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

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**Background:** International comparisons of perinatal health indicators are complicated by the heterogeneity of data sources on pregnancy, maternal and neonatal outcomes. Record linkage can extend the range of data items available and thus can improve the validity and quality of routine data. We sought to assess the extent to which data are linked routinely for perinatal health research and reporting. **Methods:** We conducted a systematic review of the literature by searching PubMed for perinatal health studies from 2001 to 2011 based on linkage of routine data (data collected continuously at various time intervals). We also surveyed European health monitoring professionals about use of linkage for national perinatal health surveillance. **Results:** 516 studies fit our inclusion criteria. Denmark, Finland, Norway and Sweden, the US and the UK contributed 76% of the publications; a further 29 countries contributed at least one publication. Most studies linked vital statistics, hospital records, medical birth registries and cohort data. Other sources were specific registers for: cancer (70), congenital anomalies (56), ART (19), census (19), health professionals (37), insurance (22) prescription (31), and level of education (18). Eighteen of 29 countries (62%) reported linking data for routine perinatal health monitoring. **Conclusion:** Research using linkage is concentrated in a few countries and is not widely practiced in Europe. Broader adoption of data linkage could yield substantial gains for perinatal health research and surveillance.

## Introduction

International comparisons of perinatal health indicators provide valuable evidence for public policy planning and practice by allowing benchmarking across countries, and revealing the diversity in clinical practice related to antenatal and delivery care.<sup>1,2</sup> In Europe, recent results from the European Perinatal Health Report 2010 (EPHR 2010) showed wide differences in health outcomes and indicators of clinical practice. For example in 2010, stillbirth rates ranged from 2.0 to 4.0 per 1000 births and cesarean section rates ranged from 13% to 47% of total births.<sup>1,3–5</sup>

International comparisons are limited by the quality and completeness of information held in national data systems however. The EPHR 2010, which reported on population-based aggregate data from 26 EU Member States, plus Iceland, Norway and Switzerland<sup>6</sup> showed gaps in data availability of many

key indicators. For instance, only 19 out of 29 countries had data on the gestational age distribution of neonatal deaths, 17 on smoking during pregnancy and 5 on severe maternal morbidity.<sup>7</sup> To compile the Euro-Peristat indicators, countries used multiple data sources: birth certificates, death certificates, medical birth registers, specific registers or audits, hospital discharge data, professional databases and surveys. These varied in their inclusion criteria and data quality, raising questions about comparability.<sup>1,6</sup>

Record linkage between health, civil and administrative data systems is one way to increase the completeness, quality and breadth of data available for perinatal health monitoring and research. Linkage is the term used to describe the process of merging individual records from two or more datasets in order to extend the range of data items available.<sup>6</sup> Linked data have been used to generate knowledge and investigate the association between

population risk factors and a wide array of both maternal<sup>7,8</sup> and infant health outcomes.<sup>9–11</sup> However, there is currently no information on the extent to which linkage is used in Europe for surveillance and research. In this study, our objectives were to assess: the types of linkage done for perinatal health research and monitoring, the maternal and infant health themes and outcomes explored in research using linkage, and potential gaps in current record linkage practices in European countries.

## Methods

This study was based on data from a systematic review of publications on linkage, and on information collected within the Euro-Peristat project about the use of linkage in routine perinatal health monitoring.

### *Review of publications based on linked data from routine sources*

#### Search strategy

We searched PubMed for perinatal health studies based on linkage of routine data sources published between 2001 and 2011. Routine data sources are those that collect information continuously or regularly (in the case of surveys). We used the following key words: data linkage, perinat\*, matern\*, link\*, registr\*, medical record linkage, infant newborn and birth certificates. Publications were screened by the first author based on information provided in the titles and abstracts. We identified 990 studies from which we excluded conference reports, summaries and reviews. We did not include studies with data that are not regularly repeated. We included research related to the perinatal period: pregnancy, delivery and the post-partum, which linked two or more routine datasets together or paired mother and newborn records within the same data collection system. Studies linking pregnancy or birth cohorts to routine datasets were included. To increase coverage, we contacted Scientific Committee (SC) members of the Euro-Peristat network for any additional research articles that we might have missed from their countries. Our final sample included 516 studies. More information on search terms and the database are available from the authors on request.

#### Data extraction

From each study, we extracted the types and number of routine data sources used, the main outcome variables, the dependent variables, country of origin and year of publication. Principal types of sources were: civil registration (birth and death certificates), hospital discharge data (i.e. admissions, inpatient and other medical records) and medical birth registers (which hold birth data augmented with clinical information about each delivery and birth).<sup>1</sup>

We described how linkage was used in perinatal health research by classifying publications according to themes and linkage types within countries and by year. We categorized studies based on their outcome variables into the following research themes: (i) fetal, neonatal and child health, (ii) maternal health and (iii) methods – this theme included studies focused on validating data through record linkage use, or on usage of specific data linkage techniques such as probabilistic vs. deterministic methods. We further assessed which of our included studies were longitudinal. We flagged studies as ‘longitudinal’ when researchers studied the impact of health events outside the perinatal period (i.e. exposure to environmental risk factors during pre-conception) on outcomes during the perinatal period (i.e. birth weight), or when researchers studied the influence of perinatal risk factors (i.e. preterm birth) on longer term maternal or child health outcomes (i.e. educational attainment). Data extraction was carried out by the first author and validated by the co-authors.

## Analysis

We identified recurrent and less common linkages based on the types of data sources used, such as linkage of vital statistics data and medical birth register data, and how often these were linked across studies. All original data sources were accounted for in the analyses. In the Netherlands for instance, birth data held in the medical birth register are compiled from data held in the obstetric, paediatric and neonatal registers. Similarly, linked datasets such as the Oxford Record Linkage Study were described in terms of their constituent datasets (i.e. linkage of civil registration data, hospital discharge data and domiciliary midwives case notes). Data were analyzed using STATA 13.0 software (StataCorp LP, College Station, TX). We used the software to describe the overall characteristics of the studies included in this review such as the time period, country, or the topic area, and also to identify and keep track of the different possible types of linkages available in the literature and their associated study outcomes.

### *Data on routine linkages from the Euro-peristat network*

We used data collected for the EPHR 2010 supplemented by additional information from the Euro-Peristat Scientific Committee (SC). Euro-Peristat indicators were compiled from routine aggregate data available from population-based registers. As part of the data collection exercise, SC members were asked to describe the characteristics of their national data systems and in particular: inclusion criteria, year in which the data source began, estimates of coverage (i.e. nationals vs. residents), capacity and use of linkage, and plans to modify or extend the data source.

SC members were also asked to confirm the availability in routine of the most prevalent linkage types identified in our review of the literature: (i) linkage of birth and death certificates, (ii) vital statistics and medical birth register data, (iii) medical birth register data and hospital discharge data and (iv) vital statistics and hospital discharge data. In our study, vital statistics data included: birth certificates, death certificates and/or data on causes of death. We identified hospital discharge data, as all data extracted from admissions, inpatient care or other clinical records (i.e. maternity records or pediatric records). SC members could specify any other routine linkage available in their country which might not have been recorded for the Euro-Peristat data collection.

## Results

Table 1 shows that there were wide variations in the use of record linkage in perinatal health research between 2001 and 2011. There was a very strong increase in publications which linked perinatal health data over time and there were also large differences in the number of studies each country contributed, the number of routine data sources used and the types of linkage which were done.

The use of record linkage increased steadily between 2001 and 2011 and 41% of the articles were published between 2009 and 2011. Three quarters of the studies were from a selected few countries namely the Nordic countries (in particular Denmark, Finland, Norway and Sweden), the US and the UK which contributed 43%, 19% and 12% of the publications, respectively. Australia and Canada contributed another 12% of the studies but other countries contributed many fewer; twenty two European countries published between 1 and 11 studies accounting all together for about 5% of our study sample. We compared the distribution of studies by groups of countries (Nordic, US, UK and other) between two time periods (2001–2006 and 2007–2011) and it was similar ( $P = .224$ ). The number of routine data sources used varied between 1 (i.e. when mother and newborn records were paired within the same data source) and 7 (mainly in the Nordic countries), but most studies used 2–3 data sources. The majority of

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

Characteristics of studies	N	%
<b>Year of publication</b>		
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
<b>Country</b>		
Nordic countries <sup>a</sup>	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 <sup>b</sup>	30	5.8
<b>No. of data sources</b>		
1 <sup>c</sup>	9	1.7
2	293	56.8
3	134	26.0
4 or more	80	15.5
<b>Linkage types</b>		
Vital statistics: birth and death certificates	101	19.6
Vital statistics and hospital discharge data <sup>d</sup>	90	17.4
Medical birth register (MBR) and hospital discharge data	89	17.2
Vital statistics and MBR	45	8.7
Other <sup>e</sup>	191	37.0
<b>Longitudinal study</b>	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 linked birth and death files from the same data source.

d: Hospital discharge data includes inpatient data and other medical records.

e: 'Other' linkage types exclusive to studies for which vital statistics, medical birth registry and hospital discharge data were not included in the record linkage (cf. Table 2).

studies merged vital statistics data and hospital discharge data, but other linkage types were also identified.

Table 2 shows the wide variety of linkage types performed in perinatal health research between 2001 and 2011; we display the distribution of perinatal health record linkage studies for which at least two distinct types of routine data sources were used. We identified 16 types of data sources in the literature and tabulated all two-by-two linkages between these data sources as well as the total number of studies in which each type of data source was used. For example, in a Swedish study that linked three population-based data sources (the Medical birth register (MBR), hospital discharge data and the Prescription drug register),<sup>12</sup> we counted the following two-by-two linkages: (i) MBR with Hospital discharge data, (ii) MBR with Prescription drugs register and (iii) Prescription drugs register with hospital discharge data. Linkages were distributed unevenly across routine data sources. The 254 linkages involving vital statistics data were the most common. Next, 219 linkages with medical birth registers and 203 with hospital discharge data provided more detailed data on pregnancy, delivery and the postpartum; and finally, studies linking socio-economic data from other sources, e.g. census data, were the least prevalent.

In table 3, we present the themes explored in the literature using linkage based on studies' main outcome variables and their timing of occurrence. About 62% of studies focused on infant health outcomes, 20% of studies focused on maternal health outcomes and 14% of studies focused on use of linkage to validate data quality and completeness, and on the accuracy of methods for linking perinatal data. Nearly 40% of maternal and infant health studies were longitudinal and examined health issues and associations outside of the perinatal period.

Among the 342 infant health studies, 60% focused on perinatal issues such as fetal, neonatal or infant mortality, congenital anomalies, preterm births, births small-for-gestational age and low birth weight. Linkage techniques were also used to study longer term outcomes such as child health, need for health services, highest level of education, motor and cognitive development of babies born at-risk of adverse outcomes such as very preterm births, diabetes, asthma and adult mental health issues. For example in an English

**Table 2** Distribution of perinatal health record linkage studies for which at least two distinct types of routine data sources were used; *N* = 2172 two by two linkages in *N* = 516 studies<sup>4</sup>

Data Source n° 2	Data Source no. 1															
	VS	MBR	HD	POP	Cohort	Cancer	CA	PROF	DRUGS	ID	PSY	Insurance	ART	Census	EDU	Screening
Vital Statistics (VS) <sup>a</sup>	–															
Medical birth register (MBR)	45	–														
Hospital discharge data (HD) <sup>b</sup>	90	89	–													
Other population register (POP)	45	52	50	–												
Cohort study	18	31	27	14	–											
Cancer register	42	11	21	10	11	–										
Congenital anomalies register (CA)	32	22	19	6	6	4	–									
Health professional register (PROF) <sup>c</sup>	13	26	18	8	2	3	9	–								
Prescription drugs register (DRUGS)	5	22	15	6	5	1	5	3	–							
Illness/Disability register (ID)	5	25	7	4	1	2	3	5	2	–						
Psychiatric register (PSY)	9	7	8	11	7	3	3	3	2	1	–					
Insurance	14	8	4	4	0	1	2	0	3	0	0	–				
ART register (ART)	6	10	8	3	1	3	2	0	1	0	0	1	–			
Census	12	9	5	11	0	3	0	1	0	0	1	0	0	–		
Register on level of education (EDU)	9	18	4	6	1	0	2	0	0	1	0	1	1	1	–	
Screening register	10	6	7	0	2	1	5	3	0	0	1	0	0	0	0	–
<b>N 2x2 linkages<sup>d</sup></b>	<b>355</b>	<b>381</b>	<b>372</b>	<b>230</b>	<b>126</b>	<b>116</b>	<b>120</b>	<b>94</b>	<b>70</b>	<b>56</b>	<b>55</b>	<b>39</b>	<b>36</b>	<b>43</b>	<b>44</b>	<b>35</b>
<b>N studies<sup>d</sup></b>	<b>254</b>	<b>219</b>	<b>203</b>	<b>96</b>	<b>80</b>	<b>70</b>	<b>56</b>	<b>37</b>	<b>31</b>	<b>29</b>	<b>22</b>	<b>22</b>	<b>19</b>	<b>19</b>	<b>18</b>	<b>18</b>

a: Birth records, death records and cause of death data.

b: Hospital discharge data includes inpatient data and other medical records.

c: Includes registries with data on pregnancy, delivery and/or the postpartum maintained by health professionals (i.e. Midwives' register of New South Wales, NVK: Paediatric Association of the Netherlands).

d: Studies sometimes linked more than 2 databases which explains why there are more 2 × 2 linkages than number of studies per data source.

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

Theme	Main outcomes	N	%
Fetal, neonatal and child health	<b>Perinatal period</b>	<b>152</b>	
	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
	<b>Longer term outcomes</b>	<b>190</b>	
	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	<b>Perinatal period</b>	<b>40</b>
Maternal mortality/severe morbidity		8	1.6
Other maternal health outcomes		25	4.8
Mode of delivery/obstetric management		7	1.4
<b>Longer term outcomes</b>		<b>61</b>	
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
<b>Methods studies<sup>a</sup></b>		<b>73</b>	<b>14.1</b>

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

study, a cohort of 248 612 births from 1970 to 1989 in parts of the former Oxford Region in Southern England was linked to records of subsequent hospital admission for 4017 children with asthma up to 1999.<sup>13</sup> A study in Denmark looked at the association between congenital anomalies and social position among 19 874 women.<sup>14</sup> A Norwegian study analyzed the mental health outcomes of children with congenital heart defects from age 6–36 months in a cohort of 44 104 children.<sup>15</sup> Linkage techniques have also been particularly useful for childhood cancer research<sup>16–25</sup> and to study specific conditions such as: Legg Calve Perthes disease,<sup>26</sup> cerebral palsy,<sup>27–30</sup> epilepsy,<sup>31–34</sup> neonatal encephalopathy,<sup>35</sup> infantile hypertrophic pyloric stenosis<sup>36,37</sup> and schizophrenia.<sup>38–49</sup>

Among the 101 maternal health studies, 57% examined mothers' health status during the perinatal period; these publications focused on maternal morbidity (i.e. multiple sclerosis,<sup>50–53</sup> thyroiditis,<sup>54,55</sup> toxoplasmosis<sup>56</sup>), mortality, obstetric management, mode of delivery and other pregnancy complications. Record linkage was also used to study women and mothers' long term health outcomes. For example, a study in Sweden examined reproductive patterns and pregnancy outcomes of women with congenital heart disease in a population-based study of 500 245 women.<sup>57</sup> Other studies looked at pregnancy outcomes and selected conditions later in life such as hypertension and diabetes.

Among studies on methods in record linkage as applied to perinatal health, 42 focused on improvement of data quality, and other studies focused on the ascertainment of maternal and infant health outcomes, 13 and 18, respectively. Among these methods studies, 36 validated population estimates and 23 validated data items. A further 14 focused on the methods for extending routine data to serve other functions such as pharmacological surveillance and research on child abuse. From these studies, we identified procedures related to the general ascertainment of births, including underreporting of births at early gestations, completeness of population coverage and identification of multiple births. There

**Table 4** Routine linkage of perinatal health data in 2014 in 26 EU Member States<sup>1</sup>, Norway, Switzerland and Iceland by type of data linked<sup>2</sup>

Type of linkage <sup>2</sup>	Countries participating in Euro-Peristat		
	N	%	Countries
<b>Births and hospital discharge data</b>			
Birth certificates & hospital discharge data	2	7%	Sweden, UK: Scotland <sup>1</sup>
Medical birth register & hospital discharge data	6	21%	Estonia, Finland, Luxembourg, Sweden, UK: Scotland <sup>1</sup> , Iceland
<b>Births and deaths data</b>			
Medical birth register & neonatal/infant death certificates	10	34%	Cyprus, Finland, Latvia, Luxembourg, Malta, Norway, Sweden, UK: Scotland <sup>1</sup> , Iceland, Czech Republic
Birth certificates & neonatal/infant death certificates	10	34%	Austria, Belgium, Estonia, France, Germany, Poland, Sweden, Switzerland, UK: England and Wales <sup>1</sup> , UK: Scotland <sup>1</sup>
Medical birth register & birth certificates	8	28%	Estonia, Finland, Slovenia, Malta, Norway, Sweden, UK: Scotland <sup>1</sup> , Iceland
<b>Other linkages<sup>3</sup></b>	10	34%	Belgium <sup>a</sup> , Finland <sup>b</sup> , France <sup>c</sup> , Germany <sup>d</sup> , Malta <sup>b</sup> , Norway <sup>a</sup> , Sweden <sup>a,e</sup> , Switzerland <sup>a</sup> , Netherlands <sup>f</sup> , UK: Scotland <sup>1,g</sup>
<b>No routine linkage</b>	11	38%	Denmark, Greece, Hungary, Ireland, Italy, Lithuania, Portugal, Romania, Slovakia, Spain, UK: Northern Ireland <sup>1</sup> , UK (national) <sup>1</sup>

<sup>1</sup>UK's four constituent countries: England, Wales, Northern Ireland and Scotland compile data separately.

<sup>2</sup>Some countries perform several types of linkages.

<sup>3</sup>Routine linkages with: a. population registers, b. congenital anomaly registers, c. vital statistics and cause-of-death data, d. regional data sources only, e. registers on level of education, f. health professional registries, g. any other national level health database on children or mothers.

were ten which related to procedures to identify maternal deaths, 7 relating to the ascertainment of fetal and infant deaths and 7 network or register audits. Some studies focused on validation of data items: 18 on the presence and characteristics of birth defects, one on assisted reproductive techniques (ART), three on obstetric history and one on social characteristics. A further 26 studies focused on metrics to validate deterministic and probabilistic linkages.

Table 4 provides an overview of routine perinatal health linkages performed in countries reporting data to Euro-Peristat. Among the 29 European countries participating in the Euro-Peristat project, 18 report using at least one type of linkage for routine statistics and 11 do not. Supplementary Annex SI provides more information on linked sources used in the 2010 report. Some countries such as Denmark can link their data systems for research projects but these linkages are not routine. Countries which currently merge national level datasets for perinatal health surveillance essentially link birth and death data but the data sources used for this type of linkage vary. Cyprus, Finland, Latvia, Luxembourg, Malta, Norway, Sweden, UK Scotland, Iceland and the Czech Republic link data from their medical birth registers with death certificates. Austria, Belgium, Estonia, France, Germany, Poland, Switzerland and UK: England and Wales routinely link their birth and death data from vital statistics data sources alone. Similarly, data on births and from hospital discharge systems can be linked using

vital statistics as in Scotland and Sweden, or data from a medical birth register as in Luxembourg. Seven countries carry out national linkages with hospital discharge data although in Germany this is done at the regional level only, in Lower Saxony. Other reported linkages involve congenital anomaly registers, cause-of-death data, registers on level of education, or are done at the regional-level only. These other linkages are exclusively performed in countries where birth and death data are routinely linked at the national level.

## Discussion

By harmonizing data systems, and ensuring completeness of coverage, record linkage increases the information available about each birth and can enhance the quality of perinatal health data. However, our review shows that this technique is largely underused in Europe: 11 out of 29 countries do not routinely link data on births and only 18 countries perform basic linkages such as linking birth and death certificates. Also, linkage studies were concentrated in a small set of countries; almost half of the studies published from 2001 to 2011 originated from the Nordic countries ( $N=223$ ). In the Nordic countries, the types of linkages performed for perinatal health surveillance were also more diverse than anywhere else in Europe.

Historical differences in health information capacity between countries may explain some of the variation in record linkage use in Europe. In England and Wales for instance, initiatives to link birth and death certificates began in 1950 in order to maximize the value of existing routine data and develop capacity for analyses of perinatal and infant mortality<sup>58</sup>—this linkage has been routine since 1975. The Oxford Record Linkage Study (ORLS), which started in the 1960s was seminal as both a research tool and a means to improve the quality of health care services.<sup>13,58,59</sup> The Nordic countries have also had a long standing tradition of maintaining birth registers, as early as the 1950s in some countries,<sup>60,61</sup> and this has allowed for broader application of linkage techniques in perinatal health research. Longer follow-up time broadens the scope of potential research questions and enables studies across generations.

The reasons for linkage are related to the organization of the health and data collection systems and these vary across countries. For example, in the Netherlands, midwives, general practitioners, obstetricians and neonatologist have separate databases which are linked to bring together perinatal care data for women who have been client of more than one profession,<sup>62</sup> but other countries do not need to do this. Another example relates to cause of death recording: in the UK causes of death are recorded on stillbirth and death certificates, while in France linkage is necessary to access this information because civil registration of deaths is distinct from the medical certification of the causes.<sup>7</sup>

Capacity for linkage also depends on the availability of matching variables. Whereas many national registers in Europe anonymize their records, others countries and in particular the Nordic countries make universal identification numbers available in all their routine databases.<sup>8</sup> Universal identifiers facilitate linkage between statistical, administrative and health authorities, although in the absence of identifying variables probabilistic techniques can be used.<sup>63</sup> In the Netherlands, validation of the probabilistic approach applied to the Dutch Perinatal registers yielded less than 1% error.<sup>62</sup>

There are multiple obstacles associated with linkage including cultural, organizational, structural, legal and technical issues. Specific obstacles identified in research on linkage include high costs, lack of software compatibility, need for additional statistical training, poor access to electronic records, missing data or varying interpretations of data privacy frameworks across organizations.<sup>64–66</sup> Data systems are also often managed by different institutions and communication and identification of common goals may hamper efforts to merge data sources. Moreover, concerns over privacy

and the biases introduced when linkages are incomplete may influence countries' willingness to institute routine linkage. Further research is needed to explore these obstacles, particularly how they have been overcome in countries that have instituted routine linkage, and their relative weight in countries where linkage is underdeveloped.

Our results underscore the multiple ways that record linkage can improve capacity for high quality perinatal health surveillance. First of all, data from the methods studies in the literature review showed that linkage can be used for validation and to ascertain new perinatal data items and outcomes.<sup>62,65,67,68</sup> In France for instance, linkage of the deaths of women of childbearing age to birth records and hospital discharge data makes it possible to account for all maternal deaths and reduce underreporting.<sup>7</sup> Further, by linking birth certificate data on gestational age and birth weight with death certificates it is possible to calculate subgroup mortality rates which are essential for monitoring infant health status and understanding patterns of mortality over time.<sup>3,6,65,69,70</sup> Because vital statistics data are available everywhere in Europe,<sup>1</sup> basic linkage of birth and death certificates should be possible in all countries. All European countries also have hospital discharge data,<sup>71</sup> yet routine linkage of these data with birth certificates and other population datasets was only carried out in only a fourth of countries.

Data on hospitalizations contain valuable information about clinical procedures and diagnoses because their primary use is for management and financing.<sup>6</sup> Basic socioeconomic characteristics are rarely included in hospital data, but these can be retrieved from other data sources, such as census data or registers on education, occupation and income. Birth certificate data in most countries provide information on characteristics such as place of birth, place of residence, marital status or occupation. Hence, linkage between hospital discharge data and population-based registers can be used to assess the burden of health disparities across socio-economic groups.<sup>72–74</sup> The additional variables acquired through linkage allow for more refined and expanded analyses of trends and patterns in key perinatal indicators.<sup>67,69,75–82</sup>

Record linkage also enables the surveillance of specific clinical subgroups such as infants born with congenital anomalies or from ART. Whereas only two countries, Finland and Malta, conduct routine linkages with their congenital anomaly registers, these types of linkages were frequent in the literature. In about 15% of studies, researchers focused on the impact of ART as well as on the effects of teratogens and prescription drugs on congenital anomalies. For example, two US studies looked at exposure to anesthetic gases and congenital anomalies in offspring of female registered nurses<sup>83</sup> and the association between maternal exposure to ambient air pollution and congenital heart disease.<sup>84</sup>

More generally, our review shows that linkage of routine data systems is a valuable tool for research which can provide insight into maternal and infant health indicators but also into the etiology, prognosis and consequences of conditions such as Legg Calves Perthes disease, cerebral palsy, or multiple sclerosis. Linkage of routine systems also facilitates life-course research on the long term outcomes of mothers and their newborns. Half of the studies in our review were longitudinal. A cohort, e.g. of all women of reproductive age, can be identified and monitored by linking data relating to these women from multiple data sources thereby increasing the power of statistical analyses without having to incur the costs of a long follow-up time.

This systematic review builds on a large number of studies linking routine databases on perinatal health. We also identified countries in which linkage is currently undertaken for routine perinatal health monitoring to get information about the linkages put in place and to permit other countries to benefit from their experience. In countries where specific data sets are linked regularly, as in the Nordic countries, authors did not always explicitly mention 'linkage' in the abstracts. This could have led to an under-estimation of the

number of perinatal health studies published during our review period. We only included studies in referenced databases and thus did not include studies published on statistical institution's websites only or other types of grey literature such as agency health and policy reports. Also, countries differed in the terminologies they used for their data sources, especially when translating them into English and this can make it difficult to distinguish between e.g. a morbidity database, hospital records and a birth register.

Data linkage increases the availability of data for surveillance and assessment of differences across countries and over time. Linkage techniques can also contribute to the generation of knowledge about the causes and consequences of ill health. More specifically, linkage of data from birth and death certificates provides more and higher quality information about mortality and should be prioritized in countries where these sources are not yet linked. Linking hospital discharge data and civil registration data should also be a priority as it increases the amount of information available about each birth and can be used to double check the completeness of registration of births and deaths in hospital databases. Finally, linkage makes it possible to augment commonly available birth data with information on specific outcomes or exposures in relation to health and well-being across the life course. These linkages will depend on other existing databases (i.e. congenital anomalies registers, pharmaceutical databases) and the use of linkage for surveillance and research in other health areas and sectors such as education, employment or housing.

In conclusion, some countries integrate data linkage into their routine perinatal health surveillance systems and make these data available for research, but this is not a universal practice throughout Europe. Current discussion at the EU-level and across Member States includes moving towards the establishment of a European health information system, and strengthening health reporting mechanisms.<sup>85,86</sup> Linking data on perinatal health is a feasible and readily available option for improving the quality and completeness of health indicators thereby adding value to existing national and international investment in health information. Further research is needed on the obstacles to linkage in countries which do not practice it routinely. Promoting these recommendations about the linkages which are most useful for perinatal health reporting and broader adoption of linkage could yield substantial gains for research and surveillance of perinatal health nationally and internationally.

## Supplementary data

Supplementary data are available at *EURPUB* online.

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## Key points

- Record linkage has been successfully used for research on maternal, fetal and infant health risk factors and outcomes, although this research is concentrated in only a few countries.
- That linkages are not systematic practice for perinatal health surveillance could explain gaps in data availability in the European Perinatal Health Report 2010 and limitations in countries' capacity to collect data for key subgroup populations.

- Linking data on perinatal health is a feasible and readily available option for improving the quality and completeness of health indicators thereby adding value to existing national and international investments in health information systems.
- Having common recommendations in the EU about which linkages are most useful for perinatal health reporting and broader adoption of linkage could yield substantial gains for research and surveillance of perinatal health nationally and internationally.

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## Short Report

# Effects of small incentives on survey response fractions: randomised comparisons in national alcohol surveys conducted in New Zealand

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We experimentally evaluate inexpensive interventions to increase response fractions in two alcohol surveys. Residents on the New Zealand General and Māori electoral rolls were randomized to receive a survey pack with or without an offer of entry to a \$500 prize draw. Subsequent randomization of sample members who did not initially respond allowed estimation of effects of offering a \$5 donation to charity as an incentive to respond. Offering prize draw entry did not significantly increase responses in either population. Contrary to expectation, promising a \$5 donation to non-respondents reduced subsequent responding in the group previously offered the prize draw incentive.

## Background

Falling response fractions present a challenge for health research, reducing effective sample sizes and, more importantly, increasing the potential for bias in estimates due to non-response being associated with variables of interest. The problem is illustrated by a recent coronary disease study, in which 1886 patients who completed a survey about their quality of life were compared with 506 who did not complete the survey (response fraction 79%).<sup>1</sup> Consistent with the survey methods literature, non-respondents were younger, had greater body mass, and a larger proportion were smokers. They were also two to four times more likely to die in the following 3 years, leading the authors to conclude that 'Data

gathered by means of questionnaires cannot be generalized to the whole patient population due to a profound non-response bias' (p. 168).<sup>1</sup>

Correcting for non-response bias is problematic because it relies on naïve assumptions about distributions of the characteristics of interest within the non-respondents.<sup>2</sup> The best approach is to minimize non-response through study design. A systematic review of methods to increase response rates in postal surveys showed increasing response fractions from a range of strategies including the use of monetary and non-monetary incentives, unconditional incentives, reminder contacts and provision of replacement questionnaires on request.<sup>3</sup>