Biobanks in Finland

Olli Carpén,
Professor of Pathology, University of Helsinki
Research Director, Helsinki biobank
Implementation of PM will not happen without tools to translate novel information into health care

**CURRENT**
"reactive medicine"

Methods for earlier detection or prevention of disease/traits

**FUTURE**
"P4 medicine"

Population based high quality biological specimens, electronic medical records and AI tools play a key role in the transition = deeper phenotyping, "real life data"

- Evidence based = slow changes
- A revolutionary paradigm shift in clinical trial design
Special features of hospital biobanks
We are not alone.....

Mayo Clinic Awarded $142M by NIH to Create Biobank for Precision Medicine Initiative
ARTICLE: BREAKING NEWS — in Research Funding
The agency said it would disperse the funds to the clinic over the course of five years to collect, store, and distribute biospecimens for precision medicine research.

NIH Earmarks $72M for First Precision Medicine Initiative Programs
GenomeWeb, 2015

Feb 19, 2016
GenomeAsia 100K Project Aims to Close Knowledge Gap on Half the World’s Population:
ARTICLE: IN-DEPTH — in Sequencing
Collaborators will sequence 100,000 Asian genomes from various disease cohorts and generate 50 to 100 Asian-specific reference genomes.

Mar 22, 2017
U.K. BIOBANK, REGENERON AND GSK ANNOUNCE LARGEST GENE SEQUENCING INITIATIVE ON WORLD'S MOST DETAILED HEALTH DATABASE TO IMPROVE DRUG DISCOVERY AND DISEASE DIAGNOSIS

Groundbreaking UK/US Initiative Will Deliver First Data Within a Year

Jun 23, 2016
France Plans to Invest €670M in Genomics, Personalized Medicine
ARTICLE: BREAKING NEWS — in Clinical & Translational
The investment, which will be paid out over the course of five years, comes in part from industry sources.

Dec 22, 2014
NHS England Names 11 Genomic Medicine Centres for 100,000 Genomes Project
ARTICLE: BREAKING NEWS — in Regenerative News
The naming of the centers marks the main phase of the project, which is expected to recruit 75,000 participants, starting in February.
Why to build a PM platform in Finland/Norway?

- High-coverage high-quality health care system
- Comprehensive electronic medical records (on national "Kanta"-platform)
- National health registers
- Unique genetic ancestry
- Biobanks
- Government support

FINLAND

TRANSFORMATION OF PHARMACEUTICALS

PERSONALIZED MEDICINE
The Finnish biobank act – a game changer

• Professionality (Registration of biobanks)
• Protection of donors’ rights
• Possibilities (wide consent, recontacting, public-private partnership)

• Transfer of existing sample collections to biobanks (e.g. pathology archives)
• Infrastructure to combine samples and data from health records
  • Link biobank samples with hospital data (EMR)
  • Link biobank samples with data from national registries
Integrated pathway to personalized medicine

Biology (OMICS)

OMICS DATA

Consent

SAMPLE

Data Generation

Data Analytics

Integration

Integrative Analytics

Applied Analytics

Health (Phenotype)

PHENOTYPE INFORMATION (EMR/EHR)

Participant recall, deep phenotyping

Benefit to Individual and Healthcare System

Contribution by Jaana Sinipuro (Sitra)
Biobank consent as part of hospital routine
Sample collection by accredited procedures
DNA purification by accredited procedures
Sequencing and reporting by clinical diagnostic standards

Fully hospital integrated - streamlined and affordable consenting and sample collection

EVERY PATIENT HAS THE RIGHT OF BEING A RESEARCH PATIENT

Medical research, New health care modalities, R&D
FinnGen – a precompetitive project to advance precision medicine

01 PRODUCE MEDICAL INNOVATIONS BY COMBINING HEALTH REGISTRY AND GENOME DATA FROM 500,000 INDIVIDUALS

02 SUPPORT FINLAND TO BECOME A PIONEER IN BIOMEDICINE AND PERSONALIZED HEALTH

03 CREATE A CO-OPERATION MODEL BETWEEN PUBLIC SECTOR AND HEALTHCARE INDUSTRY

04 PROVIDE EARLY ACCESS TO NEW PERSONALIZED TREATMENTS AND HEALTH INNOVATIONS FOR ALL FINNS

COORDINATED BY:

HELSINGIN YLIOPISTO UNIVERSITY OF HELSINKI
HELSINGORS BIOBANK

OPPORTUNITIES FOR MULTIPLE INNOVATIVE ADD-ON PROJECTS
Digital phenotypes with real life data

1. Predict life expectancy (or any other outcome)

New patient → ML model → Died in 1 year → Died in 5 years → Survived 5 years

Data collection and processing → Feature selection → Decision Tree → Random Forest → Optimization

K-means clustering → Mean-shift clustering

Similar feature set

2. Divide patients into subgroups based on similar features
Disease trajectories provide understanding of individual variation within disease categories

A step towards digital phenotypes

Samu Kurki
Next developments

• A new act on the secondary use of health and social data
• Establishment of a centralised electronic licence service and a licensing authority

• A biobank co-operative FinBioBank (FINBB)
• Personalised preventive medicine pilots (P5.fi)
FinBioBank - FINBB

Vision: Advance Health Care

• Serve as a key contributor to making population resources available for advancements in public and personal health.

Mission: Support Biobank Creators and Users

• Provide coordinated services to help biobanks set up infrastructure and processes to create high quality, standardized collections with interoperative utility and critical-mass-based market value.

• Facilitate scalable, sustainable, revenue-generating utilization of biobank resources by academic, public, and commercial biobank users.
FINBB first activities

– 1M€ from Ministry of Health and Social Affairs

• Cancer sample collection **SAMPLE**
  • 20% of new cancer patients/2018
  • FF + ctDNA

• ICT solutions for national one stop shop for biobank customers **DATA**
P5.fi will serve as a pilot to join public and private health care providers to accomplish new public health results under a common theme.

Its goals are:

– To build a public health program based on people’s needs, using cutting edge technologies and new methods to accomplish the goal.
– To bring P4 principles into medical care, to change people’s attitudes towards genomic/personalised medicine, to combine the new technologies with digital services.
– To boost the health care economy in an ethically sustainable fashion.

Markus Perola, Matti Hämäläinen, Pia Heikkurinen et al.
P5.fi – personalised prevention of cardiovascular diseases and type 2 diabetes

- Genome (genotype) “Metabolome”
- Life style risks

>100 000 consented individuals

Disease Risk Score

Individualised reports on results, lifestyle modification advice

Physician’s appointment for high risk score individuals

INTERVENTION
Summary

• Large scale hospital biobanking, which combines biological and longitudinal comprehensive phenotype information, provides a perfect testbed for discovery and development.

• For optimal biobank performance, a platform which includes both retrospective and prospective EHR information, and capabilities to procure and utilize it, is required.

• The real world evidence, combining large scale biological and phenotypic information, paves the path towards stratified medicine.