

Original filename: Registers in studying premature children

## **Medical Birth Registers and Children (and Adults) Born Preterm**

### **Learning goals**

- To get information on the registration of newborns, including data collection on congenital anomalies
- To familiarise on the content of perinatal databases
- To understand the usefulness and prerequisites for their use in research on preterm children

### **Abstract**

Record keeping has a long tradition in the Nordic countries. Denmark, Iceland, Finland, Norway and Sweden have based their health information systems on registers, which cover the total population. Examples of computerised health registers include national cancer registers (from the 1940s), registers on infectious diseases (from the 1950s), hospital discharge registers (from the 1960s), cause-of-death registers (from the 1960s), birth and birth defect registers (from the 1960s) and health care quality registers (from the 1990s).

There are several reasons for the strong register culture. First, there is a long tradition to collect public information: population statistics have been collected more than 250 years and health statistics also more than 150 years. Second, unique personal identity codes were introduced early for all citizens and permanent residents: in 1947 Sweden, in 1953 Iceland, in 1964 Finland and Norway, and in 1968 Denmark. The existence of personal identity codes and their use in the registers improves the completeness and quality of any data and augments the available information, for example on the aggregation of service utilisation. It also enables the more efficient secondary use of data for example in research. Third, several data quality studies have shown the high completeness and data quality of routinely collected registers.

Medical Birth Registers have been compiled for a long time in the Nordic countries: Norway started the data collection in 1967, Denmark 1968, Iceland 1972, Sweden 1973, and Finland 1987. The registers cover all live births and currently there is information on stillbirths at least from 500 grams or 22 weeks of gestation. All hospital births are covered, but some countries have less information on transport births and homebirths. The content of the national registers vary by time, which means that variables have to be harmonised before they can be used. For example diagnoses are collected by using check-boxes or ICD-codes.

As a part of initiatives to get more information on quality of health care services, more detailed data on prematurely born are collected. In the Nordic countries Sweden (Swedish Neonatal Quality Register SNQ

since 2002), Finland (Register on small premature children since 2005) and Denmark (The Danish Newborn Quality Database DNQD since 2015) have been the forerunners.

Registers on congenital anomalies are linked to Medical Birth Registers. The data collection started in the same year than the Medical Birth Register, even though Finland (1963) and Sweden (1964) started even earlier. Data on congenital anomalies are more difficult to compare due to variation in inclusion and exclusion criteria, in data collection methods, and in follow-up period. Not all registers cover pregnancy terminations due to fetal problems.

Identifying prematurely born children in easy and long-term follow-up studies are feasible, since the Nordic data protection laws allow research use of register data. However, the rules applied for secondary use of such data are very strict. Each study will be carefully evaluated: the hypothesis have to be scientifically sound and the use of register can be allowed only if the study questions can be answered by using existing register data with good completeness and high quality. Even though the Nordic countries have the personal identity codes in their registers and data linkages between different data sources are technically easy, researchers can get only anonymised (no individual can be identified) or pseudonymised (the link between personal identity codes and study numbers are kept for example by the register keeper) data.

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## Questions:

1. Which was the first Nordic country to start a Medical Birth Register
  - a) Sweden
  - b) Finland
  - c) Norway
  
2. Why it is more difficult to get comparable data on congenital anomalies
  - a) data collection methods varies
  - b) follow-up period varies
  - c) all registers do not include pregnancy terminations due to fetal problems

## Right answers:

1. a
2. a, b and c