

NIHR Children and Families Policy Research Unit - Written evidence (PRT0034)

1. Introduction

- 1.1. The [Children and Families Policy Research Unit \(CPRU\)](#) is one of 20 National Institute of Health Research (NIHR) Policy Research Units commissioned by the Department of Health & Social Care through the NIHR to undertake research to inform decision-making by government and arms-length bodies. CPRU is co-led by Professor Ruth Gilbert (UCL Great Ormond Street Institute of Child Health) and Dr Jenny Woodman (IOE, UCL's Faculty of Education & Society).
- 1.2. The aim of CPRU is to conduct high-quality research to support the development of evidence-based policy to improve the health of children and families and to develop methods and data resources to improve the quality and timeliness of evidence for policy.
- 1.3. As a group we have expertise in relation to using administrative data for child health research. We are primarily providing evidence to the Committee on the topic of data collection and monitoring in relation to preterm birth. We are also providing evidence on the longer-term impacts for preterm babies in terms of educational outcomes and the importance of addressing health and psychosocial issues and inequalities for all women to reduce preterm births.

2. Data collection and monitoring in relation to preterm birth

2.1. Considerations for monitoring preterm birth rates

- 2.1.1. Preterm births are just one part of a wider, inter-related spectrum of pregnancy outcomes which contribute to infant mortality. For example, we found that the excess levels of infant mortality in England when compared to Sweden were largely explained by the unfavourable distribution of pregnancy outcomes in England, including higher rates of

preterm births but also rates of babies born at a low birth weight or with congenital anomalies.¹ These birth outcomes are partly driven by socioeconomic factors resulting in a greater proportion of mothers in England living in deprived areas or giving birth as teenagers.

2.1.2. The inter-related nature of pregnancy outcomes is particularly relevant to preterm birth rates which may increase because of interventions to reduce other unfavourable pregnancy outcomes (e.g. labour may be induced before 37 weeks to avoid stillbirth). ***When monitoring changes in preterm births, it is essential to consider changes in the entire spectrum of pregnancy outcomes, including stillbirths and neonatal deaths.***

2.1.3. Half of preterm births are now iatrogenic (i.e. they occur because of medical intervention, such as induction of labour or caesarean section).² These preterm births could be considered a good outcome if the alternative outcome for these pregnancies may have been a stillbirth. ***When monitoring changes in preterm birth rates, it is important to take into account whether preterm births occurred spontaneously or as a result of medical intervention.***

2.2. Issues with using Hospital Episode Statistics (HES) to monitor preterm births

2.2.1. Hospital Episode Statistics (HES) is an administrative dataset that includes de-identified information about admissions to NHS hospitals in England, including births.

2.2.2. Strengths of HES for research related to preterm births include its complete coverage of all births that occur in NHS hospitals, the ability to identify a range of pregnancy outcomes, including stillbirths and

¹ Zylberstejn et al. (2018) 'Child mortality in England compared with Sweden: a birth cohort study', *The Lancet*, 391 (10134), p2008-2018.

² Aughey et al. (2023) 'Iatrogenic and spontaneous preterm birth in England: A population-based cohort study' *British Journal of Obstetrics and Gynaecology*, 130 (1), p33-41

neonatal death, and the relative lower costs in comparison to collecting data.

2.2.3. However, there are some limitations of HES in relation to preterm births. Gestational age – which is needed to identify preterm births - is not recorded in a minority of births. For example, among children born between 1st September 2004 and 31st August 2005 gestational age was not recorded for almost a third (29.3%).³ As a research group we have developed robust methods to utilise the subset of HES data with complete information on gestational age,⁴ but relying on a subset of data provides an incomplete picture of the rates of preterm birth and may not be suitable for exploring rarer outcomes.

2.2.4. ***To monitor rates of preterm birth and related outcomes, the quality of data on gestational age recorded in Hospital Episodes Statistics needs to be improved in terms of completeness and accuracy.*** Data on births in HES and maternity records needs to prioritise high quality collection of key information such as accurate gestational age, birthweight and whether the baby showed signs of life at birth (i.e. liveborn) or not. Trends in preterm birth and infant mortality need to report live and still births from 24 weeks onwards, to account for changes in classification of signs of life at birth for extremely preterm babies.⁴

3. Longer term impacts for preterm babies

3.1. To understand the longer term outcomes of pregnancy, for babies born preterm and at term, routine measurement of development is needed during childhood for all babies. Policy makers can then assess whether disparities between mothers living in deprived and less deprived areas,

³ Libuy et al. (2022) 'Gestational age at birth, chronic conditions and school outcomes: a population-based data linkage study of children born in England', *International Journal of Epidemiology*, 52 (1), 132-143.

⁴ Zylberstejn et al. (2018) 'Child mortality in England compared with Sweden: a birth cohort study', *The Lancet*, 391 (10134), p2008-2018.

or from certain ethnic groups are narrowing or not over time, and whether these differences are explained by gestational age at birth, or other factors.

- 3.2. Education records containing school test results at age 5, 7, 11, 16 and 18 have been linked to children's hospital records, which includes details of their birth, to create [the ECHILD Database](#).⁵ This anonymised database will shortly be available for government analysts and UK researchers to monitor services and for research. Cognitive measures in school tests show great sensitivity at a population level to the week of birth, and by inference, fetal neurological damage or developmental delay.
- 3.3. In a recent study, we used the ECHILD Database that contained linked hospital and education records for all children born in England between 1 September 2004 and 31 August 2005. We described school attainment at Key Stage 1 (KS1; age 7) and Key Stage 2 (KS2; age 11) and any special educational needs (SEN) provision by age 11.⁶ Of 306,717 children, 5.8% were preterm (i.e. born <37 weeks gestation). The percentage of children not achieving the expected level at KS1 was 50.0% for those born at 24 weeks of gestation (compared to 7.6% born at 41 weeks). A similar pattern was seen at KS2. SEN provision ranged from 82.6% at 24 weeks to 29.0% at 41 weeks.
- 3.4. It should be noted that of all children with SEN provision in primary school only 8% were born preterm; 92% were born at 37 weeks or more. Children born early term (37–38 weeks of gestation) also had poorer outcomes than those born at 40 weeks.

⁵ Mc Grath-Lone et al (2021) 'Data Resource Profile: The Education and Child Health Insights from Linked Data (ECHILD) Database', *International Journal of Epidemiology*, 51 (1), p17-17f.

⁶ Libuy et al. (2022) 'Gestational age at birth, chronic conditions and school outcomes: a population-based data linkage study of children born in England', *International Journal of Epidemiology*, 52 (1), 132-143.

4. Prevention of preterm births

- 4.1. Preterm birth is a manifestation of adverse factors experienced by women before and during pregnancy. For example, we found that a range of pre-pregnancy psychosocial risk factors routinely recorded in hospitalisation records before 20 weeks of pregnancy were associated with substantially increased risks of preterm birth: 10.9% of births to mothers with a history of health or behavioural conditions were preterm compared to 6.4% of all births overall.⁷ Focusing on improving maternal health and wellbeing, before and during early pregnancy, could lead to reductions in preterm birth.
- 4.2. Our research has also shown that maternal age is a strong driver of preterm birth. The 25%-40% increased risk of preterm birth for teenage mothers (which corresponds to an additional 1%-2% of preterm births compared with mothers aged 30-34 years) is similar across settings with a range of teenage birth rates.⁸ Infants born to mothers aged 20-24 also experience higher rates of preterm birth than older mothers, and the majority of women with risk factors for low birth weight are aged 20+ years.⁷ This sustained gradient effect of maternal age highlights the importance of social, economic, and behavioural factors that predispose some young women to pregnancy. Policies aiming to reduce and postpone teenage pregnancies, or those targeting highly select groups during pregnancy, are therefore only part of the solution: primary preventive strategies need to address the social, welfare, and health care factors that influence pregnancies among young women.
- 4.3. Any (primary or secondary) interventions to reduce preterm births must monitor impact on the full range of pregnancy outcomes. For example,

⁷ Harron et al. (2021) 'Associations between pre-pregnancy psychosocial risk factors and infant outcomes: a population-based cohort study in England', *The Lancet Public Health*, 6 (2), e97-e105.

⁸ Harron et al. (2020) 'Preterm birth, unplanned hospital contact, and mortality in infants born to teenage mothers in five countries: An administrative data cohort study', *Pediatric and Perinatal Epidemiology*, 34 (6), p645-654.

a study evaluating the introduction of community perinatal mental health teams in England found that while the risks of preterm birth decreased, rates of small-for-gestational-age births, stillbirths and neonatal death increased.⁹

5. Acknowledgments

- 5.1. This response has been prepared by CPRU with contributions from: Prof Ruth Gilbert, Dr Ania Zylberzstejn, Prof Katie Harron (UCL GOS Institute of Child Health), Dr Jenny Woodman and Dr Louise Mc Grath-Lone (UCL Social Research Institute).

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⁹ Gurol-Urganci et al. (2024) 'Community perinatal mental health teams and associations with perinatal mental health and obstetric and neonatal outcomes in pregnant women with a history of secondary mental health care in England: a national population-based cohort study', *The Lancet Psychiatry*, 11 (3), p174-182.