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

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**VIRTUAL BIOBANK DIRECTORY INFRASTRUCTURE:**

VBD (virtual biobank directory) - open to partners

Samples and data

dx developer, end user
CREATE AN ACCOUNT

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

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

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.

**Edit Biobank details**

- Name *
- Description *
- URL
- Contact email *
- Contact phone number
- Logo
  - *No Logo*

**Address Details**

- Address *
- City *
- Country *
- Postcode *
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. Add collection

- Disease status
- Title
- Description
- Year started

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

Collection type
- Disease specific
- Case-control
- Cohort
- Cross-sectional
- Longitudinal
- Population-based
- Quality control
- Clinical Trial

Collection status
- Not-started
- In progress
- Completed

Collection point
- Pre-diagnosis
- During diagnosis
- Post-diagnosis
- Multiple points in patient pathway
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

<table>
<thead>
<tr>
<th>Data type</th>
<th>Provision time (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality Data</td>
<td></td>
</tr>
<tr>
<td>- Freezer temperature logs</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Quality indicators</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>Research Data</td>
<td></td>
</tr>
<tr>
<td>- Biomarker datasets</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Genomic datasets</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>Annotation Data</td>
<td></td>
</tr>
<tr>
<td>- Clinical records</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Followup records</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Genealogical records</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Imaging data</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- National registries</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Pre-analytical data</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Physiological/biochemical measurements</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Primary care records</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Survey data</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Treatment records</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Psychological data</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Participant Ethnicity</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
<tr>
<td>- Microbiological results</td>
<td>Immediate, 0-3, 3-6, &gt;6</td>
</tr>
</tbody>
</table>
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).
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 it is not there please get in touch.

- Serum
- Bronchoalveolar lavage
- Breast milk
- Buffy coat
- Cells from non-blood specimen type (viable)
- Cord blood
- Disrupted tissue (non-viable)
- Nasal washing
- Isolated peripheral blood mononuclear cells (viable)
- Plasma (single spun)
- Red Blood Cells
- Semen
- Sputum
- Swab medium
- Urine (first morning)
- Isolated pathogens (Derivative)
- Host cDNA (Derivative)
- Pathogen DNA (Derivative)
- Pathogen protein extracts (Derivative)
- Amniotic fluid
- Blood (whole)
- Buccal cells
- Cells from non-blood specimen type (non-viable)
- Cells from fine needle aspirate
- Cerebrospinal fluid
- Dried whole blood
- Isolated peripheral blood mononuclear cells (non-viable)
- Nails
- Placenta
- Plasma (double spun)
- Saliva
- Solid tissue (non viable)
- Stool
- Urine (random)
- Other
- Host genomic DNA (Derivative)
- Host scRNA (Derivative)
- Pathogen RNA (Derivative)
- Cell lines (Derivative)

Storage Temperature *
- Select how the samples are currently stored. If there is something missing please contact us.

- RT
- -35°C to -18°C
- -85°C to -60°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
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.

1. Fill the requested information at the Add capability step.

2. Add capability

<table>
<thead>
<tr>
<th>Disease status</th>
<th>Protocols</th>
<th>Associated data</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Bespoke consent form</td>
<td>□ Bespoke SOP</td>
</tr>
<tr>
<td></td>
<td>□ Bespoke SOP</td>
<td>e.g. 120</td>
</tr>
</tbody>
</table>

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  

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<table>
<thead>
<tr>
<th>Annotation Data</th>
<th>Action 1</th>
<th>Action 2</th>
<th>Action 3</th>
<th>Action 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical records</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Followup records</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Genealogical records</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Imaging data</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>National registries</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Pre-analytical data</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Physiological/biochemical measurements</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Primary care records</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Survey data</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Treatment records</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Psychological data</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Participant Ethnicity</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
<tr>
<td>Microbiological results</td>
<td>Immediate</td>
<td>0-3</td>
<td>3-6</td>
<td>&gt;6</td>
</tr>
</tbody>
</table>
REFERENCE GUIDE TO:
FIELD DESCRIPTIONS
<table>
<thead>
<tr>
<th><strong>BIOBANK DETAIL</strong></th>
<th><strong>ADDITIONAL INFORMATION</strong></th>
<th><strong>EXAMPLE</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Name</strong></td>
<td>What is the name of the resource you are registering? It is up to you to present your biobank the way you want.</td>
<td>Tuberculosis biobank</td>
</tr>
<tr>
<td><strong>Description</strong></td>
<td>Use this for general information that is not captured in other fields. You can use as much space as needed.</td>
<td>A collection of human bodily fluids form Tuberculosis positive patients.</td>
</tr>
<tr>
<td><strong>URL</strong></td>
<td>If your biobank has a website or page you can include it here.</td>
<td><a href="http://www.biobanktb.com">www.biobanktb.com</a></td>
</tr>
<tr>
<td><strong>Contact email</strong></td>
<td>The email address that people will use to contact you.</td>
<td><a href="mailto:contact@biobanktb.com">contact@biobanktb.com</a></td>
</tr>
<tr>
<td><strong>Contact phone number</strong></td>
<td>The phone number that people will use to contact you.</td>
<td>Tel: country code, city code, number</td>
</tr>
<tr>
<td><strong>Logo</strong></td>
<td>If your biobank has a logo you can put it here and it will be displayed on the FIND VBD website.</td>
<td></td>
</tr>
<tr>
<td><strong>Address</strong></td>
<td>Use the address where access to the samples is based rather than where they are stored.</td>
<td>9 Chemin des Mines, 1202, Geneva, Switzerland</td>
</tr>
<tr>
<td><strong>Institution</strong></td>
<td>The organization where your governance is managed.</td>
<td>Foundation of Innovative New Diagnostics (FIND)</td>
</tr>
<tr>
<td><strong>Ethics Committee Approval</strong></td>
<td>Check if your collections are approved by an Ethics Committee (i.e. IRB)</td>
<td></td>
</tr>
<tr>
<td><strong>Services</strong></td>
<td>Does your biobank offer any extra services? If so indicate that here.</td>
<td></td>
</tr>
<tr>
<td>• Infectious strain isolation</td>
<td>Check if your collections are approved by an Ethics Committee (i.e. IRB)</td>
<td></td>
</tr>
<tr>
<td>• Ability to recontact</td>
<td>Does your biobank offer any extra services? If so indicate that here.</td>
<td></td>
</tr>
<tr>
<td>• Access to the full pathology archive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Cell culture</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Data analytics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Digital imaging</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Molecular extractions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Immunohistochemistry - scoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Immunohistochemistry - staining</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Nucleic acid extraction</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Reasons for registering</strong></td>
<td>Select the reasons for registering your sample resource with the directory. You may select multiple reasons.</td>
<td></td>
</tr>
<tr>
<td>• Conditions for local ethics approval</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Condition for funding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Requirement set by host institution</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Desire to make sample collections visible</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Desire to make collection service visible</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>If there is any other useful information you would like to communicate you can put it here.</td>
<td></td>
</tr>
</tbody>
</table>

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### ADD COLLECTION

**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

**Collection point:**
- Pre-diagnosis
- Post-diagnosis
- During diagnosis
- Multiple points in patient pathway

**Collection type:**
- Disease-specific
- Case-control
- Cohort
- Cross-sectional
- Longitudinal
- Population-based
- Quality control
- Clinical trial

**Collection status:**
- Not started
- In progress
- Completed

**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

**Associated data**
See table [ADD ASSOCIATED DATA TO COLLECTION AND CAPABILITY on page 18](#)
### ADD SAMPLE SET

**Sex:**
- Male
- Female
- Unknown
- Both sexes
- Undifferentiated

**Age range:**
- Fetus
- Neonate
- Infant
- Young child
- Child
- Adolescent
- Young adult
- Adult
- Data not recorded

**Number of donors**
Use the slide bar to select the approximative range of the number of donors in the sample set.

### ADD MATERIAL PRESENTATION DETAILS

**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.

**Storage temperature**
Choose appropriate temperature category based on the options provided.

### ADD CAPABILITY

**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'.

**Protocols**
- Bespoke consent form
- Bespoke SOP

**Annual donor expectation**
Provide an estimate of the number of patients from whom you collected samples and data in a year.

### ADDITIONAL INFORMATION

**EXAMPLE**

- **Sex:** Both sexes
- **Age range:** Young adult (18-40 years)
- **Number of donors:** 1001-3000
- **Material type:** Serum
- **Storage temperature:** -35°C to -18°C
- **Disease status:** Tuberculosis

**Associated data**
See table ADD ASSOCIATED DATA TO COLLECTION AND CAPABILITY on page 18
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.

<table>
<thead>
<tr>
<th>Quality data:</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Freezer temperature logs</td>
<td>• If you keep records of freezer temperatures over time.</td>
</tr>
<tr>
<td>• Quality indicators</td>
<td>• 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.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Research data:</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Biomarker datasets</td>
<td>• Results of an assay of anything that can be used as an indicator of a particular disease state or some other physiological state.</td>
</tr>
<tr>
<td>• Genomic datasets</td>
<td>• Results of any genome analysis.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Annotation data:</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Clinical records</td>
<td>• Data obtained from accessing clinical records.</td>
</tr>
<tr>
<td>• Follow up records</td>
<td>• Data recorded about a patient after the sample was taken.</td>
</tr>
<tr>
<td>• Genealogical records</td>
<td>• Data recorded about the lines of family descent.</td>
</tr>
<tr>
<td>• Imaging data</td>
<td>• Access to images or data recorded from images.</td>
</tr>
<tr>
<td>• National registries</td>
<td>• Data obtained from national registries such as NCRAS.</td>
</tr>
<tr>
<td>• Pre-analytical data</td>
<td>• Data obtained from pathology records.</td>
</tr>
<tr>
<td>• Physiological/biochemical measurements</td>
<td>• Assay results.</td>
</tr>
<tr>
<td>• Primary care records</td>
<td>• Results from any surveys the participants were involved in</td>
</tr>
<tr>
<td>• Survey data</td>
<td>• Data obtained from accessing treatment records.</td>
</tr>
<tr>
<td>• Psychological data</td>
<td>• Data obtained from accessing psychological records.</td>
</tr>
<tr>
<td>• Participant ethnicity</td>
<td>• Ethnicity of the participant.</td>
</tr>
<tr>
<td>• Microbiological results</td>
<td>• Microbiological indicators associated to the samples.</td>
</tr>
</tbody>
</table>