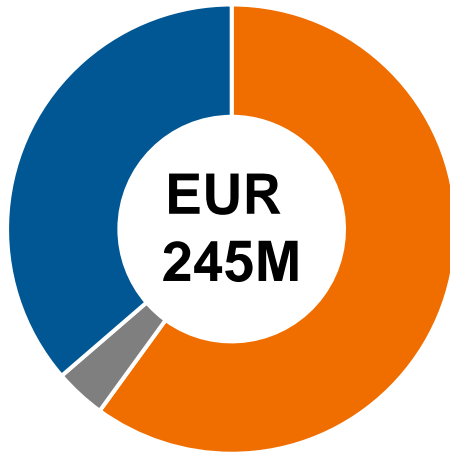


# Data donation landscape – a Finnish perspective

Kari Kohtamäki, VTT  
ECHAlliance Pop-Up Ecosystem Webinar  
June 24, 2020

24/06/2020 VTT – beyond the obvious

## VTT today



**147 M€** Turnover (parent 147 M€)  
**9 M€** Other operating income  
**89 M€** Government grant

# 2,103

employees

# 47%

of turnover from abroad\*

# 36%

of Finnish innovations  
have links with VTT's  
competences

# 406

patent families

## VTT

is under the state ownership steering of the Ministry  
of Economic Affairs and Employment

# We advance technology to improve quality of life, health and well-being at affordable costs

**1**

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## **Preventive health support**

24/7/365 health and wellbeing data coupled with motivational support technologies

Decision support for citizens

**2**

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## **Predictive, personalised diagnostics and care**

Home diagnostics, biobanks, and clinical data as input to decision support for risk assessment and optimised treatments

Decision support for healthcare professionals

**3**

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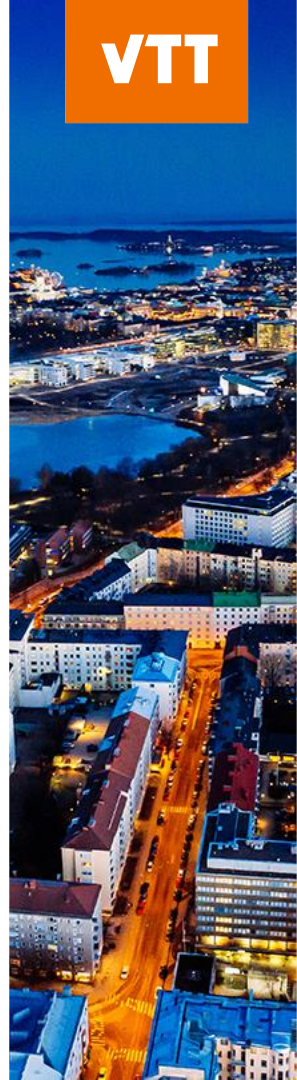
## **Healthcare process optimisation**

Impact assessment as input to healthcare process optimisation

Decision support for policy makers

# Data donation landscape in Finland

- Data repositories as part of the national healthcare infrastructure
  - Patient data repository (Kanta)
  - Personal Health Record (MyKanta)
  - National registers
  - Biobanks
- Legislation
  - Biobank law
  - Secondary use of health data
- Data donation in practice and how to nurture it



# Data donation is widely accepted in Finland

- Good health and wellness are valued highly
- “Scandinavian culture” (welfare state with solidarity)
- Educated population
- Trust on authorities
- Tradition of blood donation etc.

# Patient Data Repository (Kanta)

Patient Data Repository is a service where patient data is safely accessible by professionals and in long-term storage in one place.

Information about patients' consents is recorded in the service, including

- patient's consent to sharing patient data
- withdrawal of consent
- refusals to share patient data
- withdrawals of refusals to share information
- declarations of intent (living will, organ donation will)

# Personal Health Record (as part of Kanta)

- MyKanta is part of the national healthcare infrastructure, providing access to citizen's own patient records
- MyKanta PHR is a new Kanta service in which users may enter information on their wellbeing.
- Users may give their consent to social and healthcare service providers for the use of the data in support of decisions concerning their health and wellbeing.
- To access a user's PHRs, the service provider must have
  - the user's consent
  - a treatment relationship
  - a professional application authorised for PHR for the purpose.

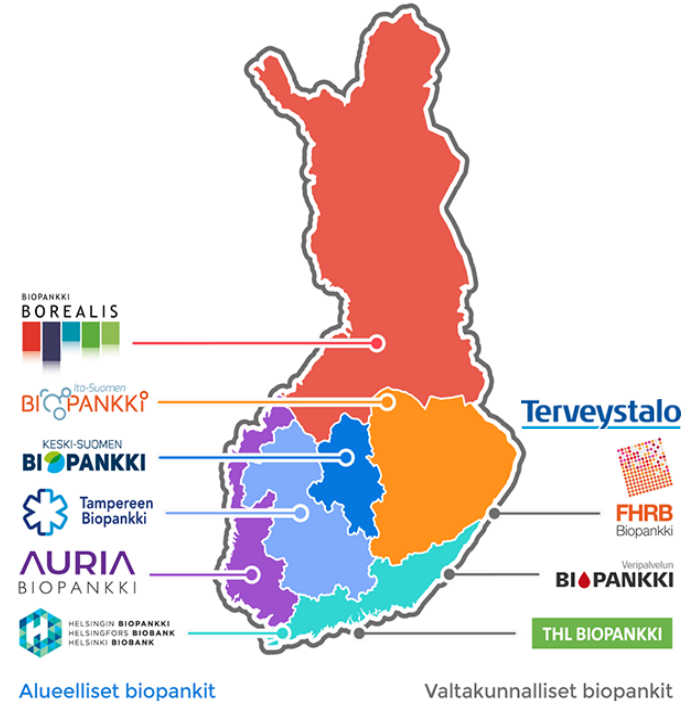
# Biobank ecosystem for personalised medicine

Finnish biobanks form the key research infrastructure for conducting biomedical studies.

With business partnerships, the biological and health data can be translated to innovations which potentially transform the healthcare

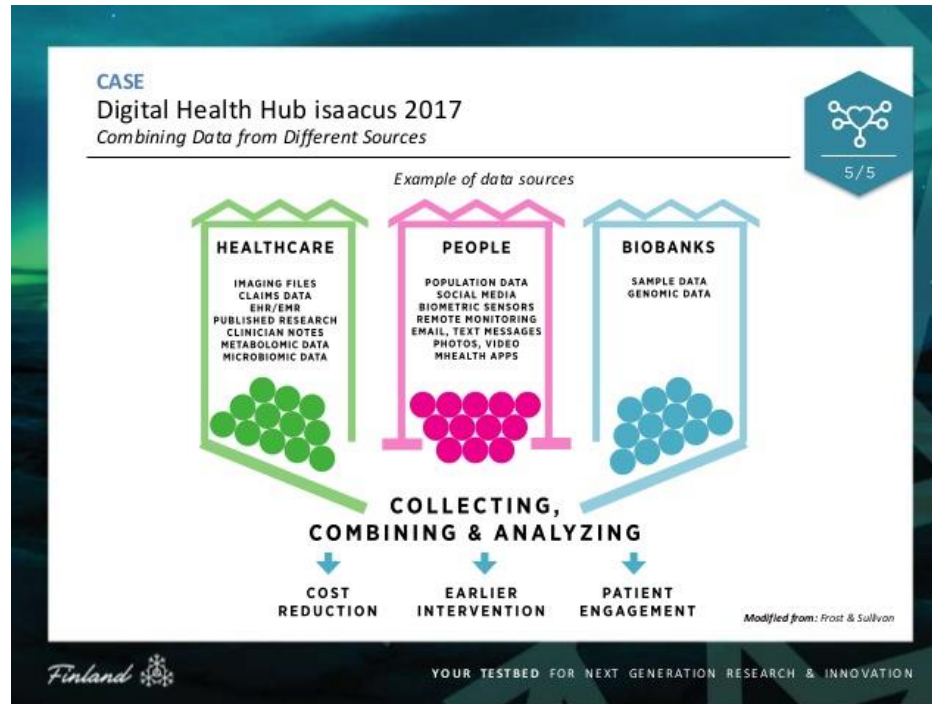
- Wide consent and protection of participants
- Possibility to link biobank samples and hospital data (EHR)
- Link biobank samples with data from national registries
- Possibility to recontact patients

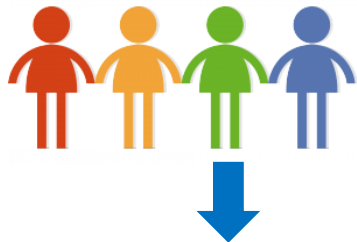
Source: Helsinki Biobank





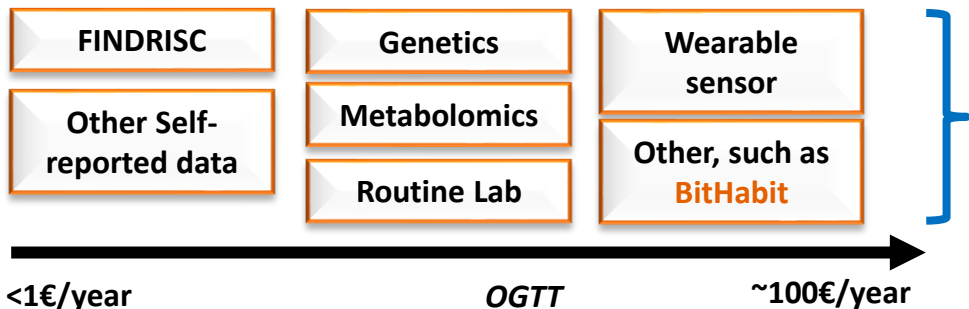
# Objective: Combining high quality data for getting the whole picture





# Example: User profile translated to a personalized care model

## Different methods to stratify



Personalization based on:

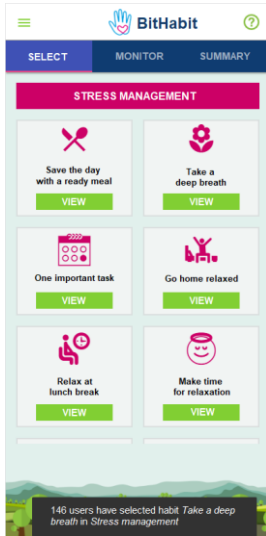
- 1) Risk level (risk stratification)
- 2) Expected response to actions



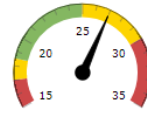
"NOT one size fits all"



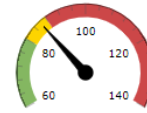
# Solution: Digital tools for health behaviour coaching



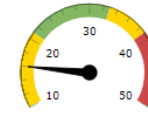
## METERS



BMI 27



Waist 86 cm

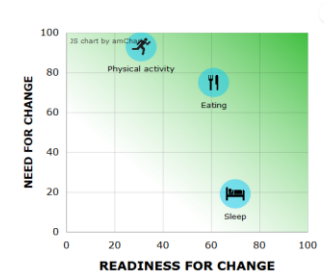


Fat 16 %

## STRENGTHS & CHALLENGES

- Motivation for weight management**
- Readiness for changing exercise habits**
  - Motivation
  - Self-efficacy
  - Beliefs and attitudes
  - Social support
  - Environmental factors
- Readiness for changing eating habits**
  - Motivation
  - Self-efficacy
  - Beliefs and attitudes
  - Social support
  - Abilities and skills
- Readiness for changing sleep habits**
  - Motivation
  - Self-efficacy
  - Beliefs and attitudes

## PERSONAL POTENTIAL FOR CHANGE



BitHabit platform enables building fully customized data-driven interventions for behavioural change

Web-based health profiling service for citizens. Identifies personal health needs and motivation towards change

# Data donation in practice

- What is needed
  - Awareness
  - Motivation
  - Sense of urgency (Covid!)
  - Tools and infrastructure, such as biobanks
  - Trust - “rules of the game”
  
- But who benefits and who to trust?
  - Public authorities (common good)
  - Medical research platforms (science)
  - Leading technology providers (access to services)
  - “Nobody”

# How to nurture data donation

- Transparency on “my data”
- Balanced regulation
- Culture of sharing for common benefit
- Public investments in data infrastructure
- Communication and motivation of people

# bey<sup>0</sup>nd

## the obvious

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