OXFORD POPULATION HEALTH

UNIVERSITY OF OXFORD

NPEU

Rt Hon Caroline Nokes MP
Chair, Women and Equalities Committee
House of Commons
Palace of Westminster
Westminster
SW1A 0AA

By email

31st October 2022

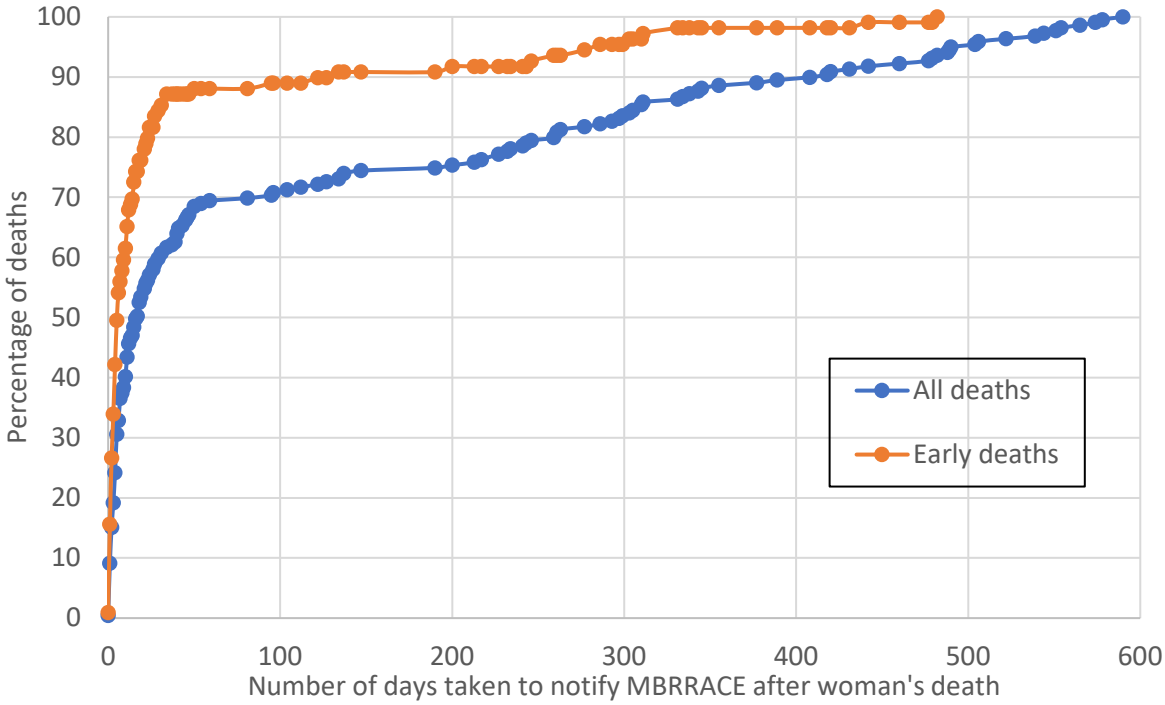
Dear Caroline,

Many thanks for getting in touch and for your continued interest in ensuring timely data to improve maternity care. I have divided my response to your questions according to the three main sources of delay.

1. Hospitals

Maternal deaths notifications and receipt of records:

There continues to be extreme variability in the speed with which hospitals notify MBRRACE-UK when a woman has died, and the speed with which they return surveillance information and copies of medical records which we request after a woman's death has been notified to us. The graph below indicates the number of days between a woman's death occurring and it being reported to MBRRACE-UK, for all women who died in 2021 (blue line).



25% of women's deaths are notified to us within 5 days, 50% within 17 days, and 75% within 200 days. The longest time to notify a maternal death was 590 days after her death, noting that

Richard Doll Building, Old Road Campus, Roosevelt Drive, Oxford OX3 7LF
+44(0)1865 289727 marian.knight@npeu.ox.ac.uk

the final few deaths are identified by us from linked ONS data. This timing is therefore a result of the timing with which we receive linked data on deaths from ONS (discussed further below) and is not a hospital delay. Deaths which occur during pregnancy or up to six weeks after pregnancy are notified to us more quickly (orange line above), reflecting that these notifications mostly come from maternity units, but note that notifications of more than 1 in 10 of these deaths are significantly delayed.

The timeliness with which surveillance data are received is also highly variable. The data on these forms are what we need to be able to describe the women who died, their causes of death, overall maternal mortality rates and inequalities in maternal mortality rates between different groups (for example according to ethnicity). Of those surveillance forms that we have received for women who died in 2021, 25% were received within 9 days of a request from the MBRRACE-UK admin team, 50% within 21 days, and 75% within 73 days. Up to the date of this analysis, the longest time to receive a surveillance form is 535 days, but nearly 20% of forms are yet to be received.

We see a similar pattern when requesting copies of maternity notes, which we need for completing the confidential enquiry and for confirming women's cause of death. Of those that we have received for women who died in 2021, 25% were received within 16 days of a request from the MBRRACE-UK admin team, 50% within 29 days, and 75% within 79 days. Up to the date of this analysis, the longest time to receive a surveillance form is 594 days, but nearly 35% of maternity notes are yet to be received.

The situation is more extreme when considering other types of health records we request for women who have died. For deaths in 2021, we are still awaiting 36% of GP records, for example, and we have the greatest challenges with obtaining mental health records, such that we made the following recommendation in the 2018 report:

> "*There is an urgent need to establish pathways for release of mental health records with the Chief Medical Officers and Departments of Health of Ireland and the four UK nations. Records for all women who die during or in the year following pregnancy should be released to MBRRACE-UK from risk/governance departments"*.

We reiterated this in 2021, and will be reiterating it again in the 2022 report (currently planned for publication on 10th November 2022 but still awaiting NHS England clearance processes described below.)

Stillbirths and neonatal deaths notifications and receipt of records:
Neonatal deaths are statutorily notifiable within one working day of death to Child Death Overview Panels in England. MBRRACE-UK and the National Child Mortality Database have developed a joint notification system which we are in the process of launching with the phase 1 roll out of volunteer Trusts underway, thus notifications of neonatal deaths are received rapidly. Since 2017, in England, early notification of stillbirths and neonatal deaths and completion of reviews have been elements of the Maternity Incentive Scheme, which rewards Trusts with lower indemnity payments if all elements are met. This has significantly decreased delays in reporting of baby deaths.

Perinatal confidential enquiries, however, which require copies of medical records, are subject to the same delays in receipt as the maternal confidential enquiry, as detailed above.

Richard Doll Building, Old Road Campus, Roosevelt Drive, Oxford OX3 7LF
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RECOMMENDATIONS: Earlier receipt of maternal data and copies of maternal and perinatal records from maternity units could be facilitated in England by addition of elements to the Maternity Incentive Scheme and/or statutory requirements.

Other parts of the health service not covered by the Maternity Incentive Scheme (for example mental health units, GPs) should also be required to return records to MBRRACE-UK in a timely manner either through existing incentive schemes or statute.

2. NHS England/HQIP report approval processes

The standard provisional timetable for NHS England approval processes is three months, but we have no guarantee that this timetable will be met, and the future process will become more burdensome. There has been no repetition of the expedited process which was carried out for the two reports we released in 2020 specifically relating to the pandemic. I submitted the 2022 maternal report to HQIP on 4th August 2022, together with the four additional forms which are now required. I have subsequently made minor revisions to the report on 5 separate occasions, have been required to have an hour-long virtual meeting with HQIP and NHSE representatives and still, at the time of writing (31st October 2022), am awaiting news of whether the report will be signed off for publication on the 10th November.

The new MBRRACE-UK contract (from 1st October 2022 onwards) has been changed to require us to produce three maternal reports, thus tripling the admin burden and burden of the sign-off processes. I understand this change was made because of an NHSE requirement that all reports should include no more than 5 recommendations and consist of no more than 20 pages. Division into three reports will mean that the report length is only cut by approximately half from its previous length, but the additional burden of this to me personally and the rest of the team has not been recognised.

Division into three reports does allow for the potential release of surveillance data earlier (December of the year after which women died), provided report sign-off processes are truncated. The MBRRACE-UK Independent Advisory Group (chaired by Dr Matthew Jolly) is supportive of this earlier data release, noting that it would solely be release of data without any interpretation or recommendations, and discussions are ongoing as to whether this might be possible.

Note that sign-off processes for the reports from parts of the MBRRACE-UK programme that are directly funded through DHSC (such as the Perinatal Mortality Review Tool) are far shorter and less onerous, and no restrictions are placed on report contents.

RECOMMENDATION: DHSC sign-off process and timelines should be adopted for all future MBRRACE-UK reports.

3. Office for National Statistics (ONS)

We cannot produce accurate data on maternal mortality rates until we have cross-checked that we have been notified about all deaths (numerator data), and until we have data about all births and all women giving birth (denominator data). We are reliant on ONS (and equivalents in the devolved nations) for this information. Discussions are ongoing with ONS about how data can be provided in a more timely manner.

Richard Doll Building, Old Road Campus, Roosevelt Drive, Oxford OX3 7LF
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The table below shows the provisional timetable for the provision of information from ONS for 2023:

Data	Data for quarter 3 2022	Data for quarter 4 2022 +Annual refresh (full update of all data) for 2022	Data for quarter 1 2023	Data for quarter 2 2023
Still births and infant deaths	January 2023	June 2023	July 2023	October 2023
Live births	January 2023	June 2023	July 2023	October 2023
Maternal deaths	January 2023	June 2023	July 2023	October 2023
Maternal deaths identified from linking death records with birth records from the previous year (Linked maternal deaths) (annual)	-	June 2023	-	-

Two of these datasets are particularly critical to our timelines, the annual refresh, and the linked maternal deaths data. We have never yet received linked maternal deaths data in June of any given year (this year we received the data in August, there were greater delays in the previous year due to pandemic changes). This linked dataset is pivotal in our timelines as it is the most accurate cross-check to ensure we have identified all maternal deaths (without this only about 60% of deaths are identified) and, notably, provides us with information about deaths occurring between six weeks and a year after women have given birth, which is when many maternal suicide deaths occur. Earlier receipt of these linked data would speed up our timelines considerably. Given the statutory timescales for deaths reporting, this linkage could be undertaken in January rather than June.

The annual refresh provides us with the denominator data we need to be able to calculate mortality rates overall, for different geographical regions and amongst different populations (for example ethnic minority groups). We do not receive this dataset until the data has been publicly published. Other users of the data have approval to receive 'pre-release' copies of the data on an earlier timescale. Permission to obtain pre-release data would also significantly improve our timelines. The data could be provided in April rather than June. We are in discussions with ONS about the provision of pre-release data.

RECOMMENDATIONS: ONS should provide MBRRACE-UK with maternal linked data in January of each year.

ONS should provide MBRRACE-UK with pre-release births/deaths data in April of the year following the events rather than June.

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I apologise that this is a long response but I wanted to provide you with the full information underpinning these recommendations.

Yours sincerely,

Professor Marian Knight MA MBChB MPH DPhil FFPH FRCPE FRCOG FMedSci

Professor of Maternal and Child Population Health

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