User journey for maternity
(summary taken from the LHCRE assurance document)

This user story looks at the high-level cross-Wessex border maternity journey. We are developing more focused sub-use case stories that will link to this summary.

The context

Individuals who are identified as having fetal abnormalities during pregnancy will move from a community midwife led pathway to a specialist care pathway, often involving two care teams in different geographical locations, supporting them through their pregnancy journey.

Mothers within a fetal medicine pathway will undergo an increased number of appointments and procedures with their care teams, generating a significant amount of additional pregnancy information. It is often the mother's responsibility to be the anchor point in her maternity care, carrying her medical notes and sharing these with the clinicians involved within her care. Onus is placed on the mother at an already difficult and challenging time, and the failure of the system and clinicians to share information in a timely and accurate manner, puts additional undue pressure on the patient.

Fetal medicine can become a requirement at any stage in a pregnancy, from a pre-existing condition to an abnormality or issue that occurs with the fetus.

Now read Jane's story.

Jane is a 38-year-old single woman living in Poole, Dorset who is going through her first pregnancy following several rounds of IVF. She has anxiety and high blood pressure and has prescribed medication for both.

She has a straightforward early pregnancy, self-referring to her **local midwifery team,** and being allocated to a midwife. Her current medical history results in a diversion to a **consultant led pathway**, which increases the number of appointments Jane is required to attend.

At 20 weeks, Jane attends her detailed anomaly scan, at which point a congenital heart defect is detected in her unborn baby. She is immediately referred for fetal medicine support at **Princess Anne Hospital, Southampton.**

For the duration of her pregnancy, Jane receives dual support from both her **local and remote (cross-border) specialist midwifery teams**. She is subjected to increased numbers of appointments, assessments, and tests; these take place in a range of settings both locally (Dorset) and further afield (Hampshire).

Jane's anxiety issues continue and heighten through her maternity journey and she seeks additional support from her **GP.**

Her son is born via an early planned C-section in Southampton and he immediately undergoes corrective surgery, which is successful, but requires extensive ongoing treatment. Jane has no further complications and is discharged home, where she continues to be supported by her **local midwifery team.**

Janes story is predominantly about cross-border maternity care, with fetal medicine being the primary reason for this need. This is a genuine cross-border flow that occurs within the Wessex region for expectant mothers requiring additional specialist support.

What is the current situation across Wessex?

University Hospital Southampton NHS Foundation Trust (UHS), specifically Princess Anne Hospital, is the dedicated tertiary centre for all fetal medicine cases within Wessex. Expectant mothers diagnosed with fetal abnormalities will be referred to UHS for specialist treatment, which will result in the mother undergoing both local midwifery-led care and specialist care from her fetal medicine team. In the case of Dorset residents, this will result in a cross-border transfer, with the mother interacting with two different Local Maternity Systems (LMSs) during her pregnancy.

Both Dorset and Hampshire LMSs are currently procuring new maternity systems. There is currently a mixed estate of maternity systems in place, with one acute hospital having no electronic maternity record. Mothers are required to carry their maternity notes with them to appointments, and where these are not available, clinicians can spend a considerable amount of time following up details or repeatedly collecting the information from the expectant mother, impacting on effective or suitable care planning and delivery.

The lack of information sharing between LMSs and the tertiary team also result in unnecessary repeated procedures for an expectant mother; Blood tests, sonography scans etc. This also leads to clashes with appointments, with the mother required to manage this, and can often result in Did Not Attend (DNA), further costing the NHS. After birth the baby can require additional treatment for a prolonged period, which will often mean the mother and baby are separated. The mother is heavily reliant on the neonatal team to provide information about the condition and status of the baby and details often not known by the local maternity team.

What Wessex Care Records wants to achieve

A woman pregnant with her first child is receiving antenatal care in Dorset where she resides. She has been diagnosed with anxiety and high blood pressure prior to pregnancy, conditions which are being managed by her GP. Her midwifery team is already aware of pre-existing conditions and medication prior to the first appointment, thanks in part to the patient providing information via her personal health record and the GP record which are held within the shared care record. Conception was by NHS funded IVF, the details of which are also available via the shared care record.

At her 20-week detailed anomaly scan an abnormality is detected with her fetus. The woman is immediately referred to St Anne's Hospital, Southampton, the fetal medicine tertiary centre for Wessex.

The maternity team in Southampton can view her shared care record from Dorset, enabling them to see her medical history, medications and associated allergies, along with all tests conducted and results to date. There is limited time available, so this means there is no need for the mother to repeat details or retell her story.

With this information, the team in Southampton can immediately devise a maternity / pregnancy care plan and birth plan that can be shared and jointly managed with colleagues in Dorset via the shared care record.

During her pregnancy, episodes of increased anxiety can be managed cohesively by all parties involved in her care, including her GP, through the shared awareness of each other's involvements, clear plans and detailed medication summaries.

The mother, through her personal health record, can track progress of her maternity journey, view the same medical information as her clinicians, and interact with those providing her care, further helping to reduce her anxiety and provide confidence in the care she is receiving. Medical appointments are accessible to all parties, reducing appointment clashes, and enabling joined up planning of activities.

Post-birth the mother returns home to Dorset, whilst her baby remains for a period under neonatal support in Southampton. During this period, all parties, including the patient, can keep track of the baby and any procedures or additional support required.

The mother's post-natal support is provided by her local midwifery team, always joined up with colleagues in Southampton. Early referrals can be made to the appropriate perinatal mental health support services, based on well informed pre, during, and post birth information.

The baby returns home and the mother returns to full support from her local midwifery team. Her health visitor can regularly check on mother's progress via the patient's use of the personal health record.

Future pregnancies can be managed with a clear history, reducing the burden on the patient to provide the information again.

All clinicians involved in the patient’s care have access to a single, electronically held, medical and maternity record. This data to include, but not limited to; patient demographics and wishes, medical history, current and historical medications and allergies, appointments, activities and investigations, pathology and radiology including results and imagery, assessments and care plans, current and historic clinical involvements and role, social care involvement and activities.

Patients will have increased levels of awareness, control and input into their care through a shared common platform.

- Clinicians, irrespective of setting and geographic location, will be able to access the same level of information without requiring a patient to retell their story, or the need to re-key information into secondary systems.

- A patient’s full medication history, irrespective of the prescribing body, is presented within a common interface, enabling all clinicians to have a shared awareness of historical and current medication.

- Clinical procedures are not having to be replicated due to lack of information sharing

- Information is by default, held and exchanged in electronic format;
    - Making information clearer
    - Information being available in near or real time
    - Reducing the burden on the patient to carry physical notes

> “As an expectant mother requiring fetal medicine support, I want all clinicians involved in my care to have access to my medical and maternity record (including history), irrespective of their geographical location, so that the care of my baby and me, is managed in the most efficient and medically safe way without requiring me as a patient to be responsible for the repeated carrying and passing of information.”