Health & Social Care Overview and Scrutiny Committee: Infant Mortality Inquiry

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Written submissions: highlighting the focus of those presenting on Key Lines of Enquiry

1. Infant Mortality in Birmingham: the headline figures

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Our presentation for the Health and Social Care Overview and Scrutiny Committee at Birmingham City Council will be a general overview and introduction to infant mortality rates in Birmingham, using PHE Fingertips, which predominantly draws its data from ONS datasets. We will present the headline figures, positioning both Birmingham and the West Midlands as areas which have statistically significantly worse rates of infant mortality compared to the England average.

Our presentation will include introductions to some key definitions; present where the West Midlands and Birmingham stand in comparison to the national average; investigate the different rates of infant mortality across the different local authorities in the West Midlands and in comparison to its CIPFA nearest neighbours (areas which have the most similar statistical characteristics in terms of socio economic features) across the country.

We will breakdown the infant mortality rate into the neonatal mortality rate (deaths under 28 days), combining neonatal deaths with still births (foetal deaths after 24 weeks gestation), and the post-neonatal mortality rate (deaths occurring after 28 days of age and before one year) to investigate where the raised rates of infant mortality can best be pin pointed.

We then investigate the infant mortality rate in Birmingham over time (since 2000) to look at trends. We then go on to give an overview of some of the risk factors associated with increased rates of infant mortality such as obesity, socio-economic status, low and very low birth weight and smoking in pregnancy.

We then review the key points from our presentation and highlight next steps.

2. Perinatal Mortality

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Perinatal mortality includes neonatal deaths (all live born babies that die within 28 days of life) and all stillbirths (babies that are born without signs of live >/= 24 weeks gestation). Perinatal deaths are analysed and reported through a national audit called MBRRACE. MBRRACE compares systems, STPs and providers and adjusts rates according to confounders and so provides our best available comparator data albeit reported two years in arrears. All rates are generally expressed as a number per thousand births.

The LMS headline figures in April 2019 are PNM: 8.73; Stillbirth: 5.42; Neonatal Deaths: 3.33. The most recent data shows PNM: 6.19; Stillbirth: 4.38; Neonatal Deaths: 1.82. This compares to the England crude rates: EPNM 5.33; SB 3.68; NND 1.65 and Level 3 + neonatal surgery comparator group (stabilised and adjusted): SB 3.76 NND 1.26; EPNM 5.01(MBRRACE 2019, 2017 Birth Cohort). In short our perinatal death rates are significantly higher than national and comparator groups.

The three most important modifiable factors for perinatal mortality are preterm birth, smoking and detection of fetal growth restriction. Pregnancies complicated in these ways also impact on long term outcomes for live babies and our performance falls short of national ambition and best in class.

One of the major contributors to perinatal mortality is ethnicity. Local data is to be presented which demonstrates increased rates in women who are Black and Asian. An important caveat to this data is that the numbers of deaths are small in certain groups. The most important comparison locally is women who are Pakistani, which accounts for the largest group other that British. The graphs to be presented, demonstrate the gap in mortality in the last 18 months. This is also reflected in national data.

Finally, data will be presented on causation, based on detailed case review. For our LMS the leading cause of stillbirths is “placental” meaning reduced placental function which is similar to the national data. The leading cause of neonatal deaths is congenital abnormality closely followed by premature. This is again similar to the national data albeit our rate of NNDs due to congenital abnormalities particularly in births at Birmingham Women’s Hospital (BWH) is significantly higher than the national figure, partly because BWH is a referral centre for pregnancies with baby’s with suspected abnormalities. Consanguinity is a factor but probably not a major cause of perinatal mortality.

The national target is to reduce perinatal miortality by 50% from its 2010 level by 2025. We are tracking in the right direction but our trajectory needs to be sharpened if we are to achieve this goal. The key interventions will be referred to by Ernestine Diedrick in her presentation and the most impactful is the full implementation of the Saving Babies Lives Care Bundle V2 and specifically targeting those groups most at risk.

3. Child Death Overview Panel (CDOP) Data

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Background to CDOP Data

CDOP reviews deaths of live-born children who were normally resident in Birmingham; this excludes stillborn infants at any gestation, terminations of pregnancy and deaths of non-Birmingham resident children in Birmingham hospitals. It includes deaths of infants born before viability and deaths of Birmingham children occurring outside of Birmingham. The CDOP year runs from 01 April to 31 March, and data are analysed by year of review not year of death; there is typically a delay of around 9 months between death and reviews being finalised. CDOP categorises deaths into broad causes, for infants the relevant categories are perinatal or neonatal events; chromosomal, congenital and genetic abnormalities; infection and sudden unexpected and unexplained deaths.

Infant Deaths 2018-2020

In the two years from 01 April 2018 to 31 March 2020, there were 296 deaths reviewed, of these 194 (66%) were of infants less than one year old. 136/194 (70%) occurred in the first month of life. Perinatal or neonatal causes accounted for 104/194 (54%) of infant deaths, and chromosomal, congenital and genetic abnormalities for 64/194 (33%).

42/104 (40%) of perinatal and neonatal deaths occurred in pre-viable infants born at less than 23 weeks gestation, a further 44 (42%) occurred in infants born extremely prematurely between 23 and 28 weeks gestation.

In 50/64 (78%) infant deaths from chromosomal, congenital and genetic the condition was incompatible with life, the remainder died following treatment for the condition.

Ethnicity

According to 2011 Birmingham census data, 14% of the population are of Pakistani ethnicity or heritage. The Pakistani population are over-represented in all child deaths in Birmingham accounting for 34% of total child deaths, 45% of chromosomal, congenital and genetic deaths and 21% of perinatal and neonatal deaths.

4. Exploring National policy/guidance and NHS initiatives relevant to reducing infant mortality

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It is important that the context for the mortality of babies and infants is clear. In health we monitor more than only infant deaths. The definitions we use are set out below: -

Late fetal loss - baby delivered between 22 weeks +0 days and 23 weeks +6 days gestational age showing no signs of life, irrespective of when the death occurred.

Stillbirth - baby born after 24 weeks with no signs of life

Early Neonatal Death -baby of any gestation born with signs of life dying before 7 days

Late Neonatal Death - baby of any gestation born with signs of life dying between 7-28 days

Infant Death – baby dying between 28 days-1 year

National policy / guidance

Many factors can influence the outcome of a birth including: -

The lifestyle of parents, genetic factors, underlying health conditions or health conditions that are brought about by pregnancy.

Better Births: Improving outcomes of maternity services in England – A Five Year Forward View for Maternity Care

In March 2015 Simon Stevens, who was then the Chief Executive of NHS England, commissioned a major review of maternity services. As a result Better Births was published which sets out the vision for the planning, design and safe delivery of maternity services; how women, babies and families will be able to get the type of care they want; and how staff will be supported to deliver such care.

The report includes a set of recommendations for action: -

- Personalised care
- Continuity of Carer
- Safer care
- Better postnatal and perinatal mental health care
- Multi-professional working
- Working across boundaries
- A payment system

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

The guidance sets out five elements of care that are widely recognised as evidenced-based and / or nest 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

The NHS Long Term Plan was first published in January 2019 by NHS England in response to concerns about funding, staffing and inequalities to facilitate improved outcomes.

The LTP included some specific measures for maternity / neonatal / mental health services, CCGs and regional NHSE/I teams: -

- Implementing the Savings 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

NHS initiatives relevant to this issue

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

- Improving Neonatal Critical Care
- Targeted and enhanced continuity of carer
- Improved and increasing access to Specialist Perinatal Mental Health services
- Targeted services to help to decrease maternal smoking
- Improving postnatal physiotherapy services
- The LTP sets out plans to establish multidisciplinary pelvic health clinics and pathways to ante-natal and post-natal pelvic health focussing mainly on physiotherapy.
- Improve infant feeding programmes
- Risk assessment, prevention and surveillance of pregnancies at risk of fetal growth restriction (FGR)
- Raising awareness of reduced fetal movement (RFM)
- Effective fetal monitoring during labour
- Reducing pre-term birth

5. Reviewing the data/analysis on the impact of consanguinity locally and of the current service provision in terms of clinical genetics, genetic testing and counselling for families

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Birmingham has consistently high infant mortality rates, almost double the national average in England and Wales. In a 2016 report by Public Health England for the period 2012 to 2014, infant mortality in England was an average of 4.0 per 1,000 births. In the West Midlands, for the infant mortality rate was 5.5 ranging from 3.3 per 1,000 births in Shropshire to significantly a higher rate of 7.2 per 1,000 births in Birmingham. There were 1,178 infant deaths in the West Midlands between 2012 and 2014 equating to about 393 infant deaths annually with 80% occurring in the neonatal period compared with 70% nationally. This is important as mortality in infancy is used as a proxy for the overall health of a population and can also reflect the quality of maternity services (Royal College of Paediatrics and Child Health National Children's Bureau, 2014).

Asian or Asian British are the second largest ethnic group in the West Midlands, making up 13% of the population in the West Midlands. Asian or Asian British account for around 25% of the population of Birmingham (Infant and Perinatal Mortality in the West Midlands, Public Health England 2016). Socioeconomic factors and prematurity are major factors in the perinatal and infant morbidity and mortality, however it is also recognised that the contribution of genetic conditions is also significant. Congenital abnormalities occur in 2-3% of pregnancies however this risk is doubled in consanguineous couples to around 6% (Sheridan et al., 2013).

The West Midlands Regional Genetics Service is one of the largest centres nationally and has a longstanding interest in the impact of genetic diseases in the British Pakistani community (Bundey *et al.,* 1990, Bundey et al., 1993 and Hutchesson et al.,1998). In 2010 the estimated the prevalence of the West Midlands consanguineous unions was around

16% but around 50% in Pakistani mothers, Perinatal Episode Electronic Record (PEER). Mortality from congenital anomalies was also statistically significantly higher in Pakistani (OR 3.0) and Bangladeshi (OR 2.1) mothers. Linking mortality to clinical genetic cases, rates were highest in deaths to Pakistani and Indian mothers, which could suggest a higher rate of mortality due to genetic causes in these groups. In a Birmingham study period from 2006–2010, Tonks et al., 2014 reported that Autosomal recessive (AR) conditions were the cause of around 10% of stillbirths and infant deaths and over a third of deaths from congenital anomalies. Of the Pakistani births, AR conditions were present in around a quarter of deaths and almost two thirds of deaths from congenital anomaly. Mortality from AR disorders was also higher in the Pakistani group. Overall it was concluded that deaths from AR conditions contribute to the excess of stillbirth and infant mortality seen in Pakistani and Bangladeshi births in Birmingham.

Strategies have been developed in the West Midlands to improve access for the Pakistani population encourage appropriate and early referral of patients and families at risk of genetic disorders. This has included the permanent employment of specialist Asian Genetic Counsellors with expertise and knowledge of the cultural and religious issues. The Enhanced Genetics Services Project was established to address excess infant and childhood morbidity in Birmingham linked to AR conditions identified by the former Heart of Birmingham Primary Care Trust (HoBtPCT) to be contributing to the excess infant mortality rate in Birmingham, in November 2008. It ran over three years from December 2008 - December 2011 and aimed to improve the detection of AR diseases by developing genetic laboratory testing, identifying and offering relatives carrier testing for these conditions and to increase specialist Genetic Counsellor support for Pakistani ethnic minority families. A major thread was community and primary care involvement to enhance awareness of those that may benefit from clinical genetics input and tailored educational resources for professionals and families.

Having worked with minority ethnic families for over twenty years, there has been a huge change in the understanding of the benefits of genetic services and education. It is important for our service build on previous initiatives and to evolve to encompass the new developments and opportunities afforded by genomic technologies for this population.

Practical experience of offering genetic investigations and extended family testing to consanguineous families in the West Midlands has highlighted important issues to be considered in developing more comprehensive services nationally, and have education and training implications. Families may be seen in the primary or care setting, they can present to any specialty, or they may self-refer because of the awareness in the community. However families may decline referral to the genetics service for a range of reasons including concerns around trust and confidentiality, the timing of the referral for example in an acutely unwell child, misconceptions or perceived utility by patients and professionals, and the practicalities and limitations of genetic counselling and testing. Accessibility may also be affected by the implementation of automated referral and booking processes particularly for those may not have English as a first language and the practical difficulties attending multiple appointments particularly with disabled children. A lower uptake of prenatal testing and services and an increased risk of perinatal death and fetal recurrence has recently been observed in consanguineous pregnancies in Birmingham by Mone et al., 2020.

Measures which ameliorate these difficulties for families may include the matching of counsellors to population at risk, both geographically and culturally where possible, and a shift in emphasis from consanguinity to rare AR disease. Opportunistic testing offered for other genetic conditions depending on familial or ancestry factors together with appropriate genetic counselling may enhance efficacy. In addition, broader and more accessible

preconception and prenatal counselling coupled with advances in the availability of prenatal testing and other pregnancy options for couples may enhance uptake of genetics services. More work is needed to looks at the acceptability of genetic testing, the timing and demand, as well as the level of risk at which testing is required. Data should be collated about how the genetic testing information is used and the cost effectiveness.

We work closely with the paediatric neurometobolic team on the Birmingham Children's Hospital site. This is crucial as the majority of patients attending this service are of South Asian descent. An early study in the West Midlands by Hutchesson et al.,1998 showed a tenfold higher incidence of rare inherited metabolic disorders among Pakistani children compared to white children and life-limiting condition were over-represented by 1.8 (Fraser et al, 2012). Although individually rare, inherited metabolic disorders are important as they are usually severe, often life limiting conditions with a high morbidity and mortality in childhood, requiring frequent and prolonged medical, social and educational resources. We are fully integrated into the mainstream service and are able to provide support around family history interpretation, diagnosis and prenatal testing as well as carrier testing of the wider family. This also provides a mutually extension of our educational opportunities with our paediatric colleagues. We are increasingly aware that as well as the complex issues around consanguinity, these families are also genetically complex, thus it is important that an appropriate time is allocated to these consultations. Over the coming years, more consistent and continuous work needs to be undertaken to build a robust network to fully incorporate other main stream specialities.

The West Midlands Regional Clinical Genetics Service has tried to improve its services to reach out to these families and over time the hard work of establishing good relationships, community involvement, funded projects, outreach clinics, focus groups, educational work at all levels both with families and professionals have all helped to gain the trust of families, leading to a significant increase in referrals. In order to monitor the provision of services and the effects of service developments on ethnic minorities, accurate recording and retrieval of ethnicity and data collated on referral numbers and outcomes is critical. It will also be important for the development of our local projects and the implementation of national initiatives, to have clinical staff with the appropriate skills, community support and resources, to ensure that this can be equitably provided and benefit the disadvantaged communities in greatest need to prevent widening the inequalities in health

6. Close relative marriage and genetic risk: addressing unmet need for information and services in Birmingham

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What are the benefits and risks associated with close relative marriage?

- Close relative (consanguineous) marriage is widely practised globally with recognised benefits to couples and their families. This marriage pattern has often been stigmatised in the UK.
- Marriage between close blood relatives is linked to an increased risk of genetic disorders, particularly single gene (autosomal) recessive genetic disorders.
- Population risk of any congenital anomaly is around 6% among cousin couples compared to around 3% among unrelated individuals.[i] This increased risk has often been exaggerated.

- Risk clusters in families. Around 90% of couples who are close blood relatives will not have affected children.[ii] Other families experience repeated affected births and infant deaths.

What has been done to support families and communities?

- Improving understanding about recessive genetic inheritance can be empowering for families and reduce unexpected, affected births. However, inadequate access to culturally sensitive information and services compromises informed decisions around marriage and childbearing.
- Evidence indicates that inconsistent referral mechanisms, and sub-optimal encounters within genetic services, leave families poorly supported in many localities across the country.
- In Birmingham, the Enhanced Genetics Services Project (2009-12) made some good progress, but this was not sustained. Promising models have also been developed elsewhere.
- Until recently, a lack of national policy and resources has resulted in variable (and in some cases harmful) local initiatives. Opportunities to share knowledge and practice have been few.
- Between 2018-19 a structured process of consensus building involving a wide range of professionals and members of the public led to agreed principles for action on this issue.[iii]
- Establishment of a National Steering Group (SG) followed with representation from: PHE; NHSE/I; National Clinical Reference Group for Genomics; Clinical Genetics; Local Authority public health; Midwifery; Health Visiting; General Practice; Neonatology; Paediatrics; CDOP; VCF sector; and public/patient stakeholders. Birmingham is represented on this Steering Group.

7. Liaise with community leaders and with local councillors to agree how to explore the public/community perspective and service needs with a culturally sensitive approach.

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The presentation will explore ways that we can engage with our local communities through research to understand their areas of concern and service needs better. Too often diverse communities are not engaged in either quantitative or qualitative research as it is deemed too difficult or they are seen as "hard to reach".

Accepting that our communities are knowledge experts of their own experience and have in-depth understanding of their own health, we can begin to draw upon this knowledge to better develop services. Tapping into this resource through the knowledge of local community leaders, local councillors and the communities itself is crucial.

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[i] Sheridan et al. (2013) *Lancet*. https://doi.org/10.1016/S0140-6736(13)61132-0
[ii] Modell and Darr (2002). *Nat Rev Genet*. https://doi.org/10.1038/nrg754
[iii] Salway et al. (2019) *BMJ Open*. https://bmjopen.bmj.com/content/9/7/e028928

The presentation will create a space for a dialogue between all the players to agree a way forward for better engagement with the diverse communities of Birmingham. Empowering individuals in communities as researchers is well established as good practice in participatory community research. The presentation will end with a discussion with those present on the way forward for community engagement.

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