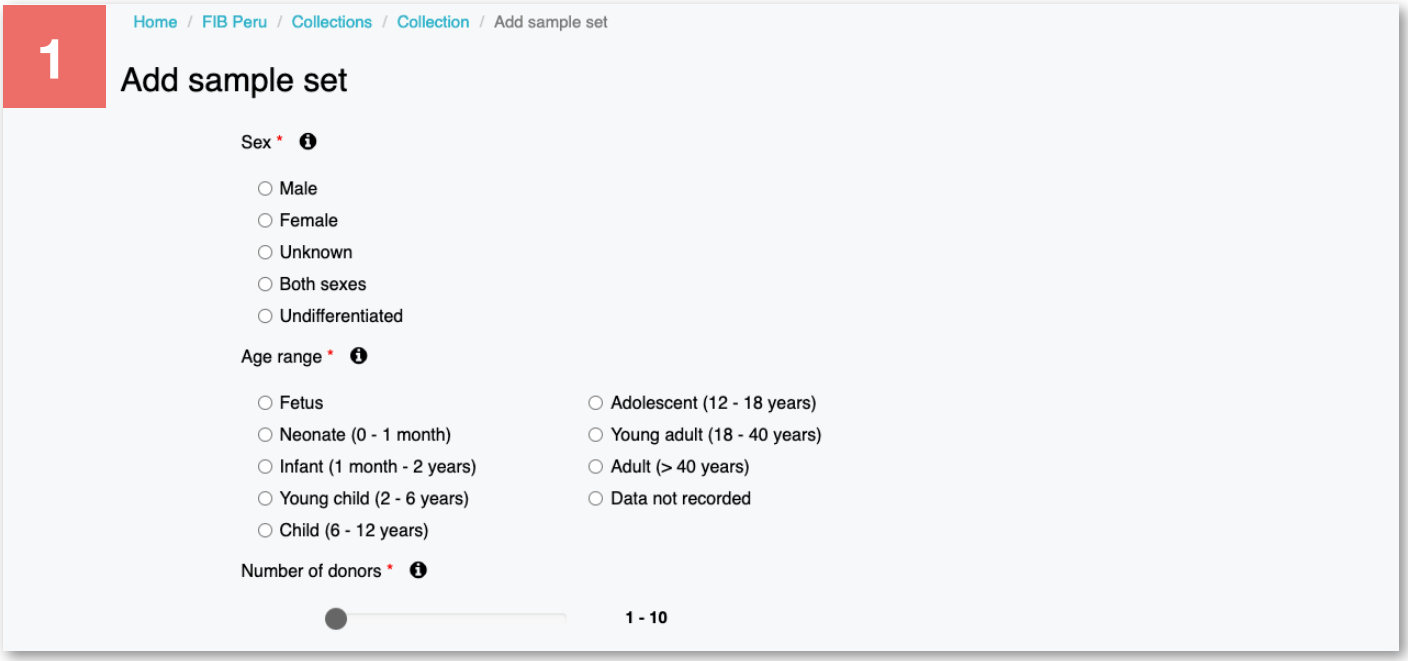
Data type	Provision time (months)
Quality Data	
Freezer temperature logs	Immediate 0-3 3-6 >6
Quality indicators	Immediate 0-3 3-6 >6
Research Data	
Biomarker datasets	Immediate 0-3 3-6 >6
Genomic datasets	Immediate 0-3 3-6 >6
Annotation Data	
Clinical records	Immediate 0-3 3-6 >6
Followup records	Immediate 0-3 3-6 >6
Genealogical records	Immediate 0-3 3-6 >6
Imaging data	Immediate 0-3 3-6 >6
National registries	Immediate 0-3 3-6 >6
Pre-analytical data	Immediate 0-3 3-6 >6
Physiological/biochemical measurements	Immediate 0-3 3-6 >6
Primary care records	Immediate 0-3 3-6 >6
Survey data	Immediate 0-3 3-6 >6
Treatment records	Immediate 0-3 3-6 >6
Psychological data	Immediate 0-3 3-6 >6
Participant Ethnicity	Immediate 0-3 3-6 >6
Microbiological results	Immediate 0-3 3-6 >6

Cancel Create collection

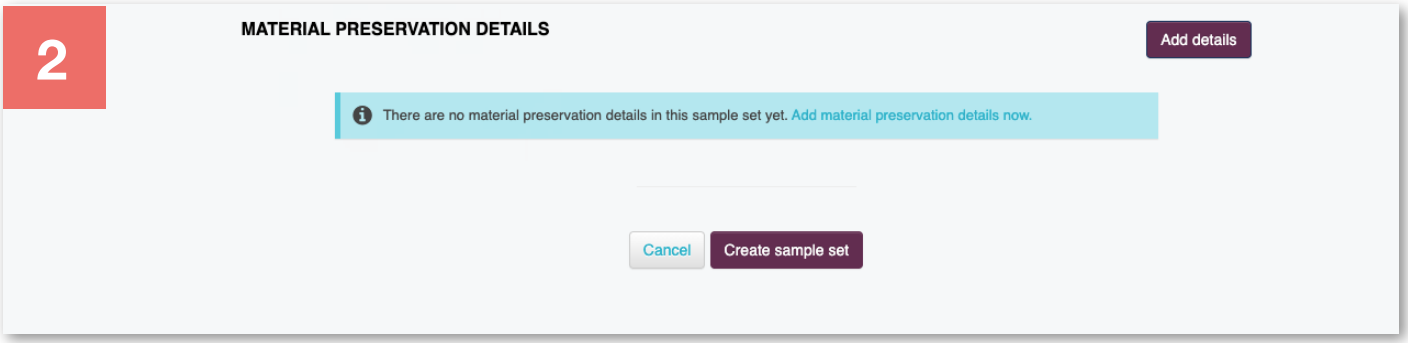
STEP FOUR:

ADD SAMPLE SET DETAILS

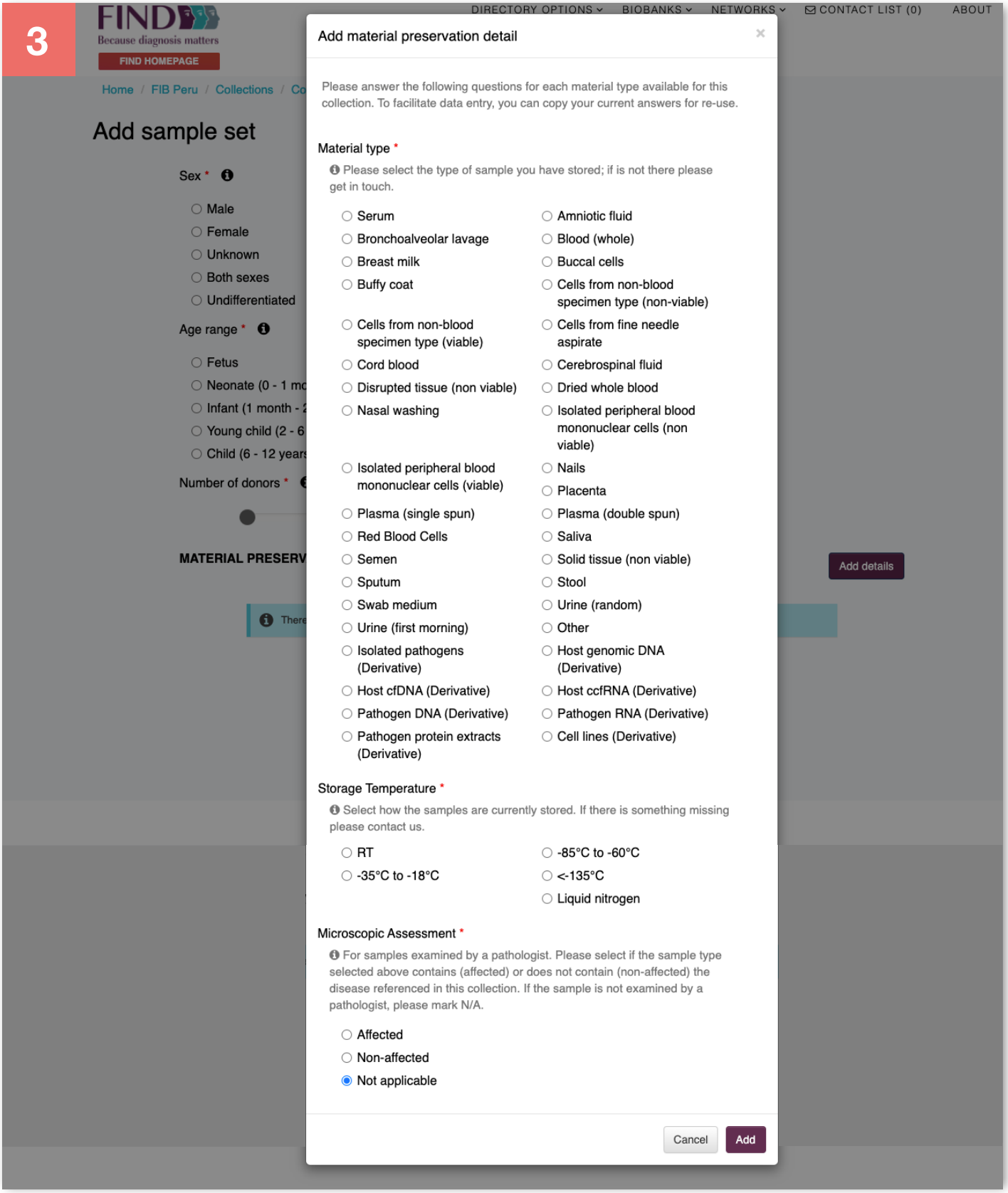
- For each collection, add and describe the sample sets.



- You should also give details about the preservation of the samples, by clicking on the “Add details” button.



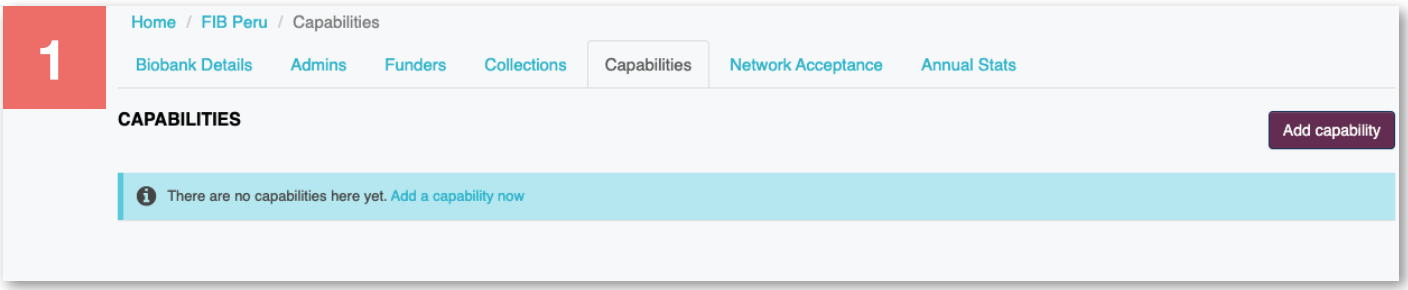
- A new window will pop up, where you will be asked to fill the material preservation details (i.e. Material Type, Storage Temperature, Microscopic Assessment).


3
FIND
Because diagnosis matters
FIND HOMEPAGE
DIRECTORY OPTIONS
BIOBANKS
NETWORKS
CONTACT LIST (0)
ABOUT
Home / FIB Peru / Collections / Co
Add sample set
Sex *
Male
Female
Unknown
Both sexes
Undifferentiated
Age range *
Fetus
Neonate (0 - 1 mo
Infant (1 month - 2
Young child (2 - 6
Child (6 - 12 years
Number of donors *
MATERIAL PRESERV
Add details
There
Add material preservation detail
Please answer the following questions for each material type available for this collection. To facilitate data entry, you can copy your current answers for re-use.
Material type *
Please select the type of sample you have stored; if is not there please get in touch.
Serum
Amniotic fluid
Bronchoalveolar lavage
Blood (whole)
Breast milk
Buccal cells
Buffy coat
Cells from non-blood specimen type (non-viable)
Cells from non-blood specimen type (viable)
Cells from fine needle aspirate
Cord blood
Cerebrospinal fluid
Disrupted tissue (non viable)
Dried whole blood
Nasal washing
Isolated peripheral blood mononuclear cells (non viable)
Isolated peripheral blood mononuclear cells (viable)
Nails
Placenta
Plasma (single spun)
Plasma (double spun)
Red Blood Cells
Saliva
Semen
Solid tissue (non viable)
Sputum
Stool
Swab medium
Urine (random)
Urine (first morning)
Other
Isolated pathogens (Derivative)
Host genomic DNA (Derivative)
Host cfDNA (Derivative)
Host ccfRNA (Derivative)
Pathogen DNA (Derivative)
Pathogen RNA (Derivative)
Pathogen protein extracts (Derivative)
Cell lines (Derivative)
Storage Temperature *
Select how the samples are currently stored. If there is something missing please contact us.
RT
-85°C to -60°C
-35°C to -18°C
<-135°C
Liquid nitrogen
Microscopic Assessment *
For samples examined by a pathologist. Please select if the sample type selected above contains (affected) or does not contain (non-affected) the disease referenced in this collection. If the sample is not examined by a pathologist, please mark N/A.
Affected
Non-affected
Not applicable
Cancel
Add

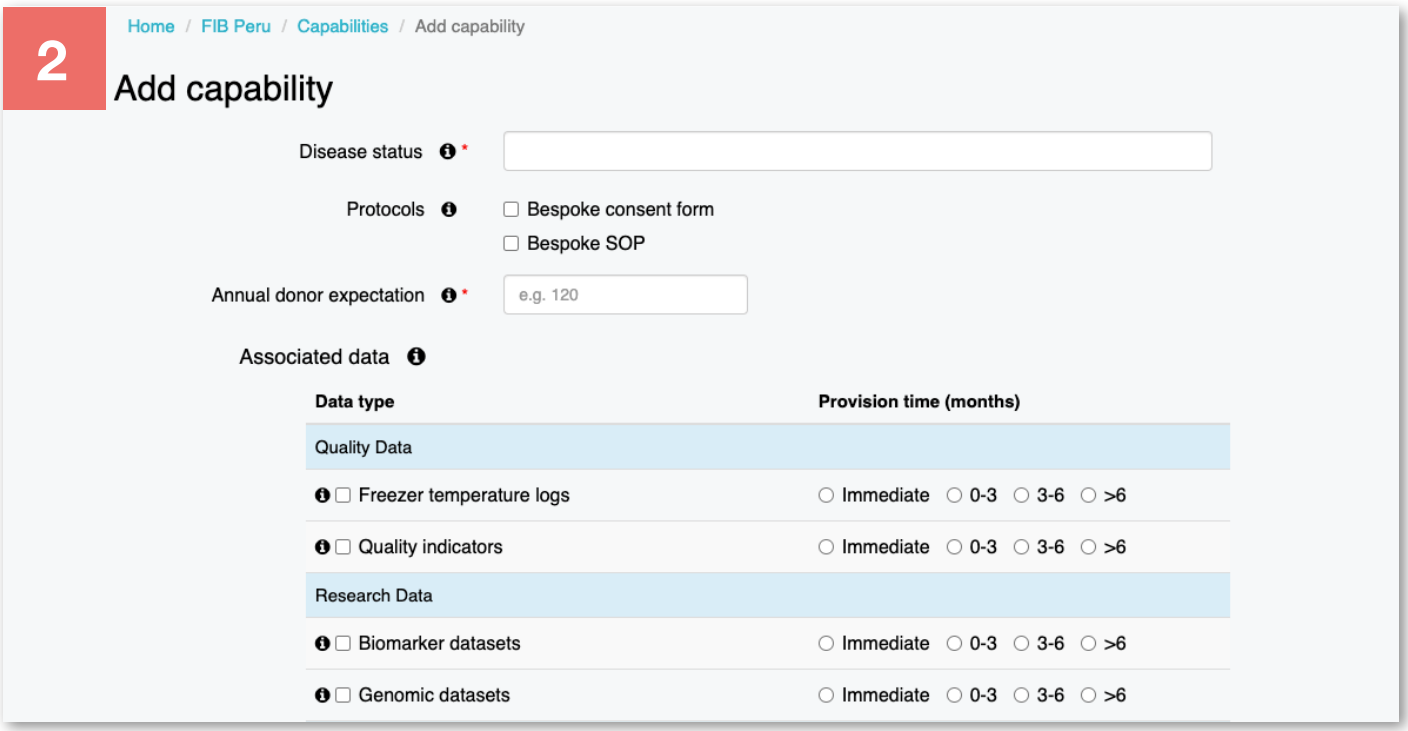
STEP FIVE:

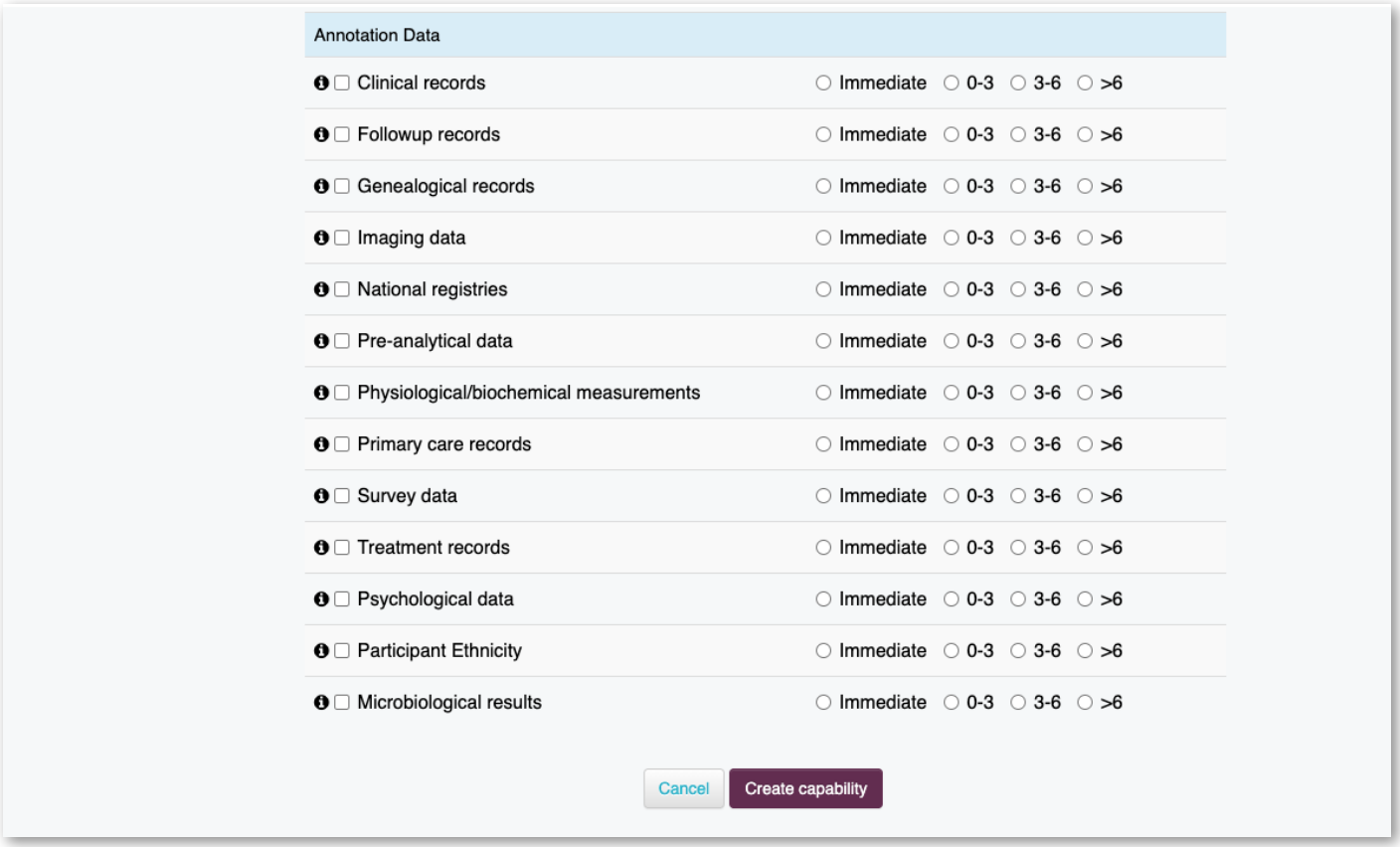
ADD CAPABILITIES

Complete information about your ability to prospectively collect samples, based on disease, consent, how many sample donors you expect approximately at a usual timeframe of a collection, other associated data and the amount of time necessary to provide that data.



- Fill the requested information at the Add capability step.




Annotation Data
Clinical records
Followup records
Genealogical records
Imaging data
National registries
Pre-analytical data
Physiological/biochemical measurements
Primary care records
Survey data
Treatment records
Psychological data
Participant Ethnicity
Microbiological results
Immediate
0-3
3-6
>6
Cancel
Create capability

REFERENCE GUIDE TO:

FIELD DESCRIPTIONS

CONTACT US: vbd@finddx.org VBD WEBSITE: https://vbd.finddx.org FIND WEBSITE: http://finddx.org

BIOBANK DETAIL	ADDITIONAL INFORMATION	EXAMPLE
Name	What is the name of the resource you are registering? It is up to you to present your biobank the way you want.	Tuberculosis biobank
Description	Use this for general information that is not captured in other fields. You can use as much space as needed.	A collection of human bodily fluids form Tuberculosis positive patients.
URL	If your biobank has a website or page you can include it here.	www.biobanktb.com
Contact email	The email address that people will use to contact you.	contact@biobanktb.com
Contact phone number	The phone number that people will use to contact you.	Tel: country code, city code, number
Logo	If your biobank has a logo you can put it here and it will be displayed on the FIND VBD website.	
Address	Use the address where access to the samples is based rather than where they are stored.	9 Chemin des Mines, 1202, Geneva, Switzerland
Institution	The organization where your governance is managed.	Foundation of Innovative New Diagnostics (FIND)
Ethics Committee Approval	Check if your collections are approved by an Ethics Committee (i.e. IRB)	
Services • Infectious strain isolation • Ability to recontact • Access to the full pathology archive • Cell culture • Data analytics • Digital imaging • Molecular extractions • Immunohistochemistry - scoring • Immunohistochemistry - staining • Nucleic acid extraction	Does your biobank offer any extra services? If so indicate that here.	
Reasons for registering • Conditions for local ethics approval • Condition for funding • Requirement set by host institution • Desire to make sample collections visible • Desire to make collection service visible	Select the reasons for registering your sample resource with the directory. You may select multiple reasons.	
Other	If there is any other useful information you would like to communicate you can put it here.	

ADD COLLECTION	ADDITIONAL INFORMATION	EXAMPLE
Disease status	We are seeking to harmonize the terms used to describe diseases and have adopted 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 presented on the form, please contact us. If you are collecting from healthy volunteers, use the term 'Fit and Well'.	Tuberculosis
Title	This is an optional field in case your collection has a specific title.	TB in country X
Description	Add a description of your collection.	Sputum samples from *Mycobacterium tuberculosis* sputum positive patients from country X
Year started	The year when the first samples were collected.	2012
Access condition: • Open to applicants • Open in response to specific calls • Open only through collaboration • Data access only • Access restricted at present • Closed to access	Please choose one of the access conditions applicable to your facility	
Collection type: • Disease-specific • Case-control • Cohort • Cross-sectional • Longitudinal • Population-based • Quality control • Clinical trial	Select the category that best describes your collection. If you think a category is missing, please contact us.	
Collection status: • Not started • In progress • Completed	Indicate your collection status.	
Collection point: • Pre-diagnosis • Post-diagnosis • During diagnosis • Multiple points in patient pathway	Select the category that best describes the point in the diagnosis pathway at which your samples were collected.	
Consent restriction: • Genetic analysis restriction • Human genetic analysis restriction • Scope of use restriction • Export restriction • Disease area restriction • Project specific restriction • Commercial restriction associated data	Please indicate any areas of research for which you do not have consent.	
Associated data	See table ADD ASSOCIATED DATA TO COLLECTION AND CAPABILITY on page 18	

ADD SAMPLE SET	ADDITIONAL INFORMATION	EXAMPLE
Sex: • Male • Female • Unknown • Both sexes • Undifferentiated	Choose gender category based on the options provided.	Both sexes
Age range: • Fetus • Neonate • Infant • Young child • Child • Adolescent • Young adult • Adult • Data not recorded	Select the age category that best reflects the sample set.	Young adult (18-40 years)
Number of donors	Use the slide bar to select the approximative range of the number of donors in the sample set.	1001-3000

ADD MATERIAL PRESENTATION DETAILS	ADDITIONAL INFORMATION	EXAMPLE
Material type	Divide your sample set into the different types of material you have sampled. If you think a material type, is missing please contact us.	Serum -35°C to -18°C
Storage temperature	Choose appropriate temperature category based on the options provided.	
Microscopic assessment • Affected • Non-affected • Not applicable	If samples were examined by a pathologist, indicate if the sample type contains (affected) or does not contain (non-affected) the disease referenced in this collection. If the sample was not examined by a pathologist, select "Not applicable".	

ADD CAPABILITY	ADDITIONAL INFORMATION	EXAMPLE
Disease status	We are seeking to harmonize the terms used to describe diseases and have adopted 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, please contact us. If you are collecting from healthy volunteers, use the term 'Fit and Well'.	Tuberculosis
Protocols • Bespoke consent form • Bespoke SOP	Select these if you can offer custom-made SOPs and consent procedures.	
Annual donor expectation	Provide an estimate of the number of patients from whom you collected samples and data in a year.	120
Associated data	See table ADD ASSOCIATED DATA TO COLLECTION AND CAPABILITY on page 18	

ADD ASSOCIATED DATA TO COLLECTION AND CAPABILITY	DESCRIPTION
These fields will permit you to show what data you have and how long it would take you to provide it. Provision times are: immediate, 0 to 3 months, 3 to 6 months, or more than 6 months. If you are unable to provide any of the data listed here, do not tick anything.	
Quality data:	
• Freezer temperature logs	• If you keep records of freezer temperatures over time.
• Quality indicators	• If you keep any records that would indicate the quality of the sample or if a QMS system is followed, tick this field. It could, for example, be following an ISO protocol or checking a random sample for yield.
Research data:	
• 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.
Annotation data:	• Data obtained from accessing clinical records.
• Clinical records	• Data recorded about a patient after the sample was taken.
• Follow up records	• Data recorded about the lines of family descent.
• Genealogical records	• Access to images or data recorded from images.
• Imaging data	• Data obtained from national registries such as NCRAS.
• National registries	• Data obtained from pathology records.
• Pre-analytical data	• Assay results.
• Physiological/biochemical measurements	• Data obtained from accessing primary care records.
• Primary care records	• Results from any surveys the participants were involved in
• Survey data	• Data obtained from accessing treatment records.
• Psychological data	• Data obtained from accessing psychological records.
• Participant ethnicity	• Ethnicity of the participant.
• Microbiological results	• Microbiological indicators associated to the samples.