

Linkage of birth data in Europe

Marie Delnord
EPOPé INSERM



BETTER STATISTICS FOR BETTER HEALTH
for pregnant women and their babies

Perinatal health data sources

- Perinatal care is multidisciplinary :
Involves midwives, obstetricians,
paediatricians, and other sub-specialists.
- Data are often held in separate registers
e.g. UK: 17 data sources for EPHR2010
- Variations in coverage, inclusion criteria
and data quality

Gissler M, Mohangoo A, Blondel B, Chalmers J, Macfarlane A, Gaizauskiene A, Gatt M, Lack N, Sakkeus L, Zeitlin J for the EURO-PERISTAT group: Perinatal health monitoring in Europe: results from the EURO-PERISTAT project. Informatics for Social and Health Care 35 (2): 64-79, 2010.

Data linkage

- Has been shown to improve the validity and quality of data held in national registries.¹
- To improve the ascertainment of short and long term maternal and infant outcomes¹⁻³.

To what extent routine data sources are linked for perinatal health research and reporting in Europe?

What impact on data availability of Euro-Peristat indicators?

1. Gissler M, Mohangoo A, Blondel B, Chalmers J, Macfarlane A, Gaizauskiene A, Gatt M, Lack N, Sakkeus L, Zeitlin J for the EURO-PERISTAT group: Perinatal health monitoring in Europe: results from the EURO-PERISTAT project. *Informatics for Social and Health Care* 35 (2): 64-79, 2010. 3
2. Bouvier-Colle MH, Mohangoo AD, Gissler M, Novak-Antolic Z, Vutuc C, Szamotulska K, et al. What about the mothers? An analysis of maternal mortality and morbidity in perinatal health surveillance systems in Europe. *BJOG : an international journal of obstetrics and gynaecology*. 2012;119(7):880-9; discussion 90.
3. Henningsen AK, Romundstad LB, Gissler M, Nygren KG, Lidegaard O, Skjaerven R, et al. Infant and maternal health monitoring using a combined Nordic database on ART and safety. *Acta obstetrica et gynecologica Scandinavica*. 2011;90(7):683-91.



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Linking databases on perinatal health: a review of the literature and current practices in Europe

M. Delnord, K. Szamotulska, A.D. Hindori-Mohangoo, B. Blondel, A.J. Macfarlane, N. Dattani, C. Barona, S. Berrut, I. Zile, R. Wood, L. Sakkeus, M. Gissler, J. Zeitlin,

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- **Exhaustive review of the literature on the use of data linkage in perinatal health research, 2001-2011**
 - N=516 studies
 - Types of routine data sources used, maternal and child health outcomes studied, linkage techniques
- **Identified countries where linkages are done routinely**

Table 1 Description of perinatal health record linkage studies included in review, *N*=516

Characteristics of studies	N	%
Year of publication		
2001–2002	48	9.3
2003–2004	58	11.2
2005–2006	90	17.4
2007–2008	112	21.5
2009–2011	208	40.5
Country		
Nordic countries ^a	223	43.2
US	99	19.2
UK	63	12.2
Australia	43	8.3
Canada	18	3.5
Taiwan	14	2.7
Brazil	14	2.7
Netherlands	12	2.3
Other countries with 1–11 studies ^b	30	5.8
No. of data sources		
1 ^c	9	1.7
2	293	56.8
3	134	26.0
4 or more	80	15.5
Linkage types		
Vital statistics: birth and death certificates	101	19.6
Vital statistics and hospital discharge data ^d	90	17.4
Medical birth register (MBR) and hospital discharge data	89	17.2
Vital statistics and MBR	45	8.7
Other ^e	191	37.0
Longitudinal study	257	50.0

a: Nordic countries include Denmark, Finland, Norway and Sweden.

b: Countries include 21 EU member states, Switzerland, Singapore, China, Cuba, Ghana, Malawi, Mexico and New Zealand.

c: Linkage of mother and baby records within the same registry, or

Routine linkages and data availability EPHR2010

Countries who use linkage	Countries who do not use linkage
Austria	Belgium
Cyprus	Denmark
Czech Republic	Greece
Estonia	Hungary
Finland	Ireland
France	Italy
Germany	Lithuania
Iceland	Portugal
Latvia	Romania
Luxembourg	Slovakia
Malta	Spain
Netherlands	UK : Northern Ireland
Norway	United Kingdom
Poland	
Slovenia	
Sweden	
Switzerland	
UK: England and Wales	
UK :Scotland	

Countries with routinely linked data systems produced: **9 core and 16 recommended** indicators, on average

Countries without routinely linked data systems produced: **8 core and 10 recommended** indicators.

Conclusion

- Linkage of routine data systems is a readily available option to develop capacity for high quality perinatal health monitoring.
- This is done in only a limited number of countries.
- Promotion of linkage is a priority for Euro-Peristat's future work.
- **Broader adoption of linkage techniques can yield substantial gains for research and surveillance of perinatal health both nationally and internationally.**

Data linkage survey 2016, N=17

- Czech Republic
- Lithuania
- Belgium wiv-isp
- Ireland
- Cyprus
- Iceland
- Sweden*
- Wales
- Switzerland *
- Spain
- Finland*
- Norway
- Slovenia*
- Germany*
- Italy
- UK: England and Wales*
- UK:Scotland*

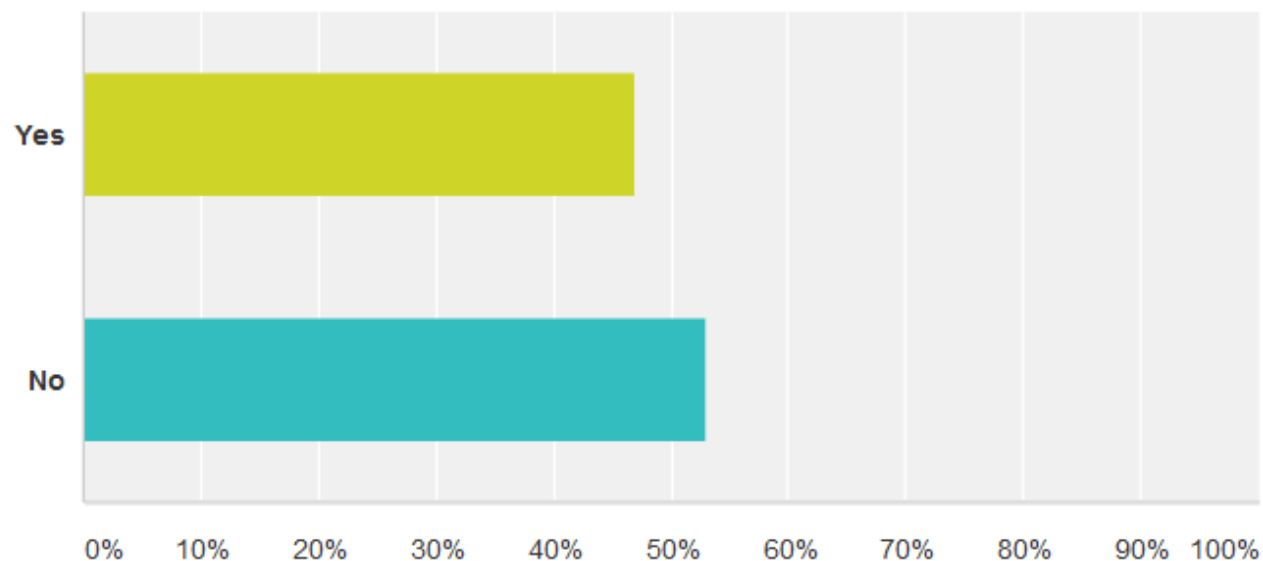
Q3

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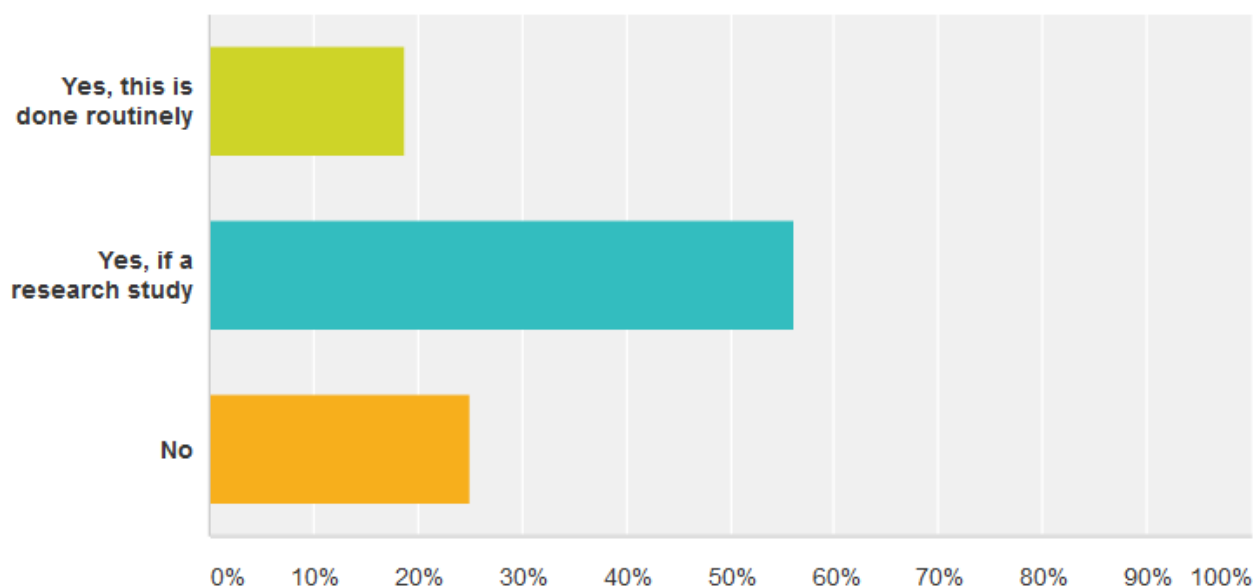
Since the last data collection round, have there been any new routine linkage of birth data or are there plans to implement new linkages?

Answered: 17 Skipped: 0



Is it possible to link birth data to routine sources of data on the person's health, use of health services in childhood or adulthood, or health-related benefits (e.g. disability allowances)?

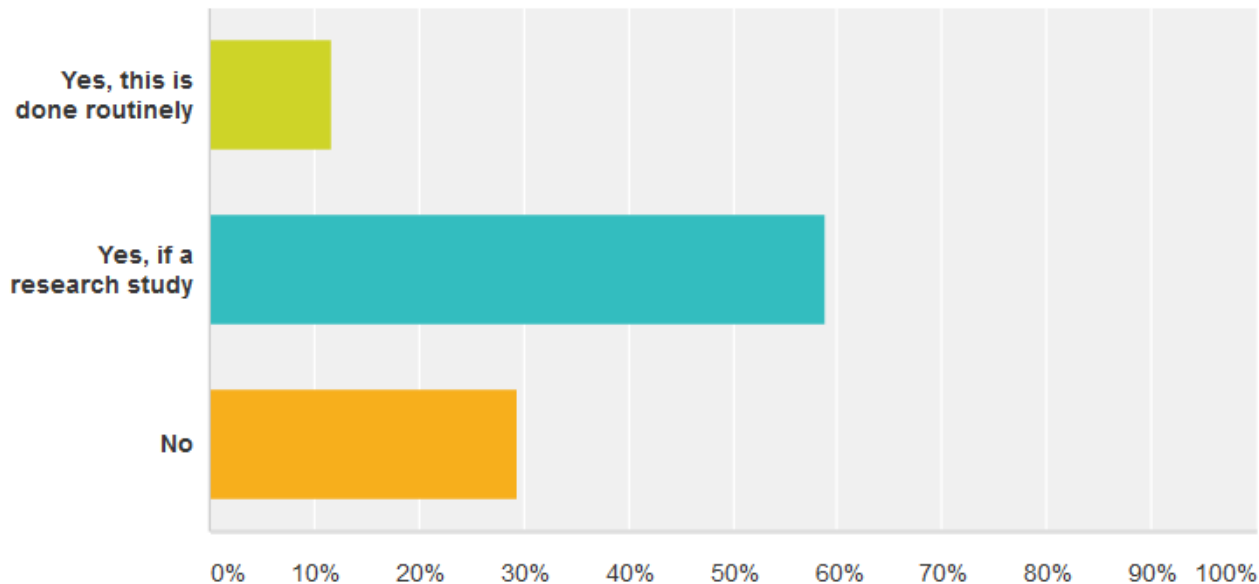
Answered: 16 Skipped: 1



Answer Choices ▾	Responses ▾
▾ Yes, this is done routinely	18.75% 3
▾ Yes, if a research study	56.25% 9
▾ No	25.00% 4

Is it possible to link data on pregnant women/mothers to data on their later health, use of health services, or health-related benefits (e.g. disability allowance)

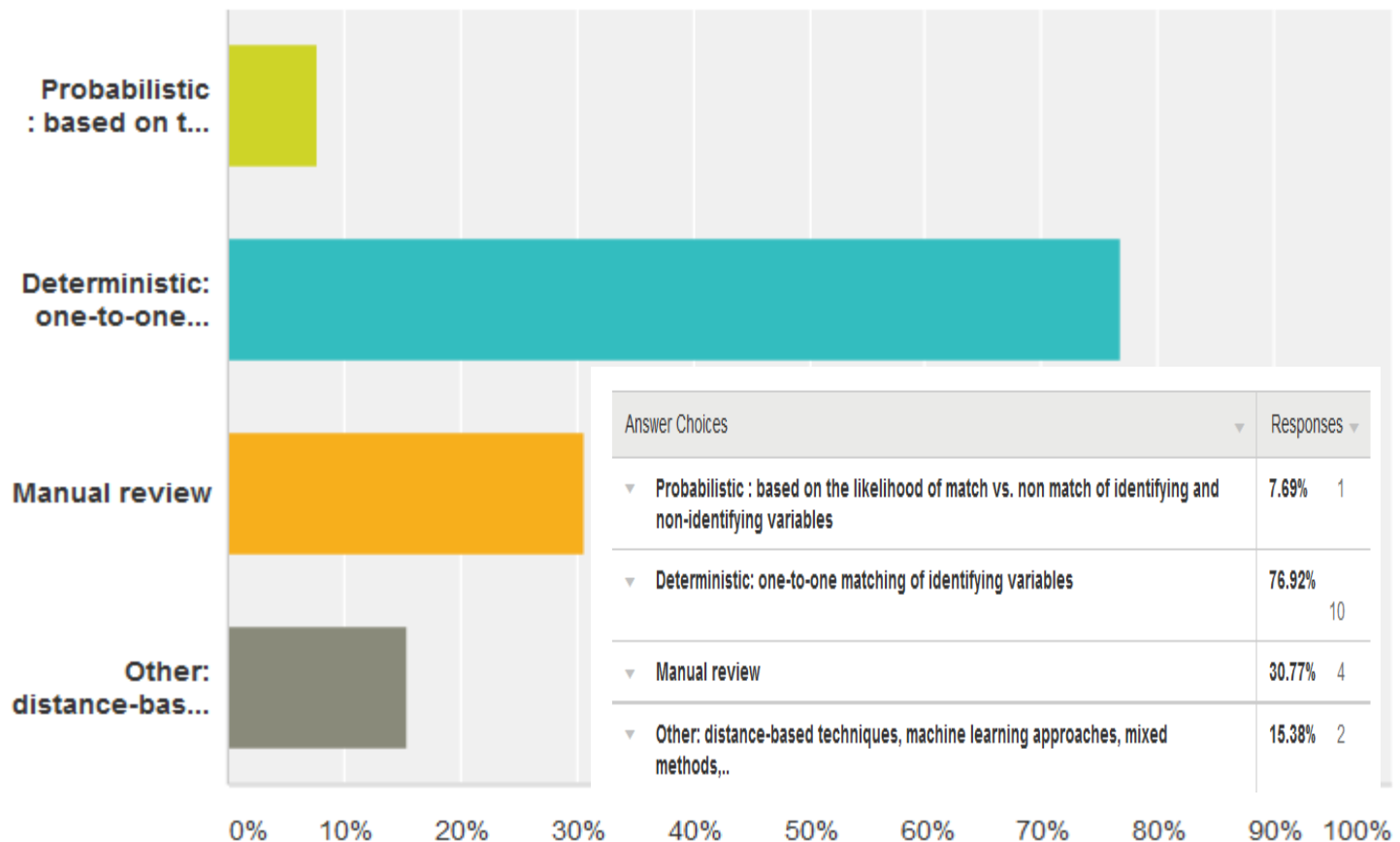
Answered: 17 Skipped: 0



Answer Choices ▾	Responses ▾	
▾ Yes, this is done routinely	11.76%	2
▾ Yes, if a research study	58.82%	10
▾ No	29.41%	5
Total		17

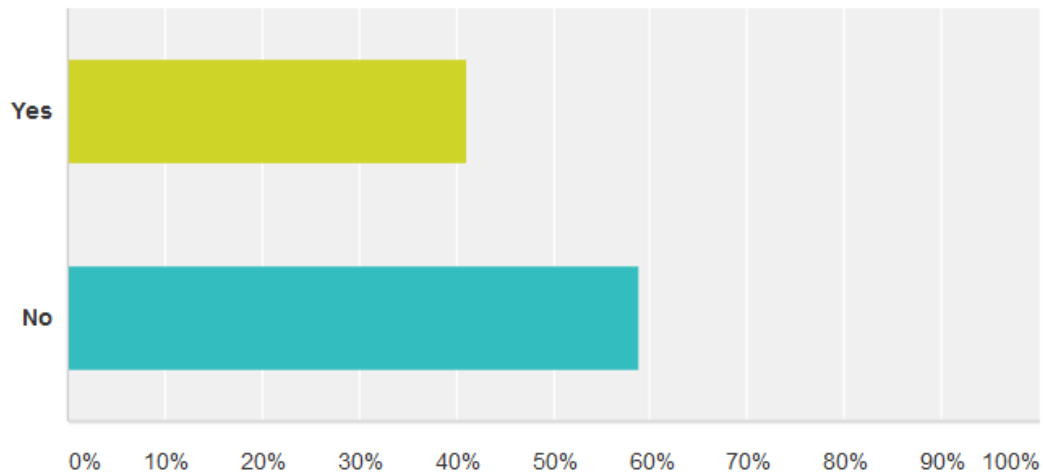
If data on births are linked to routine databases, what are the types of matching techniques used in your country?

Answered: 13 Skipped: 4



**Do you know if any birth cohorts
(longitudinal studies of people starting in
pregnancy/birth into childhood and
adulthood) have ever been linked with
routine data in your country?**

Answered: 17 Skipped: 0



Answer Choices ▾	Responses ▾	
▾ Yes	41.18%	7
▾ No	58.82%	10
Total	17	

Cohorts

- Millenium Cohort study, UK
- INMA cohort (*environmental exposures*), Spain
- Growing Up in Scotland longitudinal survey (*health and level of education data*)
- Norwegian mother and child cohort study
- Finish Birth Cohort 1987

Supplementary slides

Distance-based record linkage methods

- Simple to implement and to operate.
- Consists of computing distances between records in the two data files being considered
- In particular, distances for categorical variables (in ordinal and nominal scales) are required.
- Allows the inclusion of subjective information (about individuals or variables) in the re-identification process.

Searched PubMed for linkage studies on maternal or perinatal health between 2001 -2011

5 different searches based on permutations of our key words : medical record linkage, infant newborn and birth certificates, data linkage, perinat*, matern*, link*, registr*. **N= 990**



Excluded genetic studies unrelated to linkage or perinatal health (searched for “gene”), N= 805

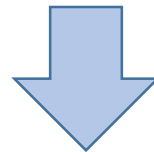


Excluded reviews, commentaries (searched for “review”), N = 763



Excluded duplicates + manual screen of studies based on titles and abstracts :

- **Use of original data**
- **Risk factors, determinants and/or outcomes occurred during the perinatal period**
- **Use of linkage: 2+ routine databases or a cohort study to a routine database(s)**



We extracted:

- types of routine data sources used
- study outcome variables



N= 525

Validation by a second author prior to data analysis.

Table 3 Primary outcomes in perinatal health studies using record linkage, *N* = 516

Theme	Main outcomes	N	%
Fetal, neonatal and child health	Perinatal period	152	
	Stillbirth, neonatal or infant mortality	61	11.8
	Congenital anomalies	20	3.9
	Preterm birth, SGA, LBW and other health outcomes with or without mortality	71	13.8
	Longer term outcomes	190	
	Child health and development	84	16.3
	Cancer	33	6.4
	Auto-immune diseases: diabetes, asthma, allergies during childhood or adulthood	23	4.5
	Other adult health issues	50	9.7
	Maternal health	40	
	Perinatal period	40	
	Maternal mortality/severe morbidity	8	1.6
	Other maternal health outcomes	25	4.8
	Mode of delivery/obstetric management	7	1.4
	Longer term outcomes	61	
	Women's health pre-conception or more than 1 year post delivery	16	3.1
	Cancer	19	3.7
	Auto-immune diseases	3	0.6
	Other health issues	23	4.5
Methods studies^a		73	14.1

a: Includes studies focused on validating data through record linkage use, or on usage of specific data linkage techniques.

SGA: small for gestational age, LBW: low birth weight