Oxford University Hospitals
NHS Foundation Trust

Cover Sheet

Public Trust Board Meeting: Wednesday 08 September 2021

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Title:	**Experience of being supported by the Oxford Fetal and Maternal Medicine Unit (FMMU)**

Status:	**For Information**
History:	**Regular Reporting**

Board Lead:	**Chief Nursing Officer**
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Confidential:	**No**
Key Purpose:	**Assurance**

Executive Summary

1. The purpose of this paper is to
   - tell the story of families who have been supported by the Fetal and Maternal Medicine Service.
   - Explain the service and how it supports women, babies, and families.
2. Maternal death from indirect causes is not falling in the UK at the same rate as direct deaths. The most recent MBRRACE(UK) report showed that 68% of women who died had medical co-morbidities. Maternal medical conditions are also significantly associated with neonatal morbidity and mortality. In approximately two to three in every 100 pregnancies the baby is affected by a condition which requires specialist care before or after birth.
3. Pre-conceptual assessment is important for all women with medical conditions for optimisation of their health and their medication and women with high-risk medical conditions should be referred for specialist pre-conceptual advice. Close partnership working with primary care is crucial.
4. Maryam and Catriona's story shares the close relationship they developed with the team through challenging and uncertain pregnancies. Rachel and Celia discuss the complexity and the challenge in supporting women and the tenderness expressed for the women they support, and the complexity of their work is very moving.
5. National leadership is provided by British Maternal and Fetal Medicine Society (BMFMS), who aim to improve the standard of care for fetal medicine; maternal medicine; labour and delivery; and outcomes of pregnancy. The regional leadership is provided by the Thames Valley region maternal medicine, has been developed to improve the care of all women with medical co morbidities; and encompassing training, shared learning, audit, and governance.
6. The Oxford Fetal and Maternal Medicine Unit (Oxford FMMU) is a multidisciplinary team of professionals based at the John Radcliffe Hospital. The team provides diagnosis, counselling and treatment for families across Oxfordshire, Buckinghamshire, Berkshire, Northamptonshire and Wiltshire. For some conditions advice is offered, so that the pregnancy and birth can be managed close to home. For more complex conditions diagnosis, treatment or even planned birth is led by the FMMU at the John Radcliffe Hospital.
7. The paper will finish with the three stories, which have not been amended and are written as they were told.

Recommendations

8. The Public Trust Board is asked to:
   - Support the recommendations in this report.

Note the contents of this report.

Contents

1. Purpose

1.1. The purpose of this paper is to

- tell the story of families who have been supported by the Oxford Fetal and Maternal Medicine Unit (FMMU).
- Explain the service and how it supports women, babies, and families.
- Provide real stories from women who have been supported by the FMMU, the complexities of their births to highlight the importance of this service.
- Raise the profile of the unit to ensure all women who require this extra support during their pregnancy are made aware of these additional services to reduce the risks.

1.2. There are three stories in total. Two from women who shared their stories of pregnancy, childbirth, and family life and one joint story from the Lead Midwife for Maternal Medicine / FMMU Manager and consultant with the team.

1.3. These stories are all very personal and give a moving insight into the humanity and compassion of running a highly technical, and challenging tertiary service.

2. Background

2.1. Maternal death from indirect causes is not falling in the UK at the same rate as direct deaths[1]. 68% of women dying in the most recent MBRRACE(UK) report had medical co-morbidities (excluding obesity) and in 41% of cases, assessment identified improvements to care which may have made a difference to the outcome. Maternal medical conditions are also significantly associated with neonatal morbidity and mortality[2].

2.2. In approximately two to three in every 100 pregnancies the baby is affected by a condition which requires specialist care before or after birth.

2.3. All women with medical conditions should be assessed pre-conceptually for optimisation of their health and their medication and women with high-risk

[1] Saving Lives, Improving Mothers' Care. Surveillance of maternal deaths in the UK and lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2013-15. December 2017 https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK Maternal Report 2017 - Web.pdf

[2] MBRRACE(UK) Perinatal confidential enquiry, November 2017. https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK Intrapartum Confidential Enquiry Report 2017 - final version.pdf

medical conditions should be referred for specialist pre-conceptual advice. This requires close liaison with primary care.

2.4. Maryam and Catriona's story shares the close relationship they developed with the team through challenging and uncertain pregnancies. They both talk touchingly about their pregnancy and the fears for their unborn babies, and the midwives and consultants support both medically and at a human level to work through what was happening to maintain their own and their baby's safety.

2.5. Rachel and Celia discuss the complexity and the challenge in supporting women and their families who live with such risk when embarking on their pregnancy. The tenderness expressed for the women they support, and the complexity of their work is very moving.

2.6. To give background and context to these very personal stories, the national and regional leadership and network will be explained followed by the FMMU team team's clinical services, maternity guidelines, and process of referral.

2.7. The paper will finish with the three stories, which have not been amended and are written as they were told.

3. National and local Leadership

3.1. National best practice leadership is given by the British Maternal and Fetal Medicine Society (BMFMS), who aim to improve the standard of pregnancy care by disseminating knowledge, promoting and funding research, contributing to the development and implementation of high-quality training and providing a forum where issues relevant to pregnancy care are discussed. There are four main areas of focus: fetal medicine; maternal medicine; labour and delivery; and outcomes of pregnancy.

3.2. BMFMS provide input to relevant RCOG committee and provides advice on maternal and fetal medicine training to the RCOG. The BMFMS also makes representation to other royal medical colleges and other national bodies/organisations when appropriate. The Society also aims to develop links to other similar societies based in different geographical locations. The BMFMS also provides a forum where issues of relevance to obstetricians and other affiliated professionals involved in pregnancy care are discussed.

3.3. The local leadership is given by the Oxford Fetal and Maternal Medicine Unit and the Thames Valley Regional Maternal Medicine Network.

3.4. The Thames Valley region maternal medicine network was developed following the recommendations in Safer Maternity Care (November 2017)3, and aims to deliver improved coordinated and specialist care for women in the region with complex medical conditions. This encompasses training, shared learning, audit, and governance.

3.5. Local maternity service guidelines for common and serious medical problems in pregnancy have been developed and include the criteria for referral for opinion/ transfer of care to an obstetric medicine tertiary referral centre, to reduce the risk of severe maternal morbidity and mortality. The aim of the Thames Valley Networked Maternal Medicine Service Regional Guideline to improve the Care of Women with Medical Problems in Pregnancy is to reduce the risk of (indirect) maternal mortality and severe morbidity and the associated neonatal mortality and morbidity.

3.6. The members of the TVNMMS include:

- Royal Berkshire NHSFT
- Buckinghamshire Healthcare NHST
- Frimley Health NHSFT
- Milton Keynes University Hospital NHSFT
- Northampton General NHST
- Great Western Hospitals NHSFT
- Oxford University Hospitals NHSFT is also the Thames Valley Maternal Medicine Network Centre

3.7. The Oxford Fetal Maternal Medicine Unit (Oxford FMMU) is a multidisciplinary team of professionals, with a core team of consultants and specialist midwives based at the John Radcliffe Hospital.

3.8. Oxford FMMU provides diagnosis, counselling and treatment for families across Oxfordshire, Buckinghamshire, Berkshire, Northamptonshire and Wiltshire.

3.9. For some conditions advice is offered, so that the pregnancy and birth can be managed in a local hospital close to home. For more complex conditions diagnosis, treatment or even planned birth is led by the FMMU at the John Radcliffe Hospital. The team's services are considerable and included in Appendix 1.

[3] https://www.gov.uk/government/publications/safer-maternity-care-progress-and-next-steps

4. Pre-conceptual counselling

4.1. Pre-conceptual counselling for women with medical problems is advocated by several professional bodies, national guidelines, confidential enquiries, and audits including RCOG, NICE[4][5], and MBRRACE(UK). The purpose of pre-conceptual counselling is to:

- inform women of the potential risks of pregnancy
- ensure understanding of the need for increased monitoring during pregnancy
- optimise health and medications prior to pregnancy.

4.2. This can be delivered in primary care. However, for particularly high risk of pregnancy complications or where medications may be particularly harmful to the baby, referral for secondary or tertiary level counselling is appropriate. A pre-conceptual counselling service is available at OUH for all medical conditions (Email: silver.star@nhs.net). Examples of such are conditions include:

- Women with heart disease
- Women on long term anticoagulation
- Women with T1 or T2 diabetes mellitus and HbA1c >7.5%
- Women with epilepsy on AEDs
- Women on known teratogenic medication e.g., methotrexate, sodium valproate, warfarin
- Women with CKD 4 or 5

4.3. It is acknowledged that timely identification of such women in primary care will be challenging, and it is recommended that representatives from primary care are invited to a meeting to discuss how this could be achieved.

5. Maternity Guidelines.

5.1. Conditions which require a local guideline specific to management of women in pregnancy include:

- Epilepsy
- Hypertension in pregnancy including pre-eclampsia
- Diabetes mellitus (T1, T2, GDM)
- Bleeding disorders e.g., haemophilia, thrombocytopenia

[4] Hypertension in Pregnancy: Diagnosis and management. NICE NG133. 2019. https://www.nice.org.uk/guidance/ng133

[5] Diabetes in pregnancy: management from preconception to the postnatal period. NICE NG3. 2015. https://www.nice.org.uk/guidance/ng3

- Heart disease (ECS, 2018)[6]
- Acute VTE (RCOG, 2015) [7]
- Prevention of VTE (RCOG, 2015) [8]
- Sickle cell disease (RCOG, 2011) [9]
- Epilepsy (RCOG, 2016)[10]
- Hypertension (NICE, 2019)
- Diabetes (NICE, 2015)
- Inherited bleeding disorders (RCOG, 2017) [11]

5.2. Local guidelines incorporate an individualised care plan for women to ensure women don't get 'lost to follow-up' at this critical time. This includes

- when and by whom they will be followed up once discharged from hospital
- Clear documentation of communication between all the healthcare teams including the lead obstetrician, anaesthetist, physician, GP, community midwife and obstetric physician where applicable.

6. Referral for an opinion/ transfer to an obstetric medicine tertiary referral centre.

6.1. The threshold for referral should depend on local obstetric and anaesthetic expertise and on the availability of anaesthetic and intensive care services. Appendix 1 lists the conditions where early pregnancy referral to an obstetric medicine tertiary referral centre for an opinion/ transfer should be considered by the local hospital.

6.2. Where women meeting criteria for referral are not referred this should be agreed by the responsible local obstetrician, the relevant physician and anaesthetic services and, preferably, local neonatology services.

6.3. A process of communication between the local and tertiary referral hospital should be developed to ensure all healthcare professionals have access to, and up-to-date knowledge of, the woman and her current clinical situation (with

[6] ESC Guidelines on the management of cardiovascular diseases during pregnancy: Eur Heart J. 39(34) p 3165-3241.2018 https://doi.org/10.1093/eurheartj/ehy340

[7] Thrombosis and Embolism during Pregnancy and the Puerperium, the Acute Management of. GTG37b. 2015. https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg37b/

[8] Thrombosis and Embolism during Pregnancy and the Puerperium, Reducing the Risk. GTG 37a. 2015. https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg37a/

[9] Sickle Cell Disease in Pregnancy, Management of. GTG61. 2011. https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg61/

[10] RCOG Epilepsy in Pregnancy GTG68. 2016. https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg68/

[11] RCOG Inherited Bleeding Disorders. GTG71. 2017. https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg71/

documented evidence of this). It is anticipated that access to a secure database of ‘high risk’ cases could be developed.

6.4. Obstetric medicine consultant review comprises a recommended pregnancy plan, which will be developed in conjunction with, as appropriate, anaesthetic, obstetric and specialist medical (e.g., cardiology) input. If transfer of care is not performed there will be a list of indications for re-referral.

7. Maryam’s Story

This story tells the experience of Maryam’s story when she was expecting her first and second baby. In 2017 I was pregnant with my first baby. I was referred to FMMU because I had a rare autoimmune disorder diagnosed in 2014, called Antisynthetase syndrome**,** which means my immune system began to attack my own muscles as a form of defence. The diagnosis itself was a difficult one as it doesn’t occur in people of my age group, I was then in my 30’s at the time of diagnosis, its routinely seen in the older population. No one with my syndrome had given birth at that point, so there was no research, and I was a rare case. The referral to FMMU began with an initial consult at the early stages of pregnancy, to take a detailed history of my condition, this felt really nice as it made me feel they really knew my story before the pregnancy took off. My doctor was amazing – I had regular appointments and she was thorough, understanding and caring, she always paid detailed attention to all my medication and adjusted them throughout, as needed. She always involved my husband in my care and discussions which was very appreciated. I had extreme sickness throughout my pregnancy and was sick most of the time; it was hard to keep food down. My doctor kept an eye on this and changed my medicine on several occasions to try and control this.

The service was amazing; everyone was very friendly and welcoming, from the support and administration staff to the consultant. I particularly liked the fact that any blood tests were done within the unit, as I had lots of blood tests, well monthly in fact - to keep track of my condition. It was valuable and convenient service.

My consultant also referred me to the fetal cardiac service as there was a worry that my baby’s heart could be affected; they wanted to check that the baby’s heart was developing as expected.

I was on antidepressants; the team took this into account and reassured me that this was safe, as I was a first-time mum.

My pregnancy went well because my doctor kept on top of everything and was so thorough with my care.

My little boy was born with bilateral coloboma which is rare, he was diagnosed when he was 3 months old. I was worried that I must have done something wrong when I was pregnant – and I was worried it must have been the drugs.

I got in touch with my FMMU consultant who researched this for me, to help find out if it could have been the drugs. She told me that it couldn't have been predicted and that bilateral coloboma of the eyes was not listed as a side effect for any of the drugs I was on. I was so grateful as I was feeling very guilty about this and was beginning to blame myself for my son's condition. She also sent me the research papers to read – so I could satisfy myself, which I appreciated very much. We now know that my little boy has issues with long distance vision; thankfully we are managing his condition and he is doing really well.

After having my son, I made the decision to wean myself off antidepressants, and I was free for a couple of years, so when we tried for our second baby, I was completely antidepressants free, and it turned in to a very traumatic pregnancy. I developed perinatal depression in my first trimester– I woke up one morning and I couldn't function. My GP referred me to the perinatal specialist mental health team – I had suicidal thoughts, it was a very scary time in my life, the worst episode of depression I've had. I just thought – not again – why, why, why!

I also still had my muscle condition which meant I was referred to FMMU like last time. I had my initial appointment when I was pretty low, and I wasn't getting on well. The consultant I saw referred me to the Psychological Medicine Consultant - which was very reassuring. At the next appointment I asked if I could see the consultant, I had seen with my first pregnancy – the support worker happily said she would tell her I'm here. Within a few minutes the consultant came out to say hi and looked at me saying are you OK? I said no – I am not OK I have depression. She said Ok – we need to figure this out – I will see you today- she said she had a few complicated patients, but she will see me, but I might be a little delayed. However, she didn't keep me waiting long and adjusted her list and saw me sooner than expected. When I sat with her, I couldn't even get my sentences out - my husband had to help me. I wanted to know why it had happened and how I could get back on track. She said it's most likely the hormones but even if I didn't find a reason for the depression, that was ok – this really stuck with me and put my thought processes at ease. Once again, she was as thorough and kind as ever and involved my husband like last time. As we talked, we realised I hadn't been on antidepressants during this pregnancy - I had been with my son, just a small maintenance dose- I think that saved me the first-time round. She referred me to the Diabetes Specialist Nurse team and also bleeped the consultant psychologist attached to the service to check if he could see me. I left that appointment feeling so relieved, in good care and trusting my consultant implicitly.

Then COVID hit! The follow-up appointments were by video and phone because of COVID. That was fine but felt slightly weird because I was depressed and seeing people in-person always feels better. My appointments were always on time, smooth, thorough and on point.

To add to everything because I was depressed, I wasn't drinking enough and was dehydrated somewhat, I got a salivary duct infection in my cheek. I went to the Emergency Department, was seen at the West Wing and put on intravenous antibiotics and then admitted to the Women's Centre for a few days. At the time I had also developed Cholestasis and I was itching all the time and had the Gestational Diabetes; due to these complications it was decided it was best to be an inpatient at The Women's Centre -to keep an eye on me. My consultant's office is based on the ward I was in but due to COVID she could not come to see me, instead she gave me a call to check how I was – I really appreciated this.

The day after I was discharged, I went into labour – 2 months early!
I thought I can't believe this is happening – my husband couldn't come in with me until it was confirmed I was in labour, due to COVID. I couldn't have any pain relief as I had just had Heparin – they were all so sorry and said I couldn't have any pain relief until 9 am the following morning. I managed just with breathing and the midwives were fantastic. My waters broke and my baby came out very quickly, there had to put out a crash call and she was rushed to the Special Care Baby Unit (SCBU). She was just 3lbs when she was born, so tiny. She stayed in NICU for 2 months until her due date, 24 July 2020. Our time at NICU was challenging as my son was 3 and at home, luckily my husband had been furloughed so we managed. My daughter is 14 months now and thriving.

With all my conditions and experiences with my health over the years I have nothing but praise for the entire NHS and especially my FMMU consultant and team, who I feel went above and beyond their role.

8. Catriona's Story

This is Catriona's story and shares her experience when she was pregnant and when she delivered her baby.

My story starts at 14 weeks when I was having polyuria I was waking up between 3-4 times a night to go to the loo and I was always thirsty. I went to my GP and although everything was ok with the tests, I was still worried, so I ordered Blood Glucose tests online. The tests showed I had raised blood sugars which was unusual for my stage in pregnancy.

I went for a glucose tolerance test and put on to the gestational diabetes pathway – this was good because it was early in my pregnancy.

My first appointment was for an hour online with my consultant. She was very nice, holistic in her approach, really listened to me - I felt cared for and it was the best appointment I had experienced at that point in my pregnancy.

I had another appointment with a Registrar at the general Monday morning Silver Star Clinic and I saw different members of the team. I was also cared for on the diabetes Ultrasound pathway which involved using the blood sugar meter fasting and after meals blood sugars form this early point in my pregnancy.

I had a private nutritional coach as I wanted to be organised. I did attend the NHS dietician session, but I had most of this information already but for women who didn't have a coach it would have been helpful. I wanted the nuances of information - the fine detail.

On my scans my baby was on the 95th centile for head measurements. I worried I was harming my baby with my diabetes and my focus was a feeling of guilt all the time.

By my second trimester, my blood sugars were creeping up. The diabetes obstetrics consultant phoned to tell me to start taking medication - I was scared as I hadn't met her. With my nutritional coach I was able to further modify my diet and so I was able to avoid medication.

At 30 weeks I saw an Obstetric Registrar and I started to think about where to give birth – they called their consultant who I saw for 20 minutes. Before this I felt labelled as diabetic, and I didn't understand where I stood. She was so comforting because she told me that my gestational diabetes had been picked up so early and she told me that my risk wasn't that high and helped me to put it into perspective. We also agreed that I could wait until 41 weeks before I would need to be induced – if I hadn't started labour by then. There was the caveat of the 36-week scan to check everything was Ok - but I felt normal, on a normal pathway – it was a huge comfort.

Despite this appointment, it was still stressful at home trying to keep under the blood sugar threshold and life was certainly getting harder.

I had a difficult appointment at 36 weeks. I had my scan – and my baby was breech. I was referred to the breech clinic that afternoon. The consultant I saw told me that the combination of my breech baby and my diabetes was too much of a risk and she wanted to book me in for a planned Caesarean section at 39 weeks – for there to be '0' risk. I was shocked and angry as this felt doctor centred to me.

I had a successful External cephalic version (ECV) - the midwife was very calming, but I thought oh my God this is painful, and I tried to stay calm - my heart rate was 140 after the salbutamol injection. I still thought a C section at 39 weeks or an induction if the baby was no longer breech.

I went to see the community midwife the following week – and she really changed the course of things – as a pregnant woman you really want to understand the spectrum of things. I asked about my baby's measurements ad she told me that they

were within normal parameters – I was not off track, I could aim for a normal delivery, and I wouldn't need to be induced. She said she would email the consultant to delay induction until 41 weeks.

So, it was a seesaw of a problem and then normal. This made a big difference for me in terms of mental preparation. I was discharged from Silver Star and my induction was confirmed for 41 weeks. I could deliver at the spires as I was a diet controlled diabetic.

Whilst pregnant I had read a lot of different approaches to birth. I had normalised it as a natural process and I was in the mindset that this has been done for thousands of years.

Medicine was my ally and made me feel safe. I wanted to be sensible and at the same time natural. In my last 2 weeks I went for acupuncture. I had been told and read that it can be helpful to increase oxytocin and aid delivery. It isn't recommended by the NHS, but I went for 3 sessions; I felt tired in between and the baby's head felt more engaged with every appointment.

On the morning of induction day, it was a Monday – I started having contractions at 4 am. I had wanted to avoid induction and an epidural if possible. I called the induction people at 9 am and I monitored my contractions regularly. By 6 pm the contractions were becoming regular. – I monitored diligently so I could know when to go in. I phoned the hospital who said to keep monitoring and to phone at 8pm. I did and told them that my contractions were every 3 minutes. They sent a triage midwife to my home – she came from Witney and arrived at 11pm (The Spires and home births midwives are part of the same team – so the same midwife would meet me and look after me if I went into hospital).

She examined me – and I was having strong contractions. I had done the antenatal mindfulness course at the JR and hypnotherapy at home. My husband was applying sacral pressure (he was amazing – he had previously been very worried and wanted to be at the head end). She told me that I was 1.5 cms dilated and my cervix was paper thin. I was 20 hours into labour by this time and I was exhausted but still making sense in between my contractions. I was in so much pain and I was scared about the baby's position and whether he would get stuck as I knew he was on the big side size-wise.

The midwife told me from her examination that I 'wasn't in established labour yet' but that all was safe. I asked if I should go into hospital? She told me that I would be offered codeine and asked to go home until 3am when I could be examined again. By the time she had written her notes she left at 1 am. I asked if I could be examined again but she told me it was too early.

I was left at home contracting for 21 hours – I was being incontinent of urine and vomiting – thinking how bad can this get? I had no medical pain relief. I was using sacral pressure and had a shower as pain relief – it wasn't civilised.

About an hour later – around 2.30 am – my waters broke. I felt a huge pressure. We phoned the hospital and they asked me to wait another hour - I thought I don't know if I can cope – they said don't come in.

I squatted on all 4s and examined myself. I felt a bulge which could be the baby's head and it felt that I was dilated by possibly 3-4 cms.

I screamed – I think I can feel the head!! I felt sick and panicked but we got to hospital around 3.15 am. We had to go from Botley to the JR. I was on my knees in the car and holding onto the headrest. We almost ran out of petrol on the way – my husband asked if we could stop but I said we must keep going!

We arrived – in the middle of the night and in the middle of COVID – all doors were shut, and no one answered when we rang the door.

We eventually got in and met the on-call spires midwife and student – I was covered in vomit. I said I can feel something – please examine me and assess. They wanted to ask me the introductory questions and take my observations - so I stripped off, got on all 4s. They said OK, looked inside and said: – you are 10 cms dilated, the head is coming out! They sounded surprised and worried. They told me not to move and to stay where I was. I was in stage 2 of labour and vomiting with every push – it wasn't nice. The room was tiny - with me, my husband and 2 midwives and an emergency trolley. My baby was born at 4:06 am.

I had gone through this entire journey without being able to do much of my birth plan – I had had my bagged packed, with fairy lights, an oil diffuser, the nightie I have especially bought for labour, my squatty potty etc. Everything was still in the car. I never set anything up at home either because I thought I would be in hospital for the most part – but I ended up being at home for 24 hours and in hospital for 40 minutes. I had been told about 2-3 hours before baby was actually born that I wasn't in established labour but was 'establishing labour'.

I think when my waters broke, I quickly went from 1.5 cms to 10 cms dilated because my cervix was so thin, and I was far more advanced than my midwife thought. I had a lot of tears by the end.

Stage 2 was really painful, and I was also worried the entire time because everything came as a shock. Once baby came out, I remember being covered in vomit, urine, meconium, and feeling so much pain in my perineum, asking for ice to be put down there as 'I felt burning below'.

They put my baby on me and he was fine – 3.9 KG.

I didn't have anything with me – it was all in the car as we had rushed upstairs in a panic.

Post-delivery I felt fine – I felt normal, and this is what I expected.

I had many apologies form the midwives who were concerned they hadn't taken me seriously when I was explaining what was happening whilst at home – they said as a

first-time mum they hadn't expected me to be so sure of what was going on. The next day, the midwife who came to see me at home told me it wasn't usual for a first-time mum to go through the whole of labour with no pain relief and said how amazingly I had coped with everything.

They said they could see why I was upset, as it was nothing like my expectations – that was calming and comforting as I had been so traumatised.

I thought I would have had longer and wonder whether the acupuncture speeded things up?

We talked that it was a shame that in the end I couldn't have a home delivery as I had laboured so much at home.

I did wonder about calling an ambulance, but I didn't want to answer 25 questions and to wait half an hour would have freaked me out. It was probably quicker to drive.

Not many women would examine themselves in labour, I must have been in so much pain at the time too.

Eventually – thank God – I listened to my instincts and my learning point is – listen to myself.

My personality is to listen to experts – which I did, and I had to make a lot of decisions in huge discomfort – be brave, be a fighter, make decisions which work.

The last 5 hours my husband was doing sacral pressure as I had lower back pain – I never had contractions all over – that never happened to me. My back hurt for a week afterwards!

The drive for him was scary – he was tired and had no sleep for 2 nights.

It has been therapeutic to tell my story to friends – I feel healed now. I am very grateful the baby is fine, and I am accepting that it didn't work out how I wanted it to.

I learned you can only plan so far – things may be different and accept it – embrace unpredictability.

I was upset with the system that I couldn't go in earlier to prepare – if I could have prepared to get my environment nice whether hospital or home that would have been good for us.

The best book I have read is why my baby cries. I think when women prepare, they experience things differently. Hypnotherapy and mindfulness – work.

9. **Rachel and Celia's story** – looking after women and their babies

We have a close cooperation with the doctors and our job together is to get women safely to delivery and sadly a lot don't make it.

The midwife is a woman's advocate. The cohort of women is markedly different to 10 years ago. For example, women who are waiting for a renal transplant, we are familiar with now – it isn't out of the ordinary for us.

Things are more complex for women because of IVF[12], technical advances, cancer, obesity, hypertension – women who would not have survived years ago – there are degrees of high risk.

Women with chronic medical conditions often have complex social issues so we have to offer and give holistic care.

We have a considerable number of tertiary referrals. And so, we must have excellent communication across the Trust and outside. Handovers must be holistic and involve the whole team - not just one profession.

We need to be extremely careful that safeguarding issues don't slip through the net.

We have 5 consultants – 3 obstetricians and 2 obstetric physicians (an obstetric physician started the Silver Star unit).

Maternal deaths are few and far between. These very sad and tragic deaths must be investigated. It is important to remember though that we look after women living with extremely high risk all the time.

In society we are not prepared for things to go wrong – but women need to know the risks involved and then they can make their own choices. We work in an area of maternity high risk.

Just as an example we looked after a woman who was pregnant and had COVID, she went to the intensive care unit and had an emergency delivery. We completed a duty of candour and there was a strong tendency to think of this as a failure. However, she had a severe complication, and nothing had gone wrong.

We tend to normalise good care for women supported by the Silver Star unit, if we take a step back, and think what other hospitals do – we would celebrate – but because we are so used to it, we take it in our stride.

The team are highly motivated and skilled and the wonderful thing about working with specialists in the Trust and as a Tertiary centre is that we can have a highly skilled multidisciplinary team formed and meeting on MS Teams within 10 minutes.

An obstetric physician needs to be a good project manager as you must be holistic, work in a team within a complex setting – you cannot be a lone professional. We must be able to pull together.

We have 3 core midwives and a team of rotating midwives. It isn't everyone's chosen career - but it is a new concept and important not to dilute midwife's knowledge and experience.

Our job is to support mum and baby safely to delivery - to have ~~a~~ healthy babies and healthy mums. We are often making very hard decisions in the operating theatre and with resuscitation. We make complex antenatal and delivery plans with the woman and often the only reason delivery goes well is because we have co-produced a complex and detailed mum and baby centred plan.

12 In vitro fertilisation (IVF) is one of several techniques available to help people with fertility problems have a baby. IVF - NHS (www.nhs.uk)

Informal and formal support is key for all staff – but especially less experienced staff for example when mums are receiving end of life care in the obstetric setting, or with a HSIB investigation (Healthcare Safety Investigation Branch) [13].

With medical and surgical knowledge, research, skills, and techniques improving, it is important we can find a sustainable model of care for all of us.

As a team, we all love working with the women - to help work through their worries about pregnancy, delivery, and their health.

We are in awe of each other's skills, from the medical colleagues piecing together the jigsaw puzzle to the admin team organising us. We are all equal in the part we play.

I love to work out the complexity and that's why I choose obstetric medicine. I have the time to work out the complex issues and to do it properly with the luxury of time. I feel that my clinical skills are respected.

It is easy for us to assume that the health problem is the woman's main concern, but it may not be, so we must be woman centred and follow her lead.

We do have overbooked clinics, so for example we should have 35 women in a clinic, and we will often see up to 45. We worry that this impacts on the woman's experience as they often have had a long way to travel, have small children with them and then on top of it can wait for 2 hours before their appointment. We are surprised that women aren't grumpier.

With the increase in demand and technological advances, we need to review whether we can increase in clinic time. We know that the clinics are valued. We want to shine a light on obstetric medicine and specialist midwives and the work we do locally and nationally as leaders in fetal and maternal medicine tertiary services.

10. Conclusion

10.1. This story has shared the lived experience of two women, their families, and clinical staff within the Oxford FMMU. Their experience has shown the complexity and challenges through the lens of receiving and delivering the service.

10.2. These stories are all very personal and give a moving insight into the humanity and compassion of running a highly technical, and challenging tertiary service. They also raise the profile of the unit to ensure all women who require this extra support during their pregnancy are made aware of these additional services to reduce the risks.

11. Recommendations

11.1. The Public Trust Board is asked to

[13] Maternity investigations - Healthcare Safety Investigation Branch (hsib.org.uk)

- Note the contents of this report.
- receive the next steps as recommendations, as further Trust investment will be involved, led by the Chief Nursing Officer.

Appendix 1: Oxford FMMU services

- **Fetal medicine ultrasound**: If a problem is suspected during a routine scan, a referral will be made to Oxford Fetal Medicine Unit: most babies however do not need a specialist fetal medicine scan.
- **Small for gestational age clinic**: A dedicated clinic to monitor babies who are small for their gestational age, "so the most appropriate timing for birth can be advised"
- **Fetal cardiology:** Cardiologists carry out specialist scans to diagnose conditions which might require heart surgery after birth. These scans are done at the same appointments as fetal medicine scans, so that families do not have to come to hospital more than necessary.
- **Placenta clinic**: Specialist ultrasound scans for the diagnosis of an abnormally invasive placenta.
- **Multiple pregnancies**: care for complex twin pregnancies, triplets, and quadruplets etc.
- **Genetic counselling**: diagnosis and prevention of inherited and genetic fetal conditions.
- **Non-invasive prenatal testing (NIPT):** A blood test in pregnancy can identify a small amount of the baby's DNA in order to diagnose genetic conditions, such as Down's syndrome or rare inherited disorders.
- **Invasive diagnostic tests**: These are tests where a thin needle is inserted into the womb to obtain a sample of amniotic fluid (**amniocentesis**), placenta (**chorionic villous sample** [CVS]) or umbilical cord blood (**cordocentesis**).
- **Fetal therapy**: **fetal transfusion**, a life-saving procedure for unborn babies who suffer from a serious blood condition and **fetal shunt insertions**, where abnormal fluid inside a baby's body is removed to allow normal development.
- **Fetal Surgical Clinic:** Care during pregnancy and delivery in cases where the baby will need surgery after birth.
- **Preterm labour clinic**: treatment to prevent premature birth where families have had a previous premature baby, or those who have risk factors.