



Llywodraeth Cymru
Welsh Government



The All-Wales Perinatal Engagement Framework Report

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The terms woman/women have been used throughout this framework as this is the way the majority of those who are pregnant and having a baby will identify. However, it also includes those whose gender identity does not correspond with their birth sex or who may have a non-binary identity. All professionals should be respectful and responsive to individual needs and individuals should be asked how they wish to be addressed throughout their care.



This document aligns to the Quality Statement for Maternity and Neonatal services, attribute 18.

Executive summary

Pregnancy and childbirth are life-changing events for women, parents and families. It is a time of new beginnings, momentous and often eagerly anticipated.

The perinatal workforce has the great privilege of being a significant part of the family's journey, not only ensuring they receive a safe, compassionate, quality service but one that encompasses a holistic sense of emotional, spiritual, and psychological safety.

To achieve this, engagement and collaboration with women, parents and families to understand what 'good looks like' must be at the forefront.

The All-Wales Perinatal Engagement Framework (the Framework) sets out the **minimum** standard for high quality service user engagement across all Welsh health boards and provides details of the ten commitments required to meet this standard.

The Framework will support the implementation of engagement methodologies and mechanisms required to capture and embed feedback in service design and improvement, aiming to ensure that the maternity and neonatal care continuum is represented, where required, by using a joined-up approach.

This report has been produced to provide more detail and background to the ten commitments and should be read in conjunction with the Framework to give context.

By implementing the Framework, women, parents and families are actively involved in influencing change and improvement, shaping the services they want and need.

The voices of those using perinatal services are placed at the heart of service design, delivery and evaluation, including local and national policy.

Feedback to families and communities will demonstrate the value that is held in those sharing their individual experiences to influence and improve perinatal services.

Listening to women, parents and families can and does save lives. Engagement, especially with those using the service and those from under-represented groups adds an element of safety from a different angle and perspective.

An active listening culture is not a 'nice to have' but is core to the delivery of safe perinatal services.

It is essential that reflective feedback is not perceived as criticism, but as the opportunity to gain a rich understanding of what care looked and felt like for those who experienced it.

Background



A number of high-profile maternity and neonatal reports^{1, 2, 3} have repeatedly highlighted the poor outcomes and experiences of women and babies and the long-lasting effects that these have upon individuals, families, and communities.

In November 2020, Health Inspectorate Wales (HIW) published its **phase one report** following the National Review of Maternity Services in Wales⁴.

This review was prompted by the external **review** conducted jointly by the Royal College of Obstetricians and Gynaecologists (RCOG) and the Royal College of Midwives (RCM) into the maternity services provided by the former Cwm Taf Morgannwg University Health Board (CTMUHB)⁵. Learning was identified for perinatal care provision and the impact of avoidable harm to women and their babies.

Both the internal and external review of CTMUHB recognised the significant impact of women, parents and families' voices being ignored. Further learning took place around the lack of service user engagement and how this can become a fundamental contributor to inferior care.

An extensive programme of improvement, with several innovative and exemplar mechanisms to undertake engagement, gain feedback, co-produce and optimise families' experiences have subsequently been successfully implemented. These key recommendations and improvements provide a legacy with families at the heart, to continue driving service improvement and development across Wales.

In 2021, in collaboration with the West Glamorgan Regional Partnership Board, Swansea Bay University Health Board (SBUHB), created a framework for engaging with women and families.

This included the recommendation of a pilot using Maternity Voice Partnerships (MVP), a tried and tested engagement methodology model. SBUHB used the recommendations of the CTMUHB review to explore their systems and processes and consider the application of the MVP modelling within NHS structures. SBUHB developed and evaluated this methodology providing a funded business model to facilitate the implementation of a MVP which included a scheme to remunerate both the Lay Chair and Vice Chair.

The pilot report offers evidence of the successful translation of maternity partnership modelling⁶ into Welsh NHS infrastructure and identifies the local and national learning and essential components required for national scale up.

Wales has increased its emphasis on improving maternity and neonatal collaboration and coordination in order to provide a seamless perinatal service for women, parents and families. This approach has extended to MVPs, as historically neonatal services have gained feedback from families using other methods. MVPs across Wales are evolving into Maternity and Neonatal Voice Partnerships (MNVP).

This joined up approach does not come without its challenges and careful consideration of the unique and difficult journey that neonatal parents and families have encountered is needed as well as ensuring the expectations of all represented service users are understood and met.

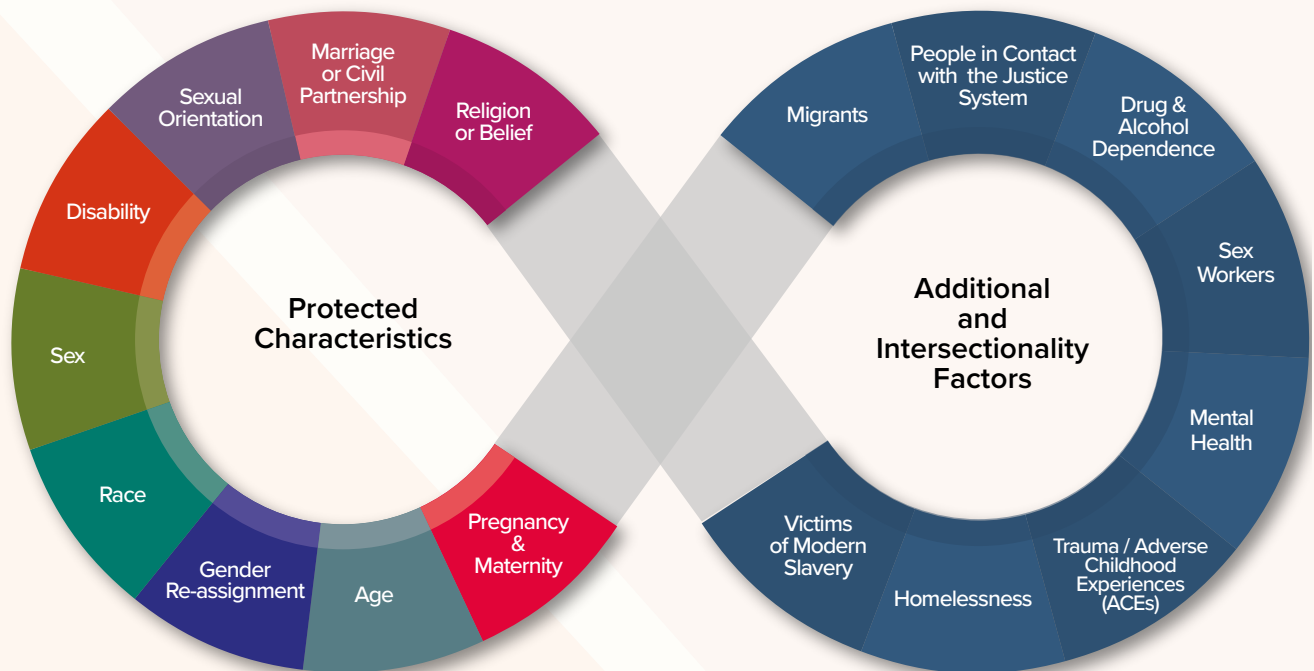
All parents should have the opportunity to give feedback about their baby's care both within a neonatal or maternity care setting, and after discharge⁷. Feedback should be shared with women, parents and staff and used to guide quality improvement and inform organisational design.

The implementation of the Framework into national and local governance structure mechanisms will ensure that engagement and co-production with women and their families, based on their lived experiences always remains at the heart of service delivery and improvement.

The foundations of the Framework will utilise learning to guide and implement strategic direction in Wales, in addition to supporting wider dissemination and whole system learning.

The ten commitments in the Framework build on existing work, and assets across Wales, and direct future action in a coherent and structured manner. The aim is to foster a culture of excellence in service user engagement in which innovation, flexibility, and responsiveness flourishes.

Equality, Diversity, and Inclusion



Equality, diversity, and inclusion are essential principles which promote fairness, respect, and understanding, ensuring services provided are equitable and accessible to all.

To meet these principles, it is essential that the composition of staff within perinatal services reflect the communities they serve.

Engagement with families from under-represented communities, those experiencing inequalities and those with an increased chance of discrimination, is essential to improve the quality and safety of healthcare. In the absence of this, inequalities in access to care, treatment and support, poor experiences and outcomes are often compounded.

Involvement and participation can often be prevented by factors including communication, language, and cultural differences.

It can also be hindered by a lack of trust stemming from the lack of diversity in health care staff. Inequalities in access to healthcare, and meaningful engagement and involvement can be negatively affected where there is ignorance of problems, lack of knowledge about how to solve them, and the use of a “one size fits all” approach.

An equitable service must include all voices, which also encompasses women, parents and families who may otherwise be overlooked, such as surrogates, foster carers, parents that may not raise their children themselves, and bereaved parents and families.

To guarantee that services are provided in a way that fulfils the unique needs and requirements for all, and reduces negative experiences and

consequences; active participation, collaboration and co-production are crucial, using bespoke and innovative ways to engage and build trusting, respectful and meaningful relationships between those receiving and those facilitating care.

The Framework reflects the intention of equity, diversity and inclusion being central to and weaved throughout perinatal services, not an add-on.

Ethnicity

The Welsh Government set out its commitment to becoming an anti-racist nation by 2030 in the **Anti-Racist Wales Action Plan**⁸. The plan includes the specific action to reduce poor outcomes and improve experiences for Black, Asian and Minority Ethnic women using perinatal services.

It is well evidenced that Black, Asian and Minority Ethnic women are exposed to more risks and encounter poorer experiences when receiving care and treatment. These inequalities and the corresponding outcome for their babies is well documented and **MBRRACE-UK**⁹ highlight that disparities in equitable care and socio-economic factors are widening. The **Five X more report**¹⁰ identified the need to put a voice to these alarming figures, and the vital importance of listening to women's lived experiences and recognising the full impact of inequalities in care.

Invisible¹¹ highlighted the maternity experiences of Muslim women and the Birthrights inquiry **systematic racism not broken bodies**¹² highlighted that Black, Asian and Minority Ethnic women were not heard, with a historical mistrust of maternity services. The same experiences were echoed by people with other protected characteristics including physical and learning disabilities, neurodiversity and LGBTQ+ communities as documented within the **Locked out report**¹³.

Targeted engagement activities and involvement of women, parents, and families from Black, Asian and Minority Ethnic groups and those living in deprived areas will support addressing these issues and assist in reducing the disparities experienced.

Perinatal Mental Health

One in five women experience¹⁴ mental illness during pregnancy or in the postnatal period. This can lead to barriers such as trauma, stigma and discrimination, alongside challenges with accessing services and good quality care^{15, 16}. It is recognised that, due to many of the reasons listed above, people with poor mental health are under-represented in traditional NHS experience and engagement forums, and yet their experiences are valuable for organisations to learn and improve, therefore engagement provision must be adapted to hear those voices.

The Birth Trauma Inquiry 2024¹⁷ highlights the impact of birth trauma on women, parents and families.

Again, listening to the thoughts, feelings and experiences of this group of people, is important to provide trauma informed care. Consideration must also be given to fathers as the maternity journey can be a stressful and isolating experience and they are often overlooked¹⁸.

The MBRRACE⁹ report 2022 outlines how services need to commit to implementing trauma-informed principles and recognise the importance of trauma history and professional sensitive enquiry about underlying factors.

There are crucial elements to maximising the well-being of neonatal parents and families during their baby's stay on the unit and following discharge. The unfamiliar and intense environment of the neonatal unit, medical interventions, and fear for their baby's well-being and often survival, can have long lasting impacts and consequences.

Studies have shown that parents with a premature baby are fifty percent more likely to experience psychological distress with many experiencing elevated traumatic stress responses with ongoing effects felt many months or years after discharge¹⁹. The recognition of this traumatic stress prior to any request for engagement must be considered.

For women, parents and families who have experienced poor mental health, birth related trauma, a baby in the neonatal unit, or other elements of psychological stress it is important to build trust, partnerships and clear communication channels. Sensitivity is vital in all aspects of care provision, and no less important when engaging with people to gain insight into their experiences and interpret their feedback.

Lesbian, gay, bisexual, transgender, queer, +



Lesbian, gay, bisexual, transgender, queer, plus (LGBTQ+) individuals who are pregnant or want to become pregnant experience more adverse outcomes and experiences than their heterosexual counterparts.

Whilst many more individuals within this community become pregnant, LGBTQ+ service users continue to experience difficulties during their encounters with maternity care.

It is well acknowledged that the perinatal period presents an increased risk of physiological and emotional stress for all birthing people, however, preliminary studies^{13, 20} have suggested that LGBTQ+ individuals are at an even greater risk, and this may be due to the unique challenges faced when navigating the gendered sphere of pregnancy and childbirth, compounded by the inadequate mental health support received by this group.

It is imperative that throughout their perinatal journey the LGBTQ+ community are spoken to in a way which respects their gender, and their voice is heard and acted upon to ensure service delivery is equipped to meet their specific needs.

People living with disabilities

Women, parents and families living with disabilities face many barriers when accessing perinatal services due to difficulties understanding the care offered and received, leading to a higher risk of adverse clinical outcomes¹³.

Women with learning disabilities or those who are neurodivergent may struggle to communicate effectively and feel unsure about which details to share with health professionals or how to seek advice.

Coping mechanisms for new situations may include not accessing healthcare, which may be interpreted as disengagement, potentially leading to health inequalities.

Pregnant women living with disabilities have described feeling discriminated against, disempowered, and excluded from the decision-making process.

Research and national guidance^{21, 22} have repeatedly emphasised the importance of assessing individual needs, and understanding the elements associated with disabilities.

Accessible engagement with women, parents and families living with disabilities will help ensure perinatal services are adequately adapted.

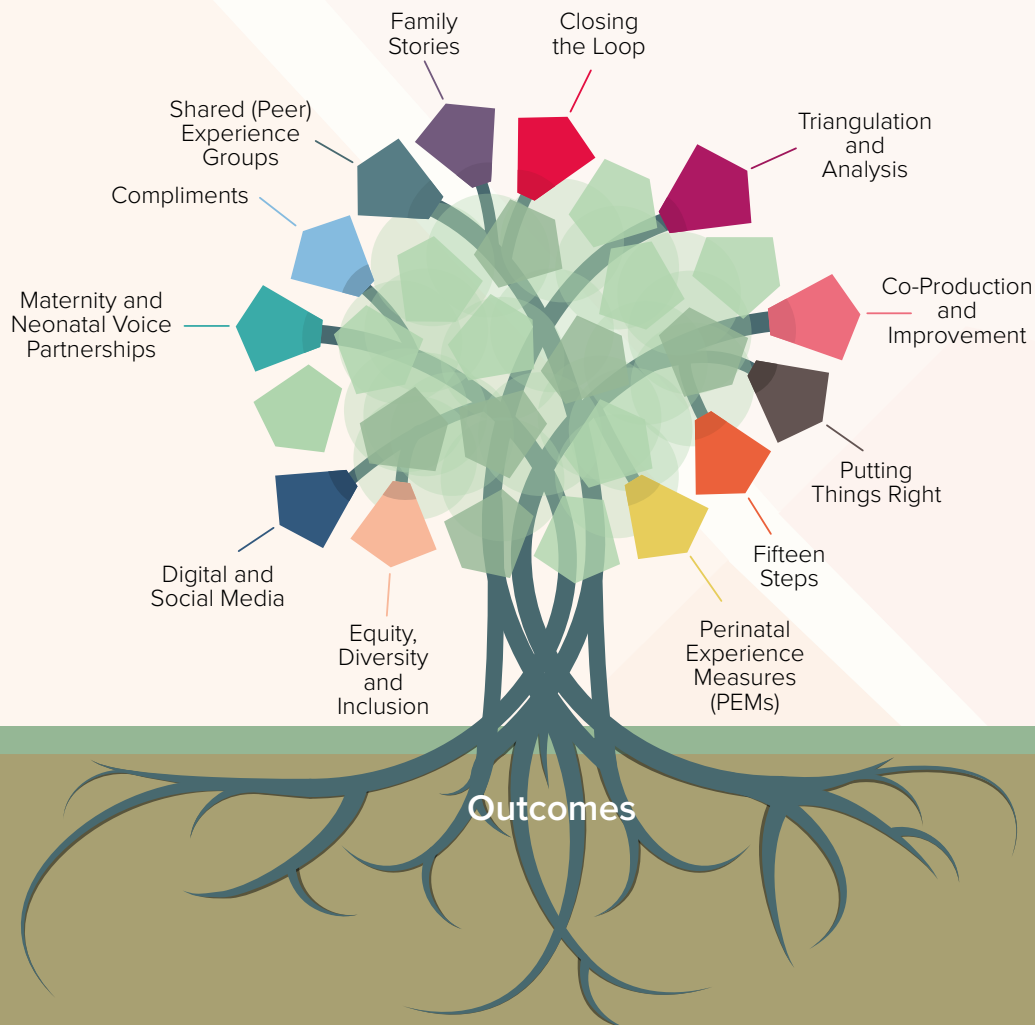
Engagement Initiatives and Methodology

Engagement and collaboration are enshrined within the Well-being of Future Generations (Wales) Act, 2015²³ and should be adhered to throughout the delivery and development of any health and social care service in Wales.

The Framework details different approaches to engagement that should be explored to obtain all voices, including those of under-represented groups using local strategies and solutions.

Organisations should also routinely collect qualitative information as described by the All-Wales Maternity Performance Indicator dataset.

Listening, Learning and Improving Tree



To achieve the commitments set out in the Framework, women, parents and families experiences must be captured and measured through a broad range of innovative methodologies aiming to ensure engagement, and meaningful analysis of rich feedback data.

The sections below outline various methods that can be used for gathering experience data. No single feedback mechanism can fully capture service needs, so organisations should use multiple methods to improve perinatal care.

Maternity and Neonatal Voice Partnerships

Maternity & Neonatal Voice Partnerships (MNVP) function as a forum which bring together women, parents and families, voluntary and third sector organisations and the perinatal workforce. MNVPs are an independent voice working in collaboration with health boards.

This independence is an essential criterion to ensure the direction of improvement work remains sensitive to a ‘value based’ approach outside of the agenda of healthcare systems. This is to ensure that local perinatal services meet the needs of the community they serve.

MNVP members should be the voice of the people who use perinatal services within Wales, and as a group should have significant influence on how perinatal services are provided, improved and developed, with a key principle of a co-production approach.

MNVPs aim to hear from people who use perinatal services from all communities and backgrounds with varied perspectives and experiences of care.

There is recognition of the need to focus on closing inequality gaps, including those from marginalised groups and communities, and this will be approached through a ‘listening to understand’, and not ‘listening to reply’ ethos. Engagement to gain the voices of fathers is also lacking¹⁸ and MNVPs are in a unique position to gain these experiences.

There are five core principles which MNVPs²⁴ are based upon:

1. Work creatively, respectfully, and collaboratively to co-produce solutions together as equals, promoting and valuing participation.
2. Seek out and listen to the voices of women, parents and families using perinatal services.
3. Champion the use of those using perinatal services insights and experiences as evidence when reviewing services.
4. Understand and work with the interdependency that exists between the experience of staff and positive outcomes for women, babies, parents and families.
5. Pursue continuous quality improvement in local perinatal services with a particular focus on closing inequality gaps.

Although MNVPs are representative of the whole perinatal journey, parents who have experienced a neonatal stay can often feel more comfortable using their voices in a space shared with others who have had a similar journey. It is recognised that these parents may have unique maternity experience that provides valuable insight, however appreciation and acknowledgment should be made to ensure the right environment is provided for their voices to be included. Again, consideration should be given at every stage of the partnership to acknowledge the views and experiences of fathers and co-parents. The impact of a neonatal stay on fathers and this experience, when shared, will play a vital part in shaping perinatal care in Wales.

Perinatal Experience Measures (PEMs)

Monitoring and evaluating experience data as part of organisational accreditation and performance indicators, can be powerful in orientating the efforts and direction of perinatal services.

This enhances more integrated and person-centred care, and fosters changes driven by lived experience positively impacting organisational performance.

PEMs will gather longitudinal data on women, parents, and families' views and experiences whilst receiving perinatal care, in the form of questionnaires and look at the process of care upon a person's experience rather than evaluating outcomes.

Measuring experience differs from satisfaction surveys that have been traditionally used across services by reporting objective experiences, removing the ability to report subjective views.

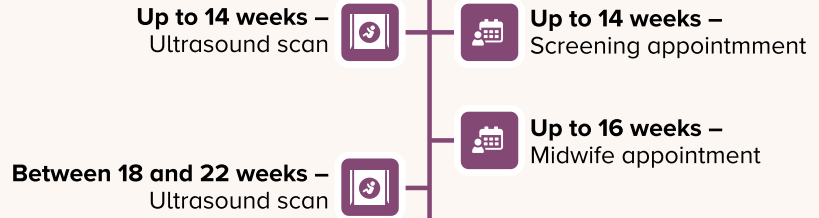
Relational experience measures identify a woman, parent and families' experience of relationships during care and treatment, for example, whether they felt listened to, and functional experience measures examine more practical issues, such as the choices and facilities available.

The Civica system that will be used, is programmed to automatically distribute questionnaire links to all service users at key points, throughout pregnancy, after a neonatal unit admission and into early parenthood.

Civica is available in all Welsh health boards and will be digitally linked with health board maternity and neonatal information systems to distribute at agreed standardised intervals. Governance and data safeguards are in place to ensure questionnaires are not distributed inappropriately.

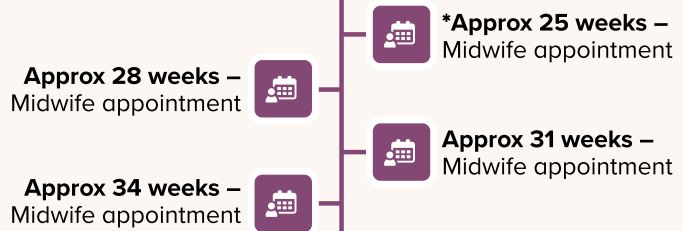
Women under 10 weeks pregnant
Midwife appointment / Booking

PHASE 1



SURVEY

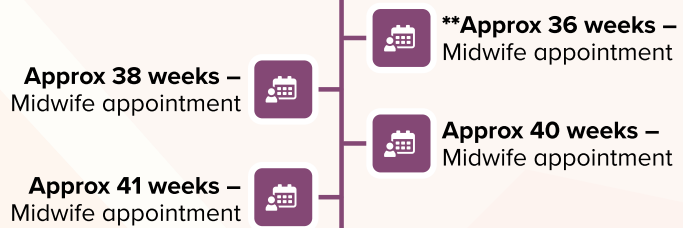
PHASE 2



SURVEY

(Approx 36 weeks)

PHASE 3



Admitted to Neonatal unit



If baby is admitted to Neonatal unit post birth

Birth



Discharge from Neonatal unit



Around 14-21 days post birth – Health visitor initial appointment



0-28 days post birth Midwife support



NEONATAL

SURVEY

SURVEY

PHASE 4



8 weeks post birth

SURVEY



*(If woman births between phase 1 survey and 36 weeks before receiving 2nd survey, they jump to survey 3)

** (If woman births between 36 and 41+ weeks, they jump to survey 3)

Stakeholder Pool – Mailing List

The Strategic Maternity and Neonatal Network has a virtual parent advisory group engaged in co-producing patient information, attending meetings, and national events on an ad-hoc basis.

This group has recently been updated to include several third sector organisations supporting protected characteristics who have agreed to join a mailing list to ensure their voice is included in ongoing initiatives.

Health boards should encourage parent partners to register with the network, which will maintain contact without sharing personal details externally.

This process ensures diverse engagement across Wales.

Informal Feedback

Informal feedback on perinatal services will come in various forms, relative to the mechanisms available across each individual health board. Collectively, this feedback contributes to a comprehensive understanding of service user experience and preferences, aiding perinatal services in adapting and enhancing care provision.

These may include:

- **Verbal feedback and conversations** – Direct conversations with women, parents and families provide valuable insight. The establishment of a robust mechanism for staff to share appropriate discussions with their experience lead ensures that ongoing themes are noted and addressed appropriately.
- **Cards, notes and letters** – Women, parents and families often choose to give a note or card of thanks to an individual staff member or collective staff group. Collation of these positive messages can evidence bright spots in care which may otherwise go unrecognised. Staff surveys show that recognition from women, parents, families and peers has a positive impact on staff well-being and can contribute to a psychologically safe environment.
- **Focus groups** – Some perinatal services organise women, parent and family focus groups to gather in-depth feedback on specific experiences. These sessions allow for interactive discussions around specific experiences in detail.
- **Anonymous feedback channels** – Providing anonymous channels for feedback can encourage individuals to share their experiences candidly. This could include suggestion boxes, anonymous online forms, or feedback white boards on the units. Feedback can also be gained from other means such as Patient Advice and Liaison services and Llais.

Social Media

Social media can play a significant role in enhancing perinatal services by providing a platform for communication, education, and support. Engaging women, parents and families with social media effectively, requires a combination of relevant content, community building and interactive strategies, with a sensitive approach and clear escalation pathways.

Understanding the demographics of each health board will enable personalisation of social media platforms to reach a high number and diversity of users. Online translation platforms make it easy to translate content into multiple languages and create 'easy read' and accessible versions.

Social media platforms have the option to access free analytic data so that organisations can gain insight into how many people are accessing their content, whereas others have the option to understand demographic data. This supports organisations to monitor engagement metrics to understand what content resonates most with their population, as well as the opportunity to use these insights to adjust and improve engagement.

However, social media does come with challenges. There is significant variation across health boards regarding what social media platforms are accepted and how staff manage these.

Each platform has unique features and reach, so perinatal services should tailor their content and engagement strategies to fit the specific characteristics and user behaviour of each platform.

Key considerations include privacy and confidentiality, the dangers of misinformation, the potential for boundaries to be blurred in the professional relationship, data protection and the impact on an individual's mental health. Prompt monitoring is therefore necessary to maintain a supportive environment.

Managing negative comments or complaints effectively, without escalating conflicts, requires sensitivity to reduce undermining an individual's opinion or experience.

Lived Experience Peer Groups

Lived experience refers to the unique and personal encounters, perspectives, and insights that individuals gain through direct involvement in particular situations or circumstances.

It encompasses the real-life experiences, emotions, challenges, and lessons learned by individuals as they navigate various aspects of their lives.

Lived experience is deeply subjective and can be influenced by a person's background, culture, beliefs, and personal circumstances.

Many neonatal units run peer groups, which allow new parents to meet others in similar situations. These groups often continue after discharge from the neonatal unit and may include parentcraft sessions and opportunities to discuss ongoing concerns with staff or other professionals.

These groups have the potential to gain valuable feedback in trusted environments. Organisations are expected to consult with these lived experience groups, capturing, triangulating, and reporting feedback as part of their improvement work.

Families' reflections of pregnancy, birth and neonatal experiences of care

All women, parents and families should have the opportunity to discuss their pregnancy and birth experience including the need for any neonatal service involvement. It is essential to recognise the individual subjectivity around challenging experiences and the need to provide a safe space for listening opportunities.

Birth reflections present several opportunities for women, parents and families including:

- Providing clarity about what happened during pregnancy, labour, and birth.
- The opportunity for a clinician to offer insight into the clinical processes or rationale around perinatal care and experiences.
- Aiding preparations and identifying areas for additional support or clarification of need for future pregnancies.
- An opportunity to listen, whilst also providing opportunities for women, parents and families to express their feelings.
- A safe space to support women, parents and families to process feelings of trauma or distress (with a valuable role in supporting the emotional well-being of new parents).

Pregnancy and Baby Loss

Engaging with women, parents, and families regarding baby loss necessitates a highly sensitive, multi-faceted, and flexible approach that clearly acknowledges both the magnitude of the loss and its lifelong impact. It is also essential to address the diverse needs of women, parents, and families throughout their grieving process.

The NHS Executive, in collaboration with Sands, will lead the development and implementation of the National Bereavement Care Pathways for Pregnancy and Baby Loss in Wales²⁵.

To ensure that the voices of parents and families are heard, and accurate data is collected, a tool will be designed to capture patient-reported bereavement experience measures.

This will enable local and national monitoring of bereavement experience data as part of organisational accreditation and performance evaluation to drive improvement.

The National Perinatal Epidemiology Unit recognises the importance of listening to parents and addressing their questions and concerns through the Perinatal Mortality Review Tool (PMRT) process^{26, 27}.

Providing parents with the information they want and need, along with explanations and answers to their questions, will support families in processing the loss of their baby and moving through their grief. Additionally, parental feedback offers important insights and should provide opportunities for organisational learning, including identifying areas for improvement in care.

Putting things right

Within Wales, each health board has a Putting Things Right²⁸ process, and in line with the Duty of Candour²⁹, should consider all feedback a gift, recognising the value in families spending time sharing their experiences.

Issues and barriers to this, particularly the ability of the organisation to respond and make meaningful changes, were highlighted in the Ombudsman report³⁰. The report describes that all too often, health boards respond to complaints defensively, rather than seeing them as an opportunity for learning and improving the services they deliver.

It is also recognised that there are barriers to equal access, with those who encounter inequalities and barriers to communication, language and culture differences, having limitations in the ability to raise concerns.

The Health and Social Care (Quality and Engagement Wales) Act³¹ places a duty on all NHS bodies in Wales to strengthen the quality of service provision and promote openness and transparency where there has been harm, poor experience, or dissatisfaction³².

Analysis, Triangulation, Governance, Learning and Improvement

Health boards need reliable processes to measure, record and analyse all feedback methods, reporting on feedback volume, themes, and key learning actions monitored through data and local action plans.

Each health board must have a governance process to analyse and learn from engagement, using appropriate measures. Feedback should be triangulated to inform learning and regularly reported to the Board.

Shared thematic learning is necessary for cross-border care and crucial in improving services across Wales. The Strategic Maternity and Neonatal Network will provide a coordinating role to bring health boards together to share learning and associated improvement actions. Reporting to the Welsh Government will occur via quarterly perinatal focused integrated quality, planning and delivery (IQPD) meetings.

Health boards must review PEMs feedback monthly, using time series and QI data analysis methods, with significant changes reported locally. An annual PEMs report should highlight themes, trends, and learning, allowing benchmarking across Wales. Nationally collected PEMs will be reported through the NHS Executive to the Beacon dashboard along with complaints, compliments and birth reflections, which will enable core dataset benchmarking.

The MNVP will create an annual workplan and report of thematic learning to inform health board service plans. The health board will formally respond to the MNVP to acknowledge findings and identify associated actions.

Closing the loop is fundamental in validating and valuing feedback to ensure women, parents, and families feel heard. Effective closed-loop feedback systems, which consistently inform communities about the actions taken in response to their feedback are crucial. Failure to demonstrate tangible improvements or provide follow-up can lead to feelings of discouragement, dis-empowerment, and perceptions of tokenism.

'You said, we did' initiatives can illustrate that services are actively listening and responding to feedback by publicising comments, suggestions, and subsequent actions taken. Perinatal services can utilise various communication methods to provide this feedback, including MNVP mechanisms, newsletters, mailing list updates, posters, social media, and websites.

Conclusion

The optimal experience of women, parents, and families within perinatal services is an essential aspect of demonstrating quality. Incorporating active listening and methods to support services in hearing and responding to feedback is crucial for effective service improvement and development.

Co-production and collaboration ensure individuals contribute significantly to decision-making processes and promote meaningful service improvement and development to achieve the best possible outcomes and experiences. Triangulation of experience together with quality outcomes ensures a comprehensive understanding of service provision, synthesizing and interpreting data from various sources.

The accompanying Framework outlines the ten key commitments required from organisations to ensure women, parents and families are at the heart of service development and improvement in addition to supporting wider dissemination and whole system learning.

These commitments support the achievement of optimal and exemplary perinatal engagement in which innovation, flexibility, and responsiveness flourishes. It positions perinatal services as leaders in engagement across NHS health boards across Wales.

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www.gov.wales/health-and-social-care-quality-and-engagement-wales-act-summary-html
- 32 Duty of Quality (2023) www.gov.wales/duty-quality