Independent National Maternity and Neonatal Investigation: information pack for family evidence panels

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This document sets out important information for women and families, including fathers and non-birthing partners, who are engaging with the independent National Maternity and Neonatal Investigation ('the Investigation').

We ask that ahead of your meeting with the Investigation, you read through the information in this pack. You will also be asked to complete a participation form. If you are participating in a virtual or in-person setting, you will need to send this to us in advance. If this poses a problem to complete in advance, please speak to the team who can support and advise.

You will be provided a link to the participation form to complete via Microsoft forms. We can provide this in word/pdf format if you cannot use the Microsoft form.

The response to some frequently asked questions is at **Annex A.**

If you have any questions, please contact matneoinvestigation@dhsc.gov.uk

1. Introduction to the Independent National Maternity and Neonatal Investigation

The Investigation will review the quality and safety of maternity and neonatal care delivered to women, babies and families across England. The aims of the Investigation are to:

- develop and publish one set of national recommendations to drive the improvements needed to ensure high-quality and safe maternity and neonatal care across England, reduce inequalities and promote health equity in the delivery of those services, and help bereaved and harmed families to receive justice and accountability in the future
- ensure that the lived experiences of women, babies and families, including fathers and non-birthing partners, are fully heard and used to inform the development of the national recommendations
- conduct and publish 14 local investigations of maternity and neonatal services in NHS trusts and use these alongside other sources of data and evidence gathered by the investigation to inform the development of the national recommendations

A particular focus in the terms of reference is to understand the lived experiences of women, babies and families in England at all stages of the maternity and neonatal care pathway, hearing directly from those individuals. The Investigation will gather a wide range of evidence, including through family evidence panels.

Further detail is set out in the terms of reference for the Investigation: https://www.gov.uk/government/publications/independent-maternity-and-neonatal-investigation-terms-of-reference

2. About the evidence panel/ family meeting

Agenda:

The standard agenda for a family panel/ meeting is:

1. Introductions from attendees
2. Housekeeping information e.g. health and safety
3. Meeting information e.g. guidance on sharing personal testimonies, review of values and behaviours, psychological support available, transcription of the meeting
4. Group discussion of the themes
5. Next steps and reminder of psychological support available
6. Thank you and close

Family evidence panels themes and questions:

The following themes will be discussed in evidence panels:

- Treatment during your care (Q1)
- Team working (Q2)
- Raising concerns (Q3)
- Support after events (Q4 and 5)

The specific questions are:

1. Would anyone like to share reflections about how they were treated during their care?
2. How well do you feel that healthcare staff worked together as a team during your care?
3. After your experience, what conversations did you have with healthcare staff to talk through what happened?
4. After your experience, how did the staff deal with your concerns or complaint?
5. How did the hospital (or Trust) respond to the issues you raised?
6. Thinking about all the things we've covered today, is there anything else you would like to share with us?

We know every family's experience is unique, but these sessions focus on shared themes and lessons we can draw from them. The information families share will help us to understand the patterns in experiences of maternity care.

Evidence panels will be audio recorded and transcribed. The transcript from the group evidence panels will be anonymised. The transcript from the evidence panels will be available to any participant who attended that panel and who wishes to see them. The Investigation may use information given during evidence panel, including quotations, in its final report. This information will be anonymised.

3. Emotional and psychological support available to families

We understand that engaging with the investigation may involve discussing and hearing distressing and traumatic experiences.

An independent emotional and psychological support service is available to families engaging with the investigation. This is provided by **PAM Wellness**, who are an independent organisation. This will be available to families before, during and after meetings.

The telephone number of the service is: **0800 098 3790.**

This emotional support helpline is available 24 hours a day every day of the year. Individuals contacting the helpline for any trauma-related or psychological concerns will be able to speak to a counsellor either immediately or a call back will be arranged within four hours

Additionally, families have access to preparatory support with a PAM practitioner; a counsellor will be available for an hour before sessions and/or you can book a preparatory support call in the days leading up to engagement. Booking information will be provided. This number is available 0800-1700 Monday to Friday and is **01925 939 427.**

4. Values and behaviours in meetings

We want to ensure that meetings are psychologically safe and inclusive. We will seek to ensure that everyone can contribute**,** including encouraging contributions from members who may find it more difficult to make their voices heard.

To achieve this, we expect everyone including the Chair, Expert Advisors and investigation support team to act with fairness, honesty, integrity and openness, to respect the opinions of others and treat all with dignity and respect.

All families, organisations and members of the investigation team who are involved in the investigation**,** must be able to participate without fear of discrimination based on ethnicity, sexuality, nationality, age, gender identity, gender presentation, language, ability or disability, asylum status, political or religious affiliation.

We ask that everyone commits to the following values and behaviours:

- **Respect for others:** be considerate of other family participants, especially when they have expressed views or shared difficult experiences. Differences

of opinion are welcomed but responses should be kind and respectful, with awareness of the difficult experiences being revisited. Communication should remain respectful towards other family participants, the Chair, Expert Advisors and investigation support team.

- **Treat everyone equally:** support the fair, equal and respectful inclusion of all members regardless of age, disability, gender reassignment, marital or civil partnership status, pregnancy or maternity, race, religion or belief, sex or sexual orientation
- **Act with honesty and integrity**: including disclosing any potential conflicts of interest. The Chair, Expert Advisors and Investigation support team have all completed a declaration of interest. Any potential conflicts of interest will be disclosed to meeting participants at the beginning of the meeting.
- **Protecting confidentiality of personal testimony**: Treat other people's personal experiences as confidential and do not share others' personal experiences with anyone outside of the meeting.

If conduct is deemed to be inappropriate, harmful or threatening towards another person, you may be asked to leave the meeting.

Social media: we understand that social media is a useful tool for connecting to others, sharing views and learning. The investigation will not monitor any individual's social media use. We ask that you remain considerate when using social media to communicate with other families, organisations and individuals outside of meetings. This includes protecting the confidentiality of other people's personal experiences and views expressed within meetings.

5. Remuneration and expenses

The Investigation is committed to inclusive participation, and to minimising the barriers that can prevent or discourage participation of family members.

Travel and expenses incurred when participating in a meeting can be submitted for reimbursement in line with the Department of Health and Social Care expenses policy. This also includes reimbursing costs for childcare and other caring responsibilities if needed. The policy is attached at **Annex B**. A separate word document will be shared with a template for you to complete to claim expenses. You will need to keep any receipts and claim expenses within 90 days. If you are unable to book your travel and wait for reimbursement, please contact the team at matneoinvestigation@dhsc.gov.uk.

In recognition of the time families have made available to participate in a family evidence panel, families will be offered £75 as a thank you. This will be in the format of a pre-paid card.

It is important to be aware that monetary awards and vouchers are classed as income. As a family member contributing to the Investigation, it is your responsibility to declare your income. The payment you receive for your involvement may be

considered taxable income. Whether or not you will have to pay tax depends on how much other income you have.

You have the right to decline payment or ask for a lower amount, which might be important if you are receiving welfare benefits. More information can be found here: https://www.citizensadvice.org.uk/

6. Investigation protocols to read ahead of your meeting

How we'll use your data: The Investigation is committed to handling personal information or data in compliance with data protection legislation: We will process your data in accordance with the Investigation's privacy notice, which is attached separately.

Safeguarding: We have a safeguarding protocol which is attached separately. This sets out how the Investigation will support the welfare of people engaging with the Investigation and manage any safeguarding concerns that emerge. It also sets out when we might need to share information with relevant authorities without the consent of the person or people involved.

Complaints: The Investigation is committed to providing a high-quality service to everyone who engages with the investigation. If you would like to provide feedback or make a complaint, the policy is attached separately.

Annex A: Frequently asked questions

1. Will my feedback remain anonymous?

Yes, your feedback will be anonymous. The in-person family evidence panels will be audio recorded and transcribed, and virtual family evidence panels will be recorded on Microsoft teams and transcribed. The transcript will be anonymised.

2. Will you share the transcript with families attending a group meeting/evidence panel?

Yes, family members attending an evidence panel can request a copy of the transcript for that specific panel. Families are asked not to share this with anyone else.

3. How will you use my contributions?

The Investigation may use information given during evidence panel, including quotations, in its final report. This information will be anonymised.

4. What happens if I change my mind before the panel?

It is entirely up to you to decide whether you would like to take part. If you have any questions about taking part you can talk to a member of the investigation team. If you agree to take part, but then decide to withdraw, then that is fine, and you do not have to give a reason. Simply tell the investigation team prior to the meeting and we will remove your name from our participant list.

5. What happens to my contributions if I decide part-way through the meeting that I no longer want to take part?

It is entirely up to you to decide whether you would like to take part. If you decide you no longer want to take part during the meeting, due to the nature of the group discussion it will not be possible for you to withdraw the information you have shared during the Family Evidence Panel once it has begun. Participants will be reminded of this at the start of the evidence panel.

6. Will we use quotes from individual family members in the report? Will we check with the family member first?

As the transcript will be anonymised, we will not be able to contact individual family members before using a quotation in the final reports. Quotations will not contain any identifiable information.

7. If I don't feel comfortable participating in a group evidence panel or I'm unable to make the dates given for evidence panels, will there be an alternate way I can contribute to the investigation?

Yes, there will be a public call for evidence open to women and families. If you want to be informed when this opens, please contact the team by email: matneoinvestigation@dhsc.gov.uk

You can also share written evidence with us via the same email address.

8. How will the investigation use/ analyse the evidence gathered in 1:1 interviews and family evidence panels?

Our experienced analysts will gather all the views and experiences shared with us into a database where they can look for common themes, report the range of experiences, and share any ideas that could improve services. Using a database helps us keep track of everything people have said in their own words, so that we can group things that are common between experiences while still understanding what is unique to each person.

9. Can I leave the meetings at any time? If I need support, who can I speak to?

You can leave the meeting at any time if you need a break and you do not need to ask for permission to do this. There will be a counsellor at all meetings. They will be available for a time after the meeting, and the helpline is available 24/7.

10. Can I bring my baby/ child to the evidence panel or meeting?

Unfortunately we cannot accommodate babies or children at family evidence panels. This is due to the nature of discussions and to protect the wellbeing of all attendees. We are able to reimburse you for any additional childcare/ other caring costs incurred. Information on expenses can be found in **Annex C.**

11. Can I bring a support person to the evidence panel?

Yes you can bring a support person, for example a partner or friend. Please speak to the team know in advance so we can make sure the venue has enough capacity. It is important that the support person remains an observer and does not actively participate in the session.

12. How long can I expect to wait for my expenses claim to be processed? Will there be a nominated point of contact who I can keep in touch with on this?

We aim to process all expenses claims within 10 days, and will let you know if there will be any delays, for example if we need further information from you or if we receive a particularly large volume of expenses claims at once.

13. Will there be reimbursement available to cover my caring responsibility costs to enable me to join the meeting, what can I claim for and how much?

Yes, information is provided in the expenses policy in Annex C. this says:

> Dependants Care: Unavoidable costs of caring for children, elderly/infirmed relatives, or pets when you are absent from home may be reimbursed, but only if alternative arrangements cannot be made.

As with other expenses claims, you will need to provide a receipt for this to be able to be processed.

14. How will I receive the £75 thank you?

This will be a pre-paid card which you can spend in-store or withdraw as cash.

15. Do I have to accept the £75 thank you?

No. It is important to be aware that monetary awards and vouchers are classed as income. As a family member contributing to the Investigation, it is your responsibility to declare your income. The payment you receive for your involvement may be considered taxable income. Whether or not you will have to pay tax depends on how much other income you have.

You have the right to decline payment or ask for a lower amount, which might be important if you are receiving welfare benefits. More information can be found here: https://www.citizensadvice.org.uk/

16. If I require a translator or have other accessibility requirements, how do I raise this, and will there be access to an interpreter?

Please get in touch with the team at matneoinvestigation@dhsc.gov.uk.

Annex B: expenses policy

Overarching Principles

- Personnel safety and wellbeing is of paramount importance.
- Take into account the environmental footprint of any travel: you should select the most environmentally friendly mode of transport wherever possible. Typically, this will be public transport, including rail.
- Once the mode of transport has been chosen, the lowest cost fare should be the default: you should provide a clear business justification when this is not the case, with this endorsed and approved by the investigation team.
- You should understand the terms and conditions when purchasing travel and accommodation: you should purchase the most suitable ticket for your trip, which should enable you to make amendments easily and cheaply, and to keep cancellations to an absolute minimum.
- Individuals should not personally benefit from business travel.
- Expenses need to be submitted within 90 days.

Expense Rates

Accommodation: Overnight accommodation will only be covered where it is not reasonably possible to travel on the day. The lowest cost option should be the default.

- £160 for London
- £85 elsewhere
- Alternatively, if you stay anywhere other than a hotel or guest house (for example, staying with friends or family), you may claim a ‘friends and family’ allowance of £25 per night, for which a receipt is not required.

Subsistence: Food & beverages purchased can be claimed up to the below rates. No alcohol, tobacco or tips can be claimed. You are only able to claim for your own expenses and not those of others – where there is a shared bill, it should be paid by each person as appropriate, and claimed individually, with a copy of the receipt.

- Day subsistence, away over 5 hours – Limit of £6.50 for the day.
- Day subsistence, away over 10 hours – Limit of £13 for the day.
- Day subsistence, away over 5 hours (and ongoing at 8pm) – Limit of £19.50 for the day.
- Day subsistence away over 10 hours (and ongoing at 8pm) – Limit of £26 for the day.
- Day subsistence away over 15 hours (and ongoing at 8pm) – Limit of £32.50 for the day.

You cannot claim subsistence if:

- you do not purchase a meal

- you don't provide a receipt/ evidence in support of the costs.
- suitable food is provided free of charge, for example at meetings or training venues.
- suitable meals are included in the cost of your accommodation, air, or rail booking.

Mileage Rates: Individuals who own their own vehicle and have insured it for business use may be reimbursed the following rates:

- 45p per mile for the first 10,000 miles in any tax year (starting 6 April) and
- 25p per mile for any subsequent miles
- 5p supplement per mile per passenger

The mileage rate is set by HMRC to cover fuel and additional, associated motoring costs, such as additional insurance premiums, repairs, maintenance etc.

Taxi Travel: You should travel by public transport wherever possible. However, there may be exceptional circumstances where travelling by taxi is necessary, this reasoning should be clearly stated on the expense claim. This could include:

- where there is a personal safety risk
- if you are required to travel very early in the morning or late into the evening and, as a result, cannot use your usual mode of transport, either because it is unavailable, inappropriate, or unsafe.
- where there is a demonstrable and necessary saving in time, for example where public transport is not readily available for the journey or it would take significantly longer.
- if it is to accommodate special needs, for example a disability.
- where heavy luggage or equipment is being transported.

Other Travel: If using buses or underground, proof of payment should support these expenses (e.g., extract from bank statement).

Dependants Care: Unavoidable costs of caring for children, elderly/infirmed relatives, or pets when you are absent from home may be reimbursed, but only if alternative arrangements cannot be made.

Justification for non-standard class travel

Only in exceptional circumstances would it be appropriate for travel not to be in standard class. Justifiable criteria would include:

- standard class facilities do not accommodate disability or other special needs requirements that you may have.
- where non-standard class travel is found to be the cheapest option for a leg of a journey, it is permitted to book this as it demonstrates best value for money – however, travellers should retain proof of that by screenshotting the comparable costs when booking and sharing with the team.