Improving perinatal statistics using data linkage: a review of the literature

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### Background

- Many European countries have integrated data linkage into their routine surveillance systems but this is not systematic practice within the EU
- Data linkage procedures have been used to improve data quality and help provide a more comprehensive picture of perinatal health within countries – but how?

### Objectives of the review

- Describe the types of data sources used within countries (SC Jan 2012 meeting)
- Identify themes explored in studies
- Describe linkage methods and methodology issues

### Preliminary results

• Gross analysis of themes:

Birth outcomes, cognitive outcomes, delivery, health service use, healthcare policy, infant morbidity, infant mortality, long term outcomes, maternal health during pregnancy, maternal mortality, maternal morbidity, methodology, perinatal risk factors, reproductive outcomes, screening,...

Studies collapsed into 16 categories but too subjective, especially since categories often overlap (i.e. preterm delivery -> delivery?,infant morbidity?)

Best to use a more detailed and straightforward approach:

- Main outcome
- Independant variable

# Preliminary results by main outcome

• Top 10 applications of data linkage:

108 individual main outcomes (N=535 studies).

Main Outcome	Studies (n)	
mortality		70
improved data quality		57
cancer	!	52
pregnancy outcomes (length, unspecified)	4	42
psychosocial/affective disorders		26
congenital anomalies		21
infant death/adverse outcomes		20
auto-immune diseases		19
other morbidity		16
hospitalisation		13
TOTAL	33	36

# Preliminary results by Independant variable

132 IVs (N=525 studies)

Independant variable	Studies (n)
perinatal risk factors (multiple, unspecified)	83
linkage	40
drug use	22
congenital anomalies	22
teratogens	21
birth characteristics unspecified	20
socio-economic factors	16
pregnancy (unspecified)	16
birthweight	15
psychosocial/affective disorders	14
cancer	12
ART	12

#### Next steps

- Validating coding
- Identifying recurrent linkage types (i.e. medical birth registry and death records or hospital discharge and cohort data)
- Identifying original linkages and contacting authors with expertise in the field of linkage as applied to perinatal health..

Limits:

- Inclusion criteria: "linkage", identifying researchers
- Terminology of datasources
- Also, while linkage can improve perinatal health surveillance, linkage of records is not always possible due to political and economical constraints.