

The data we have: Pregnancy and birth related data collection in Australia, Canada, Europe and the USA – A web-based survey of practice

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Submission History

Submitted:	09/07/2020
Accepted:	23/10/2020
Published:	22/03/2021

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Abstract

Objectives

To determine the feasibility of combining routinely recorded perinatal data from several databases in high-income countries to assess the risk of recurrent stillbirth.

Methods

Web-based questionnaire survey with reminder emails and searching of relevant country websites.

Results

120 countries/regions in Canada, Europe and the USA were invited to participate and 83 (69%) responded. Of those one had no data, and two did not wish to take part. The remaining 80 were sent the questionnaire and 63 (53%) were completed. Twenty-seven countries/regions reported that they collect information on all perinatal events (including early pregnancy loss), 34 on live births and stillbirths and two only live births (stillbirths recorded in a separate database). Most countries (53/63) can link two or more pregnancies occurring in the same woman. Data and information extracted from the Australian and New Zealand Government websites showed that information on all perinatal events is collected nationally in New Zealand and in 5/8 regions in Australia. Both Australia and New Zealand can link two or more pregnancies occurring in the same woman. Maternal age and caffeine consumption were the most and least consistently collected demographic indicators respectively. Diabetes mellitus and mental health problems, birthweight and obstetric cholestasis the most and least consistently collected for medical conditions and pregnancy condition/complications. Procedures for gaining access to data vary between countries.

Conclusion

This study demonstrates that it is possible to link pregnancies in the same woman to assess the risk of recurrent stillbirth using routinely collected perinatal data in all states/territories in Australia, 7/8 responding provinces/territories in Canada, 21/27 responding countries/regions in Europe, New Zealand and 26/28 responding states in the USA. The scope of the databases and quality and extent of data collected (thus their potential use) varied, as did procedures for accessing their data.

Keywords

Perinatal health, information systems; data; pregnancy; high-income countries

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Introduction

Variation in stillbirth rates across high-income countries (HICs) shows that further reduction in stillbirths is possible [1]. There is no universally accepted definition of stillbirth, different countries and states specifying their own definition in line with legal registration and reporting requirements. Gestational cut-offs distinguish a miscarriage from a stillbirth and typically reflect gestational viability, which is linked to availability of neonatal care. Continued improvement in neonatal care means that definitions of stillbirth are still evolving, but at present, gestational age cut-offs range from 16 to 28 weeks' gestation. Birth weight is often included in the definition and ranges from 350 to 1000 grams [2].

As part of health management information systems, most HICs have a comprehensive system of data capture of pregnancy and birth related data at the national level [3]. Studies using routinely collected national/regional perinatal data have been conducted in many countries. A systematic review and meta-analysis identified 96 studies conducted in 13 HICs that used population-based data to investigate risk factors for stillbirth. Many factors are implicated as contributing to stillbirths and these include previous adverse pregnancy outcomes, advanced maternal age, smoking, low socioeconomic status, overweight and obesity, medical disorders such as diabetes and hypertension and pregnancy complications such as pre-eclampsia, foetal growth restriction and placental abruption [4]. The availability of good health care in HICs means that stillbirth is a relatively rare event occurring in <1% of pregnancies in Australia, UK and USA [1]. As a result national datasets may be too limited in sample size to evaluate outcomes such as stillbirth recurrence, and the concept and value of combining data sets from different countries has been recognised [5, 6].

In theory, meta-analysis of primary studies allows for pooling of results. However, heterogeneity in design and conduct between studies can hinder combining studies and interpretation of results. These limitations can be addressed or substantially reduced using Individual Participant Data (IPD) meta-analysis [7]. An IPD meta-analysis synthesizes the raw individual level data from multiple sources that are standardised in terms of definition of variables and inclusion and exclusion criteria for participants. It is an ideal method to study rare events where primary studies do not have the power to answer a clinical question.

As perinatal databases collect similar information there may be potential for collaborative efforts. The aim of this study was to conduct a web-based survey of perinatal databases in HICs to explore whether data routinely collected in perinatal databases can support and facilitate robust research into recurrent stillbirth and other perinatal outcomes using datasets from multiple countries.

Methods

Identification of potential perinatal databases

Europe has 51 independent states (including Armenia, Azerbaijan, Cyprus, Georgia, Kazakhstan and Turkey). As the constituent countries of the UK (England, Northern

Ireland, Scotland, Wales) collect and compile their own vital statistics data we counted them independently. We also included Israel, the Isle of Man (a self-governing British crown dependency) the Faroe Islands (a self-governing country within the Kingdom of Denmark) and Greenland. Accordingly 57 relevant countries/regions in Europe were identified for inclusion. Collection and recording of vital statistics is done provincially in Canada and at state level in the USA. Thus, for this research, the 10 provinces and three territories in Canada and the 50 states in the USA were counted independently. Thus a final total of 120 countries and regions were identified for inclusion in the online perinatal data survey.

In Australia, the National Perinatal Data Collection (NPDC) is a mandatory national population-based cross-sectional collection of data that provides nationally consistent and comprehensive maternal and perinatal morbidity and mortality data. The Perinatal National Minimum Data Set (NMDS) includes uniform data on all live births and stillbirths that occur in all hospitals, birth centres and in the community in Australia. Data items include demographic information relating to the mother, information regarding pregnancy and birth conditions/complications and information relating to the baby. The data are provided annually from each state and territory health authority to the Australian Institute of Health and Welfare (AIHW) [8]. New Zealand (NZ) has a centralised and harmonised structure in place for data collection. The Ministry of Health (MoH) collates the mandatory reported National Maternity collection (MAT) that includes antenatal and postnatal event data obtained from primary maternity services and the NMDS. Data on maternal deaths and stillborn babies is recorded in the Mortality Collection and is not included in the National Maternity Collection. Statistics about stillborn babies are presented in the Foetal and Infant Deaths series and in the annual report of the Perinatal and Maternal Mortality Review Committee. (PMMRC). The information requested in our perinatal survey questionnaire was available from the Maternity Information Matrix on the Australian Government website [9] and from information on data collections (MAT, NMDS, PMMRC) on the MoH, NZ Government website [10]. One researcher (KL) accessed the government websites (Australia, September 2016; NZ, September 2020) and extracted the relevant details. For the other countries with perinatal databases, an online questionnaire survey was conducted.

Development and administration of the questionnaire

The questionnaire was based on evidence from the literature [4, 11] and developed in consultation with members of the research team. It was then piloted by colleagues using databases that they have access to, suggested amendments implemented, and the questionnaire transferred onto the *Snap*[®] Webhost for administration. Custodians for the relevant databases were identified through web searches of Euro-Peristat [3] /Office of National/Vital Statistics or Department of Public Health using a snowball technique. A pre-notification email giving advance warning of the perinatal data survey along with an invitation to participate was sent. This was followed by a second email providing more detailed

information about the survey. A third and final email was sent to non-responders three weeks after the second email.

A link to the survey questionnaire was sent (Europe: August to November 2015, USA: November 2015 to May 2016, Canada: May to October 2016). The questionnaire comprised two sections. Section one asked questions about the database including time period and population covered, method of data collection and linkage to subsequent pregnancies. Section two about the type of data recorded regarding demographic details, maternal medical conditions and pregnancy related conditions and complications. There were twenty-six questions with free text boxes for any 'other' responses. The survey would take no more than 15 minutes to complete (Appendix 1). This survey did not request any information considered unsuited to the public domain, therefore, formal ethical approval was not required. As this was an online survey completion of the questionnaire was regarded as consent to participate. Statistical methods were descriptive and primarily consisted of calculation of frequencies and percentages.

Results

A total of 83 out of 120 countries/regions responded; one country informed us data was unavailable (Liechtenstein) and two States of the USA (Idaho and Kansas) that they did not wish to participate. The remaining 80 were sent the online survey and 63 were completed (8/13 in Canada, 27/57 in Europe and 28/50 in the USA (see Table 1)).

General information about the databases

Of 63 responding countries/regions, 27 reported collecting data on all perinatal events including early pregnancy loss, 34, on live/stillbirths and two (New Hampshire and New York State, USA) data only on live births. Both states reported that foetal deaths are recorded in a separate database. Differentiation of termination of pregnancy (TOP) from stillbirth was possible in 23/28 states in the USA, 3/8 provinces/territories in Canada and 13/27 countries/regions in Europe. In Australia, the NPDC collects information on early pregnancy loss; five states/provinces (Australian Capital Territory, Northern Territory, South Australia, Victoria and Western Australia) provide information on miscarriage, and all of these, plus Queensland, information on TOP. NZ collects information on all perinatal events including information on TOP.

In Canada, Europe and the USA, 55/63 datasets go back over 10 years in time and 49 of these have data that are ~ 99% complete, seven, 95–98%, one, 85–95% and two, < 85% (Cyprus because data are obtained only from the public sector (~ 40% of births) and New Brunswick, Canada because the Perinatal Health Program has only been established for one year). Datasets in Australia and NZ also go back over 10 years and in both countries all births are included in the database. In Australia, to ensure quality and completeness, data are frequently validated through annual audits to compare the number of births reported to Perinatal Data Collection Online Systems with the numbers recorded in individual hospitals. There is no national data quality framework in NZ. However,

each district health board (DHB) has data quality teams that address data quality issues as they arise. In addition, data quality analysts in the MoH may query any data quality issues or request further verification of data submitted by DHBs.

Most countries capture and enter data into the database manually or using a combination of manual and electronic methods. Denmark, Finland and Florida, USA use entirely electronic methods. Australia is also increasingly switching to online systems. Western Australia and Northern Territory are almost fully electronic, other areas using a combination of manual and electronic methods with up to 20% of forms paper-based. Mandatory and additional voluntary perinatal data from each state/territory is sent as a standardised extract of electronic data for inclusion in the NMDS and/or the NPDC as appropriate. NZ also operates electronic transfer of a minimum dataset of maternity information into the MoH's national collections.

Linking pregnancies in the same woman

53/63 countries/regions (7/8 in Canada, 20/27 in Europe and 26/28 in the USA) reported that it is possible to link two or more pregnancies in the same woman. Italy reported that data linkage is possible for some regions and Germany, that although data linkage is not performed a code for previous pregnancy outcome e.g. stillbirth may be entered in the database and in this way linked to another pregnancy in the same woman. Minnesota, Oregon, Mississippi and Wisconsin, USA added that although it is technically possible, it is not easy to link pregnancies within and between the birth and foetal death datasets and may need to be linked manually. In Utah and Vermont pregnancies in the same woman can be linked through a special database, (the Utah population database) or by a specially trained analyst respectively. Nevada reported that data linkage is possible since 2006. Saskatchewan, Canada reported that data linkage is performed between the Discharge Abstract database and the Vital Statistics database and Manitoba that the Manitoba Centre for Health Policy at the University of Manitoba can link several data files from government and other sources that includes a dataset based on midwifery discharge summary reports. Data linkage in Australia is currently performed at the state/territory level, whereas in NZ data linkage is conducted nationally.

Information on stillbirth

13/27 countries in Europe reported using a definition of stillbirth as ≥ 22 weeks gestation, 5/8 provinces/territories in Canada and 19/28 states in the USA a definition of ≥ 20 weeks gestation, some regions including a birthweight of at least 350g, 400g or 500g if gestation is unknown. The definition varied between the remaining countries/regions, most using a gestational age cut-off rather than birthweight. Despite using a definition of ≥ 24 weeks gestation Portugal reported that in circumstances where parents would like a funeral, births at gestations of ≥ 22 weeks - 23 weeks+6 days may be included as stillbirths. Across all states/territories in Australia and also in NZ a definition of ≥ 20 weeks gestation is used. A birthweight of at least 400g is included if gestational age is unknown.

Data on causes of stillbirth

Of 63 respondents, 50 (2/8 in Canada, 22/27 in Europe and 26/28 in the USA) reported that causes of stillbirth data are collected. Eight countries/regions questioned the completeness and/or accuracy of data on causes of stillbirth (British Columbia, Canada, Cyprus, Denmark, Germany, Ireland, Italy, Sweden and Oregon, USA), five (Cyprus, Germany, Ireland, Italy and Oregon, USA) adding that they would not recommend cause of stillbirth data for analysis. Estonia reported that stillbirths are registered by a perinatal death certificate and collected in the death registry but cause of death is not entered into the database. Each state/territory in Australia collects perinatal mortality data, including cause of death information. Data collected at the time of birth undergoes multidisciplinary perinatal review. It is then forwarded in a standardised electronic extract to AIHW. At times information is known to be incomplete and procedures for reviewing perinatal death inconsistent between authorities. In NZ the PMMRC review all stillbirths. Local PMMRC coordinators oversee and collect the required data. Local clinical reviews of each case include assigning the Perinatal Society of Australia Perinatal Death Classification system (PSANZ-PDC) [12, 13] for cause of death, determining contributory factors and potentially avoidable

deaths, and ensuring appropriate, timely follow-up with parents.

Classification of causes of stillbirth

Most countries/regions (14 in Europe, 12 states in the USA and Saskatchewan, Canada) reported using international classification of diseases (ICD) 9 or –10 codes [14, 15] (ICD-CA in Canada [16]) to assign cause of death. Eleven states in the USA reported using the Centers for Disease Control (CDC) and the National Center for Health Statistics (NCHS) 2003 revised certificate of foetal death form, one reported using both ICD-10 codes and the CDC and NCHS foetal death form and one local codes. Four countries (Belgium, Greenland, Serbia and Slovakia) reported classifying cause of death using the cause of death and associated conditions (CODAC) classification system [17] and the Isle of Man and Alberta, Canada Wigglesworth [18]. Norway reported that although a pilot study using the CODAC [17] classification system was conducted between 2006 and 2008, no decision has been made to use this routinely. Based on hospital and post mortem reports and the birth notification form, causes of death are collected and ordered as underlying cause of death, associated cause of death and other. Stillbirth registration data provided to the Australian Bureau of Statistics from

Table 1: Responding countries/regions for each geographical area added Table 1

Responses from 57 countries in Europe identified for inclusion

Survey completed	Responding countries		Non-responding countries
		Survey sent not completed	
Austria	Armenia		Albania
Belgium	Bosnia and Herzegovina		Andorra**
Cyprus	Croatia*		Azerbaijan
Denmark	England		Belarus
Estonia	France		Bulgaria
Finland	Greece		Czech Republic
Germany	Macedonia		Faroe Islands
Greenland	Netherlands		Georgia
Hungary	Northern Ireland		Kazakhstan
Iceland			Kosovo
Ireland			Moldova
Isle of Man			Monaco**
Israel			Montenegro
Italy			Poland
Latvia			Romania
Liechtenstein***			Russia
Lithuania			San Marino
Luxembourg			Turkey
Malta			Ukraine
Norway			Wales
Portugal			
Scotland			
Serbia			
Slovakia			
Slovenia			
Spain			
Sweden			
Switzerland			



Responses from 50 States of the United States of America

Responding states		Responded No	Non-responding states
Survey completed	Survey not completed		
Alaska	Hawaii	Idaho	Alabama
Arkansas	Maine	Kansas	Arizona
California	Montana		Georgia
Colorado	New Mexico		Indiana
Connecticut	Ohio		Kentucky
Delaware	Wyoming		Louisiana
Florida			Maryland
Iowa			Oklahoma
Massachusetts			Rhode Island
Michigan			Tennessee
Minnesota			Virginia
Mississippi			Washington
Missouri			Washington DC
Nebraska			West Virginia
Nevada			
New Hampshire			
New Jersey			
New York State			
North Carolina			
North Dakota			
Oregon			
Pennsylvania			
South Carolina			
South Dakota			
Texas			
Utah			
Vermont			
Wisconsin			

Responses from 13 Provinces/Territories of Canada

Responding Provinces/Territories		Non-responding
Survey completed	Survey not completed	
Alberta	Nova Scotia	Prince Edward Island
British Columbia	Ontario	Northwest Territories
Manitoba		Yukon
New Brunswick		
Newfoundland and Labrador		
Nunavut		
Quebec		
Saskatchewan		

Countries that participate in Euro-Peristat, *currently participates in Eurocat (European Surveillance of Congenital Anomalies), **contacted through link on website, ***no data.

each of the states /territories in Australia is recorded in accordance with ICD-10-AM (Australian modification) codes [19]. The multidisciplinary perinatal review process assigns cause of death using PSANZ-PDC. Table 2 tabulates some key responses.

Accessing the data

Requirements for allowing researchers access to their data varied. Some countries reported that only completion of a data request form is required, others require the researcher to be a resident, yet others had further specifications. For

example, in Denmark it is only possible to gain access to data if the researcher is affiliated with a Danish research institution. Permission is also required from the Danish Data Protection Agency and the data must be stored safely in Denmark at either the State Serum Institute or, if the data requires linkages with non-health registers at Statistics Denmark. Requests for German data must be made to the Institute for Quality Assurance and Transparency. No raw data is allowed to leave this Institute but analysis of data can be conducted on request and following approval from the Federal Joint Committee, aggregated outputs made available to researchers. Quebec, Canada and Mississippi, USA, also only provide

Table 2: Responses for a selection of questions from the perinatal data survey

Country	Link 2 pregnancies in same woman	Differentiate TOP from miscarriage	Definition stillbirth	Causes registered in database	Classification system used
Austria	No	No	$\geq 500\text{g}$	No	
Belgium	Y	No	≥ 22 weeks	Y	CODAC/ amended CODAC
Cyprus	Y	No	≥ 22 weeks or $\geq 500\text{g}$ or $\geq 25\text{cm}$ length	Y	ICD-10
Denmark	Y	Y	≥ 22 weeks (≥ 28 weeks used until 2003)	Y	No information provided
Estonia	Y	Y	≥ 20 weeks	Recorded in cause of death registry	ICD-10
Finland	Y	Y	≥ 22 weeks or $\geq 500\text{g}$	Y	ICD-10
Germany	No, but code for previous stillbirth may be entered as a pregnancy risk factor for multiparous pregnancies. Data quality not perfect but useable.	TOP collected in separate database)	$\geq 500\text{g}$	Y	ICD-10
Greenland	Y	Y	≥ 28 weeks	Y	CODAC
Hungary	Y	Y	≥ 24 weeks	No	
Iceland	Y	Y	≥ 22 weeks	Recorded in mother's medical notes	No information provided
Ireland	No	No	≥ 24 weeks	Y	ICD-10

data in aggregate form. For access to Israeli data a special request must be made and following approval data can only be accessed at the Central Bureau of Statistics. Luxembourg reported that no guidelines are currently in place for accessing data but procedures are being determined for 'controlled' access to data.

Italy, Slovakia and New York state, USA reported that only anonymised individual level data can be obtained. Nunavut, Canada reported that as well as the standard procedures that are required to gain access to their data a data sharing agreement is necessary. With regard to accessing data from Australia, it is not clear from the information on the AIHW website whether anonymised IPD data can leave Australia or if only aggregate data is available to researchers.

Socio-demographic information collected

Maternal age was the only demographic variable collected by all responding countries/regions. Collection of other demographics varied between countries/regions, although Australia and the USA were better at collecting this information. Forty-eight of 63, (76%) countries/regions reported collecting information on smoking during pregnancy, 31 (49%) also collecting information on smoking before

pregnancy, and 7/63 (11%), (three in Europe, two in Canada and two in the USA) exposure to passive smoking. All states/territories in Australia collect information on smoking before pregnancy; five collect information on the number of cigarettes smoked per day during the first 20 weeks and all collect information on the number of cigarettes smoked per day after 20 weeks. Fewer countries/regions reported collecting information on maternal BMI, 30/63, (48%); three in Canada (two collect pre-pregnancy BMI and one pre-and late pregnancy BMI), 11 in Europe (three collect pre-pregnancy BMI, three early pregnancy BMI, three pre-and late pregnancy BMI and two early and late pregnancy BMI) and 16 in the USA (10 collect pre-pregnancy BMI, four pre-and late pregnancy BMI and two pre, early and late pregnancy BMI). Five states/territories in Australia collect information on BMI (one on BMI at booking, the others pre-pregnancy BMI). Only 23/63 (37%) and 17/63 (27%), countries/regions reported collecting information on alcohol and illicit drug use respectively. Three states/territories in Australia collect information on alcohol use during pregnancy and three, information on illicit drug use. No country reported collecting information on caffeine consumption.

In the free text box for other responses Estonia reported that the same socio-demographic variables collected for the

Table 2: Responses for a selection of questions from the perinatal data survey

Country	Link pregnancies in same woman	2 Differentiate TOP from miscarriage	Definition stillbirth	Causes registered in database	Classification system used
Isle of Man	Y	Y	≥ 24 weeks	Y	Wigglesworth
Israel	Y	Y	≥ 500g or ≥ 22 weeks	Y	ICD-10
Italy	Some possibility	Y	180 days gestation	Y	ICD-9
Latvia	Y	No	≥ 22 weeks	Y	ICD-10
Lithuania	No	No	≥ 22 weeks	Y	ICD10-AM
Luxembourg	Y	Y	≥ 22 weeks	Y	ICD10
Malta	Y	Terminations are illegal, miscarriages not registered	≥ 22 weeks	Y	ICD10
Norway	Y	Y	≥ 22 weeks	Collected in a separate database	No classification system routinely in use
Portugal	Y	No	≥ 24 weeks or ≥ 500g	Y	No information provided
Scotland	Y	Y in MBRRACE-UK data**	≥ 24 weeks	Y	ICD-10
Serbia	No	Y	≥ 28 weeks	Y	CODAC
Slovakia	Y	Y	≥ 28 weeks	Y	CODAC
Slovenia	Y	No	≥ 500g	No	
Spain	Y	Y	≥ 22 weeks	Y	ICD-10
Sweden	Y	No	≥ 22 weeks (≥ 28 weeks used until 2008)	Y	ICD-10
Switzerland	Y	Y	≥ 22 weeks	Y	ICD-10
Australia NMDS	Y	No	≥ 20 weeks or ≥ 400g	No	
Australia NPDC	Y	Y	≥ 20 weeks or ≥ 400g	Y	PSANZ-PDC
Canada Alberta	Y	No	≥ 20 weeks	Y	Wigglesworth
Canada British Columbia	Y	No	≥ 20 weeks	No	
Canada Manitoba	Y	Y	≥ 20 weeks or ≥ 500g	No	

** Mothers and Babies Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK (20) use the CODAC classification system (17).

mother are collected for the father (although there are a lot of missing values), Spain that the father's occupation is recorded, Lithuania, whether the birth was urban or rural and Sweden that information is collected on the mother's use of snuff. Florida and Missouri, USA reported that information regarding whether the mother participated in a supplemental nutrition food stamp programme for Women, Infants and Children during the pregnancy is recorded, and Missouri, that information regarding the payment source for the delivery is also recorded. Saskatchewan, Canada reported that there is a flag in the database for anyone of registered native Indian status, but data quality is of concern. In Australia information on indigenous status is recorded. Figure 1 shows proportions of responding states/territories in Australia, provinces/territories in Canada, countries in Europe and states in the USA that record information on each demographic variable.

Information collected on medical conditions

55/63 (87%), countries/regions 7/8 in Canada, 22/27 in Europe and 26/28 in the USA provided details regarding data collected on maternal medical conditions with Canada and Europe better at collecting information on these. Diabetes mellitus 52/55 and hypertension 50/55 were the most consistently recorded medical conditions and mental health problems the least 15/55. In Australia, medical conditions are collected through the NPDC and here diabetes mellitus and hypertension were also the most consistently collected and autoimmune conditions the least. Other than New South Wales, all states/territories collect information on other medical conditions. All use different collection forms, with some including a free text field for 'other' non-specified conditions, several US states highlighting that non-specified

Table 2: Responses for a selection of questions from the perinatal data survey

Country	Link 2 pregnancies in same woman	Differentiate in TOP from miscarriage	Definition stillbirth	Causes registered in database	Classification system used
Canada New Brunswick	Y	Y	≥ 20 weeks	No	
Canada Newfoundland and Labrador	Y	Y	≥ 20 weeks	No	
Canada Nunavut	No information provided	No	≥ 500g or ≥ 20 weeks	No	
Canada Quebec	Y	No	≥ 20 weeks	No	
Canada Saskatchewan Gov't ministry	Y	Y	≥ 500g or ≥ 20 weeks	No	
Canada Saskatchewan eHealth	Y	Y using ICD-10-CA codes	≥ 500g	Y	ICD-10-CA
New Zealand MAT NMDS PMMRC	Y	Y	≥ 20 weeks, or ≥ 400g if gestation not known	Y	PSANZ-PDC
USA Alaska	Y	Y	≥ 20 weeks	Y	ICD-10
USA Arkansas	Y	Y	≥ 350g, or if weight unknown ≥ 20 weeks	Y	ICD-10
USA California	Y	No	≥ 20 weeks	Y	ICD-10
USA Colorado	Y	Y	≥ 20 weeks	Y	CDC/NCHS 2003 USA revised certificate of foetal death, cause of death categories
USA Connecticut	Y	No information provided	≥ 20 weeks	Y	CDC/NCHS foetal death form
USA Delaware	Y	No	≥ 20 weeks	Y	No information provided
USA Florida	Y	No	≥ 20 weeks	Y	ICD-10

conditions can also be noted under a field for 'other' in the US national standard CDC/NCHS birth and foetal death certificates. Several countries in Europe (Cyprus, Malta and Norway also indicated that a free text field is available for entering any medical conditions encountered.

Figure 2 shows proportions of responding states/territories in Australia, provinces/territories in Canada, countries in Europe and states in the USA that record information on each maternal medical condition. In the free text box for other information Denmark noted that information is available on any maternal medical condition that involves contact with in- or out-patient clinics, Luxembourg, that any pre-existing medical condition of the mother should be recorded, but quality or extent of the records could not be guaranteed and Scotland that any maternal medical condition that influenced maternal care or contributed to a stillbirth, whether a direct cause or not, was recorded. Switzerland reported that maternal medical conditions are only recorded for miscarriage and not for stillbirth, Italy that data for most of the medical conditions

asked about are collected in the hospital discharge form for deliveries occurring in hospital (almost all births in Italy and found in a different database).

Information collected on pregnancy conditions and complications

Fifty-seven countries/regions (7/8 in Canada, 25/27 in Europe and 25/28 in the USA) provided information on the pregnancy related conditions and complications that are recorded. Birthweight was the most consistently recorded and for countries in Europe, obstetric cholestasis (11/25, 44%) the least. In the USA threatened miscarriage (1/28, 4%), was least likely to be recorded. Several US states again highlighted that other pregnancy related conditions or complications could be noted under a specified field in the birth and foetal death certificates. In Australia, obstetric complications are collected through the NPDC. All states/territories in Australia collect information on birthweight, gestational diabetes, gestational

Table 2: Responses for a selection of questions from the perinatal data survey

Country	Link 2 pregnancies in same woman	Differentiate TOP from miscarriage	Definition stillbirth	Causes registered in database	Classification system used
USA Iowa	Y	Y	≥ 20 weeks	Y	The Surveillance Foetal Death Evaluation Form ICD-10
USA Massachusetts	Y	Y	≥ 20 weeks or ≥350g	Y	ICD-9/10
USA Michigan	Y	Y	≥ 20 weeks	Y	ICD-10, non-coded cause information collected as per USA NCHS standard foetal death record
USA Minnesota	Y but not easy to link pregnancies within / between birth and foetal death data sets	Induced abortions are in a separate database	≥ 20 weeks	Y	The USA National standard foetal death certificate
USA Mississippi	Y possible but must be done manually	Y	≥ 20 weeks or ≥350g	Y	ICD-10
USA Missouri	Y	Y	≥ 20 weeks	Y	ICD-10
USA Nebraska	Y	Y	≥ 20 weeks	Y	ICD-10
USA Nevada	Y	Y	≥ 20 weeks	No	
USA New Hampshire	Y	Y	≥ 20 weeks	Y	CDC/NCHS
USA New Jersey	Y	Y	≥ 19 weeks	Y	Local codes
USA New York State	Y	Y	≥ 20 weeks	Y	CDC/NCHS
USA North Carolina	Y	Y	≥ 20 weeks	Y	ICD-10
USA North Dakota	Y	Y	≥ 20 weeks	Y	Coding rules provided by NCH/CDC and prevention
USA Oregon	Y not commonly done	Y	≥ 350g or ≥20 weeks	Y	ICD-10

hypertension, gestational age at delivery and type of delivery including caesarean section and whether it is elective or emergency. Collection of other pregnancy related conditions varied between states/territories, none routinely collecting information on obstetric cholestasis. However, again it may be captured as a free text field 'other complication of pregnancy'. Figure 3 shows the proportions of responding states/territories in Australia, provinces/ territories in Canada, countries in Europe and states in the USA that record information on each pregnancy related condition/complication. In the free text box for other information Denmark reported that that if there is an ICD code information will be available, and Malta, that a free text field is available for conditions encountered in pregnancy. California, USA reported that information on any maternal infections that are present is collected. Italy and Switzerland reported that most of these variables are collected in hospital deliveries, Switzerland also pointing out that currently it is not possible to link data collected for the infant (birthweight, gestational age) with data collected for the mother (age, nationality, type of delivery, maternal condition).

Collection of information on intra-uterine growth restriction (IUGR)

23/63 (37%) countries/regions reported collecting data on IUGR (4/8 in Canada, 13/27 in Europe and 6/28 in the USA), 11 reporting how it is measured. Denmark, Norway, Sweden, Florida, USA and Saskatchewan, Canada, reported using birthweight and gestational age. Norway added that researchers must use the recorded birthweight and gestational age measures to estimate growth based on national published standards. Utah, USA reported using only birthweight, Iceland, Slovakia and Spain that echographic parameters from serial ultrasound scanning are used, and the Isle of Man, that foetal biometrics are plotted on computerised growth charts (changing soon to customised growth charts). New Brunswick in Canada reported that physicians use Lubchenco charts to calculate foetal growth. Malta reported that IUGR is only recorded if referenced by the obstetrician on the mother's hospital notes. Only three states/territories in Australia were found to collect information on IUGR. However, the other states/territories in Australia may capture

Table 2: Responses for a selection of questions from the perinatal data survey

Country	Link 2 pregnancies in same woman	Differentiate TOP from miscarriage	Definition stillbirth	Causes registered in database	Classification system used
USA Pennsylvania	No	Y	≥ 16 weeks	Y	Cause of death and associated conditions foetal death record
USA South Carolina	Y	Y	≥ 20 weeks or ≥350g	Y	Cause of death and associated conditions foetal death record
USA South Dakota	No	Y	≥ 20 weeks	No	
USA Texas	Y	No	≥ 350g or ≥20 weeks	Y	ICD-10
USA Utah	Y Pregnancies can be linked through the Utah population database (not easily linked in vital statistics)	Y	≥ 20 weeks	Y	No actual system - just associated conditions
USA Vermont	Y Linkage is not done automatically	Y	≥ 20 weeks or ≥400g	Y	Cause of death and associated conditions foetal death record
USA Wisconsin	Y	Y	≥ 20 weeks	Y	ICD-10

it as a free text field; 'other complications of pregnancy. In Australia, IUGR is verified/confirmed through ultrasound examination.

Collection of information on previous history of miscarriage/stillbirth

45/63 (71%) responding countries/regions reported collecting data on both previous history of miscarriage and previous history of stillbirth (6/8 in Canada, 19/27 in Europe and 20/28 in the USA). Four countries in Europe (Austria, Belgium Greenland and Iceland), Nunavut and Quebec in Canada and Massachusetts, USA reported collecting data on previous history of stillbirth, but not previous history of miscarriage. Slovenia, Arkansas and Delaware, USA reported collecting data on previous history of miscarriage, but not previous stillbirth. Five states in the USA (California, Connecticut, Iowa, New York and North Dakota) reported that information on poor previous outcomes is collected, but neither miscarriage nor stillbirth is specified. All states/territories in Australia other than New South Wales collect information on previous stillbirth in their perinatal database. For New South Wales information is only collected in the Births, Deaths and Marriages registry. Five states/territories collect information on previous miscarriage (Australian Capital Territory, Northern Territory, South Australia, Tasmania and Victoria).

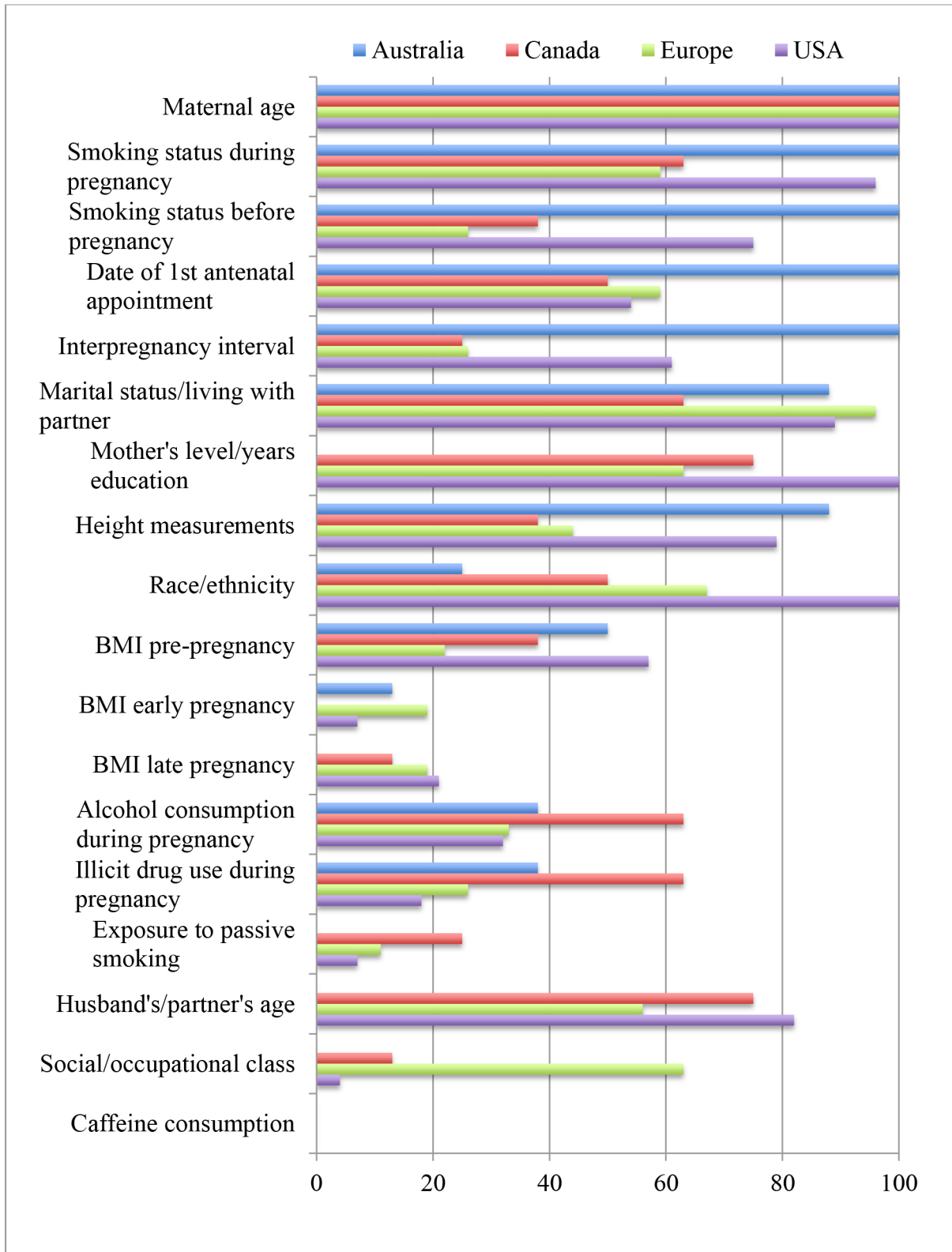
Discussion

In this perinatal data survey we found that of 63 responding countries/regions across Canada, Europe and the US and 8 states/territories in Australia (information extracted from the AIHW website) 63/71 (89%) have been collecting perinatal data for over 10 years and 57/71 (80%) have data that are ~99% complete. Smaller countries tend to collect population-based data while large countries collect data regionally, supplemented with national mandatory collection. Some countries/regions (32/71, 45%), collect information on all pregnancy events, including miscarriage and TOP, but most (37/71, 52%), collect information only for live births and stillbirths and for 49/71 (69%) countries/regions information on miscarriages and TOPs can be differentiated from stillbirths. The availability of linked data on two or more pregnancies in the same woman is invaluable for conducting perinatal epidemiological research and this is possible for 63/71 (89%) countries/regions.

Strengths and limitations

We have produced a detailed description of perinatal databases and the routinely collected perinatal data across Australia, Canada, Europe and the USA providing useful information for researchers interested in undertaking global collaborative

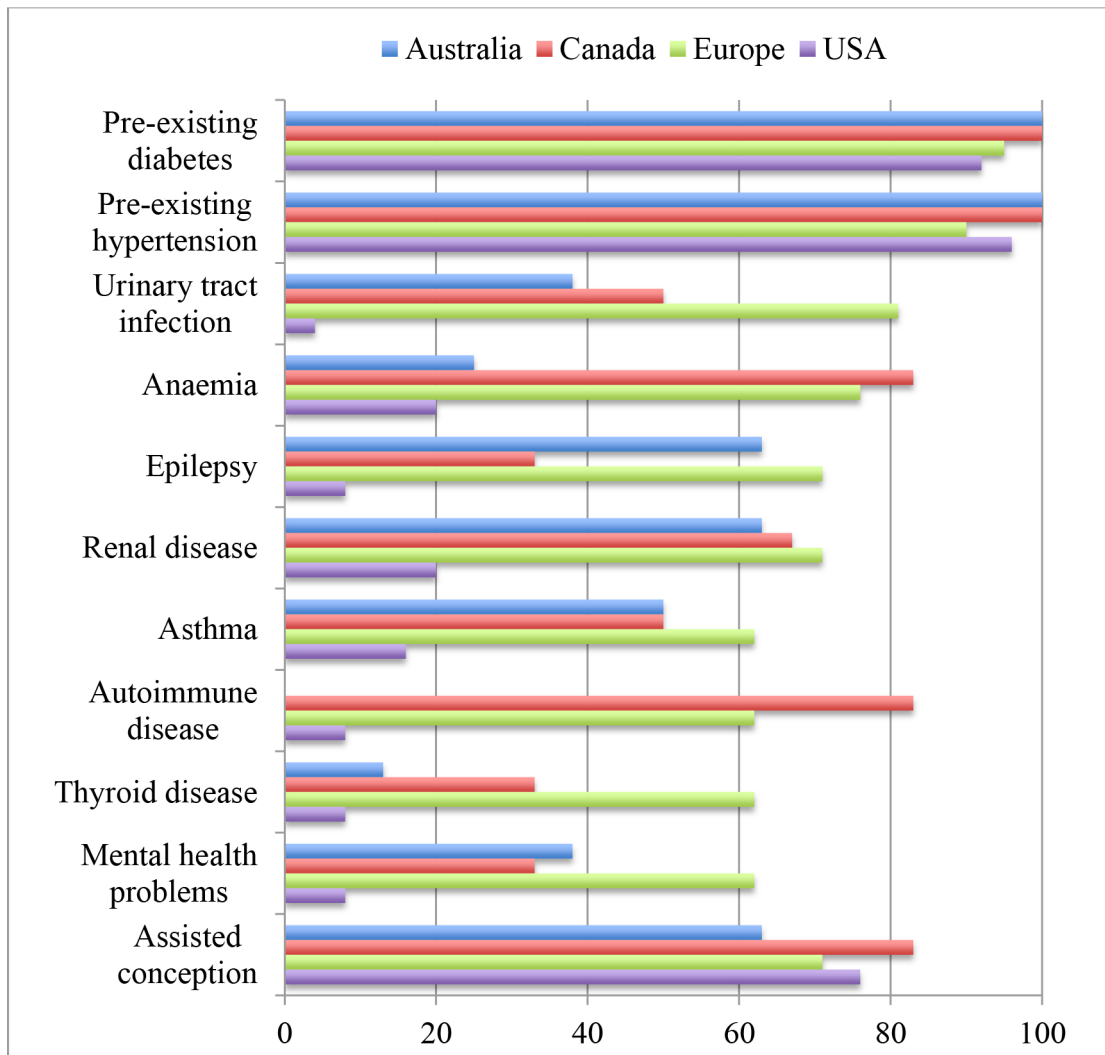
Figure 1: Proportions of responding countries/regions in each geographical area that collect the demographic information asked about in the questionnaire



perinatal research. However, our survey is subject to several limitations. As with any survey, we had to rely on the knowledge of the data custodian/responder and it is possible that they may have missed some relevant data sources or indicators. Despite piloting of our questionnaire we found that there may have been an interpretation issue. When asked

about the data collected in relation to covariates we did not explicitly say to include variables that may be collected in other databases and available through linkage. Although some informants did include these, there may have been others who did not. Nevertheless, for Europe, validation of our findings was possible through comparison of indicators that overlap

Figure 2: Proportions of responding countries/regions in each geographical area that collect the medical conditions asked about in the questionnaire



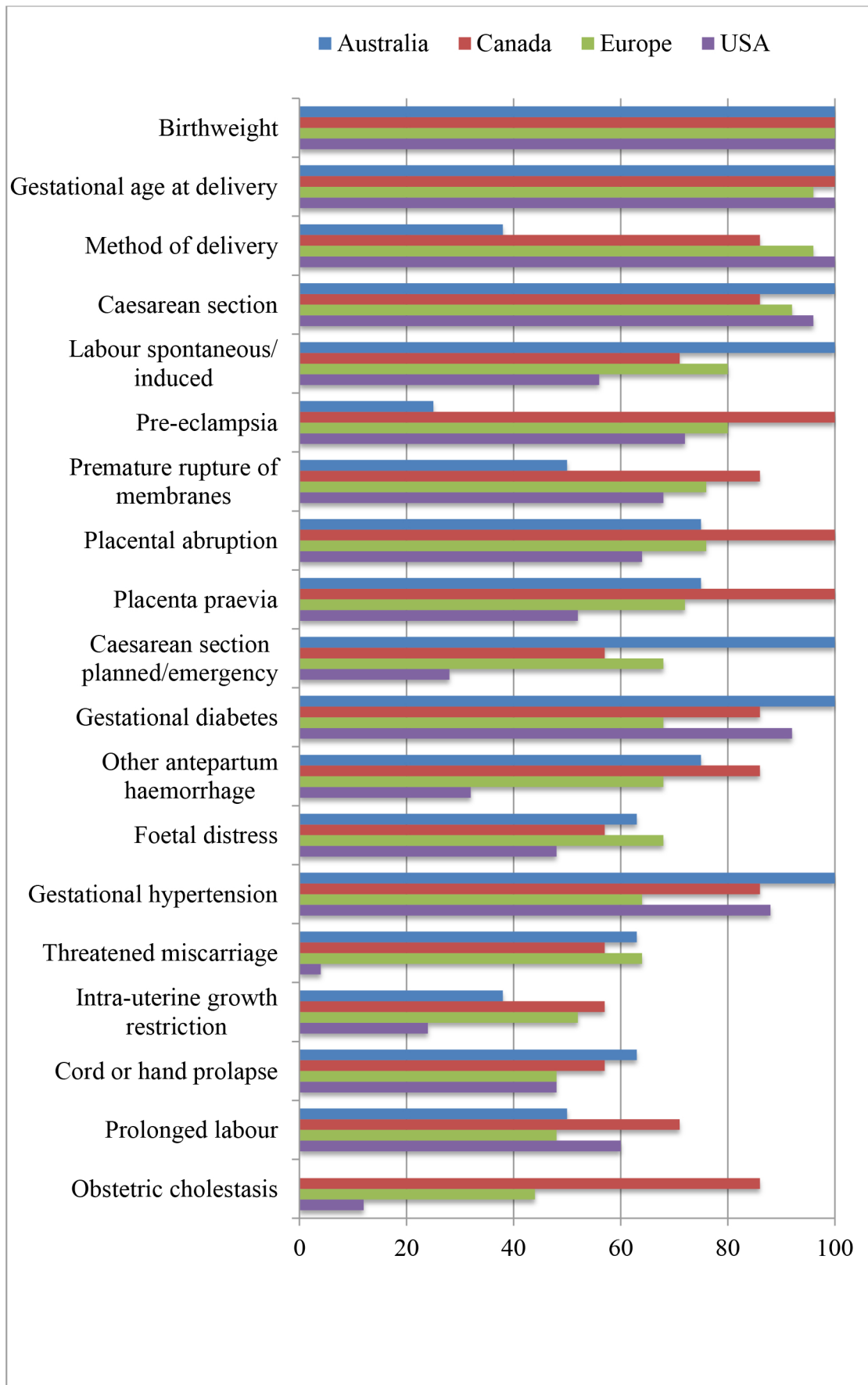
with core indicators collected by Euro-Peristat [3]. In addition, while we did ask about the completeness of the data, we did not attempt to determine the quality of the data collected in the databases.

Despite requiring only approximately 15 minutes to complete and three email reminders being sent, only 80 out of 120 countries/regions invited to participate agreed, and only 63 (53%) completed the questionnaire. Nevertheless, this response rate compares favourably with response rates for other online surveys [21]. For Europe, most of the countries that responded to the survey are in Western Europe, and most (23/27 countries), participate in Euro-Peristat [3]. Consequently, this survey is subject to reporting bias and may not reflect the perinatal data collected across all countries in Europe. Many of the countries that did not respond can broadly be classified as Eastern European countries. It is not possible to rule out non-response bias, as non-responders may be those that do not have a complete and robust system of data capture. Attempts to improve data collections systems and reliability of data are currently ongoing for many of these countries [22]. Or, it may be that these countries do not have the resources to respond to an English language survey.

Comparison with the literature

Euro-Peristat, a perinatal health-monitoring programme that collects perinatal data from 31 countries in Europe aimed to provide comparable data about the health and care of pregnant women and babies in Europe, while at the same time offer opportunities to share information. Euro-Peristat has reached consensus on a core-set of perinatal indicators for international European comparison. Much as Euro-Peristat has tried to improve consistency in data collection and definitions across countries in Europe, differences between countries remain with many countries unable to provide data on key indicators, and in the case of stillbirth [3]. Our survey also found differences between countries in the availability of perinatal data. For countries in Europe, we found that medical conditions and pregnancy complications were better covered than socio-demographics; a reverse pattern seen for the USA. Many respondents from the USA reported using the US 2003 revision of the foetal death certificate to record this information; currently the primary source of data collected through the CDC on stillbirths. Maternal medical conditions and perinatal risk factors are a series of check boxes with a field to note conditions not specified (can either be completed with

Figure 3: Proportions of responding countries/areas in each geographical area that collect each pregnancy condition asked about in the questionnaire



descriptions or ICD codes). Some respondents reported that it is possible to record conditions that are not specified, others did not. In a study that assessed accuracy of recording of perinatal risk factors using the foetal death certificate relative to maternal medical records, Lydon-Rochelle and colleagues [23] found inaccuracies in reporting of a number of maternal and perinatal risk factors. Compared to medical records, foetal death certificates had substantial missing data. The authors suspect that conditions that are not specified and belong in the 'other' category often go unreported. In our survey, most respondents from the USA reported collecting few medical conditions, and most reported recording only those specified on the foetal death certificate. In the USA, birth and foetal death certificates are key data sources. To better understand pregnancy and birth related outcomes accurate data must be recorded. Quality assurance checks on birth and foetal death certificate completion may improve reliability of the information collected [23].

IUGR is a condition associated with high-risk pregnancies, including stillbirth, yet less than half of responding countries/regions reported collecting information on IUGR [1, 24]. Detection of IUGR can be an effective method of reducing stillbirths, thus, antenatal detection rates of foetal growth restriction is a key indicator of quality of care [25]. In 2016, Flenady *et al* [1] highlighted the need for improvement in the perinatal data collected, to improve comparability and standardise the definition of stillbirth across HICs. While most countries/regions use gestational age cut-offs for defining stillbirth, we found that the exact cut-offs varied in different databases. Half of responding countries/regions in Europe use a definition of ≥ 22 weeks gestation while Australia and most regions in Canada and the USA use a definition of ≥ 20 weeks gestation. Most other countries use a 24-week cut-off to define stillbirth. Nine countries/regions reported using a birthweight. Advancement in neonatal intensive care has increased neonatal survival at lower gestational ages; consequently many HICs have reduced the gestational age cut-off for registration of stillbirths. It is unlikely that the legal requirements for registration of stillbirth can be harmonised across countries, however it is important that committed groups and organisations [3, 26, 27] continue efforts towards collection of data that is comparable.

Determining the cause of stillbirth is important as not only does it provide insight into the contributing factors but it also provides parents with an explanation for why it happened and can influence management of future pregnancies. Yet, in our survey, a number of countries/regions questioned the quality/accuracy of the information collected on the causes of stillbirth. We also found inconsistency between countries/regions in approaches to classification of stillbirth, although most reported that cause of stillbirth is classified in accordance with ICD10 codes. While ICD codes have the advantage of being international, limitations in ICD-10 for classifying cause(s) of stillbirth (failure to recognise foetal and placental conditions) results in exclusion of important information and high proportions of stillbirths classified as unexplained [1]. Suboptimal classification and poor data quality on the causes of stillbirth was highlighted by Flenady *et al* in 2016 [1]. Following calls for a uniform approach to classification of stillbirths a classification for global use is now in the testing phase; the WHO Application of

ICD-10 to Perinatal Deaths: ICD-Perinatal Mortality (ICD-PM) [28]. The ICD-PM uses a layered approach based on the time of death (antepartum and intrapartum) and then further assigns foetal and/or maternal causes. This will provide improved interpretation and comparability of cause of death data not only across countries, but also across settings.

For most responding countries/regions for researchers to gain access to their data, completion of a data access request form, ethical approval from committees or bodies that govern the data and a cost recovery for the data management is sufficient. For other countries, accessing the data is not so straightforward and can only be obtained if the researcher is a resident or affiliated with a research institution of that country. Permission may also be required from data protection agencies, and for some countries, only aggregated data is available to researchers. A number of responding countries/regions reported that no cost was involved when requesting data. Although no cost is required for the data, a cost is typically involved for data recovery. This might suggest that requests for data from researchers in other countries are uncommon.

Implications

Our survey has demonstrated that most perinatal databases in Australia, Canada, Europe and the USA can link pregnancies occurring in the same woman. However, databases varied in the extent of information collected on the causes of stillbirth as well as in the collection of maternal sociodemographic and pregnancy related factors, thus limiting their potential usefulness.

Conclusions

Continued improvement in National perinatal datasets in Australia and the UK (MBRRACE-UK [20]), and steps towards data harmonisation in Canada (Canadian Minimal Dataset proposed by the Canadian Perinatal Programs Coalition of Canadian Perinatal Health Programs) is crucial, as is collective consideration of alignment where feasible. Further, for public health purposes, it is important that the accuracy of data collected on the cause of death in stillbirth is improved. The Nordic countries have long standing national medical birth registers (MBRs), with high quality data that extends for over four decades. The MBRs have been widely used for research and their value is increasingly being recognised [29]. The Nordic countries have consistently been among the countries in Europe with the lowest stillbirth rates [1]. It is an observation that through investment in perinatal health information systems, these countries have been able to use the information collected to gain insight into the factors that affect perinatal outcomes. High quality health information systems with comparable data about the health care of women and their babies is key for epidemiological and medical research. If standardised definitions and improvements in data quality are to be achieved the value of comparable data must be recognised.

Acknowledgements

The authors would like to thank all of the databank custodians who participated in the survey in order to help us determine the pregnancy and birth data that is collected across Europe, Canada and the USA.

Conflict of interest statement

The authors report no conflicts of interest

Ethics statement

Ethical committee approval was not required for this survey because it related to data holdings, not personal data.

Abbreviations

Australian Institute of Health and Welfare (AIHW); Cause of death and associated conditions (CODAC); Centers for Disease Control (CDC); District Health Board (DHB); High-income countries (HICs); Individual participant data (IPD); international classification of diseases (ICD); ICD-Perinatal Mortality (ICD-PM); Individual participant data (IPD); Intra-uterine growth restriction (IUGR); National Maternity Collection (MAT); Medical birth register (MBR); Mothers and Babies Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK); Ministry of Health (MoH); National minimum data set (NMDS); National perinatal data collection (NPDC); New Zealand (NZ); Perinatal and Maternal Mortality Review Committee (PMMRC); Termination of pregnancy (TOP); United Kingdom (UK); United States of America (USA); World Health Organization (WHO).

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