Estonian Biobank – from basic research to public health

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Estonian Biobank

- Estonian Genome Center, University of Tartu
- A prospective, longitudinal, population-based database with health records and biological materials
- 52,000 participants - 5% of the adult population
- Individuals are recruited by medical personnel
- Broad informed consent
- Legislation: Estonian Human Genes Research Act
Estonian E-services

- **Mandatory** ID document for all Estonian residents
- Enables secure digital authentication and signing
- Active cards: 1 209 594 (95% of citizens) [13 Sept 2013]

**Public e-services**

- **DigiDoc**
  - ID
  - DigiDoc is a system widely used in Estonia for storing, sharing, and digitally signing documents.

- **Digital Signature**
  - Electronic ID
  - Digital signature enables secure, legally binding, electronic document signing.

- **e-Business Register**
  - e-Business ID
  - Enables entrepreneurs to register their new business online in minutes.

- **e-Cabinet**
  - e-Cabinet ID
  - A powerful tool used by the Estonian government to streamline its decision-making process.

- **e-Law**
  - e-Law ID
  - Allows public access to every piece of draft law that has been submitted since February 2003.

- **e-Prescription**
  - e-Prescription ID
  - A centralized, paperless system for issuing and handling medical prescriptions.

- **e-School**
  - e-School ID
  - Enables students, teachers, and parents to collaborate in the learning process.

- **e-Tax**
  - e-Tax ID
  - e-Tax has drastically reduced the time spent by individuals and entrepreneurs on filing taxes.

- **Electronic ID Card**
  - Electronic ID Card ID
  - e-ID acts as definitive proof of ID in secure electronic environments.

- **Electronic Land Register**
  - Electronic Land Register ID
  - A one-of-a-kind information system for storing real estate and land data.

- **i-Voting**
  - i-Voting ID
  - i-Voting allows voters to cast their ballots over the Internet, from anywhere in the world.

- **Keyless Signature Infrastructure**
  - Keyless Signature Infrastructure ID
  - Estonian digital society ensures the integrity of its systems and data by using the KSI technology.

- **Location-Based Services**
  - Location-Based Services ID
  - A positioning service that detects device location & provides location information.

**Electronic Health Information System**

- **X-Road, ID-card, State IS Service Register**
  - Patient Portal 2009
  - X-Road Gateway Service 2009
  - Nation-wide Health Information Exchange Platform 2008 December
  - Prescription Centre 2010 January

- **HAAPABUSINESSES**
  - State Agency of Medicines
  - Coding Centre
  - Handlers of medicines

- **HEALTHCARE PROVIDERS**
  - Health care providers
  - Dispensing chemists

- **POLICE**
  - Police
  - Crime prevention

- **SCHOOL NURSES**
  - School nurses
  - 2010 September

- **STATE AGENCY OF MEDICINES**
  - State Agency of Medicines
  - Coding Centre
  - Handlers of medicines

- **X-Road Gateway Service**
  - Gateway Service 2009

- **X-Road, ID-card, State IS Service Register**
  - X-Road, ID-card, State IS Service Register
  - Patient Portal 2009
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  - Nation-wide Health Information Exchange Platform 2008 December
  - Prescription Centre 2010 January
From questionnaires to the national registries

Population Registry
Estonian Causes of Death Registry
Estonian Cancer Registry
Estonian Myocardial Infarction Registry
Tuberculosis Registry

National Digital Health Record Database
Health Insurance Fund

Tartu University Hospital
North Estonia Medical Center

Coding center **High security area.**

Data collector: baseline phenotype data

The broad informed consent. Phenotype data

Phenotype database

estonian genome center
university of tartu
Individual risks

- Genetics
- Age
- Environment, lifestyle, comorbidities

Disease

Age
# Measures of prevention

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Mean (95% CI)</th>
<th>Control (n = 358)</th>
<th>Mean Difference (95% CI)</th>
<th>P Value for Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary end point</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LDL-C, mg/dL (n = 352)</td>
<td>79 (76 to 82)</td>
<td>84 (81 to 87)</td>
<td>-5 (-9 to 0)</td>
<td>.04</td>
</tr>
<tr>
<td><strong>Secondary end points</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Blood pressure, mm Hg</td>
<td></td>
<td></td>
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<tr>
<td>Systolic</td>
<td>128 (127 to 130)</td>
<td>136 (134 to 137)</td>
<td>-8 (-10 to -5)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Diastolic</td>
<td>81 (80 to 82)</td>
<td>84 (83 to 85)</td>
<td>-3 (-4 to -2)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Heart rate, /min</td>
<td>67 (66 to 68)</td>
<td>69 (68 to 70)</td>
<td>-2 (-3 to -0.4)</td>
<td>.01</td>
</tr>
<tr>
<td>BMI</td>
<td>29.0 (28.8 to 29.3)</td>
<td>30.3 (30.1 to 30.5)</td>
<td>-1.3 (-1.6 to -0.9)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Waist circumference, cm</td>
<td>100.6 (99.5 to 101.7)</td>
<td>105.0 (103.9 to 106.1)</td>
<td>-4.4 (-6.0 to -2.8)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Hip circumference, cm</td>
<td>101.7 (100.5 to 102.9)</td>
<td>106.4 (105.2 to 107.5)</td>
<td>-4.7 (-6.3 to -3.0)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Cholesterol, mg/dL</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>150 (146 to 154)</td>
<td>159 (156 to 163)</td>
<td>-9 (-15 to -4)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>HDL-C</td>
<td>43 (42 to 44)</td>
<td>44 (43 to 45)</td>
<td>-0.4 (-2 to 1)</td>
<td>.55</td>
</tr>
<tr>
<td>Triglycerides</td>
<td>140 (132 to 148)</td>
<td>160 (151 to 168)</td>
<td>-20 (-31 to -8)</td>
<td>.001</td>
</tr>
<tr>
<td>Total physical activity (MET min/wk)</td>
<td>936.1 (799.7 to 1072.5)</td>
<td>642.7 (509.2 to 776.2)</td>
<td>293.4 (102.0 to 484.8)</td>
<td>.003</td>
</tr>
<tr>
<td>Inactive (&lt;600 MET min/wk), No. (%)</td>
<td>126/338 (37.4)</td>
<td>241/351 (68.8)</td>
<td>0.55 (0.47 to 0.64)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Current smoking, No. (%)</td>
<td>88/339 (26.0)</td>
<td>152/354 (42.9)</td>
<td>0.61 (0.48 to 0.76)</td>
<td>&lt;.001</td>
</tr>
</tbody>
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*Chow et al 2015*
The Estonian Program for Personal Medicine

- **Health care**
  - Educating health care professionals
  - Educating patients
  - Further development of eHealth incl. decision support systems

- **Research and Development**
  - Sequencing 5000 individuals, genotyping array and analysis software
  - International collaboration

- **Commercialization**
  - IP
  - Business agreements
Beyond evidence-based medicine

Personalised medicine – general process

- Decision support
- Big data (personalized)
  - Clinical decision, treatment of the patient, tissue sample collection & DNA sequencing, other data collection
- Pseudonymization
- Research

STACC: Software Technology and Applications Competence Center