

## **NHS Lothian Maternity Services Liaison Committee Mothers' Voices Event - 6 June 2019**

### Why Hold a Mothers' Voices Event?

A key function of the Maternity Services Liaison Committee (MSLC) is to gather feedback from maternity services users.

It can be a real challenge for parents with babies or small children to find the time and energy to travel to a focus group or even to fill in a survey. So Mothers' Voices events, where maternity services representatives go out to meet parents in a familiar community setting, offer a practical solution and have been successful in England.

Link to English model - <http://nationalmaternityvoices.org.uk>

Lothian MSLC has a close working relationship with the Pregnancy and Parents Centre (PPC), an Edinburgh-based charity which supports parents-to-be and families. They were very enthusiastic about hosting the first of these events in Lothian.

Link to PPC website - <http://pregnancyandparents.org.uk>

NHS Lothian Maternity Services gave their full backing and the date chosen coincided with the Scottish Government led public engagement day: What Matters To You? The focus on what mattered to parents and families led to open and constructive discussions on the day.

WMTY Link - <https://www.whatmatterstoyou.scot>

The event was advertised on NHS Lothian, PPC and MSLC social media networks. A poster (appendix 1) was designed and displayed in Midwifery and Health Visiting clinics and the event mentioned by local midwives and health visitors to their clients.



## What happened?

Around 35 mothers - with babies - attended the event and some partners came too. As expected, many came from near the venue but some had travelled from West Lothian or Midlothian. A map showing participants' place of residence is included in appendix 2.

NHS Lothian Maternity Services, Health Visiting Services and the Women & Children Services Management Team were well represented. The MSLC is very grateful for the support and commitment of all those who volunteered to attend.

See NHS participants list appendix 3. Everybody thought the day had worked out very well. People seemed to enjoy having time to talk and listen or be listened to. The most valued gift of the day was 'time'. A pause to listen, share and reflect.



## What matters to mothers and their families?

Mothers told us that what mattered most to them was:

- To be treated with kindness and respect.
- To be given clear and honest information at the right time.
- To be fully involved in their care and supported in their choices.
- To receive consistent care and advice.

The themes which emerged from the conversations were:

- Maternity care and birth (perinatal mental health, home birth protocol, discussing birth plans/preferences, talking about birth postnatally).
- Neonatal Unit (parking costs, practical suggestions for support).
- Breastfeeding (preparation and information, early support).

A more detailed breakdown of the feedback as well as the response from NHS Maternity Services are included in appendices 4 (general maternity), 5 (neonatal) and 6 (infant feeding).

Reassuringly, many of the comments received were about aspects of care NHS Lothian is already working on. For instance the current work to implement The Best Start redesign of maternity services will result in better continuity of care and help keep mums and babies together. It is important to

know that NHS Lothian maternity and neonatal services developments are going into areas that matter to parents.

### What happens next?

Following the event and this report, our recommendations are:

- That other Mothers' Voices events are run in other parts of the Lothians, making best use of the lessons learned (listed in appendix 7) to enable the MSLC and NHS Lothian to build up a wider picture of what matters to recent service users.
- That the response time from NHS Lothian is kept to a minimum to ensure that the full impact and benefits of this form of public engagement are not lost.



### Appendices

- 1 – Event poster
- 2 – Attendees map
- 3 – NHS Lothian participants list
- 4 – General maternity feedback and response from service
- 5 – Neonatal feedback and response from service
- 6 – Infant Feeding – You Said, We Did
- 7 – Event Learning points

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# ***Are you pregnant or have you become a parent in the last year? What matters to you?***

Come and meet midwives, health visitors, service managers and members of NHS Lothian Maternity Services Liaison Committee to share your experience around a cup of tea, cakes and sandwiches

**Mothers' Voices Day**  
**Thursday 6<sup>th</sup> June 2019**  
**11.30 am to 3.30 pm**  
**Pregnancy and Parents Centre**  
**10 Lower Gilmore Place**  
**Edinburgh**  
**EH3 9NY**

What you tell us will help develop and shape your local maternity services

Babies and children are welcome

For more information please contact: 0131 465 5673

NHS Lothian

Maternity Services Liaison Committee

*Working in partnership to improve maternity services*

Pregnancy and Parents Centre

*Friendship, information and support for parents-to-be and families*

## Appendix 2 – Attendees map



### Appendix 3 – NHS Lothian participants list

<b>FACILITATOR</b>	<b>11.30am to 1.30pm</b>	<b>1.30pm to 3.30pm</b>
MSLC Lay Members	Liz Foster Mathilde Peace	Liz Foster Gail Stark Mathilde Peace
PPC	Daisy Dinwoodie Nadine Edwards	Sarah Denniston Val Innes
Midwives	Catriona Grainger, ward 211 Fiona Thomson, labour ward Helen Macgregor	Catriona Grainger, ward 211 Fiona Thomson, labour ward Fiona Boswell, community midwife
Napier Student Midwives	2 senior students	2 senior students
Health Visitors	Aimee Hutton, Bruntsfield Megan Charles, Tollcross	Catriona Mcpherson, Bruntsfield Carolyn Worlock, Edinburgh
Family Nurse	Jenni Bonnar	Jenni Bonnar
Health Promotion	Moyra Burns	Tracy McGillivray
Consultants	Emma Doubal Ros Burns	Emma Doubal Ros Burns
Clinical Managers	Pauline Smith	Pauline Smith

## Appendix 4 – General maternity feedback and response from service

### Comments

- Mental health – one lady was referred to Crossreach antenatally which was helpful. But felt she had no help post birth.
- Those who got a good debrief said it “helped (them) process a fairly difficult birth” and “reduced (their) fears for next time”.

### Questions with responses from the Chief Midwife and Community Midwifery Clinical Manager

Q - Is there information on the obstetric cholestasis pathway?

A - Response: Women with obstetric cholestasis should be given the RCOG patient information leaflet which explains what it is, what causes it, implications for both mum and baby and how it is diagnosed. It also describes the symptoms, treatment and the additional care required during pregnancy.

Q - Is there an ECV leaflet?

A - Yes there is an ECV leaflet and it is usually given to women when the midwife makes the appointment for ECV.

### **Home Birth**

Q - Could Home birth be allowed at 37 weeks?

A- We are currently only providing on call service from 37 weeks when requested by women.

Q- Could the home birth kit be delivered earlier.

A - We are reliant on the van service which is managed by one person. The equipment will be delivered prior to the date the midwives are going on call.

Q - Could you meet your midwife beforehand and get to know them?

A - The first on call should come from the host team and depending on the team size the mother may have met some of the midwives. Moving forward with the maternity strategy women having a homebirth should have met all the midwives who are on call for her.

Q - Could we have teams specialising in home birth?

A - We have looked at having a homebirth team, however at this time there are not enough women requesting a homebirth to make this possible. We also cover a large geographical area spanning Edinburgh, East, Mid and West Lothian.

## Postnatal

- Q - One Mum was separated from baby post birth (eg taken to theatre for PPH, retained placenta...) and she felt her husband was left without information for too long (2hrs). Could the midwife give Mums an account of what happened with baby during that time, in writing or verbally, to make up for her feeling of having lost the first few hours with her baby.
- A - I am really sorry that this woman's husband was left without information for quite some time and this has also been shared with the clinical manager to share with her staff. Baby is usually left with dad or birth partner so midwives would expect dad/birth partner to update the mum when she returned from theatre.
- Q - Could you introduce use of text message or phone call to let mum know when midwife or health visitor are likely to come for the postnatal home visits, if they are delayed or cancelled and to rearrange appointment.
- A - I am aware that the midwives working in the new continuity model (The Best Start) have had feedback that the women like the fact that the midwife contacts them by text and that they are notified of appointments etc. in that way. Midwives in the traditional model tend to give approximate times e.g. "I will visit you in the morning as I am in clinic all afternoon". I will feed these comments back to the team leaders for discussion with their community teams.
- Q - After admission to HDU (intensive care) could you send letter explaining what happened to mum, offer debrief? In general women said they would have liked more time to talk things through at some point after the birth of their baby.
- A - Medical staff would normally discuss why admission to HDU was required at the time and in the hours after admission. I appreciate that at this time mums don't always take in what is being said and very often questions arise some time later when mum and baby have gone home. I will share this feedback with medical staff to explore whether it would be possible to write to the women summarising why admission to HDU was necessary.

## Other points

- Q - Birth plans seem to be read and discussed in the birth centre but not so much on labour ward at RIE. Is this policy?
- A - I have discussed this with the clinical manager for labour ward and she will raise this at the charge midwife meetings. Midwives will be reminded to discuss women's birth plans as a routine part of care.



Q - Quite a few issues were raised around diagnosis and treatment of tongue tie. Delay with diagnosis, delay with referral, complex and lengthy process (4 months). This was from women on the day and also through the MSLC feedback page for the past few months. Is there a plan to reduce these delays?

A - Midwives refer babies to the IFA's for assessment of tongue tie and onward referral to RHSC for treatment if required. This treatment is only available at the RHSC and is outwith the remit of maternity services.

## Appendix 5 – Neonatal feedback and response from service

There were some really nice comments from mothers whose baby had been in the NNU including:

(Being able to give my expressed milk to my baby in neonatal care) "made me feel like a mum"

"kangaroo care is amazing!".

One mother came from a long way (Whitburn) to say "Thank you" and gave very detailed feedback on her experience. This is her story and suggestions: Her baby was born at **25 weeks** and looked after at the NNU of RIE.

She said her **care during the birth** had been very good in such stressful circumstances. The doctors on LW explained what would happen in a way which she appreciated (caring and personal, not just statistics). The midwives were extremely supportive and kind. Her partner was able to stay and she was given a single room, out of the way, which they appreciated.

In the 4 hours between the birth and the transfer to NNU she was able to see her baby. She had tea and toast and felt calm.

She was very grateful to be given a **tour of the NNU** which she found helpful. She stayed 8 days. A midwife helped her express milk, which was good.

She found the 8 days very long and boring.

She suggested **having a social space / room** in or near the NNU for parents to meet. She thought it would be good to have a water fountain, some fridge space/ food storage somewhere would be useful.

Some coat hooks would be useful.

Interactions with NNU staff was great. They are amazing people.

Her baby was in NNU for 11 weeks and they drove in and out every day.

She suggests **parking should be free** or at least it should be easier to claim back for expenses (parking and food). "It is very difficult to claim as you are stressed and busy. Should have expenses paid up front (voucher system?), it would take some of the stress out."

Her midwife organised a **debrief with the consultant**. This took place two months after birth. She would have liked this **earlier**.

She has a plan for next pregnancy with the pre-term clinic, and this plan has helped with her anxieties.

Baby came home 3 weeks before EDD. She felt well informed and well prepared, appreciated the help through text messages ("amazing support").

She received her appointment for the **baby check from her GP practice** when baby was still in NNU and it was difficult to get it changed afterwards.

### Response from Chief Midwife

Thank you for this positive feedback.

The clinical rooms where the babies are cared for were refurbished a couple

of years ago but unfortunately this didn't extend to the non-clinical areas. However, thanks to the Simpson's Special Care Baby charity an extensive refurbishment programme is planned which includes social space for parents, a fridge and tea and coffee making facilities. We are very excited about this and looking forward to providing parents with the space they need at such an anxious time.

Unfortunately parents do have to pay for parking although the Scottish Government has introduced funding for parents whose baby is in the NNU and they can claim back parking/public transport costs and food. Vouchers are not provided "up front" as parents can choose where to purchase their food and it doesn't have to be from on site facilities.

## Appendix 6 – Infant Feeding – You said, we did.

Thank you for your feedback on breastfeeding support. We were glad to see that many comments were made about aspects of care we are already working on as this means our improvements are happening in areas that are important to service users.

### **You said you wanted plenty of support in the early days and weeks with your baby**

We know how important it is to be well supported during the first days and weeks when you are breastfeeding your baby. Mum and baby are both learning to know each other – and having to learn a new skill as well - so it is not surprising that mothers need a lot of reassurance at this stage.

As a fully accredited Baby Friendly service, all our staff on postnatal wards are trained to a high standard to support breastfeeding mothers and guide them through the first feeds. Sometimes what mothers need most is a word of encouragement and a reassuring presence, so we are increasing the number of peer-supporters on the postnatal wards to provide that all important one-to-one support.

We are also the pilot site for Scotland looking at teaching Mothers about antenatal expressing in order to support early feeds. It is early days and we have to start small but if it works this is something that might be able to support mums where difficulties in labour cause issues with the first few feeds – something else that was commented upon.

The Best Start improvements to midwifery services which are being rolled out across Lothian mean that women will also have greater at-home support from their own midwife. Equally, the changes to the Health Visiting pathway have already increased the number of visits new families receive and soon all parts of Lothian will be offered all these new visits.

### **You said you wanted early access to specialist support.**

As you can see, we are building up a strong network of early support for breastfeeding mums and babies. We believe that, for most mothers, early support will prevent difficulties developing and reduce the need to access the specialist service. We know that there is no better place for a new mother to receive support than her home and that is what we are striving to do.

As Baby Friendly accredited services, we know that our Midwives, Health Visitors and Family Nurse Practitioners (FNPs) are all infant feeding experts who will recognise and solve early difficulties. Your Midwife, Health Visitor or Family Nurse Practitioner (FNPs) receives regular and mandatory training to the highest standard and is carefully monitored and supported to ensure all women are given the right advice, at the right time and referred to the specialist service when necessary.

Because travelling to one of our hospitals to visit the specialist service can be difficult for a new mother, where it remains necessary we offer timed appointments to ensure mums get the time they need to have a feed observed and issues diagnosed, and do not experience unnecessary waits. Follow up, where required, can be by telephone if preferred.

### **You said that our drop in groups were good but you didn't get enough information about them and there were some areas of Edinburgh or Lothian left out.**

We are redesigning both our drop in support groups leaflet that every woman receives on discharge from hospital and our website to make this information more accessible and we are expanding the number of NHS support groups as well as working with other providers (such as NCT (National Childbirth Trust) and Breastfeeding Network) to fill the gaps.

**We heard the comments that some of you made about the messages we give about formula feeding.**

We want to reassure you that NHS Lothian supports women how ever they choose to feed their baby. Health Visitors, FNPs and Midwives support families with safe and responsive formula feeding and to build their relationship with their child regardless of feeding choices. However, we will look again at how we talk about this.

**Some mothers told us they did not feel prepared for the reality of breastfeeding.**

We recognise that we are not always the best at this and we are working on improving our communication around this.

**One lady had had a poor breastfeeding experience at RHSC (Royal Hospital for Sick Children)**

Whilst we cannot look at individual issues as part of this exercise, we recognise that not all RHSC staff have been trained in breastfeeding support. We are working with staff at RHSC to offer training and to try and extend their expertise.

**Some comments made us realise that some of the general feeding advice we give can be confusing if families are concerned that their baby has a problem.**

In all cases your Health Visitor, FNP or Midwife will be able to assess your situation and offer personalised, expert advice. However, we are going to consider if we can put some of the frequently asked questions on our Feeding Your Baby website to help families who are looking for information round the clock. <https://services.nhslothian.scot/feedingyourbaby/Pages/default.aspx>

## Appendix 7 – Learning points

### Mothers' Voices 6 June 2019 – Event Learning Points

Feedback from the organisers and the facilitators who conducted the interviews.

#### **1. Date, Time, Venue and Catering.**

Date and time was good. Plenty of women came along.

Venue great. Comfortable, relaxed, informal. Nice welcoming feel.

Room was set up for individual chats but also flexible for group conversations. Perhaps a bit too busy at times.

Catering was a big success. A much appreciated feature. Some would have liked fresh fruit also.

#### **2. Guidelines for Facilitators**

Prepare a box where facilitators can pick up their bundle of papers on the way in - feedback template, paper for notes, pens, etc...

Provide a box to collect completed feedback sheets at the end.

Facilitators to do only half a session. The full session was too long.

Some facilitators were happy to jot down notes during or after the interviews. Others suggested facilitators could work in pairs, one interviewing/ one taking notes.

At the end of an interview, good idea to go over notes with women to check they reflect what was said.

If writing more than one sheet for a woman, number the sheets so that it is clear it is the same person feeding back.

Ensure facilitators get a break. Have a coordinator for that or a rota.

Give women a sticker/ badge once they have been interviewed to avoid same women talking to several different facilitators. This is to avoid duplicates of same feedback although some women may have talked about different things with different facilitators.

This would also give women the opportunity to stay on after their interview, relax and talk informally with other mums or participants.

#### **3. Volunteers**

The PPC staff and volunteers did a tremendous amount of work prior to and on the day: setting up rooms, keeping hot water urns filled, washing cups and saucers, setting up a marquee for buggies, etc...).

This is a key element to bear in mind.

#### **4. Cost**

The total cost for the day was £200.

This was for catering only, done by volunteers. Cost of ingredients mainly (£165) and £35 for the work (for two volunteers). This catered for around 60 people.

There was no charge for the venue.

A different setting / venue may have additional costs (professional catering, venue, interpreters, etc...).

#### **5. What Matters To You**

The registration with What Matters To You, which happened to be on the same day, was a clear added bonus. It set up the right tone and atmosphere. It gave the event more publicity (live tweet and possible future inclusion in the WMTY annual report) and provided us with free material (posters, pens, badges, stickers, etc...).

It would be great to make a future event coincide with WMTY day again.

#### **6. Response from Services**

It is important to provide a response within a couple of months to keep the momentum from the event and to get the maximum impact.

Due to delayed responses from maternity and neonatal, it took twice as long to produce a draft report.

It might have been more efficient for the MSLC chair to request a meeting with the Chief Midwife and Clinical Managers to discuss the feedback.

#### **7. Closing the Loop**

The final report will be uploaded onto the MSLC website and shared by the PPC through social media.

A “you said, we did” poster will be displayed at the PPC and perhaps in NHS Lothian maternity waiting areas (to be agreed).

The MSLC will follow up longer term actions generated by the feedback.

Mathilde Peace. August 2019.