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House of Commons

London SW1A 0AA

The All-Party Parliamentary Group on Baby Loss

14:00 – 16:00, Monday 20th March 2017

Committee Room 5, House of Commons

MINUTES

Attendance

Antoinette Sandbach MP (Cons)
Victoria Prentis MP (Cons)
Will Quince MP (Cons)

Speakers

Dr Matthew Jolly, Clinical Director for Maternity, NHS England
Dr Eleri Adams, Vice Chair, NHS England Neonatal Critical Care Clinical Reference Group

External guests

Abigail Wood (NCT)
Amy Overend (King's College Hospital)
Ann Chalmers (Child Bereavement UK)
Caroline Schmeer (The Mustard Tree)
Caroline Strickland (Bliss)
Celia Burrell (Barking, Havering and Redbridge University Hospitals NHS Trust)
Cheryl Gadsby (Parent)
Clea Harmer (Sands)
Dean Lomas (Lily Mae Foundation)
Debbie Kerlake (Cruse Bereavement Care)
Gabrielle Osrin (The Lullaby Trust)
Heidi Eldridge (MAMA Academy)
Jamie Leich (Interel)
Jane Denton (Multiple Births Foundation)
Jane plumb (Group B Strep Support)
Ken Lownds (n/a - self)
Manjit Obhrai (n/a - self)
Matt Tagney (NHS England)
Maya Al-Memar (Queen Charlotte's and Chelsea Hospital)
Mohamed Omer (Gardens of Peace Muslim Cemetery)
Paula Abramson (Child Bereavement UK)

Penny Kerry (The Miscarriage Association)
Rukiya Gadid (Department of Health)
Ryan Jackson (Lily Mae Foundation)
Sharon Wood (CMV Action)
Vanessa Higham (Office of Antoinette Sandbach MP)
Victoria Morgan (Every Birth a Safe Birth)
Zeshan Qureshi (King's College Hospital)

Apologies

Professor Tom Bourne (Queen Charlotte's and Chelsea Hospital)

1. Welcome and introductions

Will Quince MP welcomed the group, and asked for people to introduce themselves.

2. Approval of last meeting's minutes

Minutes were approved.

3. AGM

Will explained that the AGM would be deferred until a sufficient quorum of parliamentarians were in attendance at this meeting.

Post-script: Unfortunately no quorum was reached, so the Co-Chairs will convene an AGM after Easter recess.

4. Maternity Transformation Programme - presentation from Dr Matthew Jolly, Clinical Director for Maternity, NHS England

Will introduced Dr Matthew Jolly, National Clinical Director for Maternity Review and Women's Health. A biography is available here: <https://www.england.nhs.uk/2015/08/ncd-maternity-women/>

Dr Jolly described the Maternity Transformation Programme run by NHS England (slides will be available on the APPG website here: www.lullabytrust.org.uk/about-us/who-we-are/appg/). He reported that the Programme had had "quite extraordinary" engagement from the Department of Health and its arms-length bodies, charities, Royal Colleges, and other stakeholders.

Safety is the key workstream running throughout the programme. This is currently run by the Department of Health, but responsibility will soon move to NHS Improvement. In many places, there has been a root cause analysis of safety issues in maternity, but Dr Jolly said that there hasn't been the feedback into practice we would wish. However, the Programme is intended to help implement lessons learned. The safety workstream is a three-year programme, and was launched in February 2017, with engagement across the provider Trusts.

The Stillbirth Care Bundle began before the Programme, and is a collection of approaches to improve maternity outcomes, e.g. smoking cessation, better identification of decreased foetal movements, and other aspects too. The Programme undertook a consultation with

Trusts to check their implementation of the Bundle, which received had 111 responses from 134 Trusts. 95% of all Trusts are implementing all or part of the Bundle. Dr Jolly reported that the Bundle appears to be working well, but we await the latest (2105) data to be published which will give further insight.

Barriers to implementing the Bundle have included been the provision of ultrasound services, with gaps in provision as well as challenges in training professionals to provide ultrasounds. Both new funding and revised training are being applied to address this issue.

Once the evaluation of the Bundle has been received, Dr Jolly said the Programme team can decide what we need to do next and how to push improvements. The team need to be clear how to make sure they can implement changes without overburdening an already busy system.

Neonatal death due to pre-term birth has not yet been addressed by the Programme. Dr Jolly explained that in his local role, his team have looked to develop commissioning guidance to address some of the issues, and the charity Tommy's is helping to look at how this could be developed into a national commissioning resource.

Dr Jolly said that there is a lot of work on prevention happening. However, it would be naive to say we could prevent every instance of baby loss, so the Programme is also looking at how we can learn from instances of baby loss and improve bereavement support. For instance, the Programme is working with the charity Sands to develop a bereavement toolkit to help interact with and support bereaved parents. Dr Jolly emphasised that there is full engagement across the system on making improvements.

Dr Jolly said that the Programme Team have started the procurement of the perinatal mortality review tool. The team is working with the MMBRACE team and the charity Sands to create an online, standardised way of looking at how and when things have gone wrong, capture that knowledge, and then work on improvements.

Will thanked Dr Jolly for his presentation, and began a round of questions. Will said that on paper, it looks like the government is meeting its stillbirth and maternity care targets, but when you look into the data, some areas are really not doing well. Will asked Dr Jolly for his thoughts on how to address these disparities.

Dr Jolly agreed there is room for improvement, and said that Simon Stevens (Chief Executive of NHS England) has been very clear on NHS England's commitment to address these issues. For Clinical Commissioning Groups (CCGs) where results are below targets, £75m per CCG has been made available to help improvement.

Mohamed Omer agreed that the Programme was addressing critical issues. He asked Dr Jolly about the Programme's consultation process, specifically whether engagement was made with Muslim faith communities. Mohamed outlined that some of the bereavement packages are not appropriately supporting the Muslim community, so his organisation has begun to offer specialised support. He explained when death occurs, time is of the essence to assure a burial according to Muslim beliefs and conventions. He said that his organisation would be very happy to work with Dr Jolly and his colleagues to help train for religious requirements.

Dr Jolly answered that, off the top of his head, he did not know the details of the engagement strategy (this was handled by another of his team), but he was confident that

the specific needs of, and consultation with, religious groups including Muslims would have been considered. Dr Jolly said he was sure that the local Trusts would be absolutely delighted to have the support from Mohamed's organisation once the new packages are delivered. In response to a follow-up question from Mohamed, he said that the Programme is hoping to include postnatal support into the pathway, with funding, but this has not been guaranteed. When/if this would be available, he would hope that all Trusts take into account of the needs of their local populations.

Victoria Morgan asked about quality improvement training. What would be the opportunity for organisations who do provide training for maternity services to get into the new training models and prospectus?

Dr Jolly answered that the Programme has attempted to give flexibility with the training packages to make it possible for external charities or others to engage on this work. That said, there is nothing to stop individual Trusts to engage; what the Programme is implementing is quality improvement training.

Amy Overend asked is there going to be any funding around bereavement within the neonatal nursing? Within bereavement care, at Kings College they recently have started neonatal organ donation, which parents have welcomed with the view that their child will live on by helping other babies survive.

Dr Jolly said there are examples of good practice. He said he agreed with Kings College clinical approach, but it is a question of where the funding comes from. Neonatal care is funded through specialised commissioning, but the postnatal programme from another source.

Manjit Obhrai asked how it will be possible to achieve consistency so that the reporting requirements are the same for each Trust?

Dr Jolly answered that the perinatal mortality review tool will help us to achieve that in part, though the Programme Team will need to check the perinatal dataset to help obtain standardised data.

Zeshan Qureshi commended the APPG for its work so far. Speaking from a paediatric perspective, he said that there are some good areas of practice. But more can be done on harmonising what the doctors and midwives could do, and training is key to achieving that aim.

Dr Jolly agreed, and said sharing good practice across the system including training good practice is part of the opportunity presented by the Programme.

Paula Abramson said that she was really pleased to hear about the Perinatal Mortality Review tool, which will fill a gap in reporting and data. She made the point that the value of a standardised process is dependent in how many organisations use it. Paula asked whether the use of this standardised process will be mandatory.

Dr Jolly answered that he did not know, but from a commissioning point of view, his view was that the clinical networks and commissioners will be keen to use a consistent process.

Keith Reed said that it was really encouraging to see the Programme's support for bereavement care. Keith asked when would be a good time to come back to Dr Jolly to

check on progress about the care that families receive? In other words, what is a realistic timeline for this work?

Dr Jolly said this was a good question. There are many different components to what the Programme is doing, which is very exciting. He said that trying to work out when you are going to measure something, and even trying to attribute any changes you see the work you've done, will be a challenge. He said there will be continual mortality data coming in, with new dashboards from which to assess results coming online in the next year or so.

Matt Tagney added that every part of the country should have a plan this year for how local commissioners are going to implement the Better Births: Improving Outcomes of Maternity Services in England plan. Once the Programme has these local plans, it will be easier to identify and share the milestones.

Will thanked Dr Jolly for his time.

5. Neonatal Review for England - presentation from Dr Eleri Adams, Vice Chair of NHS England Neonatal Critical Care Clinical Reference Group

Will introduced Dr Eleri Adams, Clinical Director and Consultant Neonatologist at Oxford University Hospitals NHS Foundation Trust. Dr Adams is Clinical Director and Consultant Neonatologist at Oxford University Hospitals NHS Foundation Trust. She has been Clinical Lead for the Thames Valley Operational Delivery Network (ODN) since 2005 and Vice Chair of the NHS England Neonatology Clinical Reference Group (CRG) since 2013. She is a member of the National Neonatal Review Project Board and is leading the workstream on national pricing for neonatology. Copies of the Dr Adams' slides will be available on the APPG website here: www.lullabytrust.org.uk/about-us/who-we-are/appg/.

Dr Eleri Adams said that she had delighted to be asked to speak. She explained that the Neonatal Critical Care Review had been a result of the Better Births vision paper. The Clinical Reference Group (CRG) leading the Review sits underneath the Specialised Commissioning part of the NHS England, as neonatal critical care is undertaken by relatively small numbers of Trusts. The long-term purpose of the Review is to help reduce variation in outcomes, reduce stillbirth, learn from near-misses, and ensure delivery and care is provided in the correct place.

The CRG have agreed to collect the necessary data to understand what issues need to be addressed. The CRG have had returns from all neonatal units as of March 2017, and are analysing the data at this time.

Dr Adams said that the CRG are at the start of this process. There are four working groups on this project, looking at:

- Capacity and demand
- Workforce
- Pricing
- Communication

The Working Groups will provide headlines about the issues identified very soon, as they are finalising their data analysis now. The CRG will then start a process of stakeholder engagement around May 2017, and with regional groups to engage professionals, public and other stakeholders. News about these engagement opportunities will be shared soon.

The Review's full report is due for September 2017. The Review will outline what issues and demand are out there, and will then engage with the local maternity transformation plans and neonatal networks to produce coordinated plans (as part of regional NHS Sustainability and Transformation Plans). Once necessary outcomes are identified, delivering these outcomes of this may require some redesign of services, working closely with the Operation and Delivery Networks (ODNs) as well as external stakeholders. There will also be a public consultation on the report once this is available. The charity Bliss has been involved in this process from the outset.

Dr Adams said that the Review team really wants to work together with local maternity systems and services. She added that the local maternity pathways need to be right for everyone, including for women with high-risk pregnancies.

Will thanked Dr Adams for her presentation, and opened a round of questions.

Victoria Prentis MP said she was keen to be involved. She asked if Dr Adams could use her local area as an example of where things are not going well at the moment. She recently 'mirrored' the journey of a pregnant mother to get to a unit, and this took 1hr 30 mins. Victoria also asked Dr Adams to comment on the optimum size of units, as this has been raised to her by many people - is 8,000 babies a year what units should be aiming for?

Dr Adams said she could not comment on maternity units, as it is not her specialty. There is not a higher limit, but units need to be dealing with over 100 very low birth weight babies per year, minimum 50. She commented that the volume question is an interesting one - neonatal units tend to perform better at handling cases the more they do, though naturally if they face too many cases, this creates problems of capacity and safety. Very high-risk pregnancies require a different approach to the vast majority of pregnancies.

Antoinette Sandbach said that in Germany, they classify the expertise of doctors in a different way, which allows for smaller units. She asked whether the Review will consider classification too?

Dr Adams said that intensive care is undertaken in 46 units in England. There are 73 local neonatal units which give most care to the vast majority of babies, and small amount of intensive care. There are 40 or so other units which give more general care. As such, some babies will have a short time in an intensive care unit after which they will be safe to move to less specialised care. The key is to make sure that babies are cared for in the right place at the right time, reduce unnecessary admissions, whilst also improving families' involvement and support throughout the process.

Mohammed asked whether extra funding be given to units that can't offer the consistent support, following the Review. He also asked how the application of review guidelines will be monitored and whether parents' religion is recorded on inpatient units.

Dr Adams said that it is not mandatory to record parents' religion, but it is possible for staff to record this information. She said that the neonatal network can monitor data produced monthly, and will then work with individual Trusts to address specific problems, e.g. nursing numbers, spaces in the neonatal units, etc. What the network can't do is always influence the change that needs to happen. For instance, capital spend is expensive and takes time.

Caroline Strickland asked whether there will be funding be available to support improvements following the Review. Dr Jolly answered that at this point, there is no funding allocated to enact outputs from the Review. At present, there is no more additional money in the system, but that is not to say that funding would not be allocated later.

Amy Overend asked whether researchers would be included in the discussion about what maternity data is collected. Dr Jolly said that he leads the data workstream for the Maternity Transformation Programme. More data will be made available both to the public and to researchers via a set of different data packages. The Programme is also updating the maternity services dataset to make sure this is fit for purpose, but that is purposed mostly for clinical care. There is a balance to be struck, as if too much is added to a dataset for researcher purposes, this can undermine its usability for clinical purposes.

Cheryl Gadsby spoke briefly about her pregnancy experience. She asked how best to link up community midwives and GPs to improve mothers' experience?

Dr Adams said the Review is attempting to ensure GPs and other local professionals link into the right pathway, so mothers who need specialised support or care receive these services when they need them.

Caroline Schmeer said that her organisation is running support groups for women affected by baby loss, amongst other issues. Early intervention is extremely important for women who need a higher level of care, but one of the biggest issues faced by services like hers is funding. She asked whether funding issues could be looked at in the Review?

Dr Adams said she completely agreed that there are many charities and other organisations doing a huge amount to support families. She said she hopes that this can be linked into other services to make a more consistent experience for patients.

Dr Jolly added that a lot what Caroline had described is commissioned by CCGs. As such, unfortunately there's not a simple answer to funding issues. Hopefully the Programme and Review will create a certain amount of 'moral pressure' to get CCGs to fund necessary support.

Antoinette closed the discussion by underlining the importance of local user groups (including the charity sector) to respond to CCG consultations and other engagement efforts to show them where the issues are, and what improvements are needed. This is the most direct way to highlight, and hopefully plug, gaps in local services.

Will thanked Dr Adams and Dr Jolly for their presentations.

6. Updates

- **Meeting with Minister**

Will reported that a roundtable on maternity care was held by NHS England on 1st March. This included the Care Services Minister Philip Dunne MP, Dr Jolly, members of the APPG, and 10 baby charities who were invited.

Will and Antoinette agreed this had been a very productive discussion. Antoinette said that much of what was shared today was also covered at the roundtable. It was hugely encouraging to see the Department of health pushing change, as well as listening to

feedback from others. Antoinette was pleased to see the number of workstreams relevant to baby loss ongoing, and it is encouraging to see Trusts signing up to work on these issues.

Will added that members who attended the roundtable also raised issues that have not been covered today. For example, Antoinette said that she finds it astounding that medical staff are not routinely trained in bereavement, but was pleased to hear at the roundtable that the Royal College of Obstetricians and Gynaecologists is looking at this issue.

Will invited Keith Reed and Clea Harmer, who attended the roundtable, to share their thoughts as well.

Keith said he wished to echo what Antoinette had already said; he shared that there was lots of positivity about the direction of travel. Clea agreed, and said there was a real sense of us coming together to work in partnership, with charities presenting what they can bring to the table as well as pushing for change. Clea said that that charities have the potential to be part of the glue that joins services and parents, by helping to represent parent voices, or provide a direct dialogue with parents.

Will agreed, and added that he was pleased to say that the Minister is committed to creating change. Will finished by saying that it was very gratifying to see that within the topic of baby loss, there is not the infighting between organisations that you can see elsewhere.

- **Bereavement care pathway**

Will asked Clea Harmer from Sands to give a short update on the progress of the bereavement pathway.

Clea reported that Sands held January and February stakeholder meetings for parents with the help of several Royal Colleges. Clea expressed her gratitude for the generosity of the parents for sharing their experiences. Sands are also planning stakeholder meetings for healthcare professionals, as well as police, coroners and other groups who come into contact with parents. There will be further stakeholder events with charities following those meetings.

Sands are also reviewing existing pathways that exist both in NI and Scotland to feed into the final draft. Sands intended to pull together the content and write the pathway over June and July, and following review. launch this in October. Clea emphasised that the key challenge will be evaluating this pathway and its impact over time.

Clea finished by inviting anyone who wishes to be involved in the pathway development to get in touch with her.

- **Baby Loss Awareness Week 2017**

Will reported that the Prime Minister has responded to our request to hold an event at No.10 Downing Street over Baby Loss Awareness Week (BLAW). Sadly, there is not a date available at No.10 during this time, but it was a very supportive letter from the PM. Antoinette and Will will secure another venue for a BLAW event on the parliamentary estate and report back to the Group.

Will asked Drew and Clea to report back on the work of the charities to prepare for BLAW.

Drew said that he will be available to develop and support the APPG's parliamentary activities and events during Baby Loss Awareness Week, similar to last year. Drew will also provide strategy and coordination work for Baby Loss Awareness Week as a whole, working closely with Sands' Communication Manager. Sands will be working with all charities who wish to be partners of the Week to develop a shared core theme, shared messages and coordinate joint activities to ensure we make BLAW 2017 bigger, better and more focused than in previous years. Drew being engaged in both parts of work is aimed to help the APPG events and the wider BLAW events to be coordinated and aligned (as far as is possible) to help deliver the most impact - policy impact, parliamentary awareness, media coverage and so on.

Antoinette said that BLAW provides charities an opportunity to promote your individual strengths as well as local issues and successes. She urged charities to remember to brief their local parliamentarians two weeks out on what activities will be happening, and liaise with your local supporters. BLAW is clearly not just about what happens in parliament, so it is good to engage MPs in work going on in their constituencies.

Drew added he will also help provide mechanisms for charities to communicate these elements to local MPs if needed.

Clea said that Sands are leading on developing BLAW, but they really, really want all charities to be involved and join under one umbrella. Clea emphasised that BLAW is about all of us working together. She said that Sands are sending out emails for people to get involved now, and asked people to let her or Drew know if they want to be involved.

Will asked if any of the attendees had ideas for BLAW they would like to share now.

Ryan Jackson said that the Lily Mae Foundation will approach Birmingham library to be lighted in the BLAW colours, in line with other iconic buildings that were lit last year.

Cheryl added that it was amazing last year to have APPG members speak about baby loss issues in the parliamentary debate. She added that whatever MPs do, it's really worth it to build awareness.

8. Any other business

- Clea said that the Department of Health's consultation on Rapid Resolution and Redress Scheme for Severe Avoidable Birth Injury has a 23rd May deadline for responses, and is open for responses right now. This is the Department's suggested alternative compensation scheme for babies who have been brain damaged at birth by poor medical care. The current scheme does not include stillbirth and neonatal death, and Clea feels that this should be included. She encouraged the attendees present to respond to the consultation.
- Heidi Eldridge said that the baby wallets are given to women in their booking appointment, which has the key issues and things to watch for. Now getting great feedback on wallet/packages on monitoring movement.
- Will said that at 7pm there will be a half hour adjournment debate on smoking in pregnancy. He expressed his thanks to all the charities who have contributed.

- Will said that a number of people came to watch the 'Still Loved ' documentary screening in Parliament the other week. Will is encouraging MPs to write to the BBC Director General asking them to screen this during BLAW during Baby Loss Awareness Week. He said if it would help if other organisations wrote to the Director General too.

9. Date of next meeting: Monday 5th June, 4pm - 6pm

Postscript: The following meeting was cancelled due to a general election called for 9th June.