



Health and Social Care Committee

House of Commons London SW1A 0AA

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From Rt Hon. Jeremy Hunt MP

Rt hon Matt Hancock MP

Secretary of State for Health and Social Care

Letter by email to mb-sofs@dhsc.gov.uk

26 August 2020

Dear Matt,

Re: Special exemptions from NHS patient data opt-out rules

I have recently been alerted by Sands, Baby Lifeline, and the Lullaby Trust to important problems with the new rules on data sharing of patient records that are coming into force from next month.

As I understand it when these new rules are in place it is possible to have a special exemption that means certain data can still be shared. However, at the moment there will be no special exemption for MBRRACE-UK. This would mean that if someone opts out of sharing their data MBRRACE-UK will not be told about a baby's death.

You will be aware of how vital the MBRRACE-UK data is for the 'halve it' campaign to halve the rates of neonatal and maternal death and disability by 2025. If this data can no longer be collected it will be impossible to monitor progress and understand where improvements need to be made. Additionally if the wide variation across different Trusts in the number of people who opt out of sharing data at the moment continues, the data on baby deaths submitted to MBRRACE-UK could become heavily skewed. Those with high opt out rates would potentially look to have low levels of baby deaths and vice versa.

I therefore have serious concerns about what this could mean for the monitoring of baby deaths in England and fear it would mean the data we collect on stillbirths and neonatal deaths are rendered meaningless.

I would therefore be grateful if you could grant a special urgent exemption for MBRRACE-UK from these new rules to ensure accurate monitoring of baby deaths in England.

I know how committed you are to the objective of improving maternity safety and am most grateful for your attention to this pressing matter. If for any reason you are not able to grant this exemption I would be grateful if you could let me know as soon as possible.

Yours sincerely,

Rt hon Jeremy Hunt MP

Chair, Health and Social Care Committee



Department
of Health &
Social Care

*From the Rt Hon Matt Hancock MP
Secretary of State for Health and Social Care*

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The Rt Hon Jeremy Hunt MP
Chair
Health and Social Care Committee
House of Commons
Westminster
London SW1A 0AA

29 September 2020

Dear Jeremy,

Re: Special exemptions for NHS patient data opt-out rules

Thank you for your letter of 26 August in which you asked me to consider granting a special urgent exemption for MBRRACE-UK from the national data opt-out to ensure accurate monitoring of baby deaths in England.

The national data opt-out policy was introduced on 25 May 2018, enabling patients to opt out from the use of their data for anything other than their individual care and treatment in line with the recommendations of the National Data Guardian in her Review of Data Security, Consent and Opt-Outs.

By March 2020 all health and adult social care organisations were required to be compliant with the national data opt-out policy, where they are using confidential patient information for purposes beyond an individual's care and treatment. In March, we extended the compliance deadline for six months up to 30 September 2020 in order to enable NHS staff to focus on the significant pressures due to the COVID-19 outbreak. We also said that we would review the position in September. As you will be aware the priority of the health and care sector remains the response to the pandemic and after further reviewing the current situation, I have decided to extend the compliance deadline to 31 March 2021.

The Government is committed to achieving the ambition set in 2015 to halve the 2010 rates of stillbirths, neonatal and maternal deaths and brain injuries that occur during or soon after birth. The data surveillance, analysis and confidential enquiries undertaken by MBRRACE-UK helps us to track progress towards achieving this ambition, especially maternal mortality, and also helps us to better understand some of the causes of maternal and perinatal deaths and how clinical care might be improved.

I understand the reason for an exemption from the opt out for MBRRACE-UK. I am considering how we can ensure that robust decisions are made on these remaining questions and I will look at the appropriate position for MBRRACE-UK.

Yours ever,

A handwritten signature in blue ink that reads "Matt". The signature is fluid and cursive, with a long horizontal stroke at the end.

MATT HANCOCK