



Using Data Linkage to Improve Perinatal Statistics



Background

- Objective: develop capacity at the European and national levels in order to achieve high quality health reporting for mothers and babies by improving and harmonising data collection and reporting
- One problem: multiplicity of data sources used to generate indicators and their heterogeneity with respect to inclusion criteria and quality (Gissler, 2010).



Background

- Perinatal care is multidisciplinary, involving midwives, obstetricians, neonatologist, paediatricians, general practitioners and other sub-specialists. Can have separate data systems.
- Routine data collection is primarily hospital-based and often only includes information about care and outcomes in the unit where the pregnant woman delivers.
- Separate systems exist for recording specific, but related, events (example: births and deaths).



Background

- Linkage of existing data sources can improve data quality and provide a more comprehensive picture of perinatal health.
- Many European countries have integrated linkage of multiple data sources into routine reporting systems, but this is not systematic practice in EU countries.
- Aim : to identify best practices and issue recommendations about data linkage procedures with the aim of improving perinatal health surveillance.

Objectives of literature review

- **General objective:** to describe the perinatal and maternal health studies which use record linkage as a way of collecting and/or improving their data.
- **Specific objectives**
 - Describe the types of data sources used for linkage studies;
 - Identify themes explored in studies using linkage;
 - Identify national/regional systems that use linkage routinely.
 - Describe linkage methods (nominative, probabilistic) and methodological issues (success rate (% of cases linked), biases, privacy/confidentiality issues, ...)



Methodology: systematic review

- **The search was based on:** PubMed and consultation with Euro-Peristat SC members and data providers
- **We used the following terms:**
 - Mesh terms: birth certificates, infant newborn, medical record linkage
 - Key words: data linkage, perinat*, matern*, link*, registr*
- **We extracted data based on:** country of publication, type of datasource used, themes explored



Methodology: systematic review

■ Inclusion and Exclusion criteria:

Our inclusion criteria were the following:

- Study exploring maternal and/or infant health
- Available abstract
- Published in the last ten years
- Linking two or more national registries or cohort data linked to one other registry

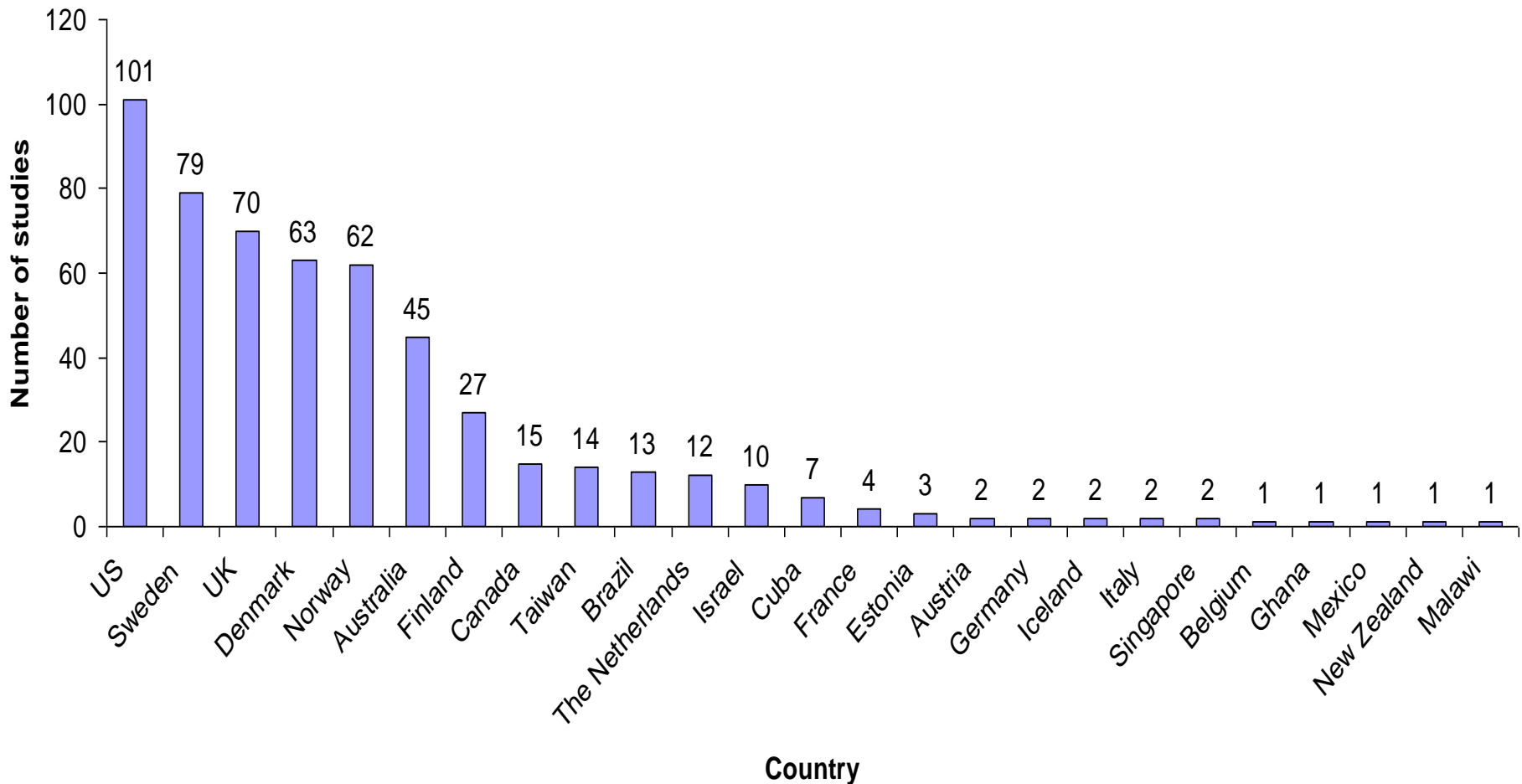
Our exclusion criteria consisted of:

- studies unrelated to perinatal/maternal health
- reviews, conference reports or other types of summaries

■ **Final yield:** n= 530 studies

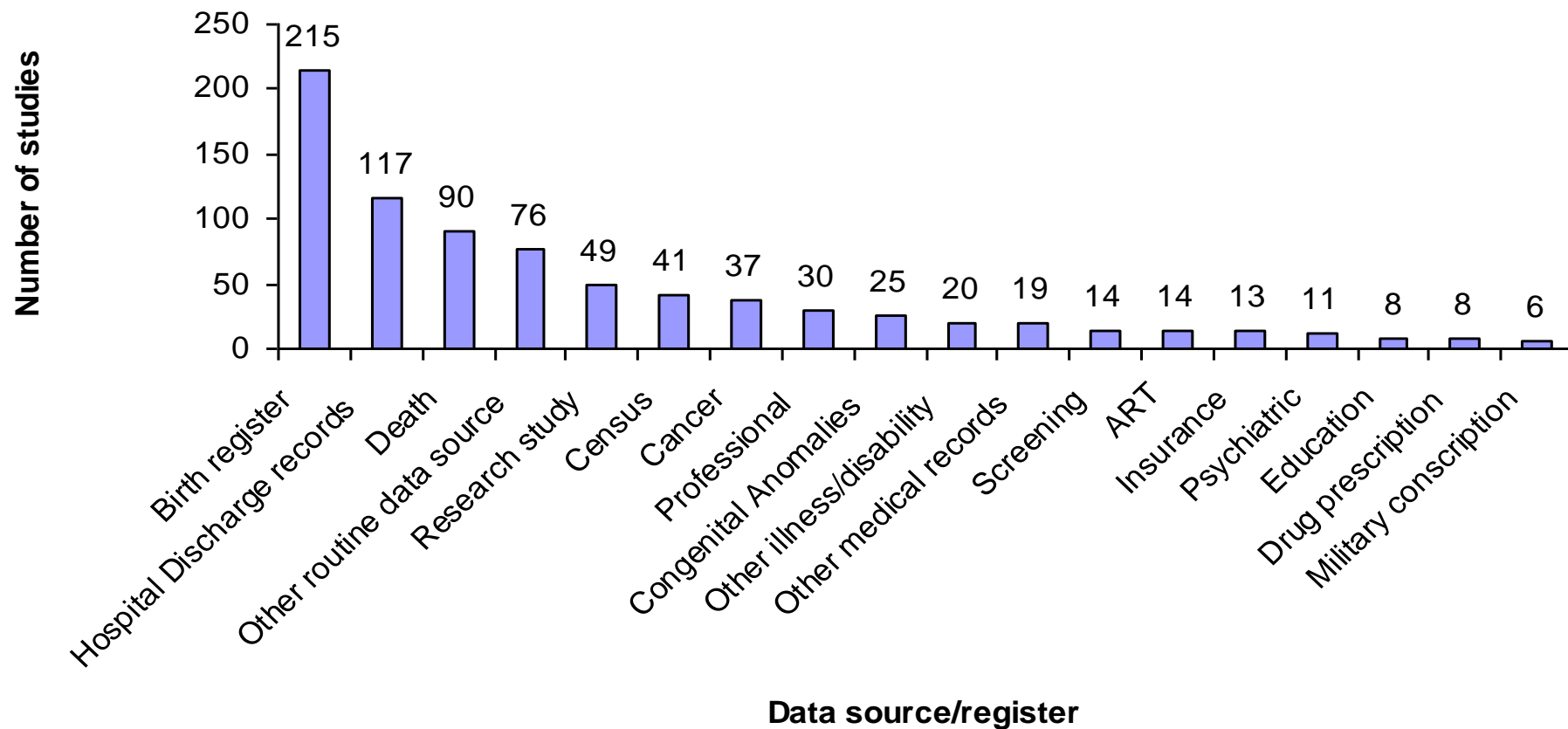
Preliminary Results: by country

Record linkage studies by country



Preliminary results: by data source

Record linkage studies by data source





Other routine data sources:

- Stillbirth registers
- Twin registers
- Induced abortion register
- Multigeneration register
- Child abuse register
- Geographic, economic and environmental data

Variations in register use: US vs. Nordic countries (Denmark, Finland, Norway, Sweden) vs. UK

US Registers	Studies US	Nordic Registers	Nordic Studies	UK Registers	UK Studies
Birth register	46	Birth register	81	Hospital Discharge records	38
Death	24	Hospital Discharge records	37	Birth register	27
Hospital Discharge records	17	Other routine data source	26	Death	23
Cancer	13	Census	18	Other routine data source	20
Other routine data source	10	Death	15	Research study	16
Congenital Anomalies	6	Research study	13	Census	11
Other medical records	5	Other illness/disability	10	Professional	8
Census	3	ART	10	Screening	6
Insurance	3	Cancer	8	Cancer	5
Research study	2	Education	8	Other medical records	4
Screening	2	Drug prescription	7	Congenital Anomalies	1
ART	2	Other medical records	6	Other illness/disability	1
Psychiatric	2	Psychiatric	6	Psychiatric	1
		Congenital Anomalies	5	Drug prescription	1
		Military conscription	6		
		Professional	2		
		Screening	1		



Limitations

- Countries' use of various terminologies for their registries makes their differentiation sometimes imprecise (i.e: Morbidity database vs hospital records)
- In countries where specific data sets are linked routinely, authors might not mention “linkage” within the abstract (Finland – 100 new articles!)

Questions and discussion

- Have you participated in any initiatives linking different routine data sources? Which themes were explored? What challenges might you have encountered?
- Is anybody interested in being part of the analysis of the review?

