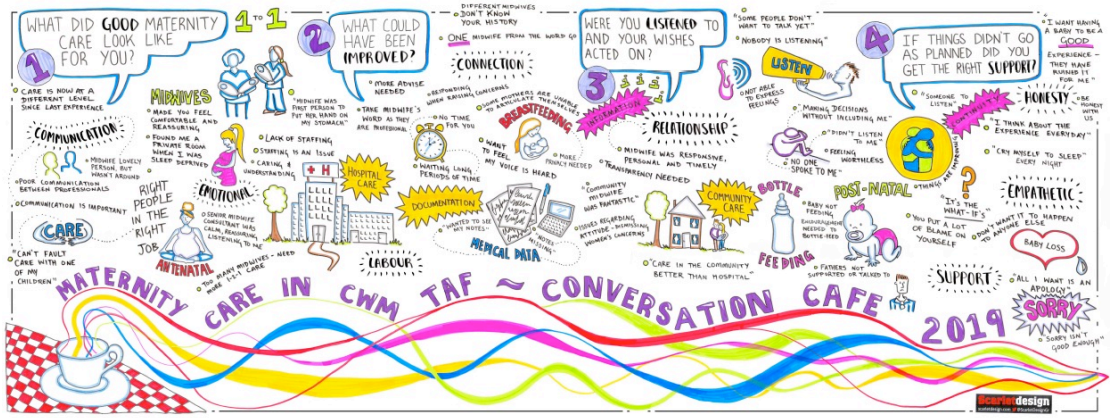
Listening to women and families about Maternity Care in Cwm Taf

A report of outcomes from engagement to inform the RCOG Invited Review of Maternity Services in Cwm Taf



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1. ACKNOWLEDGEMENTS

- Our heartfelt thanks to all of the women and families who gave their time and spoke about their experiences, often sharing distressing stories. It took courage to come forward and talk about the events that stirred such sad memories. Thank you – your contribution will make a difference and, as you told us, ensure that it doesn't happen to anyone else.
- Thanks to Heather Payne and Karen Jewell at the Welsh Government for their support to enable the engagement to take place before, during and after our visit. The strong response and opportunity to hear the voices of so many women and families has provided valuable information for this review.
- Thanks to the members of the RCOG Invited Review team for their invaluable support in interviewing and supporting women and families who came to share their experiences at the engagement event.
- Thanks to Cwm Taf Health Board staff for arrangements and organisation to support the engagement event and to the communications team for publicising the survey
- Thanks to Scarlet Designs and Lois Smith for their inspiring visual mapping of the engagement event

2. EXECUTIVE SUMMARY

"For the great majority, pregnancy and childbirth should be a positive and happy experience that culminates in a healthy mother and baby. This means, however, that on those occasions when things do go wrong, the effects are even more devastating than in other areas of healthcare. Maternity care must reconcile these dual aspects in order to be safe, effective and responsive. When it does not, the consequences may be stark." (Dr Bill Kirkup)

It is four years on from the report of the Kirkup investigation into failures in maternity services at Furness General Hospital (University Hospitals of Morecambe Bay NHS Foundation Trust) resulting in avoidable harm to mothers and babies and tragic deaths. The strong message heard from women and families in Cwm Taf is that they don't want their experiences to happen to anyone else and they want there to be learning by the organisation to ensure that improvement and change occurs. They hope that their words and stories will be a major driver for change.

It is important to set the context for women's experience of maternity services in Cwm Taf. There are currently two consultant led units with approximately 1 764 births annually on the Prince Charles site and approximately 1 929 on the Royal Glamorgan site. The sites are 22 miles apart (up to 55 minutes travelling time).

There has been recognition for some time that change and improvement was important in maternity services and in 2014 extensive consultation took place for the South Wales Plan. Following consultation it was agreed that paediatric services, and hence maternity, would not be provided from Royal Glamorgan Hospital and alternative local services would be developed. Engagement with women and families continues in the implementation of change to services.

Following the identification of 43 potential Serious Untoward Incidents (SUIs) between January 2016 to September 2018 that included Stillbirths, Neonatal Deaths and complications of pregnancy or delivery in maternity services provided by the Royal Glamorgan and Prince Charles Hospitals, the Royal College of Obstetricians and Gynaecologists was invited to undertake a further review.

Understanding the perspectives of women and families who had used maternity services at the hospitals was central to this review. RCOG believes that engaging with women and families using maternity services, and learning from their experience, especially when things go wrong, is at the heart of improving future care and quality of maternity services.

Review Term of Reference 8 asked the review team to**: assess the level of engagement with women and their involvement within the maternity services and determine if engagement with women and families is evident in all elements of planning and service provision. Assess whether services are woman-centred, open and transparent.** The team therefore undertook a detailed exercise to seek the views of women and their families as a key part of the review.

As a core part of the invited review the RCOG review team wanted to build a comprehensive picture of the care and issues surrounding stillbirth and baby loss experienced by women and families. The perspectives of women and families were explored to find their views and experiences of maternity care.

We asked about what women's experience of maternity care had been, both positive and negative, and what could have been improved or changed to better meet their needs in particular:

1. How women were supported and provided with information to help them to make informed decisions and choices about their care,
2. Whether women felt listened to and their decisions and choices were supported
3. Whether women felt that they received high quality, safe maternity care
4. What happened if things didn't go as planned and whether the support they received met their needs adequately
5. The location of services and staffing levels, and whether the planned relocation of services had affected their care;
6. What happened when women raised concerns and involvement of women and their families in the investigation of incidents
7. What involvement of women and their families had taken place during the design of services

Messages from engagement with women and families

The words of the women and families who were involved in this engagement exercise were powerful and deserve to be heard.

There was feedback that reflected individual good practice in maternity care and praise was heard for individual members of staff working in difficult circumstances. However, overwhelmingly, the women and families who came forward to contribute to this engagement exercise spoke about distressing experiences and poor care.

The conclusion must be that there are significant issues to be addressed within maternity care in Cwm Taf to ensure that women experience the evidence based, safe, personalised care they want and need.

1. Were women supported and provided with information to help them to make informed decisions and choices about their care, did they feel listened to and their wishes respected?

Women did not feel that they had been treated with respect, provided with information they needed and given the care and support they required. The consequence of this had both physical and psychological impacts on them and their families.

"I'm broken from the whole experience, the lack of care and compassion. That terrible experience I was put through because of the staff that treated me. That experience will stay with me forever"

"I felt worthless, like I did not matter – that's how I felt"

Women repeatedly stated they were not listened to and their concerns were not taken seriously or valued. Often, their suspicions and concerns were found to have reflected a genuine problem that emerged later, but at the time they were dismissed when they tried to voice their concerns. Many women had felt something was wrong with their baby or tried to convey the level of pain they were experiencing but they were ignored or patronised, and no action was taken, with tragic outcomes including stillbirth and neonatal death of their babies.

The prime issue for most people sharing their experiences was the need for the service to be personal, focused around the needs of women and to listen to women and to be responsive. This was not the experience of many of the women who engaged with the review, who told us that the care had not met the standard that they had expected, with physical and psychological consequences for them, their babies and families.

Communication, compassion and empathy

Although there was good feedback in the survey about the excellence of individual staff, many women told us that they felt that communication during their care was extremely poor, that they were treated without compassion and that staff were not empathetic in their response. They reported a lack of kindness and empathy in staff sharing bad news or informing women that a pregnancy was at risk.

Women and families recalled the impact of overhearing staff talking about them and hearing inappropriate and insensitive language, including swearing. This made women feel disrespected and undervalued. One element of that communication failure would seem to be an attitude that clinicians assumed that some women were exaggerating their symptoms or pain.

2. Did women receive the information they needed and were their decisions and choices supported?

Women wanted accessible, timely and appropriate information in order to make decisions and support their choices about their care. They wanted information to be evidence based and available to them in a range of formats and they valued better access to advice with less ambiguity about which number to ring or where to go when they need help or reassurance. They wanted support when they made their decisions and choices.

There were examples of helpful and comprehensive information and there are future opportunities to work with women to design the formats for information they need.

Needs of younger mothers and fathers

Many younger, first time mothers needed additional support, empathy and information as they often felt dismissed. In particular they wanted to know what signs to look out for and be better informed about risks. Both parents needed support.

3. Did women receive safe, high quality maternity care?

High risk pregnancy – management and support

Repeatedly, women told us that they did not always believe that the right level of skills and expertise were available at the right time from clinicians caring for them. Women were told that their pregnancy was high risk and that specific care plans were in place. However, their

subsequent attendance at the antenatal clinic and their reception on attending A&E or the maternity unit in an emergency did not reflect this.

Skills and experience, escalation

A number of the experiences we heard about focused on a failure to seek a second, more senior opinion, and to escalate concerns, especially in the case of women with multiple complex conditions. Women and families repeatedly told us that they trusted midwives and doctors and assumed they had the skills and experience that would support the advice they were being given.

Good communication between women and health care professionals, but also across the different disciplines involved in maternity care, was seen as a key factor in ensuring the responsiveness, quality and safety of care, especially when there was a need to take action in an emergency situation.

Continuity and consistency of care

Women deserve consistent, high quality care every time they use maternity services. They wanted continuity and consistency but did not always experience either. They believed that care should be woman centred and built around her personal needs and wishes.
Women told us that their experience was affected by too many variable elements such as the time of day they contacted services, staffing levels or the communication skills of the staff they met.

4. Did the location of services, staffing levels, and the planned relocation of services affect their care?

There was a sense that staff morale was undermined and that the difficulties may have been made worse by staff shortages. This situation had an impact on staff attitudes and in many cases was transferred to women during pregnancy and when giving birth. Low staffing levels would seem to have had a significant impact on communication and, in some cases, the quality of care. Although many women were understanding about the strain placed on staff and praised them for their work, there is no doubt that these circumstances had a major effect with women not able to make contact with a midwife to help them, to ask questions or to be heard. We were told that clinicians were: *"always rushing and not listening".*

Overwhelmingly women have said throughout consultation and engagement on maternity services that they want safe, high quality, accessible services in Cwm Taf. Changes to the service model and location of maternity services continue to be of major importance with women and families expressing concern about travel and access to maternity care in more distant locations.

5. If things didn't go as planned did women receive support that met their needs?

Support, environment, bereavement counselling

Differing experiences regarding support after the loss of a baby were reported. At the time when families needed the services there were clearly gaps in provision and variation in how they were supported. Many women and families received no bereavement counselling or support and continue to experience emotional distress. All of the family are affected by the loss of a baby and support for fathers is also needed.

Families wanted to ensure that the bereavement service had the right level of personnel, with sufficient expertise to meet their needs. In some cases, families did not find out about the range of support and advocacy from other organisations such as Sands and the CHC.

Impact of poor experience

The impact of traumatic experiences has been long lasting for many families. Families reported that they felt that they continued to experience emotional and physical problems and a number of families feel that they have experienced post-traumatic stress disorder. Many women carry guilt about their experiences and believe that it was their fault that action was not taken at an appropriate time. This reflects a failure to respond to the needs of women and families after such a traumatic experience.

6. What happened when women raised concerns and how were they involved in the investigation of incidents?

In much of the feedback from women and families there is significant dissatisfaction with the way that concerns were addressed at the time. There was failure in:

- Responding to 'on the spot' concerns and examples of dismissive attitudes
- Many women were not listened to and not taken seriously *"I was laughed at when I was concerned"*
- Poor communication in follow up meetings to discuss concerns
- Lack of access to all appropriate information, including notes
- Lack of comprehensive investigation resulting in incomplete responses to concerns
- Focus on providing responses that were formulaic and seemed to be more interested in defending the reputation of individuals and the Health Board
- Lack of feedback on investigations and failure to respond or provide reports and copies of notes
- Failure to apologise, causing distress
- Responses that did not demonstrate how learning had been translated into action to ensure that this did not happen again

Already, work is being undertaken to use the lessons from the poor experience of those families affected by cases that are the subject of this review and action is being taken to change culture and behaviour.

7. Involvement of women and their families in the design of services

Women want services to be designed in a way that puts them, their babies and families at the centre. Women and their families told us that they are not currently involved in this process in a meaningful way. The Maternity Services Liaison Committee (MSLC) can provide a means of ensuring that the needs of women and families, and professionals, are listened to and can influence change and improvement

3. RECOMMENDATIONS

These recommendations are developed from the stories we heard from women and families and form the recommendations for Term of Reference 8 in the RCOG report.

ToR 8: Assess the level of patient engagement and involvement within the maternity services and determine if patient engagement is evident in all elements of planning and service provision. Assess whether services are patient centred, open and transparent.

3.1 Develop and strengthen the role and capacity of the Maternity Services Liaison Committee (MSLC) to act as a hub for service user views and involvement of women and families to improve maternity care:

- Appoint a Lay Chair as a matter of priority and increase lay membership numbers with appropriate support and resources,
- Support lay members to engage with women using services in the FMU at RGH and at PCH to assess satisfaction and to identify issues relating to choices,
- Enhance the MSLC monitoring role in order to assess whether patterns of concerns are found and to ask for regular feedback on action taken.

3.2 Utilise the role and strengths of the Community Health Council:

- Ensure appropriate resources to act effectively as an independent advocate,
- Ensure that information is available to families regarding its role and contact details,
- Explore provision of CHC to act as point of contact and provide direct support for women and families, in addition to acting as a conduit referring to other agencies and support,
- Involve the CHC in the early implementation of the new maternity facilities at PCH and the FMU at RGH so they can be assured regarding the impact on access and satisfaction with maternity services.

3.3 Develop the range and scope of engagement with women and families.

- review the effectiveness of patient experience methodology and its impact on service change and improvement as a result of feedback,
- as a priority, review and address the monitoring of the outcomes of patient experience as a key part of the governance structure,
- feedback the outcomes of all engagement to women and families,
- explore methods to hear directly from women and families about their experience including patient stories, diaries, 'mystery shopper' or observation techniques.

3.4 Continue to work with and build on the community based engagement approaches being suggested by the MSLC.

- explore working with external partners, including the CHC and community based organisations.

3.5 Ensure responses to complaints and concerns is core to the work being undertaken to improve governance and patient safety:

- Review and enhance staff training on the value of listening to women and families,
- Review the process of investigation of concerns, compiling responses, handling 'on the spot' issues and ensure that all responses and discussions are informed by comprehensive investigations and accurate notes,
- Prioritise the key issues that women and families have highlighted to improve the response,
- Ensure that promises of sharing notes and providing reports to families are delivered,
- Clarify the process regarding the triangulation of the range of information sources on patient experience, SIs, complaints and concerns and other data and ensure that there is a rigorous approach to make sense of patterns of safety and quality issues,
- Review the learning from the SIs in relation to misdiagnosis, failure to seek a second opinion and inappropriate patient discharge.

3.6 Learn from the experience of women and families affected by events

- Respond and work with families in the way they require,
- Feed the learning into the design of a comprehensive training and support programme that will give women and families confidence in the skills, expertise, communication, safety and quality of maternity care.

3.7 Review the communications, support and engagement approach and strategy.

- Ensure that the focus is not solely on management of key messages,
- Demonstrate openness, honesty and transparency, admission of fault, and learning from this.

3.8 Prioritise an engagement programme with families at its heart.

- Women and families affected by events should be part of the improvement, co-design and culture change of the new service,
- Invite women and families affected by these events to be part of the monitoring process regarding improvements in responses to concerns, engagement and communication.

3.9 Review the level and effectiveness of the bereavement service.

- Ensure that appropriate support and counselling is available for all requiring this,
- Consider implementing the National Bereavement Care Pathway (http://www.nbcpathway.org.uk/) which has been developed by Sands in collaboration with stakeholders including women and their families, RCOG and RCM.

3.10 Provide training for staff in communications skills, in particular on:

- Empathy, compassion and kindness.

4. THE VOICES OF WOMEN AND FAMILIES IN CWM TAF

4.1 Introduction

"For the great majority, pregnancy and childbirth should be a positive and happy experience that culminates in a healthy mother and baby. This means, however, that on those occasions when things do go wrong, the effects are even more devastating than in other areas of healthcare. Maternity care must reconcile these dual aspects in order to be safe, effective and responsive. When it does not, the consequences may be stark." (Dr Bill Kirkup)

It is four years on from the report of the Kirkup investigation into failures in maternity services at Furness General Hospital (University Hospitals of Morecambe Bay NHS Foundation Trust) resulting in avoidable harm to mothers and babies and tragic deaths. In the report of that investigation Dr Kirkup highlights "*a pattern of failure to recognise the nature and severity of the problem, with, in some cases, denial that any problem existed, and a series of missed opportunities to intervene that involved almost every level of the NHS. Had any of those opportunities been taken, the sequence of failures of care and unnecessary deaths could have been broken*" [1]

It has been difficult to hear about the experiences of many women and families using maternity services in Cwm Taf and disappointing to find that learning from the Kirkup report has not always been built into practice here. The strong message heard from women and families in Cwm Taf is that they don't want their experiences to happen to anyone else and the importance to them that the organisation learns from these experiences to ensure that improvement and change occurs. They hope that their words and stories will be a major driver for change.

As a core part of the invited review the RCOG Review Team wanted to build a comprehensive picture of the care and issues surrounding the identified stillbirth and baby loss experienced by women and families. It was decided that the approach should be in depth and specifically designed. A mixed methods approach was designed to reach as many people as possible within the timeframe built around the review.

In addition to informing the RCOG review the outcomes of the engagement exercise have relevance and importance for:

- The Welsh Government in understanding local perceptions of the quality and safety of care and to support planning of maternity services at a time of change in South Wales;
- The development of local maternity services in Cwm Taf to meet the needs and wishes of the local women and families who use them, particularly at a time of service change and reconfiguration;
- Local women and families using maternity services to support their understanding of the quality and safety of the services and care they use;
- Ensuring that the experiences and ideas of women and families are at the heart of shaping future care

In the period from 20th December 2018 until 6th February 2019, using a range of methods, we heard from over 140 women, family members, friends and people who had links with women using maternity services.

- 61 people completed the *Your Maternity Care in Cwm Taf survey*
- 18 women and members of their family were interviewed face to face or by telephone
- 4 women wrote their stories and sent them to us
- Over 55 people attended the engagement event on 16th January 2019, and
- The views of people with links to women using maternity services were heard in evidence sessions and through written accounts and documented evidence.

The engagement exercise explored themes and issues parallel to the RCOG Review, in particular the Review Term of Reference 8:

Assess the level of patient engagement and involvement within the maternity services and determine if patient engagement is evident in all elements of planning and service provision. Assess whether services are patient centred, open and transparent.

Engagement was designed to discover where care had been of a high standard, as well as how care may have failed women and babies, and contribute to understanding the events leading to the tragic circumstances that resulted in the loss of babies. There was also a need to explore the resulting emotional and physical impact on women and families. In addition, we wanted to ensure that the engagement process acted as an advocacy tool whereby women's voices were heard, particularly when their concerns might not previously have been addressed fully.

4.2 KEY MESSAGES FROM ENGAGEMENT WITH WOMEN AND FAMILIES

"Providers, senior staff and all healthcare professionals should ensure that in all birth settings there is a culture of respect for each woman as an individual undergoing a significant and emotionally intense life experience, so that the woman is in control, is listened to and cared for with compassion"[1]

Although some of the feedback reflected good practice in maternity care and women and families praised some members of staff working in difficult circumstances, a significant number of the recurring themes reflect distressing experiences and poor care that had a major impact on many of those women and families who told their stories.

"I'm broken from the whole experience, the lack of care and compassion. That terrible experience I was put through because of the staff that treated me. That experience will stay with me forever"

[1] *NICE Clinical guideline [CG190] Intrapartum care for healthy women and babies, December 2014,updated February 2017 CG190 1.1.12*

The conclusion must be that there are significant issues to be addressed within maternity care in Cwm Taf to ensure that women experience the evidence based, safe, personalised care they want and need.

1. Were women supported and provided with information to help them to make informed decisions and choices about their care, did they feel listened to and their wishes respected?

Women did not always feel that they had been treated with respect, provided with information they needed and given the care and support they required. The consequence of this had both physical and psychological impacts on them, their babies and their families.

The prime issue for most people sharing their experiences was the need for the service to be personal, focused around the needs of women and to listen to women and to be responsive. These examples reflect the personalised care that women told us they wanted:

> *"We had an amazing birth experience. The midwife was great and supportive without being too pushy and she let my daughter deliver in the best way. She used the birthing pool which I felt really helped pain relief"*
>
> *"The midwife mostly allowed my body to lead the birth of my baby with hardly no intervention except for heart rate checks and internal examination once"*

However, this was not the experience of all the women who engaged with the review. They told us that the care had not met the standard that they had expected, with physical and psychological consequences for them and their babies and families.

> A good service was one where *"I felt looked after", "the relationship between midwife and mother is an important one".* The staff caring for women *"made you feel more comfortable and reassured"*
>
> Some women found that the service was *"responsive, personal, and timely"*. The "*midwife was great, calm reassuring, listening to me. The right things happened. They explained things and made sure you were involved in the process".*

Being listened to and valued

> However this was not always the case: *"I felt worthless, like I did not matter – that's how I felt".*

Women repeatedly stated they were not listened to and their concerns were not taken seriously or valued. Often, their suspicions and concerns were found to have been about reflected a genuine problem that emerged later, but at the time they were dismissed. Many women had felt something was wrong with their baby or tried to convey the level of pain they were experiencing but they were ignored or patronised, and no action was taken, with tragic outcomes including stillbirth and neonatal death of their babies.

> *"I was never asked, never believed"*
>
> *"If only they had asked the right questions"*
>
> *"Most importantly, we were not listened to. By the time we were it was too late"*

"I waved my red flag as much as possible"

"Listen to women and families and believe what they tell you when they are in pain"

Communication, compassion and empathy

Throughout the engagement process, as women and families reflected on their experiences they recalled the impact of overhearing staff talking about patients and the use of inappropriate and insensitive language. This made women feel disrespected and undervalued.

It is assumed that staff would want to uphold professional standards in all circumstances and in this case it is unclear whether the poor attitudes or inappropriate use of language described were linked to stress caused by staffing shortages or other factors. This would be for further investigation to determine. However, the way they have been treated and spoken to leaves a lasting impression on women at a time when they vulnerable and want a good experience of birth, the most memorable event of their lives.

Sadly, many women felt that communication was extremely poor, that they were treated without compassion and that staff did not demonstrate an empathetic response. They reported a lack of kindness and empathy in staff sharing bad news or informing women that a pregnancy was at risk.

Women have remembered the words they heard for years after the event.

"A member of staff raised her voice to me in the hearing of other people. She laughed at me"

"I was laughed at when I was concerned"

"There was no eye contact – it's a communication thing"

"Pick your dignity up from the floor on the way out".

"I remember a woman coming in and saying – just to let you know the baby's died. She didn't break it gently. Then she just walked away"

"Communication is a massive issue. Staff displayed poor communication skills both between themselves and myself as a patient at the hospital, which had a negative impact on the care I received. Throughout my use of the service, I spent the majority of the time feeling vulnerable and uncomfortable. I do not feel I had adequate support during or after labour. There were times I felt staff just did not have the time to support or care for me and more disappointingly, on a number of occasions where certain staff were unprofessional and did not seem to possess the qualities a midwife should have"

One element of the communication failure would seem to be an attitude that clinicians assumed that some women were exaggerating their symptoms or pain:

"Enjoy pregnancy, deal with it"

"Told I was too sensitive to being pregnant"

Women reported an almost callous and brutal use of language and disregard for the feelings of women and their families. When one woman was concerned that she may be losing her baby she was told: *"prepare for the worst – it could be a miscarriage"* and then told to go home as *"there wasn't a lot she could do".*

Another account recalls the experience of a woman awaiting an operation following the discovery of ectopic pregnancy. The lack of empathy and inappropriate timing of requests to make decisions on life changing events when she was alone and without support are clear in this story:

> *"In the anaesthetic room when I was asked – what do you want to do with your baby? I didn't know what to do about burying my baby. I was on my own as my husband was outside and we were 10-12 weeks past the date when the baby had died"*

2. Did women receive the information they needed and were their decisions and choices supported?

Women wanted accessible, timely and appropriate information in order to make decisions and choices about their care. They wanted information to be evidence based and available to them in a range of formats and they valued better access to advice with less ambiguity about which number to ring or where to go when they need help or reassurance. They wanted support when they made their decisions and choices.

There were examples of helpful and comprehensive information and there are opportunities to work with women to design the formats for information they need, including online information.

> *"We had the right amount of information in a way we could understand. For us the parent craft sessions were invaluable and saved our sanity"*

Women value better access to advice with less ambiguity about which number to ring or where to go when they need help or reassurance:

> *"From the beginning to the end everything felt very disjointed, there was no clear point of contact"*
>
> *"Review the approach where women experiencing problems around 20-26 weeks are told to attend A&E rather than the maternity unit"*

Examples show that at times specific requests or choices were refused outright with no real evidence, women weren't always given a chance to ask further questions and staff were too 'busy' to get involved, birth plans and requests were sometimes ignored:

> *"I also wanted to be midwife led which can happen with uncomplicated diabetes but they didn't listen or entertain it. I didn't even need insulin during my labour!"*
>
> *"I was not given an opportunity to talk about my concerns"*

" I had specifically asked to have delayed cord clamping and spoke about it with the midwife on the day. She either misunderstood or decided against it and clamped my son's cord straight away"

"I was told what was going to happen not asked or involved"

"I didn't realise I could say no to certain procedures"

Different types of information and support needed

Some women wanted information in a format other than leaflets, others felt that there were gaps in the information covered, and respondents said that it concentrated on an 'ideal' situation; when things didn't go as planned or parents struggled as they returned home with their baby they felt unprepared.

A larger than expected group of responses concentrated on being prepared for situations during pregnancy, labour and birth when things didn't go as planned. This is a challenging area and health care professionals may not want to alarm women and families.

In particular, during first pregnancies, women found it difficult to know what to look for. They wanted to be better informed about risks, especially symptoms they may act on, for example, reduced fetal heartbeat.

There may be some benefits in providing information on 'warning signs':

"Very formulaic and largely consisted of leaflet distribution. There was not enough preparatory support for breastfeeding prior to the birth and my husband and I felt the information given was the 'ideal world' information and not the real world reality of first time parenting"

"Not much information in regards to what foods to eat etc during pregnancy"

"Not risks if the baby is in distress. I was young, first pregnancy and didn't know what could result with lack of oxygen to the brain"

"Have an insight to how labour should progress and expected foetus monitoring timescales"

Information concentrated on pregnancy and birth and there was a definite lack of information covering emotional and physical health and situations arising in the postnatal period:

"Definitely not. The information at antenatal classes did not discuss the aftercare aspect. The focus is on labour and not other factors like how you may feel after birth, the tiredness and emotions. I feel if this was discussed I would've been more prepared for the week stay after the birth"

Needs of younger mothers and fathers

Linked to the need to listen and respect the wishes of all women using maternity services is an emerging theme that some groups of women were given less regard than others. In particular, younger, less experienced mothers needed more support, empathy and information as they often felt dismissed. In particular they wanted to know what signs to look out for and be better informed about risks.

"I was never told what to look out for"

"Very little input during the pregnancy, no information regarding what to expect as a first pregnancy or what assistance would be available after the birth"

"I would have expected more support"

"Some mums aren't able to articulate what they want or need and things get missed"

There were many examples of the need for increased breastfeeding support and more support and information around preparation for labour and birth, exercise, and relaxation. Repeatedly the assessors heard that both parents wanted support to give them confidence.

"Support offered to new parents"

"More staff for breastfeeding support – the day of birth we had support, second day we only saw the midwife once"

3. Did women receive safe, high quality maternity care?

High risk pregnancy – management and support

It is clear that many of the tragic events surrounding the birth and, in a number of cases loss of babies, present significant learning opportunities for maternity services. There was strong feedback that some of the doctors, locums and midwives they met *"didn't seem to know how to handle complex high risk pregnancies".* One woman interviewed believed that there was a lack of expertise and availability of the right level of skills at the right time: *"anything different from the norm, they didn't seem set up to deal with it".*

Women were told that their pregnancy was high risk and that specific care plans were in place however, their attendance at the antenatal clinic and their reception on attending A&E or the maternity unit in an emergency did not reflect this.

"My pregnancy was high risk but it never felt as if I was treated as high risk"

"The antenatal clinic felt like a cattle market"

Seeing many different doctors at the High Risk Antenatal clinic resulted in different opinions, and often a perceived lack of knowledge about the woman's history; *"read the notes"* was heard from women several times.

"Consultant led, but never saw them – once at the beginning and once at the end"

Women wanted to see *"better continuity during antenatal care so that women with high risk pregnancies see the same consultant and don't experience so many different opinions and conflicting advice".*

Skills and experience, escalation

A number of the experiences focused on a failure to seek a second, more senior opinion, and to escalate concerns, especially in the case of women with multiple complex conditions.

Throughout the engagement exercise we heard about the reluctance to send for a second opinion or call a consultant for advice.

"He told me there was no point calling the consultant on a Sunday as no one would come"

"The registrar who became involved when my baby got into distress said he did not need additional support. The midwifery team disagreed with him and a consultant was called.

I am concerned that other midwives without the level of experience as those looking after me, may not have felt able to speak their mind and call in someone to override the registrar"

Women and families told us that they *"put their trust in the doctor and midwives"* assuming they had the skills and experience that would support the advice they were being given.

Women spoke about their concerns regarding the failure to examine and examples of misdiagnosis. In one account a woman was in such pain that she had attended hospital and was begging to be seen by a doctor. She had been left for nearly three hours without examination. Eventually she was examined but told that: *"It's constipation, discharge with laxatives and pain relief".* The intense pain continued at home but she *"didn't know what labour was and thought it's still early in the pregnancy. I tried to sleep it off and took the painkillers to see if it went".* In desperation she also took the laxatives and that evening her baby was delivered prematurely at home by her husband and mother in law. Despite their efforts to give CPR to save her life, sadly their baby's life was lost.

This tragic story illustrates a number of serious issues:

- Inadequate levels of expertise in managing high risk pregnancies
- Failure to listen to women and to understand the level of pain being experienced and reported
- Lack of response to 'red flags' and failure to follow good practice and pathways of care
- Failure to call for a second, more senior, opinion
- Failure to support the woman after the tragic and traumatic loss of her baby

Continuity and consistency of care and carer

Women deserve consistent, high quality care every time they use maternity services. They want continuity and consistency and did not always experience either. They believed that care should be woman centred and built around her personal needs and wishes.

Women told us that their experience was affected by too many variable elements such as the time they contacted services, staffing levels or the communication skills of the staff they met. Women told the assessors many times that knowing their midwife well encouraged them to share concerns and ask questions. Women felt that they were able to build relationships, had better outcomes and felt more confident in their pregnancy and in giving birth.

When women had complex conditions they wanted to see the same midwife or consultant as much as possible:

"If I had someone who knew me they would have spotted the problems. If I'd had a midwife they would have known something was wrong"

Repeatedly, women discussed the difference between services, the variation between community and hospital care, and lack of continuity between staff due to changes and handover. Community care often emerged as a better service with staff knowing women and their needs and having more time to engage with them.

Women and families appreciate consistent relationships in order to build trust and confidence to ask questions. They were concerned that they were passing through a system that didn't know them and that something vital would be missed:

> *"I never saw the same consultant. They didn't know me, and they didn't want to know me. I was pushed in and out of rooms with all sorts of people"*

Hearing different opinions, conflicting advice and information from the healthcare professionals that women met during their care caused confusion and uncertainty.

4. Did the location of services, staffing levels, and the planned relocation of services affect their care?

Rushed and overworked – working in difficult circumstances

Low staffing levels would seem to have had a significant impact on communication and, in some cases, the quality of care. Although many women were understanding about the strain placed on staff and praised them for their work, there is no doubt that these circumstances had a major effect with women not able to make contact with a midwife to help them, to ask questions or to be heard. We were told that clinicians were "*always rushing and not listening".*

> *"This is however due to the demand on the midwives and doctors in the RGH and is in no way a reflection on them. They would always spend as much time as possible with me but unfortunately when needs must I was left with some questions but again this was due to staff shortages"*

Women felt that understaffing affected their confidence in the skills and ability of midwives to meet the needs of babies and mothers:

> *"There were some lovely midwives but equally some not as good midwives. This makes it seem like no one knows what they are doing"*
>
> *"There were so many jobs for one midwife to do and then people wonder why mistakes get made. They are human and are exhausted"*

Particular issues arose for women using busy antenatal clinics and they felt unable to ask questions or talk through their concerns and wishes:

> *"Clinics were so busy and not many staff so felt like you should be in and out"*
>
> *"Didn't feel comfortable to ask questions as appointments felt rushed"*
>
> *"The antenatal clinic felt like a cattle market"*

There was a sense that staff morale was undermined and that the difficulties may have been made worse by staff shortages. This situation had an impact on staff attitudes and in many cases was transferred to women during pregnancy and when giving birth. Low staffing levels

would seem to have had a significant impact on communication and, in some cases, the quality of care. Although many women were understanding about the strain placed on staff and praised them for their work, there is no doubt that these circumstances had a major effect with women not able to make contact with a midwife to help them, to ask questions or to be heard.

Impact of early discharge home

A number of women described their experience of being rushed into discharge home when they didn't feel ready or confident. Whether staffing shortages were the reason for ensuring that beds were made available as soon as possible, or if staff may have been exhausted, is unclear. However the staff reactions, attitudes and language which women reported are unprofessional. There are questions about the level of care and ensuring that women are confident and ready to be discharged. Two examples illustrate this:

> *"There was a general sense that they were clearing the ward (I was the 4th of the five people on the ward to be discharged that day).....On leaving the ward we thanked the staff sat in the nurses office and as we walked around the corner a loud cheer erupted from the room!! This compounded my feeling that they were keen to discharge as soon as possible. I was also keen to go home but in retrospect was not ready for discharge (my iron was very low and I was still struggling with breastfeeding)"*

> *"I was then moved to the ward at midnight and was left to repack my bags alone and without help, despite extremely heavy blood loss and a long, traumatic labour. I felt that it was easier for the midwife to move us both as it reduced her workload - I did not see her for the rest of the night and nobody came to check that I had managed to pass urine after my catheter was removed"*

Maternity service changes and relocation

Overwhelmingly women have said throughout engagement on maternity services locally that they want safe, high quality, accessible services in Cwm Taf. Changes to the service model and location of maternity services continue to be of major importance and the concerns and issues highlighted in the engagement organised for this review reflect the priorities heard in Health Board engagement activities.

Consistently women and families currently using services at Royal Glamorgan Hospital have raised concerns about the change of location of obstetric led maternity services and inpatient paediatric services to Prince Charles Hospital. The distance to travel and the quality of the roads, problems with lack of transport, and difficulty in travelling in poor weather, especially in an emergency have all been highlighted as problematic for families.

5. If things didn't go as planned did women receive support that met their needs?

Support and bereavement counselling

"Birth is supposed to be a wonderful experience – I wasn't treated like a human being"

A variety of experiences regarding support after the loss of a baby were reported; at the time that families needed kind compassionate care, counselling and support services there were clearly gaps in provision and variation in how they were supported appropriately. Many women and families received no bereavement counselling or support and continue to experience emotional distress. All of the family are affected by the loss of a baby and support for fathers is also needed. Many women carry guilt about their experiences and believe that it was their fault that action was not taken at an appropriate time.

"I cry myself to sleep every night – not my fault but it's the 'what ifs'"

"I wasn't assertive and delayed going down to the hospital. I should have said I needed a C section when things were going wrong"

"I think about the experience every day – the outcome may have been different"

"I continue to feel responsible for the outcomes for my pregnancies – I should have insisted more for a transfer to be arranged"

Sadly the impact of these traumatic experiences has been long lasting for many families. Families reported that they continued to experience emotional and physical problems and a number of families have experienced PTSD. Families wanted to ensure that the bereavement service had the right level of personnel, with sufficient expertise to meet their needs. In some cases, families did not find out about the range of support and advocacy from other organisations such as Sands and the CHC.

"I feel so angry, upset and massively let down by most of the staff that treated me"

"I want having a baby to be a good experience. It's ruined it"

Many bereaved parents talked about sharing accommodation and facilities on labour wards with those who had given birth, hearing crying new-borns, which added to their distress.

6. What happened when women raised concerns and how were they involved in the investigation of incidents?

In much of the feedback from women and families there is significant dissatisfaction with the way that concerns were addressed at the time. They report:

- Failure to respond to 'on the spot' concerns expressed and examples of dismissive attitudes regarding issues raised by women on the ward or during appointments. Often the excuse given is related to staff shortages and the busy unit.
- Many women not being listened to and not being taken seriously *"I was laughed at when I was concerned", "need to be less dismissive when women raise concerns", "they brushed things under the carpet",* families being told to *"drop it – nothing will be done".*
- Poor communication in follow up meetings to discuss concerns and 'closing down the discussion' by reassuring and promising *"things she couldn't deliver"*
- Lack of access to all appropriate information, including notes and a report from the clinicians involved, following an investigation "*the person who made the decision is not there anymore to explain*. There were a surprisingly high number of families that had experienced difficulties in not only seeing notes but also reported missing

elements from the record or inaccuracies. There was a significant loss of trust in the ability of the Health Board to maintain comprehensive and accurate records.

- Lack of comprehensive investigation resulting in incomplete responses to concerns *"complaints not acted on"*
- Focus on providing responses that were formulaic and seemed to be more interested in defending the reputation of individuals and the Health Board *"Felt like they were crisis minimising"*
- Lack of feedback on investigations and failure to respond or provide reports and copies of notes *"promised regular feedback on investigation and outcome and nothing heard for over 6 months" "Been palmed off, no lessons learnt"*
- Repeatedly women and families cited failure to apologise as a distressing factor. In addition, letters of response often provide a summary of what 'should have happened' but did not provide answers to all of the concerns raised *"no answers, wanted an apology and this was never received". "The response seemed to follow a template and was full of errors".*
- Responses received that did not demonstrate how learning had been translated into action to ensure that this did not happen again

> *"I was made to feel as if I was overreacting"*
>
> *"I forwarded a complaint to the hospital and waited months for a response. My first response was poor and skirted around the issues. I then placed a further complaint which was dealt with more seriously"*

Already, extensive work is being undertaken to use the lessons from the poor experience of those families involved in cases that are the subject of this review and action is being taken to change culture and behaviour.

Importantly, women and families wanted to see good practice in handling complaints and responding to concerns; thorough investigations, approachable staff, speedy discussions and effective meetings all provide satisfaction for families. They want to be part of the design of an effective complaints and concerns process that will incorporate all those elements.

7. Involvement of women and their families in the design of services

Women want services to be designed in a way that puts them, their babies and families at the centre. The women who have used maternity services need to be at the heart of designing them to meet their needs. In particular, those women and families affected by these events should be part of the improvement and design of the new service. They can have a role in co-creation of the new service and be part of changing the culture.

Women and their families told us that they are not currently involved in this process in a meaningful way. The MSLC can provide a means of ensuring that the needs of women and families, and professionals, are listened to and can influence change and improvement.

Learn from our experiences – make sure it doesn't happen to anyone else

If there is one piece of learning from the engagement exercise it is that all of the women and families who have shared their views, stories and feedback want their experiences not to happen to anyone else. They want everyone to have a good experience of pregnancy and

birth and their courage in sharing their views must be rewarded with action to ensure that learning results in improvement and change.

Women and families affected by these events were a key part of this independent engagement exercise and should continue to be part of the monitoring process regarding improvements in responses to concerns, engagement and communication.

"I hope the hospital does improve as if I choose to have another baby I will be apprehensive to give birth there again unless something is improved. I raised the complaint to ensure what happened to me does not happen to anyone else and I hope people have a better experience of birth than I had"

5. ENGAGEMENT AND INVOLVEMENT IN MATERNITY SERVICES

Review Term of Reference 8
Assess the level of patient engagement and involvement within the maternity services and determine if patient engagement is evident in all elements of planning and service provision. Assess whether services are patient centred, open and transparent.

In addition to undertaking an independent programme of engagement to explore and understand the experiences of women and families using maternity services in Cwm Taf a key part of the Review focused on the way in which the Cwm Taf Health Board listens to and involves women and families in developing maternity services.

In order to explore Review Term of Reference 8 this section provides an overview of the methods used and comments on the approach. Commentary on the perceived effectiveness of engagement and involvement and the openness, responsiveness and transparency of the organisation is provided.

5.1 Maternity Services Liaison Committee

The Maternity Services Liaison Committee (MSLC) is the main vehicle of opportunity for sharing developments in maternity care, hearing service user views and ensuring that they contribute to quality improvements and service change.

The number of service users involved in the MSLC varies and there are usually around 2 or 3 at any meeting; in addition, CHC members and an NCT representative regularly attend. Minutes of the meetings show that there is an average of twelve health professionals or managers present, including the Head of Midwifery (HoM), senior midwives, infant feeding nurses and patient experience leads. The assessors were informed that: *"a few other mothers, often those who have issues, want to come to meetings as they want to make sure that their experience doesn't happen to anyone else".*

It was acknowledged that *"overall it has been hard to get regular involvement from women".* The lay representatives have been looking at ways to reach out to women and families in communities, with ideas being put forward for meeting mothers in Baby and Toddler Groups

or Cafés. The MSLC minutes also confirm that a working group is being set up to explore a range of communication methods including the 'Bump Talk' Facebook page or other social media platforms such as WhatsApp. The MSLC members want to ensure that there are ways for service users to share their experiences through story telling. None of these approaches are in place yet as a result of *"everything else that is going on in terms of the Health Board and maternity services. It hasn't been a top priority for the management".*

Lay representatives believe that there are real opportunities to shape the new services via the MSLC. They have been involved to a degree by choosing décor and suggesting names for the new unit. In a really positive initiative, service user representatives had been involved in interviews for recruiting staff.

There are also moves to address the under representation of service users and to appoint a Lay Chair. There is recognition from service users involved in the MSLC that *"it is a hard position to be in as a service user and it's easy to be sucked in to their way of doing things".* The move towards a lay chair is commendable (and standard practice in Maternity Voices Partnerships in England) however it needs *"commitment, resources and support to enable this".*

Findings

The MSLC minutes reveal high levels of reporting about issues such as the planned service changes, staffing levels, community midwifery and infant feeding. There are items on 'incidents and concerns' and 'investigations' at each meeting; however there is limited discussion about patterns of issues emerging and service users are unsure whether *"they are telling us enough or not"*.

Commitment from senior midwives, maternity service leads and Patient and Public Engagement leads is demonstrated by regular attendance and bringing current information on strategy and maternity issues. The information and discussions are interesting but not a substitute for meaningful engagement. Currently, the MSLC acts more as a forum for reporting and discussion rather than a lever for action.

The MSLC has real potential for building an effective multidisciplinary forum to act as a hub for service user views, and to get women and families involved in engagement around improving maternity care and translating feedback into service design. Investment in the skills, resources and level of involvement for the MSLC and its Lay Chair in Morecambe Bay was a driver for change.

The MSLC is aware that there could be change by increasing the number of service users directly involved as members but also by acting as a conduit for the views and experiences of women and families. In the current situation (service change and the outcome from the review) the MLSC will have a vital role to play.

Increased levels of community based engagement with women and families would sit alongside engagement with women using maternity services, particularly following the move to the new unit at PCH.

The MSLC has a vital role to play in understanding how the concerns of women and families are addressed and whether there are patterns of issues emerging from concerns reported

and from engagement with women and families; regular reporting of issues takes place now however it is important that there should be discussion about recurring themes.

5.2 Community Health Council

In Cwm Taf the CHC has established a range of activities and functions to monitor the quality of services. CHCs have a right to enter and inspect NHS premises within its district, except residential accommodation, and has planned and delivered a programme of quality monitoring visits. The CHC also provides feedback on the way that patients and families are engaged and how the issues raised are addressed.

Review of the CHC's minutes and reports reveal that it has been active and engaged in terms of monitoring the development of obstetric and gynaecology services and is seen as a key stakeholder. The strength of CHCs is the right to have a response from the Health Board. Some examples of their actions include:

- In December 2018 the CHC Service Planning Committee meeting considered the new model for gynaecology services at RGH with a view to agreeing what engagement was required with the public.
- In February 2018 a CHC team visited maternity and neonatal wards at PCH with particular focus on the temporary arrangements as a result of the development of the new unit. They questioned whether patient satisfaction surveys had revealed any dissatisfaction with the current arrangements and asked the Health Board to summarise all comments, good or bad and requested numbers of surveys completed, action taken in the case of dissatisfaction
- In April 2018 the CHC expressed concern about the proposed location of the Snowdrop Room in the new development, that is in the labour suite. They believed that bereaved parents may be subject to further distress if new-born babies or mothers were heard whilst using the room.

The Health Board has responded to the CHC's concerns and issues raised, usually picking up on any positive elements in the CHC report and focusing on reassuring the CHC regarding the Health Board's priorities of quality and safety. It should be noted that an internal review of maternity services at Cwm Taf (2018) notes the 'significant inconsistencies' regarding the recording and exploration of stillbirths and whether shared lessons were ever disseminated.

Findings

The CHC has a valuable role as an advocate in terms of supporting women and families raising concerns but sometimes families are unaware of their existence and information on their role is missing from key locations. The CHC is in a key position to act as a monitor of the way in which the Health Board responds to those families affected by the issues emerging from this review. Their independence will be valuable in ensuring that the Health Board provides the right level of access to advice, counselling and support.

The CHC should ensure that they are satisfied with the response to concerns and issues identified through engagement or in quality monitoring visits. It is important that the Health Board responds fully, openly and honestly to issues raised by the CHC, particularly where there are recurring patterns of failures in care.

5.3 Engagement with women and families

In 2014 the Health Boards in South Wales undertook a large scale public consultation exercise (South Wales Programme) to explore options to address challenges faced by obstetrics, paediatrics and emergency medicine. The outcome of the consultation determined that there would be changes to Maternity and Paediatric inpatient services at RGH. This had resulted in a sense of loss for the community and a feeling that they were 'losers' in the reconfiguration.

The long lead in time to implementation of change due to the need for extensive planning and review across South Wales has presented challenges for engagement with patients and the public; a system of public forums had been long established in Cwm Taf to engage with local communities and provided effective mechanisms to engage with local people. Meetings of the forums have been held in four areas set up with the aim of keeping members of the public updated on changes in all health services delivered by Cwm Taf Health Board.

The forums are drawn from a database of residents who are informed about the date and time of open meetings that look at different services and current issues. The information sessions act as a vehicle to update the public on the process and underlying issues since the consultation on the South Wales Plan.

Awareness is raised about forum meetings, and the topics to be covered, through social media, posters in libraries and public places, via local Councillors and through local press.

5.4 Community based engagement with women and families

Over the past year pregnant women and mums with young families have become engaged through contact with midwives. Many women and families are passionate about improving the service and attend meetings with midwives. The Chief Executive and Deputy have attended meetings to share information about the changes in maternity services.

Numbers attending the local engagement around current service change have often been low although the topic to be discussed can encourage higher interest and attendance. One dedicated session held in the evening in a local leisure centre was attended by 17 Health Board staff including the Chief Executive, clinicians and planning leads. One member of the public attended with her baby. *"She was the best informed person in the area"!*

Facebook Q&A sessions have been well received and the issues emerging reflect many of the concerns heard about the change of location for obstetric led care:

- Travel in poor weather
- Transport between sites
- Accessibility of roads and terrain

Materials have been developed to support engagement, community midwives are seen as key to outreach work with women and families and one of the midwives has been focused on going to local groups where families meet. She has been talking with women about issues such as giving birth in an FMU and describing the model of care. Partners have also been involved in discussions and questions about the changes answered.

The forthcoming boundary changes are also being taken into account and discussions with families about patient flow to Princess of Wales Hospital, Bridgend rather than PCH have been explored.

The *Communication and Engagement Plan for Implementation of Changes to Obstetrics, Neonatal and Paediatric Services November 2018* outlines a programme of communication and opportunities for engagement, with clear messages about the new system, particularly around transfer of children from RGH.

A range of activities is listed and includes:

- Midwives sharing the information leaflet on changes to maternity services
- Use of social media including the Facebook 'Bump Talk' page which reaches a significant number of women and is a way to communicate with those who may not attend engagement events
- Coffee mornings are being held to share the results of a 'Your birth – we care' survey undertaken by HoM in Wales
- Named midwives discussing the changes with women whose babies are expected to be born in March 2019
- Discussions about the changes being held at antenatal classes
- Promotion of FMU and new unit videos
- Opportunities for parents to visit PCH
- Engagement event for women at RGH
- Public Forums late February and early March to focus on maternity services

Findings

The strategy and activity is focused on the communication of changes in the way the service is delivered. It is not clear how engagement with women using services following the reconfiguration will take place although this seems to be based around continuous promotion of the changes through use of videos, online, printed materials and social media.

It will be important to engage with feedback from women and families as well as communicate key messages; there will need to be a programme that explores the views and experiences of women using maternity services to assess the impact of change, their satisfaction and how the service and facilities can be improved and meet their needs.

5.5 Women's experience – learning into action

All women using maternity services are invited to participate in a patient satisfaction survey following their experience of birth. The surveys can be completed at a time of women's choosing and returned by post or via their community midwife. Surveys can be completed using iPads provided on the ward and that localised and online surveys are undertaken.

The Health Board advertises new initiatives to gather patient experience and satisfaction through surveys that explore patient views of specific topics such as catering and cleanliness services. Patients and visitors can access an app via their smart phone, website or via a QR code.

The PALS team undertakes 'Care to Share' sessions held in obstetrics and gynaecology wards and units. Their reports describe experiences shared by women and families and record how the feedback was passed on and any action taken.

The draft 2018 *Quality and Patient Safety Governance Framework* includes details of 'Internal assurance activity' and methods of reporting from 'Ward to Board' and highlights the move to make immediate change from 'real time patient feedback'. 'Unannounced Partnership Dignity Visits led by the Vice Chair' are aimed at 'gaining contemporaneous exposure to the experience of people receiving care and people providing care across a range of settings'.

Findings

The initiatives being taken to increase the influence of patient experience on quality and safety of maternity and other services are certainly welcome. However, following the feedback from women and families regarding failures in the quality of care and poor communication, it is vital that opportunities to build an even wider range of appropriate methods and approaches are developed in order to gain insight into patient experience. It is essential that feedback from patient experience is translated into action, is monitored and the outcomes fed back to women and families.

The programme of community engagement would benefit from an increase in outreach to existing forums and community activity and the development of innovative methods that meet the needs of all communities and women such as graphic recording and increased use of social media.

5.6 Responding to concerns

The Health Board notes that all concerns identified in patient experience surveys are examined and good and bad comments are communicated to individual professionals. In a response to the CHC there was assurance that *"actions are taken when necessary".* If women provide their details and indicate that they would like contact and feedback the 'concerns coordinator' will contact the woman; action will depend on individual needs and the Health Board information states that this may be via response letter, a meeting or action plan.

Information provided notes that if possible, concerns raised by women or their visitors are managed at the time. 'On the Spot' forms are completed by the Ward manager and the information reassures that the concerns raised 'are often managed appropriately at the time'.

Information provided in a response to the CHC notes that:

'If concerns are not able to be resolved this is documented on the form and further action is taken by the senior midwifery team. The woman is updated and contact is maintained. All the concerns received are captured via the Datix system. Women have access to the Health Board concerns site. Their concern is processed by the concerns team and forwarded to the department. Every effort is made to maintain contact with the woman on the day the concern is received'.

Findings

The description of the process for recording, managing and responding to concerns raised by women and families would seem to follow a thorough path and reflect good practice. However, in interviews and engagement with women and families in many cases there is dissatisfaction with the way that concerns were addressed at the time and there has been significant negative feedback from the RCOG independent engagement exercise regarding:

- Responding to 'on the spot' concerns and examples of dismissive attitudes
- Many women were not listened to and not taken seriously *"I was laughed at when I was concerned"*
- Poor communication in follow up meetings to discuss concerns
- Lack of access to all appropriate information, including notes
- Lack of comprehensive investigation resulting in incomplete responses to concerns
- Focus on providing responses that were formulaic and seemed to be more interested in defending the reputation of individuals and the Health Board
- Lack of feedback on investigations and failure to respond or provide reports and copies of notes
- Failure to apologise, causing distress
- Responses that did not demonstrate how learning had been translated into action to ensure that this did not happen again

The experience of some women and families regarding the way their concerns were received and addressed may not represent the experience of all patients and families using services at Cwm Taf and there is some feedback that provides examples of good practice, highlighting individuals who had excellent listening skills and gave comprehensive feedback with action outlined for learning from the women's experiences. However, the Health Board must ensure that the response to concerns raised is core to the work being undertaken to improve governance and patient safety.

Individual and group staff training on the value of listening to women and families and taking their concerns seriously must be a key part of any work being undertaken to build an open, honest and responsive culture in Cwm Taf. The experiences and stories of women and families must be used to contribute to reflective practice to improve practice, safety, and quality of care.

There should be a further review of the process of investigation of concerns, compiling responses, handling 'on the spot' issues and ensuring that all responses and discussions are informed by comprehensive investigations and accurate notes.

The 2018 *Quality and Patient Safety Governance Framework* highlights the value of an open, learning culture that enables people receiving care and people providing care to be heard and affect change. The document also highlights the need to 'make immediate change' and to learn from 'real time patient feedback, as well as ensuring patient feedback is a key informant for quality improvement'.

Significant work is being undertaken to use the lessons from the poor experience of those families involved in cases that are the subject of this review. Action is being taken to change

the culture and behaviour away from *"being threatened by complaints and serious incidents"* and to ensure that this *"will never be the same place again"* through cultural improvement.

5.7 Engagement with families directly affected

It is important to address the way that the Health Board has engaged with the families affected and how they can build more effective engagement and communication, in particular following the publication of this review and its findings.

Experience from the Morecambe Bay Enquiry has shown that the publication of the report and any publicity and media interest surrounding the tragic circumstances for families amplifies the emotions and concerns felt initially.

This report highlights the themes and concerns that families shared about their involvement in investigations and the way that the Health Board responds at this stage will need to demonstrate learning from mistakes made previously.

Findings

The *Communications Handling Plan* produced in September 2018 is focused on 'managing the message' with information set out regarding the helpline for families directly affected, briefings on the 'script' and approach for meetings with women and families directly affected, together with signposting to offers of support. It is acknowledged that women who are currently pregnant will also have concerns about the safety and quality of the service and the strategy suggests that there will be opportunities for them to discuss matters with their midwife.

Women and families directly affected must be a core part of the changes to improve maternity services in Cwm Taf. In particular, they should be at the heart of co-designing the support and information for bereaved families.

APPENDIX

Appendix 1

Engagement design, delivery and methodology

In designing and delivering the approach to engagement it was clear that alongside those families who had positive experiences of pregnancy and childbirth there would be many women and families who had experienced tragic loss or continuing challenges including the impact on the health and wellbeing of their baby together with longer term impact on their own emotional and physical health.

Engagement in these circumstances needed to be designed and delivered with sensitivity, empathy and compassion and requires the use of a range of methods appropriate for the issues being explored and the needs and wishes of the women and families involved.

The engagement exercise was conducted within a designated timeframe in order to meet requirements of the review report. Within those limitations however, there was a good response to all of the methods used. Publicity regarding the RCOG review and the visit to Cwm Taf, the public interest in the quality and safety of local maternity services and promotion of the survey and engagement event through networks, social media and the Health Board website were all factors in building interest and involvement.

Methodology – how we listened to women and families

Throughout this engagement exercise we heard what a major impact the experience of pregnancy and birth had made on women and families. When the experience resulted in tragic loss or had a significant impact on the emotional and physical health of women and their babies the after effects are long lasting:

"I think about the experience every day – the outcome may have been different"
"I cry myself to sleep every night – it wasn't my fault but I think about the what if's"
"I want having a baby to be a good experience. It's ruined it"

In these sensitive circumstances where people have experienced loss and may find telling their stories difficult we wanted to make sure that there were as many ways as possible for people to share their experiences.

The mixed methods approach included a range of different, flexible engagement opportunities for women and families to share their experiences:

- Survey offering opportunities to share experience against a set of key questions, and also identify how people wanted to be engaged further;
- Use of social media platforms (for example Bump Talk) and other means of communication to raise awareness of the RCOG engagement approach and invite involvement;

- Interviews, review of documentation and evidence sessions with staff and advocates working with women and families, including the MSLC (Maternity Voices Forum) and CHC;
- Conversation café and engagement event on 16 January 2019 providing informal opportunities to share experience in groups with facilitators. People could stay for the whole event or call in;
- Opportunities at the engagement event to speak to the RCOG assessors on a one-one basis to share sensitive information;
- Views and experiences captured through tablecloth topic guides and other resources to record the discussion;
- Graphic recording during the engagement event to produce a "Wall of Conversation" that reflected the themes and issues shared;
- Opportunities for women and families to write down their stories, views and experiences either at the engagement event or shared by email;
- Confidential telephone interviews, post RCOG visit, arranged with women and their families to share their experiences including sensitive or distressing issues.

A1.1 Survey Methodology

The survey questionnaire was designed to explore key issues regarding the quality, safety and responsiveness of maternity care and services from the perspective of women, family members and friends and those people who engaged with women using maternity services.

There was variation in the types of questions utilised however they were predominantly 'Yes/No' questions inviting a specific response together with open text questions inviting further explanation of the positive/negative responses.

The survey was conducted between 20th December 2018 and 4th February 2019 and the text was translated into Welsh. Confidentiality of responses was assured and no individuals are identified in the thematic analysis. Where respondents identified that they wanted to be contacted to speak in more depth on a one-one basis they provided telephone or email details; the details were used only to make initial contact to arrange interviews.

The survey was accessed via an electronic link to the RCOG website and publicised by means of:

- Local press and social media (including Bump Talk)
- Direct awareness raising from the Cwm Taf Health Board Communications team
- Posters displayed in antenatal clinics and places where women and families would see them when using maternity services
- Contacts and networks of those groups with links to women and families using maternity services
- Invitations to women and families directly affected by events leading to the RCOG Review

A total of 61 responses were received and the response was initially analysed for statistical significance using software at RCOG.

The report author conducted a thematic analysis of comments and accounts of experience in the open text boxes. A significant number of the open text box responses include stories and descriptive passages that highlight personal perceptions of services and the way that staff cared for them; in these cases the content provides key passages and they are used to illustrate a theme effectively and powerfully but do not identify individuals or characteristics that could breach confidentiality.

Every written response has been read and as significant patterns and positive or negative themes emerged under each question they were then coded into thematic headings. The findings have been summarised under each heading with quotes taken directly from the responses to illustrate the theme.

A further exercise was undertaken to identify significant thematic patterns across all questions and the findings presented as conclusions.

A1.2 Methodology – Direct engagement with women and families

In advance of the visit to Cwm Taf links were made with key people who could ensure that the RCOG reached as many women, family members and people with links to women using maternity services as possible within the timeframe of the visit and in the following weeks. Connections with the communications team in Cwm Taf and the use of social media platforms and other means of communication such as posters and newsletters were used to raise awareness of the RCOG engagement approach and invite involvement in a 'Your Maternity Services in Cwm Taf' engagement event to be held on 16 January 2019 during the visit.

Early in the process it was clear that there would be opportunities to speak with people in telephone interviews and the survey included a section whereby respondents could request further contact to share their views in different ways. RCOG set up a 'Feedback' email address so that women and families could send messages, leave written feedback via email or send their stories.

Invitations to the engagement event were also sent out directly to those families who had been directly affected by the events that were the subject of the RCOG Review.

Your Maternity Care in Cwm Taf Engagement Event

In planning and delivering the half day event there were a number of issues that needed to be addressed:

Venue, resources and accessibility

- Identifying a venue in Cwm Taf that would be accessible to the many women and families that we wanted to hear was a challenge. People were spread over a wide area and no one location would meet the needs of all. We were relying on the local knowledge of contacts within the Health Board and Welsh Government and were also mindful of the cost of the venue. The Education Department at Prince Charles Hospital had a range of available rooms for the dates required.
- The venue had one large room where activities such as group work around tables could take place and space where the artist could create visual minutes. There were also a

number of smaller rooms available where confidential and sensitive issues could be discussed. Numbers attending were difficult to assess in advance due to the drop in format.

- The event was held between 9.30 and 14.00 to enable as many people with children who may be at school to attend. We recognised that those people who were working within that timetable would find it difficult to attend and we offered other opportunities for them to share their experiences by means of the survey and interviews by telephone
- Over 50 people attended either for the whole session or for part of the event

Format

- A topic guide for facilitated discussions and interviews was produced in advance and four key questions on the paper tablecloths were used as prompts for participants to ensure that the topics under consideration reflected the survey questions. The artist used the same four key topic areas for the visual map:
    - What did good maternity care look like for you?
    - What could have been improved?
    - Were you listened to and your wishes acted on?
    - If things didn't go as planned did you get the right support?
- The event took place as a conversation café that provided informal opportunities to share experience in groups with facilitators. People could drop in or stay for the whole event.
- The RCOG assessors acted as facilitators at tables and in one-one interviews.
- People could use one way of sharing experiences or all of the methods that included:
    - Opportunities to speak to the team on a one-one basis to share sensitive information
    - Facilitated group sessions using Pinpoint 'Stick It' cards and paper tablecloths with key topic guide questions
    - Opportunities for people to write down their views and experiences
    - One to one confidential interviews as an alternative to sharing experience in groups
    - Conversations with the artist and writing thoughts on Stick It cards to inform the visual minutes
- For those people who wanted to speak further to the RCOG team on a one-one basis there were opportunities to arrange post-visit phone interviews and send in their stories.

During the event the engagement lead for the day moved between the tables to identify whether specific themes were recurring. Those issues were collected and passed to the artist creating the visual minutes. As a result the visual map reflects the themes that emerged throughout the discussions.

All of the written feedback from the different sources, including facilitator notes, Stick It card and paper tablecloths, was collected to be transcribed so that it could be analysed thematically alongside the interview feedback and written accounts

Following on from the visit to Cwm Taf people continued to share their views and experiences by:

- Completing the online survey
- Arranged telephone interviews
- Writing down their experiences and reflections and sending them to the engagement team's 'Feedback' email address

One-one Interviews

A total of 18 women and family members were interviewed either during the engagement event on 16 January or in an arranged telephone call in the weeks following the visit to Cwm Taf . In some cases women spoke to the interviewer on their own and in other interviews family members were present and contributed. Notes were taken during the interviews and then transcribed in full.

Interviewers during the engagement event were members of the RCOG review team. Cath Broderick, independent consultant in Patient and Public engagement conducted all telephone interviews.

Interviewees were informed about the focus of the RCOG review regarding thesafety and quality of maternity services and the importance of hearing from women and families about their experience, and also if something may have gone wrong.

Participants were thanked for their involvement and assured that RCOG really appreciated them sharing their stories. It is acknowledged that it may have been difficult to share these experiences.

Interviewees were assured that everything they reportedwould be anonymous and, although their words may be used to illustrate some of the important issues in the reports produced, they would not be identified.

Interviews took between 60 – 90 minutes and ensured that the participants led the discussion and focused on their stories and the important issues for them. However, the topic guide prompts were used to explore issues further for example, what interviewees felt about improvement needed in services or the response to their concerns.

Written accounts and stories

A number of women chose to write their stories and the accounts of their experiences and send them to the RCOG They were personal reflections of their pregnancies and the events surrounding the birth, or in some cases, loss of their baby. These accounts are detailed and often distressing to read and provide a huge amount of detail of the events that are of huge importance to the women who wrote them. Their words are used throughout the summary of themes in this section.

A1.3 Thematic analysis of feedback

All of the feedback from the engagement event, whether it was written on the Stick it cards, the paper tablecloths or contained in the facilitator notes, was transcribed and the record was grouped into specific stories and accounts from the tables and individuals.

The interviewers took comprehensive verbatim notes during all of the face to face and telephone interviews conducted and the notes then transcribed.

Each interview transcript, the transcribed feedback from the engagement event and the text of the written accounts was read initially to identify the key issues and then several times more to ensure that no important themes were missed.

The aim of the analysis was to generate themes and broader categories and to identify relationships between them. Analysis also sought to identify any relationships from themes between the characteristics of participants in engagement, for example, were there particular issues that young mothers experienced.

The process followed the usual stages for qualitative analysis using a thematic approach: familiarisation with the data through reading transcripts; identification and development of broader categories; comparison between participants and exploration of relationships between categories; and refinement of key descriptive findings.

Analysis identifies a number of broad themes and, as in other parts of this report, illustrative short quotes are used to amplify the issues emerging. However the nature of the stories and interviews is often harrowing and sensitive; in order to do justice to the seriousness of the events and in respect for the families telling these stories, a decision has been taken in some cases to include longer passages from the accounts as they illustrate the issues so powerfully.

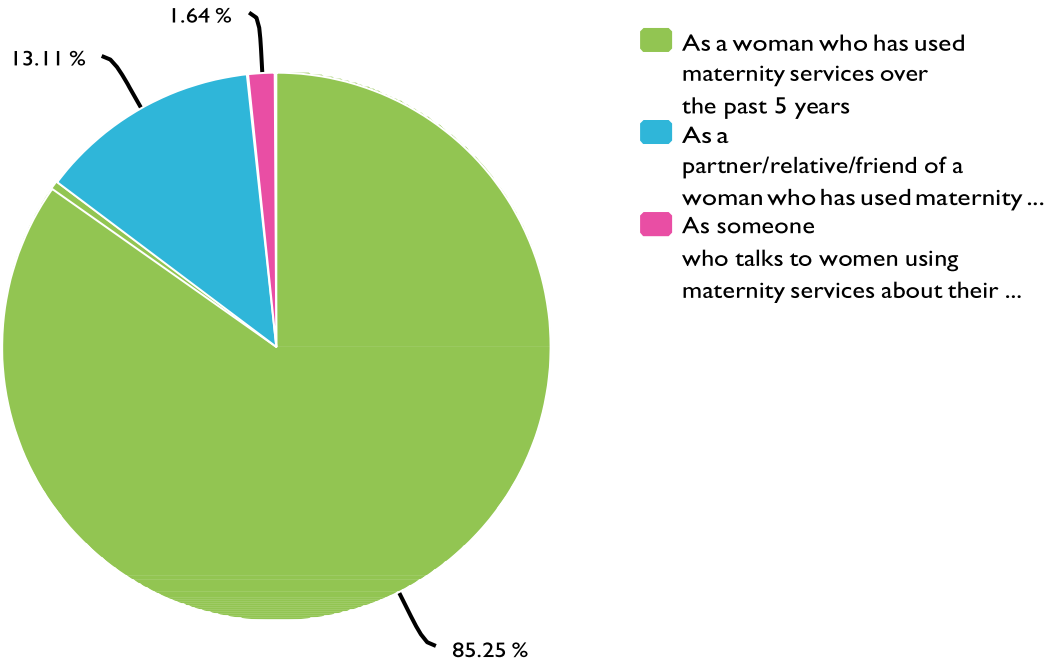
Appendix 2

Your Maternity Care in Cwm Taf survey: thematic analysis

A2.1 Findings

Who responded?

The 61 respondents were predominantly women who had used maternity services over the past five years (85.25%) together with partners, relatives or friends as the second largest group (13.11%).



Where did the respondents live?

There was a broad response rate across the Cwm Taf area with representation from women and families living predominantly in the CF postcode areas. The highest response came from women and families living in the Pontypridd area (21 respondents) and Tonypandy (11). Other respondents were spread across the Cwm Taf area including Treorchy, Merthyr Tydfil, Treharris, Aberdare and one Gwent postcode.

Age, gender, ethnicity and disability characteristics

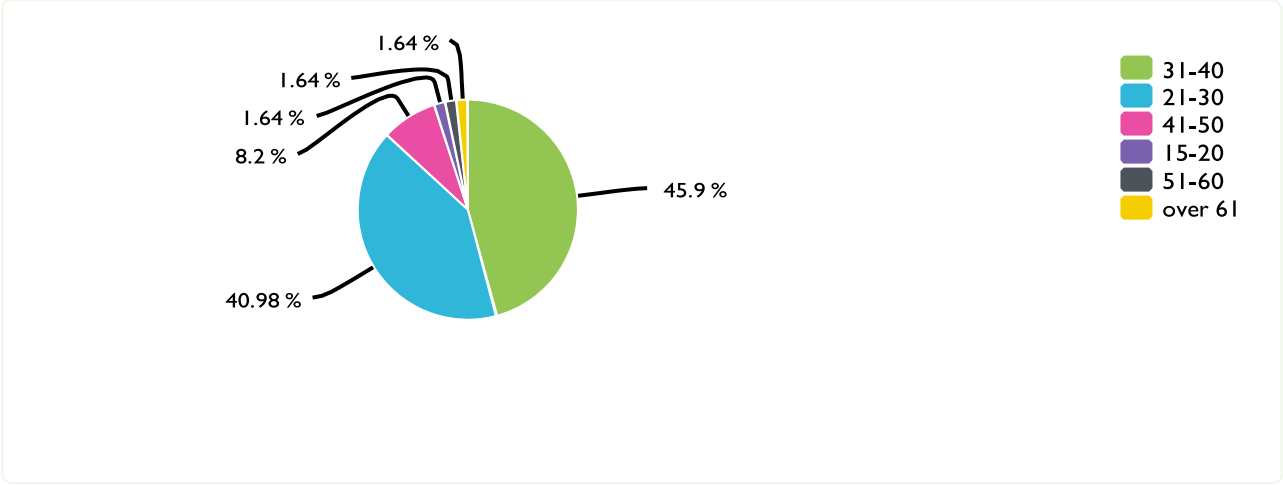
Of the 61 respondents 45.9% were aged between 31-40 and 40.98% were aged between 21-30.

95.08% of respondents were female, reflecting the population groups with specific recent experience of maternity services. The next largest group was aged 41-50.

Respondents predominantly identified themselves as White British or Welsh, with just one person describing themselves as Australian and another as American. This proportion is

statistically relevant in terms of the percentage of the population in Cwm Taf from BAME backgrounds (1.1%).

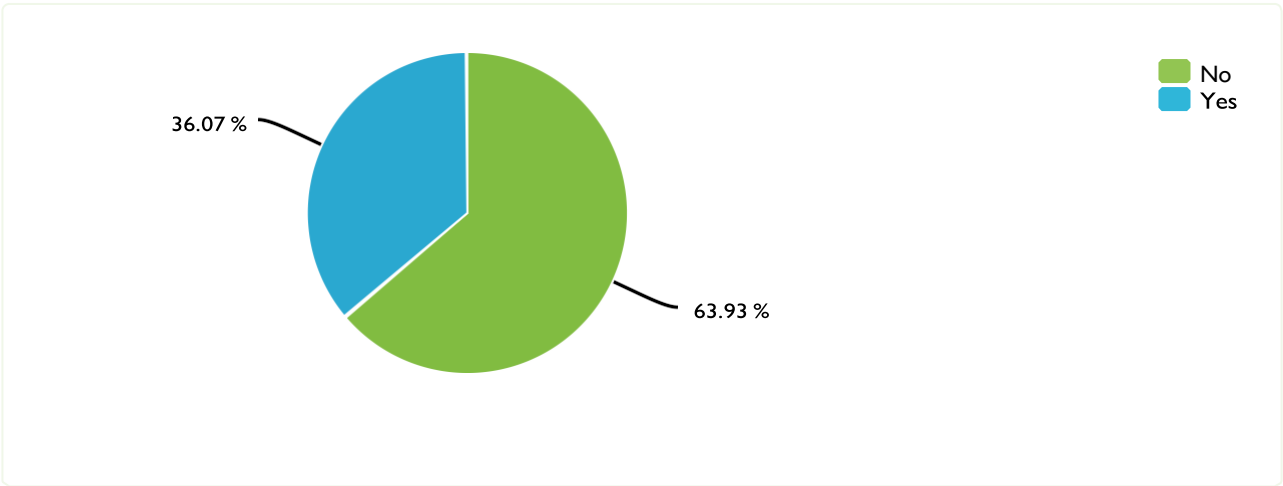
Four respondents described themselves as having a disability from a total of 61 responses.



Question 1

Do you feel that you received good quality care throughout your pregnancy, when giving birth and afterwards?

A significant proportion of respondents (63.93%) felt that they had not received good quality care throughout the whole period of their pregnancy, birth and afterwards. The findings from the thematic analysis of Questions 2 and 3 explore their experiences and the reasons underpinning this response.



Question 2

What do you think was good and worked well when using maternity services?

Variability of experience

Although the question asked for examples and experience regarding what makes good maternity care, the responses often focus on situations where care was poor in total or was

variable. Much of the feedback reflects what one respondent called *"a mixed review between yes and no".* Women compare different pregnancies and share significant inconsistencies in care, sometimes within the same pregnancy and birth experience.

From feedback there was an overriding sense that experience was wholly informed by:

- The time of contact with services
- Which team or member of staff was on duty at the time
- Whether staffing levels were low or met the needs of women being care for at the time
- Whether staff had good or poor communication skills
- The effective or ineffective relationship between members of the team from doctors to midwives and other healthcare professionals

"The care received during induction and after the birth on the RGH ward was variable. Some midwives were exceptional but others were not supportive and seemed disinterested"

"Exceptional care from induction to birth. Shambolic antenatal care"

"My care during labour was good…….However, the worst of my care came afterwards. During my stay (7 days) I was in 6 different beds in all the rooms on the ward. The doctors were not sympathetic or friendly and one midwife could not administer antibiotics to my daughter"

For women and families good maternity services are defined by their consistency of approach, standards of care, level of skill and good communication.

The impact of staffing shortages on care

There was a strong perception that staff were often working well but their performance was affected by the demands on them due to understaffing on wards and in the maternity unit:

"Staff worked professionally and exceptionally well considering you could see they were really short staffed"

"The midwives did their best they could given they were understaffed and had a huge amount of mothers in labour or being induced"

"Maternity ward midwives seemed rushed and overworked"

The impact of staffing shortages is also seen as a safety and quality factor and raises doubts and concerns for women about their care.

"The ward we waited in however was very understaffed and I felt that I was not checked as much as I should have been"

The analysis of the feedback does however highlight a number of themes that focus on the aspects of care and maternity services that women and families feel support a happy and healthy pregnancy and birth and a good outcome for everyone involved, especially mothers and babies.

Many of the factors that were identified as 'good' were linked to the people involved in care and the way that they related to women and families.

Professional, friendly, skilled, empathetic and reassuring staff

Women were clear that the relationship with midwives and staff during their pregnancy, birth and afterwards was key to their view of a 'good' experience. They appreciated midwives who were *"exceptionally supportive and full of good advice".* Women who were first time mums valued staff who supported them and were *"calm, patient with me and took the time to understand my emotions".* They appreciated the confidence that *"professional and friendly"* staff gave them.

Women identified what made the difference for them in their birth experience:

> *"Second time around was fabulous. Same community midwife throughout who was so understanding and helpful"*
>
> *"She was professional and extremely knowledgeable and made me feel 100% confident in her ability".*

The impact of poor relationships with staff was significant. Women want to feel connected with midwives and doctors and dismissive attitudes leave them feeling vulnerable and disregarded.

> *"I did not feel confident in the abilities of some midwives and was shocked by the lack of duty of care to us"*
>
> *"There was a midwife who was utterly horrible to everyone on the ward at that time. Made me feel completely inadequate because I couldn't breastfeed. I also heard her talking about me to another member of staff. Not what you need after an emergency C section"*

Support and information in decision making, empowering women

The right level of information and support that enabled women to make decisions and birth choices was highlighted in the responses. Women wanted to know what was happening at different stages of care and to have the confidence to make choices.

> *"We had an amazing birth experience. The midwife was great and supportive without being too pushy and she let my daughter deliver in the best way. She used the birthing pool which I felt really helped pain relief"*
>
> *"The midwife mostly allowed my body to lead the birth of my baby with hardly no intervention except for heart rate checks an d internal examination once"*
>
> *"The care and information I received about the situation was very good and reassuring"*
>
> *"My requests for a gentle section were listened to and, where practicable within the Trust's policies and procedures, it was granted"*
>
> *"Supportive of my decision to try the birthing pool"*

Continuity of care and carer

Women value continuity throughout pregnancy, birth and afterwards. Knowing the woman and her family was seen as helpful in building relationships, ensuring that wishes and needs were met and resulting in a successful pregnancy and healthy mother and baby. Lack of

knowledge about a woman's history of pregnancy was cited as problematic and in some cases seen to cause problems with safety and quality of care.

> *"I didn't see the same community midwife once during antenatal or post natal care. I wasn't given my notes when I left hospital and was discharged to the wrong team"*
>
> *"Same community midwife throughout who was so understanding and helpful"*
>
> *"I had regular appointments with the consultant during pregnancy and had good care when admitted to the hospital several times during the pregnancy"*
>
> *"My antenatal care was very well coordinated. The community midwives were very reassuring, supportive and professional"*

Difference of opinion and variable advice from staff causes concern, confusion and distress for many women and families:

> *"My water broke on Thursday. I phoned the hospital and they told me to wait until the night. I phoned again and they told me to come in. They examined me and said to come back the next day to be induced. It took them till Sunday to send me to the labour ward at which time me and my baby had developed an infection and had to have an emergency Caesarean under general anaesthetic. The whole experience has made me never want to go through a pregnancy again".*

Women want clear and consistent opinion and coordination and continuity of staffing and advice.

Communication and being listened to

Good communication between women and health care professionals, but also across the different disciplines involved in maternity care, was seen as a key factor in ensuring the responsiveness, quality and safety of care. At times communication was poor and had an impact on women's experience of care.

> *'There seemed to be no communication between the doctors, midwives and nurses. We were told to go home and then it kept changing"*
>
> *"The communication between the staff is absolutely atrocious"*

'Being listened to' is a major issue for women who want their needs and concerns heard and respected. When their views and opinions are dismissed women felt that the outcome was often poor.

> *"Had the midwife listened to my concerns earlier I feel this could have been avoided"*
>
> *"Not being listened to"*
>
> *"I wasn't talked to in depth about what will happen during my pregnancy"*

Question 3

Is there anything that could have been improved or changed, and if so how?

The response to Question 2 had highlighted good aspects of a maternity service but had inevitably raised areas where care had not worked well for women and families. Responses

had identified failings that needed to be addressed in order to transform a variable service into a high quality one.

Here, women and families talk about negative experiences but also identify changes that could be made.

Impact of staffing levels

Women and families again mention staff shortages and the way they had an impact on their care. They were aware of the affect on staff as they had to spend less time with women, were balancing tasks on busy wards and during labour, and often having to leave women alone.

> *"More staff available especially during the nights to be able to spend more time with mothers and babies so mums are not just left to feel how I did"*

Although women and families appreciated that staff were working under stressful conditions and doing their best, many times the rushed interactions resulted in poor communication and women felt disregarded.

Lack of continuity and consistency of care

From the start of pregnancy, through antenatal care, during labour and birth women highlight the value of building a relationship with midwives and doctors working in a team. Getting to know the history and needs of women and understanding what they want from pregnancy and birth is seen to result in a much better experience and outcome.

Women described the impact of lack of continuity of care and carer:

> *"Antenatal care in the community was shocking. Appointments ran late and midwives were difficult to contact"*

> *"There was a lack of continuity for which midwife I saw during my antenatal appointments. This must have been frustrating for the staff also and although you are advised to phone your midwife if you had concerns I was never sure whom I should contact"*
>
> *"I never saw the same consultant so continuity of care was poor"*
>
> *"I should have been under consultants from the start of my pregnancy! I feel like care is not consistent and made me feel on edge hoping there was nothing wrong with me or my baby as I hadn't received the care I should"*

Impact of early discharge home

A number of women described their experience of being rushed into discharge home when they didn't feel ready or confident. Whether staffing shortages were the reason for ensuring that beds were made available as soon as possible, or if staff may have been exhausted, is unclear. However the staff reactions, attitudes and language that women reported are unprofessional. There are questions about the level of care and ensuring that women are confident and ready to be discharged. Two examples illustrate this:

"There was a general sense that they were clearing the ward (I was the 4th of the five people on the ward to be discharged that day)…..On leaving the ward we thanked the staff sat in the nurses office and as we walked around the corner a loud cheer erupted from the room!! This compounded my feeling that they were keen to discharge as soon as possible. I was also keen to go home but in retrospect was not ready for discharge (my iron was very low and I was still struggling with breastfeeding)"

"After a particularly traumatic birth I was taken to high dependency care. Before my husband left for the evening he ensured that I had all the items I needed for overnight to hand. During the evening I was left waiting for almost an hour for my catheter to be removed while the midwife gossiped with her colleague and complained about another co-worker who had taken cakes to the staff on SCBU and not shared them with the rest of the team!! There were only two of us on HD care, so there is no reason that I should have been left waiting this long (I was exhausted and desperate to get some sleep while my baby slept).

I was then moved to the ward at midnight and was left to repack my bags alone and without help, despite extremely heavy blood loss and a long, traumatic labour. I felt that it was easier for the midwife to move us both as it reduced her workload - I did not see her for the rest of the night and nobody came to check that I had managed to pass urine after my catheter was removed"

Staff shifts and handover

An emerging theme relating to staff changes and handover highlights the impact on continuity of care. Women responding believe that different approaches and opinions from staff, a range of skills and lack of consistency affected safety and quality of care:

"During my induction when in early latent labour I waited over 2 hours for co-codamol and paracetamol as my midwife was in hand over. While I appreciate that a thorough handover is required, two hours is a long time for an individual to wait when in pain"

Staff skills and knowledge

Complexity of conditions, and factors leading to women being categorised as high risk in pregnancy, made women and families aware that they needed skilled and knowledgeable staff with experience of managing their specific condition. In some cases, even when they raised their concerns and alerted healthcare professionals, triggers were missed resulting in poor outcomes and experiences:

"Someone missed my low iron at my 28 week appointment and therefore I was not given tablets which resulted in feeling rubbish my entire pregnancy and needing iron infusions. I said to the midwives every appointment I was feeling really run down and not once did anyone discuss low iron. I even brought it up once. Had it not been for a random consultant who noticed it on the computer system I would not have been treated"

"Feeding was very painful and I was dreading each feed due to the pain. The midwife was very disinterested; she did not look at my nipples or into my baby's mouth. I came away feeling unsupported and at a loss, I felt she had already decided that I was ready for discharge and it was an inconvenience to her that I was struggling with the feeding. As it transpired my baby had a tongue tie which was later released, thanks to the support of my health visitor"

Understanding history and learning from failures

A history of women's complex or specific conditions was available from patient records however in too many cases respondents talk about the indicators that were missed. Whether this was to do with busy clinics, lack of staff knowledge or carelessness is not known but it sometimes had an adverse effect on quality, safety and outcomes:

"All staff should understand the patients background. It is literally reading a document – instead of judging and commenting"

"The fact I had had previous premature babies and one face first birth was totally disregarded on the pregnancy of my youngest child"

Another aspect of failure to learn from understanding a woman's pregnancy and birth history relates to the impact on subsequent pregnancies and care. In the following example the history of ectopic pregnancy was missed and even after investigation and promises that this would not happen again one woman had almost exactly the same experience a few years later:

"I suffered an ectopic pregnancy in 2011. I was let down badly, an investigation took place, I was left for 19 days in sheer pain unable to sit or walk properly, suffered internal bleeding also being admitted twice and they let me suffer and then had emergency surgery.

They promised things would be in place after the investigation to make it easier to treat women like me for it to happen yet again in 2013 ……left me 21 days suffering where I almost lost my life, had internal bleeding in my pelvis. Afterwards they did not offer me any support, guidance, nothing. I was young girl who could now no longer conceive naturally"

Referral for second opinion

Throughout the engagement exercise we heard about the reluctance to send for a second opinion or call a consultant for advice. In the survey the same issues were identified together with the impact on multidisciplinary working and safety:

"The registrar who became involved when my baby got into distress said he did not need additional support. The midwifery team including a senior clinical midwife disagreed with him and a consultant was called who immediately agreed that I would need help. We were taken to theatre and after a ventouse was attempted and failed I had a section.

I am concerned that other midwives without the level of experience as those looking after me, may not have felt able to speak their mind and call in someone to override the registrar"

Staff attitudes, communication

Throughout engagement event and especially in the response to the survey, women and families recalled the impact of staff attitudes and communication. This is a major life event for women and at times they may feel vulnerable and lack confidence. NICE Guideline CG190 recognises the importance of staff language and behaviour at this time for women:

1.1.12 'Providers, senior staff and all healthcare professionals should ensure that in all birth settings there is a culture of respect for each woman as an individual undergoing a significant and emotionally intense life experience, so that the woman is in control, is listened to and is cared for with compassion….'

1.1.13 recognises that: '*Senior staff should demonstrate, through their own words and behaviour, appropriate ways of relating to and talking about women and their birth companion(s)*

Intrapartum care for healthy women and babies, NICE Clinical guideline [CG190] December 2014, updated: February 2017

Too many times women and family members talk about the inappropriate way they were spoken to and the impact on them. It would seem that, from these experiences, staff are not always complying with the recommendations of guidelines and good practice:

> *"Communication is a massive issue. Staff displayed poor communication skills both between themselves and myself as a patient at the hospital, which had a negative impact on the care I received. Throughout my use of the service, I spent the majority of the time feeling vulnerable and uncomfortable. I do not feel I had adequate support during or after labour. There were times I felt staff just did not have the time to support or care for me and more disappointingly, on a number of occasions where certain staff were unprofessional and did not seem to possess the qualities a midwife should have"*

Although there was sometimes a sense that staff morale was undermined and that the difficulties may have been made worse by staff shortages, there is no doubt that language and behaviour has resulted in negative responses from respondents:

> *"During a complicated labour I did not like the way the two consultant doctors spoke to me in a very negative way and it was quite upsetting to hear a remark along the lines of – you will have to have a C section as you are not pushing properly".*
>
> *"Her attitude, she didn't care and she made it known. A woman was asking for help as her baby held its breath and she was upset. This same woman told the new mother you're being stupid"*
>
> *"More 'human' consultants who could explain why certain decisions needed to be taken out of my hands"*
>
> *"Midwives could have had a touch of empathy. I know the service is stretched and there is a huge demand on staff however there are health care support workers who could help"*

They also noticed the impact of poor communication between members of the team caring for them:

"Communication between nurses, doctors and midwives could be improved"

Listening to women and acting

Women were clear that they often knew when something was wrong and tried to convey this to midwives and doctors. Too often their views were disregarded and they were not taken seriously. In many cases this had an adverse outcome:

"They could have listened and acted and we would have had a healthy daughter"

"Yes listen to the lady when she says something's not right and to go home as they're over reacting"

Understanding the needs of all women

Linked to the need to listen and respect the wishes of all women using maternity services is an emerging theme that some groups of women were given less regard than others. In particular, young, inexperienced mothers needed more support and repeatedly the assessors heard that both parents wanted support to give them confidence. There were many examples of the need for increased breastfeeding support and more support and information around preparation for labour and birth, exercise, and relaxation. Some women had sought support privately due to the lack of available input from midwives:

"Yes I feel maybe midwives on site could have at least been given a heads up as she was treated just like any other woman and was still a child. Having a baby wasn't her choice or one she wanted but there was no customer care so to speak"

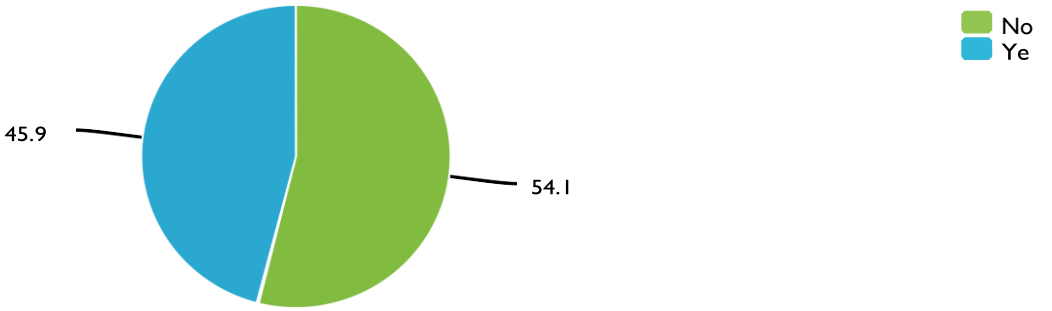
"Midwives ought to be given time to spend with expectant mothers to discuss pain relief at a better depth and practise breathing and relaxation techniques during labour. I paid privately second time around for birthing classes and education was key to a much better experience. Something community midwives could easily provide if they were given the time and resources"

"Support offered to new parents"

"More staff for breastfeeding support – the day of birth we had support, second day we only saw the midwife once"

Question 4

Did you always feel involved in decisions about your care?



Involvement and support for decisions and choices

Women and families value information during pregnancy about the different choices they have for place of birth, what they may experience and how they can keep healthy and improve outcomes for the birth of their baby. Much of this information was provided in accessible formats although this was focused on leaflets.

They also talk about the decisions and choices during labour, the way their wishes were respected and how they were informed if changes in birth choices were needed.

Positive feedback was received from 45.9% of respondents (with negative responses from 54.1%). The positive responses highlighted being kept informed at all stages and being involved in decisions even when circumstances changed. They saw evidence based information and support from staff as empowering in making their decisions:

"Always given opportunity to ask questions"

"In regards to my pregnancy and birth I don't feel that any decisions were made without my knowledge and involvement"

"I was kept informed of all options and well supported through a difficult labour. Unfortunately my birth plan went out of the window but the staff were still considerate towards my wishes"

"Apart from the locum consultant at the end of my second pregnancy, everyone discussed the options and took my opinion and requests into consideration. They never made me feel pressured into anything"

"Even when the decision about a section was made in an emergency situation, I was informed briefly and the staff all prepared around me whilst informing me of the plan"

"Staff were very supportive and always made sure I knew what was going on"

"It got very close to needing an emergency C-section and I was talked through everything multiple times and asked which anaesthesia method would suit myself better"

"Midwives were understanding and sympathetic to my first bad experience. They were willing to go with me and support my decision"

"Midwives empower women to make their own informed choices about care. Providing evidenced based advice"

Inconsistency in involvement and communication

Different levels of involvement and communication throughout the pregnancy and birth process sometimes qualified the positive experiences of some women. There were caveats in responses that reflect the variance of information and involvement. Although procedures were explained, at times women were 'told' what would happen and discovered later that they could have had more or different choices:

"I felt that any procedure was explained well but I don't feel like my options were discussed. I wasn't given choice just informed about what was happening"

"I was given an injection that I 'needed' but later found out that I could have refused or had it at a different point. I think that information should be shared"

"Whilst we could make decisions, we had to base them on inconsistent advice from different consultants"

"Because I was well informed myself and so acted as a self advocate. However there were times where I felt forced to conform to practises even when there was no risk to myself or baby"

"I stated on many occasions I did agree to certain things being done regarding the TB meds, scans etc and I was forced into agreeing"

"I was told to take medication that I know I can't take and made me ill"

"I was told what was going to happen not asked or involved

"I didn't realise I could say no to certain procedures"

Failure to listen and involve

As a balance to those women who felt involved and influential throughout pregnancy and birth there was a larger group who were disempowered. Sometimes this was linked to their lack of experience and feeling that the 'professionals know best' and in other responses women tried to express their views with no impact on decisions or outcomes. Despite asking questions they received either a poor response or were dismissed:

"As I was young and they were the professionals, I felt like I was the young one and they knew best"

"Informed the midwives on a number of occasions that I could not urinate normally and that I felt something was not right. I was in extreme pain and asking to go to the labour ward"

"My concerns were ignored"

"They didn't listen or answer our questions"

"My daughter had low blood sugar and was nearly sent to NICU which I knew nothing about until I asked why she was a bit shaky"

"The midwives and doctor didn't listen about pain, they didn't listen about when I felt things started go wrong they took further 2 hours 20 minutes to act, they didn't listen after birth"

"Every symptom I mentioned even though I had a previous ectopic they palmed me off with miscarriage even though every symptom was pointing to ectopic"

"My file was never by my bed, neither was my daughter's. We were moved several times without discussion"

"Always asking what was happening and could never give me straight answers"

"Doctors would never allow me to make any decisions or propose others"

"Doctors refusing to listen to my concerns. There is an attitude there that you cannot question the doctor"

"My birth plan was completely ignored and notes recorded inaccurately"

In some cases the behaviour and attitude of staff, and the fact that they were so busy and understaffed, dissuaded women from asking questions:

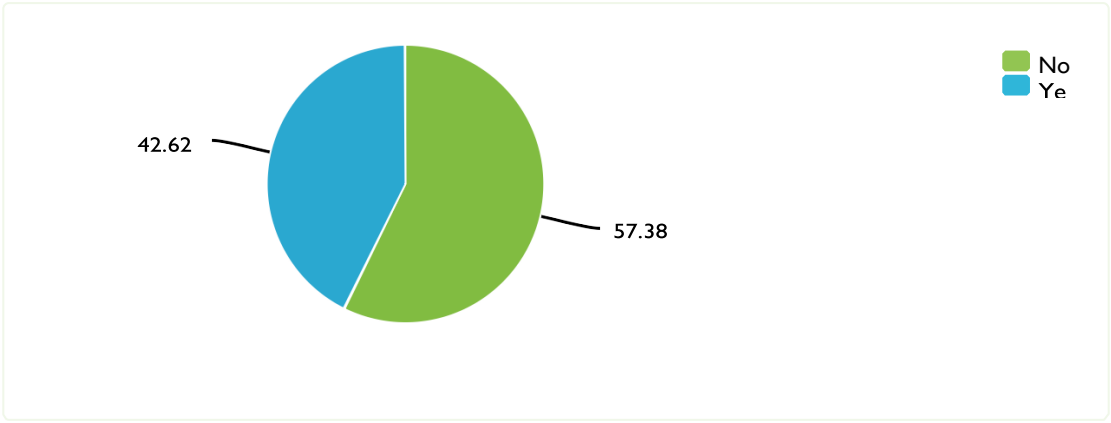
"The midwives were in full panic mode themselves. I did not feel reassured or safe. It was very scary"

"The staff were very unprofessional, arguing about my care! So I didn't trust them! They didn't ask my permission often enough!"

"My daughter in law felt that staff were too busy and that she was left alone, scared and afraid"

Question 5

Did you always feel that you had enough time with your midwife or doctor to talk through decisions and concerns at any time?



A higher proportion of respondents (57.38%) felt that they did not have enough time with staff to talk through decisions and concerns or to ask questions. Much of this was related to staffing levels.

Rushed and overworked – the impact of understaffing

The impact of low staffing levels was significant. Although many women were understanding about the strain placed on staff and often praised them for their work, there is no doubt that these circumstances had a major effect with women not able to make contact with a midwife to help them, to ask questions or to be heard:

> *"Always rushing and not listening".*
>
> *"Despite obvious strain on the NHS and in particular during a busy holiday period I could not fault the commitment to care shown and the patience in taking time with each patient to make sure needs were met"*
>
> *"Staff don't get enough praise for the demanding job they have. I received excellent support and care from everyone in maternity SCBU, radiology and the paediatric staff afterwards. I am very grateful to them for the service they provided to me and my son"*
>
> *"This is however due to the demand on the midwives and doctors in the hospital and is in no way a reflection on them. They would always spend as much time as possible with me but unfortunately when needs must I was left with some questions but again this was due to staff shortages"*

Antenatal clinics were a particular problem and many women felt that they couldn't ask questions or talk through their concerns and wishes. Women had to go in search of staff and there are significant issues for the quality and safety of care:

> *"Clinics were so busy and not many staff so felt like you should be in and out"*
>
> *"Didn't feel comfortable to ask questions as appointments felt rushed"*

"Midwives and antenatal classes cancelled. Midwife unable to offer support due to shortages and annual leave. Doctors simply do not have the time. They are non-stop constantly"

When women and families had questions or needed reassurance after the birth they didn't get opportunities to speak with midwives and doctors or ask for help:

"After the birth, on the maternity ward, it was difficult to get a midwife to help"

"Not enough time, as staff are very pressured which is apparent to patients"

"Doctors were fab but they didn't have enough time to have proper one on one time with us patients"

"I was worried but I could not get a midwife to the bed for a good while. I buzzed several times and in the end had to go to the reception myself. The doctors would rush in, say what they wanted to say then leave without much regard for questions or concerns"

"I had nowhere near enough time with any professional to talk through decisions and concerns during my care. This includes decisions and concerns during labour, caring for my new-born and the concerns I had for the health of my new-born and I"

Continuity and consistency

Repeatedly responses discuss the difference between services, the variation between community and hospital care, and lack of continuity between staff due to changes and handover. Community care often emerged as a better service with staff knowing women and their needs and having more time to engage with them.

As in other responses to questions women and families appreciate consistent relationships in order to build trust and confidence to ask questions. They were concerned that they were passing through a system that didn't know them and that something vital would be missed.

"I never saw the same consultant. They didn't know me, and they didn't want to know me. I was pushed in and out of rooms with all sorts of people"

"Second time, the continuation of care from the same midwife made me far more at ease and prepared"

"From 22 weeks to 37 weeks appointments went well but delivery all went out of window. Doctor left, midwives kept changing, didn't follow notes"

"My antenatal was great but in hospital it was like they were rushing due to too many patients"

"Yes in community however not on the ward"

"Midwife attended the house as I was quite immobile following car accident which was above and beyond (rather than attending clinic). She was very understanding and supportive throughout"

"It was one big rush because I arrived during handover, they didn't care and made me wait over an hour. There was no time to talk after that I was being rushed to theatre for a section! I had sepsis, this could have killed me and my baby!"

"Had numerous different midwives and during birth had a bank midwife and junior"

Responding to specific needs

Being unable to discuss concerns and needs fully resulted in lack of understanding regarding different procedures:

"In retrospect I did not fully understand the induction process from the description I was given. I found this process very stressful and there was a lack of support on the ward!"

Respondents explored experiences that reflected a lack of understanding about their needs, especially when they had a particular condition and required specific support, information and environment. For example a woman who was experiencing miscarriage was in a unit where she had a different experience and needs, to the women who were soon to give birth:

"Sometimes I was left on the early pregnancy unit waiting for doctors or nurses just for bloods to be taken. Even being made to sit with full term pregnant women while I was losing mine"

Another woman was in a situation where she also may have lost a baby but was sent home with little information, no opportunity to ask questions and a potential wait for further expert opinion:

"When my waters broke early at almost 19 weeks gestation, the doctors just sent us home and told us it was likely we would lose the baby. We asked to speak to our consultant and we were told we would be referred. When we eventually saw our consultant she had not been told what had happened to us"

Time for support and information

There were examples of the benefits of time to explore concerns, wishes and needs and to ask questions. However, these good experiences emphasise the variability of contact with individual staff, with different elements of the service and at various times:

"I was monitored regularly during my pregnancy and felt I was always informed about what was being done and why"

"Everyone always had plenty of time to make sure you were comfortable with decisions and any issues you had were listened to and dealt with"

"I was never rushed, after my first birth I was having problems establishing breastfeeding and the midwife always took time to help, they also kept me on their caseload for a few days after their usual 'off loading' date"

"My midwife was with me through the labour. Although there was not time to fully discuss the C section plan the key elements were explained whilst I was being prepped"

Involvement in birth plans

A number of responses explored the specific issue of discussion around birth plans. NICE Guideline CG190 is clear about the range of issues to be explored with women regarding place of birth and choices and from the comments set out here those discussions for birth planning did not happen:

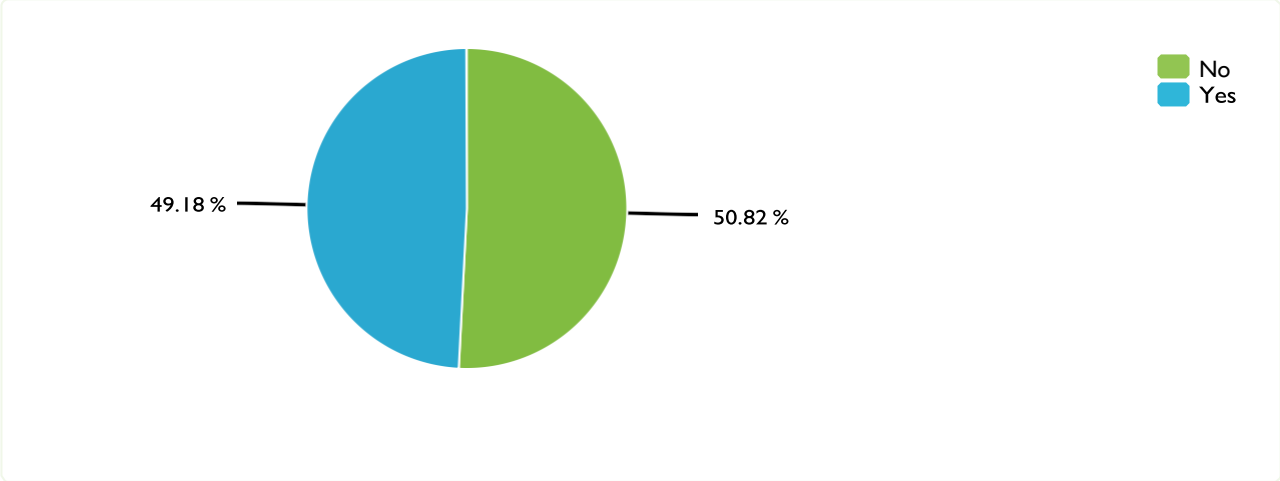
"Maybe more midwife appointments to discuss plans earlier as my son was 6 weeks early I had no plan no ideas"

"Didn't discuss birthing plan which I would like to have discussed"

"Wasn't much time to talk about things regarding birth plans and what to expect throughout labour and the processes involved"

Question 6

Did you feel after talking through your decisions and concerns they were listened to and acted on?



Not listening or acting

Respondents explored this question by relating to all aspects of their pregnancy and birth. Sometimes women were dismissed when they asked whether their baby's behaviour or development was of concern:

"My child was not feeding, but I was told that is just how babies are. Had this been acted upon while I was in hospital with him, I would not have had a very upsetting experience of my 5 day old baby being admitted to hospital with dangerous weight loss"

Examples show that specific requests were refused outright with no real evidence, women weren't given a chance to ask further questions and staff were too 'busy' to get involved, birth plans and request (for delayed cord clamping) were ignored:

"I also wanted to be midwife led which can happen with uncomplicated diabetes but they didn't listen or entertain it. I didn't even need insulin during my labour!"

"I was not given an opportunity to talk about my concerns"

"Staff were too busy to listen"

" I had specifically asked to have delayed cord clamping and spoke about it with the midwife on the day. She either misunderstood or decided against it and clamped my son's cord straight away"

Importantly, when women raised concerns and were assured that change would happen as a result a similar situation occurred again and concerns raised were not acted upon despite promises to respond:

"No, because promises were made to prevent this happening to anyone else but it did they failed me twice I carry the emotional scars with me everyday"

"I wrote an email to the Health Board listing my concerns. I was invited to meet with a lady at the hospital, who listened to my concerns and assured me that they would be acted on. I have been in contact via email a few times"

"I am still waiting to hear what the outcomes of this meeting are"

"Went to Royal Glamorgan Hospital to make a complaint and still waiting to hear the outcome"

Impact on confidence and self worth

It is of concern that many women did not feel as if they had the right to ask for help or advice when they had genuine needs. Staff dismissing their needs and making women feel as if their requests were exaggerated or frivolous resulted in lack of confidence for women themselves, feeling belittled and lacking in trust in the service:

"The arrogance of staff made me feel like a drug addict and when requesting simple pain relief such as paracetamol and ibuprofen"

"Made to feel like I was exaggerating"

"As an experienced mother I told them something was wrong they ignored it and told me to go back to bed"

"Felt vulnerable and lost faith after raising concerns over Apgar scores to our paediatrician etc. We felt lied to and pursued other avenues for help"

"Was made to feel belittled"

Influencing decisions and care

Clearly the experience of nearly half of the women responding reflected good practice and their concerns were acted on with a satisfactory outcome. Staff demonstrated understanding and a responsive caring attitude:

"At 1cm dilated I was in lots of pain and discovered baby was back to back with me, midwives allowed me to receive the pain relief I required at an early stage"

"I had a few episodes where I was concerned for lack of movement with my baby and each time was checked and reassured. I also had concerns of fluid leaking, which was also checked, and a Strep B infection was found and the doctors and midwives treated this in labour and treated my baby afterwards"

"Was very worried in case I had to have the section but all my fears were talked through and my wishes were acted on"

"Any concern I ever had was acted upon. I was admitted for reduced movements and when I got up to use the toilet at night the girls would ask about my movements and if using the toilet didn't work they would listen to his heartbeat for my reassurance"

It is important to note that some of the women replying had not always had such an effective and supportive response and this highlights once again the lack of consistency in staff attitudes and practice:

"I was so grateful for her time and understanding. If I'd had some of this first time round things would've been better"

"Sometimes. The nurses helping me breastfeed were great. They did listen but I was told that if I stopped breastfeeding I would be giving up, which isn't supportive especially just after giving birth"

Some of the comments reveal that women felt that they had the experience and information to influence the approach and choices in their pregnancy:

"If I'd not been so well informed myself I feel I would be been listened to less and automatically signed up for a 38 week induction for "large baby" (not large)"

"I was keen not to be induced before my due date (large baby) and the consultant was willing to compromise on an induction after my due date to give me a chance of going naturally"

Question 7

What did you think about the information you were given during pregnancy (i.e. did it give you the information you needed in a way you could understand?)

Even though there were more positive than negative comments overall, the response was mixed regarding the information provided to women during pregnancy. Many respondents felt that the written information they received was 'superb' and easy to understand. Feedback focused also on the information conveyed by staff, praising the time available for questions face to face. They appreciated the 'excellent' Parent Craft classes and opportunities to visit the maternity unit. However there was also feedback that although the information was often useful it could be seen as 'formulaic' and the helpful antenatal classes were often cancelled without much notice.

The lack of breastfeeding support and information helpful to new parents was highlighted as a particular gap.

Accessible, timely and helpful information

Respondents described the range of information and type of support that they found helpful:

"Yes the information I was given through the antenatal classes and pre labour experience was very helpful"

"We had the right amount of information in a way we could understand. For us the parent craft sessions were invaluable and saved our sanity"

"Good information was provided by the midwives who explained everything well"

"Yes, baby classes were also good to show you basic feeding, changing etc. I also liked being given a brief tour of the ward so you know what to expect when you go in"

"Yes had lots of information and if there was anything I did not understand they would happily explain it to me"

"All the information I was given was useful and easy to understand"

Poor information and confusing advice

There were respondents who just didn't get the right amount of information for their needs and there were gaps in the type and level of information in records. As with many criticisms in response to questions in the survey, failure to give information was linked to poor communication or rushing at appointments.

"I didn't get given enough"

"Very little given during pregnancy and brushed aside after"

"What information lol? ... They had my information including my home booking information but it was never added to my notes…. past births etc"

"Everything in regards to pregnancy was rushed and vague"

Different type of information and support needed

Some women wanted information in a format other than leaflets, others felt that there were gaps in the information covered, and respondents said that it concentrated on an 'ideal' situation; when things didn't go as planned or parents struggled as they returned home with their baby they felt unprepared.

A larger than expected group of responses concentrated on being prepared for situations during pregnancy, labour and birth when things didn't go as planned. This is a challenging area and health care professionals may not want to alarm women and families.

In particular, during first pregnancies, women found it difficult to know what to look for. They wanted to be better informed about risks, especially symptoms they may act on, for example, reduced fetal heartbeat.

There may be some benefits on providing information on 'warning signs':

"Very formulaic and largely consisted of leaflet distribution. There was not enough preparatory support for breastfeeding prior to the birth and my husband and I felt the information given was the 'ideal world' information and not the real world reality of first time parenting"

"Not much information in regards to what foods to eat etc during pregnancy"

"Not risks if the baby is in distress. I was young, first pregnancy and didn't know what could result with lack of oxygen to the brain"

"Have an insight to how labour should progress and expected foetus monitoring timescales"

Information concentrated on pregnancy and birth and there was definite lack of information covering emotional and physical health and situations arising in the postnatal period:

"Definitely not. The information at antenatal classes did not discuss the aftercare aspect. The focus is on labour and not other factors like how you may feel after birth, the tiredness and emotions. I feel if this was discussed I would've been more prepared for the week stay after the birth"

Women fed back that they wanted to check a situation or a concern with a midwife and found this difficult:

"I was given plenty of booklets to read up on anything I needed to. Although, if I did need any clarification on anything or have any concerns, I found it quite difficult to get in contact with a midwife"

Experience helps

A number of women responding felt that they didn't need information as they had experience of pregnancy and birth. Interestingly, they were sometimes not offered it with midwives assuming that it wasn't needed:

"It was a second baby so I didn't really ask for information since people don't seem to know what they are talking about"

"I wasn't given much information during pregnancy but this was not my first baby so I didn't require the same information as a first time mum but I'm sure if I needed it I would have been given it"

Doing your own research, helping yourself

Women also searched the internet and sought information and support from other sources:

"I did most of my research online"

"I paid privately to the Daisy Birthing Foundation. The best £90 I've ever spent. Midwives should provide such support if the system wasn't as stretched"

Cancelled antenatal classes and missing support

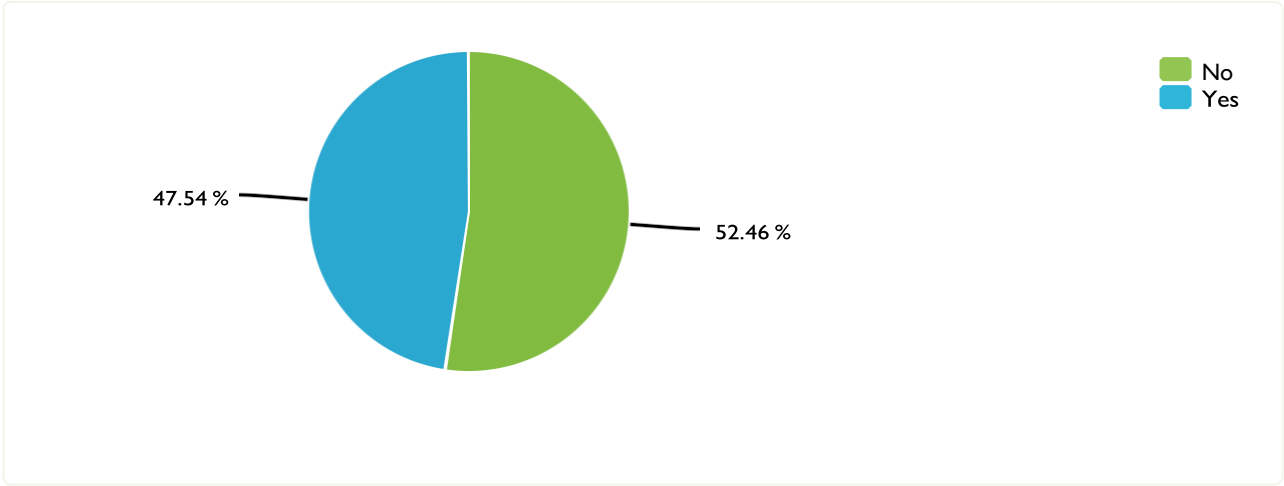
Antenatal classes were valued and sudden cancellations seemed to happen regularly. Whether this was linked to staffing shortages and community midwives supplementing hospital based services is not clear. There were support gaps when women lived in areas that could be served by different community teams.

"Halfway through my pregnancy antenatal classes were cancelled, only to be started up a short amount of weeks before my due date. These new dates were not suitable"

"When given information was easy to understand but antenatal appointments were cancelled with no substitute for this information"

"I had no health visitor or midwife as I live in between districts"

Question 8
Were you given information about how to raise concerns?



When respondents were asked about their knowledge of how to raise concerns the response was fairly balanced. This result reflects the comments received, with fewer women and families saying that they knew how to raise concerns (47.4%).

What more did you need in terms of information, communication and support in raising concerns or if things went wrong?

Someone to talk to, a point of contact

Women and families really value one point of contact, particularly if it is a single telephone number and/or a midwife known to the family. Continuity of carer and consistent easy to access advice, especially when things go wrong is important:

> *"Who to turn to, funding available, social services maybe a counsellor?"*
>
> *"Just gave me a number to phone if I needed anyone to talk to"*
>
> *"I wish that my assigned midwife could have been with me for the birth, it would have been a familiar face and someone I could trust"*
>
> *"We needed to have continuity of care. I was a high risk pregnancy and I needed someone to call who knew my history"*

I knew what to do – somebody helped me

Women regularly looked to their midwife for information on how to raise concerns or as the first point of contact. When there were questions about care families looked to their community contact, a senior member of staff on the ward or spoke to their consultant:
"Always knew I could talk to any member of staff regarding my concerns"

The awareness of how to raise concerns or who to contact was included in maternity notes that *" had information and contact numbers".*

> *"Was aware of system and had my questions and points answered"*
>
> *"Would have raised any concerns with my community midwife pre-delivery"*

"We raised a complaint whilst in the hospital and we discussed it with the sister. We were given the relevant information for making a complaint. I also submitted a formal complaint raising all my concerns"

"I was referred to a consultant to discuss my concerns"

"The community midwife who attended my daughter in law gave her the information at home after the birth"

"I was not informed of this until after I left hospital. The health visitor then pointed me in the right direction"

Found the information from another source

As with information about pregnancy and birth, women and families often used their own skills and researched the information online or sought other sources of information:

"Found out that information myself"

"I wasn't told anything I looked into it myself"

"I had to use Google in the end"

"We relied a lot on our own research"

Poor response to raising concerns

Question 9 explores whether the response to raising concerns was effective and met needs and in that section the themes and issues are examined in more depth. However, many of the responses to question 8 reflect on the outcomes of making complaints or seeking answers; there was a sense that this was a frustrating experience and there was some reluctance to raise concerns.

Those women and families who did know how to raise concerns commented on how difficult it was to get a response and were disappointed with the lack of early meetings to discuss concerns, poor access to counselling and incomplete responses. Communication was again a problem area and some families were reluctant to take their queries to staff as they had no confidence in way they may be treated.

"But did raise concerns and nothing happens other than the consultant saying doctors have different opinions"

"Very dismissive"

"I did know who to talk to but to get to them or for them to get back to me was another story"

"No counselling offered. No meeting to discuss concerns, felt vulnerable and struggling to deal with my child's prognosis"

"One thing that is really frustrating is that as a pregnant woman you are told that 'if you have any concerns or worries, call the ward and when you call, they haven't got the time of day for you! They make you feel small! They are just rude!"

"I wouldn't have gone to the staff with any concerns due to their manner"

Question 9

If you raised concerns what did you think about the way they were looked at, the explanation and response?

A good response – thorough investigation and explanation

Responses described good practice in handling complaints and responding to concerns; thorough investigations, approachable staff, speedy discussions and effective meetings all provide satisfaction for families:

> *"They were thoroughly looked into and I felt satisfied with the response"*
>
> *"Always knew I could talk to any member of staff regarding my concerns"*
>
> *"The quick response was great and put my mind at ease"*

A poor response – incomplete, defensive, not taken seriously and delayed

Many respondents also describe the characteristics of a poor complaints handling process all of which are key elements that cause dissatisfaction for women and families:

- Failure to address all concerns
- Not taking complaints seriously
- Delayed responses
- Formulaic and defensive letters and meetings
- Poor communication skills
- Dismissing concerns
- Being passed from one department and member of staff to another
- Failure to apologise

> *"Would have been no point if I'm honest as the midwife just wasn't knowledgeable in my experience"*
>
> *"I was made to feel as if I was overreacting"*
>
> *"I forwarded a complaint to the hospital and waited months for a response. My first response was poor and skirted around the issues. I then placed a further complaint which was dealt with more seriously"*
>
> *"A lot of lies were told and my explanation was 'you've gone onto have children so should be happy with that' "*
>
> *"There was an issue during pregnancy and it was passed from person to person until it eventually arrived with the HoM who said she didn't know how to sort it and basically 'tough'"*
>
> *"I had a phone call from a manager within the hospital and also a formal response about each aspect of my complaint. There were several issues. I received a list of questions from the complaints team that were going to be asked of the ward. The response was that a team leader had been appointed to deal with these issues but it did not fill me with confidence"*
>
> *"After the pregnancy I complained and did receive a response saying sorry but that wasn't good enough for me"*

"It has taken a long time to be able to get in contact with someone who is able to listen and potentially act on my concerns. I appreciated that I was finally being listened to, however I am still waiting to hear the outcomes of our meeting, despite making contact again"

"Still waiting for a response"

"Raised concerns on website following a link on the health board's website, never even acknowledged"

"Not listened to and a tit for tat attitude from services"

The lack of consistency in the response from the Health Board to women and families raising concerns is an area of concern; it would seem that a good response is based on the skills, knowledge and responsiveness of individual members of staff. It is good practice to address concerns thoroughly and effectively and to see them as a learning tool with changes fed back into practice. Themes emerging from this survey confirm that the current review into complaints handling is timely.

Question 10
Is there anything that could have been done differently to improve the response?

Being listened to and not dismissed

A theme running throughout the responses to all of the questions in the survey has been women's perception that they haven't been taken seriously, that their views and concerns have not been heard, that they have not been listened to and have been dismissed.

Respondents again highlighted the primary change they want to see – to be listened to and taken seriously. It is important to reflect the NICE Guideline CG190 again:

1.1.12 'Providers, senior staff and all healthcare professionals should ensure that in all birth settings there is a culture of respect for each woman as an individual undergoing a significant and emotionally intense life experience, so that the woman is in control, is listened to and is cared for with compassion….'

The responses describe the opposite response to good practice:

"The midwife listening to my concerns and not dismissing me as a first time mother"

"Just being listened to and asked instead of told. I felt like it was a conveyor belt situation where they were just doing the same thing day in and day out. They need to remember that it is not a daily occurrence for the mother to be"

"They could have listened to me when I was saying how I felt. I am not a doctor yet I knew it was an ectopic both times and rather than listen to me they let me suffer for 3 weeks both times to the point of almost losing my life"

"I was dismissed. For example, on the day that I was in labour, a vaginal examination was carried out (but again only through me insisting on this). During the examination, I was bleeding heavily. I asked if this was normal three times as I was concerned and I was just dismissed and told it was constipation"

Effective complaints process, meetings, investigations, outcomes and action

Respondents have described failings in the way concerns were investigated and addressed. Their suggestions for change focus on the need to respond promptly without constant chasing from women and families:

> *"The original reply could have given me the answers I originally needed instead of me having to complain further"*
>
> *"Those involved should have all met with the family, talked through all actions and outcomes, advised parents on complaints process"*
>
> *"To reply by email as promised on 2 occasions"*
>
> *"Improve communication"*

Importantly, women and families want to see change and learning take place as a result of the issues they raise. Information about the way that care had improved or changed as a result of their feedback should be communicated to women and families:

> *"Yes, they could have actually made the changes and not lied to us"*
>
> *"A lot could have been done but it was not"*

Question 11
Is there anything else you want to tell us?

The opportunity to reflect on the whole experience of using maternity services in this open question resulted in a range of themes emerging; some of the issues resonate with the criticisms and praise that respondents had already set out in their answers. However, new and significant themes emerge, in particular the intense feelings and concerns regarding the impending changes to maternity service configuration in Cwm Taf.

Concerns about maternity service changes

Women who have used the maternity services in Cwm Taf have continuing concerns about the changes:

- Women with complex needs living in Merthyr who would need to use an obstetric led service at Prince Charles Hospital are concerned about travel times of 45 minutes
- If babies are cared for in SCBU in the obstetric led unit this would have an impact on visiting, and mothers connecting with and caring for their baby
- There is concern about the capacity of one unit at Prince Charles Hospital to cope with demand
- Women are concerned about transfer from the MLU birthing centre at Royal Glamorgan in an emergency, for example needing a C section
- Women feel that they will lose confidence to have a midwife led birth if obstetric care is not close or in the same unit; this may reduce the numbers using the freestanding MLU

"As a mother who has had a baby in the SCBU unit at Royal Glamorgan I feel it is a terrible shame they are set to close. This will mean if I have another baby requiring assistance (very likely) I will be forced to go to Merthyr, which is a 45 minute drive. Last time I was forced to leave my baby in hospital while I was discharged. Knowing I was only 10minutes away if the worst was to happen was the only saving grace during this time. The thought of being 45 minutes away from her in those circumstances is unbearable and will certainly force me to make different decisions about my care in hospital. I will refuse to be discharged regardless of the implications. Forcing mothers to be away from their children is unnatural and certainly detrimental to both. I have never gotten over the guilt of leaving my child for those 2 weeks we were apart"

"It is a crying shame that the unit is being downgraded at Royal Glamorgan. Very short sighted"

"I also think closing Royal Glam consultant services is a mistake! Neither hospital can handle what they have now!!"

"I am very very concerned about the way that the maternity services will be run after the upcoming changes. In my situation I fear that I could have lost my baby as I very suddenly went from low risk in the birthing pool to requiring an emergency C section. I would have needed to be transferred from the birthing centre in RGH to a different hospital when I was fully dilated, had been pushing for over an hour and the baby was in distress. This makes me very fearful of having a baby in this hospital again"

"The notion that I could have a natural birth in a pool with additional support on hand is what helped me to feel confident about childbirth. Whilst my experience was positive on the whole the changes to her maternity department have taken away my confidence in having a natural birth close to home with future children, as I would not feel comfortable without additional support on hand"

"I feel the experience would have been so different if we had had to travel to Merthyr and feel strongly the service should be kept at Royal Glamorgan"

"The maternity care in Royal Glamorgan hospital was some of the best care I've ever received, it's an absolute shame that the department has been moved to hospitals that are so far away"

Make care woman centred – understand her needs

The whole of this engagement exercise has revealed the need to build care around women's personal needs and wishes; the same theme is emphasised in responses to this survey. Women need to be seen as individuals:

"Staff need to learn basic level of kindness and decency before they care for women! Treat all women as an individual"

"Every woman had a different pain threshold, so if someone tells you they are in labour but are standing there and not showing any signs of pain it doesn't mean the baby isn't going to come soon! So don't treat her like an idiot"

Support choice and options

A theme linked to the need to treat women as individuals and respect their choices was explored in this section. Working with women to make birth plans and to explore safe options is a high priority:

"There doesn't seem to be a champion for birthrights and options! No one discussed anything with me and anytime I tried it was 'oh we do that at another appointment'!"

Variable and inconsistent care

The variability and inconsistency of care and communication has emerged in responses to all questions in this survey. The feedback in this section emphasises the need to address the significant variation of care and raise the standard to the best that women have experienced:

"I believe I was unfortunate to have this experience post birth. I have several friends who have given birth in the same hospital who have had excellent care"

"I generally feel the care was fairly good (exceptional on labour ward) but a number of small bad incidents have hampered my experience. There are some exceptional staff, however there are also some staff who have a poor attitude"

"My midwife during labour was incredible. The team that took me to theatre for stitches was good. The women in the high dependency ward were lovely. Other than that, my whole experience was horrible. There was a lot of negligence. Midwives were not helpful. My bed was broken. There are so many things that were upsetting. It was extremely traumatic and devastating. It has put me off having another child completely"

Support and empathise with young mums

The need to provide support, empathy and information for young and first time mothers is emphasised again in this section:

"Only that I think where young mums are concerned…….felt the midwife could have put us more at ease"

"Staff appeared to be dismissive of concerns especially if first time mother"

Address understaffing – it is a safety issue

Resonating with the themes emerging in responses to a range of questions, the need to address understaffing is highlighted once again as women felt it affected their confidence in the skills and ability of staff to meet the needs of babies and mothers:

"Clearly the hospital was short staffed and this didn't personally affect me in any negative way and I did still feel confident for mine and my baby's safety but there are clearly a big issues with understaffing that need to be addressed"

"They seem overstretched and incompetent. There were some lovely midwives but equally some not as good midwives. This makes it seem like no one knows what they are doing"

"I do not agree with cutting much needed help from midwives and maternity. There were so many jobs for one midwife to do and then people wonder why mistakes get made. They are human and are exhausted"

Some excellent staff working in difficult circumstances

Although there have been criticisms of the impact of understaffing, there is strong support for the staff working in difficult circumstances and lots of responses stressed that they deserved thanks:

"Everyone went out of their way to make me comfortable and in the ward. If the baby was having a bad night the staff were more than happy to help"

"I think all of the staff in the maternity unit deserve massive praise. They are working under massive pressures but never fail to have a professional and caring approach to all women in their care. They are an amazing bunch of girls who do outstanding work and I hope they have the praise they deserve. From the bottom of my heart thank you to each and every one of you"

Expertise and knowledge to manage complex high risk pregnancies

Interviews with women and families and their written accounts focus a great deal on situations where things went wrong and mistakes were made leading to tragic outcomes. The survey responses also reflect the need to address the care of women who have been identified as high risk in their pregnancies with expertise, skills and knowledge and high level input at all stages. The impact of the loss of a baby or the long lasting effects on physical and emotional health is a major issue emerging from this survey and engagement overall:

"It's their job to take care of our unborn children. It's been a life long battle with day to day care, it affects all involved. My children will never lead a normal life and will need 1 2 1 care, and us as a family"

"There needs to be more people trained in this type of pregnancy; women who want to understand your pain or your fears. Losing both of my babies and both fallopian tubes have changed me drastically. I suffer with depression and anxiety. I was offered no aftercare whatsoever"

"The two times I have given birth there have been severe failings and on both occasions doctors have been reluctant to listen to me and take account that I am a high risk pregnancy and have also been reluctant to call on a senior consultant"

Learn from our experiences – make sure it doesn't happen to anyone else

If there is one piece of learning from this survey and the engagement exercise it is that all of the women and families who have shared their views, stories and feedback want their experiences not to happen to anyone else. They want everyone to have a good experience of pregnancy and birth and their courage in sharing their views must be rewarded with action to ensure that learning results in improvement and change:

"I hope the hospital does improve as if I choose to have another baby I will be apprehensive to give birth there again unless something is improved. I raised the complaint to ensure what happened to me does not happen to anyone else and I hope people have a better experience of birth than I had"

"My daughter in law had such a traumatic time during her admittance for the induction, labour and delivery that she has suffered post natal depression"

"My partner is both mentally and physically scarred due to the awful so called care received. As a result unlikely to have another child"

"I'm still awaiting answers. I was perfectly fine before my daughter's birth now I suffer with daily chronic pain. Nobody seems to care about what happened. My daughter and I now have to live with it. Very sad state of affairs"

"My child was suspected as having cerebral palsy from birth but failure to tell us until he was 1 was appalling, we dealt with the pain and upset twice and we have every right to know what's going on when it concerns our child"

A2.2 Recurring themes and messages from the Survey

Although there are specific issues emerging from each of the questions within the survey, overall there are some significant recurring themes:

Learn from our experiences, make sure it doesn't happen to anyone else

All of the women who have had poor experiences want the same things not to happen to anyone else. It is important that the feedback from this survey has an impact on future practice and that the stories and experiences of women and families are used as learning tools.

Being listened to and not dismissed

Throughout the responses women speak about being listened to and taken seriously. When women try to ask questions or just feel that something is wrong too often they report that midwives and doctors dismissed their concerns, particularly if they were younger inexperienced mothers. Unfortunately, some of the fears they expressed translated into adverse outcomes. Many women felt disempowered and were not involved in decisions about their care.

Variation in standard of care and the impact of understaffing

Women deserve consistent, high quality care every time they use maternity services. They want continuity and consistency and did not always experience either. Care should be woman centred and built around her personal needs and wishes.

From feedback there was a sense that experience was wholly informed by:

- The time of contact with services
- Which team or member of staff was on duty at the time
- Whether staffing levels were low or met the needs of the woman being cared for at the time
- Whether staff had good or poor communication skills

- The effectiveness of the relationship between members of the team

Responses to concerns

There is considerable variability in the response received by women and families when they raise concerns. In many cases respondents describe incomplete investigations, defensive responses, badly organised and poorly communicated meetings and lack of action in addressing concerns. Women and families deserve thorough and effective responses to their concerns with visible learning as a result.

Supporting choices and options, providing appropriate information

There was a strong theme that women wanted accessible, timely and appropriate information in order to make informed decisions and support their choices. Many younger, first time mothers wanted support, empathy and information and felt dismissed *"I was young and they were the professionals. I felt like I was the young one and they knew best"*

Managing high risk pregnancies and complex conditions

The specific needs of women who had a range of complex conditions was highlighted. Whether it was ensuring that there was continuity of care at high risk antenatal clinics or being referred for a second opinion appropriately, this did not always happen and sometimes there were adverse outcomes.

Staff attitudes and communication

Too many times women talk about the way they were spoken to and its impact. Women wanted to be cared for by professional, friendly, skilled, empathetic and reassuring staff. This did not always happen and the language and behaviour of some staff was unprofessional and hurtful.

Appendix 3

Hearing the voices of women and families in Cwm Taf:

- **'Your Maternity Care in Cwm Taf Engagement Event**
- **One to one interviews**
- **Written accounts and stories**

Thematic analysis

Meeting families during the RCOG visit to Cwm Taf, hearing their accounts and experiences through interviews and written stories provided opportunities to explore issues and perceptions in more depth.

This section describes three pieces of work:

- The 'Your Maternity Care in Cwm Taf' Engagement Event
- One to one Interviews during the event and by telephone after our visit
- Written accounts and stories from women

Feedback from all of the methods utilised was analysed thematically and results are presented as one piece of analysis.

Themes emerging from feedback from discussions, interviews, written accounts and stories

Being listened to and valued

"I felt worthless, like I did not matter – that's how I felt"

There was a clear leader in terms of the issues that emerged from engagement with women and families we talked to at the event, in interviews and through their written stories. Women repeatedly reported that they were not listened to and their concerns were not taken seriously or valued. Often, their suspicions and concerns reflected a genuine problem but they were dismissed.

Taking women's concerns seriously and listening to the clues they give are a patient safety issue.

"I was never asked, never believed"

"If only they had asked the right questions"

"Most importantly, we were not listened to. By the time we were it was too late"

"I waved my red flag as much as possible"

"I feel lied to"

"Listen to women and families and believe what they tell you when they are in pain"

Communication, compassion and empathy

Sadly, many women felt that communication was extremely poor, that they were treated without compassion and that staff did not show an empathetic response. There was a lack of kindness and empathy in sharing bad news or that a pregnancy was at risk:

"If you go into labour you will probably lose the baby"

"I remember a woman coming in and saying – just to let you know the baby's died. She didn't break it gently. Then she just walked away".

"There was no eye contact – it's a communication thing"

"Wanted someone to say let's talk about things, what can we do to make things better"

Another account recalls the experience of a woman awaiting an operation following the discovery of ectopic pregnancy. The lack of empathy and inappropriate timing of requests to make decisions on life changing events when she was alone and without support are clear in this story:

"In the anaesthetic room when I was asked – what do you want to do with your baby? I didn't know what to do about burying my baby. I was on my own as my husband was outside and we were 10-12 weeks past the date when the baby had died"

Staff attitudes, behaviour and inappropriate language

Throughout discussions, interviews and in written accounts women and families recalled the impact of overhearing staff talking about patients and swearing. There was also a sense that staff morale was undermined and that the difficulties may have been made worse by staff shortages.

However the key issue for many women was the way staff addressed them. Whether poor attitudes or inappropriate use of language was linked to stress caused by staffing shortages or other factors is for further investigation to determine. However, the way they have been treated and spoke to leaves a lasting impression on women at a time when they are vulnerable and want a good experience of birth, the most memorable event of their lives. Women have remembered the words and also the way they were disregarded and insulted for years after the event.

"A member of staff raised her voice to me in the hearing of other people. She laughed at me"

"I was laughed at when I was concerned"

"No one spoke to me"

"Staff using foul language, overheard staff swearing"

"Way they spoke to you – what are you doing here?"

"Nurses told me to wait, left for a long time, they weren't expecting me"

"I was simply asking for pain relief – told I'm very busy at the moment"

"They were too busy"

"On the hand over at the moment, you will just have to wait"

Ignoring or dismissing the concerns that women and families raised has been highlighted in this thematic analysis. One element of that communication failure would seem to be an attitude that some women were exaggerating their symptoms or pain:

> *"Enjoy pregnancy, deal with it"*
>
> *"Told I was too sensitive to being pregnant"*

Women reported an almost callous and brutal use of language and disregard for the feelings of women and their families. When one woman was concerned that she may be losing her baby she was told: *"prepare for the worst – it could be a miscarriage"* and then told to go home as *"there wasn't a lot she could do".*

Following a premature birth, concerned parents were told: *"it is not looking good".*

The assessors heard from a family that had paid for a non-invasive test as they were concerned about inherited Down's Syndrome. At the birth it was realised that their baby had Down's Syndrome and they were concerned about comments from the midwife at the time who told them that *"they hadn't got value for money"* from the test.

A story sent to the RCOG described the experience of a woman who had been informed that her baby had a rare condition that meant the baby would not survive. She was given the option of terminating her pregnancy and *"wanted the kindest solution for myself at that time, the less painful and less emotionally damaging solution".* Her choice was a surgical approach and on a ward with other patients she was *"extremely upset, frightened and anxious".* In this vulnerable state she *"found one nurse in particular to be quite abrupt. I felt as if I was being treated as someone that was just getting rid of their baby. It wasn't until I explained that this was not a wanted termination did she soften".*

Support and empowerment of women

In terms of decision making and influencing the care and choices made, there were many examples of women reporting they did not feel empowered nor were they taken seriously.

Induction *"seems to be dictated and mothers often felt that they didn't have much choice. It takes a lot to challenge and articulate your choices.*

> *"Women are often not in a powerful position… people stay close to families and do what friends and relatives have done in terms of choices"*
>
> *"If you are willing to make a fuss they will respond to you"*
>
> *"If you are middle class, educated, you can communicate and find out information. If you are working class and don't always have the confidence to ask questions you are relying on their skills. They take advantage"*
>
> *"Some mums aren't able to articulate what they want or need and things get missed"*
>
> *"They were making decisions without including me"*

What did good care look like?

One of the questions women and families explored was around what good care meant to them. The prime issue for most people sharing their experiences was for the service to be personal, focused around the needs of women and listening to them and to be responsive.

"A good experience would be being listened to".

A good service was one where *"I felt looked after", "the relationship between midwife and mother is an important one".* The staff caring for women *"made you feel more comfortable and reassured"*

The service was *"responsive, personal, and timely"*. The "*midwife was great, calm reassuring, listening to me. The right things happened. They explained things and made sure you were involved in the process".*

Staff were pleasant, looked as if they enjoyed their work. Women said they *"needed to see happy faces"*.

Continuity of care and carer

As in many pieces of engagement with women regarding what they value in maternity services continuity of care and carer has a prominent place. Women told us many times that knowing their midwife well encouraged them to share concerns and ask questions. Women felt that they were able to build relationships, had better outcomes and felt more confident in their pregnancy and in giving birth.

When women had complex conditions they wanted to see the same midwife or consultant as much as possible:

"If I had someone who knew me they would have spotted the problems. If I'd had a midwife they would have known something was wrong"
"They don't know you, don't know your history"
"One midwife from the word go"
"A 'go to point' – build a relationship"

Community midwifery

There seemed to be stronger satisfaction and support for community midwifery and more positive comments were heard.

"Care in community was slightly better than hospital based"
"The community midwife was good"
"Community midwife was amazing"

Advice and information

Women and families value better access to advice and information with less ambiguity about which number to ring or where to go when they need help or reassurance.

> *"From the beginning everything felt very disjointed, there was no clear point of contact"*
>
> *"Need to extend to A&E regarding understanding of problems in pregnancy"*
>
> *"Review the approach where women experiencing problems around 20-26 weeks are told to attend A&E rather than the maternity unit"*
>
> *"Look at the information and support that women are given when sent home at the weekend"*

Support for first time mums

The lack of information and support for first time mums was highlighted in a number of cases:

> *"I was never told what to look out for"*
>
> *"Very little input during the pregnancy, no information regarding what to expect as a first pregnancy or what assistance would be available after the birth"*
>
> *"I would have expected more support"*

High risk pregnancy – management and support

It is clear that many of the tragic events surrounding the birth and in a number of cases, loss of babies have significant learning for maternity services. There was strong feedback that some of the doctors, locums and midwives they met *"didn't seem to know how to handle complex high risk pregnancies".* One woman interviewed believed that there was a lack of expertise and availability of the right level of skills: *"anything different from the norm, they didn't seem set up to deal with it".*

Repeatedly, women reported that they didn't always believe that the right level of skills and expertise were available at the right time and that *"anything different from the norm they weren't set up to manage it".*

Women were told that their pregnancy was high risk and that specific care plans were in place however, their attendance at the antenatal clinic and their reception on attending A&E or the maternity unit in an emergency did not reflect this.

> *"My pregnancy was high risk but it never felt as if I was treated as high risk"*
>
> *"The antenatal clinic felt like a cattle market"*

Seeing many different doctors at the High Risk Antenatal clinic resulted in different opinions, and often a perceived lack of knowledge about the woman's history; *"read the notes"* was heard from women several times.

"Consultant led, but never saw them – once at the beginning and once at the end"

Women wanted to see *"better continuity during antenatal care so that women with high risk pregnancies see the same consultant and don't experience so many different opinions and conflicting advice".*

Skills and experience, escalation

A number of the experiences heard focused on a failure to seek a second, more senior opinion and to escalate matters as a matter of safe practice, especially in the case of women with complex, multiple conditions. "*Ensure that there is an appropriate senior opinion at the right time and appropriate escalation of care".*

"The doctor wasn't expert enough to manage my care and treated it like a normal pregnancy".

"If there is anything that doctors or midwives are unsure about they should have the confidence to call for a second opinion or contact the consultants on call"

Variation in standard of care and the impact of understaffing

Women deserve consistent, high quality care every time they use maternity services. They want continuity and consistency and did not always experience either. Care should be woman centred and built around her personal needs and wishes.

From feedback there was a sense that experience was informed by:

- The time of contact with services
- Which team or member of staff was on duty at the time
- Whether staffing levels were low or met the needs of the woman being cared for at the time
- Whether staff had good or poor communication skills
- The effectiveness of the relationship between members of the team

The feedback from engagement highlights the impact of understaffing. One woman interviewed described having *"a lasting feeling that I was left on my own not knowing what was going on"* and the effect was *"I wasn't treated like an individual".*

Impact of poor experience

"Birth is supposed to be a wonderful experience – I wasn't treated like a human being"

Sadly the impact of traumatic experiences has been long lasting for many families. Families reported that they felt that they continued to experience emotional and physical problems and a number of families feel that they have experienced PTSD.

"I feel so angry, upset and massively let down by most of the staff that treated me"

"I want having a baby to be a good experience. It's ruined it"

"Although what happened to my baby was nobody's fault I'm broken from the whole experience, the lack of care and compassion. That terrible experience I was put through because of the staff that treated me. That experience will stay with me forever"

Many women carry guilt about their experiences and believe that it was their fault that action wasn't taken at an appropriate time:

"I cry myself to sleep every night – not my fault but it's the 'what if's'"

"I wasn't assertive and delayed going down to the hospital. I should have said I needed a C section when things were going wrong"

"I think about the experience every day – the outcome may have been different"

"I continue to feel responsible for the outcomes for my pregnancies – I should have insisted more for a transfer to be arranged"

Support, environment, bereavement counselling

A variety of experiences regarding support after the loss of a baby were reported but at the time that families needed the services there were clearly gaps in provision and variation in how they were supported appropriately. Many women and families received no bereavement counselling or support and continue to experience emotional distress.

Many families talked about the need to remember that all of the family are affected by the loss of a baby and support for fathers is also needed. The effects are long lasting and there were a number of families who told their stories and had been diagnosed with post-traumatic stress disorder. All of the extended family continue to have counselling.

When they returned home after the tragic loss of their baby one family said they *"were able to function during the day but not at night. I couldn't go in the bath, couldn't be on my own and had flashbacks".*

Families wanted to ensure that the bereavement service had the right level of personnel with sufficient expertise to meet their needs. In some cases families did not find out about the range of support and advocacy from organisations such as Sands and the Community Health Council. Communication and support are also needed at all service points and staffing levels "*It is the responsibility of all staff to have bereavement training*"

Families suggested that there should be a coordinated approach to addressing needs of patients and families when *'things go wrong'.* They wanted the Health Board to explore the instigation of a role such as *"a Liaison Officer who could provide instant support, know what to do, someone to talk to, reassure you and provide help"*

Maternity service changes and relocation

Overwhelmingly women have said throughout consultation and engagement on maternity services that they want safe, high quality, accessible services in Cwm Taf. The changes to the service model and location of maternity services continues to be of major importance and the concerns and issues highlighted in the engagement organised for this review reflect the priorities heard in Health Board engagement activities.

Travel and access

Consistently women and families currently using services at Royal Glamorgan Hospital have concerns about the change of location of obstetric led maternity services and inpatient paediatric services to Prince Charles Hospital. The distance to travel and the quality of the

roads, problems with lack of transport, and difficulty in travelling in poor weather, especially in an emergency have all been highlighted.

There is also uncertainty about potential use of the free standing midwifery led unit and whether women will meet the protocols, capacity of the Prince Charles Hospital new unit, quality, safety, and access.

There are concerns that management and staff are not prepared for the service move and families did not always feel confident that the move will be smooth and trouble free. Publicly the message is that *"everything is fine and all circumstances are accounted for, but people are not reassured and if one person loses a child, or a mother there will be consequences that confirm public concerns".*

Appendix 4

Maternity Services in Cwm Taf – the Visual Map

The Conversation Café used innovative graphic recording as a key part of the engagement event on 16th January. Using visual methods was effective in demonstrating to women and families taking part that their views and experiences were being recorded live not only in written format but drawn in real time by an artist.

The RCOG worked with an artist from Scarlet Design Group using the successful approach that had been a central part of engagement conducted with women and families in Morecambe Bay as part of the development and improvement of maternity services.

The visual map is divided into the same questions and topic guide used for the table discussions and the themes emerging reflect many of those detailed in this report.


WHAT DID GOOD MATERNITY CARE LOOK LIKE FOR YOU?
1
1 TO 1
CARE IS NOW AT A DIFFERENT LEVEL SINCE LAST EXPERIENCE
MIDWIVES
MADE YOU FEEL COMFORTABLE AND REASSURING
FOUND ME A PRIVATE ROOM WHEN I WAS SLEEP DEPRIVED
"MIDWIFE WAS FIRST PERSON TO PUT HER HAND ON MY STOMACH"
COMMUNICATION
MIDWIFE LOVELY PERSON, BUT WASN'T AROUND
POOR COMMUNICATION BETWEEN PROFESSIONALS
COMMUNICATION IS IMPORTANT
LACK OF STAFFING
STAFFING IS AN ISSUE
CARING & UNDERSTANDING
HOSPITAL CARE
EMOTIONAL
CARE
"CAN'T FAULT CARE WITH ONE OF MY CHILDREN"
RIGHT PEOPLE IN THE RIGHT JOB
SENIOR MIDWIFE CONSULTANT WAS CALM, REASSURING, LISTENING TO ME
ANTENATAL
TOO MANY MIDWIVES - NEED MORE 1-2-1 CARE


2
WHAT COULD HAVE BEEN IMPROVED?
DIFFERENT MIDWIVES DON'T KNOW YOUR HISTORY
ONE MIDWIFE FROM THE WORD GO
CONNECTION
MORE ADVISE NEEDED
RESPONDING WHEN RAISING CONCERNS
SOME MOTHERS ARE UNABLE TO ARTICULATE THEMSELVES
"MIDWIFE WAS FIRST PERSON TO PUT HER HAND ON MY STOMACH"
TAKE MIDWIFE'S WORD AS THEY ARE PROFESSIONAL
NO TIME FOR YOU
BREASTFEEDING
WANT TO FEEL MY VOICE IS HEARD
MORE PRIVACY NEEDED
WAITING LONG PERIODS OF TIME
HOSPITAL CARE
DOCUMENTATION
"WANTED TO SEE MY NOTES"
"NOTES MISSING"
MEDICAL DATA