

BIOBANK REGISTER @ DANISH NATIONAL BIOBANK



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- About me:
 - Employed at the Danish National Biobank since 16.06.2011
 - Architect and developer of the Biobank Register system
 - Ph.D. in Biomedical Informatics (Technical University of Denmark)
 - M.Sc. in Telecommunications and Computer Science (Technical University of Lodz, Poland)
- About Biobank Register:
 - Released online on March 21, 2012
 - Integrates data from various Danish registers and biobanks

Support for epidemiological register-based research

What kind and how many samples I can find in DK for my research project?

Support for clinical hospital biobanks

What kind of samples do we keep in our freezers?



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Registers:

- Centrale personregisteret
- Fødselsregisteret
- Landpatientsregisteret
- Patologiregisteret
- Recept registeret

Challenge!

X

Biobanks:

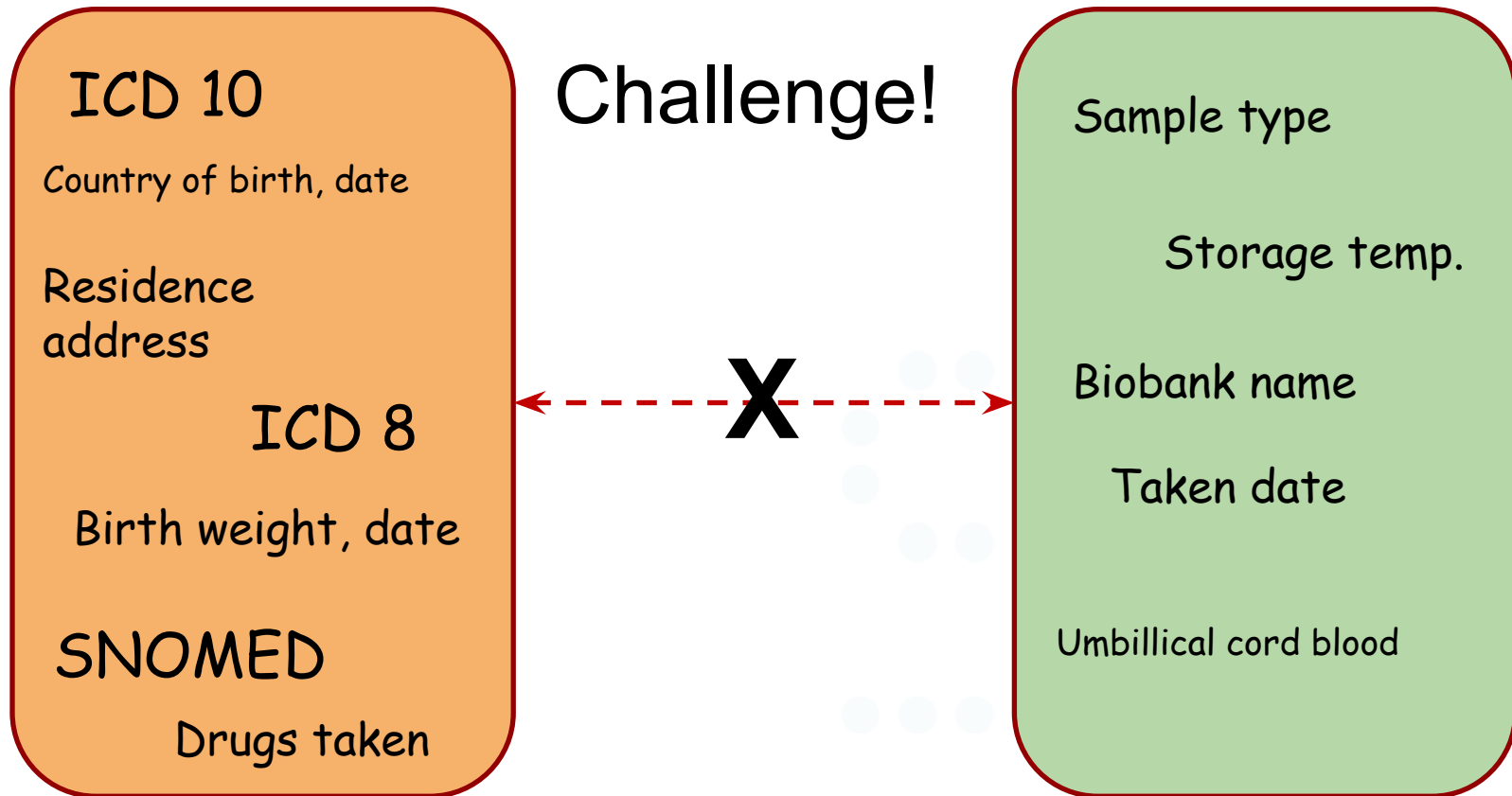
- Danmarks Nationale Biobank
- Kræftens bekæmpelse
- Sygehus biobanker
- Patologi biobanker
- Neonatale Screenings biobank (PKU)
- Andre forskning biobanker
- Andre diagnostisk biobanker

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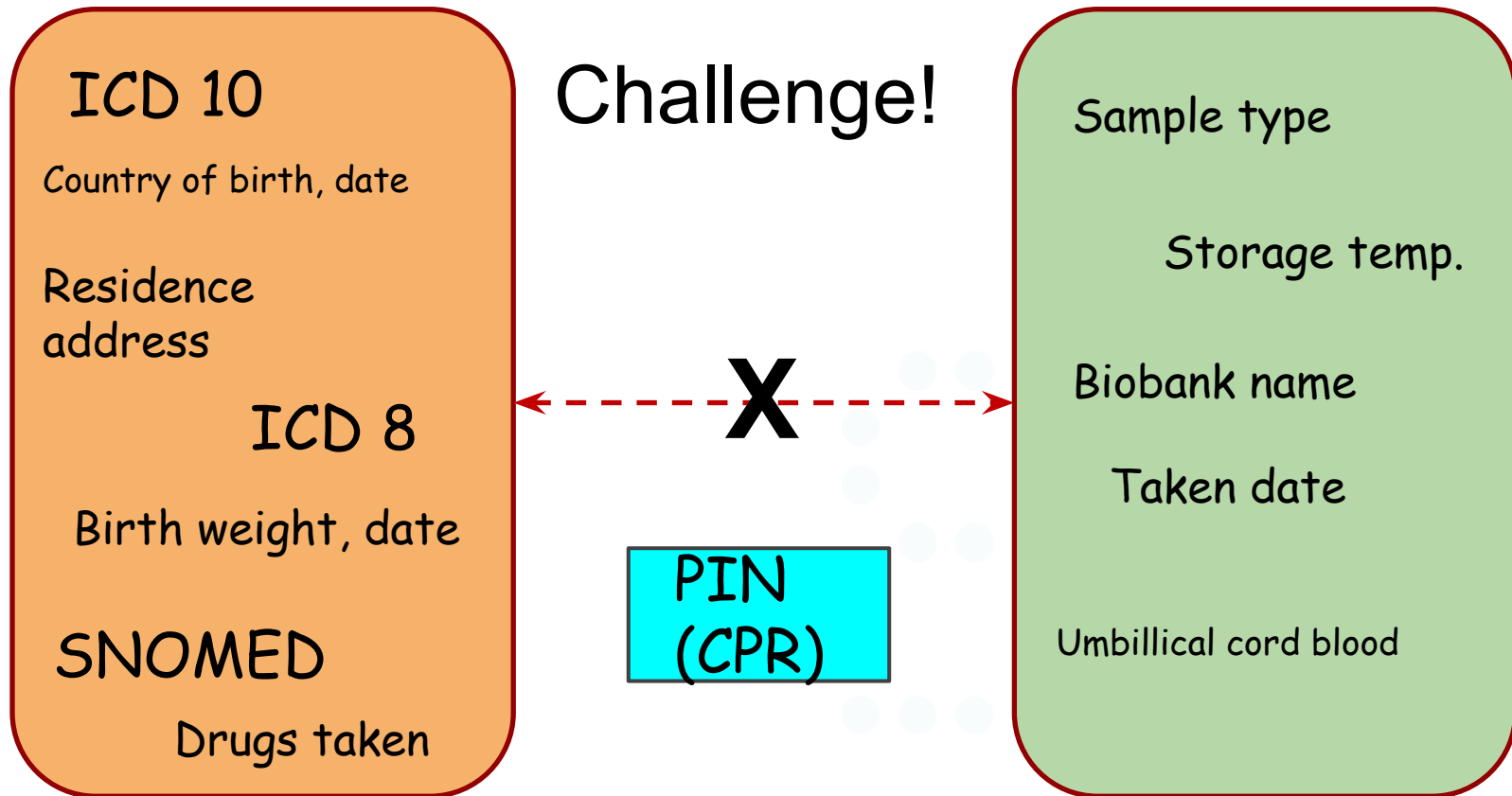


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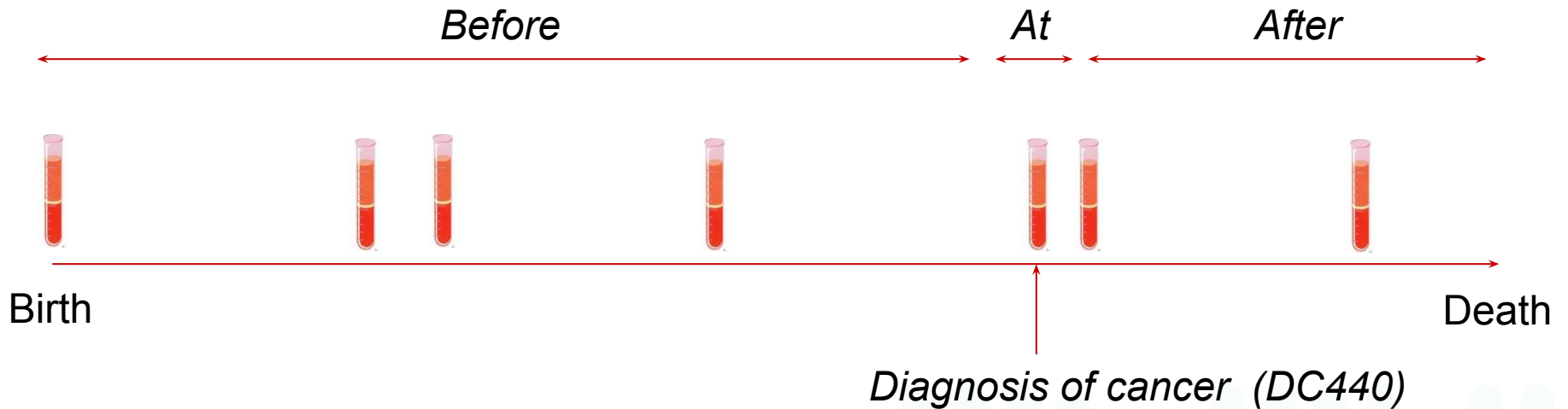
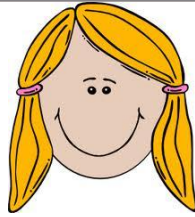
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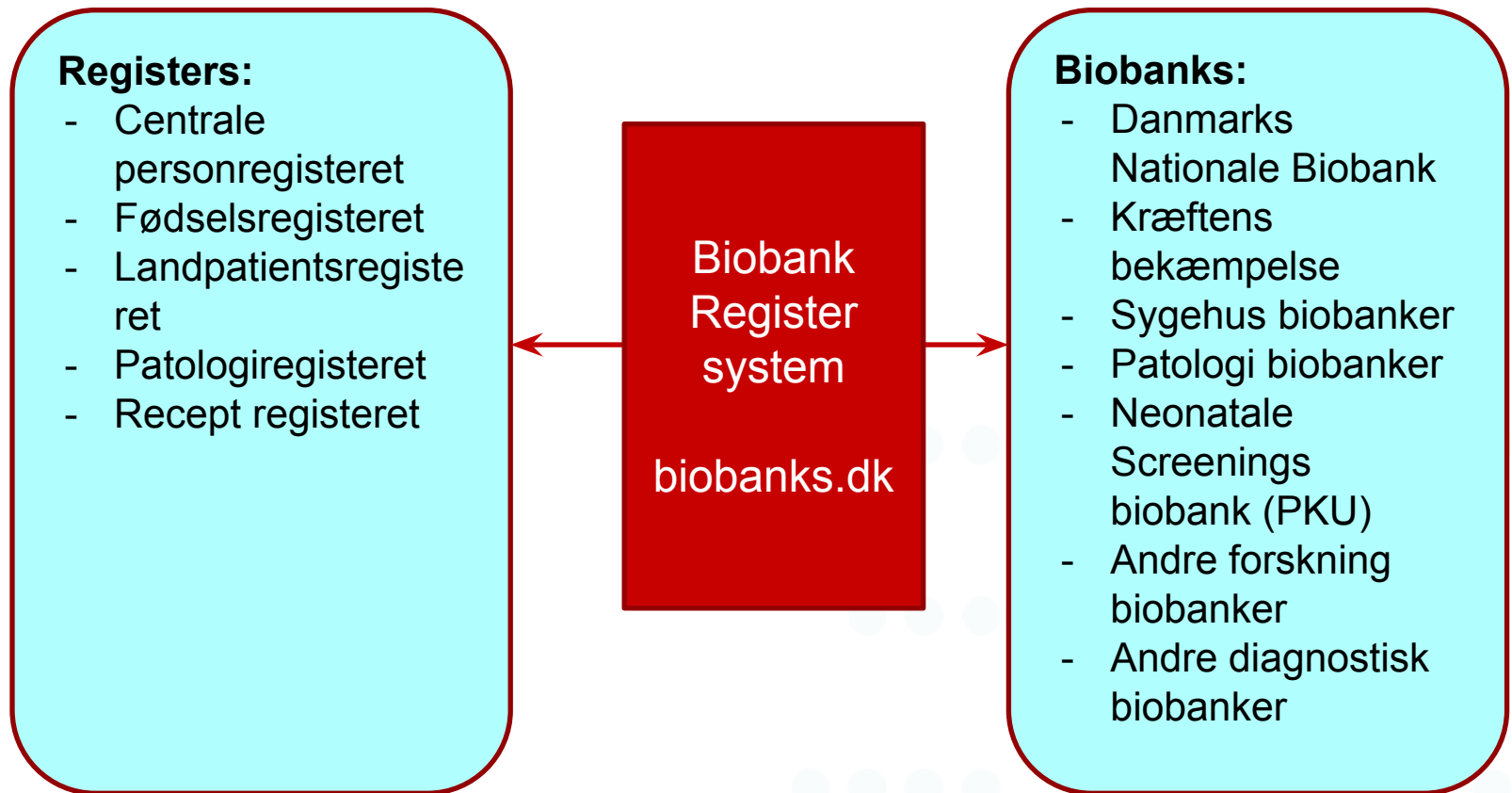


TRACKING OF SAMPLES/DIAGNOSES

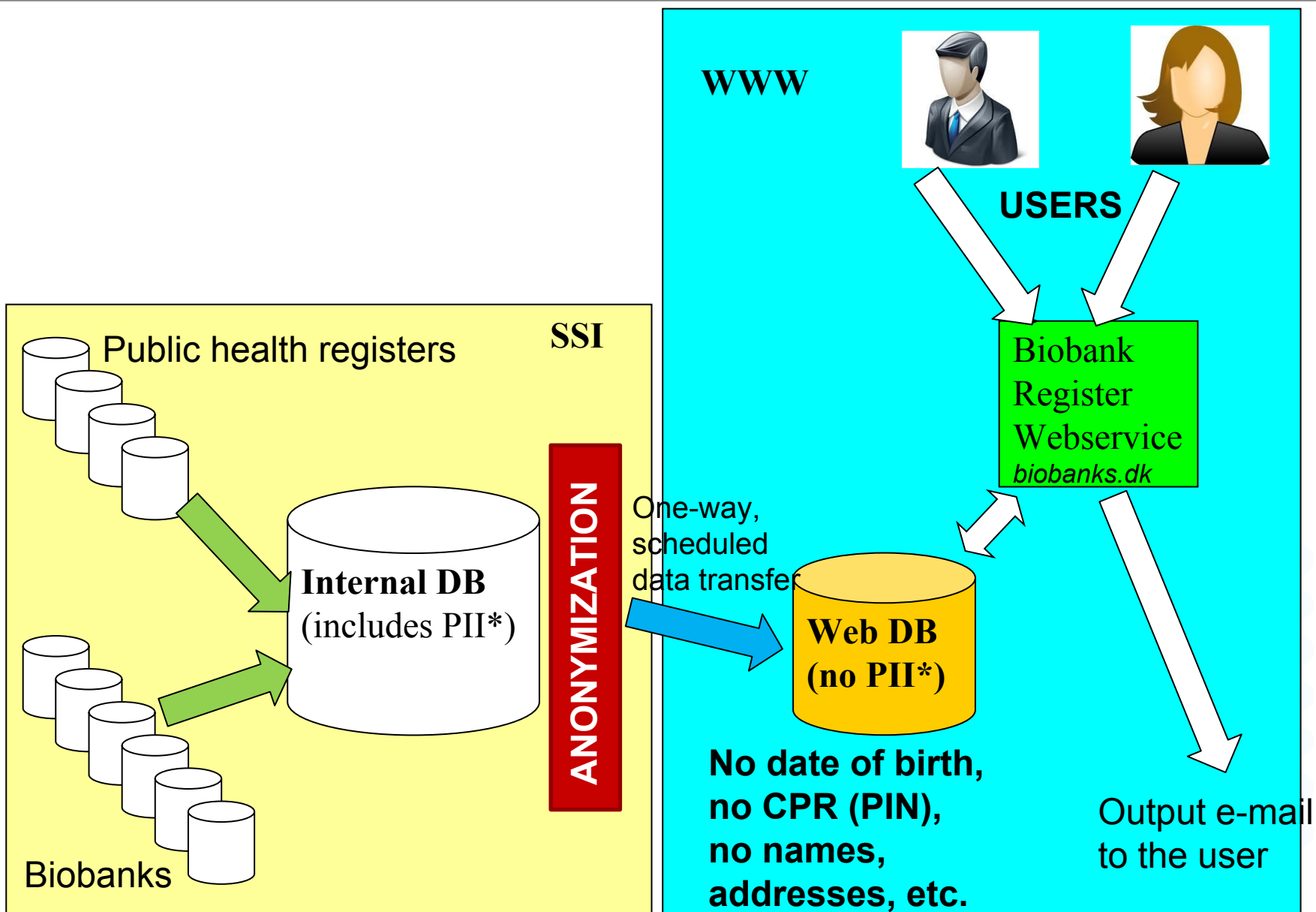
An individual



The Biobank Register system allows to link samples and diagnoses of individuals, and highlight which samples were taken before, at or after a diagnosis.



BIOBANK REGISTER ARCHITECTURE



*PII - Personally Identifiable Information

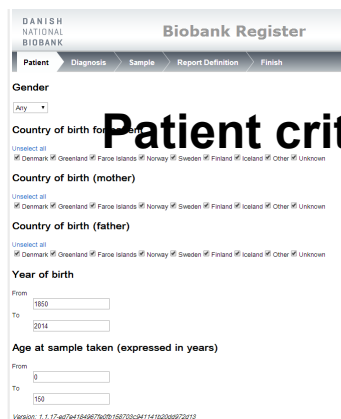


- www.nationalbiobank.dk – main site of the Danish National Biobank
- www.biobanks.dk – direct access to the Biobank Register

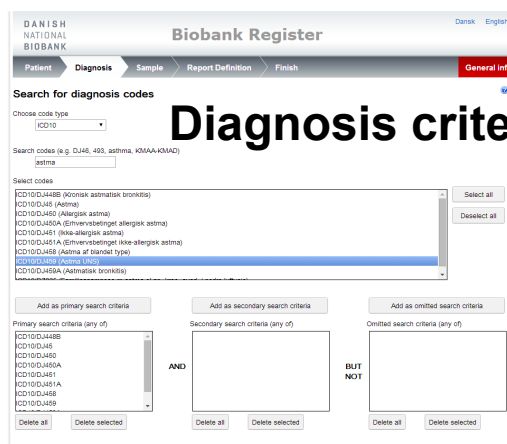


BIOBANK REGISTER ONLINE

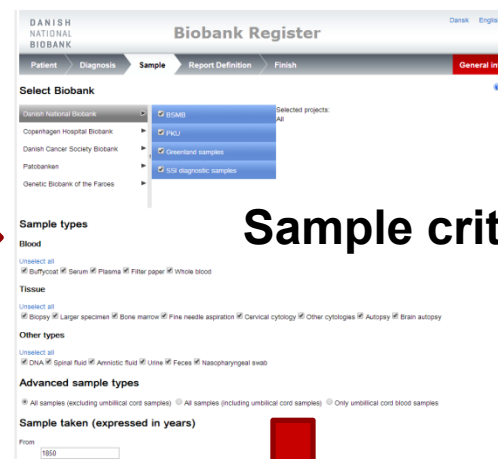
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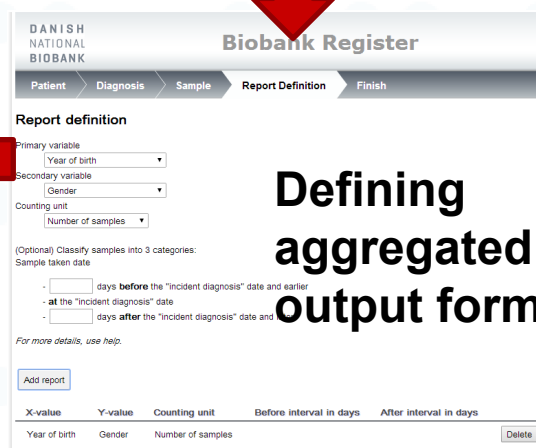
Patient criteria

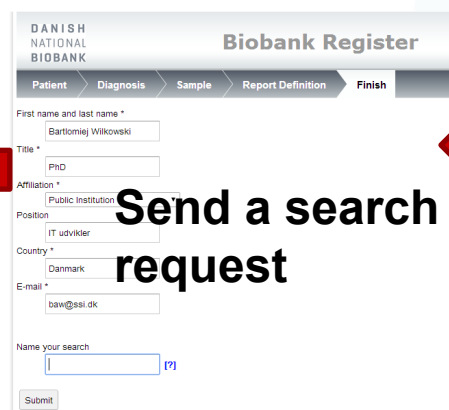
Diagnosis criteria

Sample criteria

Defining aggregated output format

Send a search request



Output tables
Values between 1 and 5 are shown as *

Get email with results

1. [Gender] - [Sample type] - [Number of samples]

	Gender	
	F	M
Autopsy	1304	1121
Biopsy	114781	86971
Bone marrow	4303	4182
Brain autopsy	69	56
Buffyc Coat	472	*
Cervical cytology	70921	7
DNA	1395	946

Biobank: Danish National Biobank-BSMB, Danish National Biobank-PKU, Danish Copenhagen Hospital Biobank-ALL, SAMPLES (Copenhagen Hospital Biobank), Da SAMPLES (Patobanken), Genetic Biobank of the Faeroes, Panic anxiety, Schizophrenia Biobank of the Faeroes, Autism (FO)
Sample types: Buffycoat, Serum, Plasma, Filter paper, Whole blood, Biopsy, Laryng, Autopsy, Brain autopsy, DNA, Spinal fluid, Amniotic fluid, Urine, Feces, Nasal
Advanced sample types: All samples except umbilical cord samples
Sample taken: 1850 to 2014

- An individual's **date of birth** and CPR number (**PIN**)
- Data about the **diagnoses** assigned to an individual during hospitalization (ICD8/ICD10 codes + diagnosis date)
- Data about **pathologies** found and registered by any pathology center (Patobanken) in Denmark (SNOMED codes + pathology date)
- Data about the individual's **biological materials** (blood, tissue, etc.), including sample taken date

Requirements to **build** such a system / **participate** in the system:

- **Data Protection Agency** permission
 - Danish National Biobank -> part of Statens Serum Institut, the owner of all healthcare-related data in Denmark

- How do we recruit new participating biobanks?
 1. direct contact (they contact us, or we contact them)
 2. why should they participate?
 - a. better visibility of their samples to the researchers =
= higher usage of their samples in research =
= fame & funds ↑
 - b. better understanding of the collected materials
(linkage of the existing samples to the donor's historical,
current and future diagnoses)

Input data template:

PIN number

Sample type

Sample taken date

Umbilical (Y/N)



Collection name	# samples / # donors	Sample types
Patobank	12.3 million / 3.4 million	Various paraffin embedded tissue samples
Neonatal Screening Biobank (PKU)	~ 2 million / ~ 2 million	Filter paper;
SSI diagnostic samples	~ 850.000 / ~ 560.000	Plasma; Serum; Filter paper; Whole blood; Amniotic fluid; Spinal fluid; Biopsy; Bone marrow; Cytology; Urine; Feces; Nasopharyngeal swab;
Danish National Birth Cohort (BSMB)	~ 620.000 / ~ 149.000	Buffy coat; Plasma; Filter paper;
Copenhagen Hospital Biobank	~ 195.000 / ~ 192.000	Whole blood
Diet, Cancer and Health Cohort	~ 170.000 / ~ 57.000	DNA; Plasma; Serum
Greenland samples	~ 38.000 / ~ 17.000	Buffy coat; Plasma; Serum; Filter paper; Whole blood; Urine; Feces; Nasopharyngeal swab;

Total: 16.3 million samples
5.1 million donors

155 million diagnoses (ICD-8/ICD-10)
35 million pathologies (SNOMED)

THANK YOU!



register@nationalbiobank.dk

