BIRMINGHAM CITY COUNCIL

HEALTH AND SOCIAL CARE OVERVIEW AND SCRUTINY COMMITTEE

TUESDAY, 08 DECEMBER 2020 AT 14:00 HOURS
IN ON-LINE MEETING, MICROSOFT TEAMS

A G E N D A

1 **NOTICE OF RECORDING/WEBCAST**

The Chairman to advise/meeting to note that this meeting will be webcast for live or subsequent broadcast via the Council's Internet site (www.civico.net/birmingham) and that members of the press/public may record and take photographs except where there are confidential or exempt items.

2 **APOLOGIES**

To receive any apologies.

3 **DECLARATIONS OF INTERESTS**

Members are reminded that they must declare all relevant pecuniary and non pecuniary interests arising from any business to be discussed at this meeting. If a disclosable pecuniary interest is declared a Member must not speak or take part in that agenda item. Any declarations will be recorded in the minutes of the meeting.

4 **ACTION NOTES/ISSUES ARISING** **3 - 8**

To confirm the action notes of the meeting held on 17th November 2020.
(1400-1405hrs)

5 **PUBLIC HEALTH UPDATE**

Dr Justin Varney, Director of Public Health
(1405-1420hrs)

6 **INFANT MORTALITY INQUIRY - EVIDENCE GATHERING** **9 - 20**

Please see attached Session Plan for list of contributors.
(1420-1700hrs)

21 - 30

7 **WORK PROGRAMME - NOVEMBER (UPDATED)**

For discussion.

8 **REQUEST(S) FOR CALL IN/COUNCILLOR CALL FOR ACTION/PETITIONS RECEIVED (IF ANY)**

To consider any request for call in/councillor call for action/petitions (if received).

9 **OTHER URGENT BUSINESS**

To consider any items of business by reason of special circumstances (to be specified) that in the opinion of the Chairman are matters of urgency.

10 **AUTHORITY TO CHAIRMAN AND OFFICERS**

Chairman to move:-

'In an urgent situation between meetings, the Chairman jointly with the relevant Chief Officer has authority to act on behalf of the Committee'.

BIRMINGHAM CITY COUNCIL

HEALTH AND SOCIAL CARE O&S COMMITTEE

1400 hours on 17th November 2020, via Microsoft Teams – Actions

Present:

Councillor Rob Pocock (Chair), Mick Brown, Debbie Clancy, Diane Donaldson, Peter Fowler, Mohammed Idrees, Ziaul Islam and Paul Tilsley.

Also Present:

Karl Beese, Commissioning Manager, Adults Public Health.

Dr Marion Gibbon, Assistant Director, Partnerships, Insight and Prevention, Public Health.

Elizabeth Griffiths, Assistant Director of Public Health.

Kate Homer, Birmingham Service Manager, Aquarius.

Gail Sadler, Scrutiny Officer.

Sian Warmer, Deputy Director, Change, Grow, Live (CGL).

Emma Williamson, Head of Scrutiny Services.

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1. NOTICE OF RECORDING

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The whole of the meeting would be filmed except where there were confidential or exempt items.

2. DECLARATIONS OF INTEREST

None.

3. APOLOGIES

None.

4. ACTION NOTES/ISSUES ARISING

The action notes for the meeting held on 6th October 2020 were agreed.

Day Opportunities Proposals Consultation: Outcome of NDTI Report Investigation

On behalf of the committee, the Chair sent a letter to Catherine Parkinson, Acting City Solicitor, on 14th October expressing the concerns raised. A response was

received and circulated to the committee on 30th October and a copy of the NDTI report was published on CMIS on 30th October and was attached to the agenda item of the previous meeting on 6th October.

Forward Thinking Birmingham

Information on Chronic Fatigue Syndrome pathways was circulated to members on 17th November 2020.

Adult Social Care Performance Monitoring – April-June 2020

Maria Gavin confirmed that, due to Covid-19, the service user survey is not being conducted this year.

A cross-party informal meeting to discuss the current status of performance indicators and reporting timelines has been arranged for 24th November 2020.

Work Programme

- The next Birmingham/Sandwell JHOSC will take place at 2.00pm on Thursday 19th November 2020.
- The disproportionate impact on health of people living in exempt accommodation and house of multiple occupancy (HMOs) will be included as part of an inquiry into exempt accommodation being undertaken by the Coordinating O&S Committee.
- An informal briefing took place on 12th November to discuss the Adult Social Care Vision and Strategy.

5. PUBLIC HEALTH UPDATE

Elizabeth Griffiths (Assistant Director of Public Health) set out the key current data for Birmingham and the West Midlands regarding case rates and demographics including ethnicity; the breakdown of cases into Wards; testing uptake; death data; Community Champions and testing the asymptomatic population.

In discussion, and in response to Members' questions, the following were among the main points raised:

- In response to a question regarding how people could sign up to be Community Champions, Elizabeth said she would provide the link to the BCC website.
- The national NHS team are leading on communication for the vaccine but there is a role for public health and partners around myth-busting and dispelling mis-information.
- Have data on the uptake of vaccinations across the city at a GP level, which does not equate to Ward level, but that information can be shared with NHS colleagues as a useful insight in planning for the vaccine roll-out.
- Hospital admissions are closely monitored and there is a detailed plan in place should the Nightingale Hospital be needed.

- A lot of communications around Covid safe measures are being targeted at areas where high rates of infection are being observed. Also, local action is required working with partners and GPs and wide stakeholder groups to enforce the message.
- Social mixing between households is one of the largest causes of infection i.e. if one person has the infection it is quite likely that others residing in the same household will also become infected.
- Further information was required regarding non-porcine vaccination to reassure communities.
- Notices should be displayed at hospitals to encourage the public to dispose of PPE, in particular face masks, in a responsible manner.

RESOLVED:

Elizabeth to clarify:-

- The area 'West Midlands' data covers.
- Public Health England definitions relating to case breakdown by ethnicity to identify if the Bangladeshi population is included in 'Asian Other'.
- The link for information on becoming a Community Champion:-

  https://www.birmingham.gov.uk/info/50231/coronavirus_covid-19/2256/covid-19_champions/3
- Contact Birmingham and Solihull CCG to make enquiries about a non-porcine vaccination.
- Feedback to NHS colleagues suggestion about discarded PPE.

A further update to the next meeting including any additional information on the Covid-19 vaccination roll out programme.

6. SUBSTANCE MISUSE: BIRMINGHAM'S ADULT AND YOUNG PEOPLES TREATMENT SERVICES

Karl Beese (Commissioning Manager, Adults Public Health) presented a brief overview of the service from a commissioning perspective including the key commissioning intentions of the CGL contract including supporting families during the recovery process and reducing any associated harm that could be caused to children. The young people's substance misuse service is delivered by Aquarius. Sian Warmer (Deputy Director, CGL) and Kate Homer (Birmingham Service Manager, Aquarius) respectively set out how their services had adapted to be more accessible in order too support clients through the pandemic.

In discussion, and in response to Members' questions, the following were among the main points raised:

- Clarification was sought about the 2-year extension to the CGL contract and Aquarius contract and associated funding.

- Looking to further extend the CGL contract for an additional year to the end of February 2023 in order to mitigate against delays to the re-procurement timeline as a result of Covid-19. There is also an option to extend Aquarius' contract to come into line with the re-procurement of the adult's service.
- More information was requested about the success story of the Home Detox Programme. Previously, clients would go to the service to take part in a therapeutic programme in order to detox. Now clients can choose whether they want to do that or take part via Zoom or Teams etc.
- For clients with substance misuse and a mental health issue, one of the main barriers to working with the Birmingham and Solihull Mental Health Trust is around data sharing and where dual consent is required. Discussions have taken place with BSMHT to explore potential possibilities to overcome this e.g. secondment opportunities and co-location.
- Aquarius work in partnership with Forward Thinking Birmingham so every young person who enters the service is screened for their mental health. There is a Consultant Psychiatrist on hand who can look at what support may be required.
- There could be a number of factors why there are more substance misuse clients in particular Wards including deprivation, unemployment etc.
- There are 4 CGL Hubs across the city in the north, central west, east and south. Also, specialist venues such as the Women's and Families Team and Criminal Justice Team. It was suggested that closer engagement of local Councillors in the vicinity of these hubs would help them embed them within local communities.
- Aquarius has a Head Office in Edgbaston but is essentially an outreach service with appointments taking place in schools, Youth Offending offices and home visits.
- Aquarius is working in partnership with the Birmingham Children's Trust and looking to partners to be involved in offering a multi-agency approach to support to families in areas of the city where there are a large number of issues around child protection, children in need cases etc.

RESOLVED:

- Councillor Debbie Clancy to be sent information regarding the ring-fenced public health budget.
- Karl Beese to circulate information on the Home Detox Programme and location of the CGL Hubs.
- Next year, during the commissioning cycle, the committee could look at the joint commissioning of a substance misuse service for adults and young people including mental health support.

7. PROGRESS REPORT ON IMPLEMENTATION: TACKLING PERIOD POVERTY AND RAISING PERIOD AWARENESS

Dr Marion Gibbon (Assistant Director, Partnerships, Insight and Prevention, Public Health) introduced the report and explained the background to the inquiry. Furthermore, she explained that, due to Covid-19, colleagues had been unable to take some of the work forward and asked that progress against those recommendations be deferred to a later date.

In discussion, and in response to Members' questions, the following were among the main points raised:

- Evidence was sought in relation to whether the increased uptake at food banks had led to period products being distributed more widely.
- In order to tackle the stigma attached to periods there needs to be more education in communities. Public Health are looking to employ Community Researchers to conduct a piece of work on infant mortality. Once the researchers are trained there would be the potential to utilise them to look into some of the issues faced by different communities going forward.
- It was felt that the wording of recommendation 2 should have been expanded to include stigma in communities. Therefore, it was suggested that when the committee receives the next progress report it would also be interested to receive evidence of progress "in the wider communities".

RESOLVED: -

The following assessments were agreed:-

R01 – Achieved

R02 – Not Achieved (Obstacle)

R03 – Not Achieved (Obstacle)

R04 – Not Achieved

R05 – Not Achieved

R06 – In Progress

Marion to contact voluntarily organisations colleagues about the dissemination of period products at food banks.

That a further update report is presented in July 2021.

8. WORK PROGRAMME – NOVEMBER 2020

- The Adult Social Care and Public Health budgets for the coming year was scheduled on the work programme for the December meeting. This will not be available until the 26th January 2021 meeting.
- The December meeting will be an in-depth evidence gathering session for the Infant Mortality review. A draft programme of key lines of enquiry/presenters will be circulated in advance of the meeting in order for members to identify any initial questions that they would like answered.

Those questions should be emailed to the Scrutiny Officer who will forward them to the contributors to prepare a response. At the meeting itself there will be a very limited amount of time for questions. Therefore, any unanswered questions from the December meeting will be addressed at the January meeting.

- Councillor Debbie Clancy to receive a copy of the Terms of Reference and scoping paper for the Infant Mortality review.
- The Coordinating O&S Committee will be undertaking a review of Exempt Accommodation which has cross-cutting themes which includes health. If that review does not address the issues of homelessness and health the committee will request an update report in the new municipal year.

9. REQUEST(S) FOR CALL IN/COUNCILLOR CALL FOR ACTION/PETITIONS RECEIVED (IF ANY)

None.

10. OTHER URGENT BUSINESS

None.

11. AUTHORITY TO CHAIRMAN AND OFFICERS

RESOLVED: -

That in an urgent situation between meetings the Chair, jointly with the relevant Chief Officer, has authority to act on behalf of the Committee.

The meeting ended at 1600 hours.

Health & Social Care O&S Committee
Infant Mortality

Session 1: 8th December 2020 – 1420-1700hrs
Via Microsoft Teams

Purpose: The key question and aim of the inquiry is to focus on options for improving the advice and support to families at the pre-conception stage, particularly amongst communities with the highest prevalence of infant mortality. The inquiry aims to add value by acting as a stimulus to possible interventions which could improve the infant mortality rate in Birmingham.

Meeting type: Public meeting live-streamed via the internet.

Time	
1420-1425	Welcome & introduction by Chair, Councillor Rob Pocock
	KEY LINE OF ENQUIRY / PRESENTERS
1425-1445	Establish the existing data on the infant mortality trend in Birmingham and how that compares to the England trend and other core/comparator cities. **Marion Gibbon** – Assistant Director of Public Health, Birmingham City Council **Laura Griffith** – Public Health England
1445-1505	Undertake an in-depth analysis to reveal the multiple causes of infant mortality and the geographical/demographic variations across the city that highlight the extent of this health inequality. **Richard Kennedy** – Medical Director, Birmingham Local Maternity System **Jo Garstang** – Designated Doctor for Child Death, Birmingham Community Healthcare NHS Trust
1505-1525	Explore national policy/guidance and NHS initiatives relevant to this issue. **Ernestine Diedrick** – Senior Commissioning Manager, Children's and Maternity Commissioning Team, Birmingham and Solihull CCG Supported by:- **Angela Brady** – Deputy Chief Medical Officer, Birmingham and Solihull CCG **Helen Jenkinson** – Chief Nurse, Birmingham and Solihull CCG **Di Rhoden** – Associate Director of Nursing – Safeguarding, Birmingham and Solihull CCG **Dr Richard Mendelsohn** – Chief Medical Officer, Birmingham and Solihull CCG
1525-1545	Review 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. **Julie Vogt** – Consultant Clinical Geneticist, Birmingham Women's and Children's NHS Foundation Trust

1545-1605	Liaise with other regions in England such as Bradford, Sheffield and Tower Hamlets, where there is a high prevalence of consanguinity which have implemented an approach to respond to the increased genetic risk associated with consanguineous marriage. **Professor Sarah Salway** – Professor of Public Health, University of Sheffield.
1605-1625	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. **Dr Qulsom Fazil** – University of Birmingham
1625-1655	Identify possible interventions which could be undertaken, with a focus on pre-conception advice and support, in order to improve the infant mortality rate in Birmingham and underpin the development of a Birmingham Infant Mortality Strategy. Research into infant mortality and consanguinity with a culturally sensitive approach and train local people as community researchers. **Marion Gibbon** – Assistant Director of Public Health, Birmingham City Council
1655-1700	Closing Statement from Councillor Rob Pocock

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

8th December 2020

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

1. Infant Mortality in Birmingham: the headline figures

Dr Marion Gibbon: Interim Assistant Director of Public Health, Birmingham City Council
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Dr Laura Griffith: Senior Knowledge Transfer Facilitator, Local Knowledge and Intelligence Service, Public Health England (PHE)
laura.griffith@phe.gov.uk

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

Richard Kennedy: Medical Director, Birmingham and Solihull Local Maternity System (BSoL LMS)
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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

Dr Joanna Garstang: Designated Doctor for Child Death, Birmingham and Solihull (BSol) Clinical Commissioning Group (CCG)
joanna.garstang@nhs.net

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

Ernestine Diedrick: Senior Commissioning Manager, Children's and Maternity Commissioning Team, NHS Birmingham and Solihull (BSol) Clinical Commissioning Group (CCG)
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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

Julie Vogt: Consultant Clinical Geneticist, Birmingham Women's and Children's NHS Foundation Trust
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Mrs Shagufta Khan: Genetic Counsellor, Birmingham Women's and Children's NHS Foundation Trust
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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

Sarah Salway: Professor of Public Health, University of Sheffield
s.salway@sheffield.ac.uk

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.

Dr Qulsom Fazil: University of Birmingham
Q.A.Fazil@bham.ac.uk

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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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).

Health & Social Care O&S Committee: Work Programme 2020/21

Chair:	Cllr Rob Pocock
Deputy Chair:	Cllr Mick Brown
Committee Members:	Cllrs Debbie Clancy, Diane Donaldson, Peter Fowler, Mohammed Idrees, Ziaul Islam and Paul Tilsley
Officer Support:	Scrutiny Officer: Gail Sadler (303 1901) / Emma Williamson (464 6870) Committee Manager: Errol Wilson (675 0955)

1 Meeting Schedule

Date	Agenda Item	Officer Contact / Attendees
16th June 2020 1400 hours (via Microsoft Teams) Report Deadline: 4th June	COVID-19 UPDATE • Cabinet Member for Health and Social Care • Implementation of Track and Trace in Birmingham • West Midlands Care Association • Healthwatch Birmingham	Councillor Paulette Hamilton; Dr Justin Varney/Elizabeth Griffiths; Debbie Le Quesne/Alison Malik; Andy Cave.
21st July 2020 1400 hours (via Microsoft Teams) Report Deadline: 9th July	COVID-19 UPDATE 2019/20 End of Year Adult Social Care Performance Monitoring Report	Maria Gavin, Assistant Director, Quality and Improvement, Adult Social Care.
1st September 2020 1400 hours (via Microsoft Teams) Report Deadline: 20th August	Black Country and West Birmingham CCGs Future Commissioning Intentions Public Health Update • Triple Zero Strategy – draft presentation on 'Substance Misuse Data' previously noted at July meeting. • Covid-19 Update Healthwatch Birmingham Annual Report	Pip Mayo, Managing Director for West Birmingham, SWB CCG Dr Justin Varney, Director of Public Health / Elizabeth Griffiths, Assistant Director, Public Health. Andy Cave, Chief Executive Officer, Healthwatch Birmingham

Date	Agenda Item	Officer Contact / Attendees
1st September 2020 1000 hours Committee Rooms 3 & 4 Report Deadline: 20th August	INFORMAL SESSION Work Programme 2020/21:- • Engaging with Citizens and Service Users – Discussion Paper • Public Health • Adult Social Care • Healthwatch Birmingham	Councillor Rob Pocock June Marshall, Citizen Involvement Manager Dr Justin Varney, Director of Public Health Andy Cave, Chief Executive Officer, Healthwatch Birmingham
6th October 2020 1400 hours Via Microsoft Teams Report Deadline: 24th September	Day Opportunities Proposals Consultation: Outcome of NDTi Report Investigation Public Health Update Forward Thinking Birmingham Adult Social Care Performance Monitoring	Professor Graeme Betts, Director of Adult Social Care Dr Justin Varney, Director of Public Health Elaine Kirwan, Deputy Chief Nurse, Mental Health Services/FTB Maria Gavin, Assistant Director Quality and Improvement, Adult Social Care
17th November 2020 1400 hours Via Microsoft Teams Report Deadline: 5th November	Public Health Update Birmingham Substance Misuse Recovery System (CGL) Period Poverty and Raising Period Awareness - Tracking Report	Dr Justin Varney, Director of Public Health Saba Rai, Interim Lead, Universal and Prevention Services, Adult Social Care and Health; Karl Beese, Commissioning Manager, Adult Public Health Services. Councillor Paulette Hamilton, Cabinet Member for Health & Social Care
8th December 2020 1400 hours Via Microsoft Teams Report Deadline: 26th November	Public Health Update Infant Mortality – Evidence Gathering	Dr Justin Varney, Director of Public Health

Date	Agenda Item	Officer Contact / Attendees
26th January 2021 1000 hours Via Microsoft Teams Report Deadline: 14th January	Public Health Update Budget Consultation:- • Adult Social Care • Public Health Birmingham Safeguarding Adults Board Annual Report Adult Social Care Performance Monitoring Infant Mortality – Evidence Gathering	Dr Justin Varney, Director of Public Health Cabinet Member for Health & Social Care; Professor Graeme Betts, Director of Adult Social Care. Dr Justin Varney, Director of Public Health. Cherry Dale, Independent Chair of the Birmingham Safeguarding Adults Board. Maria Gavin, Assistant Director Quality and Improvement, Adult Social Care
16th February 2021 1000 hours Committee Rooms 3 & 4 Report Deadline: 4th February	Public Health Update Birmingham Sexual Health Services – Umbrella (UHB) Direct Payments Preparation for Adulthood	Dr Justin Varney, Director of Public Health Saba Rai, Interim Lead, Universal and Prevention Services, Adult Social Care and Health; Karl Beese, Commissioning Manager, Adult Public Health Services. John Williams, Assistant Director, Adult Social Care / June Marshall, Citizen Involvement Manager, Adult Social Care John Williams, Assistant Director, Adult Social Care / Dionne McAndrews, Assistant Director, Birmingham Children's Trust
23rd March 2021 1000 hours Committee Rooms 3 & 4 Report Deadline:11th March	Public Health Update Health Inequalities in Birmingham	Dr Justin Varney, Director of Public Health Councillor John Cotton, Cabinet Member for Social Inclusion, Community Safety & Equalities; Andy Cave, Chief Executive Officer, Healthwatch Birmingham

Date	Agenda Item	Officer Contact / Attendees
23rd March 2021 1000 hours Committee Rooms 3 & 4 Report Deadline:11th March	Delayed Transfers of Care / Early Intervention Update Adult Social Care Performance Monitoring	Balwinder Kaur, Assistant Director, Adult Social Care / June Marshall, Citizen Involvement Manager, Adult Social Care Maria Gavin, Assistant Director Quality and Improvement, Adult Social Care
27th April 2021 1000 hours Committee Rooms 3 & 4 Report Deadline:15th April	Cabinet Member for Health and Social Care - Public Health Update. Birmingham Dementia Strategy Refresh Black Country and West Birmingham CCGs Commissioning Arrangements - Update	Councillor Paulette Hamilton, Cabinet Member for Health & Social Care; Dr Justin Varney, Director of Public Health. Rhona Woosey, Head of Integration and Long Term Conditions, BSol CCG Pip Mayo, Managing Director for West Birmingham, SWB CCG

2 Work to be programmed/Further work areas of interest

2.1 The following items could be scheduled into the work programme if members wish to investigate further:

- Adult Social Care Commissioning Strategy (Graeme Betts)
- Ageing Well Programme (Graeme Betts)
- Shared Lives Service Re-Design (Graeme Betts)
- Immunisation and Screening
- Childhood Obesity – Stocktake Report – Dr Justin Varney
- Neighbourhood Working (Joint presentation BSol CCG/BCC)
- Adult Social Care – Self Funders
- Triple Zero Strategy – Outcome of Consultation – Elizabeth Griffiths
- Covid-19 – Update from West Midlands Care Association
- Birmingham Community Healthcare – Public Health Contracts – Elizabeth Griffiths
- Integrated Care Systems (Rachel O'Connor, Assistant Chief Executive of the STP)
- Annual Review of the Adult Social Care Vision & Delivery Plan 2020-2024
- Homeless Health Update
- Period Poverty Tracking Report (July 2021)

3 Chair & Committee Visits

Date	Organisation	Contact

4 Inquiry

Title:	Infant Mortality
Lead Member:	Councillor Rob Pocock
Inquiry Members:	Councillors Mick Brown, Debbie Clancy, Diane Donaldson, Peter Fowler, Mohammed Idrees, Ziaul Islam and Paul Tilsley
Evidence Gathering:	8th December 2020 and 26th January 2021
Drafting of Report:	February 2021
Report to Council:	13th April 2021

5 Councillor Call for Action requests

6 Forward Plan for Cabinet Decisions

The following decisions, extracted from the Cabinet Office Forward Plan of Decisions, are likely to be relevant to the Health and Social Care O&S Committee's remit. **Please note this is correct at the time of publication.**

Reference	Title	Portfolio	Proposed Date of Decision
005730/2018	Sport and Leisure Transformation - Wellbeing Service	Health & Social Care	29 June 21
007924/2020	Rough Sleeping Addendum and Action Plan 2020-23, Homelessness Prevention Strategy - Consultation Outcome	Health & Social Care	15 Dec 20
008119/2020	Rough Sleeping Drug and Alcohol Treatment Grant Funding Submission	Health & Social Care	10 Nov 20
008003/2020	Refresh of Adult Social Care Vision and Strategy Delivery Plan	Health & Social Care	15 Dec 20

7 Joint Birmingham & Sandwell Scrutiny Committee Work

Members	Cllrs Rob Pocock, Mick Brown, Debbie Clancy, Ziaul Islam and Paul Tilsley	
Meeting Date	**Key Topics**	**Contacts**
19th November 2020 @ 2.00pm Sandwell	Sandwell and West Birmingham CCG Primary Care Networks Update	Carla Evans, Head of Primary Care; Leon Mallett, Commissioning Transformation Manager
	Midland Metropolitan Hospital Update	David Carruthers, Acting Chief Executive, Sandwell & West Birmingham Hospitals NHS Trust
	Black Country Acute Hospital NHS Trusts Hospital Group Model	Jayne Salter-Scott; Head of Engagement and Communications, SWB CCG.
11th February 2021 @ 2.00pm Birmingham	Delivering Solid Tumour Oncology Cancer Services for Sandwell and West Birmingham Update	Kieran Caldwell, West Midlands Commissioning Unit, NHS England; David Carruthers, Acting Chief Executive, Sandwell & West Birmingham Hospitals NHS Trust; Cherry West, UHB NHS Foundation Trust.
	Population Management Approach to Chronic Kidney Disease (Black Country) and Blood Borne Viruses (Birmingham etc.)	Kieran Caldwell, West Midlands Commissioning Unit, NHS England
	Midland Metropolitan University Hospital Update	David Carruthers, Acting Chief Executive, Sandwell & West Birmingham Hospitals NHS Trust.
	Primary Care Networks in Sandwell and West Birmingham Update	Carla Evans, Head of Primary Care, SWBCCG

11th February 2021 @ 2.00pm Birmingham	Merger of Provider Trust update (Royal Wolverhampton Trust, Walsall Healthcare Trust and the Dudley Group FT)	Jayne Salter-Scott, Head of Engagement, SWBCCG
April 2021 Sandwell		

8 Further work areas of interest/Work to be programmed

8.1 The following items could be scheduled into the work programme if members wish to investigate further:

- Local Health Workforce Issues.
- Access to GP Appointments.

9 Joint Birmingham & Solihull Scrutiny Committee Work

Members	Cllrs Rob Pocock, Mick Brown, Diane Donaldson, Peter Fowler and Paul Tilsley	
Meeting Date	**Key Topics**	**Contacts**
11th June 2020 @ 2.00pm Birmingham	• Restoration of services at University Hospitals Birmingham NHS Foundation Trust (UHB) • Birmingham and Solihull STP COVID-19 Service Changes – progress update	Jonathan Brotherton, Chief Operating Officer, UHB Phil Johns, Deputy Chief Executive, BSol CCG
13th October 2020 @ 6.00pm Solihull	• Update on the Restoration and Recovery Plan • Urgent Care update	
16th December 2020 @ 5.00pm Birmingham	• Update on the Restoration and Recovery Plan • Birmingham and Solihull System Finance Update • Urgent Care Update and NHS 111 First	Harvir Lawrence, Director of Planning & Delivery, BSol CCG; Ian Sharp, Clinical Lead, Elective Care, UHB; Paul Sherriff, Director of Organisational Development & Partnerships, BSol CCG. Paul Athey, Chief Finance Officer, BSol CCG Helen Kelly, Associate Director of Integration (Urgent Care/Community), BSol CCG
9th March 2021 @ 6.00pm Solihull		
TO BE SCHEDULED	• Update on the implementation of Phase 3 treatment policies • Update on future QIPP plans • Long Term Plan / Integrated Care Systems / Sustainability Transformation Partnership • NHS Birmingham & Solihull Health App	Paul Jennings, Chief Executive, BSol CCG