

The unique Nordic health registries: The case of Sweden

ISPOR, Copenhagen 2-6 November 2019

Workshop W19:

NORDIC REGISTRIES IN SAFETY STUDIES AND OUTCOME RESEARCH: USING REAL WORLD EVIDENCE. ADVANTAGES AND CHALLENGES OF POOLING REGISTER DATA FROM DENMARK, SWEDEN, FINLAND AND NORWAY.

6 November 2019



Introduction

- Welcome
- Experiences and challenges with pooling Nordic data
 - Professor Kristian Bolin - applications
 - University of Gothenburg, partner ApHER
 - Professor Lau Caspar Thygesen – example
 - University of Southern Denmark
 - Professor Anders Green - challenges
 - University of Southern Denmark, partner ApHER
- Panel discussion

Points for review

- 1 What registries are available – what information do they comprise?
- 2 The application process
- 3 Exportation of data from registry holders to researchers
- 4 Conclusions and discussion

Points for review

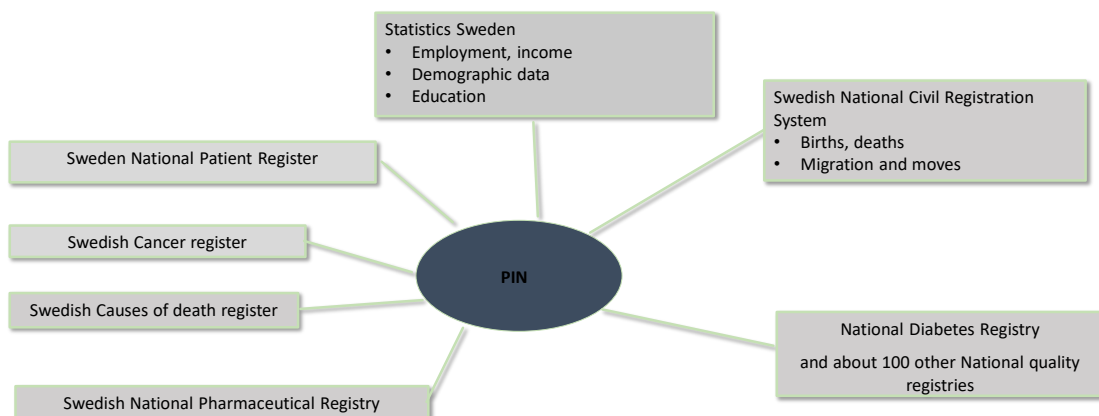
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Nordic countries

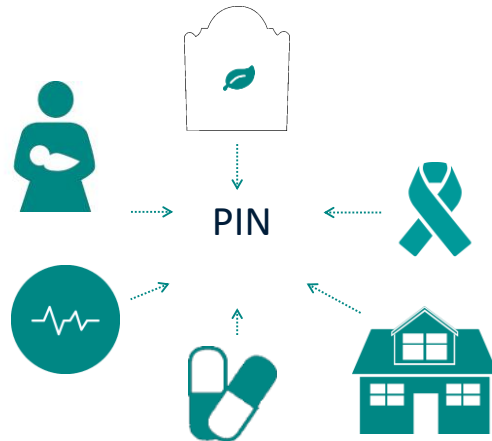
- Similar register set up
- Universal healthcare
- Publicly owned
- Possibilities for both safety and effectiveness
- ~26 million
 - Rare diseases
 - Heterogeneity
 - Natural experiment (different treatment regimes)



Registers comprising information on health, health-related behaviour, labour market behaviour, etc
Main data register holders: Statistics Sweden and the Swedish National Board of Health and Welfare



Cradle to grave



Complete history of a patient

- Long term
 - Longer than claims data
- High quality
- Other registers
 - Quality register (>100)
 - Diabetes (SE)
 - Oncology (all countries)
 - Pathology registers (DK)

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2 **The application process**

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The application

- All access to individual data must be assessed by an ethics committee.
- A research plan, including a description for how data will be handled and who will have access to the data.
- Applications and the ethics-committee approval are sent to each register
- In practise: Authorities assess whether the application is consistent with the regulation for how individual data shall be handled and processed.

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Export of data

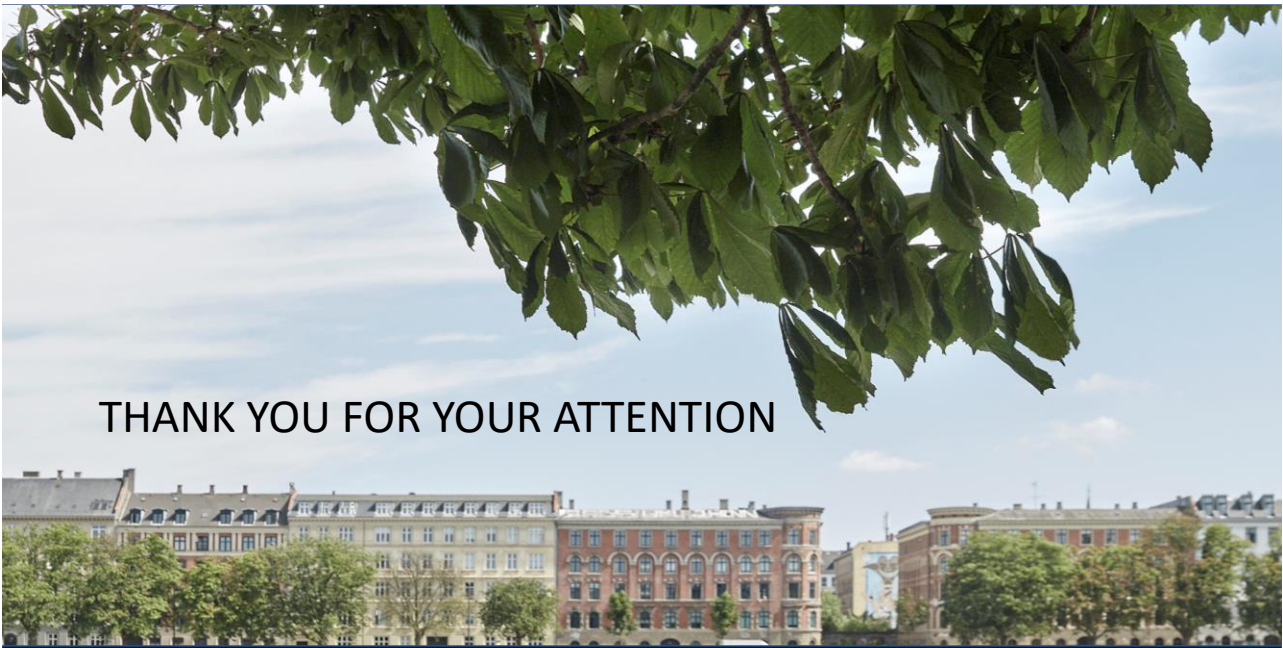
- It is possible to export data
- Important to understand:
 - Transparency
 - GDPR
 - Legal framework
- The same is true for the other Nordic countries, except Denmark
 - Study set up is done in Denmark

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CONCLUSIONS

- Individual data describing health-, health-care, labour- market behaviour, and demographic history is (readily) available
- Great care needs to be taken when formulating the applications. The registry holders are very careful when assessing applications.
- Data may be exported to a second country, which facilitates the creation of pooled Nordic research data



THANK YOU FOR YOUR ATTENTION