

AURIA BIOBANK

Finnish big data lakes for better healthcare and research – from discovery to feasibility studies

7th Conference on Clinical Trials
in the Nordic Countries

19.11.2019, Oslo, Norway

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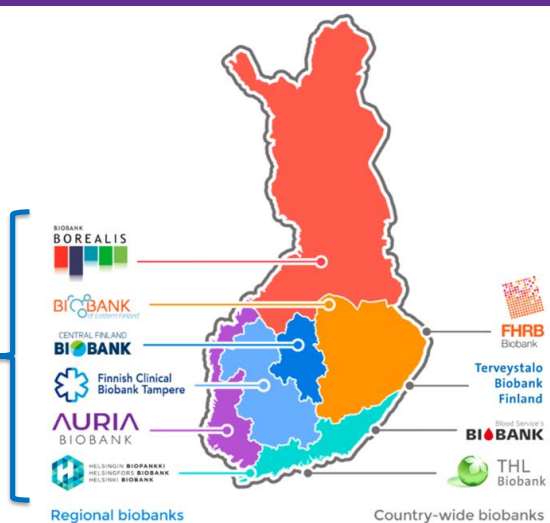
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Finnish biobanks and data lakes



Finnish Biobank Cooperative FINBB
Founded in 2017, domicile Turku

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Bio(data)banks and legislation

- GDPR (general, EU)
- Data protection act (Tietosuojalaki, general, national)
- Biobank act (1.9.2013), under rewriting
 - **Regulation** by national authorities (professionalism, quality standards)
 - **Protection** of donors' rights (informed consent, privacy protection, sample pseudonymization, right to know in which projects samples have been used)
 - **Promotion** of research and R&D (broad consent, permission to link samples with information from hospital databases and national registries, all raw data from biobank projects return to biobank)
- Act on secondary use of social and healthcare data (5/2019, Toisiolaki)
- Act on medical research (Tutkimuslaki, muutoksia)
- Act on medical use of human organs, tissues and cells (Kudoslaki)
- Genome act (Genomilaki, new, in preparation)
- Act on clinical medicines research (Laki kliinisistä lääketutkimuksista, new, in preparation)

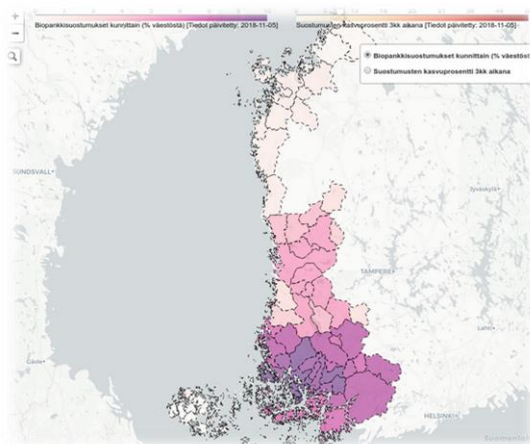
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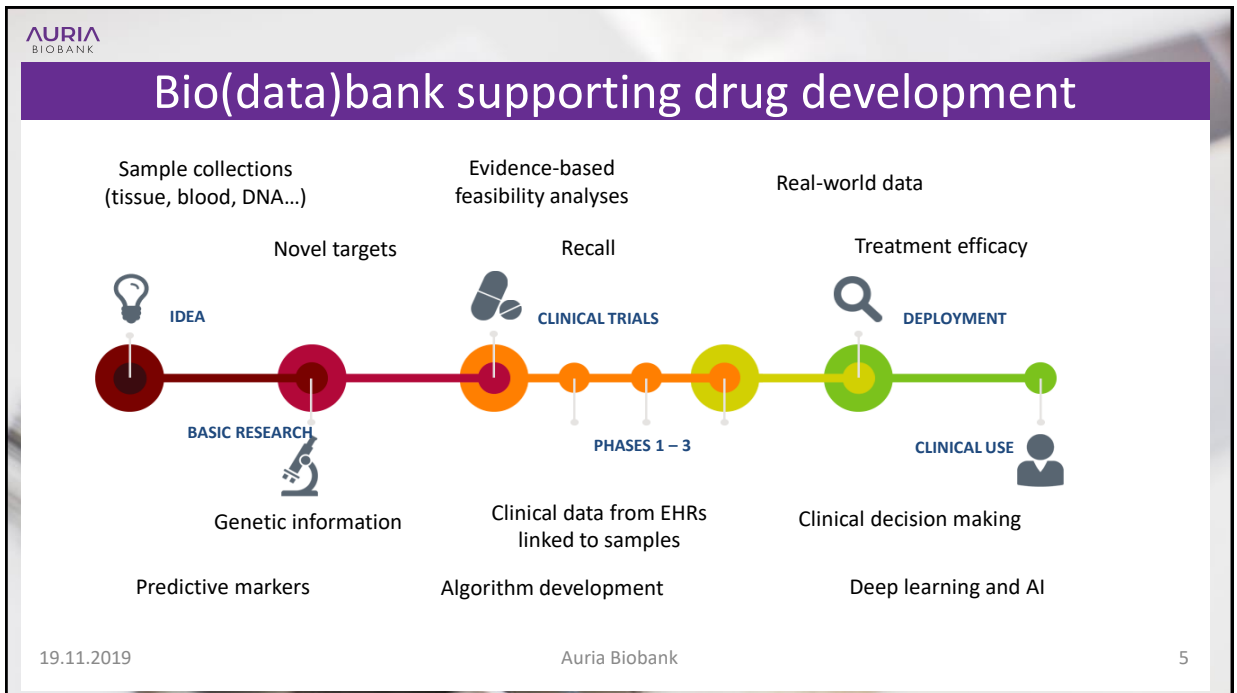
- A hospital-integrated biobank = biobank that processes clinical specimens and data in a hospital setting
- Owned by the University of Turku and Hospital districts of Southwest Finland, Satakunta and Vaasa
- Catchment population ~900 000 people
- Authorized to operate in March 2014
- A research infrastructure for academic investigators and company R&D
- Nearly 200 biobank studies with pharma industry and academic researchers

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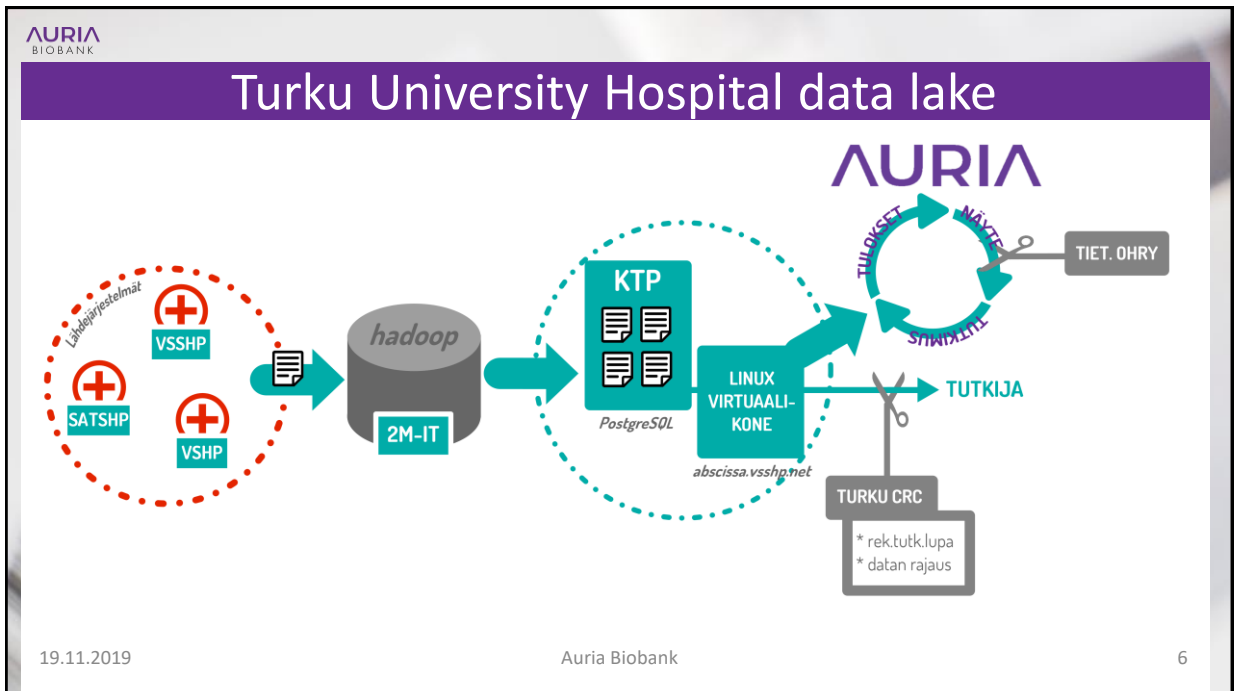
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Real-world data linked to samples

Real-world data: Clinical patient data that is generated in healthcare outside clinical trials

Auria Biobank's sample and data register

Hospital Electronic Health Records → **Clinical data in data lake** → **Person ID**

National registers
Biobank studies

- Pathology 1993 - Morphology, TNM staging, immunohistochemistry, molecular pathology
- Clinical Diagnoses 2004 - ICD-10 Codes
- Biobank Study Data
- Patient Data 2004 - Date of Birth etc.
- Clinical Operations 2004 -
- Cardiology 2003 - Lung Function
- Hospital Pharmacy 2000 - Chemotherapy, dose
- Radiation Therapy 2000 - Target, dose
- Laboratory results 2005 - Measurement, value and reference value

- ✓ Clinical data is already existing
- ✓ Longitudinal information
- ✓ In electronic format ~2004 onwards
- ✓ Possible to combine hospital EHRs with biobank specimens

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Digital timeline of a patient

Clinical diagnoses

Pathology specimens

Oncology treatments

Laboratory measurements

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Timeline (Age 55-60):

- 55: M06.0 (rheumatoid arthritis)
- 56: A41.9 (septicaemia), C90.0 (multiple myeloma)
- 57: J18.9 (pneumonia)
- 58: Z94.8 (transplanted organ), K04.5 (chronic periodontitis)
- 59: A46 (erysipelas), H11.3 (conjunctival haemorrhage)
- 60: R60.0 (localized oedema), H53.1 (visual disturbances)

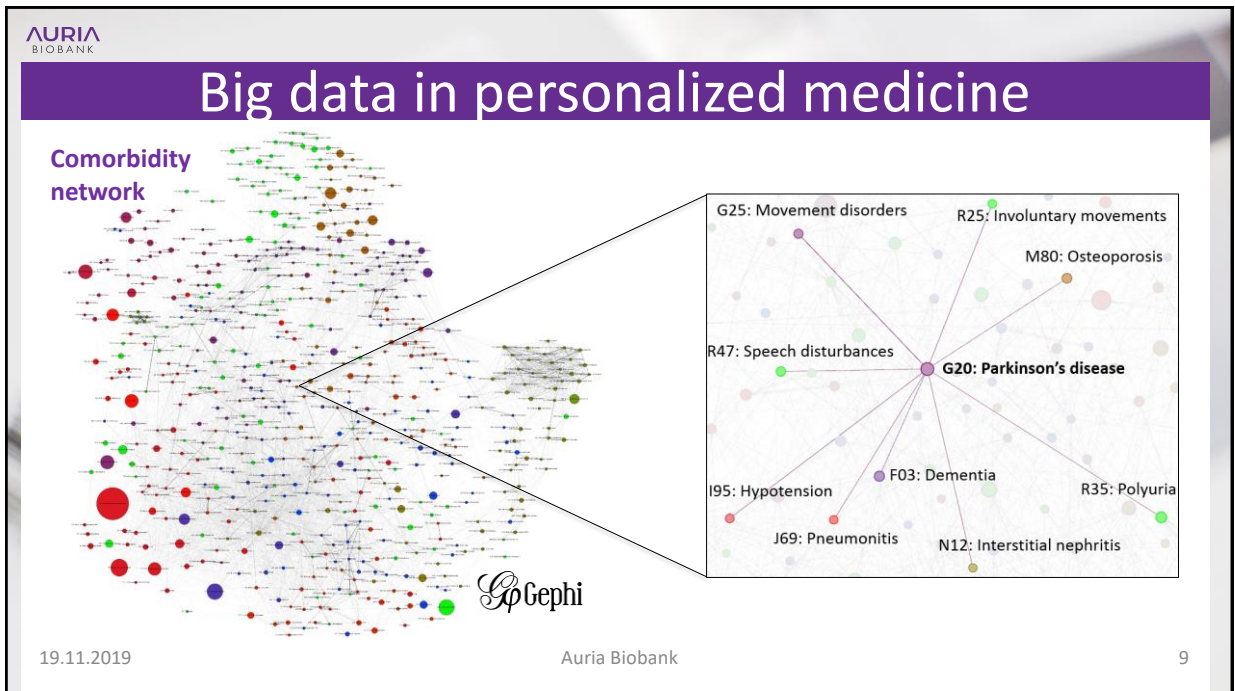
Pathology specimens: Histology sample Tissue: SACRUM Diagnosis: MULTIPLE MYELOMA; Histology sample Tissue: SKIN Diagnosis: LENTIGO

Oncology treatments: chemotherapy, radiation treat.

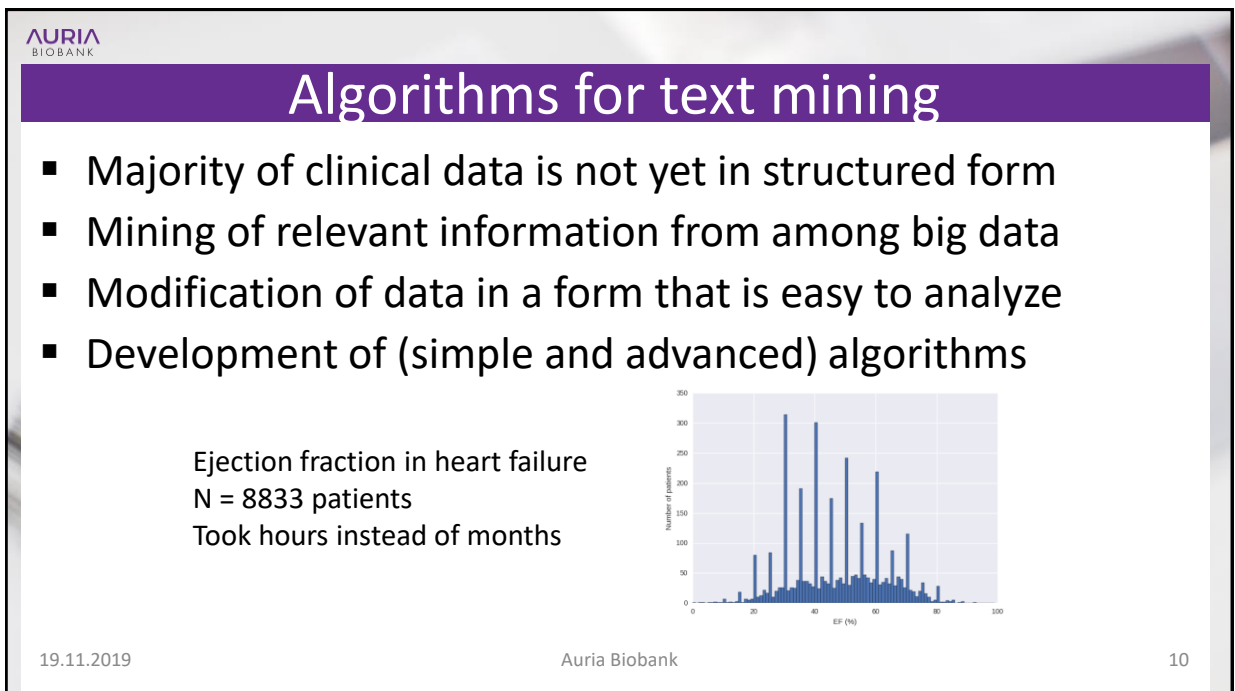
Laboratory measurements: dU-IgLCk (immunoglobulin kappa) [mg], B-Hb (hemoglobin) [g/l]

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Biobank recall – based on EHR and omics data

In addition, I consent to Auria Biobank contacting me in the following circumstances:

To inform me of findings from my samples which are of significance to my health Yes No

To discuss whether I would like to provide additional samples or participate in some form of research that is not covered by this consent Yes No

Recall option

- Majority of biobank consented patients give permission for recall
- Recall with inclusion/exclusion criteria based on deep phenotype and molecular information
- Evidence-based feasibility simulations and clinical trial protocol optimization

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Recall option

After ethical approval of clinical study and biobank approval of recontact study,

1. Biobank sample and data register: select donors based on inclusion/exclusion criteria
2. Biobank consent register: verify consent for recontact
3. Finland's population register: verify current address and that donor is alive
4. Recontact donors with letter: Ethics Committee approved wording in letter

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Dashboards for data-driven feasibility

The dashboard displays several key metrics:

- ORISAN CATEGORY:** A donut chart showing the distribution of samples across different ORISAN categories, with 'Digestive system' being the most prominent.
- DIAGNOSIS CATEGORY:** A donut chart showing the distribution of samples across various diagnosis categories, including 'Inflammation and fibrosis' and 'Mechanical abnormality'.
- NUMBER OF SAMPLES PER AGE:** A bar chart showing the number of samples collected across different age groups, peaking in the 20-30 age range.
- GENDER:** A pie chart showing the distribution of samples by gender.
- NUMBER OF SAMPLES PER YEAR:** A line chart showing the number of samples collected annually from 1993 to 2012.

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www.auria.fi

The website features a word cloud with terms related to cancer research, such as 'cancer', 'treatment', 'diagnosis', 'genetic', and 'biobank'. Below the word cloud is a timeline of biobank projects from 2014 to 2018.

BIOBANK STUDIES

Auria Biobank serves both academic research and R&D of medical companies.

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Biobank projects % in 2014-18

Category	Percentage
Academic	~55%
Industry	~45%

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