

Co-designed solutions:
'Nobody's Patient' #MatExp

Best practice case studies



London Clinical Networks



WHOSE SHOES![®]

March 2017



INTRODUCTION

London Clinical Networks

The London Maternity Clinical Network aims to improve maternity user experience and involvement across London. Aligned to this, the network worked in collaboration with Nutshell Communications and five hospitals in the London region to pilot *Whose Shoes?*[®] user experience workshops 2014 - 2015.

These workshops provided participants with the chance to explore local concerns, challenges and opportunities, working together to achieve positive change. Nine months after completion of the pilots, the London Maternity Clinical Network published a booklet of best practice case studies (<http://bit.do/matexp-case-studies-1>). These were quality improvement solutions, generated collaboratively with women at the workshops, which had the potential to be easily replicated by other organisations.

Developing and testing our crowdsourced material for the 'Nobody's Patient' project has given us the opportunity to identify existing best practice as well as develop some new co-produced solutions to improve care for women and families in our three groups:

- Families with babies in neonatal units (NNU) and paediatrics.
- Women faced with an unexpectedly serious illness, sometimes life threatening, in pregnancy or the immediate postnatal period.
- Women who miscarry in the second trimester.

This is a sample of just a few of the actions that have resulted from 'Nobody's Patient'; many other pledges are still in progress. We have chosen these ideas as we feel they are relatively easy for other organisations to implement. Due to the shorter time frame of our project, some of these solutions are only just underway so this is by no means an end point, however we hope that sharing them at this stage will help organisations get a jump start on some simple actions that will improve care for women and families. We have also chosen to include a small number of ideas that are not the direct result of 'Nobody's Patient' but which we have come across during the project and feel are worth sharing.

We are very grateful to all the organisations and individuals who have been willing to share their experiences in putting these solutions in place. We believe sharing the challenges will make it easier for others to successfully replicate the solutions and improve care for women and families.



Some of the #MatExp gang at the Kingston Hospital 'Nobody's Patient' event, in front of one of Anna Geyer's wonderful graphic records

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WHOSE SHOES?®



To co-produce a more empathetic risk letter from the maternity unit

Aims

Letters are sent from the 'risk midwives' to families in the event of an incident warranting investigation or in the event of a stillbirth or neonatal death, informing them of the investigation and inviting them to ask questions.

By involving women in the writing of the letter, we hoped to make the letter more empathetic to minimise distress as well as to encourage families to feel able to ask questions as part of the investigation.

Rationale

Already implemented.

Development

Developed with the assistance of Leigh Kendall immediately after the 'Nobody's Patient' workshop at Kingston Hospital.

The letter templates can be downloaded here:

<http://bit.do/risk-letter-pre-1>

<http://bit.do/risk-letter-pre-2>

<http://bit.do/risk-letter-post-1>

<http://bit.do/risk-letter-post-2>

Challenges

None, very easy to change standard letter.

Outcomes

Following the implementation of the new letter template, we have received an increased number of responses to our letters. Within the new template, it is much more explicit that the family needs to confirm if they would like a copy of the report and a special appointment to discuss the outcome.

This means that once the investigation is complete, there is no delay in the family receiving the reports and appointments as we are already aware of their wishes and therefore can arrange their appointments to tie in with the completion dates for the reports.

In addition, the letter is more explicit in informing the families that we value their input. In consequence, we have found that more families are keen to be actively involved, including sending their own timelines of events and sending in lists of questions for the panel to consider.

Top tips for providers & commissioners



As we said in the introduction, the case studies are still evolving.

What would be most helpful here?

This makes for a much for robust investigation process and the families can bring poignant information to the forefront. The main aim is that we hope the letters display more sympathy and empathy to the families involved and, although this cannot be measured, the increased response rate and communication with the families leaves us feeling positive that this is the case.

Contact

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Family Integrated Care on the neonatal unit

Aims

To implement a Family Integrated Care model on a 22-bedded neonatal unit (NNU). Prompted by the work at the neonatal unit in Mount Sinai Hospital in Toronto.

Rationale

It is strongly supported that parents should be at the centre of the child's care. However, within neonatal care, health professionals have assumed total care of the baby, whilst parents are passive and often feeling like onlookers in their baby's care.

In considering the evidence supporting the UNICEF Baby Friendly Standards and the Bliss Family Friendly audit tool, the Family Integrated Care project looked to address this.

Development

Using a multi-disciplinary team approach, a staff education team was put in place to support and enable staff to move from prime care giver to 'parental coach'. A formal parental package was developed. This provided explicit guidance for staff and parent responsibilities, one-to-one parent education and competency assessments.

Formal teaching sessions were and still are delivered 5 days a week, from a multi-professional team. Developmental and kangaroo care was promoted. Parents were supported in learning traditional nursing skills to care for their baby e.g. taking temperatures, giving medication, weighing and recording feeds. In order to facilitate them in becoming confident and fully involved in their baby's care, parents were asked to commit to spending at least 6 hours a day on the NNU.

Challenges

This was not only a change in practice, but a change in culture. Staff engagement was challenging.

Introducing new paperwork and difficulties releasing staff for training added to this. Staff raised concerns over 'allowing' parents to be more involved in caring for their baby, how that altered the way they practised and how that affected professional registration.

Outcomes

Early data suggests that the approach led to

Top tips for providers & commissioners



Preparation is the key - ensure you have a firm foundation to the project and a multi-disciplinary approach.

Give staff time to talk about their concerns.

Celebrate your achievements - it's too easy to criticise your failings.

improved breastfeeding rates at discharge and reduced length of stay as well as reduced parental anxiety following discharge. Staff satisfaction has increased.

Contact

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ITU checklist for severely ill postpartum women who wish to have their babies with them on the ward

Aims

Sometimes a mother needs specialist care immediately following birth, either at the hospital where she has recently given birth or, less frequently, at a different Trust. Ideally, a mother and her baby should not be separated.

The aim was to produce a checklist that can be completed by staff when a baby accompanies its mother on a non-maternity ward or the ITU, to ensure staff and the woman's family are clear on what is expected of each other during the woman's stay.

Rationale

The 'Nobody's Patient' project highlighted that women and their families value staff welcoming the new baby on to the ward to spend precious time with the severely ill woman. Only the partner and the family of the severely ill woman take care of the baby. If necessary, breastfeeding can continue and the bonding and attachment between mother and baby is ongoing during this time.

It is vital for the woman's social / psychological wellbeing that she is with her baby and, if she has other children, that they can visit.

Development

- In-depth discussions with Maternity, Obstetrics & Gynaecology and ITU regarding logistics.
- Challenging assumptions and being realistic with small changes that can make enormous differences to care and experiences e.g. siblings come to hospital to do homework with Mum, or read a book, or watch a movie on an iPad.

Challenges

- Does the woman need a postnatal check-up?
- What are her physical capabilities?
- Will she be a long-term inpatient?
- Is there a clinical need for mother and baby to be separated?
- Challenging long standing views on care.
- Ensure that the family are supported as the main carers of the baby.
- Women may get overlooked by maternity as they are not on the maternity ward, therefore

Top tips for providers & commissioners



Allocate a family advocate for the woman.

Confirm what her wishes are for feeding the baby.

Produce a 'memory log' or photos, cards / videos / diary, especially if the woman may die.

If the baby is not in the hospital, it is important that staff are aware of when the baby will be visiting so that the baby is not turned away by staff who are unaware of the arrangements.

Provide support if the woman wants to express breastmilk – maternity should be able to provide an infant feeding specialist to help with this.

staff need good communication and hand over of care at every shift change.

These robust procedures ensure the best possible care and experience for the woman and her family. Ward staff may be focused on the condition, and may not see the need / understand the family perspective.

'Ownership' of the woman by a named clinician / midwife, who will book the woman and baby onto the ward and liaise with ITU / Oncology / specialist staff regarding care requirements.

Difficulties in breaking down barriers to old ways of thinking / doing things can be positive in the future for other women.

Outcomes

Women and families value this time which may be short depending on the prognosis. Women value small events, such as weighing the baby or the NBBS test being done in front of her whilst she is in hospital.

Take a look at our checklist:

<http://bit.do/ITU-checklist-postpartum>

Contact

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Follow up of women cared for in High Dependency

Aims

To improve the experience of women who are cared for in the High Dependency Unit (HDU) both during their stay on the postnatal ward and after discharge from hospital.

Rationale

Women felt routine postnatal care was not sufficient for their complex medical and emotional needs after severe illness in pregnancy or immediately after delivery.

Development

Provide all women with a written discharge letter and a copy that goes to their GP and community midwifery team. Phone all women 2-3 weeks after they get home.

Offer all women an outpatient follow up / debrief with the consultant obstetrician. They get a midwifery phone call first to see how they are, how the baby is (particularly if they delivered prematurely) and check that the date is suitable.

Challenges

We pledged to visit women on the postnatal ward after they are transferred out of HDU. This is part of broader work to improve discharge from HDU and communication.

This was often not possible as the midwife caring for the woman was off the following day or the delivery suite was busy.

The HDU nurses and midwives work downstairs in the HDU rooms on their labour ward. They are expanding the numbers so that the HDU team will have sufficient time to be able to visit the women on the postnatal ward (on a different floor) the day after they are discharged from HDU. I believe this will be in place in 3 - 4 months once the new staff have started.

Outcomes

We now provide a written summary of the HDU admission and events. The feedback from women has been positive:

"I don't have to tell the same story over and over again..."

Communication with the community midwifery teams and GP has also improved. Telephone follow up is now in place.

We have provided support and helped many

Top tips for providers & commissioners



Work across boundaries: we work with our critical care service in staff training and development. All midwives in our HDU team spend time working with nurses in critical care. Nurses working alongside midwives are an important part of our team.

Listen to the stories of your women who have experienced critical illness. We have learned that often the most difficult times and need for support occur after they have been told 'they are better'.

Following up at a time that suits them is so important as events are difficult to remember and most have the need to put together 'the story' of what happened.

Invest in your obstetric HDU team; women who are critically ill in pregnancy need specialist midwifery and nursing care. A core team of nurses and midwives with these additional skills, working together with obstetricians and anaesthetists, can reduce unnecessary admissions to general critical care allowing women to stay with their babies. A team with a strong identity can provide continuity of care beyond the admission with critical illness.

women resolve problems without needing to attend A+E as an emergency.

A woman who was unable to return immediately to her own home, had difficulties in registering as a temporary patient at her parents' address:

"I was going round in circles and no one would listen. They wanted me to come in person to fill in forms and I could barely walk at that time..."

We liaised directly with the local surgery and resolved the issue for her. The contact also provides emotional support in the first difficult weeks at home:

"It was just nice to hear a familiar voice and feel like I could call if I needed to..."

Contact

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Free text box on the maternity self-referral form

Aims

To improve communication of what is most important to each individual woman so that staff can best cater to her needs and avoid her having repeatedly to share sensitive or upsetting information.

Rationale

To provide a free text box on the maternity self-referral form so that women are able to communicate clearly to staff what is important to them.

In the month of January 2017, we received 746 referrals; out of these 326 were self-referrals via the maternity website. From these self-referrals, 87 added 'what I would like you to know about me...' comments.

Development

Add free text box to electronic self-referral form, titled 'what I would like you to know about me...'

Challenges

The self-referrals are taken from the maternity website and added into the maternity dataset. A mail merge has been developed so that all the information added from the women are transferred on the referral form for the booking midwife to review on the midwifery assessment.

There are various details that help the admin team allocate to a certain consultant, avoid dates and times that are not suitable and for nuchal appointments to be scheduled.

Outcomes

Since the box was made available in November 2016, there have been a total of 338 comments added by our women. There have been a range of issues included. Clinical comments include; anxiety following previous birth experience, medical conditions and previous pregnancy complications and IVF treatment.

Non clinical comments include documentation of booked annual leave and working days to be avoided for appointments, dates of moving house and need for assistance with language.

We have also had personal comments, such as disclosing experience of sexual abuse or domestic violence, which have caused conversations to

Top tips for providers & commissioners

What would be most helpful here if other organisations wished to replicate this?



be opened in a different way and really helped promote personalised and sensitive care.

The practical information provided assists the team when the booking and nuchal appointment is made. All the women are contacted to ensure that the date and time is suitable to help us reduce the cancellation and re-booking rate. The comments do assist in this process. Ideally we would like all the GP referrals to come via the website and to adopt this comment box into these referrals too.

Contact

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Komal reads her pledge at Kingston Hospital

Introduction of diaries / notebooks for each baby in NNU

Aims

To improve communication between staff and parents of babies admitted to the neonatal unit.

Parents can write their questions down when they think of them in a diary / notebook. They also use it as a journal to document their journey, especially when it is a long or complicated one.

Staff can also contribute, writing a more personal update rather than an official assessment and record of care.

Rationale

Feedback from parents highlighted numerous communication problems between staff and parents about their baby. This could lead to parents feeling uninvolved in their baby's care or being unaware of any issues or investigations that had happened when they were not present.

It could also lead to staff not being aware of what parents felt able to manage or what additional emotional pressure they may be under. A trial of a two-way diary or notebook for each baby, in which parents and staff could write, was suggested.

Development

This has gone through several rounds of design and is as yet being finalised. In the meantime, blank journals are given to mothers when we think it is likely to be a long journey.

Final version will be sponsored by Born Too Soon (our local neonatal charity) and a printing company has offered cost price for printing.

Challenges

Staff sickness halted the design.

Too many opinions lead to several design changes.

Question of confidentiality, if staff write in it, is currently being looked at.

Outcomes

Once completed, it will require a change of practice for nurses to write in diaries. However a keepsake to remind parents of their journey, the memories of which can become blurred, has been highlighted as important by our parents.

Parents using the blank journal have said they look forward to writing in it and some use it more privately so they can write truthful notes about their

Top tips for providers & commissioners



Start with a blank journal and then get tips from parents on what information they would like in it or, if they prefer, a separate information booklet.

Use your charity logo on the front if sponsored by your charity, this may prompt parents to consider fundraising in the future.

feelings and emotions at the time.

Contact

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Changing the language we commonly use

Aims

Changing language that is commonly used by professionals that can have a negative impact on women and families.

Rationale

The workshop has really made us think of the importance of language and the impact these words have when they are remembered in vivid detail by the women and their families.

Development

Produced a poster to be displayed in clinical areas and on the maternity service facebook page (see opposite).

Challenges

Some of the language changes are a challenge for the medics and midwives but we are trying to kindly remind each other and it has really made us think of the importance of language and the lasting impact it has on women and their families.

Outcomes

The poster has been well received by both staff and the women and the message is travelling! One of the team went to a workshop at Sheffield University and the midwives there had seen it and were planning on doing something similar!

Contact

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Jo Osborne, Consultant obstetrician, Colchester Hospital University NHS Foundation Trust

Top tips for providers & commissioners

What would be most helpful here if other organisations wished to replicate this?



Colchester Hospital University NHS Foundation Trust

We are listening...

Language is important so we are changing ours

We will “recommend” rather than allow.

There are no “failures” only **delays**.

Sometimes induction can be “**ineffective**”.

Sandra Gosling, Clinical Specialist Midwife Delivery Suite, January 2017



This graphic record is an example of the excellent work by New Possibilities. Graphic recording of key messages is an essential part of our #MatExp Whose Shoes? workshops and action-focused approach.

Case study 8: Kingston Hospital NHS Foundation Trust



Use of iPads to Skype to enable mothers to see their baby if separated for medical reasons

Aims

For women in ITU or HDU who have a baby in NNU, or need to be separated for medical reasons, to be able to see their baby via Skype and have an update from the nurses.

Rationale

Separation of the mother and baby should be minimised if at all possible, especially in the early hours and days after delivery. Where it is not possible to keep mothers and babies together, because of complex medical needs of both, use of technology is a reasonable alternative that may provide reassurance and promote bonding.

Development

We have reallocated the use of two iPads which were once purchased for a different use. The stands have been designed and are awaiting order. 'Born Too Soon' are purchasing these for £570.00.

The hold up at the moment is with IT who have yet to approve a patient-use IT system using the hospital WiFi. We hope this will be resolved shortly.

Challenges

Patience with the processes that need to be followed. IT Governance have other priorities but we will get there eventually.

Outcomes

I can see its immediate benefits each time we have an admission and the mother is unable to come to NNU.

Contact

Marie Richter

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Top tips for providers & commissioners



Go to IT Governance immediately as this takes the time.

If you have the funding, buy a SIM card and contract for each iPad so they can be owned by the charity and are outside the need for IT Governance. However this may lead to maintenance problems.



Case study 9: St George's Foundation Trust



Home blood pressure monitoring in pregnancy: extending antenatal monitoring into the postnatal period

Aims

To improve the postnatal experience of women with hypertension in pregnancy. In particular to allow women a degree of control over their blood pressure (BP) management.

Rationale

Women felt they 'fell between the cracks' on going home following pregnancies complicated by pre-eclampsia or hypertension.

Several women in our user feedback described needing to attend A+E out of hours with poorly controlled hypertension and struggling to access support.

Development

Provide all women with a written management plan for their blood pressure with a copy to their GP and community midwife.

Provide a contact number so that women or their community midwives can contact the specialist Mulberry maternal medicine team for advice and obstetric input as needed.

Offer access to the Obstetric Hypertension clinic to postnatal women who are struggling with BP control in the first few weeks.

Extend the successful antenatal programme of home blood pressure monitoring to the first two weeks postnatally.

The St George's 'Hampton Medical' app allows our Day Assessment Unit (DAU) staff to remotely review all recorded home BP readings and provide advice. We plan to allow women to keep their monitors for a further two weeks and provide a day assessment telephone review 3 - 4 days postnatally, with support through our DAU. The app was developed by St. George's with a health innovation fund but can be used by other organisations. Download the app by searching 'Hampton Medical' in the Play store or Apple store.

Challenges

Finding suitable time and space in our busy Day Assessment Unit to see postnatal women.

Staffing challenges mean postnatal home BP monitoring is a work in progress. The use of smartphones and remote monitoring via the Hampton home blood pressure app allows follow

Top tips for providers & commissioners



Postnatal care remains an under-resourced area. Women with complex pregnancies require support and monitoring that extends beyond delivery.

Involve your teams on the ground in developing any service that utilises new technologies. The programme of home BP monitoring has been driven by our staff and is designed to extend the clinical service we provide.

up reviews by telephone. Women have told us that they value this ongoing support and we are seeking to overcome the barriers to extending antenatal monitoring into the postnatal period.

The use of new technologies does not replace the need for clinical care and teams need to be involved in the design of any programmes using these.

Outcomes

We have had good feedback from women and community midwives on the developments so far.

We are seeking to engage with our local primary care teams and seek their views.

Contact

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Newborn Thermal Care Safety Bundle

Aims

To prevent avoidable admissions to NNU for babies with a low temperature and / or low blood sugar level.

Rationale

In the UK, between 50 - 60% of admissions to neonatal units are term with hypoglycaemia being one of the most common reasons. Hypoglycaemia is found to be significantly more common in hypothermic babies.

Admissions are a cause of harm and separation of mother and baby.

A baby is kept at a constant temperature inside the womb during pregnancy (38°C inside) and there is no need for thermoregulation until the baby is born. In order to keep warm, the baby will need to use nutrients or alternatively use its brown fat storage.

As the nutrient intake of a baby in the first few days is minimal and the baby has not been exposed to colder environments before, it may cause the core temperature to drop. When temperature drops, the baby is less likely to thrive well and likely to feed poorly. This can lead to further temperature issues, jaundice and lethargy, weight loss and lower blood glucose levels.

By supporting the baby to keep an optimum temperature, the baby can feed better and use its energy to grow. Some babies struggle more with this process than others as some will be born with a lot more brown fat tissue to be used in those first few days whilst others have a lot less, putting them at a higher risk.

By assessing each baby's risk at birth, a suitable care plan can be initiated. Different coloured hats serve as a very good visual reminder to everybody involved in baby care of each individual baby's needs.

Development

Royal Surrey County Hospital developed the Bobble Hats initiative and this great idea was brought back by a senior midwife to implement the project in Derby Hospital as part of the Maternity Safety Improvement Plan.

Another senior midwife with a specific interest in breastfeeding took on the initiative to begin the process. However, we soon found out that there

Top tips for providers & commissioners



Include members of staff from all different levels and make sure there are open discussions to identify barriers in the early stages. Take the time to provide information and training and to overcome those barriers and increase buy-in as it helps with implementation.

were challenges to be overcome in order for the initiative to be positively implemented and work well.

Guidelines and Audit then became involved and steps were taken to overcome these barriers:

- an audit was carried out
- information leaflets / posters to raise awareness on the importance of keeping baby at the 'right' temperature were developed
- the initial project was amended to reflect hospital guidance and changed into a total care bundle tool
- stickers were developed to indicate the start and completion of a care bundle
- training was provided.



Cindy with baby and hats
Picture courtesy of Derby Teaching Hospitals NHS FT

Challenges

The biggest challenge was that staff were concerned about the possibility of overheating babies if hats were used routinely on every baby, due to a perceived increased risk of cot death. In other European countries however, it is standard procedure for babies to wear a hat in the first

Newborn Thermal Care Safety Bundle

few days of life until they have stabilised their temperatures and weight.

Research did not show a link with this to cot death; large research projects worldwide actually showed that hypothermia and hypoglycaemia in newborn babies was an underestimated problem and a cause of preventable morbidity.

We then did a small audit on our wards in the warmest weeks of the year by taking the temperatures of babies on our wards, the temperatures of their cot and collecting the data. We could then actually showed our staff that all our babies had a temperature below 37°C, except for the ones that were skin to skin, and that a majority had a temperature between 36.0 - 36.5°C.

To acknowledge the fact that a high temperature is not a good sign and that both a high as well as a low temperature can be signs of infection with the baby's body shutting down, we developed a 'goldilocks poster'. Information to make sure baby is not too cold, not too warm but just right! The posters were put up on the wards and in NICU.

On every training day, we reinforced this message and staff were noticeably changing their opinions and supporting the project.

The next challenge came from community midwives as they struggle to take temperatures in a home situation. We again supported them with audit and made sure techniques were adjusted and

awareness was raised to:

- take a temperature more often in cases where a baby was not thriving or feeding well.
- think about the possibility of a temperature problem sooner as it is an easy one to solve and could possibly prevent admission and, with that, the separation of mother and baby.

Another challenge was the number of hats needed to start the project so we looked for help from the media and had a lot of support.

Outcomes

We ended up with fantastic team effort and positive input from all members of staff. Parents were asked on a regular basis and the feedback was all very positive.

So far, we have not had any DATIX reports of a baby avoidably being (re)admitted with a low temperature and / or glucose level.

The implementation appears to be a success with all babies having been risk assessed on labour ward and the appropriate care plan initiated. We intend to monitor this closely as well as the impact on admissions.

Contact

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Poster courtesy of Derby Teaching Hospitals NHS Foundation Trust

London Clinical Networks

With special thanks to the London Clinical Networks who produced the original case studies booklet based on learning from the five original *Whose Shoes?* pilot workshops across London and who have fully supported the whole #MatExp project, including this second phase as part of the NHS England #MatExp Challenge Fund to develop the 'Nobody's Patient' resources.