Submissions to London Assembly Health Committee call for evidence on maternal health and care in London

In June 2022, the London Assembly Health Committee launched an investigation into maternal health and care in London. The Committee set out to understand the impact of the pandemic on maternal health and services in London, and the experiences of Londoners who had used maternity services since the start of the pandemic. As part of this investigation, the Committee invited those who had accessed or had supported someone accessing maternity services since March 2020 to share information with us. The responses to this call for evidence are collated in this document.

Response to call for evidence received from Sands

As the Covid-19 pandemic unfolded, Sands received a number of Covid-19 related queries through our Helpline. As concerns and questions increased, we launched a rapid survey which was live on Sands social media channels from 19 - 27 May 2020. 120 responses were received.

Evidence in this submission is taken from the findings of the survey that we conducted unless otherwise stated.

1. **Whether women felt well supported by maternity services throughout pregnancy and during and after birth**

Pregnant women

During the Covid-19 pandemic and initial national lockdown, the Government identified pregnant women as a vulnerable category. These women were encouraged to take additional precautions and many women felt as though 'stay at home' guidance meant they could not seek medical attention if they had concerns or worries about their pregnancy.

Throughout the pandemic, we offered support to pregnant women and their families. They raised the following concerns with us:

- Whether it was safe to attend hospital to give birth
- Whether it was safe to report pregnancy related health concerns, such as reduced foetal movements, and whether these concerns would be acted upon
    - For example, Sands was contacted by one woman who reported such concerns, and was told that under normal circumstances she would be kept in for monitoring, but was sent home and her baby died
- Cancellation of face-to-face antenatal appointments
- Having to attend scans alone and not being able to video link to their partners during scans to share images
- Restrictions on support from partners during birth
- Possible transmission of the virus to the foetus or post-birth
- Whether birth choices were still available, such as options for home births

Bereaved parents & families

We also supported many bereaved parents and families, who experienced additional challenges and stresses during the pandemic. These included:

- Parental access to neonatal intensive care units for neonatal end-of-life care
- Needing to leave hospital soon after birth and therefore not having time create memories of their baby
- Not being able to take their baby home with them in a special cold cot to say goodbye
- As bereavement suites were re-purposed as COVID wards, many women were forced to give birth to their stillborn babies on labour wards alongside women giving birth to live babies
- COVID positive women were devastated to have their babies removed in body bags, uncertain if post-mortems would be undertaken

- The heartbreak of not having wider family or friends with them in hospital or being able to meet their baby
- Difficulties registering their baby
- Struggling to understand funeral arrangements, and not being able to have family and friends at their baby's funeral
- Not being able to meet other bereaved parents for face-to-face support
- Delays in getting answers as to why their baby died, for example, delays to post mortems and the cancellation of follow up appointments

Support when leaving hospital

We also heard from many parents who had concerns over support when they left hospital, for example, no contact from the bereavement midwife, GP or consultant. We heard that this was a problem even where parents had called to specifically ask for support.

Parents told us about:

- No home visits
- Follow up appointments only available over the phone
- Counselling cancelled/unavailable
- Unable to see family/friends for support
- Delay to PM results or review, left with no answers as to why their baby died
- Only 10 people were allowed at the funeral
- Invited to scans/appointments even though they have lost their baby
- Left hospital with no details about how to find support

In a feedback form that was live from 19 - 27 May 2020, only 7% of respondents stated that they agree that they had all the support that they needed from healthcare professionals after they went home, with 44% disagreeing or strongly disagreeing. Only 5% agreed that healthcare professionals and in the community communicated well with each other about their specific needs, compared to 52% who disagreed or strongly disagreed.

2. How well maternity services adapted during the Covid-19 pandemic

Due to social distancing guidelines and procedures in hospitals, many pregnant women had to attend scans and appointments alone. Partners or family members were not able to join remotely or virtually, and sometimes ultrasound appointments were unavailable to be booked or attended altogether (even when pregnant women reported significant and persistent bleeding or changes to fetal movements).

Many of the women that we support are pregnant again following a previous loss (stillbirth, neonatal death or other types of pregnancy or baby loss). This experience comes with additional stresses, and appointments and scans can be the source of extreme worry for fear of recurring bad news. We heard many examples of women feeling rushed at appointments and clinicians offering no

reassurance about the pregnancy. Some were also unable to book appointments with their midwife for long periods throughout their pregnancy and were unable to meet with their consultant.

For those that are pregnant following a loss, additional scans and monitoring for reassurance may be offered. Many women told us that these scans were cancelled leaving them having to plead for their appointments, prove their anxiety and if unsuccessful, potentially be forced to pay for a private scan. Women also told us about additional monitoring being refused, despite them reporting concerns as the risk of COVID outweighed the benefit of coming for an assessment. Unfortunately, we heard examples of these experiences where the baby then died.

We also spoke to women and families that had experienced receiving bad news about their baby or pregnancy during the pandemic. As with previous experiences, when women did receive bad news they did so alone and were then left to relay information to partners, often without receiving full information or prognoses. Many women were then left alone for extended periods, or even sent home and told to come back for the birth, with no understanding of what will happen, no referral for support and no assessment of the woman's physical health.

As a provision for Covid-19 positive patients, bereavement suites and labour rooms were often repurposed leaving women to give birth on labour wards where women were giving birth to live babies. Many bereavement services were also halted whilst staff were redeployed to other areas of the hospital, meaning that services like photographs of baby, handprints & footprints, taking baby home after birth and other ways of memory making were not offered or facilitated.

There were immense delays in post-mortems and hospital reviews meaning that babies were often sent away from their parents to different hospitals and potentially even different countries for extended periods. We heard some examples of parents not knowing what had happened to their baby's body. This is exacerbated by the existing staffing crisis in perinatal and paediatric pathology.

> *"Even before I fell pregnant I had anxiety surrounding falling pregnant again due to what happened with my daughter. I voiced these to many medical professionals who promised me they would closely monitor me and do all they could to protect my unborn baby yet my monitoring was called off early as the "risk of catching covid our weight the benefit to come to hospital" yet exactly what COULD have happened to my baby DID happen to my baby."*

3. Whether maternity services are meeting the diverse needs of London's population

In the UK, Black babies are 2 times more likely to die than White babies. Asian babies are 1.6 times more likely to die, and those from the most deprived socio-economic backgrounds are 1.7 times more likely to die.

In October 2021, MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK) released their *Perinatal Mortality Surveillance Report* which outlined the multidimensional effects of ethnicity, deprivation and mother's age on perinatal mortality.

MBRRACE-UK found a general trend of increasing rates of stillbirth and neonatal mortality with increasing deprivation for babies born to mothers aged under 25 and over 35 from all ethnic groups. However, this risk was greater increased when looking at mortality rates for Black and Black British, and Asian and Asian British.

Ethnicity	Mother's age	Stillbirth rate/1,000	Neonatal mortality rate/1,000
White	Over 35	5.79 per 1,000	2.43 per 1,000
Asian and Asian British	Over 35	6.91 per 1,000	3.45 per 1,000
Black and Black British	Over 35	10.54 per 1,000	3.10 per 1,000
Source: https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_-_Final_v2.pdf (page 26)			

MBRRACE-UK also published data on the proportion of mothers giving birth in population characteristic groups by Clinical Commissioning Group (CCG) in England. When cross-referenced with the Trust for London's *'Median income deprivation ranking relative to London and rest of England'* (source), it shows a clear picture that many women living in London boroughs will be disproportionately impacted by inequalities in maternity and neonatal care.

London Borough	The proportion of mothers giving birth in a population that are Asian or Asian British (Source, pages 8-15)	The proportion of mothers giving birth in the population that are Black or Black British (Source, page 8-15)	Income deprivation ranking relative to the rest of England (>1 signifies boroughs which are more deprived than average) (Source)
Tower Hamlets*	49.4%	6.1%	2.67
Barking and Dagenham	27.5%	20.0%	2.5
Islington	6.5%	15.0%	2.07
Southwark	6.7%	24.4%	1.97
Enfield	8.3%	18.0%	1.97
Newham	42.1%	14.4%	1.96
Haringey	5.9%	16.4%	1.88
Lewisham	6.0%	21.1%	1.83
**Tower Hamlets is the most deprived borough in London*			

Sands runs the National Bereavement Care Pathway which, seeks to improve the quality and consistency of bereavement care received by parents from the NHS after pregnancy or baby loss. It is based on nine standards of bereavement care and includes pathways for miscarriage, termination

of pregnancy for foetal anomaly, stillbirth, neonatal death and sudden unexpected death of an infant up to 12 months.

Across England, over 80% of NHS Trusts have committed to implementing the NBCP. Across NHS Trusts in London, 59% of Trusts are signed up (10 Trusts committed to the scheme, 7 are not) – this is clearly not representative of the wider rate of sign up. A lack of parity across London Trusts means that a bereaved parent is likely to experience differences in care depending on which suburb their care is delivered in, feeding into the postcode lottery of good bereavement care.

An introduction to Sands

Sands exist to save babies' lives and to improve care and support for anyone affected by the death of a baby.

In the UK:

- one in four pregnancies end in miscarriage
- one in eighty pregnancies are ectopic
- 5,000 wanted pregnancies are terminated for medical reasons every year, and
- 13 babies are stillborn or die shortly after birth every day.

We provide bereavement support services nationally through our helpline, mobile app, online community and resources, and locally through a UK-wide network of around 100 local support groups. We have 5 local support groups in London.

We work in partnership with health care professionals, trusts and health boards and offer a range of training programmes and bereavement care resources to ensure that every bereaved parent and family receives the best possible care wherever they are in the UK.

We also work with employers to ensure they are equipped to offer the best support to all staff affected by pregnancy loss or the death of a baby.

We support and promote research to better understand the causes of baby deaths and save babies lives. We also raise awareness of baby loss and works with governments, key influencers and other stakeholders to make saving babies' lives and improving bereavement care a priority nationally and locally.

Response to call for evidence received from National Childbirth Trust (NCT)

The National Childbirth Trust (NCT) provides services for expectant and new parents across the UK, including antenatal preparation courses, infant feeding support and a variety of postnatal provision for new parents. In addition we run funded and targeted peer-support programmes in a number of areas, including the London Boroughs of Hounslow and Newham.

We have responded to your survey as an organisation, as well as sending the link to all our London branches and via London-based Facebook groups.

Covid-19 lockdown experiences

The feedback we have received in general over the Covid-19 lockdown has included themes of:

- Isolation: from family; from health services, especially postnatal; and from other new parents. While this effect was clearly nationwide, London has on average a young adult population often with their own parents far away, thus exacerbating the lack of support for new parents in the city, whose extended family members either could not visit at all or at other times in lockdown could not stay overnight
- Fear of going to hospital: especially before the introduction of vaccines – and during the period before vaccination was confirmed safe in pregnancy – there was genuine fear of going to a setting that clearly housed numerous acutely ill and highly infectious patients. Again this feeling prevailed across the UK, but major teaching hospitals in London had some of the most serious cases of Covid, while also being centres of referral for women with complicated pregnancy or sick newborns.
- Maternity services reduced or conducted remotely: while remotely organised appointments were more acceptable to women who did not want to visit a hospital, they felt inadequate to those with anxiety about their pregnancy or baby. In particular, the lack of postnatal visits caused extreme worry to some, as community midwives were moved to the labour ward and health visitors redeployed to nursing.
- Banning partners from hospital: this practice was widespread and caused real distress to women during antenatal scans; while in labour; and in postnatal wards. With understaffed midwifery services this meant in practice women in labour were often alone, in pain and anxious. While certain measures were necessary, unclear information was often reported, with couples having understood the partner could be present in labour/for a scan but being turned away at the door, causing extra distress and frustration.

NCT survey of new parents' experiences and impact from staffing shortages

In the summer of 2022, NCT conducted a survey of those who had given birth in the previous year, asking about the effects of short-staffing in antenatal, intrapartum, postnatal and neonatal care. The following extracts are all from respondents who lived in London:

- Antenatal care was generally good and the birth was generally positive despite the problems faced. However postnatal care was abysmal and made worse by the heavy restrictions on my husband being able to visit and offer support and assistance. Effectively I was wheeled post long labour, c-section and haemorrhage into the ward and left with my baby for 12 hours until my husband could come back. I couldn't reach the baby or do much and no one was around to support me. Another mother on the ward who was on her third baby helped me instead.
- My birth and antenatal experience was very badly affected by short staffing of midwives. I was told this repeatedly throughout my 6 day stay in hospital. The birth centre had to close. I waited 12 hours with minimal pain relief and no midwife support in a holding bay to be

admitted to the labour ward as there were no midwives available and then no beds. After a traumatic birth I then had to wait again back in the holding ward for a bed on the postnatal ward. I saw a midwife once that whole day who came to me in the morning and said 'I am sorry but I am on my own and I have 3 high risk antenatal women I won't be able to see you today. Here is your2pm medication and you will be moved to the postnatal ward when we can'. I eventually got moved at 9pm. During this time I was experiencing breastfeeding difficulties without any support or guidance. My baby eventually became dehydrated and we were in hospital for 5nights. There was no consistency of care from midwives, no handovers- I had to keep doing the handovers to ensure some sort of consistency. There was high agency usage. There was repeated conflicting advice and changes to treatment. The care for me and my baby suffered hugely as a result and I still am affected by this.

- There was only one midwife on the floor when I came into hospital to give birth. It took 90 min to be checked in and then I was left on my own for 4 hours as they only had one midwife working who was with another woman.
- During labour the midwives were so stretched I didn't have a qualified midwife with me while in labour and I didn't feel listened to. I didn't see a midwife once I got home.
- After birth we had 2 scheduled visits which never happened. The first was meant to be our first visit out of hospital, day 5, and no one ever arrived and there was no explanation about this. Another later visit was cancelled due to lack of staff and I had to arrange an appointment to go to a children's centre on another day instead. I also received different/conflicting information from different midwives across my care.
- I discharged myself from hospital due to busy midwives who did not have the time to do it.
- Too few midwives are having to carry too heavy a load.

NCT programmes in London

We have a large number of branch-based activities in greater London, but one of the most active and much-needed programmes is in the London Borough of Newham and is called 'Newham Nurture' https://www.nct.org.uk/about-us/community-support-programmes/newham-nurture . A partner in this work is the charity support organisation Compost London and I have attached one of their detailed evaluation reports on the programme.

Our Head of Programmes has also helpfully summarised for this submission some of the issues that arise among women in Newham as they go through the journey of pregnancy and birth. These are listed below and will make clear some of the distressing range of unmet needs:

- Lack of access to interpreters, thus women unable to communicate their needs
- A key concern and safeguarding risk is that no childcare is provided for those women who, during birth, have no-one to look after their other children because they have no support network
- Difficulties in applying for Healthy Start Vitamins and Vouchers. For the vitamins recommended during pregnancy and up to four years after, women were expected to go to a Children's Centre: often this presents too many barriers and they run out. Eligibility criteria for vouchers when the woman is an asylum-seeker is not clear or fair https://www.healthystart.nhs.uk/
- Concern and fear among our clients re: NHS charging for Maternity Care, despite the Royal College of Midwives (RCM) calling for these charges to be scrapped RCM calls for end to migrant women maternity charging over safety fears
- Difficulties in navigating the healthcare system: the impact of stigma, migration status, language barriers, being new to the country and not knowing what help they are eligible for.
- Healthcare professionals having a lack of understanding of clear referral pathways. During the height of the Covid-19 pandemic, many provisions changed; the offer differed; programmes offering help shut down temporarily; a lack of communication saw women isolated and not receiving the support they required.

- Poor housing and poor diet due to poverty: many women supported by Newham Nurture (NN) have complex pregnancies and experience gestational diabetes or other health conditions due to not being able to eat a healthy diet. Obstacles include: having nowhere to cook; no money to buy food; or having to eat what the hotels provide (which is often rice/cereal/bread but no fresh vegetables or fruit). Many NN families/pregnant women are living off foodbank provisions and therefore have very limited access to fresh foods.

On behalf of our clients at Newham Nurture and many others we cannot reach, we urge service providers to:

- Think more holistically; make the healthcare system more accessible; think how we can reduce the barriers.
- Offer longer time slots and continuity of care to build trust and ensure women feel heard and understood.
- Co-produce: ask and listen to the women with lived experience what they need and want - Newham Nurture is founded on this and the feedback has been overwhelmingly positive. NN also supports other organisations with focus groups and involvement in research programmes to share learning.
- Create clear, documented referral pathways that are easy to access for both parents and health care professionals.
- Provide multilingual maternity resources e.g. support videos for antenatal preparation, breastfeeding etc.
- Make use of a 'communication card', for pregnant women who have limited or no English, to aid in the quick triage of women arriving at the hospital with concerns. The NN programme manager Belinda Ngugi has been involved in co-designing with the London Maternity Clinical Network.

This report compiled by Elizabeth Duff, Senior Policy Adviser; Jo Corfield, Head of Campaigns & Communications; Helen Lloyd, Head of Programmes - 16 September 2022.

Response to call for evidence received from Healthwatch Greenwich

To London Assembly Health Committee,
In response to your call for evidence on maternal health and care in London, please see Healthwatch Greenwich's report on the differences between community and hospital based maternity care in Greenwich.
In-depth interviews were carried out with seven English-speaking women of colour from a migrant or refugee background who all had experience of giving birth in the last two years. Our research identified key differences in the level of satisfaction and perception of the quality of maternity care between community-based care and hospital services at Queen Elizabeth Hospital (QEH). Overall, the women we spoke to had positive experiences with their midwifery and community-based care and poorer experiences with in and outpatient maternity care at QEH. The positive aspects of community maternity care related to strong levels of emotional and practical support received, as well as the degree of information provided that enabled women to make informed choices. The negative experiences of hospital based maternity care at QEH arose from two main themes – (1) institutional and administrative issues, such as difficulty organising appointments, long waiting times, and lack of continuity of care, and (2) communication styles of healthcare professionals, such as a lack of adequate information and/or not signposting to additional sources of support and information, a lack of insight on the impact of poor communication for the recipient, and the feeling of not being listened to.
Healthwatch Greenwich hopes that this report is useful for your investigation, please don't hesitate to get in contact should you require further information.
Kind regards,

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Response to call for evidence received from Healthwatch Wandsworth

Hello,
I came across your call for information about maternal mental health. I wondered if you would find our report on the subject interesting as it may cover some of your questions: Experiences of perinatal mental health in Wandsworth | Healthwatch Wandsworth
Please do let me know if you'd like to discuss this further around your specific questions.
Many thanks,
Sarah Cook
Healthwatch Manager, Healthwatch Wandsworth

Working days: Mon - Thurs

Delivered by Wandsworth Care Alliance

Experiences of perinatal mental health in Wandsworth

Report – 26 May 2021

Read more about the experiences of mental health for new parents in Wandsworth. Thanks to everyone who shared their experiences we have a number of recommendations to improve perinatal mental health support in Wandsworth.

The perinatal period is officially defined to include pregnancy and up to 12 months after childbirth. We set out to hear from people who live in Wandsworth about their experiences of managing emotional and mental health wellbeing in pregnancy, childbirth or the first year after giving birth and becoming a parent.

What we did

We developed an online survey to ask Wandsworth residents about their recent experience of mental health and wellbeing during the perinatal period. The survey was promoted to various contacts through social media, outreach work and contacts at the Perinatal Mental Health Service, SWLStG.

The survey included questions on people's general experience of mental health and wellbeing as well as asking about specific services available in Wandsworth. The survey was open from December 2020 until April 2021 and 64 people responded to the survey.

We also attended a workshop held by Talk Wandsworth attended by new and expectant mothers and held a workshop discussion with a Cedar House support group for women who are experiencing postnatal depression.

Key findings

There were many positive comments about support from services. However, there were comments that suggested room for some improvements relating to:

- Getting a referral and reducing waiting times for mental health support
- Ensuring that issues are understood by health and care professionals who can then identify and refer people who need support
- Co-ordination between services and continuity of care
- Availability of support from community settings and forums
- Availability of information about support available
- Face to face appointments are needed some times. Although 'virtual' appointments are a useful part of care, they shouldn't be the only form of care.
- Inclusion of family, friends and relatives, particularly partners has an impact on mental health wellbeing.

Some people told us they had lost faith in the system due to difficulties accessing support or because they felt they experienced unsupportive attitudes from some health and care staff. Some reported the need for a determined effort, attempting different routes to make sure they got the support they needed.

Recommendations:

- GPs, midwives and health visitors could do more to provide information and space to check that someone is all right and knows how to maintain mental health wellbeing.
- Some women highlighted that their problems and referrals could have led to more prompt support if there were better knowledge and understanding around mental health from the various professionals they were in contact with.
- There should be further promotion of mental health support, including Talk Wandsworth or less formal peer support.

- We would like reassurance about waiting times for access to Talk Wandsworth services, length of support offered and that priority is made for pregnant women and new mothers as a number of people reported waiting times and specifically mentioned this service.
- Partners and support networks need to be better involved to provide support as far as possible, more information could be provided to them to provide support during the pregnancy and early parenthood.

Maternity services

- Providing continuity of care from healthcare team throughout perinatal period should be prioritised.
- Effort should be made for greater co-ordination of services, closer working and information sharing between services.
- There should be at least a minimum number of face-to-face appointments with one or more of the services to ensure a relationship is built to ensure a better understanding of and conversation about wellbeing.
- There were comments about attitudes and approaches of staff and that people felt they would seek support and feel more supported if staff attitudes had been more supportive and understanding. Consider how the culture may be developed to increase understanding of patients' experiences and feedback and increase their involvement in their care.

Health visiting and early years services

- The support and opportunities for identification of mental health needs available from Health Visitors during restrictions and possible future restrictions should be reviewed, ensuring on and offline support. Ensuring meaningful interactions rather than a tick-box exercise.
- Low level support networks like child health clinics, breast feeding support groups and children's centres have an important role which must be prioritised.

Finally, we should highlight that the number responses we received from ethnic minority respondents were low despite attempts to circulate the survey amongst a variety of community contacts. More needs to be done to specifically understand if there are any issues at referral stage and to understand experiences from across our diverse community.

What happens next?

This information will be used to feed back to local services to make sure they understand what is working and areas of improvements in order to provide the support people need.

Read more in our report

We are grateful to those who shared with us their experiences in what can be quite a tricky topic to talk about. To hear the rich picture of experiences, please do read our report, which can be downloaded below.

Healthwatch Wandsworth Experiences of Perinatal Mental Health Report Final.pdf