Data linkages in the Finnish Reproductive Health Registers

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Data on reproductive health at THL

• Abortions and sterilisations since 1983 (statistics since 1950/1939)
• Congenital anomalies since 1963
• Parturients, deliveries and newborns since 1987
  – Premature live born children (< 32 weeks and/or < 1501 grams) since 2005
• Statistics on fertility treatments since 1992
  – Donations since 2001
  – Inseminations since 2005
Data on reproductive health at THL

• Drugs and pregnancy – database since 1996
  – Prescribed and reimbursed medication 3 months before pregnancy, during pregnancy and 3 months after pregnancy (Social Insurance Institution)
  – Pregnancies ending in an induced abortion or birth

• Care Register at Health Care Institutions
  – Inpatient care since 1967/1969
  – Day surgery since 1994
  – Hospital outpatient care since 1998
  – Health care centre visits since 2011
THL Malformation Register

THL Medical Birth Register

THL Hospital Discharge Register

Central Population Register

Social Insurance Institution: Medication

Valvira: Induced abortions

THL Register on Sterilisations

THL Register on Induced Abortions

Statistics Finland: Causes of Death

Home-births

Hospitals

Notifications

Feedback

New cases

New data

Ad hoc data
Missing data

• Prenatal screening
  – The data on prenatal screening in the registers is not accurate enough to monitor prenatal screening practices and effectiveness.

• Causes-of-Death Register remains at Statistics Finland
  – No continuous surveillance of causes of death, maternal deaths and pregnancy-related deaths.

• Background information at Statistics Finland
  – Education, income and migrant status (country of birth, first immigration year, language, nationality).
Future?

• New legislation 2013...?
  – Combine the Medical Birth Register and the Malformation Register
  – Include new routine data sources for the new Birth Register:
    • Medication, prenatal screening, parturients’ and newborns’ deaths and their causes, migrant status, GIS-codes
  – Consider registration of all fertility treatments and the started pregnancies
  – Consider discontinuation of registration of sterilisations.
Registers in Finland

- At national level, population data have been collected for more than 250 years and health data for more than 150 years.
- Registers are less used in other fields, such as social welfare research and criminology.
- First health registers were started in the 1940-1950s, when improved computers were available, e.g. cancer register.
- Personal identification numbers were given for all citizens and permanent residents in 1964-1968, which makes the data linkages technically easy.
- Several data quality studies have shown the high quality of routinely collected registers.
- Data protection allows the use of register data in research.
The 1987 Finnish Birth Cohort

- All children born in Finland in 1987 (n=60 069)
- Focus on mental health, behaviour and wellbeing from uterus to childhood and adulthood
- Follow-up from fetal period until early adulthood using register data only:
  - Second study 1987-2008/2009
  - Third study 1987-2011/2012
# Health registers: 1987 Finnish Birth Cohort

<table>
<thead>
<tr>
<th>Register</th>
<th>Data</th>
<th>Period covered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finnish Medical Birth Register</td>
<td>Pregnancy and birth outcomes</td>
<td>1987</td>
</tr>
<tr>
<td>Finnish Hospital Discharge Register</td>
<td>Hospitalisation data (discharge diagnosis, date, duration, etc.)</td>
<td>1987-2008, outpatient visits since 1998</td>
</tr>
<tr>
<td>Cause of Death Register</td>
<td>Dates and causes of death</td>
<td>1987-2008</td>
</tr>
<tr>
<td>Register on Prescribed Medicine and Special Refunded Medicine</td>
<td>Redeemed prescriptions of psychotropic medication (ATC codes, date)</td>
<td>1994-2008</td>
</tr>
<tr>
<td>Infectious Disease Register</td>
<td>Sexually transmitted infections</td>
<td>2004-2008</td>
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<tr>
<td>Register on Induced Abortions</td>
<td>Induced abortions</td>
<td>2000-2008</td>
</tr>
<tr>
<td>Finnish Medical Birth Register</td>
<td>Pregnancy and birth outcomes</td>
<td>2000-2008</td>
</tr>
</tbody>
</table>
## Other registers: 1987 Finnish Birth Conrot

<table>
<thead>
<tr>
<th>Register</th>
<th>Data</th>
<th>Period covered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statistics Finland &amp; Central Population Register</td>
<td>Births and deaths, parents’ marriages and divorces, migration, education, occupations</td>
<td>1987-2009</td>
</tr>
<tr>
<td>Register on Social Assistance</td>
<td>Social assistance for parents and cohort members</td>
<td>2002-2008 for cohort members</td>
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<td>1987-2008 for parents</td>
</tr>
<tr>
<td>Register on Child Welfare</td>
<td>Information on children taken into custody</td>
<td>1987-2008</td>
</tr>
<tr>
<td>Finnish Defence Forces Registers</td>
<td>Data on service and results of aptitude tests</td>
<td>2005-2009</td>
</tr>
<tr>
<td>Finnish Legal Register Centre</td>
<td>Information on criminality, offences and court decisions</td>
<td>2002-2009</td>
</tr>
</tbody>
</table>