Maternity and Neonatal Independent Investigation Privacy Notice (Version 1)

Summary of initiative or policy

On 14 August 2025, the Secretary of State for Health and Social Care announced the appointment of Baroness Amos as Chair of the Independent National Maternity and Neonatal Investigation (here on referred to as 'the investigation') to understand the systemic issues behind why so many women, babies and families experience unacceptable care.

The investigation will review the quality and safety of maternity and neonatal services delivered to women, babies and families across England, identifying routes to reduce the incidence and severity of harm done to women, babies and families. This will have a particular focus on the experiences of women, babies and families as they engage with all stages of the maternity and neonatal care pathway.

The voices of women and families, including fathers and non-birthing partners, are critical to the Investigation and will shape the national recommendations it will publish.

Data controller

The Department of Health and Social Care (DHSC) is the data controller.

Data processors include:

- NHS England for the purpose of providing analytical support to the investigation
- Supplier of trauma, critical incident and emotional and psychological support service (contract to be agreed)
- Supplier of transcription service (contract to be agreed)

What personal data we collect

In the course of the Investigation, we will collect information through a range of means, including interviews and evidence sessions and local trust investigations. We will update this notice with the full list of evidence collection methods in due course.

In the course of the investigation, we may collect personal information such as:

- name
- contact details
- voice recording

- geographical location
- nationality/immigration status
- children and other family members
- bank details

We may also collect “special category data”, such as data relating to health, race/ethnicity, religious beliefs, racial or ethnic origin, trade union membership and matters relating to sex and sexual orientation. It may also include disciplinary or regulatory breaches including alleged breaches and outcomes. The Investigation may also process personal data relating to criminal offences.

All personal data we receive will be handled fairly and lawfully in accordance with data protection legislation.

How we use your data (purposes)

The voices of women and families, including fathers and non-birthing partners, are at the heart of the Investigation. Their experiences will guide the Investigation’s work and shape the national recommendations it will publish. We anticipate receiving a significant amount of personal information in the course of our work.

The Investigation collects and uses, and will in time destroy, personal information and sensitive personal information, for the purposes of fulfilling the investigation’s terms of reference, which are published at https://www.gov.uk/government/publications/independent-maternity-and-neonatal-investigation-terms-of-reference/national-maternity-and-neonatal-investigation-terms-of-reference

The Investigation may receive this personal information from individuals themselves, particularly given its focus on understanding the experiences of women and families. It could also receive personal information through public engagement activities in the event that this information is volunteered.

It may also receive information about individuals via its evidence gathering from hospital trusts and other bodies.

The Investigation will produce one clear set of national recommendations to achieve high quality, safe care across maternity and neonatal services, and ensure that women and families are listened to. These will have taken previous recommendations into consideration and will therefore take primacy over previous recommendations.

Legal basis for processing personal data

Under Article 6 of the United Kingdom General Data Protection Regulation (UK GDPR), the lawful basis we rely on for processing personal data is:

(e) the processing is necessary to perform a task or function in the public interest or for our official functions and the task or function has a clear basis in law

In addition, we are also processing special category data under the following conditions per Article 9 of the UK GDPR:

(g) reasons of substantial public interest (with a basis in law)

Data processors and other recipients of personal data

During the course of the Investigation, personal information may be shared by with the following main groups:

- NHS England for the purpose of providing analytical support to the investigation. Identifiable personal information will be anonymised.
- Supplier of trauma, critical incident and emotional and psychological support service - PAM Wellness
- Supplier of transcription service (contract to be agreed)
- Supplier of pre-paid cards to remunerate family members giving evidence to the investigation for their time (contract to be agreed)

Each organisation is responsible for holding personal information securely in accordance with data protection legislation.

International data transfers and storage locations

Any personal information collected will be stored in the UK and managed in line with the DHSC's personal information charter.

Retention and disposal policy

Personal data will be retained by the investigation on DHSC systems for the planned lifespan of the investigation (six months) and for the time it will take the DHSC Maternity Taskforce to develop a new national action plan to drive improvements across maternity and neonatal care (at least one year, then to be reviewed on an annual basis).

How we keep your data secure

DHSC uses a range of technical, organisational and administrative security measures to protect any information we hold in our records from:

- Loss
- Misuse
- Unauthorised access
- Disclosure
- Alteration
- Destruction

Your rights as a data subject

By law, data subjects have a number of rights, and this processing does not take away or reduce these rights under the UK General Data Protection Regulation and the UK Data Protection Act 2018 applies.

These rights are:

1. The right to get copies of information – individuals have the right to ask for a copy of any information about them that is used.
2. The right to get information corrected – individuals have the right to ask for any information held about them that they think is inaccurate, to be corrected.
3. The right to limit how the information is used – individuals have the right to ask for any of the information held about them to be restricted, for example, if they think inaccurate information is being used.
4. The right to object to the information being used – individuals can ask for any information held about them not to be used. However, this is not an absolute right, and continued use of the information may be necessary, with individuals being advised if this is the case.
5. The right to get information deleted – this is not an absolute right, and continued use of the information may be necessary, with individuals being advised if this is the case.

Comments or complaints

Anyone unhappy or wishing to complain about how personal data is used as part of this programme, should contact DHSC's Data Protection Officer:

Email: data_protection@dhsc.gov.uk

Post:
Data Protection Officer
1st Floor North
39 Victoria Street
London
SW1H 0EU

Anyone who is still not satisfied can complain to the Information Commissioner's Office. Its website address is www.ico.org.uk and its postal address is:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Automated decision making or profiling

No decision will be made about individuals solely based on automated decision making (where a decision is taken about them using an electronic system without human involvement) which has a significant impact on them.

Changes to this policy

This privacy notice is kept under regular review. This privacy notice was last updated on 13 October 2025.