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Population birth data and pandemic readiness in Europe

Euro-Peristat Research Network*

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Introduction

The SARS-CoV-2 pandemic exposed multiple shortcomings in national and international capacity to respond to an outbreak of infectious disease. It is essential to learn from these deficiencies to prepare for future epidemics. One major gap is the limited availability of timely and comprehensive population-based routine data on the impact of COVID-19 on pregnant women and babies. As part of the Horizon 2020 Population Health Information Research Infrastructure (PHIRI) project on the use of population data for COVID-19 surveillance, the Euro-Peristat Research Network investigated the extent to which routine information systems could be used to assess the effects of the pandemic by constructing indicators of maternal and child health and COVID-19 infection. The Euro-Peristat network brings together researchers and statisticians from 31 countries to monitor population indicators of perinatal health in Europe, and periodically compiles data on a set of ten core and 20 recommended indicators.[1]

The effect of the pandemic on the health of pregnant women and babies

At the onset of the pandemic, single-centre hospital studies and rapidly mounted population-based studies provided vital information to guide clinical care and policy by documenting the greater risks of admission to intensive care and of pregnancy complications, such as preterm delivery and pre-eclampsia, among pregnant women with COVID-19.[2] They also showed generally good outcomes for most infected pregnant women and babies.[2] Systematic reviews of this growing body of work have provided more robust guidance, but are limited in their ability to capture key population outcomes such as stillbirth and neonatal death, which occur too infrequently to be included as outcomes in most single- and even multi-centre studies. The most recent update of a living systematic review, based on 192 studies of pregnant women with COVID-19, with 97 studies investigating perinatal outcomes, included only 72 stillbirths and 41 neonatal deaths.[3]

Research has also accumulated on the effects of the pandemic on the general population of pregnant women. These indirect effects may result from changes in health care access or quality, through health-system failures, policies to reorganise care, such as moving to telemedicine consultations, or women's reluctance to seek care for fear of infection, as well as from economic adversity and increased stress. A recent systematic review provides a valuable overview of 40 studies on the indirect effects of the pandemic on multiple maternal and perinatal outcomes, but also reveals the lack of research using population birth data.[4] For example, some very small studies reported unexpected decreases in preterm birth rates during the first lockdown in March and April 2020.[5,6] Ten further studies on preterm birth in high-income countries were identified by the review, yielding an overall pooled effect in favour of a decrease in preterm birth, but with substantial heterogeneity.[4] However, only three studies were population-based regional or national studies. Only one of the eight studies on stillbirth included in the review was population based.

Surveillance of perinatal health during a pandemic requires population-based data

As pregnant women and newborns are generally in good health, studies to monitor their health require large population-based samples. Further, trend data from previous years are required for reliable assessments of change because

seasonal effects, secular trends in birth rates and pandemic-related changes in fertility, as observed during CoV-SARS-2,[7] can impact on perinatal outcomes. A population approach is also essential because single- and multi-centre studies may not detect systemic changes that result from disruption to the organisation of healthcare services. They may also be unreliable if population movements affect their activity levels and patient case mix. For instance, 17% of residents of the Parisian region moved to other parts of France during the first lockdown.[8] Finally, comprehensive coverage, including disadvantaged populations, is needed because perinatal outcomes are sensitive to changes in socio-economic circumstances, and social disadvantage increases vulnerability to infection and its consequences.[2]

Population birth data in Europe: a survey of the availability and timeliness of key indicators

To assess the availability of population birth data in Europe, the Euro-Peristat network developed an online survey for participating countries asking about the availability of preliminary and verified finalised birth data for constructing core perinatal health indicators, including stillbirth, neonatal mortality, preterm birth, low birthweight and caesarean rates for births from (i) January–April 2020 and (ii) all of 2020. We also enquired about whether codes had been routinely added to birth data to indicate COVID-19 infection. The initial survey was completed in June–July 2020 and updated in November–December 2020 to include information on linkage and disruptions to reporting systems after a discussion of preliminary results by the country teams. Twenty-seven countries and the constituent nations of the UK provided data (Table S1).

Some countries used several data sources, including birth and death certificates, birth notification systems, or stillbirth and abortion registers, to generate the full set of core indicators. In these cases, we asked for information about the availability of data to generate stillbirth, preterm birth, low birthweight and caesarean rates, as they are often available earlier than data on neonatal or infant deaths.

Timeliness of data

Figure 1 presents the estimated timing for accessing preliminary and final population data on births in 2020 and illustrates the considerable heterogeneity between countries. About half of the countries had preliminary data on the first lockdown period by November of 2020, with half having the final data by May 2021. Final data for the year 2020 started to become available in March 2021, with half of the countries having data available by September 2021. Figures distinguishing between sources that rely solely on civil registration data and those using medical registers or hospital discharge databases show that, especially for preliminary data, medical registers provided more rapid access.

Some countries reported disruptions or changes of data procedures related to the pandemic that may impact on quality or completeness, particularly for preliminary data. These were mainly as a result of personnel being repurposed for other data or clinical duties, resulting in backlogs in processing, mentioned by eight countries. Several countries mentioned delays to birth registration. For instance, in the UK the civil registration of live births was paused for several months during the first lockdown. It was then continued in Scotland and Northern Ireland, but varied locally in England and Wales, during subsequent lockdowns. Other changes to procedures, such as in France, where the hospital budgets for 2020 and 2021 will not be determined by activity measures from hospital discharge data, may affect the coding of complications or outcomes.

Integrating COVID-19 codes into birth sources

Specific codes indicating COVID-19 infection are necessary for monitoring outcomes associated with infection, but also for exploring indirect effects where and when the prevalence of infection is high. Only two of the 11 countries that use civil registration sources have the option of adding COVID-19 codes from the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) to birth data, as shown in Table 1. In contrast, 17 out of 19 countries that use sources based on clinical or medical databases reported that this code is already or will be added to birth data. In some countries, there is a potential to link COVID-19 codes to birth data, but this is not currently planned. Overall, 23% of the countries cannot add COVID-19 codes to routine birth data.

Remaining questions for European data systems

This overview focused on the availability and timeliness of key data items, but other questions remain. For instance, it is important to evaluate whether disruptions to data procedures affected the quality or completeness of the data. Verifying the coding of key variables or trends over time in numbers of births by hospital or region could reveal system dysfunctions; these quantitative assessments could be complemented by qualitative studies. Further research is also needed on the quality and reliability of COVID-19 codes. At the onset of the pandemic, the World Health Organization (WHO) issued guidelines for coding confirmed

All sources (N=30 countries)
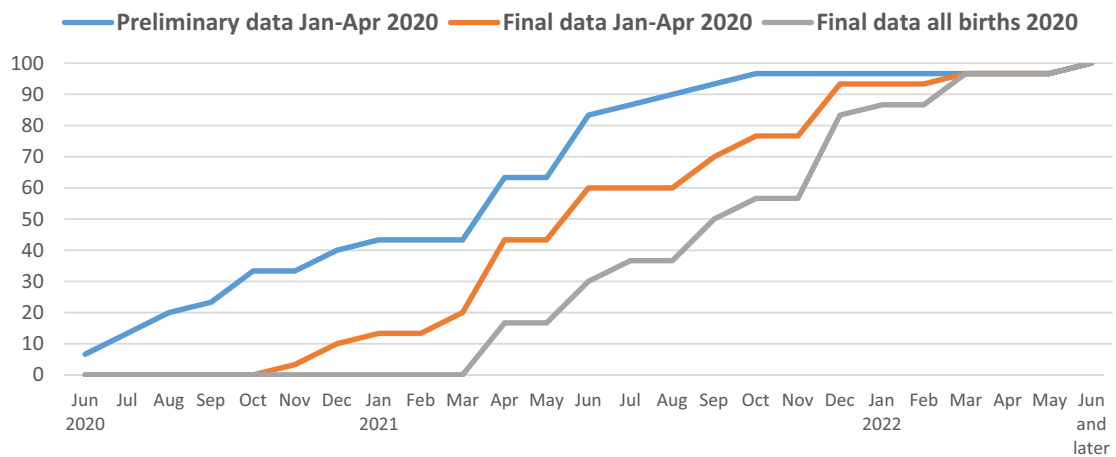
Civil Registers (N=11 countries)
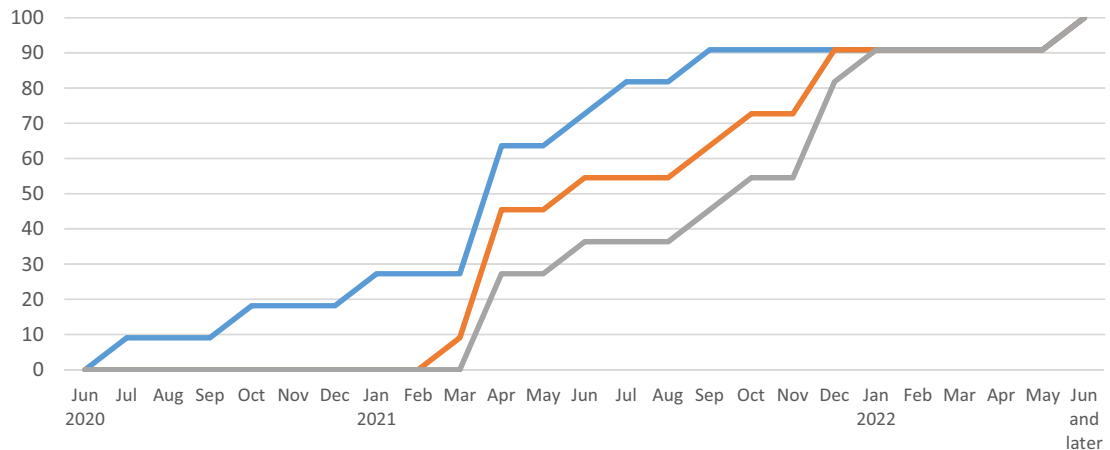
Medical Registers (N=19 countries)
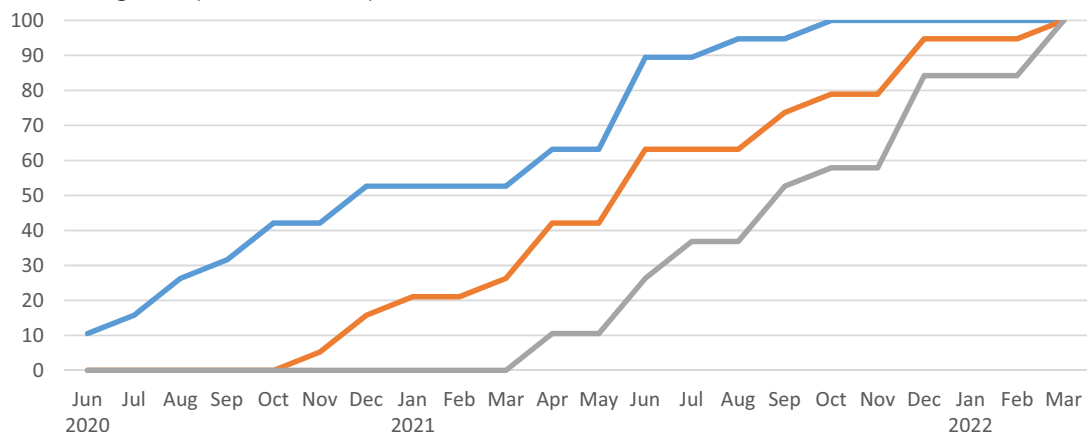
Figure 1. Availability of core perinatal health indicators in European countries overall and by source. When several sources were used to generate Euro-Peristat data, we requested information on birth data that could be used to generate stillbirth, preterm and low birthweight rates (as opposed to neonatal or infant deaths, which may become available later). See Table S1 for data by country.

Table 1. Capacity to identify confirmed or suspected COVID-19 infections using ICD codes in routine birth data

	Civil registration only	Clinical/ hospital discharge databases	Total	%
ICD codes for COVID-19 included in birth data (directly or by linking to another source)	2[a]	14[b]	16	53
Linkage is planned to another source with COVID-19 codes	2[c]	3[d]	5	17
Potential to link to other source, but not planned	2[e]		2	7
Not possible to include COVID-19 codes	5[f]	2[g]	7	23
Total no. of countries responding	11	19	30	100

Refers to data on births used to compute stillbirth, preterm birth and low birthweight rates, using several data sources (using COVID-19 codes for deaths only was not counted as a 'yes').
[a]Czech Republic, Romania.
[b]Croatia, Denmark, England and Wales, Finland, France, Germany, Iceland, Latvia, Luxembourg (code is present, but not based on ICD codes), Malta, Norway, Sweden, Northern Ireland, Scotland.
[c]Belgium, Cyprus.
[d]Estonia, Lithuania, the Netherlands.
[e]Poland, Portugal.
[f]Austria, Bulgaria, Italy, Spain, Switzerland.
[g]Ireland, Slovenia.

COVID-19 infection using ICD codes; these were updated to include guidelines for suspected infection and specific guidelines were developed for mothers and babies. Studies are beginning to address the issue of coding quality as applied generally, finding good results overall,[9] but this is likely to differ across countries and hospitals and has not been assessed for pregnant women and babies. Unique questions exist for the mother–child dyad: for instance, although it may be easy to identify babies with a symptomatic mother testing positive for COVID-19 at delivery, identifying children born to mothers with a resolved or asymptomatic COVID-19 infection during pregnancy is more challenging. The ability to link hospital testing strategies will be crucial for the interpretation of positivity rates as it is estimated that about three-quarters of infections at delivery are asymptomatic.[3]

A final question concerns the data in population data sources beyond the core perinatal health outcomes discussed here. The Euro-Peristat indicator set has a limited number of health service measures, in part because of the complexity of defining comparable indicators between health systems. In line with broader WHO initiatives to develop population health indicators in the context of COVID-19,[10] countries should assess whether they are able to report on population health service indicators to enable rapid feedback on problems with access or quality of care that can affect women and babies during a pandemic.

Larger lessons and strategies for change

This overview draws attention to the delays in the availability of population birth data; in general, finalised data from the first lockdown period were not available until the spring of the following year. However, there was marked heterogeneity, suggesting that workable solutions to producing more rapid data already exist. Some of the variation was linked to the types of data systems, with a generally longer lag for preliminary information when countries derive birth data from civil registration rather than from clinical databases or hospital discharge systems. This illustrates the importance of using these medical databases for reporting on perinatal indicators at a population level, if this is the case. Many countries relied on linkage to obtain information on COVID-19. Linkage of routine data, underused in many countries, emerges as a central component of a strategy to improve the pandemic readiness of population birth data. It is being exploited in some countries to make further investigations possible,[11] and ambitious initiatives to provide longitudinal maternal–newborn databases for routine surveillance could provide a road map for the future.[12] Finally, a future plan should include procedures for the rapid international synthesis of data. Compiling data at a European level, a central objective of the PHIRI project, permits insight into the generalisability of national trends and generates knowledge to inform European policy.

This overview of information systems in Europe, highlighting the limits of routine birth data, calls for urgent attention to population monitoring capacity to improve preparedness for a future pandemic. The SARS-CoV-2 virus has been most deadly for older people and adults with respiratory and other comorbidities. In contrast, a future pandemic could be more dangerous for pregnant women and newborns who remain uniquely vulnerable to major adverse effects from viral infections and are at risk when health systems are disrupted because of their non-deferrable need for health services during pregnancy, childbirth and the postpartum period.

Disclosure of interests
None declared. Completed disclosure of interests form available to view online as supporting information.

Contribution to authorship

All members of the Euro-Peristat network, listed as a group author, participated in the design of the study, provided data for their country, assisted with interpretation of the data and revision of the article and approved the final version. Several online meetings were held to discuss this study. From the Institut national de la santé et de la recherche médicale (Inserm) team, MD and MP designed the data collection instrument and carried out the data analyses. JZ drafted the article.

Details of ethics approval

Not required.

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Data availability statement

Data are provided in Table S1.

Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Table S1. Data sources, type, data available and new ICD codes for COVID-19. ∎

References

1 Zeitlin J, Alexander S, Barros H, Blondel B, Delnord M, Durox M, et al. Perinatal health monitoring through a European lens: eight lessons from the Euro-Peristat report on 2015 births. *BJOG* 2019;126:1518–22.

2 Knight M, Bunch K, Vousden N, Morris E, Simpson N, Gale C, et al. Characteristics and outcomes of pregnant women admitted to hospital with confirmed SARS-CoV-2 infection in UK: national population based cohort study. *BMJ* 2020;369:m2107.

3 Allotey J, Stallings E, Bonet M, Yap M, Chatterjee S, Kew T, et al. Clinical manifestations, risk factors, and maternal and perinatal outcomes of coronavirus disease 2019 in pregnancy: living systematic review and meta-analysis. *BMJ* 2020;370:m3320.

4 Chmielewska B, Barratt I, Townsend R, Kalafat E, van der Meulen J, Gurol-Urganci I, et al. Effects of the COVID-19 pandemic on maternal and perinatal outcomes: a systematic review and meta-analysis. *Lancet Glob Health* 2021;9:e759–72.

5 Hedermann G, Hedley PL, Bækvad-Hansen M, Hjalgrim H, Rostgaard K, Poorisrisak P, et al. Danish premature birth rates during the COVID-19 lockdown. *Arch Dis Child Fetal Neonatal Ed* 2021;106:93–5.

6 Philip RK, Purtill H, Reidy E, Daly M, Imcha M, McGrath D, et al. Unprecedented reduction in births of very low birthweight (VLBW) and extremely low birthweight (ELBW) infants during the COVID-19 lockdown in Ireland: a 'natural experiment' allowing analysis of data from the prior two decades. *BMJ Glob Health* 2020;5:e003075.

7 Aassve A, Cavalli N, Mencarini L, Plach S, Sanders S. Early assessment of the relationship between the COVID-19 pandemic and births in high-income countries. *Proceedings of the National Academy of Sciences of the United States of America 2021* preprint 2021; 118. this version posted March 25, 2021.

8 Pullano G, Valdano E, Scarpa N, Rubrichi S, Colizza V. Evaluating the effect of demographic factors, socioeconomic factors, and risk aversion on mobility during the COVID-19 epidemic in France under lockdown: a population-based study. *Lancet Digit Health* 2020;2:e638–49.

9 Kadri SS, Gundrum J, Warner S, Cao Z, Babiker A, Klompas M, et al. Uptake and accuracy of the diagnosis code for COVID-19 among US hospitalizations. *JAMA* 2020;324:2553–4.

10 World Health Organization. Strengthening monitoring of population health to signal and address the wider effects of the COVID-19 pandemic. 2020.

11 Stock SJ, McAllister D, Vasileiou E, Simpson CR, Stagg HR, Agrawal U, et al. COVID-19 in Pregnancy in Scotland (COPS): protocol for an observational study using linked Scottish national data. *BMJ Open* 2020;10:e042813.

12 Woodworth KR, Reynolds MR, Burkel V, Gates C, Eckert V, McDermott C, et al. A preparedness model for mother-baby linked longitudinal surveillance for emerging threats. *Matern Child Health J* 2021;25:198–206.

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