Scrutiny Inquiry: Infant Mortality

Health and Social Care Overview and Scrutiny Committee

1 Introduction

1.1 Infant mortality is defined as death before the child reaches the age of one year. The infant mortality rate is the number of deaths under one year of age occurring among the live births in a given geographical area during a given year, per 1,000 live births. Nationally, the rate of infant mortality has been declining steadily since the 2001/03 period but in Birmingham infant mortality rates have been statistically high for several years, nearly twice the national average. Currently, out of every 1,000 births in the city, seven babies will not live to their first birthday. This is an indicator of the general health of an entire population, as well as a tragedy for all families affected by such a death.

1.2 Members of the Health and Social Care O&S Committee therefore agreed to undertake a scrutiny inquiry to look at the extent of the issue, to identify the factors which are affecting the rate of infant mortality in Birmingham and to explore possible interventions. The City Council's Delivery Plan contains a commitment from Public Health Services to develop an Infant Mortality Strategy by May 2021. We intend that evidence from this inquiry will provide a base from which a policy can be formed to tackle the issue.

1.3 Two evidence gathering sessions were held in December 2020 and January 2021. The first session focused on the data, the multiple causes of infant mortality, national policy/guidance, NHS initiatives relevant to this issue and the contribution of various risk factors including recessive genetic disorders related to consanguinity. Current service provision in terms of clinical genetics, genetic testing and counselling for families was shared. Members also heard about the work being done in Sheffield. The presentations for that session can be found here and the session is available to watch here. At a second session held in January 2021, Members heard from a local community organisation. The presentation for that session can be found here and the session is available to watch here.

1.4 A list of participants in both sessions can be found in Appendix 1.

2 Findings – What the Data Tells us

Infant Mortality

2.1 The infant mortality rate consists of three components:

- Early neonatal – the first 0 to 6 days after birth;
- Late neonatal – 7 to 28 days after birth;
- Post-neonatal morality rate - the number of infants who die between 28 days and less than one year.

2.2 It is important to note that infant mortality is not only important in itself but is also used as an indicator of the general health of an entire population. Infant mortality affects different parts of the population unequally and correlates with several determinants of population health e.g. socio-economic status, ethnicity, environmental condition, health care, obesity, smoking etc. So, infant mortality is a proxy indicator for a lot of other public health issues.

2.3 The current England rate of infant mortality is 3.9 deaths per 1,000 live births (this is pooled data from 2017-2019). The West Midlands[1] has a much higher rate as a region at 5.6 deaths per 1,000 births, which is the highest in the country. All local authorities in the West Midlands have rates above the England average except for Warwickshire which has a rate of 3.6. The top four local authorities in England with the highest rates of infant mortality are all in the West Midlands. Stoke on Trent has the highest rate, then Sandwell, and Birmingham is third highest nationally, at seven deaths per 1,000 live births. In terms of the actual numbers, this equates to around 112 deaths per year (336 infant deaths within Birmingham according to the most recent data, 2017-19).

2.4 Areas outside of the West Midlands which have a level of infant mortality statistically higher than the national average include Blackpool, Kirklees, Manchester, Bradford, Leicester, Oldham, Nottingham, Rochdale, Derby, Liverpool and Luton. However, these all have an infant mortality rate lower than Birmingham.

2.5 Birmingham has had consistently high rates of infant mortality that exceed that of England. In 2018-20 there were 296 deaths of children and young people in Birmingham (0-19 years). Infant deaths (under 1 year) account for 65% (192 deaths) of these.

Perinatal Mortality

2.6 The definition of perinatal mortality is the summation of stillbirth babies (born from 24 weeks onwards with no sign of life) and neonatal deaths (babies which die within the first 28 days of birth). The perinatal mortality rate is the number of perinatal deaths per 1,000 births.

2.7 Again, Birmingham has a higher rate than its neighbours: eight areas in the West Midlands are higher than the national average and Birmingham has the second highest with a rate of 5.47 deaths per 1,000 births.

Infant Mortality and Deprivation

2.8 There are significantly higher rates of infant mortality in deprived populations compared to the population as a whole. This is important in understanding what is happening in Birmingham as there is a significant level of deprivation in the city. In Birmingham, 28.1% of children live in low-income families compared to 17% nationally.

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[1] West Midlands here refers to the seven metropolitan boroughs: the city of Birmingham, the city of Coventry, and the boroughs of Dudley, Sandwell, Solihull, Walsall, and Wolverhampton, plus Stoke on Trent, Herefordshire, Staffordshire, Shropshire, Telford and Wrekin, Worcestershire and Warwickshire

2.9 In comparing Birmingham with those areas that are most similar in terms of socio-economic features, Birmingham has the second highest infant mortality rate, Sandwell has the highest. The most recent national report on perinatal mortality reported that 42% of births at University Hospitals Birmingham (UHB) and 38% of births at Birmingham Women's Hospital (BWH) were in the most deprived decile.

2.10 Nationally, there is a recognised correlation between higher infant mortality rates and deprivation. Reducing infant mortality overall and the gap between the richest and poorest groups are part of the Government's strategy for public health. A map showing the number of deaths of children under one year and levels of deprivation, included in Appendix 2, demonstrates this point. However, further work is required to better understand the complex local relationship between population level risk factors and individual outcomes.

Infant Mortality and Ethnicity

2.11 Data seen by the Committee shows that there are significant variations in infant mortality and perinatal mortality between communities of different ethnic identity. Analysis undertaken by the Child Death Overview Panel (CDOP – see section 2.14 below), shows a disproportionate percentage of child deaths amongst those who identify as 'Asian – Pakistani' than the percentage of 'Asian – Pakistani' in the wider population. Conversely, there is a lower percentage of CDOP cases in the 'White' ethnic group compared to the 16-44 'White' female population. Care does need to be taken with these figures, firstly as the comparative population data is from 2011 and the data on deaths is from 2018-20, so the actual population by ethnic group could be different now.

2.12 The latest Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries (MBRRACE) report (Dec 2020)[2] shows mortality rates remain exceptionally high for babies of Black and Black British ethnicity: stillbirth rates are over twice those for babies of White ethnicity and neonatal mortality rates are 45% higher. Similarly, mortality rates remain high for babies of Asian and Asian British ethnicity: stillbirth and neonatal mortality rates are both around 60% higher than for babies of White ethnicity.

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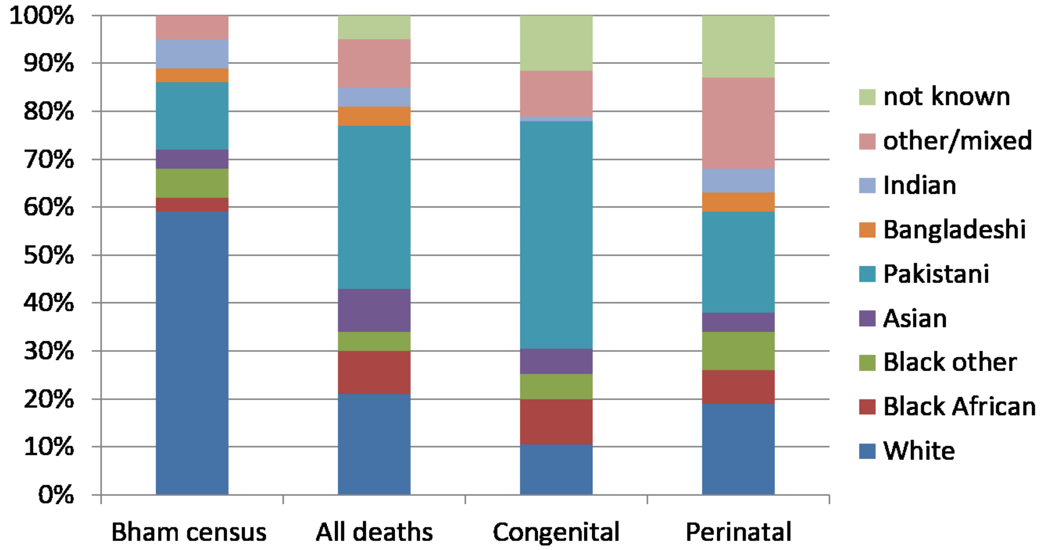
[2] 'MBRRACE-UK' is the collaboration appointed by the Healthcare Quality Improvement Partnership (HQIP) to run the national Maternal, Newborn and Infant clinical Outcome Review Programme (MNI-CORP) which continues the national programme of work conducting surveillance and investigating the causes of maternal deaths, stillbirths and infant deaths

Comparison of ethnicity and cause of death[3]



2.13 The perinatal mortality rate by ethnicity, which is the combination of stillbirths and neonatal deaths, also shows that the Pakistani population is over-represented. This has declined but not as much as for the White population. And whilst caution should be exercised in using these figures as the numbers involved are very small, it is worth noting that national data based on larger numbers (published in January 2021) shows that for neonatal deaths 1 in 606 white babies die compared to 1 in 420 black and 1 in 380 Asian babies. So, a correlation can be demonstrated.

Child Death Overview Panel – Infant Mortality and Ethnicity 2018-2020

2.14 The Child Death Overview Panel (CDOP) reviews the death of every child residing in Birmingham, collecting data of children that die from birth to 18 years old regardless of gestation, i.e. even those born so extremely prematurely that they could not possibly survive. Stillborn babies and those dying as a result of the termination of a pregnancy are not reviewed. The home address of the child is used rather than the location of death. The data presented to the Committee related to children whose deaths had been reviewed between April 2018 and March 2020 (they may have died the year before).

2.15 In that time period, 296 deaths of under 18 year olds were reviewed. The number of deaths each year has remained stable, at around 150 to 170 deaths. CDOP categorises deaths looking at the underlying cause rather than the actual event, and the two most common causes in infancy are:

- Chromosomal, genetic and congenital abnormalities – including trisomies[4], other congenital disorders, single gene defects, cystic fibrosis and other congenital anomalies including cardiac

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[3] Based on the 2011 Census

[4] a condition in which an extra copy of a chromosome is present in the cell nuclei, causing developmental abnormalities

- Perinatal/Neonatal event – i.e. death ultimately related to perinatal events, e.g. prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, post-haemorrhagic hydrocephalus, irrespective of age at death. It includes cerebral palsy without evidence of cause and congenital or early onset bacterial infection (onset in first postnatal week).

2.16 During 2018-2020, there were 296 deaths reviewed in the 0-18 age group of which there were 138 deaths of babies in the first month of life and 54 deaths from one month to one year old. By far the largest category was perinatal/neonatal deaths accounting for 102 babies but a further 65 dying of chromosomal, genetic and congenital abnormalities. 50 of those 65 babies had conditions that were not compatible with life i.e. there was no treatment option. The remaining 15 children were mainly those with a complex congenital heart disease who died following complex heart surgery.

2.17 Of the perinatal deaths, 42 out of 102 were born at less than 23 weeks gestation so would have had very limited chance of survival; those born at 21 weeks gestation or less would not have been admitted to the Neonatal Unit but would have been kept comfortable with their mother. There were 44 deaths of babies between 23 and 27 weeks; 6 between 28-31 weeks and 5 babies who died between 32 to 36 weeks and 5 at 37 weeks or more.

2.18 Using the Birmingham 2011 census to compare death and ethnicity the Pakistani, Black African and Afro-Caribbean populations is over-represented in all child deaths, particularly in deaths from chromosomal, genetic and congenital abnormalities but, also, in the perinatal/neonatal deaths, which is concurrent with prematurity.

2.19 A further 39 deaths of children aged 1-17 years from chromosomal, genetic and congenital abnormalities occurred in 2018-20. Congenital causes also have considerable morbidity associated with them throughout the lifetime and many of these children grow up to be adults but have complex health problems and need a lot of care and support.

2.20 Members asked if failure in maternity care was a significant factor in deaths in Birmingham. In response, practitioners said that whilst there were a couple of cases where that may have contributed, these were very rare and so had no impact on the statistics. For this reason, it was concluded by practitioners that standards of maternity care are not a significant causal factor in the City's disproportionally high infant mortality rate.

2.21 In summary, perinatal/neonatal causes are responsible for the majority of infant deaths, and babies born within families of Pakistani and Black African ethnicity are over-represented in deaths from both perinatal and congenital causes.

3 Findings – Risk Factors

3.1 There are many known risk factors associated with infant mortality including:

- **Smoking in pregnancy** – Birmingham has a statistically lower rate of smoking amongst pregnant women of 11.6% compared to the England average of 12.8%. Smoking in pregnancy causes a significant number of premature births, miscarriages and perinatal deaths. The statistics for those smoking at the time of delivery are at 10.7% in Birmingham compared to 10.4% in England and 12.1% in the West Midlands. We note with concern however, that the most recent data show the levels of smoking in pregnancy are now rising.

- **Low birth weight** which constitutes the birth weight of a baby that is under 2,500 grams and a very low birth rate under 1,500 grams. Low birth weight is not necessarily a direct risk factor, but it does signify relevant issues – premature delivery being the most obvious. In 2018, 1.72% of babies were born with a very low birth rate in Birmingham compared to an England average of 1.16%.
- **Obesity** – One quarter of women in Birmingham are classed as obese in pregnancy and that rate is higher than the England average of 22.1%. However, this relationship is complex as obesity is also highly correlated with socio-economic status.

3.2 The three most modifiable factors related to pregnancy which influence perinatal mortality were reported to the Committee as:

- **Pre-term birth** i.e. babies born before 37 weeks of pregnancy: The national target for pre-term birth rate is 6%. The England average is 8% and in Birmingham and Solihull it varies around 10%, showing no real improvement. A reduction in the pre-term birth rate would be expected to significantly impact on the perinatal mortality rate.
- **Fetal growth restriction detection:** Defined as less than the 10th centile for gestation i.e. a term for a baby who is growth restricted but not small. Growth restricted babies are more likely to succumb to stillbirth but, if they do survive, are likely to have long-term poorer outcomes. It is difficult to detect foetal restriction in pregnancy with 100% accuracy; 50% detection levels would be regarded as good performance, but the local rate is around 30%.
- **Smoking**: Smoking in pregnancy is regarded as a modifiable factor and improving that rate would also impact on perinatal mortality outcomes

4 Findings – Responses to Infant Mortality

The National Response – *Better Births: Improving Outcomes of Maternity Services in England*

4.1 There is a national improvement target to reduce the perinatal mortality and stillbirth rate by 50% by 2025 which was based on the 2010 baseline. National focus on this issue follows a major review of maternity services, triggered by a number of unexplained perinatal and maternal deaths in Morecambe Bay in 2015.

4.2 That same year, the Secretary of State for Health commissioned a major review of maternity services and in November 2015, the Department of Health announced an ambition to reduce the rate of stillbirths, neonatal and maternal deaths in England by 50% by 2030. The date by which this is to be achieved has since been revised to 2025.

4.3 In 2016, the *Better Births: Improving Outcomes of Maternity Services in England – A Five Year Forward View for Maternity Care* was published. It sets out the vision for a holistic approach to maternity care.

"Our vision for maternity services across England is for them to become safer, more personalised, kinder, professional and more family friendly; where every woman has access to information to enable her to make decisions about her care; and where she and her baby can access support that is centred around their individual needs and circumstances. And for all staff to be supported to deliver care which is woman centred, working in high performing teams, in organisations which are well led and in cultures which promote innovation, continuous learning, and break down organisational and professional boundaries."

4.4 The report made seven recommendations based on the following:

- **Personalised Care** – based on the needs and decisions of the woman, her baby and family.
- **Continuity of Carer** – the woman and her family are supported by a midwife or small group of midwives throughout the entire journey of the pregnancy.
- **Safer Care** – references quality improvement initiatives that have been set up by the NHS. For example, Saving Babies Lives Care Bundle (SBLCB) which is particularly focussed on reducing stillbirths and perinatal mortality and how health care services can impact on that. The SBLCB is an evolving picture. Nationally, evidence is collated and fed back to the local maternity system. Therefore, using national data to inform local decisions.
- **Better Postnatal and Perinatal Mental Health Care** – for example, locally, implementing the Maternal Mental Health Service which is to improve mental health services to women who suffer trauma and loss during pregnancy.
- **Multi-Professional Working** – multi-professionals working to ensure that there are no barriers between members of a team e.g. midwives, consultants and other professionals.
- **Working Across Boundaries** – to commission maternity services to provide support and choice and specialist services.
- **A Payment System** – which is fair and pays providers of services appropriately while ensuring that the money follows women and their babies through their care.

4.5 More information can be found here.

Saving Babies Lives Care Bundle (version 2)

4.6 **The Saving Babies Lives Care Bundle (version 2)** is a guidance document for Maternity Services and Commissioners developed by NHS England / Improvement (NHSE/I) in March 2019 which provides detailed information on how to reduce perinatal mortality across England.

4.7 The guidance sets out five elements of care within the Maternity Services, that are widely recognised as evidenced-based and / or best practice:

1. Reducing smoking in pregnancy.
2. Risk assessment, prevention and surveillance of pregnancies at risk of Fetal Growth Restriction (FGR).
3. Raising awareness of Reduced Fetal Movement (RFM).
4. Effective fetal monitoring during labour.
5. Reducing pre-term birth.

NHS Long Term Plan

4.8 The NHS Long Term Plan (LTP) was published in January 2019 by NHS England in response to funding, staffing and inequalities to facilitate improved outcomes. The LTP includes some specific measures for maternity/neonatal/mental health services, Clinical Commissioning Groups and regional National Health Service England and NHS Improvement teams:

- Implementing the Saving Babies' Lives Care Bundle.
- Improving Neonatal Critical Care.
- Targeted and enhanced continuity of carer.
- Improved and increasing access to Specialist Perinatal Mental Health Services.
- Introduction of maternal medicine networks.
- Targeted services to help to decrease maternal smoking.
- Improving postnatal physiotherapy services.
- Improve infant feeding programmes.

4.9 The LTP incorporates **Better Births** reinforcing the message of holistic improvement in care and empowerment for women but adding extra features such as the postnatal physiotherapy services, infant feeding programmes and NHS specific care such as Neonatal Critical Care. Findings and recommendations from the Ockenden review of maternity services at Shrewsbury and Telford Hospital NHS Trust, published in December 2020, will also be incorporated.

Local Interventions

4.10 Birmingham and Solihull have two main maternity services providers i.e. University Hospitals Birmingham (UHB) NHS Foundation Trust (which includes Good Hope, Heartlands and Solihull) and Birmingham Women's and Children's Hospital NHS Foundation Trust (BWH) who deliver circa 18,000 babies per annum. The most recent data available locally (January 2021) indicates a combined unadjusted perinatal mortality rate for 2019 of 6.2. For UHB, the perinatal mortality rate was 5.21, and for BWH 5.18.

4.11 The Local Maternity System (LMS), Birmingham Women's and Children's NHS Foundation Trust and University Hospitals Birmingham NHS Foundation Trust across Birmingham and Solihull have a transformation plan in place to meet the requirements of the guidance.

4.12 The actions that are being taken locally are:

- **Improving Neonatal Critical Care:** The LMS is working in partnership with the Neonatal Operational Delivery Network to implement the recommendations of the Neonatal Critical Care Review, which is to ensure that women who give birth before 27 weeks are able to do so in a unit with on-site neonatal intensive care. Local plans have been submitted for regional and national consideration. A <27-week pathway has been in place in Birmingham and Solihull since January 2020 and a 6-month evaluation has taken place. Ongoing meetings with partners are taking place with a proposal in development to expand on the current service criteria. Providers also report on neonatal deaths.
- **Targeted and enhanced Continuity of Carer:** Continuity of carer (CoC) refers to consistency of the midwife or clinical team that provides care for a woman throughout the three phases of her maternity journey: pregnancy, labour and the postnatal period. Evidence has shown that this model of care improves clinical outcomes, safety and patient experience. In addition to the universal offer of 35% of women receiving CoC by March 2021, due to the widening inequalities faced by Black, Asian and Minority Ethnic (BAME) women and Covid-19, 75% of BAME women and those living in the most deprived areas will receive CoC by 2024. Due to the impacts of Covid-19 and staffing challenges providers will struggle to meet the target however plans are in place to continue to work towards implementation.
- **Improved and increased access to Specialist Perinatal Mental Health services**: The first 1001 critical days from pregnancy to the first 2-years of a child's life is a crucial developmental stage to lay the foundation for a child's emotional wellbeing, health, resilience and learning potential. Birmingham and Solihull Mental Health Foundation Trust deliver a specialist Perinatal Mental Health (PNMH) Service to pregnant women suffering with moderate to severe mental illness. Plans are in place to increase the number of women accessing the service by March 2021. Phased plans are in place to extend the existing provision from pre-conception to 24 months after birth with increased availability of evidence based psychological therapies. It also offers support to partners of women accessing the service and development of a Maternal Mental Health Service offer which will focus on trauma which includes fear of giving birth and loss.
- Targeted services to help to decrease maternal smoking: Smoking during pregnancy increases the risk of stillbirth, miscarriage, low birth weight, prematurity and birth defects. The Birmingham and Solihull Stop Smoking Service went live 21st September 2020, providing Smoking Cessation Support, ongoing personalised support, if required, for up to 12 months or 6 weeks postnatal and access to Nicotine Replacement Therapy prescriptions.

- **Improved infant feeding programmes:** A study of optimal breastfeeding practices and infant and child mortality: a systematic review and meta-analysis evidenced the effects of optimal breastfeeding on all-cause and infection-related mortality in infants and children aged 0–23 months. The authors found higher rates of mortality among infants never breastfed compared to those exclusively breastfed in the first six months of life and receiving continued breastfeeding. There is an established infant feeding workstream in place progressing key actions including analysis of infant feeding data trends, and the Maternity Voices Partnership (MVP) is in the process of facilitating an infant feeding survey. A review and scoping of Tongue Tie Services is taking place and ongoing work in line with the Baby Friendly Initiative (BFI), an evidence based accredited programme which supports maternity, neonatal, health visiting and children's centre services to improve their care.
- **Risk assessment, prevention and surveillance of pregnancies at risk of Fetal Growth Restriction (FGR)**: There is strong evidence to suggest FGR is the biggest risk factor for stillbirth. Therefore, antenatal detection of growth restricted babies is vital and has been shown to reduce stillbirth risk significantly because it gives the option to consider timely delivery of a baby at risk. Prevention and surveillance include detection of smoking status and efforts to be smoke free by 16-weeks, medication, risk assessment, surveillance and management of women at greater risk of FGR, growth disorders in multiple pregnancies and small gestational age. Policies for managing FGR detection have made a positive impact whilst ensuring sufficient scanning services capacity remains challenging. Providers also continue to learn from best practice, errors and incidents to evidence continuous improvement.
- **Raising awareness of Reduced Fetal Movement (RFM)**: Enquiries into stillbirth have consistently described a relationship between episodes of RFM and stillbirth. Unrecognised or poorly managed episodes of RFM have been highlighted as contributory factors to avoidable stillbirths. Locally, providers have a communication strategy in place, with enhanced communications with women during Covid-19, including a bespoke telephone triage assessment tool, availability of leaflets in multiple languages, 'Ask the Midwife' sessions and use of social media, radio and digital platforms. Training will be delivered to focus on raising awareness of reduced fetal movement and effective fetal monitoring.
- **Effective fetal monitoring during labour**: Evidence suggests effective fetal monitoring during labour could support a reduction in stillbirths and avoidable fetal morbidity related to brain injury causing conditions. Fetal surveillance midwives are in post at each Trust. The Fresh Eyes and Ears protocol has been reinforced with all staff and local monitoring is in place. Some face to face mandatory training is on hold due to Covid-19.
- **Reducing Pre-Term Birth (PTB)**: PTB is defined as delivery at less than 37+0 weeks' gestation. It is the most important single determinant of adverse infant outcome with regards to survival and quality of life. There are major national quality improvement programmes to support reduction in PTB and optimisation for those babies born prematurely e.g. British Association of Perinatal Medicine antenatal optimisation toolkit. Pre-term prevention services are

in place across Trusts and work continues in relation to the development of guidelines, data validation, clinical audit, training and addressing service pressures.

5 Findings – Consanguinity

5.1 One of the questions that prompted this inquiry was to explore the evidence suggesting that consanguinity is a potentially significant causal factor in congenital abnormality, and consequently in increasing the risks of infant mortality.

5.2 Consanguineous marriage is a union between couples related as second cousins or closer. Globally, 10.4% of the population are married to a blood relative or a child of such a relationship[5], though the Committee understands that in terms of non-traditional families such marriages are declining with younger generations choosing to marry distant relatives, where the risk is not as great, or using social networks to meet possible suitors. Such marriages occur in many cultures, and have potential social, economic, and genetic advantages. However, there is also an association between consanguinity and increased risk of infant mortality, linked to congenital defects arising from autosomal recessive inheritance.

5.3 The evidence the Committee received further emphasised that these risks do not relate only to infant mortality but also to childhood morbidity and mortality, with consanguinity observed in 86% of children with progressive intellectual and neurological deterioration.[6] Thus there is also an association with disability and other lifelong conditions, which has long term consequences for both the individual and health/public services needed to support the individual and family.

5.4 The evidence received shows mixed views amongst professionals on the causes and significance of consanguinity, particularly as it relates to ethnicity. The Committee notes that accurate estimates of the increased genetic risk associated with consanguinity are hampered by poor data availability and the fact that cases cannot always be confirmed.

5.5 Recent studies include the "Born in Bradford" study, the most recent large-scale birth cohort study published in the Lancet, which demonstrates a doubling of risk of any congenital disorder (since recessive genetic conditions could not be isolated with certainty) from around 3 per 100 live births among unrelated couples to around 6 per 100 live births among first cousin couples. The increased risk was found to remain after adjusting for deprivation.[7] The Committee was informed that these figures are in line with several other investigations in other contexts.

5.6 A review of regional data derived from the Perinatal Episode Electronic Record (PEER) investigating mortality over a 2-year period (2009-2010), found that congenital anomaly related deaths occurred in about one third of stillbirths and infant deaths and the mortality rate was significantly higher in

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[5] Bittles and Black, 2010. The impact of consanguinity on neonatal and infant health. Early Human Development 86 (2010) 737–741

[6] Fraser and Parslow., 2017, Verity et al., 2021

[7] Sheridan et al. 2013 https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61132-0/fulltext

Pakistani and Bangladeshi mothers.[8] Deaths due to metabolic disorders, renal anomalies and neural tube defects were also significantly higher in Pakistani babies. Antenatal folate use was low in most ethnic minority groups and late booking may have contributed to later detection of congenital abnormalities. When the cause of death was examined in more detail, in the case of Pakistani births autosomal recessive conditions represented a quarter of deaths and two thirds of deaths from congenital abnormality, compared to 10% and over a third respectively in the rest of the population.

5.7 However, as noted above, accurate estimates of the increased genetic risk associated with consanguinity are hampered by poor data availability.[9] In addition there are other variables known to influence childhood health including social conditions, maternal age and education, birth order, and birth intervals which also have an impact and must be considered alongside consanguinity as a factor in infant mortality.

Data in Birmingham

5.8 So, what does the data in Birmingham tell us? Looking at the Birmingham data from the CDOP (as above), it can be seen that perinatal causes are responsible for the majority of infant deaths (102 out of 298) in Birmingham, and congenital factors are the second main cause (65 of 298). Therefore, congenital factors are a cause in around a fifth of deaths – a significant factor but not the main cause. The data from Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries (MBRRACE) on Causes of Death and Associated Conditions of perinatal deaths for babies delivered in 2018 differs slightly in that it identifies rates as higher and it is the MBRRACE data that maternity outcomes are judged on.

Interventions

5.9 Strategies developed in the West Midlands to improve access and encourage appropriate and early referral of patients and families at risk of genetic disorders include the permanent employment of specialist Asian Genetic Counsellors (1 full time equivalent) with expertise and knowledge of the cultural and religious issues. The Enhanced Genetics Services Project (December 2008 – December 2011) was established to address excess infant and childhood morbidity linked to autosomal recessive (AR) conditions identified by the former Heart of Birmingham Primary Care Trust. It aimed to improve the detection of AR diseases by developing genetic laboratory testing, identifying and offering relatives carrier testing and increasing specialist Genetic Counsellor support for South Asian ethnic minority families. A major component was community and primary care involvement to enhance awareness of those that may benefit from clinical genetics input and tailored educational

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[8] Tonks, A. M., Williamson, A., Williams, D. and Gardosi, J. O. (2013) Mortality, congenital anomaly, & maternal risk factors across ethnic groups in Birmingham. Archives of Disease in Childhood. 98, Suppl.1;
Tonks, A. M., Fowler, T., Williams, D. (2014) Stillbirth and infant mortality from congenital anomalies and autosomal recessive (AR) conditions in Birmingham ethnic groups. Archives of Disease in Childhood. 99(A153-A154)

[9] Salway et al (2012). Responding to increased genetic risk associated with consanguineous marriage: A formative review of current service approaches in England. Available at http://clahrcsy.nihr.ac.uk/images/health%20inequalities/resources/Responding%20to%20increased%20genetic%20risk.pdf

resources to professionals and families. However, a shift in emphasis from consanguinity to rare AR diseases, and a more sustained approach, is required.

5.10 Research and clinical audit have repeatedly demonstrated that families at risk of affected births commonly have poor access to information and support, and that healthcare professionals may miss opportunities to address this inequity.

5.11 A number of areas in the UK where there is a high prevalence of consanguinity have implemented interventions to respond to the unmet need for genetic information and services. Further work needs to be carried out to consider if such an approach should be undertaken in Birmingham. However, it is important to acknowledge that the challenge in tackling this potential risk can be complicated by cultural sensitivities, preconceptions and misconceptions around consanguinity, as well as inadequate knowledge and skills among healthcare professionals and low levels of trust among communities that have past experience of discrimination.

5.12 The witnesses to the inquiry emphasised that this was a sensitive area and, sometimes, the risk of birth abnormality linked to consanguinity was exaggerated. As noted above in section 3, there are many other factors that contribute to infant mortality and all must be taken into consideration.

5.13 Specialist family-centred services for genetics conditions is available from the West Midlands Regional Clinical Genetics Service. The current referral pathway into the Clinical Genetics Service is mainly through hospital and community paediatricians, antenatal/fetal medicine services and self-referral. Once patients have been referred to the service, family history details are collected, clinical assessments, diagnostic testing and carrier testing, if available, can be offered to relatives. In addition, options for, pre-natal testing and pre-implantation genetic diagnosis can be explained. Barriers to service uptake may disadvantage certain ethnic communities, particularly where there are language, accessibility, trust and confidentiality issues as well as misconceptions or perceived lack of utility by patients and professionals.

5.14 Members heard evidence from the Wellbeing Project perspective, who reported that they have not been aware that this is a point of discussion in the community. There is a lot more awareness around diabetes, depression, obesity and hypertension but there is always a willingness to improve health outcomes through the Wellbeing Project.

5.15 At the evidence gathering session, participants put forward the following suggestions to improve access to services to communities:

- Missed opportunities by GP’s and other health care professionals to make referrals into the genetics service. Equally, health care professionals may not always understand the levels of risk and exaggerate them or presenting information in a way that is confusing to parents.
- Issues around trust and confidentiality regarding dealing with family information and sharing genetic information, so families need reassurance that information will be handled appropriately. The staff group should be specialists, where possible, and geographically and culturally matched to the population so they are able to provide information, education and training, not only to health professionals, but people in the community in an accessible format.

- Responses around the country to this unmet need for genetic information and services have been patchy, short lived and often alienating with not enough involvement from local communities so there needs to be resources to ensure the longevity of programmes.
- Language can be an issue, particularly when trying to explain complex scientific matters which may not be easily understood.
- The timing of the referral i.e. it would be inappropriate to discuss issues around genetic testing when seeing an acutely unwell child. So, there can be missed opportunities.
- There are also misconceptions and perceptions by families and professionals around what genetic services can offer and professionals may see it more in a research capacity rather than a utility to help the management of the child and family. It is important for the service to be accessible, being delivered by health workers in community hubs and have networks of other service providers to support and facilitate this.
- In terms of reducing health inequalities in infant mortalities across specific communities, interventions that support quality nutrition, an active lifestyle and personal space for self-care are just as important.
- There is also a lack of advice and practical knowledge on providing high quality nutrition and breastfeeding babies to support their development and disease prevention.
- Improve awareness of the services provided to help manage pregnancy from start to end. Further knowledge is also required to improve understanding of pregnancy and positive health choices which are available to ensure the health of mother and baby. More work is also needed with BAME women around preconception to increase their chances of healthy pregnancies, whilst maintaining good mental and physical health, and using stress reduction strategies before becoming pregnant are thought to increase the chance of giving birth to a healthy baby.

6 Conclusions and Recommendations

6.1 In pulling together the strands of this inquiry, the Committee concluded that the stubbornness of Birmingham's high infant mortality rate required a solution that brings together all partners, including those communities who suffer most from infant mortality. The first recommendation is therefore that a multi-agency 'Reducing Infant Mortality in Birmingham' Task Force be established, to oversee a concerted effort by all relevant agencies to achieve a substantial reduction in Infant Mortality in the City.

6.2 The Task Force should include the existing Local Maternity System, Clinical Genetics Service (Birmingham Women's and Children's NHS Foundation Trusts and University Hospitals Birmingham NHS Foundation Trust), including Birmingham Community Healthcare NHS Foundation Trust and commissioners and providers, plus the City Council's Public Health team, along with representatives of the community and voluntary sector, faith groups and elected Members, with a brief to bring the threads of all related interventions together in a concerted and mutually reinforcing programme.

6.3 This should be backed up by an ambitious goal, for example to reduce infant mortality by 50% in Birmingham by 2025 (from 2015 figures, matching the national target) but to go further and aim to eliminate the gap between infant mortality rates in Birmingham and the England average by this date. As Birmingham's rate is higher than most others, it is important that this disproportionally high health inequality is addressed. Key to this is understanding that parents will always have the choice to proceed with affected births, and the focus should be on "unanticipated deaths" so as to avoid moves towards unsafe practices such as encouraging terminations.

6.4 Key to success will be effective grassroots engagement, and so a strong community awareness strand should be developed within the Task Force work programme, led by respected and trusted community groups, local leaders and community influencers engaged in social media. This awareness work should focus on the range of different communities and causal factors that most contribute to preventable infant mortality. Helping people minimise risk including identifying and supporting families facing material hardship and adverse stressful circumstances is also important here. The use of community hubs should be explored. The proposed Public Health community researcher initiative should be part of this work. It is also important to have up to date information on matters such as consanguineous unions, so the task force is asked to assess the current scale and likely future trends of this in Birmingham.

6.5 The work of the Task Force should look at the comprehensive 'four strands' approach put to us by Professor Salway (which refer to unmet need for genetic information and services) and see how these can be adapted for addressing infant mortality more broadly:

- Family-centred enhanced approach to provision of clinical genetic services.
- Educate and equip professionals at the interface with the community (health visitors, midwives and GPs).
- Raise genetic literacy at community level.
- Strengthen access to specialist genomic diagnostic services.

6.6 All this should be co-ordinated by the multi-professional group with active community engagement as outlined above. The Committee agrees that the national proposal for new investment (across Clinical Genetics, Maternity, Health Visiting & Community Genetic Literacy) should be pursued.

6.7 It is also important to approach the contributory factors in a balanced way, avoiding stigmatisation and covering the five elements of the Saving Babies Lives Care Bundle, plus wider environmental factors and consanguineous relationships, ensuring parents and wider families are empowered to make informed decisions to maximise their children's life chances.

Ref	Recommendation	Responsibility	Completion Date
R01	To work with partners to establish a multi-agency 'Reducing Infant Mortality in Birmingham' Task Force to oversee a concerted effort by all relevant agencies to achieve a substantial and reduction in Infant Mortality in the City. The Task Force should include the existing Local Maternity System, Clinical Genetics representation, commissioners and other maternity services such as BCHC, plus BCC Public Health, representatives of the CVS sector and elected Members, with a brief to bring the threads of all related interventions together in a concerted and mutually reinforcing programme. It should also identify and address any factors that may discourage some parents from engaging effectively with their maternity service professionals.	Cabinet Member, Health and Social Care	July 2021
R02	To set an ambitious goal to reduce infant mortality by 50% in Birmingham by 2025 (from 2015 figures, matching the national target) but to then go further and eliminate the gap between infant mortality rates in Birmingham and the England average by this date. This should be accompanied by a delivery plan that can plausibly demonstrate how these targets can be met, identifying both the structural and modifiable factors underlying the inequalities in infant mortality within the City.	Cabinet Member, Health and Social Care	July 2021 October 2021
R03	To develop a strong community awareness strand within the Task Force work programme, led by respected and trusted community groups, local community and faith leaders, and other influencers who are engaged in social media. This should be targeted at improved health behaviours, identifying and supporting families facing material hardship and adverse stressful circumstances, early detection of poor baby growth, and empowering people to make healthy life choices that minimise their infant mortality risk factors. This will include ensuring up to date information is available, including the current scale and likely future trends in consanguineous unions in Birmingham.	Cabinet Member, Health and Social Care	February 2022

Ref	Recommendation	Responsibility	Completion Date
R04	The work of the Task Force should be tasked to consider and adapt the 'four strands' approach put to us by Professor Salway (outlined above) and access any resource and support available nationally.	Cabinet Member, Health and Social Care	March 2022

7 Progress against Implementation and Motion

7.1 To keep the Committee informed of progress on implementing the recommendations within this report, the Executive is recommended to report back on progress periodically.

Ref	Recommendation	Responsibility	Completion Date
R05	Progress towards achievement of these recommendations should be reported to the Health and Social Care Overview and Scrutiny Committee no later than 31 October 2021. Subsequent progress reports will be scheduled by the Committee thereafter, until all recommendations are implemented.	Cabinet Member, Health and Social Care	October 2021 To be confirmed

7.2 Full Council is asked to agree the following motion:

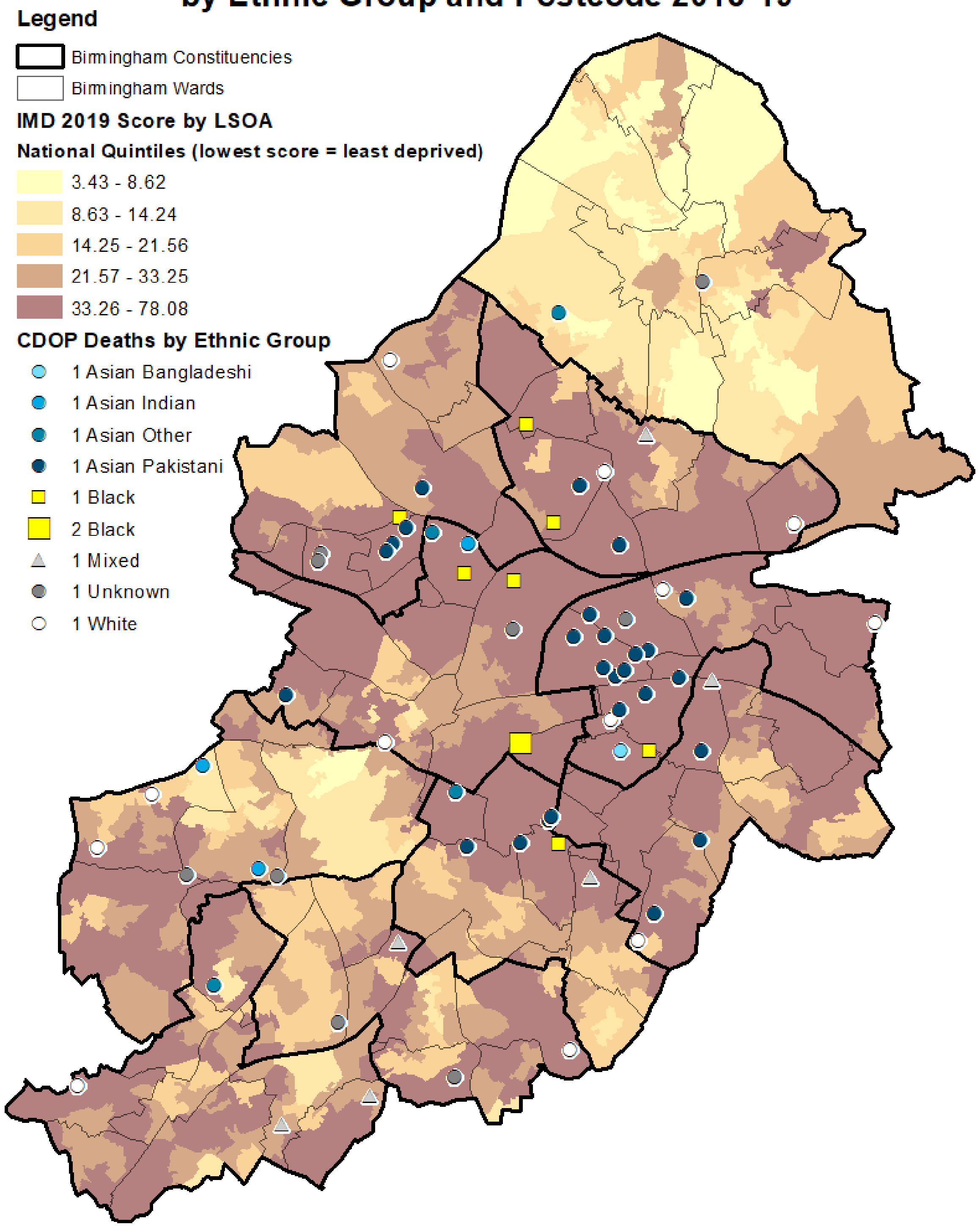
That recommendations R01 to R05 be approved, and that the Executive be requested to pursue their implementation.

Appendix 1 – List of Participants

NAME	ORGANISATION
Angela Brady	Deputy Chief Medical Officer, Birmingham and Solihull Clinical Commissioning Group
Ernestine Diedrick	Senior Commissioning Manager, Maternity, Children and Young People, Birmingham and Solihull Clinical Commissioning Group
Dr Qulsom Fazil	Institute of Applied Health Research, University of Birmingham
Dr Jo Garstang	Designated Doctor for Child Death, Birmingham and Solihull Clinical Commissioning Group
Dr Marion Gibbon	Assistant Director, Partnerships, Insight and Prevention, Public Health
Dr Laura Griffith	Senior Knowledge Transfer Facilitator, Local Knowledge Intelligence Service, Public Health England Midlands
Helen Jenkinson	Chief Nurse, Birmingham and Solihull Clinical Commissioning Group
Richard Kennedy	Medical Director, Birmingham Local Maternity System
Shagufta Khan	Genetic Counsellor, Birmingham Women's and Children's NHS Foundation Trust
Shabana Qureshi	Project Manager, Ashiana Community Project
Professor Sarah Salway	Professor of Public Health, University of Sheffield
Dr Julie Vogt	Consultant Clinical Geneticist, Birmingham Women's and Children's NHS Foundation Trust.

Appendix 2

Number of Deaths Aged Under 1 reported to CDOP by Ethnic Group and Postcode 2018-19



Source: Birmingham Child Death Overview Panel annual report
Produced by Birmingham Public Health Division (2020).
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