



**umcg**

# BBMRI-NL: Biobanks & Registers in The Netherlands

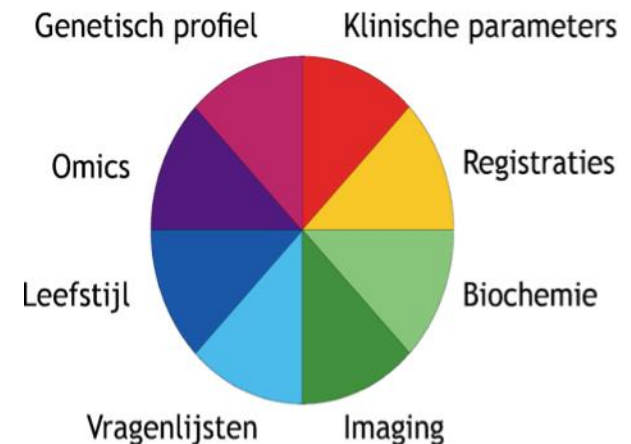
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- Biobanks:
  - BBMRI
  - Palga
  - Parelsnoer
- Quality of care:
  - DICA
- Diseases:
  - IKNL (Cancer)
  - RIVM (Population screenings)
  - GGD (Infectious diseases)
  - Many other disease specific registers and biobanks



More than 200 biobanks...



...with diverse data.

- Current developments:
  - Registration at the source
  - Nationwide electronic patient record
  - Centralisation of biobank facilities
    - Including a catalogue
  - Standardisation for TTP (NEN)
  - Data stewardship
  - Infrastructure



- 200 'Biobanks', e.g.: Palga (11M), RIVM (900k), LifeLines (165k)
- Several rainbow projects to improve sharing of data and use of samples:
  - National catalogue since 2012
  - RP 5: [A national infrastructure for linkage of biobanks to medical and socioeconomic registries: an integrative approach, Dr O.H. Klungel, Prof dr J.H. Smit](#)
  - RP 8: [Dutch National Tissue Portal \(DNTP\), Prof G.A. Meijer, Dr F. van Kemenade, Dr L. Overbeek](#)
  - RP11: [Catalogue 2.0, Dr Morris Swertz](#)

- BBMRI-NL 2.0 grant approved end 2014
  - Joining together CTMM TraIT and BBMRI-NL
- NWO National Roadmap grant
  - Workstream 1: Visibility and public access
  - Workstream 2: Productivity and controlled access
  - Workstream 3: Outreach and sustainability



## Catalogue of Dutch biobanks

*Biobanking and Biomolecular Research Infrastructure*

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Welcome

Welcome

Login

Help

Contact

### Welcome to the Catalogue of Dutch biobanks

This catalogue provides a systematic database of collections of biomaterial and associated data subsumed under the umbrella of BBMRI-NL. BBMRI-NL is designed to provide infrastructure for biomedical studies. Over 170 major clinical and population biobanks in the Netherlands (size 500 subjects or more) are associated with BBMRI-NL.

Material and data of biobanks associated with BBMRI-NL are available for biomedical research in the public domain. Access conditions for scientific cooperation are subject to legal and ethical constraints, which may vary between biobanks. BBMRI-NL aims to harmonize and enrich these biobanks in order to stimulate cooperative studies.

To apply for inclusion of your biobank in this catalogue, please [contact the BBMRI-NL office](#).

To find your way around the application, you might want to check out the [User manual](#).

If you have any questions or remarks, please do not hesitate to [contact us](#).

*This database was generated using the open source [MOLGENIS database generator](#) version 4.0.0-testing.*

*Please cite [Swertz et al \(2010\)](#) or [Swertz & Jansen \(2007\)](#) on use.*

# Catalogue - Dutch National Tissue Portal (Palga)

The screenshot shows the PALGA Openbare Databank website. The browser address bar displays 'palgaopenbare databank.nl'. The page header includes the PALGA logo, a search bar with the text 'Zoekvraag PALGA Openbare Databank', a 'Feedback' link, and a 'Sign in' button.

## PALGA Openbare Databank

**Toegepaste filters**

Wijzig zoekvraag

**Sorteren op** Materiaal x Geslacht

	Man	Vrouw	Aantal excerpten
Cytologie	2469930	3235348	5705278
Histologie	10882737	15066241	25948978
Aantal excerpten	13352667	18301589	31654256

# Catalogue - Trait Study catalogue

The screenshot shows a web browser window with the URL `catalogue-acc.ctmm-trait.nl`. The page title is "MOLGENIS". The navigation menu includes "News", "Datasets", "About", "Entities", "Admin", and "Account", with a "Sign out" link on the right. The main content area is titled "Example Example study".

On the left side, there is a search bar labeled "Search data values" and a "Wizard" button. Below these are two sections: "Data item filters" and "Data item selection".

The "Data item filters" section shows two active filters: "Specimen type (code): ('DNA') ✕" and "Age: (from 35 to 50) ✕".

The "Data item selection" section shows a tree view with three items: "collection\_protocol", "participant\_protocol", and "sample\_protocol".

The main data table is titled "Data" and "Aggregates". It has the following columns: Gender, Diagnosis (code), Specimen type (code), Anatomic source (code), Preservation (code), Age, Unit, Count, and Storage. The table contains 20 rows of data.

Gender	Diagnosis (code)	Specimen type (code)	Anatomic source (code)	Preservation (code)	Age	Unit	Count	Storage
Female	Rectal Carcinoma, Metastatic	DNA	Rectum	Buffered, Frozen Specimen	44	year	1	tube
Female	Healthy Control, Tissue	DNA	Rectum	Buffered, Frozen Specimen	44	year	1	tube
Male	Rectal Carcinoma, Metastatic	DNA	Rectum	Buffered, Frozen Specimen	47	year	1	tube
Male	Healthy Control, Tissue	DNA	Rectum	Buffered, Frozen Specimen	47	year	1	tube
Female	Colon Carcinoma, Metastatic	DNA	Colon	Buffered, Frozen Specimen	37	year	1	tube
Male	Rectal Carcinoma, Metastatic	DNA	Rectum	Buffered, Frozen Specimen	48	year	1	tube
Male	Healthy Control, Tissue	DNA	Rectum	Buffered, Frozen Specimen	48	year	1	tube
Male	Colon Carcinoma, Metastatic	DNA	Colon	Buffered, Frozen Specimen	45	year	1	tube
Male	Healthy Control, Tissue	DNA	Colon	Buffered, Frozen Specimen	45	year	1	tube
Female	Healthy Control, Tissue	DNA	Rectum	Buffered, Frozen Specimen	49	year	1	tube
Male	Rectal Carcinoma, Metastatic	DNA	Rectum	Buffered, Frozen Specimen	36	year	1	tube
Male	Rectal Carcinoma, Metastasis	DNA	Liver	Buffered, Frozen Specimen	36	year	1	tube
Male	Rectal Carcinoma, Metastasis	DNA	Lung	Buffered, Frozen Specimen	36	year	1	tube
Male	Healthy Control, Tissue	DNA	Rectum	Buffered, Frozen Specimen	36	year	1	tube
Male	Colon Carcinoma, Metastatic	DNA	Colon	Buffered, Frozen Specimen	49	year	1	tube
Male	Colon Carcinoma, Metastasis	DNA	Liver	Buffered, Frozen Specimen	49	year	1	tube
Male	Healthy Control, Tissue	DNA	Colon	Buffered, Frozen Specimen	49	year	1	tube
Male	Rectal Carcinoma, Metastatic	DNA	Rectum	Buffered, Frozen Specimen	50	year	1	tube
Male	Healthy Control, Tissue	DNA	Rectum	Buffered, Frozen Specimen	50	year	1	tube



# Catalogue - Radboud Biobank

The screenshot shows a web browser window with the URL [radboudbiobank.nl](http://radboudbiobank.nl). The page title is "Radboud Biobank catalogus".

**Navigation and Contact Links:**

- [Catalogus](#)
- [Materiaal opvragen](#)
- [Ondergebrachte collecties](#)
- [Aanmelden nieuwsbrief](#)
- [Aansluiten bij de Radboud Biobank](#)
- [Email: info.rbb.labgk@umcn.nl](mailto:info.rbb.labgk@umcn.nl)
- [Catalogus](#)
- [Tel. \(024\) 366 89 77](tel:(024)3668977)
- [Links](#)

**Page Content:**

Collecties / Catalogus

### Catalogus

Via de catalogus van de Radboud Biobank kunt u zoeken in onze collectie biomaterialen. Op basis van een klinische zoekterm (bijv. "diabetes", "hypospadie", "gezond") kunt u opvragen welke soort en aantallen biomaterialen beschikbaar zijn voor een bepaalde diagnose. Van de resulterende set biomaterialen ziet u wat de verdeling qua leeftijd en geslacht is en kunt u details over de bijbehorende klinische data inzien. Daarnaast is er informatie beschikbaar over de verschillende biobanken, zoals de start datum, contactinformatie en een korte beschrijving van het aandachtsgebied. Als u interesse heeft in de biomaterialen van een bepaalde biobank, dan kunt u de genoemde contactpersoon benaderen.

Heeft u vragen over het gebruik van de catalogus, neem dan contact op met [Remco.denOuden@radboudumc.nl](mailto:Remco.denOuden@radboudumc.nl).

**Resultaat voor zoeken naar "diabetes"**

401 participanten uit de deelbiobank [Parelsnoer Diabetes](#), met diagnoses:

- diabetes mellitus

**waarvan:**  
Algemeen

- 164 vrouwen, 237 mannen, 0 onbekend of anders
- Geboortjaar tussen 1924 en 1980
- Laatste inclusiedatum: 23-02-2012

# Catalogue - LifeLines

The screenshot shows a web browser window with the URL `molgenis18.target.rug.nl`. The page title is "LifeLines" and the breadcrumb is "Catalog". A "Sign in" button is in the top right. A blue banner at the top says "Info! You need to sign in to order catalog items".

The main content is divided into two panels:

- Browse variables:** A search bar with a magnifying glass icon and a close button. Below it is a tree view of the catalog structure. The "Participant" folder is expanded, and the "Sex" variable is selected.
- Variable description:** A panel showing details for the selected variable.

**Variable description details:**

- Name:** Sex
- Identifier:** Lifelines.PATIENT.GESLACHT.6.1.1
- Description (en):** Sex
- Description (nl):** Geslacht
- Data type:** categorical

**Code table:**

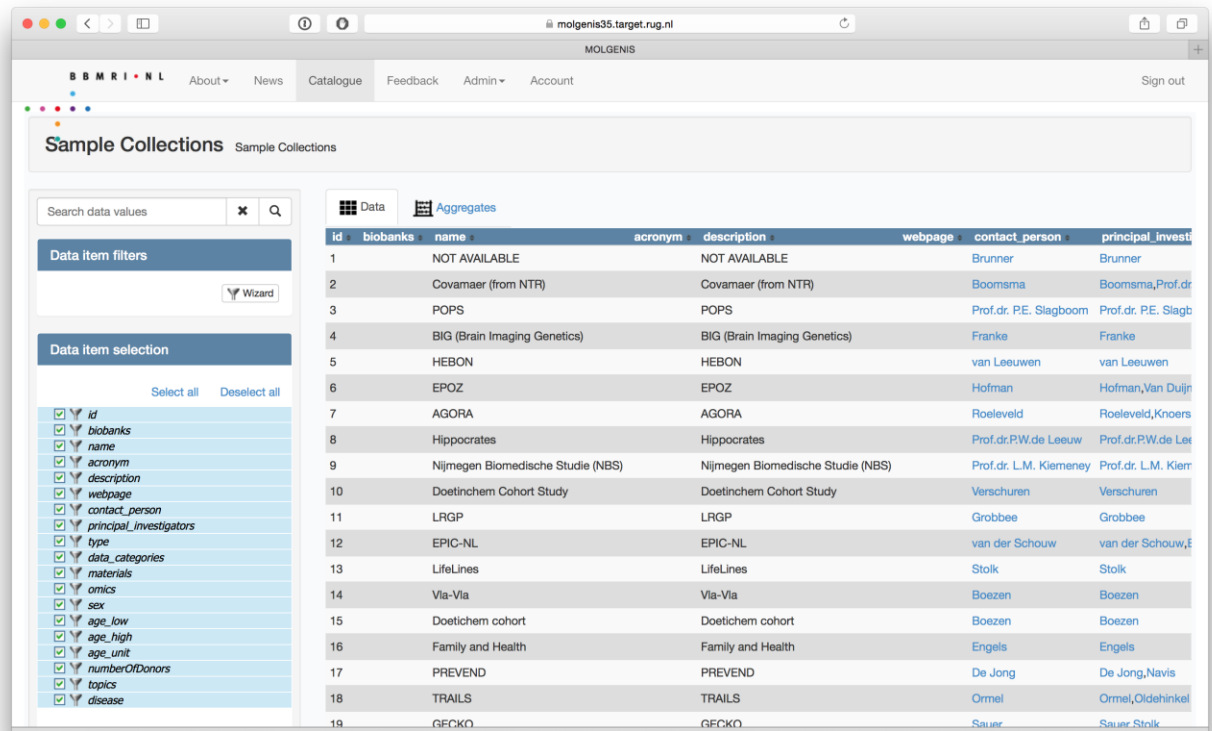
Code	Label	Description
1	Male	
2	Female	

## Challenges maintaining catalogues

- Make it a useful resource for researchers, biobanks & policy makers
- Keeping it up to date
- The right amount of information
  - Useful for researchers
  - Protecting the privacy of donors
  - Protecting the rights of the biobank
- Merging the different efforts.
  - Coarse information at the national level
  - More detailed information in local catalogue

# Catalogue 2.0

- Based on MIABIS Biobanks, Sample Collections and OMICS modules
- Aggregated data
- Open resource
- Automated import from local biobank catalogues



The screenshot displays the MolGenis Sample Collections interface. The page title is "Sample Collections" and the URL is "molgenis35.target.rug.nl". The interface includes a search bar, a "Data item filters" section with a "Wizard" button, and a "Data item selection" section with a list of checkboxes for various data fields. The main content is a table of sample collections.

id	biobanks	name	acronym	description	webpage	contact_person	principal_invest
1		NOT AVAILABLE		NOT AVAILABLE		Brunner	Brunner
2		Covamaer (from NTR)		Covamaer (from NTR)		Boomsma	Boomsma,Prof.dr
3		POPS		POPS		Prof.dr. P.E. Slagboom	Prof.dr. P.E. Slagb
4		BIG (Brain Imaging Genetics)		BIG (Brain Imaging Genetics)		Franke	Franke
5		HEBON		HEBON		van Leeuwen	van Leeuwen
6		EPOZ		EPOZ		Hofman	Hofman, Van Duijn
7		AGORA		AGORA		Roeleveld	Roeleveld,Knoers
8		Hippocrates		Hippocrates		Prof.dr.P.W.de Leeuw	Prof.dr.P.W.de Lee
9		Nijmegen Biomedische Studie (NBS)		Nijmegen Biomedische Studie (NBS)		Prof.dr. L.M. Kiemeny	Prof.dr. L.M. Kierr
10		Doetinchem Cohort Study		Doetinchem Cohort Study		Verschuren	Verschuren
11		LRGP		LRGP		Grobbee	Grobbee
12		EPIC-NL		EPIC-NL		van der Schouw	van der Schouw,E
13		LifeLines		LifeLines		Stolk	Stolk
14		Via-Via		Via-Via		Boezen	Boezen
15		Doetichem cohort		Doetichem cohort		Boezen	Boezen
16		Family and Health		Family and Health		Engels	Engels
17		PREVEND		PREVEND		De Jong	De Jong,Navis
18		TRAILS		TRAILS		Ormel	Ormel,Oidehinkel
19		GECKO		GECKO		Sauer	Sauer,Stolk

- Based on MOLGENIS
  - For biologists MOLGENIS is a suite of web databases for genotype, phenotype, QTL and analysis pipelines.
  - For bioinformaticians MOLGENIS is software generator to rapidly build web databases that make researchers happy.



The image displays a grid of 12 blue panels, each representing a different feature of the MOLGENIS software suite. The panels are arranged in a 4x3 grid. In the center of the grid is a 3D rendering of a white humanoid figure standing in front of a desk with multiple computer monitors displaying various data visualizations. The MOLGENIS logo is positioned above this central image.

Feature	Description
<b>Catalogue</b>	Find data item and sample collections
<b>Data</b>	Filter and download for further analysis
<b>Compute</b>	Run analysis workflows on big data compute infrastructure
<b>GWAS</b>	Explore summary level GWAS data
<b>Harmonisation</b>	Ontologies, standards, tools
<b>Pipelines</b>	Next-Generation Sequencing
<b>Share</b>	Friends, Groups and Permission management
<b>Mutation</b>	Explore genetic mutations and patho-genicity effects
<b>Organization</b>	Institutes, Departments, People, Locations & Containers
<b>Analyse</b>	Multi-omics association & visualization tools
<b>Integration</b>	Personalized and stratified medicine markers
<b>Imaging</b>	File storage and analysis for images and data

- Domain experts from major projects and large biobanks:
  - Parelsnoer
  - CTMM TraIT
  - Palga
  - LifeLines
  - Radboudumc Biobank
- Meet several times per year to discuss topics like:
  - Current developments
  - Standardisation
  - TTP

# Sample request workflow

The screenshot shows a web browser window displaying the 'Biosample Request Portal - New Request' form. The browser address bar shows 'workflow-acc.ctmm-trait.nl'. The page header includes a welcome message for 'David van Enkevort', a 'Sign Out' link, and a dropdown menu for 'Organizations' currently set to 'Biobank Sample'. The main form area has an orange header with the 'trait' logo and the title 'Biosample Request Portal - New Request'. Below the header, there are input fields for 'Request Description \*', 'Delivery address:', 'Telephone:', and 'Email:'. A table with three columns is visible: 'Description Sample', 'Biobank', and 'Number samples'. At the bottom of the form, there are three buttons: 'Submit', 'Cancel', and 'Show ID List Attachments'. The browser's taskbar at the bottom shows two open windows for 'Biosample Request Portal' and a 'Done' status.

Welcome David van Enkevort Sign Out Type to launch application Organizations Biobank Sample

Biosample Request Portal - New Request

**Request Description \***

**Delivery address:**

**Telephone:**

**Email:**

Description Sample	Biobank	Number samples

Submit Cancel Show ID List Attachments

Biosample Request Portal Biosample Request Portal Done

## Sample request workflow

- Track and trace samples from the initial request to shipment to the researcher.
- Implemented in TraIT, Parelsnoer
- Under development for Palga, HOVON



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