

DRAFT Minutes of the Lothian Maternity Voices Partnership meeting held on 7th April 2022 via Microsoft Teams at 10.00 am.

In Attendance:

Mathilde Peace	Lay Chair
Lyndsay Baird	Administrative Support
Alison Hagan	NCT
Laura Goullee	NCT Breastfeeding Buddies
Kat Prangle	Breastfeeding Support LENS
Kirstin Worsley	Breastfeeding Network
Sarah Denniston	La Leche League
Aurelie Tartaud	Pregnancy and Parents Centre
Thomas Lynch	Dads Rock
Kathryn Lawrence	Kin Collective
Sau Mei Fong	Minority Ethnic Health Inclusion Service
Emma Cashmore-Gordon	Aberlour Child Care Trust
Virginia Adams	Lay member
Chiara Allsup	Lay member
Hannah Bicheno	Lay member
Catherine Coales	Lay member
Ashley Cowie	Lay member
Sara Ferreira-Jeffries	Lay member
Katy King	Lay member
Julia Iddir	Lay member
Fanny Lena	Lay member
Ezinne Maduka	Lay member
Sophie Orton	Lay member
Katherine Sellar	Lay member
Susan Taylor	Lay member
Kelly Toms	Lay member
Edile Murdoch	Consultant Neonatologist
Catriona Grainger	Charge Midwife (ward 211 RIE)
Emma Westall	Charge Midwife (ward 119 RIE)
Melissa Kallat	Infant Feeding Advisor, NHS Lothian Lead
Yvonne Fairholm	IFA, Community Health Visitors
Sue Shade	Clinical Midwifery Manager, St John's Hospital
Emma Jamie	Ward Manager, St John's Hospital
Andie Hewitt	Antenatal Clinic Midwife, St John's Hospital
Lesley Scott	Community Charge Midwife
Connie McLuckie	Edinburgh Napier University
Em Thompson	Edinburgh Pregnancy Research Team (EPRT)

Guests:

Ewen Johnston	Consultant Neonatologist
Rosemary Townsend	EPRT
Lorraine Adamson	EPRT
Jennifer Ozdemir	Health Promotion

Apologies: Victoria Paterson, Helen Hudd, Carolyn Worlock, Stacy Brown, Louise Robertson, Camille Del Pozo, Nicola Welsh, Gemma Skinner, Florence Fankam, Lyndsey Murray, Alison Reid, Garry Luke, Karen Ormiston, Cat Berry and Tracy McGillivray.

Welcome and Introductions

The Chair welcomed everyone to the meeting and in particular the many lay members in attendance, some of them attending for the first time. She thanked them for joining the MVP.

She extended a warm welcome to Kathryn Lawrence, founder of the Kin Collective, a community hub supporting families in Leith.

<https://www.facebook.com/kincollectivecic/>

She was pleased to introduce Em Thompson, Research Midwife of the Edinburgh University Pregnancy Research Team (EPRT) and two of her colleagues attending as guests. Em Thompson would present the new partnership between the EPRT and the MVP during the meeting.

The Chair announced some changes to the membership:

Aurelie Tartaud is taking over as link person for the Pregnancy and Parents Centre. Mathilde Peace expressed her heartfelt thanks to Daisy Dinwoodie who had generously filled this role for many years and been an invaluable member of the MVP.

Finally, the Chair was pleased to welcome back Melissa Kallat, Infant Feeding Advisor Lead, back in post after a two-year secondment at regional level.

1. Minutes of the Previous Meeting

1.1 The minutes of the meeting on 3rd February 2022 were accepted as an accurate record.

2. Running Action Note

2.1 Baby Feeding Journal – No-one was available to give an update.

2.2 Postnatal Ward Welcome Pack at RIE – No-one was available to give an update.

- 2.3 Better Birth Group RIE and Lothian Intrapartum Group – No-one was available to take this item.

Sue Shade explained that the Intrapartum group had met on 23rd March and meetings were scheduled every 8 weeks. The agenda in March covered fetal monitoring, the Birth Choice Clinic and quality improvement projects.

Mathilde Peace suggested that it was time to **include lay representation again**. Sue Shade would speak to Emma Doubal to extend an invitation to the MVP chair. **SS**

- 2.4 Social Media – Mathilde Peace announced that a private Facebook group for the MVP lay members and the partnership organisations represented on the MVP had been created. 35 MVP lay members have joined this group.

Lay members can request to join by looking for the Facebook group “Lothian Maternity Voices Partnership – lay members”.

Mathilde Peace reminded the group that she had introduced an informal hour for lay members before each MVP meetings on Teams. 17 members had attended today’s pre-meeting.

- 2.5 Induction – MVP focus group

The setting up of this group was delayed again due to Covid-19 continuing impact. New target: first meeting in June. **Set up group / MP**

3. **Any Other Matters**

There were no other matters arising.

4. **Information About Service Improvements - Edile Murdoch**

- 4.1 Edile Murdoch explained that following a meeting with the Director and Assistant Director of Midwifery and the MVP chair, it was agreed that sharing information about service improvements should be formalised. Examples of improvements included the Pre-term Birth Clinic and the Birth Choice Clinic.

- 4.2 The members agreed that it would be beneficial to share this information and offered to support this their via social media networks and contacts. NHS Lothian could also make use of their Facebook page. **EM/ MP to progress**

5. **Breastfeeding**

- 5.1 Melissa Kallat invited the lay members and representatives from partnership organisations to share feedback about any on going issues.

- 5.2 Kirstin Worsley (BFN) spoke on behalf of the Partnership Organisations represented on the MVP (NCT, LLL, BFN and LENS). She listed the following recurring issues:
- Tongue-tie diagnosis and long delays after referral for surgical procedure.
 - Nipple shields – some women are advised to start using these on the postnatal ward and then are discharged home without a follow-up plan.
 - Covid-related challenges – some women are being told that they cannot be with their baby if they test positive. No support plan is offered. This is no longer medically advised.
 - Nappy output – different advice given by 3rd Sector compared to NHS.
 - Normal baby behaviour – normal expectations about how often baby needs to feed, especially in early stages, are not communicated to new parents.
- 5.3 Hannah Bicheno, NCT volunteer who runs support groups, explained that women often felt confused with the conflicting advice received from different midwives or health professionals. The advice given was generally not consistent enough.
- 5.4 Katherine Sellar, NCT breastfeeding peer-supporter, explained that the advice given about antenatal expressing had been unclear and confusing.
- 5.5 Katy King, lay member, expressed concerns that no clear alternative plan or support for expressing was offered to breastfeeding mums who had to be separated from their newborn baby, for example after an infection or during Covid when mum was admitted to hospital but not her baby. She also raised concerns about maintaining breastfeeding training standards for mental health nurses at the Mother and Baby Unit (for example knowledge of babies' feeding patterns, such as "cluster feeding").
- 5.6 Sophie Orton, Doula, said that when mums were discharged home with a feeding plan which included formula top-ups, they were left unsure as to when to stop this. There was a lack of follow-up support.
- 5.7 Kirstin Worsley, BFN, said the link between breastfeeding and mental health was still poorly recognised. Applications by the Breastfeeding Network for Government funding to support women kept getting turned down as that link was not understood or recognised. The BFN after many attempts eventually obtained funding to support a pilot project.
- 5.8 Edile Murdoch, Consultant Neonatologist, recommended a common approach between members of staff for women with babies in the Neonatal Unit. She thought that some flexibility in the advice given and the feeding plans would be beneficial. She felt that mother and baby should lead and have ownership of their feeding journey.

- 5.9 Melissa Kallat thanked everyone for their detailed feedback and for sharing their experiences. She said that the disruption caused by Covid was still being felt. This had particularly affected staff training and as a consequence impacted on consistency of advice. However, face-to-face training for staff was resuming and this should help improve consistency of approach and advice.

She took on board the issues raised and would look into all of them.

She welcomed the offer of a more in-depth presentation by the MVP lay representatives, based on women's stories and feedback, at the 9th June MVP meeting.

Partnership Organisations supporting breastfeeding to prepare presentation on current issues with breastfeeding support for 9th June MVP meeting

6. Perinatal Mortality Report – Lothian (EMBRRACE UK) Ewen Johnston

6.1 EMBRRACE-UK / Lothian Report

Ewen Johnston, Consultant Neonatologist, presented the report and took the members through the data collection process, analysis and findings. The presentation slides are attached.

6.2 Points to note beforehand

EMBRRACE-UK collect data from Neonatal Units (NNU) across the UK. The report is published every year in December for the data collected two years previously, allowing time for checks and corrections. This report presents data for the year 2019.

Each Neonatal Unit is given a score once the data has been adjusted (to take into account local variables).

An average score is indicated by the colour amber.

6.3 NHS Lothian

The mortality data for the Neonatal Unit in NHS Lothian is very similar to units of a comparable size in the UK and nothing has been highlighted for concern.

6.4 Questions

Sarah Denniston, la Leche League, asked how NHS Lothian were using the report and if it would lead to any local actions. Ewen Johnston explained that the report is very useful to help monitor, observe and analyse data. For example, when there was a sudden increase in the mortality rates (of babies in the NNU) in October 2021, the neonatal team was able to link this to a high

number of babies who had been transferred from outside Lothian. Sadly, they were very sick and very small babies and less likely to survive.

Chiara Allsup, lay member, asked if we could learn from Nordic Countries where more babies survive. Ewen Johnston replied that it was not so much a question of better clinical practice, but simply that their population is in better health overall. Policies to improve the health of the people living in Scotland need to address eating and drinking habits, smoking, education levels, etc...

The report also clearly shows that minority ethnic background and levels of poverty have a direct impact on the outcomes. Improving availability of information in other formats and languages and ensuring access to interpreters are key to improving outcomes.

Mathilde Peace thanked Ewen Johnston for his presentation.

7. MVP - Edinburgh University Pregnancy Research Team (EPRT)

- 7.1 The MVP and the Edinburgh University Pregnancy Research Team have entered a new partnership to support public involvement in research.

Em Thompson, Research Midwife, stressed that a key principle of the NHS Health Research Authority is that research should not be done to or for patients, but WITH them.

- 7.2 Members from the EPRT are welcome to the MVP pre-meeting reserved for lay members and can present new ideas for research projects and discuss them.

More information on the partnership can be found here:

<https://www.ed.ac.uk/edinburgh-pregnancy-research/get-involved/lothian-maternity-research-voices>

Pregnant women and their families are at the centre of our work and it is vital that they are fully involved and integrated with the research process. For this reason, we work in close association with NHS Lothian Maternity Voices Partnership.

The Partnership is open to NHS Lothian maternity service users to join (pregnant or postnatal women and families), and currently meets online. Each bi-monthly meeting has a 45 minute gathering of just the service user participants, before the main meeting with representatives from the wider maternity services. Our team of research midwives is kindly welcomed along, to share upcoming research ideas and gather feedback and ideas.

More information on the EPRT can be found here:

<https://www.ed.ac.uk/edinburgh-pregnancy-research>

8. Provision of NHS Parent education in Lothian

8.1 MVP Concerns

Mathilde Peace and the MVP lay representatives expressed their concern about:

- The fact that face-to-face antenatal classes are no longer offered in most areas.
- The fact that the Parent Education Coordinator post no longer exists.

When raised on the MVP lay members' Facebook page, this topic generated a huge response amongst the MVP lay members. Their online discussion is detailed in the attached slides.

8.2 The Best Start Recommendation (Scottish Government - 2017)

“Early access to antenatal education improves outcomes in maternity care. Antenatal education is important to promote positive health behaviours and support parenting.

High quality prenatal and antenatal education must be available to all, and NHS Boards should continue to promote and improve early access to antenatal education, including parenting, physical and emotional wellbeing, tailored to local populations”.

8.3 Discussion points

Melissa Kallat said she was concerned about the impact this could have on feeding as one of the workshops was dedicated to infant feeding and face-to-face classes are invaluable to demonstrate and practice feeding techniques.

Kirstin Worsley (BFN) and Kathryn Lawrence (Kin Collective) said that partnership working with 3rd Sector organisations could be explored. However, the universal service provided by the NHS should not be threatened. Any 3rd Sector involvement should be alongside and in partnership with NHS Classes.

Chiara Allsup (lay member) talking from her experience of delivering training and development both online and face-to-face, stressed that the coordinator role was even more important for online classes. It was a false perception that things are easier logistically with online training. People still have to be taken through new teaching material, follow-up is required, etc...

8.4 Next steps

The members felt this needed to be discussed further and urgently with senior management from across the whole of Lothian NHS. As the only senior manager in attendance was Sue Shade, Clinical Midwifery Manager (St John's Hospital), **Mathilde Peace will request an urgent meeting with all senior management to raise these concerns and present the feedback from the MVP lay representatives. She will seek answers to the questions raised.**

9 Meeting dates for 2022, on MS Teams, all Thursdays 10am to 12pm.

NOTE THE NEW DATE FOR JUNE: THURSDAY 9TH JUNE – DUE TO THE QUEEN'S PLATINUM JUBILEE BANK HOLIDAY

09 June, 25 August, 27 October, and 15 December.

Running Action Note

ACTION NO.	DESCRIPTION	LEAD
2.1	Baby feeding journal update	P Smith/ MP
2.2	Postnatal ward welcome pack update	P. Smith /MP
2.3	Better Birth Group RIE Pan-Lothian Intrapartum group update	L. Rose
2.3	Invite MVP chair to Intrapartum group	S Shade / E Doubal
2.5	Set up MVP focus group on induction	MP
4.2	Share Information about service improvements	EM/MP
5.9	3 rd Sector presentation about breastfeeding support challenges	BFN, LLL, LENS, NCT
8.4	Parent Education - Request urgent meeting with senior management	MP