NHS
Devon
Clinical Commissioning Group

Better Births in Devon

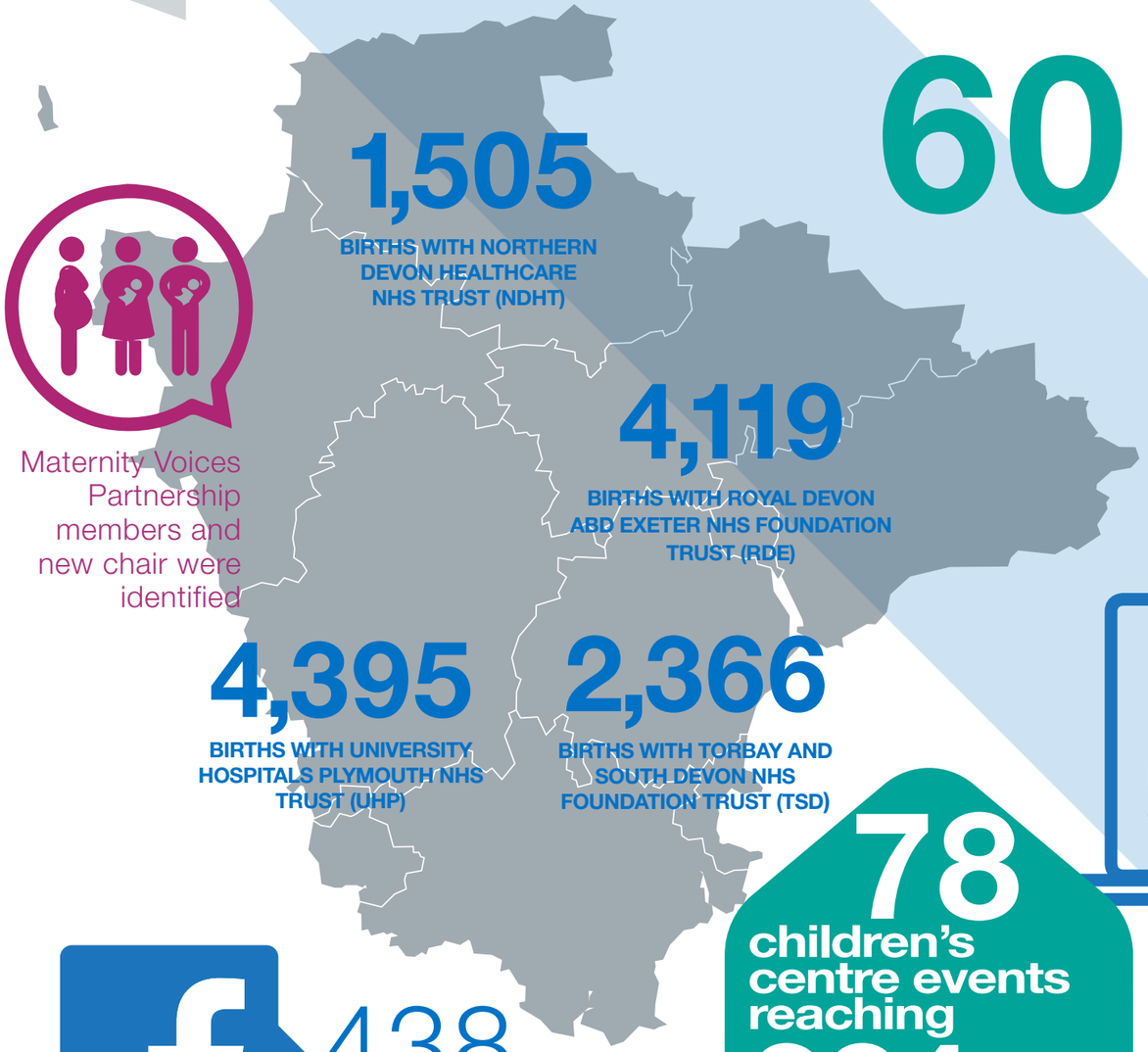
Engagement Report

June 2019

CONTENTS:

1. Headlines
2. Background
3. Our approach
4. Learning from the engagement
5. Who was involved (demographics)
6. What you told us - the key themes
7. What you told us about the choice of where to give birth
8. What you told us about making birthing plans
9. What you told us about continuity of care
10. What you told us about your antenatal experiences
11. What you told us about your postnatal experiences
12. What you told us about perinatal and postnatal mental health
13. Information provision
14. Key Findings
15. Acknowledgements

8 WEEK ENGAGEMENT



1,505
BIRTHS WITH NORTHERN DEVON HEALTHCARE NHS TRUST (NDHT)

4,119
BIRTHS WITH ROYAL DEVON ABD EXETER NHS FOUNDATION TRUST (RDE)

4,395
BIRTHS WITH UNIVERSITY HOSPITALS PLYMOUTH NHS TRUST (UHP)

2,366
BIRTHS WITH TORBAY AND SOUTH DEVON NHS FOUNDATION TRUST (TSD)

Maternity Voices Partnership members and new chair were identified

60
children's centres and voluntary groups involvled across Devon

29
FOCUS GROUPS

1,370
people completed an online survey

20%
of the 12,500 births in Devon

2,267
people gave feedback

78
children's centre events reaching
324
people

438
engagements on the dedicated 'Better Births in Devon' Facebook page (use insights on most talked about topics)

300+
people registered their interest in being further involved in the development if maternity services

FOREWORD

Over 12,000 babies are born in Devon every year, but if you consider how many people it involves bringing a baby into the world you would find four times that amount of people involved in the journey.

Parents, siblings and health professionals all play a big part in a baby being born - bringing together experience, expectation, anticipation and excitement.

Its important that people have the opportunity to share their experiences, good or bad and that we continually learn from those.

What we have heard through the Better Births work gives us a great starting point and we will continue to build on this by encouraging more people to share their experiences through the Devon Maternity Voices Partnership (MVP).

Charlotte Burrows,
Chair of Devon Maternity
Voices Partnership (MVP)

It's really important that we plan and design maternity services around those who need to use them, and who could be better to ask than those who have had a baby recently, and those who have other recent experience they would like to comment on. In Devon, we feel that feedback from parents and families is invaluable and it's vital that we learn from this.

Rachel Sturley,
Clinical Lead for
Local Maternity Services in Devon

BACKGROUND

Over the summer of 2018, the Local Maternity System, consisting of, health and care organisations undertook 8 weeks of intensive engagement to gather the thoughts, experiences and views of parents about births in Devon.

During the engagement we explored the recommendations of NHS England's Better Births review. This national review focuses on personalised care, continuity of carer (i.e. seeing the same health professionals), postnatal and perinatal mental health care, digital records and the wider planning of maternity services.

Before developing the maternity transformation and implementation plan around these recommendations we felt it was important to understand the views of parents and families.

In this report we describe the engagement approach we took and present the themes that people shared with us.

This report is being published now alongside the LMS Transformation Plan for Devon, which was approved by NHS England in March 2019.

Listen to Charlotte's story and her experiences of the Better Births in Devon engagement

SUMMARY OF KEY THEMES AND FINDINGS

Choosing where to give birth

Choosing where to give birth was a key topic of conversation. Depending on where people live in Devon choices are varied and, in some places, limited.

People who opted for home births liked the less clinical environment, finding it less stressful. However, information was limited early on in pregnancy and often hospital birth was presented as the default option. There was not enough information, advice and reassurance about the safety of home births which many women would have found helpful.

Those who opted to birth in a Freestanding Midwifery-Led Unit (FMU) liked the in-between option of hospital and home. The units were also seen as a great place for postnatal support and care but currently under utilised. Those who did not choose an FMU said they had concerns over safety. People wanted to be closer to the main hospitals in case anything went wrong. They did not want to take the risk of having to be transferred during the birth, from an FMU to a main hospital for further interventions.

Choosing to labour at, or close to one of the four main hospitals came down to safety and necessity. Those who opted for this did so because of the reassurance it brings, to be closer to clinicians if they needed a higher level of care. For some, the choice was taken away from them because of a specific health need which dictated this as necessary.

Continuity of care

The people who look after women during pregnancy, labour and after the baby is born is very important to women and their families. Familiarity, reassurance and a 'friendly face' helps guide them through the journey.

Women want to see the same health professionals, to build rapport and feel that the person caring for them knows them and their baby. Where this did not happen, women reported having difficulties later in pregnancy or health complications that were not picked up. This often happened to women who lived in very rural areas and fell between different health providers. Most mums said that they would prefer to see the same midwife/health visitor.

Information and practice

Those who lived in very rural areas felt they often got missed or 'slipped through the net'. They were often missed for appointments, overlooked for postnatal check ups and had limited access to support i.e. breastfeeding. Often the advice they got was conflicting as they did not see the same health professionals.

Breastfeeding

Breastfeeding and support for feeding were identified as a priority area. Those who experienced difficulties also reported conflicting advice and information and lack of one-to-one support. Women described the pressures associated with breastfeeding and levels of expectation placed on them. Many attributed this as a key factor in developing postnatal mental health difficulties.

Antenatal Classes

Many people felt antenatal classes were missing a real opportunity. The information was often deemed unhelpful or not relevant. They were described as limited for women with more than one baby and lacked specificity for teenage mums. Women who were not first time mums felt it was often assumed they knew what to do. They felt something was needed for them as a group, especially for those who have had a significant gap between pregnancies.

Quality of care

The quality of care that women and families receive was felt to be "good" overall. However, where care could be improved was in relation to shared decision making, parents want to be more involved in decisions concerning them and their baby. For babies that require specialist or onward care this was cited as extremely important, as parents are very anxious.

More information and support is needed for those struggling with mental health pre and post birth. (NB: This engagement was conducted before the opening of the specialist mother and baby unit in Exeter).

Staff busyness was often mentioned, but often people could see how stretched staff are and didn't want to bother them. In some instances, this led to poor care and things being missed or overlooked.

There was praise for the professionalism, care and compassion shown by clinical staff when a pregnancy or birth did not go as planned, especially for sick babies who needed specialist care and attention.

Postnatal care

People expressed concerns about the lack of postnatal support and peer-to-peer opportunities in the community. Many cited the reduction of groups in children's centres and the impact of this on wellbeing, mental health and resilience of parent groups.

In the next few sections we go into some of these key themes and findings in more detail. Feedback has been structured using the Better Births recommendations. The questions we asked were consistent at all events across Devon.

A final section identifies any feedback that does not necessarily align to Better Births recommendations.

OUR APPROACH

We worked closely with the almost 60 children's centres across Devon, as well as community and voluntary groups to shape the engagement approach.

This engagement took a completely different approach to engagement, compared to previous work the CCG has undertaken.

The very targeted approach we took and focus on social media has helped us gain rich insight that will now bring huge benefits to the work we do and the services provided in Devon.

There were three key elements to the engagement:

1 - 'Go to them' events
2 - Social media
3 - Behavioural insights

'Go to them' events

This placed parents and families firmly at the centre of the design – so rather than asking people to attend additional events and meetings, we looked for as many opportunities as possible to reach them at places that they already visit. Stay and play, music and rhyme, breastfeeding support, healthy baby clinics are just a few examples of the types of groups we attended. The key objective of our approach was to reach as many mothers, expectant mothers, fathers and wider family members as possible. The best way to do this was at the already well attended groups that exist across Devon. We didn't want to ask parents, who are already busy and under pressure to make any further commitments.

The focus was on the experiences of maternity services and identifying any key themes that arose.

For the **face to face** conversations we had the support of our colleagues in children's services and the voluntary sector. Our approach was also informed by the existing feedback report we compiled, which pulled together previous feedback on local services from Patient Advice and Liaison Services (PALS) and Friends and Family Test, for example. This can be found in Appendix 4.

Social media

After looking at the data for births in Devon and the profiles of parents (based on MOSAIC analysis), we could see that there was likely to be an active cohort of parents using social media, in particular Facebook.

Social media channels like NetMums and National Childbirth Trust (NCT) already have huge following, and there has been a significant increase in the quantity of 'mummy bloggers'. We identified that a driver for this was because these channels offer 24/7 access to peer support, chat, advice and information sharing. Parents are often up late or through the night, and these platforms provide a place of sanctuary and support.

To facilitate **online dialogue** we made use of our existing CCG Twitter account

We knew that having an active presence online would be key. A place where parents who were unable to attend groups had the opportunity to talk to us and be part of Better Births. We understand that some parents are grabbing sleep in the day and are up at night, so this is the perfect way to reach them.

To ensure that we were (a) engaging, (b) informative and (c) authentic in our approach we posted daily and often. The people who facilitated the Facebook page and interacted on it were the same people out talking to parents and families face-to-face. They shared pictures of the venues and events attended, quotes from parents, snippets from the conversations that took place and parents often thanked the health and care professionals they had met.

An **online survey** was designed that combined qualitative and quantitative questions and a company called ICE Creates was commissioned to provide the analysis of responses and a report on the findings. A dedicated email address was also set up for people to provide feedback, or to ask questions about the process. For full analysis of the survey please see Appendix 3.

The approach was supported by a **communications plan** that was supported by a clear project identity. The range of media used included; Twitter, Facebook, websites (Devon STP, NEW Devon CCG and South Devon &Torbay CCG)

Behavioural insights

The focus of our engagement was to reach parents and their families. In addition to this we asked ICE Creates, a behavioural and social insights organisation to help us with some deeper understanding about the choices people make, their motivations, decision making processes and what is most important to them. They do this by spending time listening to small **focus groups** of parents talking about these topics.

ICE were commissioned to conduct six insight focus groups across Devon. The nature of a focus group is for it to be small and enable deeper conversations to happen and for common themes and key learning to emerge. For this reason we never had more than 10 people a session.

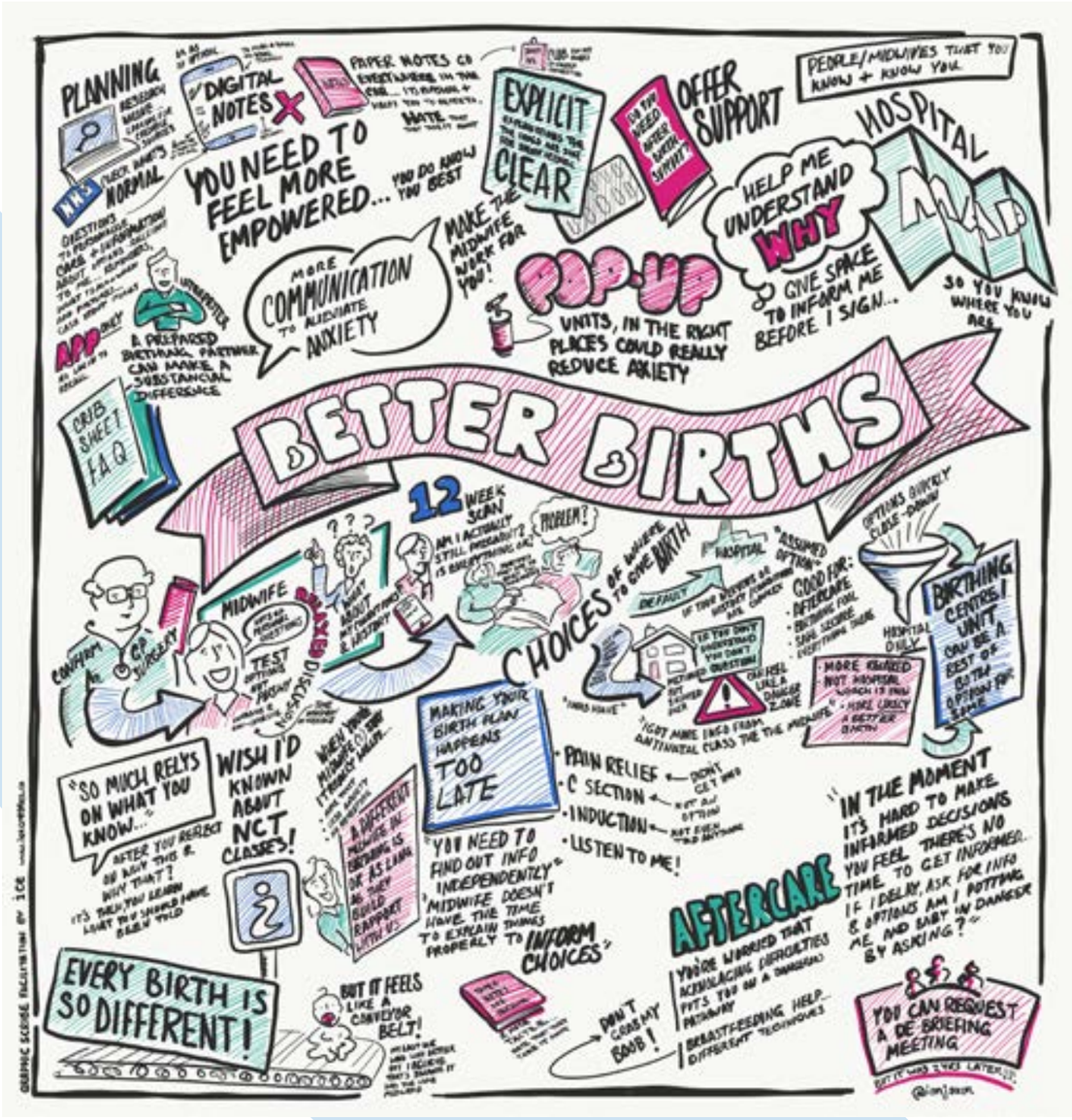
The behavioural insights findings can be found in Appendix 2.

They conducted the qualitative research to explore 5 key topics:

1. Choice – personal care plans
2. Continuity of care
3. Digital provision of information
4. Postnatal and perinatal mental health care
5. NHS personal maternity care budgets

To ensure that we had effective reach for our messaging, we worked with a wide range of partners that included:

- Health and social care heads of communications – from across the NHS and local authorities.
- Council for Voluntary Sector (CVS) in Devon.
- Healthwatch in Devon, Plymouth and Torbay.
- Specific stakeholder groups and individuals.
- CCG community representatives.



As the figures from our engagement activity show, the system wide approach has been particularly effective. For example, Tweets and Facebook pages were shared and liked widely.

438
ENGAGEMENTS

200
NEW GROUP MEMBERS

150
ENGAGEMENTS

The approach taken has created a platform that we are now starting to build on, alongside the Devon Maternity Voices Partnership (MVP).

During the engagement, over 300 people expressed an interest in being further involved in the development of maternity services. They will now be able to help us in the co-creation of local services, working as part of the Maternity Voices Partnership and alongside the LMS.

To understand how recent the experiences of people were, we asked them to confirm the age of their child/ children. This ranged from very recent i.e. those with newborns, right up to people who shared their experiences from 30 years ago. In some instances parents shared their different and often varying experiences from multiple births and pregnancies. Figure 1 provides a breakdown of the age ranges.

The chart shows that most of the feedback reported refers to experiences of services used between one month and two years ago. We wanted to focus on the feedback from people who had experienced services in the last two years.

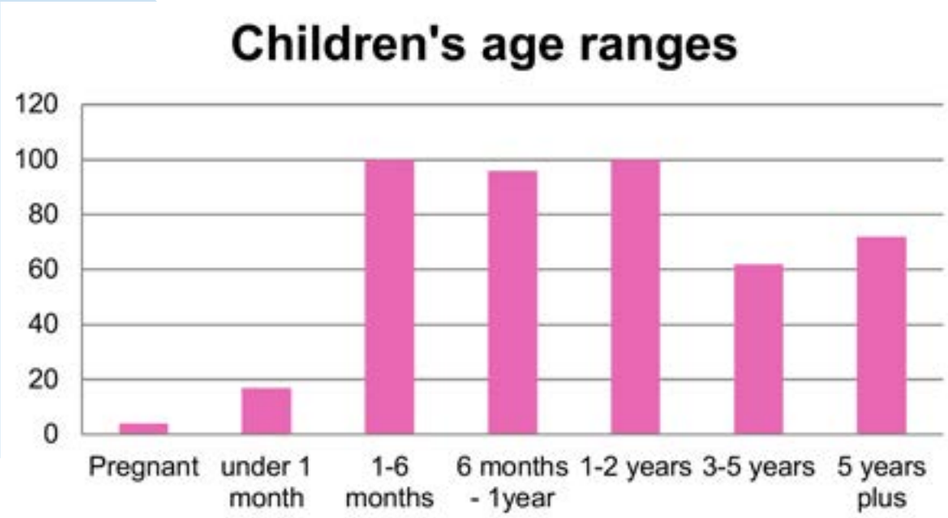


Figure 1 – Children's ages

LEARNING FROM THE ENGAGEMENT

1

The most important thing we have learned through the engagement is that it's important to plan engagement from the outset and identify where parents and their families are likely to be. They are usually busy and have limited time (often having other children to care for) so the key learning is to go to them, where they attend regularly and is familiar surroundings. Putting on additional events that they need to travel to, can be successful but its an added complication to an already busy schedule.

2

Secondly, we have found our early assumption about reaching people through online media i.e. Facebook and Twitter was correct. Often people are busy in the day but willing to engage on social media in the evening, or at an obscure time when they are looking after their new baby or older children. It has reinforced for us that presence is key, when engaging with this group of people.

3

On-going co-creation is important, parents and their wider family have views and opinions that are crucial to the on-going development and delivery of maternity services across Devon. We will do this by working closely with our Maternity Voices Partnership (MVP) and by setting up a citizen's panel online for people who have a particular interest in this area.

WHO WAS INVOLVED
(demographics)

In the survey

Respondents were asked to answer equality monitoring questions

(See Appendix 4 for the full report from ICE Creates).

Age
655 people responded to the question on age and overall the majority were aged between 26-45 years old. Figure 2 provides a full breakdown of ages.

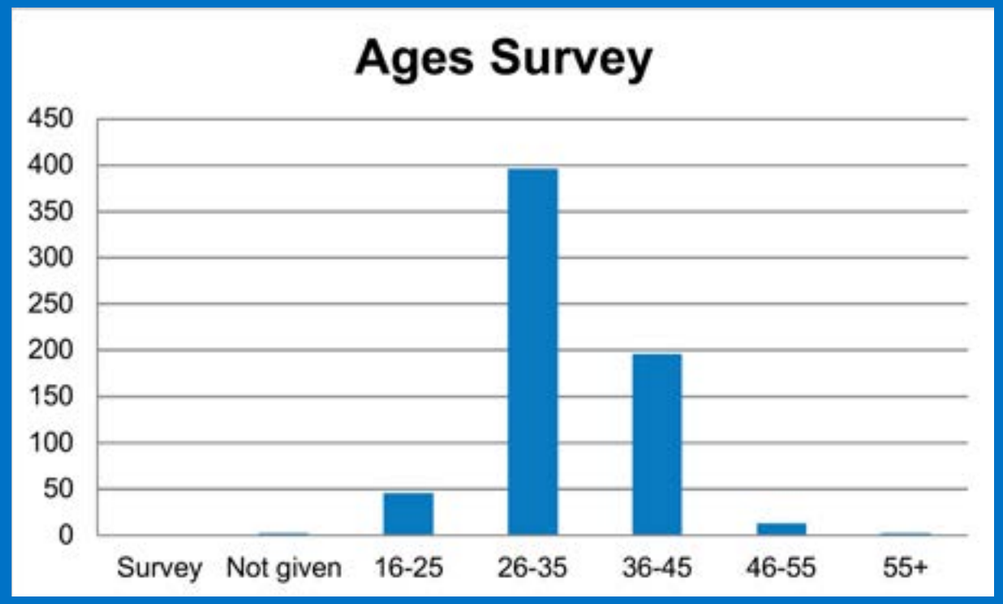


Figure 2 Age of survey respondents

Role
1366 people responded to the question about their role, the majority of respondents were mums. Figure 3 provides a breakdown of all roles.

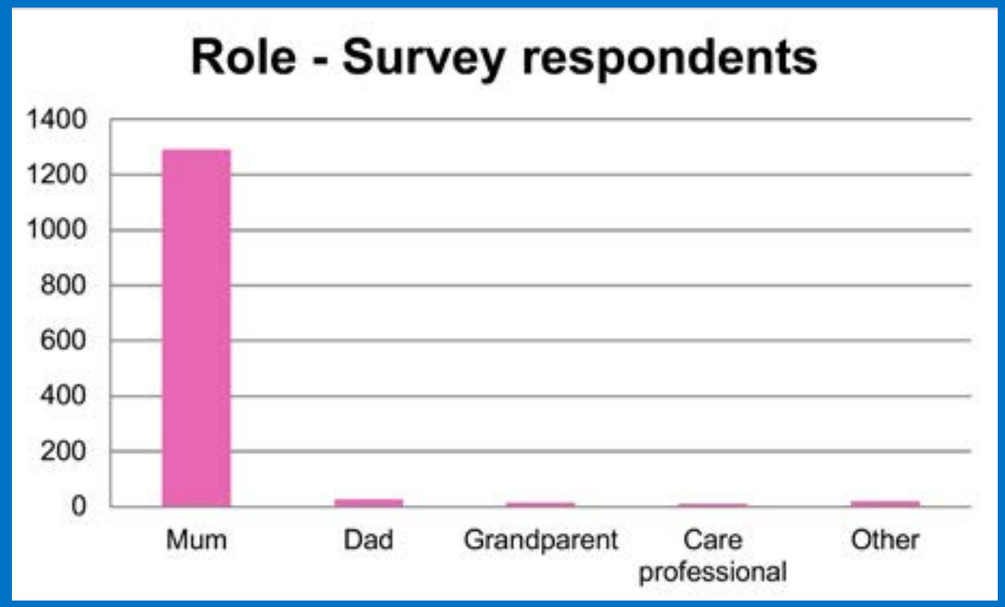


Figure 3 Age of survey respondents

Use of services

1368 people answered a question about whether they were using services at the moment. Figure 4 provides a breakdown of responses.

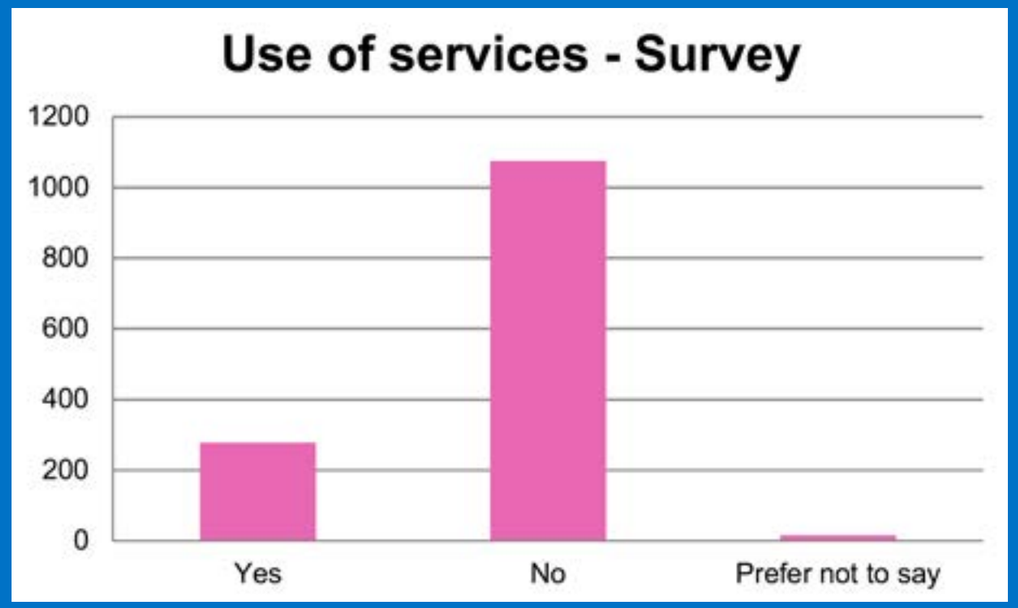


Figure 4 Survey – Use of services

Of those who replied most were describing experiences from over a year ago. Figure 5 provides the breakdown.

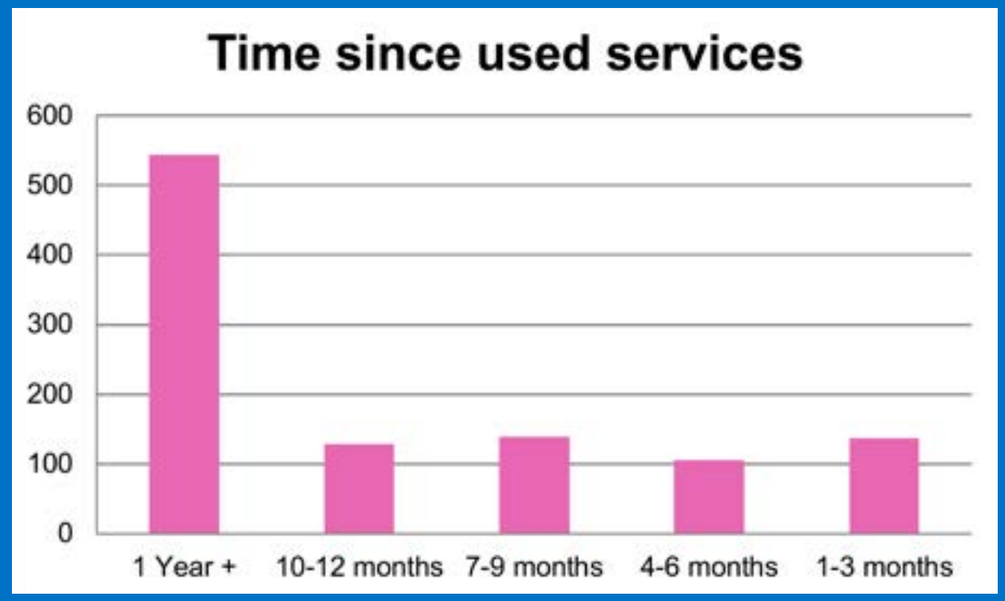


Figure 5 Survey – time since used services

- When asked about their **ethnicity** the majority of respondents identified as white British.
- 652 people answered the **gender** question. The majority of respondents (644) were women.
- When asked about any **disability** the majority of the 658 answering said they did not consider themselves to have a disability.
- For the question about **sexual orientation** most identified as heterosexual.

In face to face sessions

During the face to face sessions we spoke to a total of 324 people from across Devon. See Figure. 6.

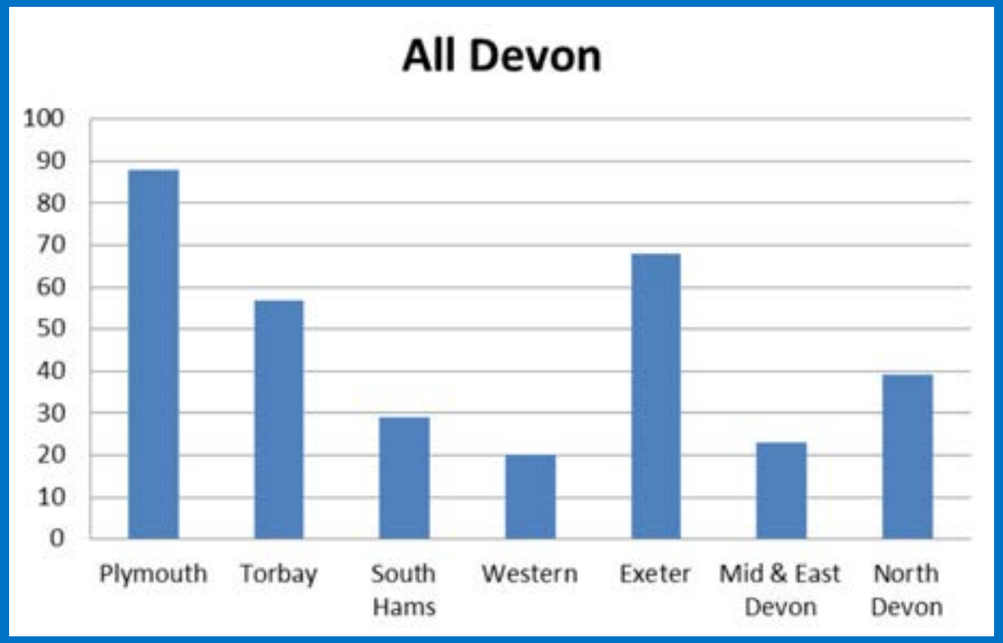


Figure 6 All Devon, by area

Of those we spoke to, the large majority were mothers but we also spoke to fathers, grandparents, health visitors, children centre staff and student health visitors. See figure 7.

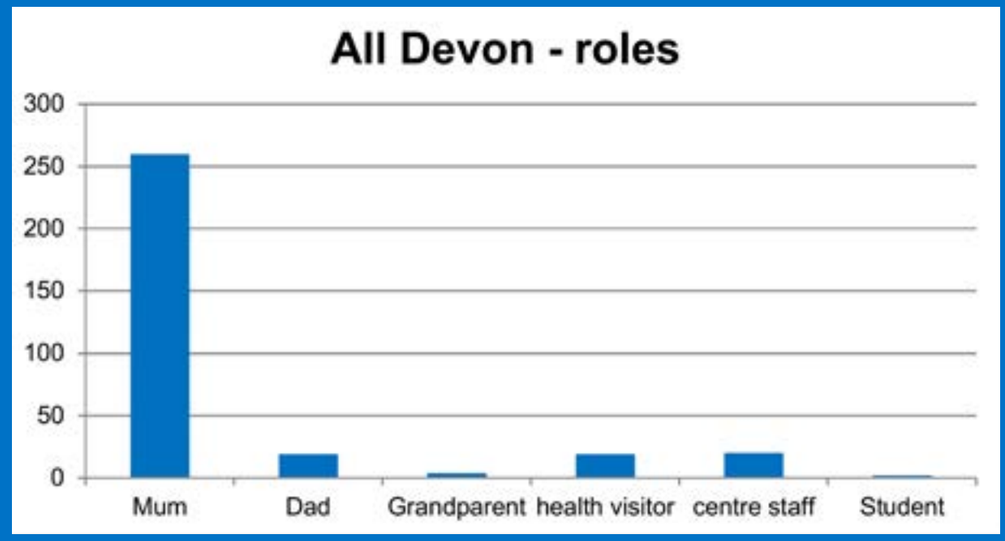


Figure 7 All Devon roles of those we spoke to

During our conversations we collected the ages of the people we spoke to, where they were happy to share this information. The age range we heard most from was between 18 - 39. Figure 8 sets out all of age range information. In general, those not giving or not asked their age were health and social care staff or children's centre staff

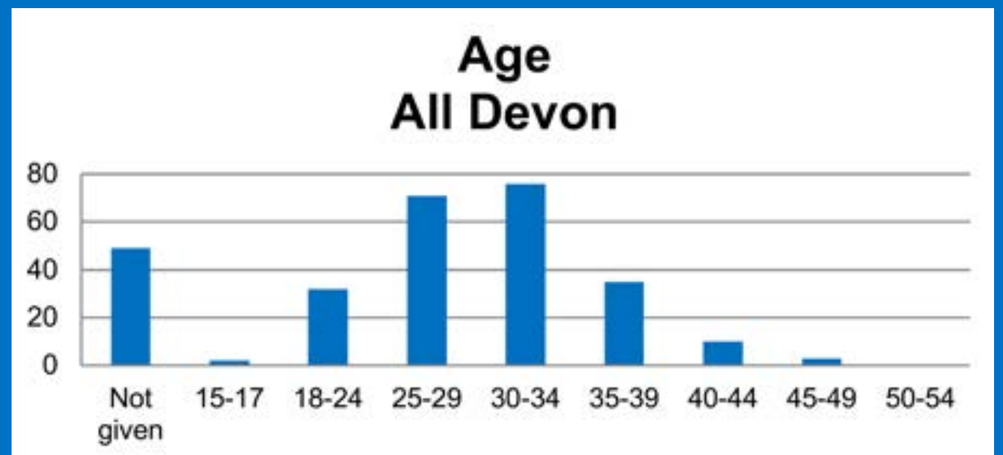


Figure 8 Ages - All Devon

We did not routinely collect other demographic data from those we listened to, as our focus was on the content of the conversation. However some people did self-identify to a particular characteristic. In particular, people self-identified in relation to their country of origin, see Figure 9. Some people did refer to their religion, belief or sexual orientation, but the figures are too small to be usable or significant.

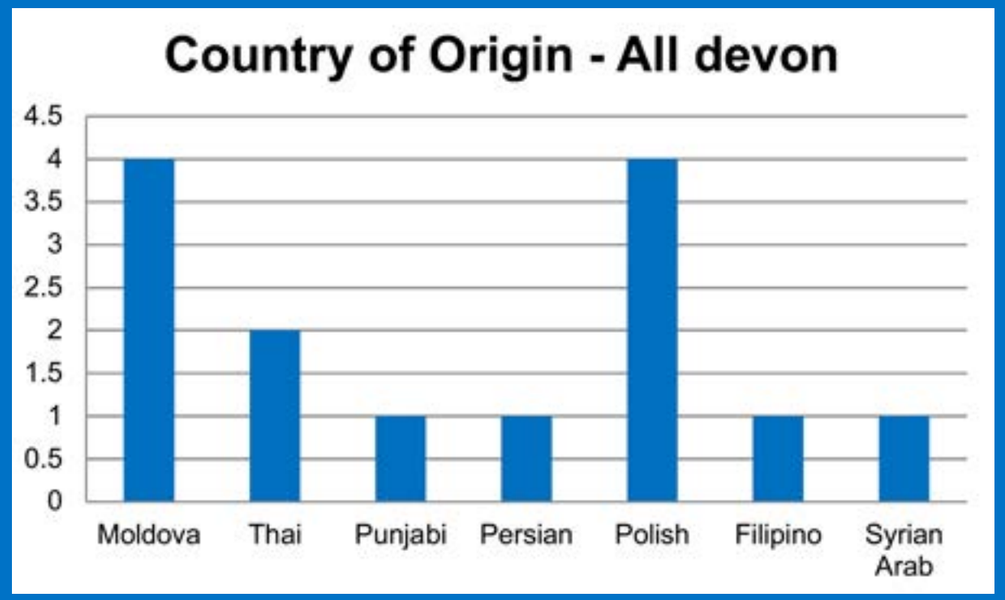


Figure 9 Country of origin (Self-identified)

Pre-existing feedback indicated that there was a need to understand younger parents' experiences and the experience of parents of twins (multiple births) and so, where we were able to do so; we arranged to attend sessions that were run specifically for these groups. (See Appendix 1). Overall, we were able to hear from parents of 18 sets of twins and 37 younger parents between the ages of 15 -25.

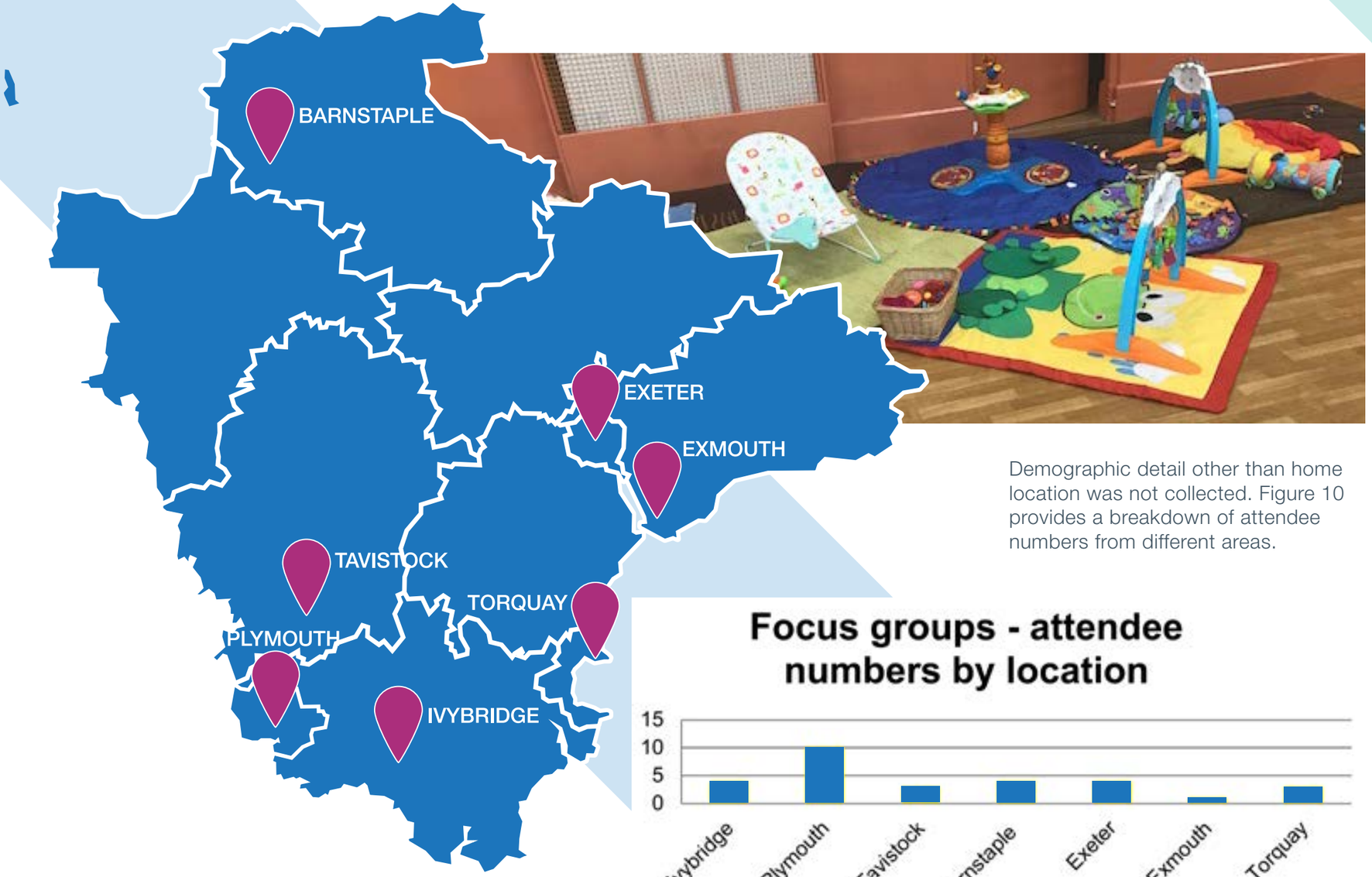
In the focus groups

The focus groups were made up of people who self-selected and the research sample was diverse and included:

- First time mums;
- Mums with multiple children;
- Pregnant women;
- Individuals who had high and low risk births (including those with consultant-led care);
- Individuals who had positive and negative experiences;
- Young mums;
- Older mums;
- Individuals who made different decisions regarding birth location and feeding choices.

Focus groups were held in various locations with the aim of ensuring involvement of people from across Devon. The seven locations were:

- Exmouth
- Exeter
- Torquay
- Tavistock
- Plymouth
- Ivybridge
- Barnstaple



Demographic detail other than home location was not collected. Figure 10 provides a breakdown of attendee numbers from different areas.

Figure 10 Focus - attendee numbers by location

What we wanted to find out

Through our engagement we sought to discover the following:

Survey and face to face events

- Was antenatal care provided in the right place?
- Preferences for where antenatal care is provided
- Was care at birth provided in the right place?
- People's preferences for birth location
- Was postnatal care provided in the right place?
- People's preference for where postnatal care is provided.
- What was good about people's experiences?
- How might their experiences have been better?
- Use of digital records

Focus groups

- Choice – personal care plans
- Continuity of care
- Digital provision of information
- Postnatal and perinatal mental health care
- NHS personal maternity care budget

"Would be good to get reminders of appointments and stages of pregnancy."

"They would have so much less work to do if they let your partner stay, you would recover quicker."

All of the feedback we received was aligned to the national Better Births recommendations, which are;

- Birth plans.
- Continuity of care.
- Multi-professional working.
- Personalised care.
- Perinatal and postnatal mental health.
- Safer cross boundary working.
- Other.

NB: We included an 'other' section for things that did not fit into one of the Better Births categories.

We also wanted to gather information from parents about how they chose where to give birth, what informed that **choice** and the options they had available when they made that decision.

"If they tailored it to your area signposting to services, that would be really useful."

"I really wanted to breastfeed but I couldn't, I had no clue I could combi-feed."

What you told us about the choice of where to give birth

In Devon women giving birth and their families have a range of choices when it comes to deciding where to give birth.

- A home birth.
- Free-Standing Midwifery-Led Unit (FMU).
- Along-Side Midwifery-Led Unit (AMU) (in or by a hospital).
- Hospital.

We know that geography plays a big part in how parents make their decisions, as availability of the full options listed above is variable depending on where you live. If you live in Plymouth, for example, there is not the option of an alongside midwifery unit or freestanding midwifery unit in close proximity.

Throughout the engagement we were keen to seek the views and experiences of parents and families about where they had their baby and what determined their choice of location. We know from the survey responses that the vast majority of respondents (91%) felt that the birth choice they made was in the right place for them – meaning fewer than 1 in 10 births were taking place in a location considered by the mother and family to be the wrong place.

What we heard about Free-Standing Midwifery-Led Units (FMUs)

FMUs are not available in all areas of Devon, a full list of these can be found in Appendix 6. Where these were available, people told us **they liked**:

- The less clinical atmosphere.
- The fact they tended to be nearer to where they lived.
- At times they received almost one to one care.
- That there were fewer medical interventions.
- That the FMUs are run by midwives who are more experienced with women who want natural births.
- They typically offer more pools for water births.
- They are a good half way house between a home birth and a hospital delivery.
- The level of postnatal support (especially for breastfeeding) that the FMUs are able to provide.
- That they provided welcome step down care from hospital to home, so women who aren't quite ready to go home but don't need to be in an a hospital.

Those we spoke to did have some concerns in relation to FMUs - they were **concerned about**:

- **Safety** and the ability of those units to care for their baby and them if complications arose.
- The need to travel (or be 'blue lighted') to another hospital if complications arose.
- They are not always open when needed, resulting in an unexpected need to travel to another location.
- Conflicting information/advice that was given i.e. on what medication or pain relief they could expect in those units.
- Issues of communication between care professionals in different locations at different points of the care pathway.

A number of people shared that they had considered having their child at an FMU but **decided against it** because of one or more of the concerns listed above, with the majority citing **safety** as the most influential concern in a person's decision-making.

In the survey people said that they were more likely to choose to give birth in a less medical unit such as an AMU as they are attached to a hospital and would mean there was no need to travel in an emergency.

In general, women who used the FMUs both recently and in the past were very positive about them and were concerned about their possible closure.

What we heard about hospital as a birth location

Women reported that they **chose a hospital birth** because:

- A hospital birth was framed as the default option by midwives.
- First time mums were least aware of the different options available.
- Fear of negative birth experiences and the potential need for interventions. Women and families want to be close to where emergencies can be resolved.
- Of the risk averse nature of discussions with midwives and the lack of positive birth stories being communicated – other women they knew were also more likely to share negative experiences with them, it was clear that negativity bias is driving choice.
- Because a medical condition or other risk factor limited their choice.

Some women who had hospital births shared that they would have **wanted an alternative birth location** and this because:

- The hospital environment is too clinical.
- Staff are too busy to give them the care they would like, but they accept this to be the norm and **don't want to bother clearly busy staff**.
- Care is less personalised.
- The need to arrange childcare for older children at home.
- Limited provision for partners to stay.
- Previous bad experiences at hospital.

What we heard about home births

Whether they chose a home birth or not women told us that there were some things **they liked about choosing a home birth**:

- It was somewhere they knew and felt safe.
- There was no need to travel.
- The good reputation of the Jubilee Team in Plymouth.
- It was calmer and less stressful.
- It is felt to be very personal, intimate and not clinical.

However, where a home birth was not chosen this was because people **had concerns about**:

- Safety - what would happen if something went wrong.
- Concerns about previous birthing difficulties.
- Not having the security of a clinical setting i.e. on site consultants and equipment if needed.

Generally, levels of home births were very low with only 4% of those providing this information choosing a home birth. There was very little difference across the different areas of Devon (see Figure 11).

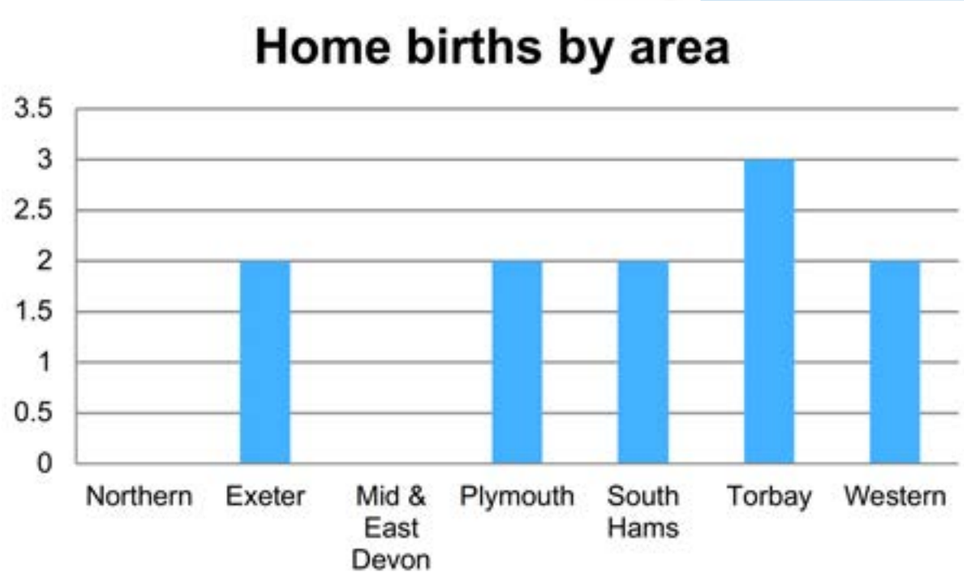


Figure 11 Home births by area

What we heard about choice and the place of birth

Women told us that:

- Conversations about where to give birth typically had to be started by the pregnant woman.
- Professionals seemed to be quite risk averse and would frequently advise a hospital delivery if a risk was perceived.

Whilst mums recognise the need for a hospital births in some circumstances, they felt some professional decisions were more arbitrary including hospitalisation for:

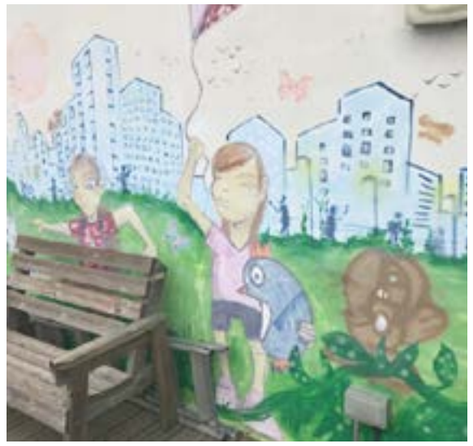
- Older mums.
- Younger mums.
- Mums who had previously had difficult births but whose pregnancy was proceeding well.
- Mums expecting twins felt a hospital birth was presented as the only option.

What you told us about making birthing plans

One of the areas Better Births identified as needing strengthening was the preparation of birth plans. Birth plans are seen as important to the outcome and experience of those using maternity services.

To understand the experience of people across Devon we asked:

- Did you have a birthing plan? If not, why not?
- Did your care go according to the birthing plan?
- If not, did you and your family receive support to cope with this?
- What support would you have liked?
- How did this experience affect you and your family?



We know from the survey findings that of those responding; only 38% of births followed the birth plan, with 17% of women not sure if they had a plan. The main reasons for births not going to plan were medical issues (79), complications (67) and cesarean sections being required (67). 91 people said they or their family member had emotional or mental health issues as a result of their experience. See Appendix 3.

Respondents said:

"Post-traumatic Stress Disorder has made me struggle to care for my children, lose my job and threatens my marriage."

"I ended up having Postnatal Depression and it will always haunt me and my relationship with my son"

102 people said they would have liked help and cited:

- An explanation of events (**27**).
- An offer of counselling (**18**).
- Compassion/reassurance (**13**).
- More information (**9**).
- The chance to talk to someone (**8**).
- Their partner to have been able to stay with them (**8**).
- Better communication (**6**).

"My husband went on to have a nervous breakdown, triggered in part by the trauma of the birth"

The full details for birth planning responses in the survey can be found in Appendix 7.

The survey findings were generally mirrored in the face to face discussions but there was also a strong message from women and their families that birth plans weren't worth bothering with as they were frequently changed by circumstances out of their control and were often not referred to at the time of birth even in those instances where no circumstances had changed the plan.

What you told us about continuity of care

Before we started the Better Births engagement we compiled local experience information we held from various sources i.e. acute trusts and their Patient Advice and Liaison Services (PALS) (see Appendix 4).

This data showed us that **continuity of care** was a key area to better understand across Devon. It was also something that came out of the national Better Births work and formed one of the recommendations.

Through our activities we asked people:

- Did you see one healthcare professional throughout your pregnancy?
- How important is having one healthcare professional providing care all the way through a pregnancy?
- For what part of a pregnancy is having one healthcare professional most important?

Through the survey and face to face discussions it was clear that **continuity of care** was of importance. In the survey, respondents said:

- Only 28% of respondents said there was one healthcare professional seen throughout pregnancy and birth – suggests few individuals experiencing continuity of care.
- 94% of respondents said seeing one healthcare professional was either quite important (32%) or very important (62%) which demonstrates the importance of continuity of care to respondents.
- Pregnancy (54%) and labour (35%) were reported as the most important times for continuity of care.
- Better Births recommends that care be provided by a small team of midwives who work closely together and share information – this was deemed acceptable during the qualitative research.

Appendix 3 detailed survey analysis. Full details on continuity of care can be found in Appendix 8.

Feedback from the face to face events indicates that continuity of carer is important because it:

- Supports consistent approaches to care and reduces the use of conflicting approaches.
- Supports consistent advice and information and reduces conflicting information and advice being given to mums and families.
- Increases the likelihood that a mother and baby's history is known and understood so it can form part of the information used to plan and manage pregnancy and birth.
- Reduces the potential for duplication of activity and effort and the need for mothers to keep repeating the same information more than once.
- Reduces the potential for important actions being missed or persistent symptoms not being monitored closely i.e. growth of baby was often cited, as midwives often measure differently.
- Lack of continuity can impact negatively on the health of the mother.

The focus groups explored with women:

- Why (if) continuity of carer is important.
- What impact continuity of care has on pregnancy and birth.
- What impact a lack of continuity of care has on pregnancy and birth.
- Expectations vs lived experience.

Appendix 2 shows results from ICE focus groups.

It was interesting to note that the key themes identified in the face to face discussions were the same as those discussed during the focus groups.

What you told us about multi-professional working

The bulk of feedback around this came from the face to face discussions and this resulted in six clear themes being identified:

That there is miscommunication or lack of communication between the different professionals supporting a mum and her family.

The loss of specialised support groups puts pressure on the remaining professionals (e.g. breastfeeding support groups).

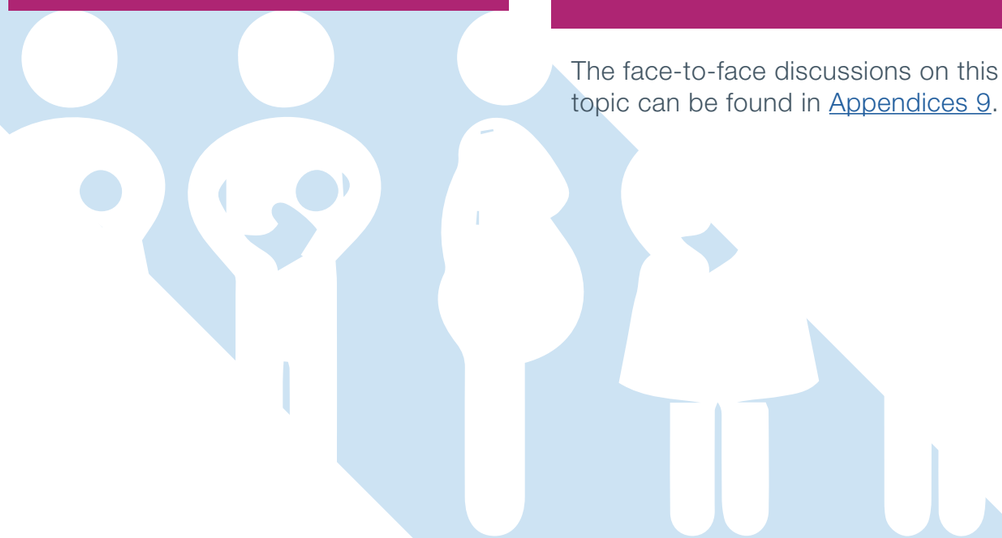
GPs need to provide more support to people with additional health problems (e.g. gestational diabetes). Information needs to be more accessible on the right referral pathways.

Where there is consultant–led care, communication between the consultant and midwife does tend to be less effective.

Better/more effective liaison between the perinatal and postnatal mental health teams is needed.

Contradictory decisions - midwife is saying one thing and the hospital are reversing it and vice versa e.g. midwife says mother needs to go in and hospital sends mother home.

The face-to-face discussions on this topic can be found in Appendices 9.



What you told us about personalised care

In face to face discussions about personalisation of care, the overriding picture is of variability. Some mothers and families were well supported and their care was personalised to them, others felt they were not well provided for with personalised care. Where people shared a less positive experience with regards to personalisation a number of themes arose:

- Assumptions of 'need' being made in relation to second (or more) time mums – i.e. an assumption that they need less attention as they have had children before.
- Families need to be more included in making decisions, especially if their baby needs onward or specialist care. People shared experiences of decisions being made quickly and feeling excluded from the conversation. It seemed to happen around them and irrespective of them.
- A need for mothers to travel for postnatal care takes no account of their individual situation e.g. first time mother of new born twins by caesarean, is not a car driver and is expected to get herself and her twins to a clinic two bus rides away.
- No tailored support for:
  - Families with twins.
  - Single parents.
  - Young parents.
- People expected to find their own information as it's not automatically provided. For example, parents of twins want to talk to other parents of twins or those expecting twins. This information is not readily provided and they have to seek it out themselves. Its important to have peer-to-peer support that helps with perinatal health and wellbeing.

In the focus groups, women felt that the following were important for personalising care Appendix 2:

Interventions

- People to be supported to proactively make a plan that includes how and when interventions should be used.
- Staff to ask what should happen rather than tell.
- The pros and cons of different birth choices to be explained. This should include a description of, when it would be absolutely necessary (for safety reasons) to use an intervention/ equipment as opposed to it just being used to speed things along.
- Familiarisation with equipment that may be used during pregnancy and/or labour will empower mothers and families to make choices and challenge medical teams when discussions regarding interventions occur during the birth.

The findings from face-to-face discussions on personalised care is in Appendices 10.

Pain relief

- Prior to birth: people need a better understanding of the pain relief options available and the impacts of each. The majority of participants had a general understanding of the pain relief options available to them but did not appear to be fully aware of the impacts each option would have on them or their baby.
- During birth: participants who were not made aware of their pain relief options (as needs arose) or were told what was going to be used rather than making an active choice felt like they were not in control of what was happening to their body. When participants were actively involved in making that choice based on informed choices, they felt much more at ease and included in the decision making process.

Birthing positions

- Challenge pre-conceived ideas about birthing position arising from TV/film depictions of birth.
- Provide information about birthing positions (i.e. through antenatal classes).
- Staff support and encouragement to discuss changing birthing positions during labour and where a change is not advisable explain why this is.

Feeding choices

- Provide balanced information regarding alternative feeding options.
- More support for mothers who are not breastfeeding, either because they are unable or choose not to.
- Improved diagnosis of tongue tie to avoid feeding issues and emotional impact on mother arising from difficulties feeding.

The themes around feeding choices are picked up later in 'other feedback' section page 46.

What you told us about perinatal and postnatal mental health

It was important to understand how people felt their mental health was looked after throughout their pregnancy, and if they could have been belter supported.

This is quite a difficult topic for some parents, especially those who have suffered major trauma as a result of their birthing experience. We were able to explore this more fully in the focus group sessions.

We explored;
- What support is expected?
- What support is needed/wanted?
- Individuals' experience of current local service provision

In the focus groups we found that;

- There are challenges with identification of Post-Traumatic Stress Disorder (PTSD).
- 41% of individuals who reported that their birth did not go to plan answered 'no' to the question – 'Did you or your family receive support to cope?'
- Lack of support with feeding was a key cause of negative experiences and often resulted in mental health issues (anxiety, guilt – believe baby unwell).
- PTSD missed by screening - people described being diagnosed with Postnatal Depression (PND) but at a later date finding out they actually had PTSD from a traumatic labour experience.

Full details from focus groups in Appendix 2

Perinatal mental health – key themes

- Many participants reported that a lack of continuity in care prevented them from receiving perinatal mental health support. They couldn't build a rapport/ relationship with their midwife which meant they felt less empowered to speak up and share their feelings and thoughts honestly.
- A lack of empathy and understanding which was needed to calm their nerves and anxieties.
- Health professionals didn't really listen to them at screening sessions. They were so focused on filling in questionnaires they weren't listening to them. Women wanted a proper conversation. Most people feared being open because they were worried their child would be taken away.

Postnatal mental health – key themes

- A lack of support with feeding caused significant negative emotional impacts that participants believe could have been resolved if better support were available.
- Women who struggled to breastfeed did not feel they were supported to transfer to bottle feeding. They received biased and mixed information which left them feeling confused, unprepared and more anxious.
- People who had experienced traumatic births wanted closure, to know what happened to them and why. Some people said their experiences would put them off having more children. The need for debriefing was cited, but in one example someone was taken back to the place where they experienced the trauma and this exacerbated their PTSD.

Many of the themes that came up in the focus groups also came up in the other face to face sessions we attended. In addition to these, we also found that:

- There were many examples of PTSD of women, and their partners who struggled to find support in the community.
- Antenatal support didn't really address mental health concerns and worries. In fact a mother of twins was signpost to a charity as she was struggling to accept she was having two babies.
- Complex cases were not always given mental health support required and sometimes PND is missed.
- The needs of dads are not always considered, one dad said; 'it was the most stressful experience of my life.'

Full details from focus groups in Appendix 2

In the survey 43% of people who responded said that their pregnancy did not go according to the birthing plan, with 41% of respondents saying that they (or their family members) did not receive the right support to cope with this. Counselling, explanation of issues (debrief) and better communication are what support they would have liked to receive. For the majority of people who responded to the question about how this affected them and their family, emotional and mental health issues was the outcome Appendix 3.

What you told us about cross boundary working

Given the rurality of Devon there are people who live in areas that sit on the boundaries of health service provision, for example people who live near to Kingsbridge fall between two major hospitals, Torbay and South Devon Foundation Trust and University Hospitals Plymouth. These areas also have different providers of community services i.e. midwives and health visitors. As a result, sometimes people can feel like they are caught in-between where service provision starts and stops.

We did not ask about this in the survey, but we did during the face-to-face events as we specifically went to places where we knew people lived in rural, isolated and in-between organisational boundary locations, Appendix 12.

Some of the feedback we heard;

- Poor co-ordination between Cornwall and Devon – parents are constantly being asked for their notes.
- Chasing of appointments - people who live in these types of areas feel they constantly have to chase appointments with midwives and health visitors otherwise they get forgotten, or 'slip through the system.' Some people did not see anyone until day 6 or 8 post-partum.
- Breastfeeding support is non-existent.

OTHER FEEDBACK

To support choice

- Decision aids are provided to women (digitally or paper based if required) to support them with key decisions regarding: where to give birth, what provider of care to choose, what antenatal support to access, pain management and their preferences regarding interventions (what, when and how). In addition to informing their choices, this will also empower women to ask the right questions during their interactions with their maternity team.
- Unbiased, trusted information needs to be made available to women to ensure they have genuine informed choice.

There is a need to explore the use of digital solutions to provide information during the antenatal and postnatal periods. Participants clearly stated that they wanted information as early as possible in their journey, therefore signposting to information needs to happen as early as possible (e.g. first midwife appointment). Participants also needed to know when they would get to discuss choices with their midwife – they would benefit from receiving a visual representation of their journey with the key decisions they need to make plotted out for them.

Information provision

From the experience data we compliled before our engagement and through the national work around Better Births the information families receive is key.
To understand the experience of people in Devon, we asked:

- Did you feel informed during pregnancy?
- How might information have been provided better?
- Was information provided at the right time?
- Would electronic notes be beneficial?

In the survey 84% of people who responded said they felt informed during pregnancy, with 69% of respondents saying they received information at the right time. Those who felt information provision could have been improved suggested;

- Enhanced two-way communication with health professionals – more time for questions and answers and less assumptions about what they already know.
- If appointments were longer there would be more opportunities for information provision and proper discussions.
- More information regarding options for birth earlier in the pregnancy, without this their ability to make an informed choice is limited.

Full information regarding the survey can be found in Appendix 3

63% of respondents said they would find it useful if their pregnancy notes were held electronically.

Through the face to face events we heard that information could have been improved;

- When women are being prepared for what to expect during labour.
- During traumatic births – could have been better informed what is going on, especially family members who are often left not knowing what is happening.
- In relation to pain relief, how it can be used, when women can and can't have it, what it does and why. There was lots of conflicting information in this area, especially regarding the freestanding units.

Information from face-to-face events can be found in Appendix 13

During the focus groups 85% believed digital notes would be extremely helpful or very helpful and the majority of workshop participants were also in favour of having access to this form of notes.

The perceived benefits of digital notes include;

- More convenient to transport.
- Easier for staff to access key information.
- Privacy – expected to be more private than carrying a folder.
- Opportunities to link out to other online content.

Full information regarding the focus groups can be found in Appendix 3.

Some feedback did suggest that people liked the association with printed notes as for many this is the main symbol of their pregnancy for at least the first trimester. So if there is a move towards digital it would be wise to consider what could replace this very symbolic element of the pregnancy journey.

Antenatal care

Antenatal care featured significantly in conversations, particularly antenatal classes.

In the focus groups, 91% of people felt that antenatal care was provided in the right place, and 69% stated that they felt information was given at the right time.

We also heard in the focus groups that antenatal care could be improved if;

- Antenatal classes were more accessible to mums and their birthing partners – inconvenient times mean birth partners are unable to attend.
- More interactivity in classes and less teaching.
- Content focused on things like, 'looking after your mental health, rather than how to use a car seat." Also some of the content could have been delivered at home, by watching videos. Time could be better spent on discussing choices.

See Appendix 2

In the survey we asked nine questions in relation to antenatal care and from those we found that;

- Women want the option to receive antenatal care at home, its more convenient, less travel is required, its private and less medical.
- It is important for mothers to build rapport and relationship with the person who is providing them with care. This further demonstrates the importance of continuity of care. Mothers often said they wanted their midwife to know them and not have to repeat themselves over and over again.
- Being listened to and having the ability to ask questions improves the experience of women and their families.

See Appendix 3

During the face-to-face events we also visited some antenatal classes (Appendix 13) and talked to some women who were pregnant at the time.

From talking to people at the face to face events we heard that;

- There is limited availability of antenatal classes for parents of twins, a lot of the information is for people who have just one baby. The questions, concerns and worries of parents with twins is often different and therefore requires specific information.
- Antenatal classes are missing a real opportunity to prepare women for their birth. Those opting to pay for classes i.e. hypnobirthing/NCT compared their experiences of birth to others, even when it didn't go according to plan. They seemed to describe strong personal resilience/buoyancy.

Postnatal care

Whilst it was important to understand the experiences of people in relation to postnatal mental health, we also wanted to understand other postnatal experiences people had that weren't mental health specific. We explored this in the online survey and also in the face-to-face events. this can be found in Appendix 2 and 3.

We wanted to understand;

- Was the postnatal care at the right place?
- What was good about the postnatal care experience?
- How might the postnatal care experience have been better?

82% of respondents said they felt their postnatal care was in the right place.

Almost all of respondents who said their postnatal care was not in the right place, said they would have preferred to receive it at home. This is because it is more convenient and there is less of an impact on recovery due to travelling around.

'Travelling to the children's centre three days post c-section with twins, it was very difficult and challenging and I was made to feel I couldn't refuse.'

Good postnatal care related to;

- The positive behaviours of healthcare professionals. The most common behaviours described were: supportive, friendly, caring, helpful.
- Support to establish feeding. When we spoke to people in some parts of Devon we gained consistent feedback about breastfeeding support i.e. in Torbay, those we spoke to talked positively about the breastfeeding support they received.

In the survey people said that postnatal care could be improved if there was more support for breastfeeding, less judgemental, improved continuity of care and person centred care. People also want to travel less to appointments and not so soon after the birth, especially if there were complications or surgery.

A focus on the behaviour of health care professionals. When positive behaviours are experienced this has a direct correlation with the perception of postnatal care received.

During the events some of the feedback we received related to;

- Health visitor appointments - people having to drive to clinics quite soon after the birth, having to chase health visitors to speak to them. Women now call one central number and ask for a health visitor to call you back, whilst its largely responsive it is impersonal.
- Health clinics (baby weigh in) – very impersonal, health visitors are not hands-on and it's not interactive, parents have to weigh their babies themselves and there is less time for peer-to-peer interaction.

Feeding choices

During the events people told us that;

- There was a lack of breastfeeding support and clinics – children's centres do not offer as many postnatal groups as they used to, so the ones that do exist are run by volunteers. This makes their long-term sustainability questionable.
- Tongue-tie – a significant number of parents who fed back to us during the engagement talked of not being able to breastfeed because their baby was tongue tied and often this was picked up a long time after birth.
- Breastfeeding support is varied depending on where you live.

Quality of care

In appendix 13 there are a number of experiences which relate to quality of care in and outside hospital.

Feedback from other health professionals

- Health visitors feel like they have lost a lot in the community i.e. groups at children's centres, less support for parents and peer-to-peer opportunities. They are very reliant on the voluntary sector and local community groups. Past experiences show them that these groups help vulnerable parents and those who are struggling.
- They do not feel that they have enough time to interact with parents.

Geographic differences

In the appendices we have recorded feedback by geography (Appendix 7, 8, 9, 10, 11, 12 and 13). This is recorded against each of the Better Births themes.

KEY FINDINGS

The findings from all engagement activities have been categorised under each of the Better Births recommendations. These findings will be shared with the Local Maternity System (LMS) and Maternity Voices Partnership (MVP) and will help improve services for the people of Devon.

Birthing options and choice

Health professionals need to have conversations with parents early on in the pregnancy about where they can give birth. Parents should be supported to make an informed choice.

There needs to be better information about safety – this plays a big role in the decision-making process for families. More information about the safety associated with each birthing option is required.

The LMS should consider the proximity of birthing options to that of the main hospitals. Women who said they would consider an alternative to hospital did not say it was because they wanted obstetricians to be there – they just wanted the security of knowing if something did go wrong they were close enough for help if it was needed.

There is a need to work closely with the Maternity Voices Partnership (MVP) to help share good birthing stories and experiences. Most information about births and pregnancy is shared by parents through peer-to-peer interactions.

Travel is important and needs to be considered as part of choice options, as this also impacts on the decision people make when weighing up safety.

Birth plans

Do not use the word ‘plan’, ‘**birthing preferences**’ was the favoured term.

The decision to have birthing preferences is a choice, and parents should be given information about why having birthing preferences can help them navigate their pregnancy. More importantly it enables them to identify their wishes more clearly. Appreciating that not all things go to plan, an early conversation with a health professional to manage expectations is important. Birthing preferences can be picked up at multiple stages during a pregnancy, either at the start or a slightly later date when parents have had time to consider what they want. Examples of how some people create birthing preferences might be an option and indeed discussing this at antenatal is also important. The option for having information people can view online or via an app resource might also be worth considering. Consistency of information was key.

When the birth doesn’t follow according to the birthing preferences then women are very keen to receive a de-brief, offer of further support if they are struggling (this could be counselling or support groups, for example), just the chance to talk it through with someone.

Continuity of care

Parents want to have better continuity of care 94% of those who completed the online survey said seeing one health care professional was important. This was a unanimous piece of feedback during the engagement and one that should take priority. The LMS should adopt the national Better Births 5 Year Forward View on maternity services.

Consistent advice and information is necessary, to minimise conflicting advice and opinions, and for there to be a better view of a woman’s pregnancy journey.

The LMS should explore how maternity teams hand over care within the hospital setting. So when one team finishes a shift and others start, there needs to be quick and easy access to information regarding the individuals they will be seeing.

Multi-professional working

Health professionals need to communicate better when supporting parents. The transfer of information needs to be consistent so that women feel well supported. Particularly when a woman is under-consultant led care, the transfer of information between consultant and community midwife is key.

Personalised care

Mothers who were having subsequent children felt that support is not the same. It is deemed that women know all of their options and are more resilient having been through a pregnancy before. These women feel that personalisation is important for each birth.

Families would like to be more involved in decision making and to have all the facts. This applies especially to babies that require onward or specialist care.

Better support and information needs to be made available for families expecting multiple babies and younger parents.

For women to personalise their care they would like more information about the type of equipment and procedures that could be used if they end up wanting or indeed needing hospital-led care or interventions.

More information about pain relief options needs to be made available – especially the impact of those options on women and their baby.

Women are asking for more balanced information on feeding choices. There are still a lot of myths surrounding feeding and an incredible amount of perceived judgement. Information needs to be consistent, available and sensitive to needs of individuals.

Perinatal and postnatal mental health

Diagnosis of Post Traumatic Stress Disorder (PTSD) or Postnatal Depression (PND) – PTSD can be missed by screening. The LMS should ensure that more training is available for health care processionals so that they can better support families who have experienced a traumatic birth would also help.

Continuity of carer was sighted as something that would have helped with perinatal mental health.

Women struggling to breastfeed felt there was more support needed for them. Many of the community breastfeeding groups were limited or reducing and the peer-to-peer support was sighted as very important, as well as support from health professionals.

Better information and advice during antenatal sessions would be helpful.

The needs of dads should also be considered, the level of information and support they require is often different. There are many community groups for women, for example, but very little for dads.

Identify and address training needs related to the screening for mental health issues.

Safer cross boundary working

Need to identify those areas that either fall between geographical areas, or indeed providers of services. It is in those places where people feel they get forgotten or missed. Need to ensure process is in place between health professionals when individuals in these areas are identified.

OTHER FINDINGS

Digital notes

Strong support for pregnancy notes to be held digitaly.

Antenatal classes

Improved antenatal classes, better information and widen access by considering times outside of working hours - so partners can attend. More interactivity and focus on things like, looking after your mental health - rather than how to fix a car seat. More provision and information for women with multiple babies.

Postnatal care

Postnatal care could be improved if there was better support for feeding, in the community and in the home. Travelling less to postnatal appointments, especially after any surgery when you may not be able to drive.

Peer-to-peer

Peer-to-peer support is important, groups that bring women and their babies together after birth are welcomed. Health clinics used to provide that but now they are less interactive and not always in places that enable conversations and interactions to take place.

Digital solutions review

A review of digital solutions is conducted to identify if existing solutions will meet the needs of local women as identified. If they do then women must be signposted to these, if they don't then alternative solutions should be explored. Explore a digital breastfeeding solution, that could provide consistent advice, information and support.

Social Prescribing

Identify and signpost to opportunities for social prescribing (e.g. peer support) – women want empathy, understanding and to hear from individuals who have been through similar experiences.

Personalised maternity care budget

There was no appetite for a personalised maternity care budget. The preference was for better decision aids to enable people to make informed choices about where they have their baby. Having control of a budget was thought to be overwhelming and added stress.

ACKNOWLEDGEMENTS – AND A BIG

THANK YOU!

Thank you to everyone who participated in the Better Births work, either by sharing experiences or giving feedback. Your input was invaluable and will help shape maternity services across Devon and the future experiences of mothers and their families.

This work could not have taken place without the support of each children's centre and voluntary group we visited, so thank you for welcoming us in to speak to parents and for sharing your own feedback as well.

To attend 78 events across Devon, took co-ordination from across partners, including the NHS, local authorities and the voluntary sector. Some specific individuals went above and beyond to ensure we reached as many people as possible, Gail Barker, Public Health Practitioner for Children and Young People, Devon County Council and Gemma Scott, Public Health Practitioner for Children and Young People, Plymouth City Council.

APPENDIX

Appendix 1 Better Births in Devon event locations

Appendix 2 Better Births findings V1 (ICE report)

Appendix 3 Better Births survey V1 (ICE analysis)

Appendix 4 Existing feedback report

Appendix 5 Children's centres

Appendix 6 Freestanding midwifery-led units

Appendix 7 Birth plans

Appendix 8 Continuity of carer

Appendix 9 Multi professional working

Appendix 10 Personalised care

Appendix 11 Postnatal and perinatal care

Appendix 12 Safer care across boundaries

Appendix 13 Other

NHS
Devon
Clinical Commissioning Group

Better Births in Devon