

# Specification development: Maternal Newborn and Infant Clinical Outcome Review Programme

## **The patient perspective**

6 December 2021



**'I miss my baby every second of every day and even though the pain will ease and the hurt will fade I will always, for the rest of my life, not have my baby'**



## **And then we let you go**

I held you in my arms,  
drank in your face,  
stroked your tiny nose.

He held your little hand so tightly.

I couldn't take my eyes off you.

I knew these were the last moments,

I dared not squander them –  
they needed to last my whole life.



“The fact them poor kids don’t have their mother, that’s the hardest part. Thinking about what they will miss out on. That is what breaks my heart.”

*Bereaved mother of an unvaccinated pregnant woman who died of Covid.*

# What families want

*“We want to know that things will be better for the next parents whose labour and birth are like ours”*

*Bereaved parent*

*“I don’t want anyone else to go through what we have been through ... and if that can be the legacy then something good will have come out of this horror”*

*Bereaved parent*

*“...want desperately to know what happened, even when the truth is difficult. After all we’ve already experienced the worst”*

*Bereaved parent*

# What does this mean for the audit?

- Active role of programme in driving change is vital, and ultimately is the whole point of it
  - Not just about reporting data
  - Timeliness is key factor in supporting this aim
- Biggest change will come with a greater focus on health inequalities
  - Highest rates but also greatest opportunity for improvements
  - Clear commitment to prioritising this focus
- Need for improved integration / data flow / seamlessness across mortality reporting and processes (CDOP / HSIB / PMRT etc)
  - Families tell story once and data used effectively

# What have we learned from Covid?

- Health inequalities persist:
  - Clear health inequalities present in both maternal and perinatal outcomes
  - Persistent higher risks for babies / mothers from specific ethnic groups, and from most deprived groups
  - Pregnant women remain an overlooked vulnerable group
- Ability to produce rapid turnaround reports based on more real-time data reporting:
  - Report on Covid maternal deaths March-May 20 published August 20
  - Report on Covid maternal deaths June 20-March 21 published July 21

# Context for next contract period

- Ongoing national initiatives which reinforce imperative of timeliness and opportunity to contribute to real change:
  - National Ambition in England > driving to 2025 target to halve stillbirths / neonatal deaths / maternal deaths / perinatal brain injury
  - Extension of Best Start implementation in Scotland > 2024
- Significant focus on tackling health inequalities across the NHS, including within maternity care
  - Opportunity to align with themed work to identify and address inequality of perinatal / maternal outcomes



# What would this mean for families?

*“The hope that in the future  
other families will be saved  
the devastation and  
heartache that mine have  
suffered”*

*Bereaved parent*

*“Hope ... that others won't feel  
the unbearable pain”*

*Bereaved parent*