PRESENT
Suzanne Jarrett (SJ) Chair, Parent Rep
Jess Keilthy (JK) Co Chair, Parent Rep

SERVICE USER REPS
Grazia Ragone (GR) Parent Rep
Nicky Thackeray (NT) NCT, Parent Rep
Julia Redburn (JR) NCT antenatal and breastfeeding
Dave Perrins (DP) The Dad Course
Gemma Hopley (GH) Parent Rep, Breastfeeding Peer Supporter
Sonia Richards (SR) UK Hypnobirthing
Manara Uddin (MU) Parent Rep

SERVICE PROVIDERS
Zoe Faulkner (ZF) Breastfeeding Peer Support Coordinator
Jo Sinclair (JS) OBS and Gynae Consultant
Joanna Fitzsimmons (JF) Midwife
Carole Whiley (CW) Children’s Centre Manager, Health Visiting Team Brighton and Hove
Kate Alexander (KA) Perinatal Mental Health Team
Jane Canning (JC) Birth Stories Midwife
Janet Everest (JE) Breastfeeding Midwife
Dawn Elson (DE) Manager
Marie Hornsby (MH) Midwife, Labour Ward Coordinator
Julie Sinden Edwards (JSE) Labour Ward Coordinator, Contact Supervisor of Midwives
Rosie Jennings (RJ) Midwife
Jane Rogers (JR) Governance lead, Women’s services

COMMISSIONERS
Kathy Felton (KF) CCG Commissioner for Brighton and Hove
APOLOGIES
Kate Stringer
Heather Brown
Pip Andrews
Marion Wilyman
Lisa Nye
Charlotte Halliwell
Gemma Akin
Jane Grogan

SJ led welcome and introductions, agreed minutes from the last meeting

ACTIONS AND UPDATES FROM LAST MEETING

Diabetes/IV insulin in labour

JS introduced herself as new in post consultant, based at PRH. Explained work has begun around re arranging the Monday clinic and results are already being seen for women.

Regarding the current position on the Lucozade test, explained she was aware that currently all women are invited to have the screening. Expressed the feeling of concerns within the trust that up to 20% of women with GD would be missed if this test was not offered. However, the evidence is currently under review, mindful that the current NICE guidelines do not recommend the test, but at the same time concerned that GD women would be missed.

Changes in the number of GTT tests required for women who have had previous GD have already been implemented.

SJ spoke from service user’s point of view. Our women do have false positives with this method of screening, and simply we don’t understand why this method is being used, we are one of only 3 trusts in the country using the Lucozade test.

JS Expressed everyone in the working group is keen to adopt parts of the NICE guidelines, but again stated that the Lucozade test does pick up women with GD who would otherwise be missed.

SJ requested that the MSLC be kept in the loop with regards to this issue.

JS agreed and affirmed that women can refuse the test.
SR expressed concern about the language used while discussing the screening with women, whether it is presented as something they must do or something that can be chosen.

KF said she was looking forward to seeing the outputs and reasoning behind future decisions, and also that a proper process was being used to evaluate and make changes.

**My Pregnancy Matters Website**

RJ provided an update. The plan to bring the website back ‘in house’ will limit the format as the trust works with an old site but at least content will be controlled and updated easily when that happens. Content will be trust specific and where possible generic information will be removed. Hoping also to add in feedback from service users.

It was also noted that following on from the parent rep feedback from GR at the last meeting regarding routine GBS testing at 37 weeks that current guidance on this would be added to the website.

**Action** All to contact RJ with feedback rosie.jennings@bsuh.nhs.uk

**Midwife Led Unit**

SJ updated all. Explained that she and JK had met with Gayle Murphy (MSLC Chair for PRH) and had decided to make contact with the local MP’s.

So far both Caroline Lucas and Simon Kirby have written to Matthew Kershaw, his response remained the same, that is to say the board remain committed to the MLU however moves (Urology) have delayed work from beginning. The trust’s financial plan for the next year is being put together and it remains a priority, unless a major event should occur.

Caroline Lucas made further contact with the new Chief Executive Amanda Fadero to query if the pot of money for the MLU is ring fenced, the reply was no, and she stated that creating the space for the MLU is not straightforward, and that the trust are currently reviewing plans against the capital available for 2016/17.

SJ outlined the planned actions. Our intention to make contact with The Argus and setting up an online petition.

EL confirmed she had no further update on the MLU’s progress, nor any information on the Urology dept. moving.

EL Stated it may be raised when the CQC come in April, as the plans have not moved on since the last visit.

**Action** SJ and JK to meet with Gayle Murphy to fine tune and begin campaign.

**Action** SJ/JK to keep EL ‘in the loop’ with the work

KF CCG have written to Amanda Fadero. Wondered if the national maternity review may contain anything of use to us.

SN Offered possibility of article/ advert in Healthwatch magazine

ZF Offered to publicise on the Sussex Community NHS Trust Breastfeeding B&H Facebook page
Newborn Hearing Screening

EL explained that from 12 February 2016 this screening is their responsibility, not of the health visiting team. Plan for babies to be screened in hospital shortly after birth with follow clinics in RSCH and PRH as required. Plan is to be reviewed after 3 months so it can be tweaked as required.

Women who homebirth now have to come to hospital for NIPE check so hearing screening will be done at this check for those babies.

Birth Stories

Following suspension of service.

JC has now caught up with backlog of women in the system waiting to be seen.

JC New pathway being put in place, likely referrals will need to come from healthcare professionals not self-referral system as before. Have capacity to see approx. 28 women per month, self-referral is unsustainable. New key criteria of women having to be within 12 months of giving birth, unless exceptional circumstances. Also need to look at other places women can be signposted to.

NT What if it is over a year since birth?

EL those women outside the year period will be seen if needed, but the service will be aimed primarily at women within the first year. Explained for some women, a VBAC clinic or health visitor group may be more appropriate.

JC stated there is flexibility but wanting to avoid women coming to the service when other avenues would be more appropriate.

Interpreters

At the last meeting it came to light that an interpreter is only able to be used for a 2 hour period. EL explained that the concern is that after the 2 hour period the interpreter may struggle to keep up the required level of concentration. She was clear that family are not used as interpreters and if a woman was in active labour then they would work with the interpreter to extend the 2 hour period where possible.

MULTIPLE BIRTHS

A Parent’s Perspective

Abigail Pride, a parent rep, mother of 3 year old twins spoke about her experiences and those of women she had contact with through a local Facebook multiples group.

POSITIVES – Universal praise for Joanna Fitzsimons’ antenatal class

- Groups are very well attended and well thought of, some women now host groups independent of Children’s Centre’s

NEGATIVES - Attending breastfeeding support groups very challenging with newborn twins, also lack of understanding that it is different to breastfeeding a singleton. Perhaps a way forward would be breastfeeding support at home.
- Children’s centre groups have reduced in number/frequency
- Lots of groups are inaccessible to parents of multiples, sometimes you simply cannot get the buggy in the door! Real sense of isolation among mothers of twins
- General confusion. Continuity of care, different providers giving conflicting information to women. Women are unaware of the care they should be receiving during pregnancy, one woman said her care was no different to that of her singleton pregnancy.

AP also spoke of it being difficult to time antenatal classes correctly. Women are advised to start them earlier but if like her they go to term then they are out of step with the others in that group.

NT Said NCT do not run a specific course for twins and there are not enough women locally to do so, the distance between them is too large for them to gel properly. Agreed that NCT would advise completion before 33 weeks.

SR Agreed hypnobirthing would ideally be finished by 30-32 weeks.

SJ Mentioned Twins in Brighton and Twins town.me as sources of information

**Action** JK to add the above to the MSLC website

**Multiple Births Paper**

Kathy Felton spoke about the Health and Wellbeing Board. Explained it’s a formal council board and that a question had been raised, linked to poor outcomes both locally and nationally for multiples and quoting Jeremy Hunt’s pledge on reducing stillbirth and neonatal death. Explained a care bundle has been produced regionally to tackle key issues.

KF said the councillors have expressed an interest in feedback form parents locally, and that we need to be sure we are doing the best that we can

JR Explained that while not all stillbirth is investigated, as a team it has been decided that every stillbirth will be reviewed. This will help ensure best practice and and make changes where needs be.

EL Agreed to look at continuity of care, stressed how difficult it is as women don’t always see the same person but can look at ensuring consistent messages across the board.

KA Confirmed women who experience a stillbirth or neonatal death go through the perinatal mental health service, though this does have an impact on the other parts of the service

JF asked about the roll out for twin specific growth charts

JS a lot of work is being done on personalised growth charts

JF Spoke of TAMBA’s ambition to roll out a new twin growth chart they have been developing across the country

KF Stated that the NICE guidelines are due for revision and that she is expected to report back to the Health and Wellbeing Board with progress made.

**Multiple Births Joanna Fitzsimons Community Midwife PRH**

JF has been running the multiples specific classes at PRH since 2012. Passionate about the care these
women receive. Enjoys working in the twin specific role, also has links with TAMBA. Spoke about the higher risk of ante and postnatal depression in mothers of multiples.

Women have said to her that while the care on labour ward is good, there is no continuity antenatally and no specialist midwife.

Also issues with getting scans at RSCH due to capacity in the department.

Spoke of a great working model in Leeds, specialist midwife in place and continuity of care is there. Women therefore can have a more community led experience and also are able to be seen at home.

**Action** SJ to send out link to this model.

JR was keen to look at how we can link national best practice within our local practice, identifying gaps and what needs to be done. Suggested possibility of a champion to move some of the best practice into our already existing ways of working.

**Action** JR and JF to report back at next meeting regarding moving forward JF as champion of multiple births and what can be done to improve experiences and services for women.

**UPDATE FROM MATERNITY SERVICES BSUH**

EL Went through the national patient’s survey, Responses collected from births in February 2015. 51% of Brighton based women responded. Key measures of seeing the same midwife antenatally we outperformed the average, but postnataally we underperformed.

Plan to set up a working group around our postnatal care offer, Marion Wilyman will be setting this up. Limited funds available to work with, however feeling is that something different needs to happen with post natal care.

JE Expressed the need to remember that we need to support all women, those considered ‘fine’ as well as those obviously needing support so that those who are ‘fine’ stay that way.

EL Announced that some antenatal care will be moving into Goodwood Court and that the site could potentially be used for postnatal care as well in the future.

**PERINATAL RESEARCH GROUP**

KA Spoke about the formation of a specialist perinatal mental health research group. A small conference was held where ideas were brainstormed and aims for the research were formulated for the bid.

SJ Explained a lot of our feedback is around being listened to, and a lot of the discussion had gone from there. Main examples focusing on triage and that women feel they are told they are not in established labour, particularly if they are not screaming or obviously in pain.

SR Pointed out that if a woman is hypnobirthing then they won’t be making noise

KA explained the grant available. Explained the research group was looking at ‘barriers to speaking’

JC agreed, key theme of birth stories feedback is how important it is to be heard.

KA Said a planning meeting would be taking place in the next fortnight to formally plan the bid for the funding.
EL Concurred that work could be done, in particular training for midwives in how they talk and respond to women so they feel listened to.

**HOMEBIRTH POSTER**

SJ showed the poster to the group and invited feedback.

ZF suggested that the text could be broken into bullet points

SR was uncomfortable with the use of the word ‘risk’

**Action** SJ to email out copy to all and invite feedback so changes can be made.

Poster to be launched ASAP as soon as changes are made and funding for printing approved.

**AOB**

DP introduced himself. He is the founder of ‘The Dad Course’, set up specifically to work with new fathers to support them with the early days of parenting and the support role they provide to their partners. The course is run over 3 sessions, it’s not intended to replace antenatal classes as it is not medically based but a useful place for men to chat to others. The cost is £65.

SJ raised concern over the figures for one to one care during labour as according to the maternity dashboard.

EL responded that it is being looked at as they don’t feel the figures reflect the true picture on the ground. Part of it may be that not everyone on the labour ward actually needs one to one care, if they are not actually in labour.

EL also gave notice that the CQC are due inspection on April 4th and they may make contact before.

**Dates for future meetings**

17th May 10-12.30 at The Brighthelm Centre

20th July

30th September

16th November