



THL Biobank's Availability Service utilizes national register data for feasibility studies

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Nordic Biobank Conference 2022

Conflict of interest

No Disclosures.

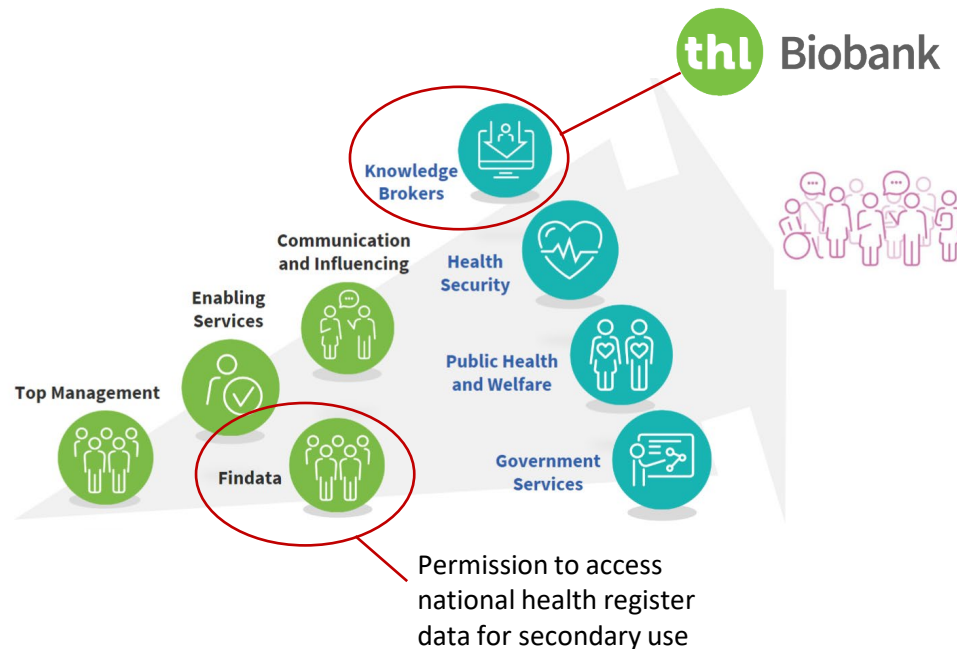
THL Biobank

- Part of the Finnish Institute for Health and Welfare (THL)
- Significant nationwide collections
 - 30 research collections
 - Population based cohorts
 - Disease-specific and other collections
 - 230 000 sample donors
 - Broad consent for future use



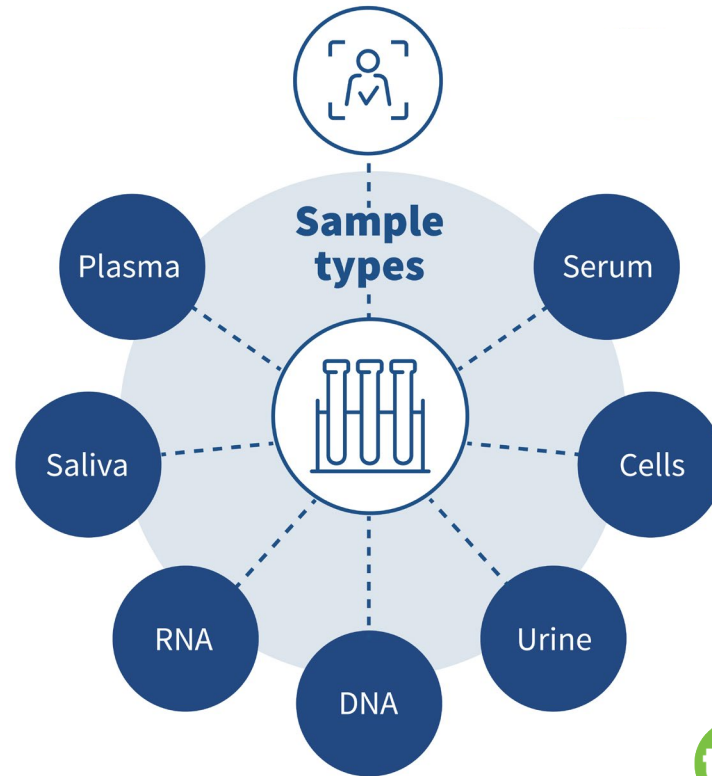
Finnish institute for
health and welfare

thl Biobank

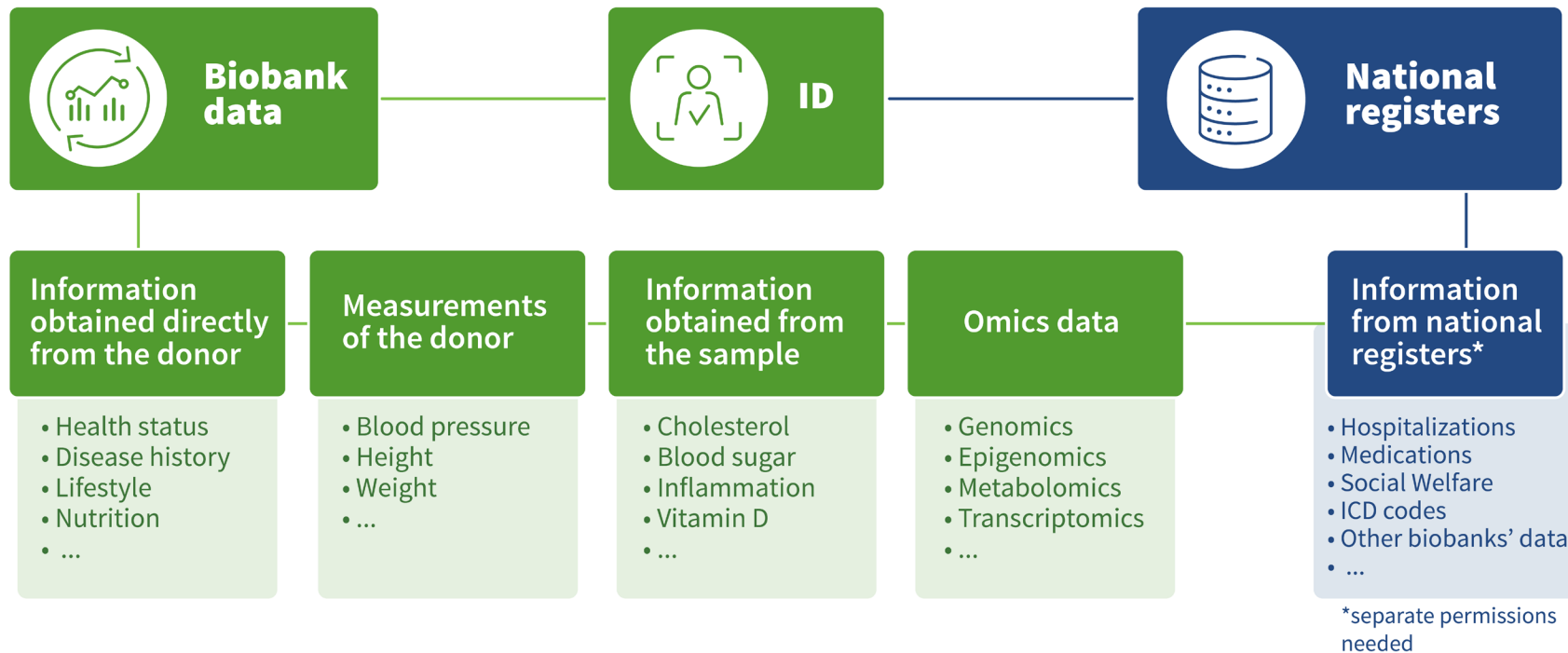


THL Biobank samples

- High quality samples
- Standardized sample collection and storage methods
- Sample processing services



Combination of THL Biobank data with data from national registers



National registers in THL

- **Care Register for Health Care (Hilmo)**
- **Register of Primary Health Care Visits (Avohilmo)**
- **Cancer Registry**
- **Medical Birth Register**
- Infectious Diseases Register
- Register of Child Welfare
- Register of Congenital Malformations
- Register of Implants
- Register of Induced Abortions
- Register of Sterilisations
- Register of Visual Impairment
- Register of Social Assistance
- Register of Personell of Social and Welfare Services
- Register of Basic Social Assistance



FINDATA

Social and Health Data Permit Authority

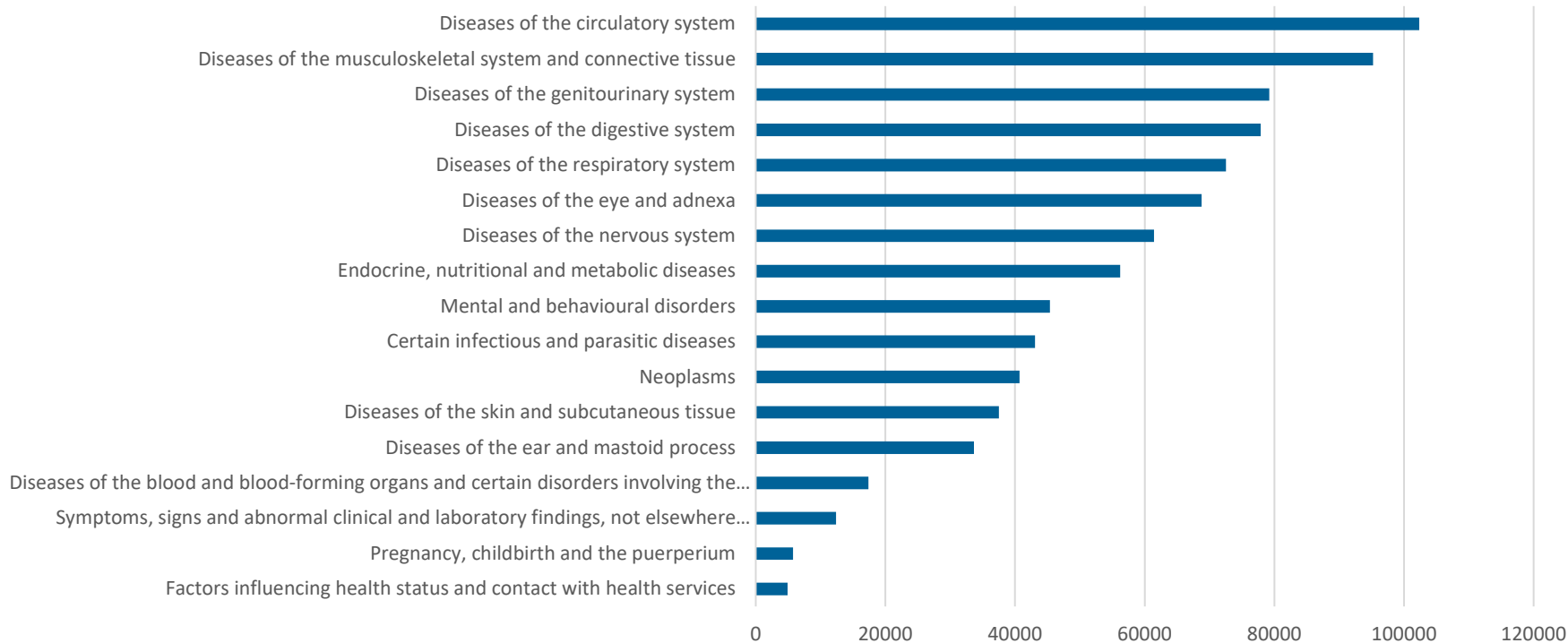
Utilizing national register data in biobank research

1. The **Finnish Biobank Act allows linkage** of biobank data to the national health and welfare registers.
2. Researchers have the **right to enquire the availability** of samples and data required for their planned biobank research.
3. THL Biobank may utilize the diagnosis data extracted from *Care Register for Health Care (Hilmo)* and *Register of Primary Health Care Visits (Avohilmo)* for **feasibility study purposes**.
4. To access the data from national registers in a biobank study, a **separate permission is needed from competent authorities, usually from Findata**.

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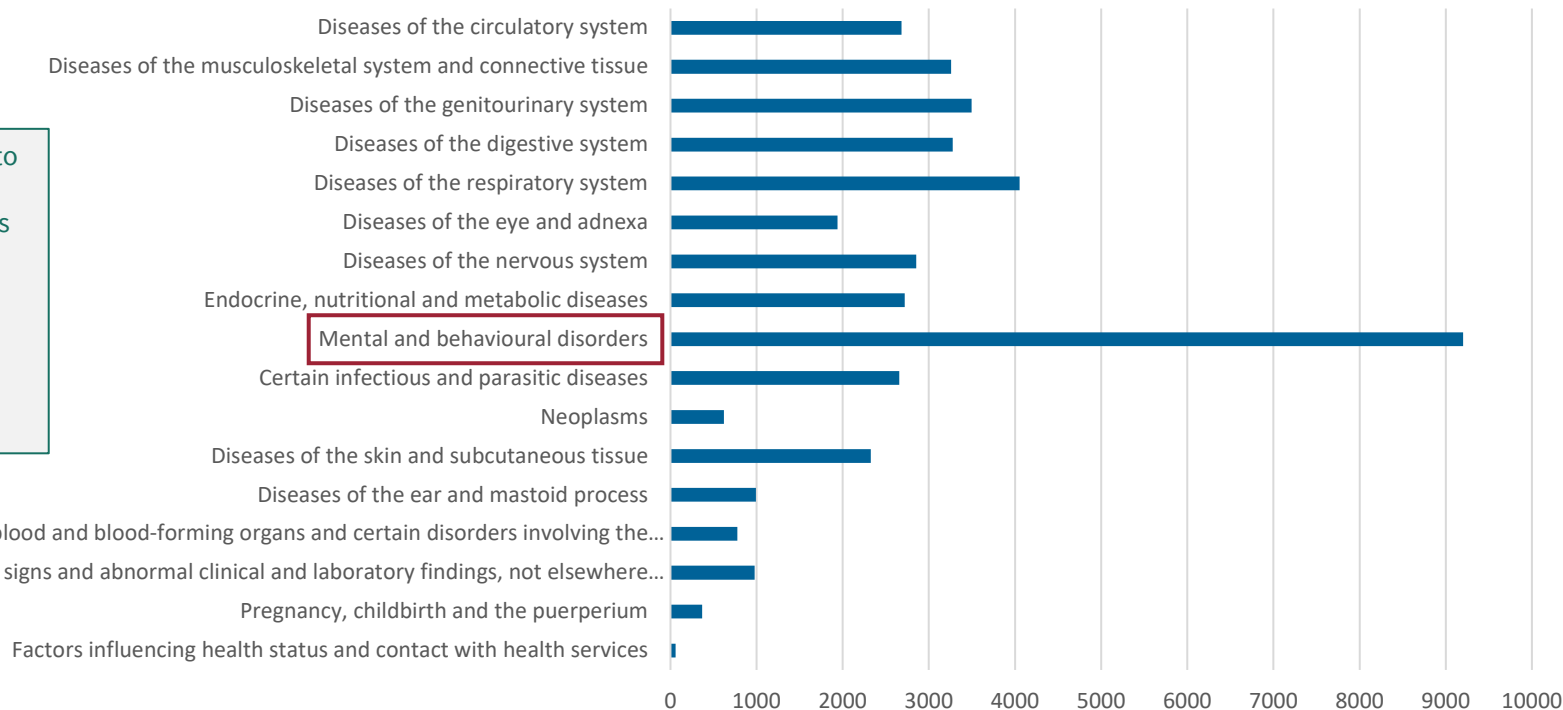
ICD-10 codes in THL Biobank: All sample donors



Comorbidities in the SUPER Study (severe mental illness)

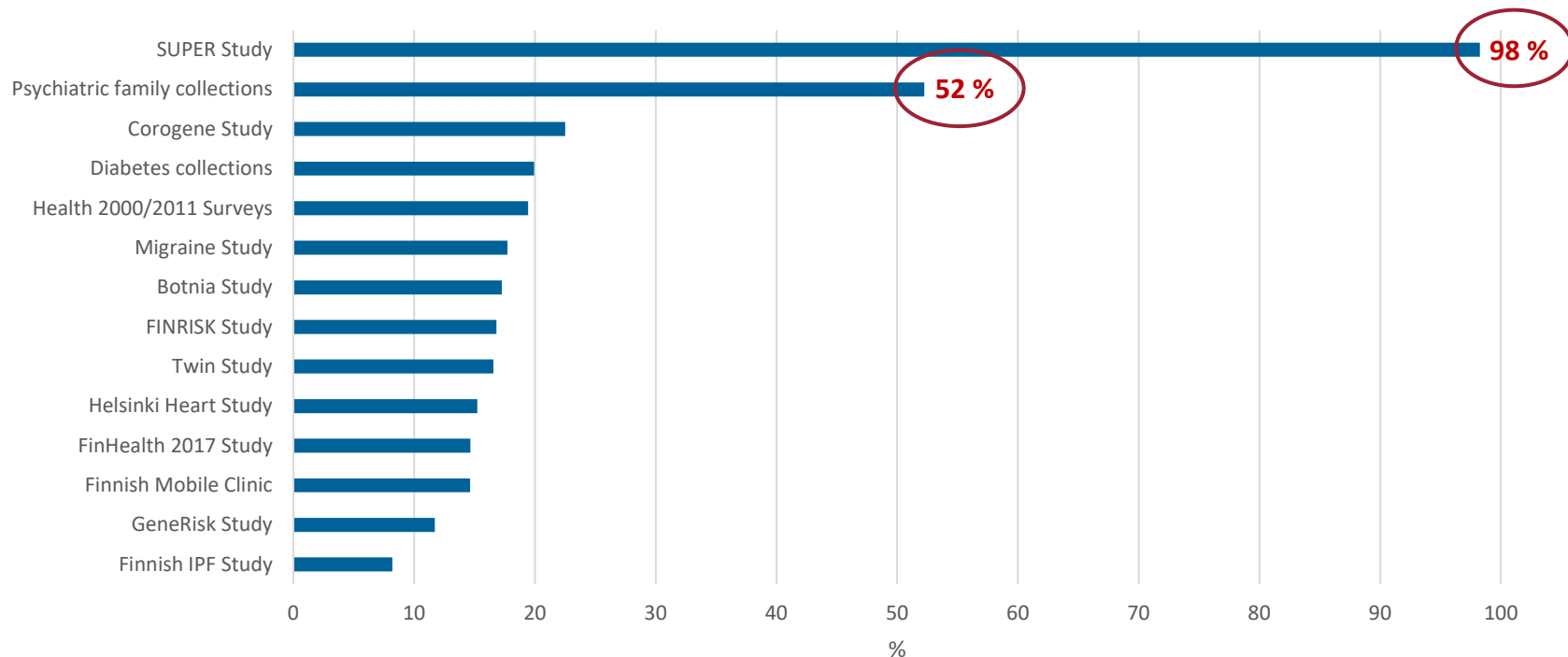
Inclusion criteria to
SUPER Study:
psychotic illnesses
ICD-10 codes

- F20-F29
- F30.2
- F31.2, F31.5
- F32.3
- F33.3



Prevalence of mental and behavioural disorders in THL Biobank's research cohorts

NORDIC Biobank
Conference

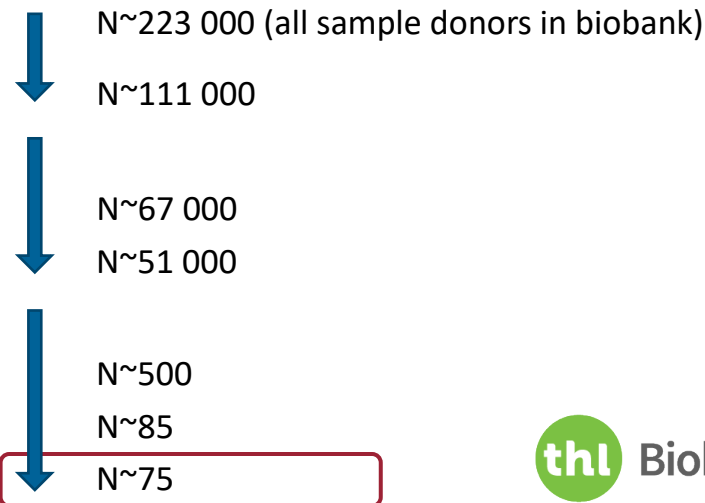


THL Biobank's Availability Service: Query example

- Researchers **request:** *"Inquiry about the availability of serum samples from individuals having type 1 diabetes (E10) and retinopathy (H36) diagnoses, but no diabetic retinopathy (E10.3). Genome data is also requested. In addition data on smoking status, BMI and eating habits are required for the study."*

- **Queries** in biobank:

- Availability of serum samples
- Availability of phenotype data:
 - imputed genotype data
 - smoking, BMI, eating habits and lipid measurements
- Inclusion/exclusion by diagnosis:
 - IDC-10 code E10
 - IDC-10 code E10 **and** H36
 - IDC-10 code E10 **and** H36, but **no** E10.3



National register data used in THL Biobank's research projects

- ❖ National register data in feasibility queries: > 60%
- ❖ National register data in biobank projects: ~ 50%
- Most commonly used national registers in biobank projects:
 - Care Register for Health Care (Hilmo), Register of Primary Health Care Visits (Avohilmo), Cancer Register – THL
 - Causes of Death Register – Statistics Finland
 - Drug Purchases and Drug Imbursement Registers – Kela

Utilizing national register data to create end-points

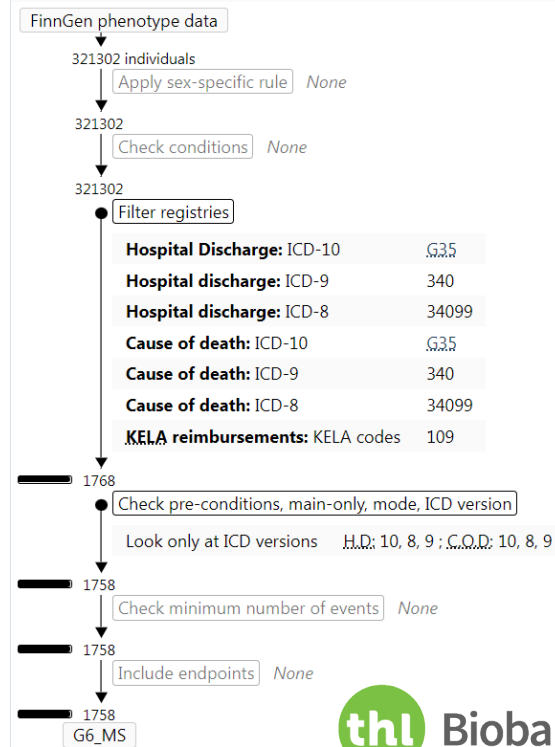
- **Clinical endpoint** is the combination of different events in the register data describing the individual's health status.
 - Summary of diagnoses + medications + causes of death



FINNGEN

- Utilizing genetic strategies to understand disease mechanisms
- Combining genome data with national health register data
- Target: 500,000 biobank donors with genomic & register data
- >4000 defined clinical end points based on register data
- <https://risteys.finnngen.fi/>

Endpoint definition Multiple sclerosis



Thank you!

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