21_WP08_04_REGISTER_DATA_IN_THE_NORDIC_COUNTRIES_METSALA_PULAKKA_SCRIPT

Abstract

We will briefly present the register data available in the RECAP project in the four Nordic countries. Some special characteristics of the data available in each country are also presented along with sources for further information

Learning aims
To be aware of the differences in the register data in different countries
To know sources for further information of the special features of the register data in different countries

Script
SLIDE 1: Title slide - no video-

SLIDE 2: Denmark (Josephine Bilsteen)

Hi, I am Josephine Bilsteen and I work with the Danish register data. For the RECAP Preterm, the key registers have been the Medical Birth Register, the National Patient Register and the Causes of Death Register. These registers were established back in 1970's, which means that for the oldest individuals we have around 40 years of follow-up. We also have information about sociodemographics from other administrative registers.

One of the main challenges with Danish registers have been, that it is not possible to transfer of share individual level data from Statistics Denmark with other research institutions. Therefor we have had to conduct very detailed analysis plan and have a researcher in Denmark to conduct the analysis.

Within the Danish registers you have great possibilities, for instance to link cohort data with register data. For instance, when the data collection ends for a cohort you can follow these individuals even for longer period in the national registers. This has been done in the ETFOL cohort of preterm children. If you want to work with the Danish register data, you should be affiliated to a Danish research institution to apply access via Statistics Denmark.

SLIDE 3: Norway (Signe Opdahl)

I will give you an overview of the study population generated by data linkage between Norwegian registries. The Medical Birth Registry is the basis of the study population, and it includes all deliveries between 1967 and 2016 in Norway. Data on all children born during this period, as well as their parents, are linked to data on causes of death from the Cause of Death registry, incident cancer diagnoses from the Cancer Registry of Norway, yearly educational level from the National Education database, and data on whether the study individuals receive welfare benefits such as a disability pension. Finally, we also have data on selected diagnoses made in specialist health care through linkage with the Patient registry, although this registry has recorded individual level data only since 2008.

To access these individual level data, you should contact the Norwegian PI (see final slide) with a specific research question. You also need approval from our regional ethical committee for medical research, from the registry-keeping authorities and from our university (NTNU). Our data are kept at an analysis server from which they cannot be exported, but you can do the analyses inside this server.

Also, be aware that approvals take time, and that you need to invest time to understand the data.

If you want to read more about Norwegian health registries and other data sources that may be relevant for medical research, you should check out the webpage https://helsedata.no/en/

SLIDE 4: Finland (Eero Kajantie)

Finland differs from the other large Nordic countries in terms of Medical Births Register, which started relatively late, in 1987. After that, Medical Birth Register caught up with other Nordic registers, and today is largely similar than in the other large Nordic countries. Much of the outcome data comes from the Hospital Discharge Register, which, in turn, started in Finland relatively early, such that inpatient stays and their ICD diagnosis codes have been recorder since 1969, and since 1998 outpatient visits in specialty health care have been recorded. Primary care is not included in this register, although since 2011 it is possible to link primary care data for the register study. However, in the RECAP register this has not been done.

There is a plethora of other register data available, just to name a few: socioeconomic census data: education, occupation, and socioeconomic status can be received from census data from Statistics Finland. It is relatively easy to link relatives, if you want to have parents, siblings, or even grandparents this is possible from the Population Register.

What is specific to Finland in regards to RECAP, is that we have also address history data, which through other geocoded databases makes it possible to study for example environmental exposures or area socioeconomic status. Another specific issue is that in addition to medication purchases we have data for special reimbursement, which you can get when you have a certain chronic disorder. Your physician writes a statement, there are specifically defined strict criteria for the special reimbursement for specific disorders. This statement is further approved by another physician at the Social Insurance Institution. This special reimbursement is usually a very specific indicator for specific diseases.

Somewhat special is the Act on Secondary Use of Social and Healthcare Data, which is now already in effect. In principle, register researchers should only be able access the data through a remote access server. However, our institution, THL, is an exception to this rule, and we are able to continue working with register data through our institution's own servers, and also to certain limit data sharing with other Nordic and possibly other European countries as well.

SLIDE 5: Sweden - no video-

SLIDE 6: More information - no video -