



Office for Health  
Improvement  
& Disparities

# Reducing Infant Mortality in London

**A strategic action plan for improving outcomes and reducing inequalities**

February 2025

In partnership with:



IN PARTNERSHIP WITH  
MAYOR OF LONDON



# Contents

Forward and acknowledgements	Slides 3-5
Executive summary and abbreviations	Slides 6-7
Introduction and context	Slides 8-9
Key themes from data	Slides 10-23
Recommendations for action	Slides 24-58
Appendix A: London Reducing Infant Mortality Task and Finish Group Membership	Slide 59-60
Appendix B: Further details on case studies	Slides 60-64

# Foreword

The health, wellbeing and survival of every child, from birth into adulthood, reflects a society's priorities and the conditions in which babies and their families live, play, learn and grow. Every death of a baby in London is a tragedy and too many infants continue to die unnecessarily – more than a quarter of infant deaths reviewed by London's Child Death Review Panels in 2024 identified at least one modifiable contributory factor. There are stark inequities too – the risk of dying in infancy is higher in London's communities experiencing social and economic deprivation and in London's Black and Asian communities. Addressing these unacceptable and avoidable differences in infant deaths in our city must sit at the heart of our collective efforts to improve outcomes for children and families.

Most infant deaths occur in the first 28 days of life, over half of which are caused by premature birth or congenital anomalies. These causes are associated with a complex and interdependent set of factors operating at the individual, family, community and societal level. This means that a broad range of policies and interventions are needed - from maternal health and preconception through to infancy. So much is already being done to promote, improve and protect the health and wellbeing of babies and families in London, such as maternity transformation to support in the community. But we can go further, through the co-ordinated efforts of a wide range of partners working together across our city to end preventable infant deaths no matter where they live or who they are. Moreover, actions and interventions we can take to prevent avoidable infant deaths will also contribute to wider improvements in the overall health and wellbeing of our city's children and families, supporting them to flourish and thrive.

This strategic plan is intended to provide a broad framework for action by drawing out ten priority areas where the data, evidence and, importantly, partners and stakeholders tell us there are opportunities to go further. Next steps will involve engaging and supporting individuals, organisations, partnerships and communities across London working at the hyper-local, community, place, sub-regional and regional levels to engage with this strategic plan and to consider how and where they can contribute to delivery. The work of the current government through the health mission, development of the new 10-year health plan and establishment of a child poverty taskforce and more locally the work of the London mayor through the health mission, can support key elements of the strategic plan.



**Professor Kevin Fenton**  
Regional Director, Office for Health Improvement and Disparities (OHID) London, Regional Director of Public Health, NHS London and Statutory Health Advisor to the Mayor of London

# Foreword

The mortality rates of infants are a strong indicator of a community's wellbeing and health. In Greater London communities living in areas with the greatest levels of deprivation have persistently higher rates of infant mortality than those living in areas with greatest affluence. The variance seen in neonatal and infant mortality across the five Integrated Care Systems in London is profound. This inequity gap is widening. There is an urgent need to change course. The first step in effecting change is knowing. Knowledge about the causes and circumstances of individual infant deaths and the modifiable contributory factors, gathered by the statutory Child Death Review process and child death overview panels, and analysed by the National Child Mortality Database formed the foundation of this strategic action plan. Wide stakeholder involvement and a task finish group with expertise from across the system informed the strategy for action.

The policies and interventions set out in ten priority areas are wide ranging and inclusive, with a key focus on improving the life chances of the most vulnerable families. Full implementation will transform the lives of babies and their families.

I would like to commend every individual who contributed to producing this ground breaking infant mortality reduction strategy and appeal to every person and organisation with agency to endorse and enable translation into action.



**Professor Karen Luyt**  
Programme Director  
National Child Mortality  
Database, Professor of  
Neonatal Medicine,  
University of Bristol

# Acknowledgements

We would like to thank all individuals and organisations who have contributed to the development of the strategic action plan and in particular the members of the Reducing Infant Mortality Task and Finish Group. The time, dedication and expert input of partners across London have been instrumental in developing a comprehensive and bold action plan.

The development of this Strategic Action Plan for reducing infant mortality in London and the identification of priority actions has been overseen by a multi-agency Task and Finish Group. Membership of that Task and Finish group is listed in Appendix A.

We also wish to acknowledge all the families and communities who have been affected by the loss of a baby, child or young person and the ongoing efforts of all those who support them.

Finally, with special thanks to the following individuals who played a major role in producing and authoring this report:

- Katie Patrick: lead author, Specialist Registrar in Public Health, OHID London and Honorary Research Fellow, London School of Hygiene and Tropical Medicine
- Dr May CI van Schalkwyk, Specialist Registrar in Public Health, OHID London and Honorary Research Fellow, London School of Hygiene and Tropical Medicine
- Robert Pears, Consultant in Public Health, OHID London
- Julie Billett, Deputy Regional Director of Public Health, OHID London
- Dr Nayab Nasir, Programme Lead, OHID London
- Dr Abigail Foster, Specialist Registrar in Public Health, OHID London
- Dr Marilena Korkodilos, Deputy Director for Health and Wellbeing, OHID London

# Executive Summary

In 2022 the London Health Board endorsed the development of a strategic action plan to address preventable infant deaths. Since 2014 the Infant Mortality Rate in London has seen a gradual upward trend and the latest Child Death Overview Panel Reports indicated over one quarter of deaths had modifiable factors. There are considerable inequities by deprivation with the gap between the most and least deprived widening and there are stark inequities by ethnicity. There is complex intersectionality between ethnicity and deprivation within London. Pregnant women are overrepresented in the two most deprived deciles; furthermore, there is a changing profile with increasing maternal age and an increase in birth from mothers whose place of birth was outside the UK. System leaders report women giving birth in the UK are becoming more medically and socially complex and yet many pregnant women are booking later in pregnancy, beyond the NICE recommended 70-day guidelines.

Risk factors for infant mortality are complex and interact and relate to characteristics of the mother and baby, social and physical environment and service provision. To reflect the complexity of the risk factors a set of recommendations have been co-developed with system partners and incorporate established ongoing work in the NHS and other local systems.

10 recommendations have been developed covering: preconception health, early booking and access to care, optimising maternal mental and physical health during pregnancy, infant feeding, safer sleep, income maximisation and welfare support, women and families with complex needs, antiracism and cultural competency, bereavement support and data and learning from Child Death Overview Panels.

It is recognised that delivering these recommendations will require joint working and will require the combined efforts of multiple partners across several years. A delivery overview plan has been developed, that outlines which actions within each recommendation will be relevant to key partners, proposed year 1 priorities and a communication and dissemination plan.

# Abbreviations

BCYP: Babies, Children, and Young People  
BMI: Body Mass Index  
CAN: Community Activity and Nutrition  
CDOP: Child Death Overview Panel  
CDR: Child Death Review  
GLA: Greater London Authority  
ICB: Integrated Care Board  
IMR: Infant Mortality Rate  
IMD: Index of Multiple Deprivation  
LARCH: London Anti-Racism Collaboration for Health  
LEAP: Lambeth Early Action Partnership  
LMNS: Local Maternity and Neonatal System  
MaTDaT: Maternity Disadvantage Assessment Tool

NBCP: National Bereavement Care Pathway  
NCMD: National Child Mortality Database  
NHSE: National Health Service England  
NICE: National Institute for Health and Care Excellence  
OHID: Office for Health Improvement and Disparities  
SEL: South East London  
TPHC: Transformation Partners in Healthcare  
RCM: Royal College of Midwives  
UNICEF: United Nations International Children's Emergency Fund  
- BFI: Baby Friendly Initiative  
VCO: Voluntary and Community Sector Organisations  
VCSE: Voluntary, Community and Social Enterprise

## Terminology

This action plan uses the terms 'women' and 'mothers'. Not all people who access perinatal and maternity services identify as women; our action plan applies to all people who are pregnant or have given birth.

Infant Death: Under 1 year  
Neonatal Death: Under 28 days  
Early Neonatal: Under 7 days  
Late Neonatal: Between 7 and 27 days  
Post Neonatal: Between 28 days and 1 year

# Introduction

**We want every child in London to be healthy, safe and to thrive. Our shared ambition is to reduce avoidable infant deaths in London. Our plan aims to reduce inequities in the risk of death among infants from different groups across our city and to support families that are bereaved following the loss of a child.**

In July 2022, the London Health Board recognised that more needed to be done to improve outcomes for all babies, children and young people (BCYP) in the city and endorsed the development of a strategic action plan to address preventable infant and child deaths. The Office for Health Improvement and Disparities (OHID) London in collaboration with a wide range of London system partners has supported the development of this Strategic Action Plan and agreed in Autumn 2023 to initially focus on an action plan for reducing mortality in infants. The action plan is intended to support and embed data-led and evidence-based actions, interventions and approaches to the prevention of infant deaths in all systems and at all levels across London.

## Methodology

To understand what is working well, what is missing or what needs to be strengthened, a series of engagement activities and events with key stakeholders were coordinated by OHID London throughout 2023. These included surveys, reviews of the evidence and data and engagement with stakeholders through workshops and individual feedback and discussion sessions.

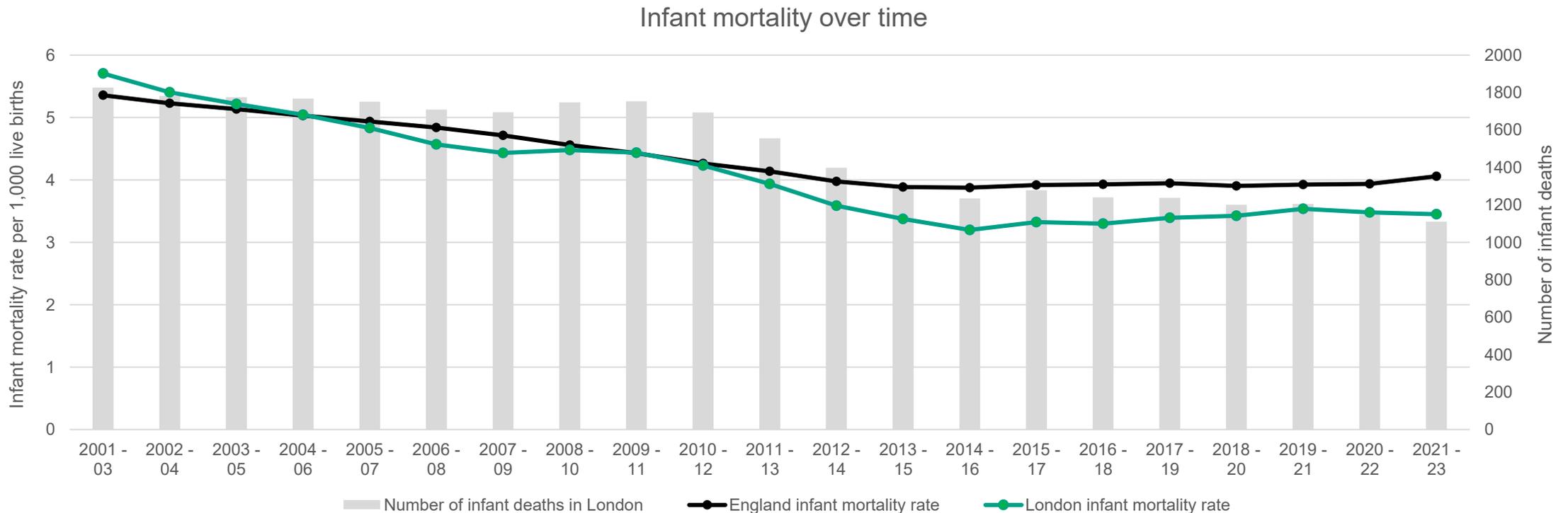
Following agreement by system leaders to focus on the development of a reducing infant mortality action plan the further work was undertaken with system partners to develop the areas of recommendation including:

- Establishment of an Infant Mortality Task and Finish Group
- Hosting a workshop attended by OHID London, GLA and NHSE London to develop 10 areas of recommendation
- Individual conversations with system experts on potential areas of recommendations
- Collation of case studies
- A draft action plan developed and consulted on widely with leaders from across the system

# Context

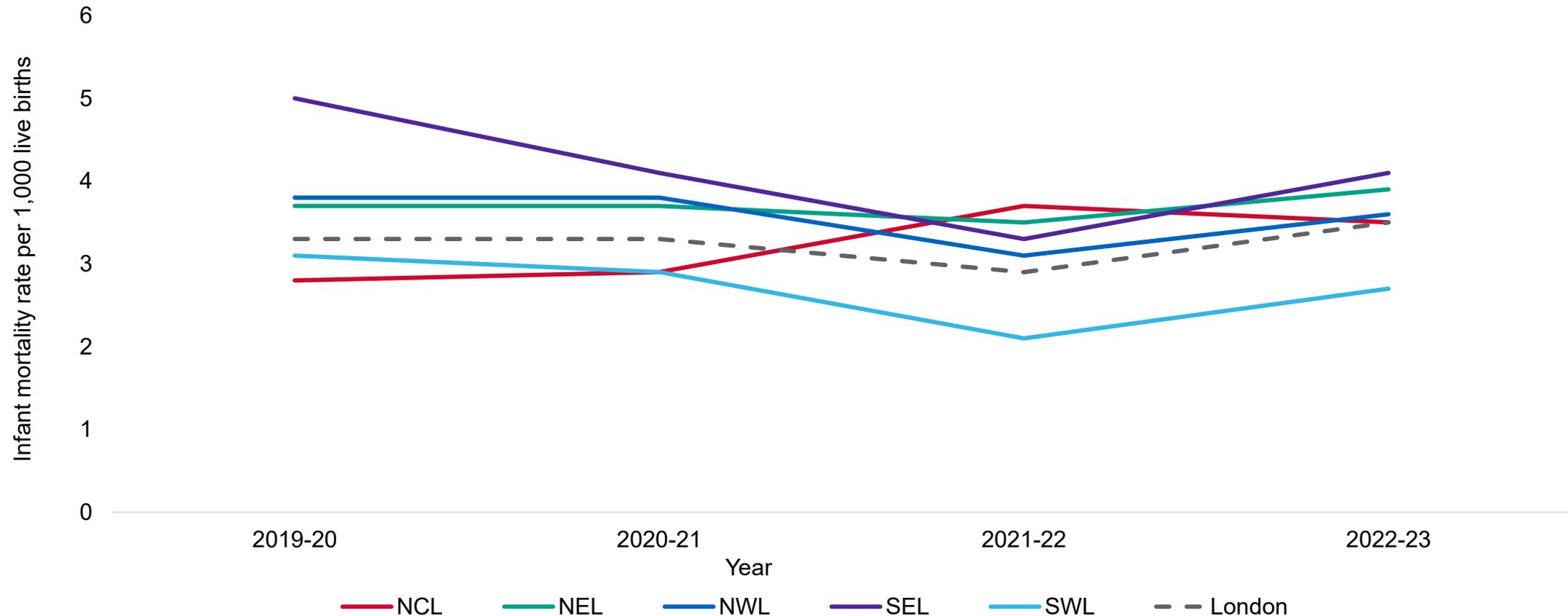
While the infant mortality rate (IMR) in London is lower than the England average - 3.5 deaths under 1 year of age per 1000 live births versus 3.9 per 1,000 (2019 – 21) – this figure masks important differences amongst the 32 London Boroughs: IMR ranging from 2.0 per 1,000 in Wandsworth to 5.3 per 1,000 in Hounslow.<sup>1</sup>

Since 2014, there has been a gradual upward trend up to 2019-21; and then plateauing; in the London IMR. This signals a reversal of the downward trends achieved in previous decades and the need for action to reverse this trend. An upward trend is also seen in the proportion of low birth weight term babies born in London, which is consistently higher in London than in England as a whole.<sup>2</sup>



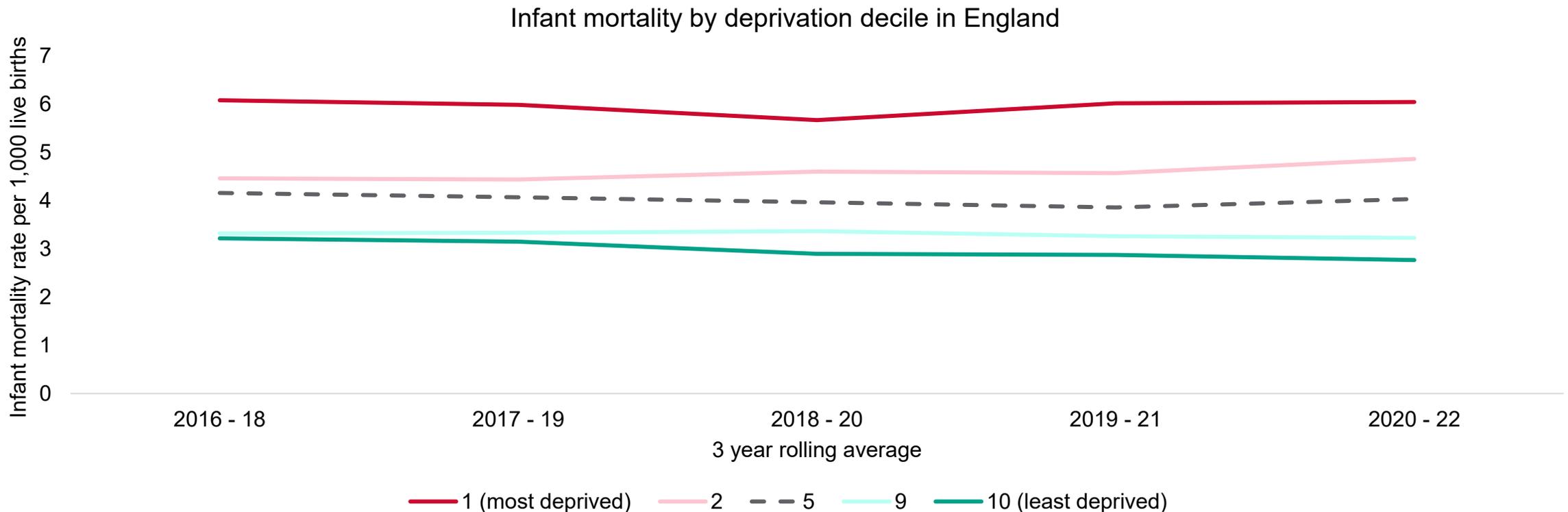
**Key themes from the data**

# Variation in IMRs is seen across London - there is a general increasing trend in IMRs since 2021/22



# The gap in infant mortality between the most and least deprived is widening

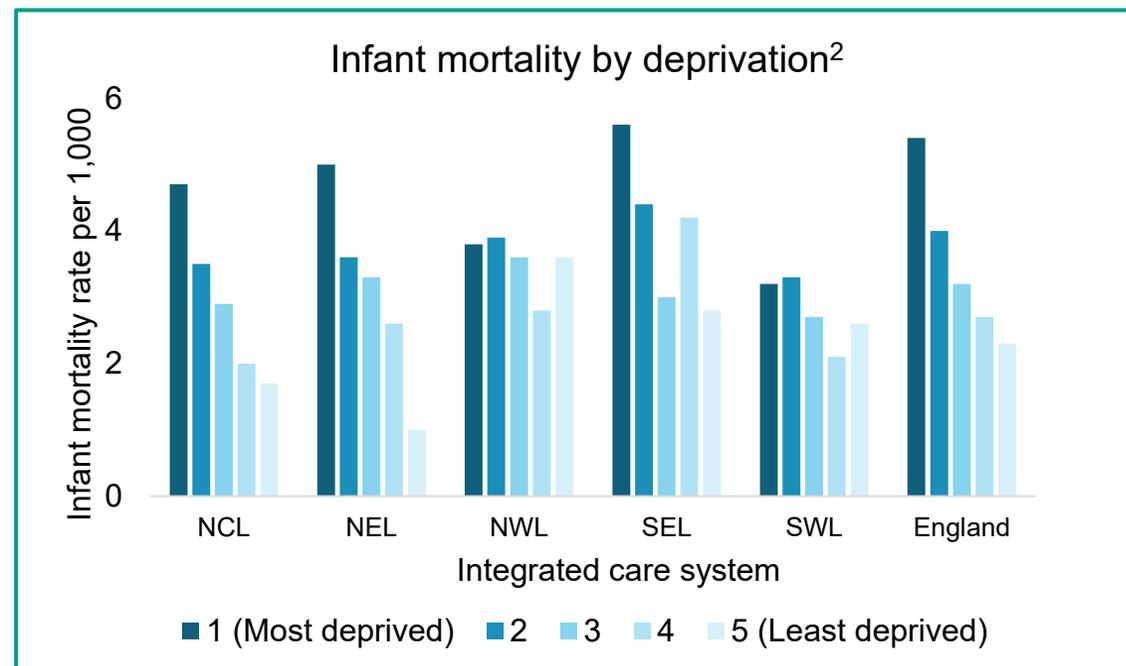
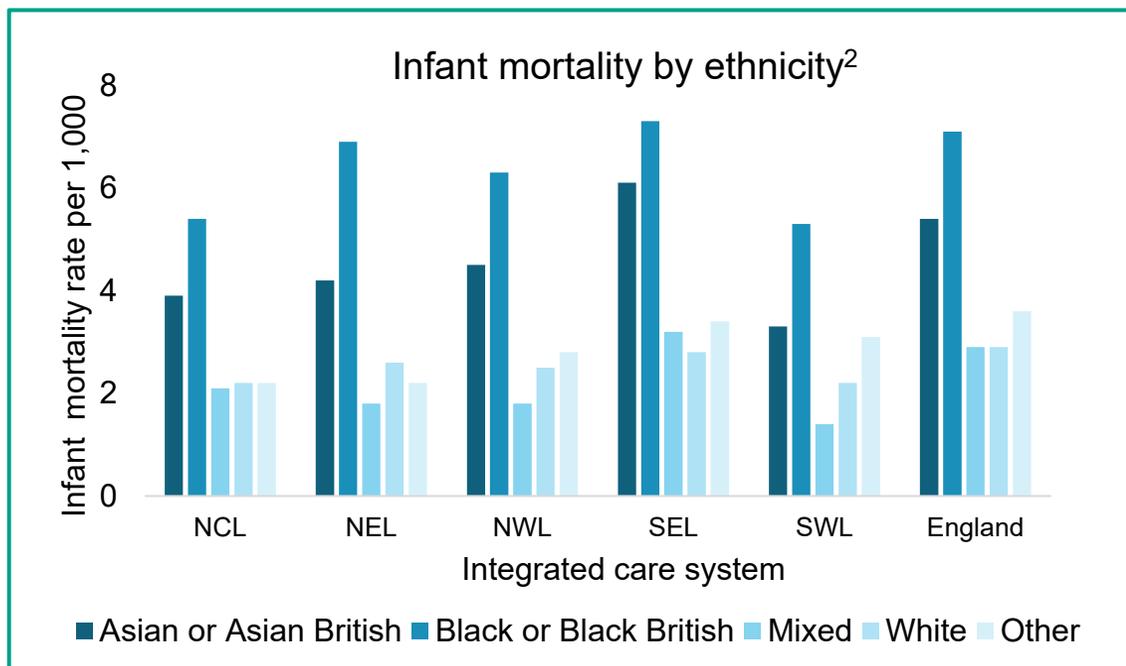
Stalling progress is being driven by inequities and therefore reducing infant mortality action must focus on groups at highest risk.



# There are stark inequities in infant mortality rates by ethnicity

There are also clear inequities by deprivation, however the picture less consistent across London Integrated Care Boards (ICBs).

Infant mortality rates are particularly high for infants of the Black ethnic category regardless of deprivation.<sup>1</sup> There are significant data quality issues that restrict our ability to draw conclusions from the data including that broad ethnic categories mask differences within groups. More granular analysis within groups is needed however is this limited by current data availability.



# The intersectionality of ethnicity and deprivation in London is a complex picture

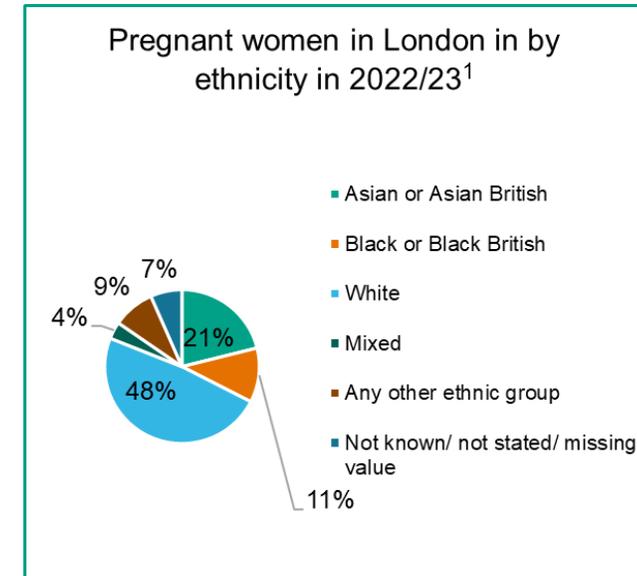
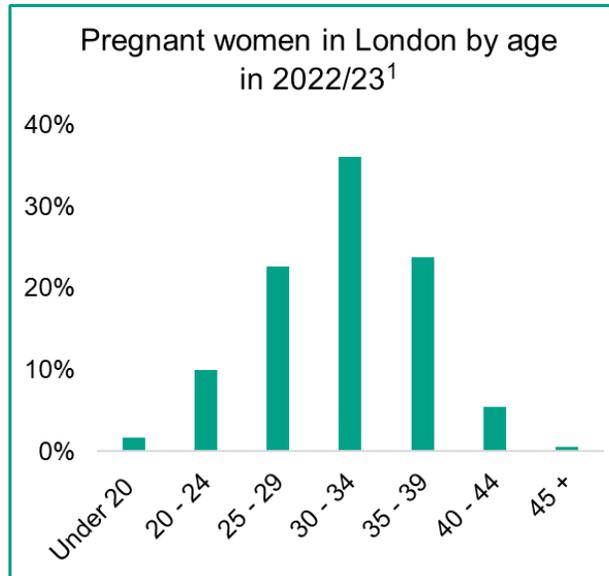
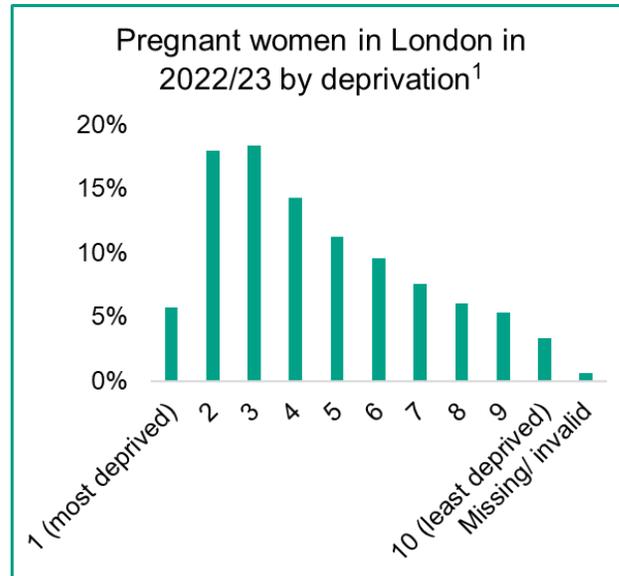
For example, neighbourhoods with the highest proportion of people of Black ethnicity are the most deprived and this trend is reversed for people of White ethnicity. More granular data is available however analysis is limited in the context of infant mortality and the intersectionality of ethnicity and deprivation due to the lack of data beyond broad ethnicity categories.



# The profile of pregnant women in London has important implications for infant mortality reduction and risk factors

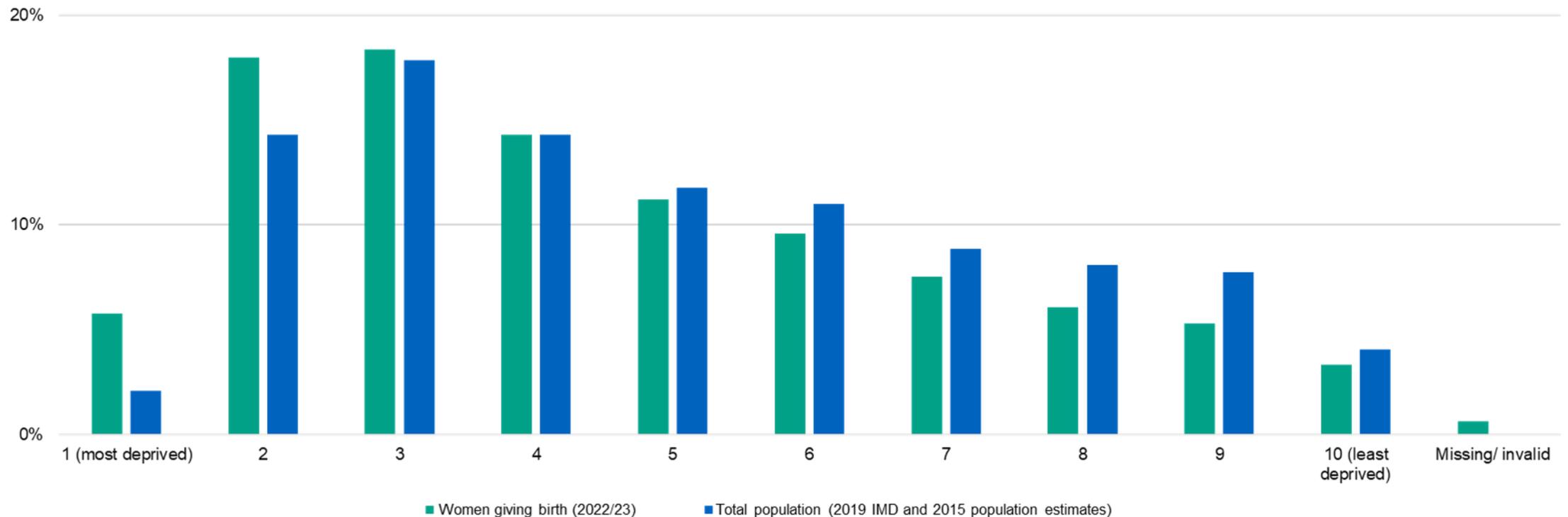
In 2022/23 there were 103,730 total deliveries in NHS hospitals in London.<sup>1</sup> Of the pregnant women:

- 35% were in the second and third deprivation deciles. A pregnant woman was over 2.5 times as likely to be in the 1<sup>st</sup> and 2<sup>nd</sup> deprivation deciles compared to the 9<sup>th</sup> and 10<sup>th</sup>.<sup>1</sup>
- 36% were aged 30 – 34 years old.
- 48% were of White ethnicity, followed by 21% of Asian or Asian British ethnicity.
- 12% had complex social factors including poverty, homelessness, substance misuse, recent arrival as a migrant, asylum seeker or refugee status, difficulty speaking or understanding English, age under 20, domestic abuse.<sup>1</sup>
- 4% were known to be smokers at time of delivery.<sup>2</sup>



# The distribution of women giving in birth by deprivation is similar to the London population overall however there is overrepresentation in the most deprived deciles

Women giving birth by deprivation compared to the total population in London



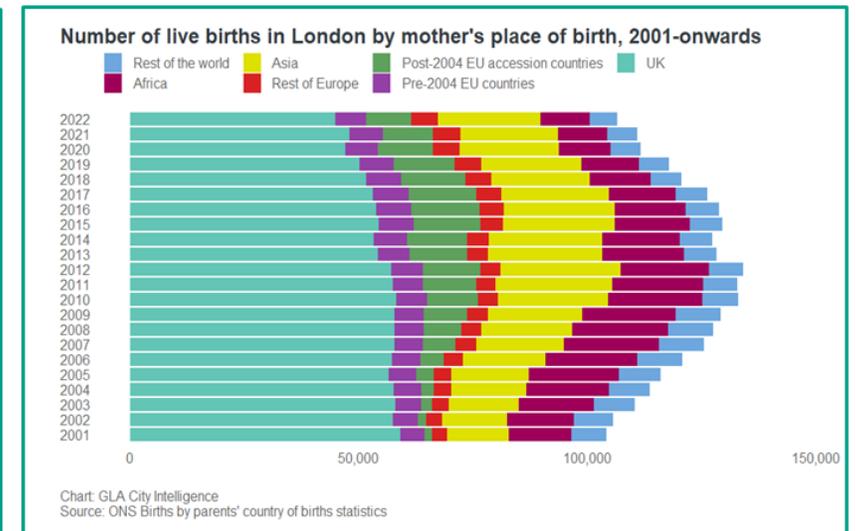
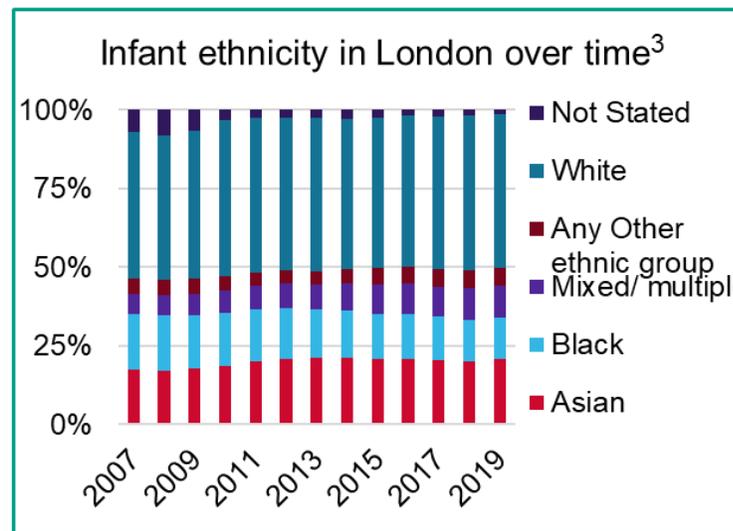
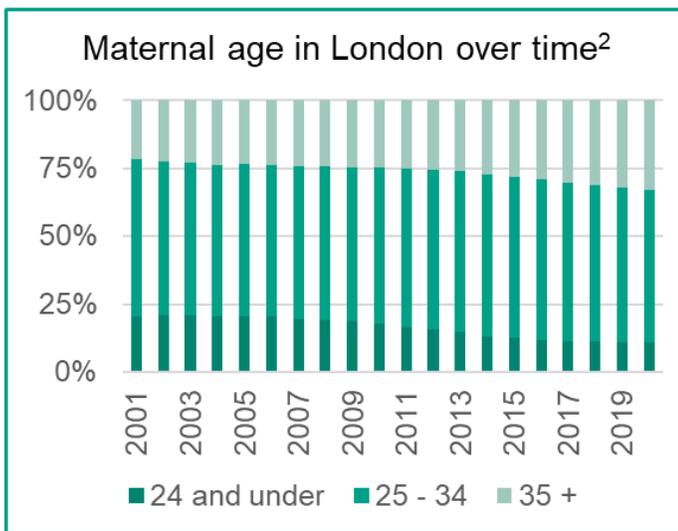
# The profile of pregnant women and births in London is shifting

Maternal age is increasing with one third of women giving birth over the age of 35 years in 2020 (an 11% increase since 2001).

Infant ethnicity is also shifting, with infants from mixed or multiple ethnicity increasing from 6% in 2007 to 10% in 2020 and infants from Asian ethnicity increasing from 17% in 2007 to 21% in 2020. Infants from Black Ethnicity have decreased from 18% to 13% in the same time period.

There has also been an increase in births from mothers whose place of birth was outside the UK, in particular EU countries and Asia.

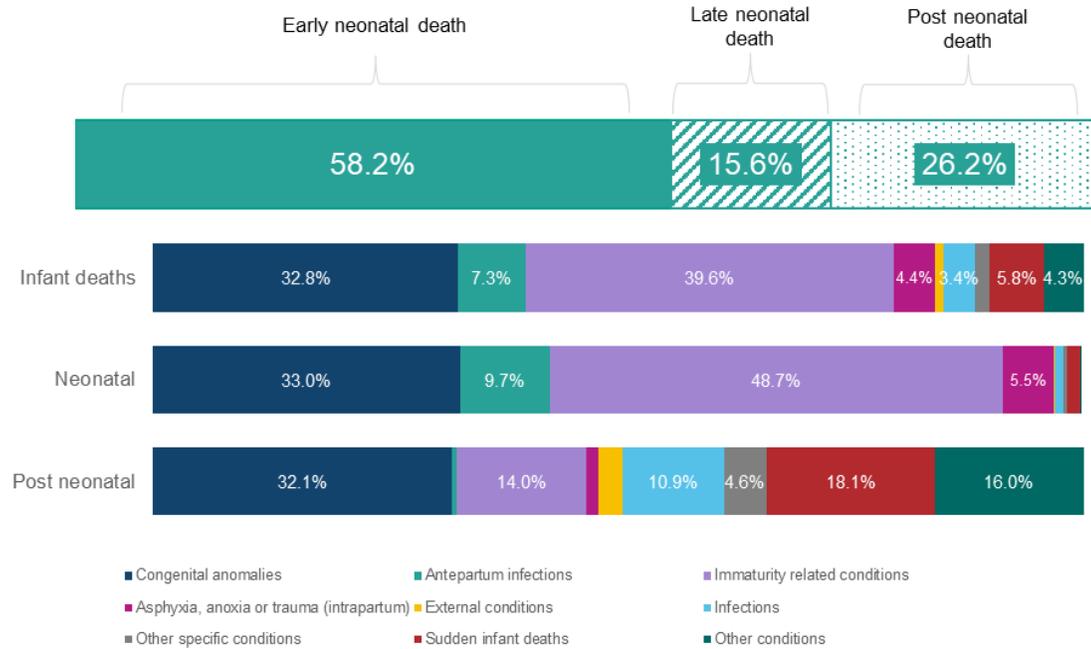
Conversations with system leaders in the NHS reported that women who are giving birth in London are becoming more medically and socially complex.



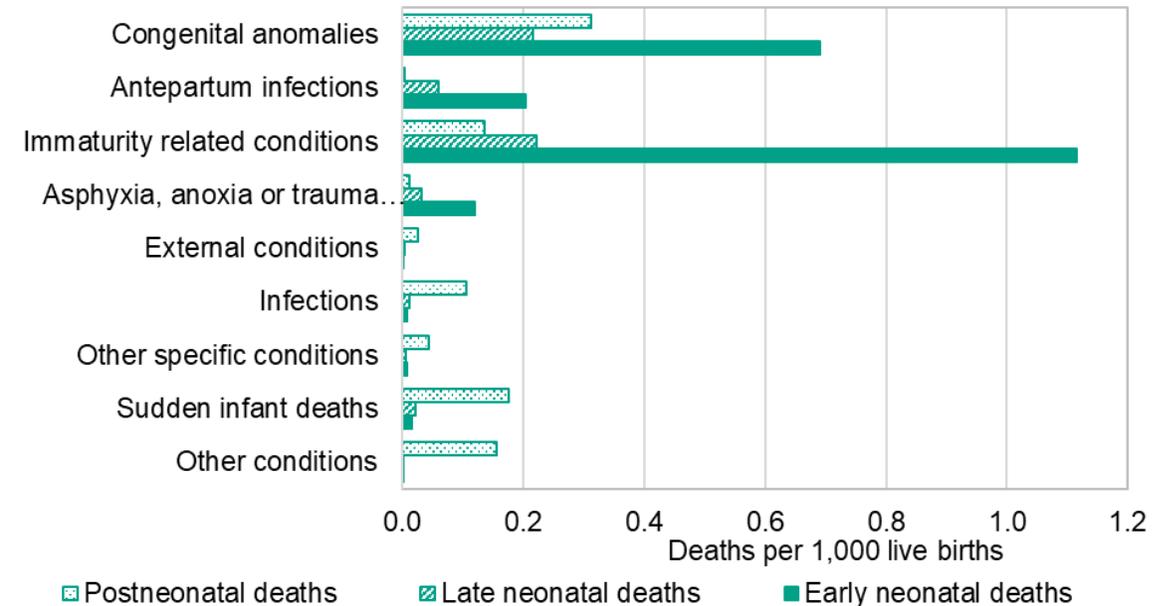
# Conditions linked to premature birth, congenital anomalies and infections prior to childbirth account for most infant deaths in England

In 2021 three quarters (74%) of infant deaths were neonatal (within 28 days of birth) and most (58%) were early neonatal (within the first 7 days).<sup>1</sup>

Proportion of Infant deaths by age in England and Wales, 2021



Infant deaths by ONS cause group in England and Wales, 2021



Infant deaths by ONS cause group in England and Wales, 2021

Early neonatal: under 7 days; late neonatal: between 7 and 27 days; post neonatal: 28 days to 1 year

# Risk factors for infant mortality are complex, interact and should not be viewed in isolation

There is a lack of robust evidence about the combined effect of these risk factors on infant mortality and on interventions to reduce infant mortality. Infant mortality is a common measure of healthcare quality and the safety of maternity services, but is also influenced by social, economic and environmental factors. Risk factors were characterised by NCMD domain and include<sup>1-4</sup>:

Characteristics of the mother	Characteristics of the baby	Social environment	Physical environment	Service provision
<ul style="list-style-type: none"> <li>• Country of birth of mother</li> <li>• Ethnicity of mother</li> <li>• Maternal age</li> <li>• Migration status</li> <li>• Mother's learning disability</li> <li>• Consanguinity</li> <li>• Smoking in pregnancy</li> <li>• Maternal alcohol misuse</li> <li>• Maternal mental ill health and stress</li> <li>• Maternal morbidity and/or multiple morbidity e.g. gestational diabetes, hypertension</li> <li>• Maternal nutrition</li> <li>• Maternal obesity or underweight</li> <li>• Maternal substance misuse</li> <li>• Short interpregnancy interval</li> </ul>	<ul style="list-style-type: none"> <li>• Ethnicity of infant</li> <li>• Sex of baby</li> <li>• Low birthweight</li> <li>• Very low birthweight</li> <li>• Multiple births</li> <li>• Not breastfed</li> <li>• Preterm (&lt;37 weeks gestation)</li> <li>• Very preterm (&lt; 28 weeks gestation)</li> <li>• Small for gestational age</li> <li>• Sex of baby</li> </ul>	<ul style="list-style-type: none"> <li>• Domestic or child abuse/neglect</li> <li>• Household smoking</li> <li>• Marital status</li> <li>• Mental ill health in parent or carer</li> <li>• Parental or carer alcohol misuse</li> <li>• Parental or carer substance misuse</li> <li>• Unemployment</li> <li>• Poverty</li> </ul>	<ul style="list-style-type: none"> <li>• Poor home environment (homelessness, cleanliness, overcrowding, houses in poor repair and the presence of damp and/or mouldy conditions)</li> <li>• Unsafe sleeping environment</li> </ul>	<ul style="list-style-type: none"> <li>• Challenges with access to services and late booking</li> <li>• Discrimination or structural racism</li> <li>• Failures in quality of care</li> <li>• Lack of suitable or timely involvement by appropriate service</li> <li>• Poor communication and information sharing with families and between professionals</li> <li>• Resource and equipment issues</li> <li>• Unimmunised</li> </ul>

# Of all the reviews completed by London Child Death Overview Panels in 2020-2024, 28% identified modifiable factors

377 reviews were completed of infants who had died in infancy, and where there were factors that had been sub-categorised by Child Death Overview Panels (CDOPs) in the years ending March 2020 – 2024. The table below includes all deaths that occurred in the years ending 31 March 2020 to 2024, and where the CDOP had reviewed the death at the time of analysis and identified at least one modifiable factor. However, due to a change in data collection systems around categories, numbers/ percentages will be an underestimate, but the intention is to give insight into most common preventable factors, where this information was available.

Category	Number of reviews
Guideline/policy/pathway available but not followed	23
Co-sleeping	21
High maternal BMI	16
Parent/carer smoked tobacco/e-cigarettes in the household	15
Unsafe sleeping arrangements	14
Poor communication/information sharing within an agency	13
Issue with treatment, including delays	11
Smoking in pregnancy	11
Other service provision factors	10
Poor communication/information sharing between agencies	8

# 43% of pregnancies in London are booked after the NICE guidance of 10 weeks (70 days)<sup>1</sup>

Early access to care is an important factor in birth outcomes and provides an opportunity for early intervention. In London and nationally there is significant opportunity to increase early booking. There are also issues with data quality, which if resolved would help identify groups who are truly booking late.



# Alignment with national work on reducing infant mortality

- In April 2024 a national commission on infant mortality was completed in response to stalling progress in this area, led by Professor Mike Wade and Dr Marilena Korkodilos.
- This included data and evidence review to give a comprehensive picture of causes and risk factors and trends in the rates of infant mortality.
- This work informed the approach taken for this Reducing Infant Mortality in London action plan.
- Policy options and actions are also being progressed and developed at a national level, and the London work will ensure it is aligned with this.
- The work was presented at the London Healthcare Inequalities Improvement Board Meeting in June 2024 and several actions agreed. These actions are referenced within this action plan.

# NHS Programmes and activity

Extensive work is being undertaken at national and local levels to improve maternity and neonatal services and pathways, including within Local Maternity and Neonatal Systems.

The [three year delivery plan for maternal and neonatal services](#) identified the following key themes:

Theme 1: Listening to and working with women and families with compassion

Theme 2: Growing, retaining, and supporting our workforce

Theme 3: Developing and sustaining a culture of safety, learning, and support

Theme 4: Standards and structures that underpin safer, more personalised, and more equitable care

## Examples of work

The Maternal Medicine Network is establishing an **acute pathway for high risk pregnancies** in London.

The NHS London Regional Maternity team is developing a **Maternity Reducing Inequalities Care Bundle (MRCIB)** focusing on **4 key elements**: interpretation and translation services, vitamin D, early access to antenatal care and reduced fetal movements.

The NHS is undertaking a piece of work targeting **those entering the country who will not be familiar with the healthcare system**. This will look at raising awareness about different ways to access care, for example for those who are not registered with a GP.

The national Health Inequalities Team is working alongside the Nursing and Maternity Programme to **support Integrated Care Boards (ICBs) with high rates of infant mortality to adopt the PERIPrem or Saving Babies' Lives Care Bundles** through the health innovation networks.

NHS England is undertaking a pilot and evaluation of **culturally competent genetics services**.



# Recommendations for action in London

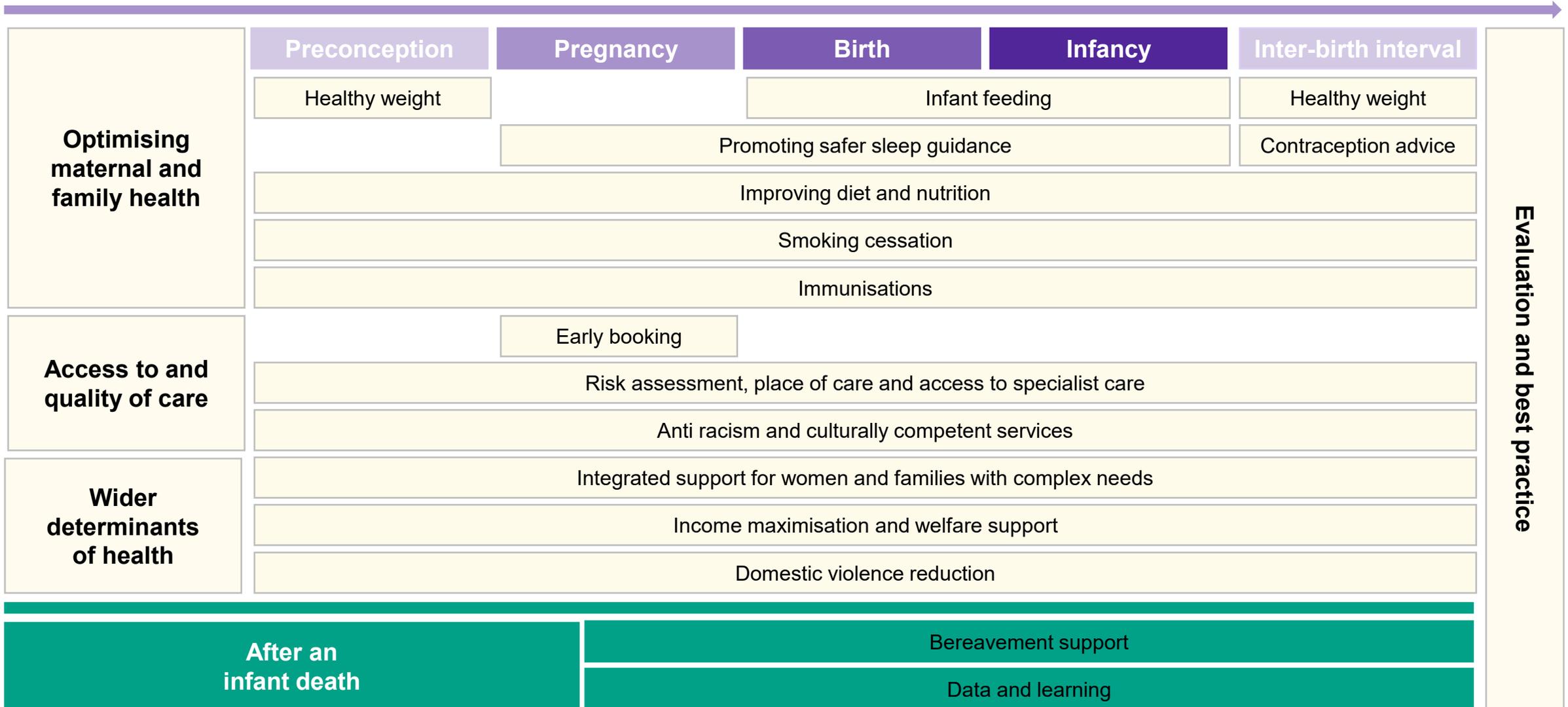
This work views reducing infant mortality through a public health lens, taking a population health approach. We recognise there are substantial NHS programmes and delivery plans in train focused on maternity and neonatal services and these along with improving quality of care are crucial to reduce infant mortality. The recommendations developed as part of this work aim to identify areas to be prioritised at a regional, system-wide level. The NHS, Local Authorities and other system partners have a key role to play in these areas, and the aim of this work is to join this up with work across the system and in the community.

Each area has next steps that will be further developed into a delivery plan.

# Areas for action to reduce infant mortality in London

Area	Recommendation
<b>Preconception health</b>	Optimise the health of women and families before pregnancy by building preconception health advice and interventions into existing health services and programmes
<b>Early booking and access to care</b>	Identify high risk women early in pregnancy and develop robust pathways to specialist care when needed
<b>Optimising maternal mental and physical health during pregnancy</b>	Identify risk factors early and offer advice and support for women to reduce risk during pregnancy, including smoking cessation, nutrition, physical activity, maternal stress, alcohol misuse, management of pre-existing conditions and immunisations
<b>Infant feeding</b>	Support the development of a consistent infant feeding offer across London to enable women who are able to or who wish to breastfeed to start and continue for longer
<b>Safer sleep</b>	Achieve a consistent and cross-agency approach across London to providing evidence-based sleep advice and support to create a safer sleep environment for families, with a focus on housing
<b>Income maximisation and welfare support</b>	Support, strengthen and build resilience in families to reduce financial stress and precariousness
<b>Women and families with complex needs</b>	Identify those most disadvantaged due to social factors and maximise service integration opportunities to provide holistic support including to those with no recourse to public funds, those who face language or health system knowledge barriers and those experiencing domestic violence
<b>Antiracism and cultural competency</b>	Tackle racism within the health service and provide high quality services fit for all of London's communities
<b>Bereavement support</b>	Strengthen pathways to support people who lose a baby to receive enhanced and holistic support
<b>Data and learning from Child Death Overview Panels</b>	Promote coordination and leadership of CDOP at a London level and shared learning between CDOPs

# Areas for action to reduce infant mortality in London



# LEAP: a cross-cutting case study

Lambeth Early Action Partnership (LEAP) was one of five local partnerships which made up 'A Better Start', a national 10-year (2015-2025) test-and-learn programme funded by the National Lottery Community Fund that aimed to improve the life chances of babies, very young children, and families. LEAP was a collective impact initiative, which meant that services and activities linked together and worked towards shared goals to improve outcomes for very young children. More information about the Story of LEAP is available [here](#).

## Who?

LEAP operated in an inner-London community where 68% of children lived in 'very deprived' neighbourhoods. The area where LEAP worked was selected based on local need, drawing on a range of local evidence that illustrated greater inequalities for young children in these areas compared with the rest of Lambeth.

## Services

LEAP funded and supported more than 20 local services to meet the needs of families through pregnancy and the early years of childhood. While LEAP had some targeted services, other services were available to all families living in Lambeth. Services fell into two groups:

- Services that worked directly with children and families to help them reach their developmental milestones
- Services that supported children indirectly, by working with early years practitioners and the wider community, so they would be better equipped to provide the responsive relationships and positive experiences that children need

LEAP services focused on three core strands of childhood development:

1. Diet and Nutrition
2. Social and Emotional Development
3. Communications and Language Development

Examples of some of these services include breastfeeding peer support, maternal weight support for pregnant women with a BMI of  $\geq 25$  and enhanced domestic abuse support. LEAP also provided a midwifery continuity of care service, which [evidenced](#) significant reductions in pre-term births in ethnically diverse women living in areas of high deprivation.

## Connecting families

LEAP aimed to connect families with various local services and activities, as well as build social capital and connect families to each other. LEAP's approach to community engagement was to work with parents and carers, recognising them as experts.

LEAP reached 14,028 children and 15,254 adults from 15,374 families over the 10 years of funding. This represents an estimated two thirds of all children under 5-years-old living in the LEAP area.

## Partnership working

LEAP had partnership at the heart of its working model based on the premise that no one organisation or service can meet the many needs of local families.

LEAP worked with over 30 local partners, meeting the needs of families through pregnancy and the early years of childhood.

## System impact

At the system level, LEAP aimed to have a sustained effect on where and how services are coordinated and delivered to improve their long-term impact on children and families. LEAP's workforce development strategy aimed to upskill the local early years workforce and embed a shared vision and common framework for working with families. LEAP delivered 208 training sessions, seminars, or webinars to 1,807 early years practitioners working in Lambeth or neighbouring boroughs.

## Evaluation and monitoring

LEAP gathered extensive data and insights since the programme started. An integrated data platform was developed to collect and link data from different sources. This innovative project brought together health and education data with service utilisation data to understand reach, engagement and outcomes. As evidence was generated, LEAP used it to inform and shape both services and decision making locally. Routine monitoring enabled adaptive programming to better respond to the needs at population level. Findings from implementation informed approaches and investments at a national level, and robust analysis of service data led to scientific publications, supporting the national evidence base.



# Preconception health

*Recommendation: Optimise the health of women and families before pregnancy by building preconception health advice and interventions into existing health services and programmes*

# Preconception health

## Contribution to infant mortality

- The health of women and their partners before conception is important for fitness for pregnancy and pregnancy outcomes, including pre-term birth, low birth weight and congenital abnormalities<sup>1</sup>
- A higher risk of negative outcomes is associated with smoking status, obesity and poor nutrition, pre-existing health conditions and stress<sup>1</sup>

## Opportunities

- Many modifiable risk factors which influence pregnancy outcomes are present and known before conception therefore intervention does not need to wait until contact with maternity<sup>5</sup>
- The preconception period, including between pregnancies, presents an opportunity for intervention when women and their partners can adopt healthier behaviours in preparation for a successful pregnancy
- There is an opportunity to anticipate future needs (as identified by the woman/family) and working across organisational silos to ensure these are addressed pre-emptively
- There is a need to improve awareness and understanding in education settings
- A lot of digital information and support is available and there is an opportunity to standardise what is being promoted

## Why focus on this in London?

- Discussions with system leads highlighted that women becoming pregnant in London are becoming more socially and medically complex
- This maternal cohort is trending towards being older and being born in a country other than the UK<sup>2,3</sup>
- In London, just under 1 in 5 women are obese in early pregnancy<sup>4</sup>

## Challenges

- Preconception care is not led by one service or sector and is relevant to a large group within the population
- 45% of pregnancies and one third of births in England are unplanned or associated with feelings of ambivalence, therefore preconception health cannot only target those planning a pregnancy<sup>5</sup>
- Greater understanding is required on the best time and way to intervene and promote preconception health, including beyond only information provision and awareness raising

# Preconception health

## Potential next steps

1. Establish a preconception workstream to develop ideas and take forward the work on this area, including engaging with and supporting community networks that can promote resilience and better wellbeing
2. Explore in person and digital opportunities to promote preconception health within Women's Health Hubs (aligning with national conversations), in primary care and in sexual and reproductive health services to inform and empower women using a variety of communication channels
3. Work with existing services, such as weight management and smoking cessation, to explore opportunities to promote preconception health
4. Work with education colleagues to consider opportunities to discuss preconception health in school and education settings and links with the curriculum, considering also contraception messaging to prevent unplanned pregnancies

## CASE STUDY

### South East London Local Maternity and Neonatal System (LMNS)

SEL LMNS is dedicated to the National Maternity Transformation Programme, focusing on reducing maternal and neonatal morbidity and mortality. Its Public Health (PH) workstream includes stakeholders from all maternity and neonatal providers and PH practitioners across South East London local authorities. Pre-conception health is a key priority.

Over 12 months, PH workstream members collaborated to identify local challenges and priorities for improving pre-conception healthcare. Key stakeholders from primary and secondary care, public health, and Maternity and Neonatal Voices Partnership leads (MNVPs) participated in two virtual co-production workshops facilitated by independent public health network practitioners.

#### Representatives:

*Jacqui Kempen (Head of Maternity for SEL LMNS and SEL Integrated Care Board (ICB), Monica Franklin (Senior Project Manager, SEL LMNS), Pauline Cross (Public Health Consultant Midwife, Lewisham)*

## Early booking and access to care

*Recommendation: Identify high risk women early in pregnancy and develop robust pathways to specialist care when needed*

# Early booking and access to care

## Contribution to infant mortality

- Timely access to good-quality antenatal care is associated with reduced risk of adverse maternal outcomes, including perinatal and neonatal mortality<sup>1</sup>
- Appropriate risk assessment for preterm birth can ensure appropriate specialist care is received to improve outcomes

## Opportunities

- The significant proportion of bookings after 10 weeks (43%) represents a large opportunity to potentially improve outcomes, and identify/ prevent other risk factors early<sup>2</sup>
- There are opportunities to make care more accessible by considering health literacy and standardising provision of information in different languages and interpretation services within primary care, the NHS and the community
- Improving and developing systems to ensure effective prediction, prevention and preparation of women at high risk of preterm birth

## Why focus on this in London?

- In 2022/23 only 57% of pregnant women in London were booked with maternity before 10 weeks (in line with NICE guidance)<sup>2</sup>
- National data shows women of Black or mixed ethnicity are more likely miss out on antenatal care than those of White or Asian ethnicity. Other groups missing out are younger and older women and those living in more deprived areas<sup>3</sup>
- Across London there are pathways for high risk women once in the system however the challenge is identifying them

## Challenges

- A lack of detailed data outlining who is booking late and why
- There are some data quality issues for example if someone transfers to another trust during pregnancy and is recorded at new trust as late booker
- This is a complex issue with action needed to ensure robust pathways and ease of access, along with promotion of trust in the healthcare system
- Operational challenges for in utero transfers and transfers to specialist centres

# Early booking and access to care

## Potential next steps

1. Conduct an audit and analysis of late booking data in London to better understand who is booking late and why, and to review data quality considering demographic, social and pregnancy specific factors (planned or unplanned)
2. Engage with groups at higher risk of booking late to understand and address barriers and consider what additional support might be appropriate for those who do book late, aligning with the work as part of the Maternity Reducing Inequalities Care Bundle
3. Consider effective models of linking maternity services with community hubs, e.g. family hubs to support early engagement
4. Work towards more accurate and systematic identification of families at risk of premature birth and low birth weight to support appropriate referral and a consistent pathway into a specific prenatal service
5. Promote more standardised translation and interpreter services across London using learning from best practice, aligning with the work as part of the Reducing inequalities care bundle

**Case study** [*Jacqui Kempen (Head of Maternity for SEL LMNS and SEL Integrated Care Board (ICB), Monica Franklin (Senior Project Manager, SEL LMNS), Octavia Wiseman (SEL Lead Midwife for Foreign Language Parent Education)*]

### Parent Education in Foreign Languages [South East London]

Language barriers significantly impact maternal and neonatal outcomes. Recent migrants and pregnant women with limited English proficiency often report negative maternity care experiences and lower antenatal attendance rates. SEL LMNS has initiated a pilot project to develop an online, co-produced Parent Education package, aligning with national guidelines and offering content in multiple languages spoken in SEL.

The project's objectives are to:

- Develop a core online co-produced Parent Education package covering Antenatal, Intrapartum, and Postnatal/Infant Feeding workshops.
- Compile language- and culture-specific resources for families.
- Identify bilingual midwives and MSWs interested in delivering Parent Education.
- Provide training for midwives to deliver engaging online parent education.
- Pilot monthly online Parent Education sessions in 4-5 key languages, promoted across SEL maternity services.
- Regularly evaluate the parent education sessions and share findings with SEL maternity providers.

# Optimising maternal mental and physical health during pregnancy

*Recommendation: Identify risk factors early and offer advice and support for women to reduce risk during pregnancy, including smoking cessation, nutrition, physical activity, maternal stress, alcohol misuse, management of pre-existing conditions and immunisations*

# Optimising maternal mental and physical health during pregnancy

## Contribution to infant mortality

- Maternal physical and mental health is strongly linked to pregnancy outcomes and infant mortality<sup>1</sup>
- Key factors include including smoking cessation, nutrition, physical activity, maternal stress, alcohol misuse, management of pre-existing conditions and immunisations<sup>1,2</sup>

## Opportunities

- To reduce premature birth and low birth weight
- To address falling rates of maternal and infant vaccination
- To support work across the system to reduce smoking in pregnancy, including the introduction of financial incentives
- To provide more consistent and evidence-based interventions on diet and nutrition during pregnancy
- Effective digitisation and shared care records across London will support identification of pre-birth risk factors and ongoing continuity of health review in pregnancy

## Why focus on this in London?

- Smoking during pregnancy is the leading modifiable risk factor for poor birth outcomes, including stillbirth, miscarriage and preterm birth. In London 4% of pregnant women known to be smokers at time of delivery<sup>3</sup>
- Prenatal pertussis vaccine coverage in the London NHS commissioning region has declined substantially since December 2019, falling 22.1 percentage points by September 2022<sup>4</sup>
- There has been an increase in mental health awareness and referrals during pregnancy in London
- 7% of pregnant women in London were not taking a folic acid supplement in 2022/23<sup>5</sup>

## Challenges

- The cohort of women having children is becoming more socially and medically complex leading to increased need with implications for the workforce
- Timely access to early intervention during pregnancy improves outcomes. Therefore consideration is needed on where to focus support offer
- Risk communication in pregnancy is challenging and often not well understood
- There are limitations with vaccination data quality
- Contributors to maternal stress are wide ranging and interventions need to consider environmental stressors that are outside of the individual's control

# Optimising maternal mental and physical health during pregnancy

## Potential next steps

1. To review the current approach for the 'health assessment and promotion' elements of the booking and antenatal health visitor appointments, including how issues are flagged, the availability of support services (e.g. mental health, welfare and Healthy Start) and cultural responsiveness
2. To review best practice and evidence on promoting good diet and nutrition during pregnancy, including folic acid and vitamin D supplementation and aligning with the work to develop a Reducing Maternity Inequalities Care Bundle
3. Explore a London wide maternal and infant vaccination campaign informed by data on who is not getting vaccinated and why, with a focus on clarity and diversity of messaging appropriate for target audiences and linked to the London 'Why Vaccinate' brand and campaign
4. Engage pregnant women in smoking cessation services when potentially beneficial. Establish separate referral processes to support the pregnant women's partners/significant others into community smoking cessation services
5. Once published (due in 2024/25), review the NHSE commissioned review of evidence of what works to support early years mental health and parent-child interaction, with a focus on any interventions in pregnancy and how this aligns with the current offer of mental health support in pregnancy in London

## CASE STUDY

### **Community Activity and Nutrition (CAN) service, delivered by the Lambeth Early Action Partnership (LEAP)**

The CAN service was offered to all LEAP-area pregnant women with a BMI  $\geq 25$  who booked to have their babies at one of the two LEAP-area NHS Trusts. CAN supports women to make behaviour changes that enable healthier eating and increased physical activity during and after pregnancy: women are given personalised, culturally appropriate 1:1 support to set goals for making food swaps and increasing their daily step count.

From 2016 – 2023, CAN supported 734 pregnant women: 70% lived in areas of deprivation in Lambeth (locally calculated IMD quintiles 1 and 2) and 80% were from Black, Asian and Multiple Ethnic groups.

Feedback about CAN was overwhelmingly positive. A short film featuring the voice of a CAN service user is available [here](#).

*Carla Stanke, Public Health Specialist, Lambeth Early Action Partnership (LEAP)*

# Infant feeding

*Recommendation: Support the development of a consistent infant feeding offer across London to enable women who are able to or who wish to breastfeed to start and continue for longer*

# Infant feeding

## Contribution to infant mortality

- Breastfeeding lowers infectious morbidity and mortality in infancy, as well as having a protective effect against non-communicable disease later in life, such as overweight and diabetes<sup>1</sup>
- Breastfeeding is a protective factor against SUDI with 'ever breastfeeding' being associated with a 36% reduction in sudden infant deaths in studies from high income countries<sup>2</sup>

## Opportunities

- The Baby Friendly Hospital and Community Initiatives are evidence-based approaches to support breastfeeding and good infant nutrition
- A global review in 2023 identified best practice for implementation
- Health worker breastfeeding\* knowledge and training along with culturally tailored educational programmes for pregnant and post-partum women as contributing to sustained exclusive breastfeeding

## Why focus on this in London?

- The method for collecting data on breastfeeding has recently changed, making looking at trend data difficult
- In 2022/23 breastfeeding prevalence at 6-8 weeks was 49% in England<sup>3</sup>

## Challenges

- Consistent and comprehensive data on breastfeeding in England is lacking
- Breastfeeding is not an option for everyone therefore messaging requires nuance: some women choose not to breastfeed and some are unable to for maternal or infant health reasons
- Enabling women to breastfeed for longer requires a combination of health, economic and social interventions, including education, good quality healthcare provision with specific breastfeeding support services, maternity entitlements and a supportive workplace culture

Sources: 1. Victora CG et al. (2016) *Breastfeeding in the 21<sup>st</sup> Century: Epidemiology, mechanisms and lifelong effect.*

2. Walsh et al. (2023) *Improving breastfeeding support through the implementation of the Baby-Friendly Hospital and Community Initiatives: a scoping review.* <https://doi.org/10.1186/s13006-023-00556-2>

3. Rollins NC et al. (2016) *Why invest, and what it will take to improve breastfeeding practices.*

# Infant feeding

## Potential next steps

1. Breastfeeding support to be available to all parents and carers as part of the universal Start for Life offer and ensure support for the delivery of Every Child a Healthier Weight Delivery Plan
2. Promote and encourage adoption of UNICEF breastfeeding friendly initiative across London - in hospitals, primary care, health visiting services and family hubs across London

## CASE STUDY

### Infant Feeding Workstream in Tower Hamlets Case Study

Baby Feeding and Wellbeing Service within Children and Family Centres, providing antenatal workshops, ward support, proactive call <48h discharge, home visit & drop in groups delivery in English & Bengali.

Peer support service delivered by the Breast Feeding Network

UNICEF BFI coordinator post at Royal London Hospital to support UNICEF BFI accreditation

Infant feeding lead within Health Visiting Service to support UNICEF BFI accreditation

Partnership work via Infant Feeding Working group, including stakeholders across the maternity system and VCO sector

Tongue Tie service at Royal London Hospital

Utilised Family Hubs funding for infant feeding social marketing campaign co-produced by the community and partners

*Emma Foord, Public Health Manager Maternity and Early Years, London Borough of Tower Hamlets*

# Safer sleep

*Recommendation: Achieve a consistent and cross-agency approach across London to providing evidence-based sleep advice and support to create a safer sleep environment for families, with a focus on housing*

# Safer sleep

## Contribution to infant mortality

- A change in infant care routine for the last sleep is a significant predictor of SUDI<sup>1</sup>
- Over 50% of deaths in 2020 occurred when the infant was sharing a sleep surface with an adult: most were in hazardous circumstances<sup>1</sup>

## Opportunities

- Utilise commissioning levers to ensure consistent and evidence-based advice and information is given to all families across London
- Multiagency working to identify and rectify unsafe sleep environments, for example between housing officers and health visitors
- There may be opportunities to partner with industry to promote safer sleep messaging on infant products

## Why focus on this in London?

- The burden of SUDI is concentrated in most disadvantaged and socially vulnerable families<sup>1</sup>

## Challenges

- Poor quality housing and overcrowding are important contributory factors for unsafe sleep environments for infants but are complex issues and present safeguarding challenges
- Lack of awareness associated with safer sleep messaging not being seen in broad public facing information

# Safer sleep

## Potential next steps

1. Advocate for all families to be given evidence-based and culturally competent safer sleeping advice with comprehensive provision in different languages
2. Identify and share best practice examples of multi-agency approaches to the identification of vulnerable families at high risk of SUDI, including the Home Office in this process
3. Train more frontline professionals on safer sleep guidance, equipping them to deliver clear and tailored messages to support families from different communities
4. Review evaluation of the Camden Council pilot that offers Moses baskets and safer sleeping guidance to families in overcrowded accommodation, alongside wider financial and Family Hub support. If the evaluation is favourable consider recommending approach across London

## CASE STUDY

### SUDI Task and Finish Group in North East London

Time-limited Task and Finish group to assist all agencies who have contact with babies, and parents and carers of babies, to reflect on their current provision with regards to safer sleeping and to seek how the multiagency response can work to reduce the number of SUDIs in Waltham Forest.

NEL data identified safeguarding and families with complex needs as important target groups.

Part of this work is the roll out of two levels of training, considering the role of all health professionals and wider agencies in raising safer sleep messages and supporting risk assessments.

*Kate Howell, Senior Public Health Strategist, Waltham Forest*

# **Income maximisation and welfare support**

*Recommendation: Support, strengthen and build resilience in families to reduce financial stress and precariousness*

# Income maximisation and welfare support

## Contribution to infant mortality

- Deprivation is a driver of infant mortality, though the complex, multifactorial mechanisms are not fully understood<sup>1</sup>
- Deprivation is associated with an increased risk of pre-term birth, low birth weight, congenital abnormalities and SUDI<sup>2</sup>
- Deprivation and welfare policy disproportionately affect those from ethnic minority communities. Up to one third of ethnic variation in preterm birth, neonatal and infant mortality has been attributable to the Index of Multiple Deprivation (IMD)<sup>3</sup>
- Recent trends show infant mortality has increased in the most deprived and reduced in the least deprived<sup>4</sup>
- Employment status and associated stress is linked to ability to access services, for example ability to attend appointments

## Opportunities

- Touchpoints during pregnancy and with families can be used to provide welfare advice and support and there is a lot of evidence to show that colocation of services is effective
- Pregnancy and the time between pregnancies represents a point of potential precariousness due to loss or reduction in income and additional costs associated with having a child, therefore this is a good opportunity to intervene to ensure income is maximised and to promote family friendly policies
- Utilise existing programmes such as the Good Work Standard to promote good maternity leave policy

## Why focus on this in London?

- Across the London there are persistent and stark inequalities in infant mortality rates by deprivation and ethnicity
- 35% of pregnant women in London were in the second and third deprivation deciles<sup>4</sup>

## Challenges

- The drivers of poverty and deprivation are complex and influenced by national and international factors, therefore activity will need to focus on mitigation for the most vulnerable families
- A lot of banking and welfare benefits have been digitised, which can be a barrier for those who have recently entered the country

# Income maximisation and welfare support

## Potential next steps

1. Explore how to facilitate communication and collaboration between agencies that come into contact with families to identify the most vulnerable to financial pressure and precariousness
2. Review and consider best practice examples of how to make maternity preventative and support services more accessible and appropriate for the needs of people experiencing financial disadvantage
3. Promote and support the co-location of welfare and housing services with health services for women and families, taking a targeted approach to those who are most disadvantaged
4. Utilise learning from the GLA's and London Anchors Institutions Network's work on the London Living Wage to promote good maternity leave policies, using available commissioning and anchor levers of the public sector
5. Increase promotion of the NHS Healthy Start scheme to support low-income families to get help to buy healthy foods and milk

## CASE STUDIES

### Healthier Wealthier Families in East London

This pilot explored the feasibility and acceptability of the co-location of a financial advisor in universal and specialist settings in East London for just over a one-year period (April 2023 to end of June 2024). It showed positive impacts in terms of financial and self-reported mental and family well-being, with the average benefits per family of £6,103.

### Social deprivation screening tool for families

This tool has been developed to aid staff and patients to proactively identify concerns and connect them to local services and support.

The screening tool consists of a set of questions that identifies areas of concern e.g. housing.

*Laura Austin Croft, Director of Population Health, East London NHS Foundation Trust. Victoria Agunloye, Paediatric Consultant.*

## **Women and families with complex needs**

*Recommendation: Identify those most disadvantaged due to social factors and maximise service integration opportunities to provide holistic support including to those with no recourse to public funds, those who face language or health system knowledge barriers and those experiencing domestic violence*

# Women and families with complex needs

## Contribution to infant mortality

- The main risk factors for adverse birth outcomes are highly socially patterned. These include maternal smoking, maternal mental health, maternal physical health (including BMI), healthcare access and working and environmental conditions<sup>1</sup>

## Opportunities

- Adopting a proportionate universalism approach by proactively identifying women and families at high risk due to multiple factors and using holistic approaches to support them
- Using existing hubs e.g. Family Hubs, to bring together multiple services and support offers into one place with consideration to the inter birth period and the role of primary care
- Strengthening access to the intensive home visiting offer by Health visitor services
- Promoting immunisations in this group where uptake is often low

## Why focus on this in London?

- Many families living in London may be particularly vulnerable because of deprivation and poverty (such as increased risk of death due to exposure to air pollution, homelessness and unsafe housing)<sup>2</sup>
- Over 1 in 10 pregnant women in London have complex social factors (including poverty, homelessness, substance misuse, recent arrival as a migrant, asylum seeker or refugee status, difficulty speaking or understanding English, age under 20, domestic abuse)<sup>3</sup>
- Vulnerable groups in London include those with no recourse to public funds, those who face language or health system knowledge barriers and those experiencing domestic violence

## Challenges

- The most vulnerable women and families may be less visible to or engaged with current services and may have had bad experiences in the past, including racism. The role of family support workers and youth workers in identifying these individuals and families is key
- Access issues, both perceived and real, include fear of charging/authorities and language barriers
- Identifying ways to identify those who use drugs who are not engaged with treatment services

# Women and families with complex needs

## Potential next steps

1. Identify and pursue service integration opportunities that support building stronger family relationships and deliver the Start for Life vision
2. Explore evidence based models of delivery within health visiting that are effective at meeting the needs of this group, for example a named lead for homelessness
3. Promote the systematic use of data, intelligence and population health management tools and approaches to inform targeted and co-produced interventions and activities that reduce the risk of infant death in the most vulnerable communities
4. Work with reproductive and sexual health services through existing touchpoints in the community (for example women's shelters, substance misuse services) to ensure a robust pathway for vulnerable pregnant women and to provide support and access to contraception between pregnancies
5. Amplify and support the planned national campaign to increase awareness and uptake of the maternity prescription exemption scheme amongst vulnerable women and families

## CASE STUDY

### Maternity Disadvantage Assessment Tool in South East London

In partnership with the Royal College of Midwives (RCM), Lambeth Early Action Partnership developed the Maternity Disadvantage Assessment Tool (MaTDaT) to support earlier and more consistent identification of social risk factors in pregnant women. The tool was designed to support midwives' decision making in response to routine questions asked at antenatal appointments. The MaTDaT is hosted by RCM and is available [here](#).

MaTDaT lists criteria for assessment across 4 levels (level 1: thriving and support needs can be met by universal services, level 4: acute level of unmet and complex need and/or require urgent intervention to protect against current or likely significant harm)

*Carla Stanke, Public Health Specialist, Lambeth Early Action Partnership (LEAP)*

# Antiracism and cultural competency

*Recommendation: Tackle racism within the health service and provide high quality services fit for all of London's communities*

# Antiracism and cultural and cultural competency

## Contribution to infant mortality

- Infant mortality is associated with race and ethnicity, with a cohort study in the UK finding a population attributable risk fraction of 12%<sup>1</sup>
- Overconservative adjustment for deprivation did not explain the overall patterns. Around half the population attributable risk fraction may be due to increased risk of preterm birth in Asian and Black communities. This suggests structural racism has a role in determining outcomes<sup>1</sup>

## Opportunities

- Inequalities in pregnancy outcomes could be reduced through action on racism and the provision of culturally competent services
- To tap into existing work on antiracism including the London Anti-Racism Collaboration for Health (LARCH)
- At a national level there is work to include preterm births by ethnicity in the health inequalities metrics and indicators which will help inform targeted work

## Why focus on this in London?

- In 2023 in London Infant mortality rates in babies of Black ethnicity were 2.5x higher and in babies of Asian ethnicity were 1.8x higher compared to babies of white ethnicity<sup>2</sup>
- There is consistent evidence of racism in maternity services<sup>3</sup>

## Challenges

- Defining and measuring the cultural competency of a service is complex
- Services need to meet the need of all of London's communities, which requires a hyper local approach and meaningful engagement with local people

# Antiracism and cultural and cultural competency

## Potential next steps

1. Identify best practice examples of cultural competency in maternity services and share across London, with consideration to different birthing choices and preferences, such as doulas, hypnobirthing and home births
2. Promote and support adoption and implementation of the London Strategic Framework to Tackling Ethnic Health Inequalities through an Anti-Racist approach, as an overarching systematic approach to tackling racism and the impacts of racism on the health and care system
3. Support maternity services and commissioners to engage with and listen to the local population to inform development of culturally competent services, taking a joined up approach with other health services and building on existing trusted relationships and community and VCSE partnerships
4. Work with providers to ensure staff have the requisite training, skills and knowledge to examine and treat people with black or brown skin (e.g. different presentation of anaemia)
5. Support the recommendations of the NHS London Faith and Health Network conference, in particular utilising the "anchor" role of faith leaders and faith networks in providing health information and engaging with communities

## CASE STUDY

### Antiracism Framework and Fellowship for Ethnic Minority Midwives

Following the publication of the Turning the Tide report, TPHC formed an advisory group of ethnic minority maternity leaders and worked with them to co-design and deliver two products to drive equity in London maternity services: a Fellowship, and an Anti-Racism Framework.

The Fellowship aimed to help band 6 and 7 midwives from ethnic minority groups move into leadership roles. 33% of Fellows moved into a more senior role during, or within three months of completing, the Fellowship.

The Anti-Racism Framework is being piloted across London and outlines nine initiatives maternity services should implement to be anti-racist, which range from making sure ethnic minority maternity staff are in leadership roles, to debiasing recruitment, to supporting the continuous professional development of ethnic minority staff.

More information is available [here](#)

# Bereavement support

*Recommendation: Strengthen pathways to support people who lose a baby to receive enhanced and holistic support*

# Bereavement support

## CDOP data

- Nationally CDOPs reviewed 2,049 infant deaths in the year ending 31st March 2023, of which just under 100% had adequate information to make an assessment about whether a death had a modifiable factor. Of those reviews with adequate information 58% did not identify a modifiable factor
- Of the 88% of infant deaths in London in 2022 that have had a completed review by CDOP, 28% identified preventable factors. It is important to note that the scope of modifiable factors varies, and it is highly likely that this is an underestimate, and that proportion would be higher if wider determinants of health, such as deprivation, were consistently considered

## Opportunities

- The public consultation on the [Women's Health Strategy for England](#) found the second most popular topic for inclusion was pregnancy, pregnancy loss and postnatal support suggesting a desire for more support and information
- To ensure a consistent and culturally appropriate bereavement support offer across London

## Why focus on this in London?

- Unfortunately, there will always be infant deaths and therefore a need for high quality bereavement support for families
- The Childhood Bereavement Network estimate that 1 in 29 children have experienced the death of a parent or sibling

## Challenges

- Frontline staff face increasing pressure within the system, however there is a need to ensure they are adequately trained and feel confident talking about bereavement and supporting families
- While the experience of grief may be similar for different people, the ways people express grief, and its associated rituals, can be very different between cultures

# Bereavement support

**Baby loss affects all communities and genders and can be looked upon differently within individual communities and genders, leading to additional barriers when parents are experiencing loss**

*It saddens me I walked in with a child and came out with a memory box. I never opened that box as I still can't bring myself to look inside*

**Mother of a baby who died at 3 months old**

*I fully believe (although it cannot be proven) that my daughter would be here living with me if I had been listened to. I raised concerns on three separate occasions and on the last instance, it was too late. When a young, inexperienced mother says she knows her body, medical staff need to LISTEN and act accordingly*

**Mother of a baby born at 24 weeks, who died neonatally**

*While we were supported, we also had people say, 'It is God's will, you will have another', 'the silent secret', 'It is better it happened now than later in his life', 'at least he died before you got to know him', the list is endless*

**The words of a bereaved South Asian mother**

*The midwives held my hand and supported me until I was well enough to travel to the hospital my little boy was transferred to. Once I arrived at the NICU, very late at night, the midwives and nurses let me see him immediately. They answered all my questions and never made me feel rushed or that I had to leave despite the time of day! They cared for my baby boy like he was their own, and I will be forever grateful that the three days he was alive, he was surrounded by such loving, caring people!*

**Mother of a baby, born at 34 weeks who died neonatally**



# Bereavement support

## Potential next steps

1. Advocate for the adoption of the National Bereavement Care Pathway (NBCP) for bereavement support to equip families with the information, services and support they require immediately after the death of a baby, child or young person and in the long term, including when planning another pregnancy
2. Review provision of bereavement support in London against the Ockenden review recommendations<sup>1</sup>, including seven day support to identify gaps and inform future service developments
3. Work towards standardising funding and service arrangements across London to ensure a dedicated doctor visit is undertaken following an infant death that occurs beyond the immediate postnatal period (i.e. when the infant has been discharged).
4. Increase the skills and confidence of frontline staff to talk about bereavement, with an appropriate level of cultural competency. In particular it is important to support vulnerable families.

## CASE STUDY

### **Impact of the Named Nurse for Child Death, Neonatal Bereavement Nurse Specialist, and Bereavement and Family Liaison Nurse Role in Paediatric Critical Care at Barts Health**

Barts Health NHS Trust acknowledges the profound impact of child death on families and the need for specialized support across the organization and into the community.

To address this need, three pivotal roles have evolved to complement the all-age Trust Bereavement Nurse Specialist: the Named Nurse for Child Death, the Neonatal Bereavement Nurse Specialist, and the Bereavement and Family Liaison Nurse, based in Paediatric Critical Care.

These roles continue to develop, improving family experiences during devastating situations, fostering support for staff providing direct care, and building a culture of continuous learning and improvement within the healthcare team.

*Kath Evans, Director of Nursing (Children) at Barts Health and Clinical Lead for Babies, Children and Young People at North East London ICS and Anna Bray, Named Nurse for Child Death, Barts Health NHS Trust*

# Data and learning from Child Death Overview Panels

*Recommendation: Promote coordination and leadership of CDOP at a London level and shared learning between CDOPs*

# Data and learning from Child Death Overview Panels

## CDOP data

- CDOPs provide detailed information on infant mortality
- In London the CDOPs have a panel that focuses on perinatal and neonatal deaths. Postnatal deaths are reviewed as part of the Child Death review

## Opportunities

- Further standardisation of processes, data and reporting between CDOPs will maximise opportunities for learning, regionally and nationally and by working jointly, CDR partners can find solutions to common challenges and barriers
- To highlight best practice between trusts

## Why focus on this in London?

- Changes to the governance arrangements in 2019 mean that London's local CDOPs now handle larger caseloads, enabling better understanding of themes and trends in child death
- London partners in the child death review process recognise clear benefits to working together. Many organisations who contribute to understanding of child deaths serve the whole of London or operate across borough and integrated care system boundaries

## Challenges

- A lack of standardisation and comparability of CDOP reports across London
- There is also a lot of valuable learning and insight from incidents that don't result in fatalities that needs to be brought together with other data and intelligence

# Data and learning from Child Death Overview Panels

## Potential next steps

1. Explore availability of sources of data on incidents/near misses during the first year of life that do not result in an infant death but which offer important learning, and consider how this data can be brought together with other data and intelligence to improve learning and practice
2. Develop a pan London CDOP action plan to identify actions that will promote regional coordination and leadership, including the reporting of booking date and birthweight, in close collaboration with the London CDOP network
3. Collaborate to produce and publish an annual London CDOP report to support identification and sharing of regional themes, issues and learning to inform action
4. Strengthen governance systems to support compliance with Child Death Review guidance and to support best practice, including empowering families to contribute to the process

## CASE STUDY

### National Child Mortality Database<sup>1</sup>

The National Child Mortality Database (NCMD) launched on 1 April 2019 and collates data collected by Child Death Overview Panels (CDOPs) in England from reviews of all children normally resident in England, who die at any time after birth and before their 18th birthday. There is a statutory requirement for CDOPs to collect this data and to provide it to the NCMD.

It includes deaths of babies of any gestational age where there was a death notification to the CDOP, and deaths that occurred outside of a hospital trust.

In 2024 NCMD produced ICB level reports. The reports should be used to review the neonatal, infant and 1-17 years mortality rate in comparison to the national average, to assess where there is room for improvement and to identify inequalities. compared to the national average.

# Appendices

# Appendix A. London Reducing Infant Mortality Task and Finish Group membership, autumn 2024

- Julie Billet [Chair], Deputy Regional Director, OHID London
- Marilena Korkodilos [Chair from November 2024 onwards], Deputy Director for Health and Wellbeing, OHID London
- Rob Pears, Consultant in Public Health, OHID London
- Katie Patrick, Public Health Registrar, OHID London
- Jane Clegg, Regional Chief Nurse, NHSE London
- Nina Khazaezadeh, Regional Chief Midwife, NHSE London
- Rachel Lundy, NHSE London
- Dr Renton Lheureux, Consultant Neonatologist, London North West University Healthcare NHS Trust
- Dr Grenville Fox, Consultant Neonatologist, Guy's & St. Thomas' NHS Foundation Trust
- Dr Alice Walker, Consultant in Public Health, GLA
- Farrah Hart, Consultant in Public Health, GLA
- Jayne Vertkin, Anna Freud
- Kirsten Watters, Director of Public Health Camden Council and ADPH London lead for children and young people
- Clive Grimshaw, Strategic Lead for Health and Social Care, London Councils
- Kate Kewley, Strategic Health Consultant, London Councils
- Ian Lewis, Strategic Health Consultant, London Councils

# Appendix B. Early booking and access to care case study further details

## Parent Education in Foreign Languages in South East London

Language barriers significantly impact maternal and neonatal outcomes. Recent migrants and pregnant women with limited English proficiency often report negative maternity care experiences and lower antenatal attendance rates. SEL LMNS has initiated a pilot project to develop an online, co-produced Parent Education package, aligning with national guidelines and offering content in multiple languages spoken in SEL.

Octavia Wiseman, an experienced midwife and researcher with a background in running Spanish and Portuguese parent education classes, leads this project. Initial steps included engaging multiple stakeholders, including parent education leads across providers and community groups. The project also involved researching the languages spoken in SEL and the most common languages used for interpretation in maternity services.

The project's objectives are to:

- Develop a core online co-produced Parent Education package covering Antenatal, Intrapartum, and Postnatal/Infant Feeding workshops.
- Compile language- and culture-specific resources for families.
- Identify bilingual midwives and MSWs interested in delivering Parent Education.
- Provide training for midwives to deliver engaging online parent education.
- Pilot monthly online Parent Education sessions in 4-5 key languages, promoted across SEL maternity services.
- Regularly evaluate the parent education sessions and share findings with SEL maternity providers.

## Progress

Languages Chosen (Spanish, Portuguese, Somali, Romanian, Arabic, and French), Content Development, Translation, Class Delivery, Resource Compilation, Follow-Up, Evaluation, Promotion, Initial Sessions

## Next steps

The pilot aims to increase satisfaction with birth experiences among women with limited English proficiency, enhance social support, and improve the use of local support services. Expected outcomes include better birth outcomes through increased uptake of healthy behaviours and empowering women to access maternity services early in pregnancy. This pilot project serves as a model for improving maternal and neonatal care for non-English speaking populations through targeted education and support, ultimately contributing to reducing health inequalities.

*Jacqui Kempen (Head of Maternity for SEL LMNS and SEL Integrated Care Board (ICB), Monica Franklin (Senior Project Manager, SEL LMNS), Octavia Wiseman (SEL Lead Midwife for Foreign Language Parent Education)*



# Appendix B. Preconception case study study further details

## South East London Local Maternity and Neonatal System (LMNS)

SEL LMNS is dedicated to the National Maternity Transformation Programme, focusing on reducing maternal and neonatal morbidity and mortality. Its Public Health (PH) workstream includes stakeholders from all maternity and neonatal providers and Public Health practitioners across South East London local authorities. Pre-conception health is a key priority.

Over 12 months, PH workstream members collaborated to identify local challenges and priorities for improving pre-conception healthcare. Key stakeholders from primary and secondary care, public health, and Maternity and Neonatal Voices Partnership leads (MNVPs) participated in two virtual co-production workshops facilitated by independent public health network practitioners.

### Key Priorities Identified

Education and training, physical and emotional preparation for pregnancy, increasing planned pregnancies, addressing trauma and promoting wellbeing, timing of interventions, ensuring equity of access

### Strategic Initiatives

Additional funds from the ICB are being utilised for advancing pre-conception health work, including:

1. Scoping and Health Needs Analysis (HNA)
2. Engagement and Co-Design (Focusing on groups at risk of inequalities)
3. Public Health Campaign
4. Developing Local Interventions

## Current Findings

An estimated 10,000 individuals in SEL could benefit from pre-conception healthcare annually.

Pre-conception care in SEL is underdeveloped, with low folic acid supplementation rates.

Research by Kings Health Partners (Lachouri & Prashant, 2024) highlights limited access to information, a shortage of healthcare provider discussions on pre-conception health, and a desire for more accessible information through GP surgeries and online engagement.

## Conclusion

This case study highlights the challenges in addressing pre-conception health, which is not routinely covered in primary or secondary care. A co-production approach involving healthcare partners and service users can identify local challenges and guide the development of interventions. LMNS, in collaboration with Public Health and the wider Integrated Care System (ICS), plays a crucial role in improving pre-conception health and reducing health inequalities in the region.

*Jacqui Kempen (Head of Maternity for SEL LMNS and SEL Integrated Care Board (ICB), Monica Franklin (Senior Project Manager, SEL LMNS), Pauline Cross (Public Health Consultant Midwife, Lewisham)*



# Appendix B. Optimising maternal mental and physical health case study further details

## Community Activity and Nutrition (CAN) service, delivered by the Lambeth Early Action Partnership (LEAP) in South East London

- The CAN service was offered to all LEAP-area pregnant women/birthing people with a BMI  $\geq 25$  who booked to have their babies at one of the two LEAP-area NHS Trusts. CAN supports women to make behaviour changes that enable healthier eating and increased physical activity during and after pregnancy: women are given personalised, culturally appropriate 1:1 support to set goals for making food swaps and increasing their daily step count.
- From 2016 – 2023, CAN supported 734 pregnant women: 70% lived in areas of deprivation in Lambeth (locally calculated IMD quintiles 1 and 2) and 80% were from Black, Asian and Multiple Ethnic groups.
- Feedback about CAN was overwhelmingly positive. A short film featuring the voice of a CAN service user is available [here](#).

## Outcomes

- Physical activity levels are measured three times using the International Physical Activity Questionnaire (IPAQ): at registration in the early 2<sup>nd</sup> trimester, at 28 weeks and again 6 months postnatally.
- For those participants who had an IPAQ assessment, 45% of participants had low and 49% had medium activity levels at registration, which improved by 28 weeks (24% low and 69% medium activity). The proportion of people who had high activity levels nearly doubled between registration (5.7%) and 6 months (10.0%).
- Average time spent walking increased by 35% on average from 240 to 339 minutes between registration and 6 months; though a slight decrease was seen between 28 weeks and 6 months. Moderate or vigorous activity minutes increased by 52% on average from 46 to 70 minutes between registration and 6 months.

*Carla Stanke, Public Health Specialist, Lambeth Early Action Partnership (LEAP)*

# Appendix B. Women and families with complex needs case study further details

## Maternity Disadvantage Assessment Tool in South East London

- In partnership with the Royal College of Midwives (RCM), Lambeth Early Action Partnership developed the Maternity Disadvantage Assessment Tool (MaTDaT) to support earlier and more consistent identification of social risk factors in pregnant women/birthing people. The tool was designed to support midwives' decision making in response to routine questions asked at antenatal appointments. The MaTDaT is hosted by RCM and is available [here](#).
- MaTDaT lists criteria for assessment across 4 levels (level 1: thriving and support needs can be met by universal services, level 4: acute level of unmet and complex need and/or require urgent intervention to protect against current or likely significant harm)
- A key aim of the tool is to prevent escalation of social complexities for those at level 2 or 3. Social complexity criteria include abuse and neglect, social isolation, unstable family environment and struggles with employment, housing or benefits.
- Two companion resources sit beside the MaTDaT: an e-learning training module for midwives and a Planning Guide which allows each level of social complexity to be mapped across to local sources of support, to enable the provision of personalised care.
- A feasibility study found that MaTDaT has value as an internal threshold document and has potential to support inexperienced or cautious midwives to make decisions about safeguarding. MaTDaT may have more value for midwives working in traditional clinics, to support communication between many health professionals working with one woman.

*Carla Stanke, Public Health Specialist, Lambeth Early Action Partnership (LEAP)*

# Appendix B. Bereavement support case study further details

## **Impact of the Named Nurse for Child Death, Neonatal Bereavement Nurse Specialist, and Bereavement and Family Liaison Nurse Role in Paediatric Critical Care at Barts Health**

Barts Health NHS Trust acknowledges the profound impact of child death on families and the need for specialized support across the organization and into the community. To address this need, three pivotal roles have evolved to complement the all-age Trust Bereavement Nurse Specialist: the Named Nurse for Child Death, the Neonatal Bereavement Nurse Specialist, and the Bereavement and Family Liaison Nurse, based in Paediatric Critical Care. These roles continue to develop, improving family experiences during devastating situations, fostering support for staff providing direct care, and building a culture of continuous learning and improvement within the healthcare team.

These roles aim to:

- Enhance Family Support: Provide emotional, psychological, and practical support to families during and after the loss of a child.
- Improve Continuity of Care: Ensure seamless communication and support throughout the end-of-life and bereavement process.
- Facilitate Continuous Support of Staff and Build Learning: Use insights from each case to refine practices and protocols in managing child death and bereavement, feed into Child Death Overview Processes (CDOP), and vitally support staff in often complex and emotionally challenging situations.

*Kath Evans, Director of Nursing (Children) at Barts and Clinical Lead for Babies, Children and Young People at North East London ICS and Anna Bray, Named Nurse for Child Death, Barts Health NHS Trust*