The HSE response to the findings of the

National Maternity Bereavement Experience Survey 2022

Listening, Responding and Improving

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Message from the CEO

The loss of a pregnancy or baby is a devastating time for women, their partners and their loved ones. I wish to acknowledge the courage and generosity of the women and their partners who have completed this survey. They have reflected on their experience of care at a very difficult time in their lives and I know this can't have been easy. Their contributions will go towards enhancing and improving the care we provide in the months and years ahead as part of our commitment to improving healthcare services for all.

Improving the care we provide requires commitment, leadership and a plan, which informs us whether or not we are making an actual measurable difference. The National Maternity Bereavement Experience Survey provides us with important insights into perceived care experiences across both hospital and community services in Ireland. It identifies areas for improvements and strengths that we can build on.

This report has been developed in direct response to feedback provided by service users. It includes many examples of improvement initiatives that are already in place and lays out our plans for ongoing quality improvement. Repetition of the National Maternity Bereavement Experience Survey in future years will allow us to continue to develop our services in response to what we have heard and to evolve our services to the highest possible standards and to track our progress in this regard.

Learning is a core component of delivering safe and effective healthcare and achieved by, amongst other things, 'listening, responding and improving' – which are the areas of focus of this HSE report. We have, and will continue to work diligently to improve healthcare services and the experience that women and partners have of maternity bereavement care.

In the last number of years, our healthcare services were severely impacted by the COVID-19 pandemic. I know that this was particularly felt by those we cared for within our maternity bereavement services, in particular the visiting restrictions that were in place in our maternity units and the restriction on partners accompanying women at their appointments. This survey has highlighted to us that women and their partners want more information and someone to talk to about their concerns at every stage of their maternity bereavement journey.

On behalf of the HSE, I wish to acknowledge and wholeheartedly thank the women and partners for their generosity in completing the survey which will be used as a learning platform for improvement in future years. I also wish to thank the National Operational Performance Office, Acute Operations, the National Women and Infants Health Programme (NWIHP), together with staff and managers from each participating unit/hospital for developing this response, designed to improve experiences of bereavement care across all maternity services in Ireland. Areas identified for improvement including shared decision-making during pregnancy, labour and birth and support post discharge will be addressed in quality improvement plans developed by each maternity unit/hospital.

Finally, I would like to acknowledge the initiative and collaboration of colleagues in the Health Information and Quality Authority and the Department of Health for partnering with us in the development of the National Care Experience Programme – a partnership, which will flourish in the years ahead to the benefit of patients and our health services.

Bernard Gloster
Chief Executive Officer, HSE

Listening, Responding and Improving

Patient engagement is at the heart of the Operational Performance and Integration function. Engagement is an integral part of our health care and a critical component of person centred care. I want to acknowledge and empathise with each individual who took the time to take part in this survey and recognise that sharing your experiences during some of your toughest times was not an easy ask.

I welcome this opportunity to listen, respond and work with colleagues to improve our services based on the findings of the National Maternity Bereavement Experience Survey (NMBES) 2022. I am delighted to present the coordinated response to the findings of the NMBES and quality improvement plans which highlights the engagement of all key stakeholders and a commitment for all involved to make a real and meaningful difference to women's and their families' experience of maternity bereavement care across Ireland.

Embracing a culture which promotes the importance of women's and their families' experience of maternity bereavement care is essential. This requires a deliberate and focused effort by all who deliver care and support and in particular, must be promoted and supported by leadership.

In total, 655 women and 232 partners participated in the National Maternity Bereavement Experience Survey 2022. In addition to rating their experience through questions, they also provided rich learnings through their comments describing what was good in their care or what could be improved for women and partners experiencing the loss of their baby.

Healthcare teams working across the health services are using the findings of the NMBES to understand what matters to women and their partners and to inform priorities for improving patient experience across maternity units and community care. Quality improvement initiatives that have been implemented during the survey period (2019-2022) are presented in this response.

Priority areas identified in the NMBES 2022 and how healthcare teams can support one another to improve women and partners experience at local level are described in this document. The initiatives and changes mentioned in this report support our health services to build a culture and environment for women and their families to have a positive experience when they come into contact with our maternity services.

Joe Ryan
National Director of Operational Performance and Integration, HSE

Foreword

> Losing a baby was the most difficult experience of my life. I am glad surveys like this are being carried out to help improve care for families.

A dedicated National Women and Infants Health Programme (NWIHP) was established in 2017 by the Health Service Executive to lead and manage the implementation of the National Maternity Strategy 2016 – 2026, Creating a Better Future Together[1]. The NWIHP welcomes the National Maternity Bereavement Experience Survey findings and acknowledges the important part the feedback provided will play in developing a roadmap for systematic improvement of bereavement services and care experiences for women and their partners in to the future. We are aware that for many women and partners, participating in this survey and reliving what was undoubtedly a hugely traumatic time in their lives, was difficult. We would like to take this opportunity to sincerely thank you for your open, honest and frank contributions to the survey which will enable us to ensure an improved care experience for others who sadly experience a pregnancy loss.

In developing and delivering on its work programmes to date, the NWIHP is fortunate that there is rich clinical and quantitative data available concerning the provision of bereavement services in Ireland. The results of the National Maternity Experience Survey 2020[2] and now, the results of the National Maternity Bereavement Experience Survey 2022 provide the Programme with valuable insights and qualitative information about what matters to women and their partners, as they journey through our maternity services and identifies from their perspective, what areas require further focus and improvement.

The NWIHP is encouraged by the feedback from the National Maternity Bereavement Experience Survey 2022 and the overall high rates of satisfaction with various aspects of the bereavement care experience therein. For example, most participants felt treated with respect and dignity both during labour and birth, and after their baby was born. Participants said that staff treated them with kindness and sensitivity, and presented their baby to them in a respectful and sensitive way. In addition, participants stated that staff members assisted when they needed it, and respected their cultural and religious needs. Participants also praised staff for their caring and sensitive attitudes, with numerous comments mentioning midwives and chaplaincy staff in particular.

There were differences in participants' overall ratings of their care, when comparing by the type of loss they experienced. Participants whose baby was stillborn were significantly more likely to give a better overall rating of the care they received than participants who experienced a second trimester loss, early neonatal death or any other type of loss. A number of areas for improvement in maternity bereavement care were also identified. These included greater parental involvement in decisions about care during labour and birth, and support for physical recovery after birth. In addition, participants identified a need for greater information-provision at discharge, particularly in relation to physical recovery, mental health, grieving, and follow-up care and appointments. When asked to describe in their own words how care could be improved, participants expressed a desire for dedicated spaces in hospital/unit for grieving parents; more consistent communication across services involved in their care; additional supports for physical and mental health; and more support for partners.

The results of the National Maternity Experience and the National Maternity Bereavement Experience Survey 2022 will inform and underpin the NWIHP work across a range of current and future projects and programmes. Responding to these findings, the NWIHP is working with key partners and stakeholders to build these findings into its work programme and to proactively respond to and address gaps and shortcomings identified by women and their partners.

Whilst significant work has been undertaken since the implementation of National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death [3], began in 2017, the NWIHP is very aware that there is further work to be done before all service users that experience a loss have access to the type of maternity services envisaged in the Standards. The NWIHP will continue to work closely and collaboratively with all its key partners in this regard, including the Department of Health and HIQA, and will continue to advocate for the additional investment in maternity services required to deliver the high standard and quality of care that women and their partners expect and deserve of our maternity services.

Messages of Support

Féileacáin

As a founding member and current chairperson of Féileacáin I welcomed the opportunity to serve on the Programme Board of the National Maternity Bereavement Experience Survey. This survey will, for the first time, formally hear the voices of parents bereaved through stillbirth, neonatal death and second trimester pregnancy loss. Their generosity in sharing their experiences will add to the improvement and development of our maternity bereavement services for the future.
Féileacáin (Stillbirth and Neonatal Death Association of Ireland) aims to support anyone affected by the death of a baby around the time of birth and has campaigned for improvement in the bereavement services since our inception in 2010. In addition to the practical resources provided to parents through the maternity units (Memory Boxes, Cuddle Cots, Cocoons, Sibling Packs and so on) Féileacáin also promotes and contributes where possible to policy formation, research and training. Féileacáin promoted the National Maternity Bereavement Experience Survey and is grateful to the parents who participated, sharing their experiences and insights into the care they received at the time of their baby's death. Revisiting the trauma of second trimester pregnancy loss, stillbirth or neonatal death is challenging for parents and we acknowledge their commitment to the process.

The survey was comprehensive, and the responses submitted raised several issues with regards to the care of bereaved families in our maternity units. For instance, some parents, following the loss of their child, were cared for in an area where the cries of new-born infants could be heard. We know from experience, research, and professional practice that parents are deeply upset by being cared for in proximity to new-born babies.

Other key themes that emerged were the fact that 74% of respondents felt that their care was good or very good – but 26% of parents stated that their experiences were fair to poor. It appears that one in four parents received sub-optimal care. We know that the care a bereaved family receives at the time of their baby's death will impact their trajectory of grief and healing. Respect and dignity, kindness and understanding are fundamental to all care but especially important when caring for recently bereaved parents. Such care should be a given, along with compassion and sensitivity. As members of the National Standards for Bereavement Care Oversight Group, we know that there is very good education programmes and resources for staff to help them deliver sensitive care that is vital to the support of parents at this time. All staff caring for bereaved parents and families should complete this education programme.

It is now well recognised and documented that the loss of a pregnancy or a baby is one of the most traumatic experiences a family can go through, and parents are often overwhelmed, confused and in shock in the immediate aftermath of their baby's death. Parents often leave the hospital/unit within days of losing their child and feel abandoned by the services as they try to come to terms with what has happened. Discharge Care featured significantly in the responses to the survey and highlights the need for a fully developed and implemented policy regarding the care, information and follow-up required by parents after they leave the maternity unit. GPs, PHNs and other appropriate professionals need to be informed of the death of the baby. Structured, clear and unambiguous arrangements must be put in place for the support of the bereaved parents once they leave the care of the hospital/unit, including information on support services. Almost half (47%) of parents were not provided with information regarding changes to their mental health that may develop in the coming months, which leaves them even more vulnerable and isolated.

Other issues that emerged was the need to use the bereavement alert signage where required (and it is also important that an alert sticker is used on mothers' files for a subsequent pregnancy to avoid the hurt to parents caused inadvertently when enquiries are made regarding previous pregnancies). It is interesting to note that parents who lost their baby due to stillbirth reported higher levels of satisfaction with their care experiences than those whose baby died in the second trimester or due to neonatal loss. Similarly, there were reported differences in care experiences from the younger cohort of parents.

It is heartening to read some of the responses by parents who were part of the 74% of participants who received appropriate care, and it's clear that the knowledge and skills are within the service to offer parents what they need at the time of their baby's death. For instance, examples cited of where parents were at the heart of all decisions that were made regarding the care of their baby, were supported to care for their child and create memories of the short time they

had with their baby. The honouring of the infant by calling him or her by their name also featured positively in the survey. The high response rate to the survey (which included partners) is testament to the need for including the voice of bereaved parents in any decisions or service development as key stakeholders. Parents welcomed the opportunity to be heard and to share their experiences in honour of their baby. We look forward to the improvements which will be implemented as a result of this survey and will continue to advocate for bereaved parents and families.

Marie Cregan
Féileacáin (Stillbirth and Neonatal Death Association of Ireland – SANDAI)

Context and Background

The National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death[3] were developed in response to recommendations in the HSE's 2013 Investigation report into the death of Savita Halappanavar. Following the 2013 report there were nine recommendations for the HSE and one for the Department of Health. The HSEs National Clinical Programme in Obstetrics and Gynaecology, was tasked with implementation of these recommendations. A number of work streams were established, including bereavement care. Several other important reports over the following years also mentioned bereavement care in maternity services. The HSE Maternity Clinical Complaints Review[4] which took place from 2014-2016 and was published in 2017 highlighted a common theme of a lack of bereavement support. One of the recommendations of the National Maternity Strategy[1] (2016) was the improvement of support services for women who have experienced the loss of a baby.

The Health Service Executive (HSE) in conjunction with the Clinical Programme in Obstetrics and Gynaecology went on to task a multidisciplinary group of Perinatal Bereavement care experts to assess what standards of care were in use in Maternity Units both nationally and internationally. It took the Standards Development Group, chaired by Dr Ciaran Browne, two years to research and develop the Standards. Following this development and review process the Standards were launched in August 2016[3]. The Standards were revised with the support of a multidisciplinary group of stakeholders (clinicians, support and advocacy groups and bereaved parents) throughout 2020 and 2021, and the updated Standards were published in July 2022[5].

The purpose of the Standards is to enhance bereavement care services for parents who experience a pregnancy loss or perinatal death. The Standards, which are also a resource for parents and professionals, cover all pregnancy loss situations that women and parents may experience, from early pregnancy loss to perinatal death, including the end of a pregnancy as well as situations where there is a diagnosis of fetal anomaly that will be life-limiting or may be fatal. The Standards promote multidisciplinary staff involvement in preparing and delivering a comprehensive range of bereavement care services that address the immediate and long-term needs of parents bereaved while under the care of the Maternity services. They guide and direct bereavement care staff on how to lead, develop and improve a hospital/unit response to parents who experience the loss of a pregnancy or a baby and will assist staff to develop care pathways that will facilitate the hospital/unit response to the grief experienced by parents and their families. The Standards also acknowledge the impact of perinatal loss on staff and the importance of having formal structures in place to support staff.

The two-year Implementation programme for the Standards commenced in March 2017. The Implementation was facilitated by a National Implementation Group (NIG) of fourteen healthcare professionals, all involved in various aspects of bereavement care in Irish Maternity Units. Implementation was supported by the NWIHP of the Health Service Executive (HSE). The National Group had input and support from the Parents Forum established in 2017 and from the various Parent Support Groups and Voluntary Organisations who worked in partnership with healthcare professionals in moving forward with the Implementation Programme. Implementation was supported and further assisted by the Bereavement teams in all of the 19 maternity hospitals/units in Ireland. Each hospital/unit has a Bereavement team comprised of different healthcare professionals, led by various disciplines. The National Implementation Group carried out its work through six work streams.

The development of a pregnancy loss website with content for Ireland was supported by all stakeholders and was launched in April 2019. The website was designed to be used as a resource for parents who experience pregnancy loss or perinatal death and for staff providing perinatal bereavement care. The website provides accurate and accessible information on pregnancy loss and perinatal death, shares the latest research into the causes of baby loss, promotes emotional well-being, and offers details on how to access the appropriate support services.

To ensure the continuation of the work of the Standards, the HSE's the NWIHP convened an Oversight Group in late 2019, after the two-year implementation programme came to an end. The purpose of this group was to oversee the continued implementation and ongoing development of the Standards in the 19 maternity hospitals/units. The development (2019-2021) and oversight (2021-2022) programmes focussed on reviewing and updating the Standards document, managing and maintaining the new website, and developing bereavement education and training opportunities for healthcare staff, while supporting the clinical specialist midwives in bereavement and loss. This involved developing, piloting and rolling out the TEARDROP education programme and supporting training facilitators for a unit wide roll out of the Irish Hospice Foundation's workshop Dealing With Loss in Maternity Settings, which is based on the Standards. Over 2020-2022, the audit tool that was used to assess perinatal bereavement care in 2017 and 2019 was revised to reflect improvements that had been made in practice since 2017; this was agreed by the oversight group and implemented in late 2020 to review services annually across all 19 maternity hospitals/units.

A report on the programmes of work undertaken since 2017 to implement the Standards was published in August 2021[10]. The content of the standards implementation report shows the dedication and hard work of both the healthcare professionals and the support groups and voluntary organisations who work with parents bereaved through pregnancy loss and perinatal death. Their support and input was necessary for the implementation and development programmes. At that time of publication of the report, the implementation team acknowledged that, since the launch of the Bereavement Standards[3] in 2016, there had been and continued to be improvements in bereavement care following pregnancy loss and perinatal death within the maternity services. A number of overarching and specific recommendations for ongoing work were presented, with accountability at local, regional and national levels of the health services. However, it was noted at that time, that while some maternity hospitals/units had addressed most recommendations presented in the report, differences remained across the 19 sites, and ongoing implementation of the Standards was recommended as a priority for every maternity hospital/unit.

The Oversight Group for the Standards was established in 2019 to oversee the continued implementation and ongoing development of the Standards in the 19 maternity hospitals/units in the Republic of Ireland. Further to the Review of the Implementation of the Standards in 2021, and the publication of the revised Standards in July 2022[10], a detailed review of the Standards Oversight Group was conducted in October 2022 to examine whether it met the needs of its membership, and if/how the Group should develop into the future. The majority of participants rated the value of the Group highly, noting the importance of multi-stakeholder representation and the need for ongoing and continuous monitoring of performance with regard to delivery of the objectives of the Group. Many spoke of the need to maintain momentum and focus in the area; they felt that the Group had many strengths (including diverse membership), much had been achieved and that there was a need to continue to make improvements to policy and practice, and ultimately care experiences. For many this meant continuing with the Groups' role and objectives, and in some cases increasing activities and advocacy around particular objectives, whilst also increasing its visibility and links with the NWIHP. A proposal setting out a revised structure and function of the Group, based on the findings of this review, was presented for approval to the NWIHP in late 2022.

The Advisory Group for the Standards will reconstitute as an Advisory Group in 2023, with widened membership and new (similar) terms of reference – largely advisory, reviewing materials for the National Women and Infants Health Programme, and suggesting issues of importance for the programme to consider in improving bereavement care and pregnancy loss supports.

The responsibility for the monitoring of the implementation of the National Bereavement Standards[5] resides under the NWIHP who continue to provide oversight to the development of the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death[3], across the 19 maternity hospitals/units.

HSE Response to the National Maternity Bereavement Experience Survey

The National Women and Infants Health Programme (NWIHP) welcomes the National Maternity Bereavement Experience Survey findings and acknowledges the important part the feedback provided will play in developing a roadmap for systematic improvement of bereavement services and care experiences for women and their partners in to the future. We are aware that for many women and partners, participating in this survey and reliving what was undoubtedly a difficult time in their lives, was challenging and again, would like to thank all who participated for doing so.

The results of the National Maternity Experience and the National Maternity Bereavement Experience Survey 2022 will inform and underpin the NWIHP work across a range of current and future projects and programmes. Responding to these findings, the NWIHP is working with key partners and stakeholders to build these findings into its work programme and to proactively respond to and address gaps and shortcomings identified by women and their partners.

Whilst significant work has been undertaken since the implementation of National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death[3], began in 2017, the NWIHP is very aware that there is further work to be done before all service users that experience a loss have access to the type of maternity services envisaged in the Standards.

From a National perspective in responding to the findings of this bereavement survey we have framed our response around the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death[5].

This document comprises of three sections:

Section 1
HSE National Response, framed in the context of the National Bereavement Standards and the 4 Pillars of bereavement care therein.

Section 2
Will provide examples of projects recently completed by some of the 19 maternity hospitals/units.

Section 3
Will provide local quality improvement initiatives which will be undertaken in response to both the National Bereavement Standards and the findings from the NMBES.

Section 1

National HSE response

This Section will provide a comprehensive account of the HSEs National response to the findings arising from the National Maternity Bereavement Experience Survey (NMBES), framed in the context of the pillars as set out in the National Bereavement Standards.

Pillar 1 – Bereavement Care
Pillar 2 – Hospital/Unit
Pillar 3 – Baby and Parent
Pillar 4 – Staff

The provision of bereavement care is based on the needs of the parents and not on the type of pregnancy loss.

PILLAR 1

Bereavement Care

Bereavement Care is central to the mission of the hospital/unit and is offered in accordance with the religious, secular, ethnic, social and cultural values of the parents who have experienced a pregnancy loss or perinatal death.

What we already know

Clinical Governance

Each hospital/unit should ensure a robust clinical governance system is in place with a clearly identifiable senior management team with the accountability and authority to ensure quality of perinatal bereavement care and to implement improvements, including implementation of local and national guidelines.

National Obstetrics and Gynaecology Guidelines

Guidelines for bereavement care and or care pathways should be in place in hospital/units to ensure best practice and that care is provided within the framework of current legislation and professional codes of practice.

The Role of Bereavement Specialist Team

The development of Bereavement Specialist Teams in Maternity Units is fundamental to the successful implementation of the Standards. Each hospital/unit has a Bereavement team comprised of different healthcare professionals and is led by various disciplines in each hospital/unit.

Critical to the establishment and function of the Bereavement Specialist Team are the Clinical Midwife Specialists (CMS) in Bereavement and Loss. The CMS is a Midwife who has undertaken specific training and education at level 8 or above in the area of bereavement, in order to meet the very specific needs of bereaved women and their partners.

The area of specialty is a defined area of midwifery practice that requires application of specially focused midwifery knowledge and skills, which are both in demand and required to improve the quality of women's care. The role of the CMS in Bereavement and Loss is to support and facilitate families through the loss and bereavement process associated with pregnancy and childbirth. It encompasses the support of women, partners and their families at the time of pregnancy loss and perinatal death supporting the grieving family before, during and/or after their loss.

Medical Social Worker Specialists in Bereavement

The Medical Social Worker Specialist in Bereavement in a maternity setting provides emotional and practical support at a time of loss to bereaved parents, children and extended family members. They are available to offer bereavement support to parents in the weeks and months following their discharge from hospital/unit and throughout subsequent pregnancies. The bereavement social worker also provides advice on children and loss and is available to do direct work with children, if this support is needed. They are an advocate for bereaved parents and work as part of the bereavement team to ensure optimum care for bereaved families. The NWIHP has funded a number of Maternity Social Workers across the 19 hospitals/units and continue to prioritise investment in this area.

Perinatal Pathology

The Perinatal Pathologist and their team ensures that within the pathology department the post mortem practice is viewed as parent-centred and that the baby and the baby's parents are treated with respect at all times. The Perinatal Pathologist is also responsible for ensuring that;

- Post mortem examinations are performed to a high standard, in keeping with national and international guidelines HSE Standards and Recommended Practices for Post Mortem Examination Service 2023[13].
- Members of the Bereavement Specialist Team and others are educated about the post mortem process and placental pathology so as to provide bereaved families with up to date and evidence based information.
- Limitations of the post mortem examination are understood by parents.

The pathologist must ensure that information obtained from the post mortem examination, placental examination, cytogenetics testing and other available investigations, is collated and integrated to formulate a cause of death (if possible) and to correlate the pathological findings identified with the clinical course leading up to the miscarriage, stillbirth or neonatal death. If a definitive cause of death is not identified, potential contributors or relevant findings can be documented. He/she communicates the results of post mortems and placental examinations to the clinical team caring for the parents. The perinatal mortality multidisciplinary team meeting is a vital forum for this communication as it ensures accurate understanding of all aspects of individual cases and thereby facilitates appropriate follow-up (e.g. specialist medical genetics referral).

Perinatal Genetics

Perinatal genetics is a clinical service that focuses on the evaluation, diagnosis, management and treatment of anomalies before birth. Perinatal anomalies may include chromosomal anomalies, hereditary disorders and metabolic conditions before or during pregnancy, as well as structural anomalies during pregnancy. A perinatal genetics service facilitates earlier diagnosis of fetal conditions, therefore improving both pregnancy and neonatal outcomes.

Coroner

Coroners are independent public officials whose function is to investigate sudden and unexplained deaths. In many cases, they will arrange for a post-mortem examination to be carried out to help them come to a conclusion. Where a Coroner believes that a death was violent, unnatural or happened suddenly and from unknown causes, they will hold an inquest to establish the facts of how the person died. The function of the inquest is not to decide if someone is legally responsible for the person's death. It is solely to establish the "who, when, where and how" of their death.

The Coroners (Amendment) Act 2019[6] was signed into Irish law in 2019. The Act contains a number of key provisions which include:

Mandatory reporting to a Coroner of all stillbirths, neonatal and infant deaths and, for the first time, a statutory basis for the Coroner to enquire into a perinatal death where there is cause for concern (this normally arises from matters raised by the bereaved parents).

What we have heard

Participants' who had a stillbirth typically gave more positive ratings of their care experiences than those who experienced a second trimester loss, early neonatal death or any other types of loss.

Participants aged between 16 and 24 years had poorer experiences overall and across several stages of care than older respondents.

With regard to privacy and dignity 83% of participants said they were in a suitable private place when they were first told that their baby had died.

Participants were asked to rate their overall care, with 74% rating their care as 'very good' or 'good', and 26% rating their care as 'fair to poor'.

Comments Included below:

Social work department were very helpful in guiding me with work and what my rights were.

I wasn't allowed to be with my wife when she was told our baby died, she was told this heart –breaking information alone. Due to COVID-19 restrictions.

Never received a phone call in regards to follow up tests from baby [Baby's Name] or myself, no 6 week check-up post birth and no call from social worker or support.

Leaving the hospital/unit, I felt this could have been dealt with much more sensitively, private door, private exit etc, it was heart-breaking passing expectant mothers and couples leaving the hospital/unit with their new-borns, all the while carrying our deceased angel baby in a basket covering in a blanket, it broke our hearts and is something that really stands out in our story when we speak about our experience.

My voice was listened to, my many questions answered from hospital/unit admission to discharge, I was treated with respect and dignity. I feel that the staff walked along with me, they felt my pain and they recognised the love we had for our son.

The time frame of post mortem were initially advised half day and then took over day and half and was very stressful waiting for our baby to return and arrived half an hour before a religious service was planned.

Although a post-mortem was carried out, no one from the hospital/unit sat down with me to understand and hear from me my experience of the pregnancy and see if there were any red flags in hindsight.

What we have learned

Dedicated Bereavement Teams

Dedicated bereavement teams contribute much to the support offered to parents, where trained professionals provide appropriate person-centred care and follow-up, and demonstrate leadership in bereavement care within the maternity unit/hospital. Each hospital/unit has a Bereavement team comprised of different healthcare professionals and is led by various disciplines.

The availability of and access to dedicated bereavement teams is critical to women and parents who experience the loss of a pregnancy or baby. The bereavement team is usually composed of staff members who have undertaken specialist and extensive education in bereavement care. The team includes; a Bereavement Coordinator, Clinical Midwife Specialist (CMS) in bereavement and loss, Chaplain and Senior Medical Social Worker. The team should be supported in its work by the hospital/unit Chief Executive Officer (CEO), Director of Midwifery, Clinical Leads, Obstetricians, Paediatricians, Neonatologists, Perinatal Psychiatrist, Midwives, Nurses, Neonatal Care Nurses, Pastoral care teams, Palliative Care Teams, Administrative and Auxiliary staff – all of whom have received training appropriate to their role in bereavement care.

Each Maternity Unit/Hospital should have a Maternity Bereavement Committee to provide a framework for clinical staff to ensure the delivery of high-quality bereavement services to women, infants, parents and families experiencing pregnancy loss and perinatal death. Each Maternity Unit should invite a parent representative to sit on their maternity bereavement Committee to ensure that the patient voice and experience is represented.

National Clinical Practice Guidelines

National Clinical Practice Guidelines for the different types of Pregnancy Loss should be available to all staff. It is expected that hospitals/units would self-assess against the National Bereavement Standards and audit clinical practice against the up-to-date National Clinical Guidelines.

Information Resources for Parents

Information resources for parents who experience a pregnancy loss or perinatal death and for staff providing perinatal bereavement care should be available. The findings of both the National Maternity Experience Survey 2020[2] and the National Maternity Bereavement Experience Survey 2022, also emphasise the need for healthcare services to improve health information about mental health changes that may occur during pregnancy and in the postnatal phase.

The national website is necessary to ensure that healthcare professionals delivering bereavement care have access to up to date, accurate information and advice. The website was designed to be used as a resource for parents who experience pregnancy loss or perinatal death and for staff providing perinatal bereavement care. The website provides accurate and accessible information on pregnancy loss and perinatal death, shares the latest research into the causes of baby loss, promotes wellbeing, and offers details on how to access the appropriate support services.

Clinical Midwife/Nurse Specialist in Bereavement (CMS)

Some units that scored lower than others in the National Maternity Bereavement Experience Survey did not have a CMS in Bereavement and Loss in post at the time of the survey, which emphasises the importance of this role, as well as the need for succession planning and for development of supports for those individuals working in these roles. During 2019 and 2020, our healthcare services were severely impacted by the COVID–19 pandemic. This was felt acutely by women and their partners, in particularly with regard to measures to reduce footfall into maternity units. Specialist Staff in some hospitals/units were redeployed as a result of sick leave and changes in work practices during the pandemic.

Restrictions on partners attending hospital/units during the pandemic had a big impact on women and their partners. However, despite the barrier of staff being gowned up with masks on their faces, the absence of the touch of a hand there was no significant difference in rating found before or after the COVID-19 pandemic. This highlights the overall good quality care and care practices provided to women and their partners. Women and partners understood why restrictions were in place.

Post Mortem Examination

The findings from the National Maternity Bereavement Experience Survey 2022 highlighted a number of issues with regards to post mortem examination and investigations and in particular regarding timeframe that these were available to parents. The findings also highlight the length of time families had to wait for a Coronial inquest.

What we have done

The NWIHP have and will continue to advocate at National Level for continued support and investment in bereavement services. The NWIHP has worked closely and collaboratively with maternity networks and the Oversight Group for the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death, towards:

- Embedding robust clinical governance systems with a clearly identifiable senior management team with accountability and authority to ensure quality of perinatal bereavement care and to implement improvements, including implementation of local and national guidelines.
- Commenced the appointment of Clinical Leads for Pregnancy Loss services in Maternity Hospitals/Units. The purpose of these posts is to provide leadership to the multidisciplinary team and to take responsibility for the provision of a quality service.
- Commenced the appointment of Clinical Leads for Early Pregnancy services in Maternity Hospitals/Units. The purpose of these posts is to provide leadership to the multidisciplinary team and to take responsibility for the provision of a quality service.

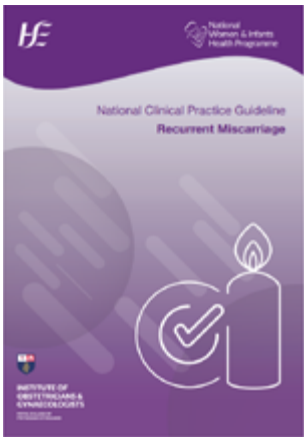
National Clinical Guidelines, care pathways and audit

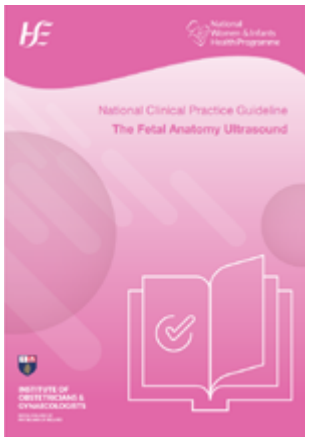
NWIHPs National Clinical Guideline Programme (Maternity and Gynaecology), in collaboration with the Institute of Obstetricians and Gynaecologists of the RCPI, have developed a number of National Clinical Guidelines[16]. The first twelve guidelines were launched in January 2023 and include:

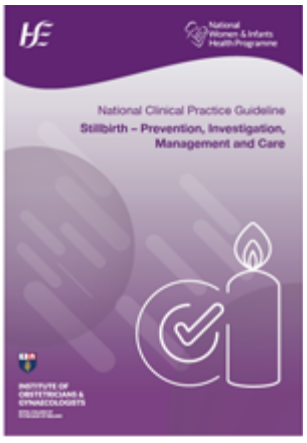
- National Clinical Practice Guideline: Stillbirth Prevention, Investigation, Management and Care (includes a plain language summary leaflet)
- National Clinical Practice Guideline: Recurrent Miscarriage (includes a plain language summary leaflet)
- National Clinical Practice Guideline: The Fetal Anatomy Ultrasound

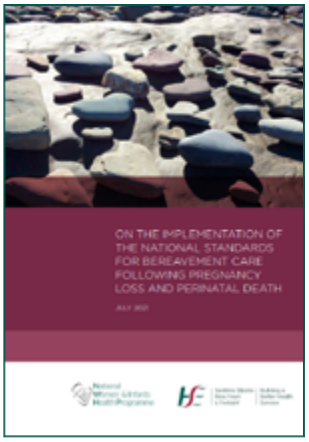
Guidelines commissioned through 2023 include:

- Reduced fetal movements in pregnancy
- Management of first trimester miscarriage
- Termination of Pregnancy for Fetal Anomaly
- Ectopic pregnancy









National Bereavement Standards Audit tool for Maternity Units

To assess the perinatal bereavement care in each Maternity Unit an audit tool was developed and approved by the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death. This was intended to enable the Clinical Lead and Programme Manager to evaluate and measure practice against the Standards. The audit tool was developed from the Standards and was organised into three separate themes; people, place and processes.

People: this section of the audit refers to the key personnel that were identified through the Standards to offer key services and support to bereaved parents and families. The appointment of these vital positions within Maternity units have an impact on the quality of care bereaved parents receive.

Place: this section of the audit refers to the dedicated spaces identified for bereavement care within each Maternity Unit to care for bereaved parents and families. Developing protected spaces within a hospital/unit to discuss, counsel and allow quiet time for parents and families is noted to be an important facet of sensitive and compassionate care for bereaved parents.

Processes: this section of the audit describes the way that bereavement care is carried out and the processes that are in place to support and sustain it. Established pathways of care and the hospital/unit structures around them are important so that the delivery of bereavement care is facilitated with ease. This includes the management team being accountable for the delivery of bereavement care in their Maternity Unit and the provision of education and training for staff.

This audit tool was used to audit perinatal bereavement care in all 19 maternity hospitals/units in the country. Over 2020 – 2022, the audit tool that was used to assess perinatal bereavement care in 2017 and 2019 was revised to reflect improvements that had been made in practice since 2017; this was agreed by the National Oversight Group and implemented in late 2020 to review services annually across all 19 maternity hospitals/units.

National Care pathways

National Care pathways for the different types of pregnancy loss were developed and published in various experts in the provision of perinatal bereavement care services through the working groups of the implementation programme, which also included parent representatives and support and advocacy groups.

Six care pathways were published on the National Pregnancy Loss Website and disseminated to all Maternity Units in 2019-2020. These will be updated as the new national clinical guidelines are published thorough out 2023 and 2024.

1. Ectopic Pregnancy Care Pathway https://pregnancyandinfantloss.ie/ectopic-pregnancy-care-pathway/
2. First Trimester Pregnancy Loss Pathway https://pregnancyandinfantloss.ie/first-trimester-pregnancy-loss-care-pathway/
3. Second Trimester Pregnancy Loss Pathway https://pregnancyandinfantloss.ie/second-trimester-pregnancy-loss-care-pathway/
4. Stillbirth Care Pathway https://pregnancyandinfantloss.ie/stillbirth-care-pathway/
5. Neonatal Death Care Pathway https://pregnancyandinfantloss.ie/neonatal-death-care-pathway/
6. Perinatal Palliative Care Pathway https://pregnancyandinfantloss.ie/perinatal-palliative-care-pathway/

Termination of Pregnancy

In April 2022, the HSE's Chief Clinical Officer (CCO) commissioned a review to improve the safety and management of termination of pregnancy services, as provided under Section 11 of the Health Regulation of Termination of Pregnancy Act 2018[7]. The Report of the review and recommendations were submitted to the CCO and Review Oversight Group in April '23, particular areas of focus include: Screening for fetal anomaly; fetal medicine and TOPFA Pathways; Perinatal Genetics; Investigation and Follow-up (Perinatal Pathology, Counselling and Bereavement Care); Clinical Audit and provision of written women/service user information.

Specialist Bereavement Teams & Support Services

Clinical Midwife Specialists in Bereavement

The Clinical Midwife Specialist (CMS) Bereavement and Loss is a Midwife who has undertaken specific training education at level 8 or above in the area of bereavement in order to meet the needs of this very specific women's group. The role of the CMS is to support and facilitate families through the loss and bereavement process associated with pregnancy and birth. It is a post very specifically focused on the maternity services. All 19 maternity hospitals/units have been funded for a minimum of one Clinical Midwife Specialist (CMS) in Bereavement and Loss in their unit. The NWIHP have provided additional funding to increase the number of dedicated Bereavement and Loss CMS resources in larger units and to continue to support replacement posts.

The Clinical Midwife Specialists (CMS) in Bereavement and Loss have developed and established their role since 2015 and are working to ensure the implementation of the Standards in their respective units as part of the local Specialist Bereavement Team. Unfortunately, in some units replacement of CMS posts has proved challenging. This has led to the NWIHP formally requesting hospital/unit management teams to actively manage succession planning for clinical midwife/nurse specialists.

Medical Social Workers

The NWIHP have funded Medical Social Workers across each of the 19 maternity hospitals/units and will continue to advocate for additional funding in to the future.

Perinatal Pathology

The NWIHP commenced investment in Perinatal Pathology with a view to building capacity and securing additional consultants and laboratory expertise in 2018. Working with the maternity networks, the NWIHP have progressed with the development of a perinatal pathology network across the SSWHG, ULHG and Saolta. This network will ultimately see three Consultants based in Cork and two in Galway that will work as a structured network, thereby addressing and managing perinatal pathology across the three Maternity Networks. With the Eastern region, the NWIHP made further investment in this service in NMH with a view to enabling and supporting NMH to provide a structured, readily accessible service to all regions and maternity services in its network.

The NWIHP have been involved in the development of the HSE's new Post Mortem Examination Guidance 2023[13]. The guidance includes a quick guidance for clinicians with regard to standards and protocols for post mortem examination.

The NWIHP have and will continue to engage with the Coroner Service of Ireland (involving the Departments of Health and Justice) regarding the clinical management of perinatal death cases in order to allow timely reporting to families and hospital/units of provisional information on cause of death e.g., consideration to providing a draft. One meeting was held in January '23 at NWIHP's offices, with a follow-up engagement scheduled to take place at the Coroners Society Annual Meeting in Dublin in May '23.

Perinatal Mental Health

A Specialist Perinatal Mental Health Model of Care for Ireland has been implemented across the HSE, it supports the seven actions on mental health outlined in the Government's National Maternity Strategy[1]. Whilst the focus of these specialist services is to manage moderate to severe mental illness, the appointment of perinatal mental health midwives in the hubs and spoke sites has facilitated the identification and management of milder mental health problems in women attending the maternity services. In addition, the perinatal mental health midwives play a central role in providing mental health education and training for those providing services to women in the antenatal and postnatal periods. The perinatal mental health midwives work closely with the clinical midwives specialist in bereavement to provide perinatal mental health service to women who have a bereavement loss.

Following the launch of the National Model of Care[8], a Specialist Perinatal Mental Health Team led by consultant perinatal psychiatrists is now available in all six hub sites. In 2021, funding was also made available to continue the full recruitment of staff in all Hub sites, allowing for the completion of the Specialist Perinatal Mental Health Service (SPMHS) at Galway University Hospital (GUH) and the addition of senior occupational therapists in all 6 hub sites. During 2021 a successful application was also made to the Women's Health Taskforce by the NWIHP, which resulted in the funding of a further four perinatal mental health midwives and a 0.4 WTE Consultant perinatal psychiatrist post for Galway University Hospital. There are now perinatal mental health midwives in all 13 spoke sites.

The specialist perinatal mental health teams continue to support women and families throughout 2021 and adapt their services to provide both individual and group work online including developing supports for women with anxiety and depression and bereavement loss[14].

A specific monthly perinatal mental health online training programme began in November 2021 for all staff working directly in SPMHS and a 2021-2022 training plan was developed. A range of teaching methods were used, including didactic teaching, and small group discussions facilitated by perinatal psychiatrists. Specific senior psychology supervision began in 2021. This training was organised by the National Programme in collaboration with the individual peer groups for these specific disciplines and funded by the NWIHP.

Perinatal Mental Health App for Healthcare professionals

Other supports were also developed for frontline workers working with women in the perinatal period. Over 1,800 frontline staff are now registered on the PMH App for healthcare professionals (PHNs and Midwives the majority). The app is regularly updated and available at https://pmh.healthcarestaff.app/. New video resources have been added such as the SPMHS in the Rotunda's Me to Mum videos as well as videos made to raise awareness for women from the travelling community on perinatal mental health supports.

National Pregnancy Loss Website

The National Pregnancy Loss Website was launched in 2019. The website was designed to be used as a resource for parents who experience pregnancy loss or perinatal death and for staff providing perinatal bereavement care. The website provides accurate and accessible information on pregnancy loss and perinatal death, shares the latest research into the causes of baby loss, promotes emotional well-being, and offers details on how to access the appropriate support services. The website is updated twice annually, with the latest information leaflets, guidelines, research, contact details and other relevant information.

What we will do

The National Women and Infants Health Programme (NWIHP) will:

- Reconstitute the Bereavement Standards Oversight Group as an Advisory Group in 2023, with widened membership and new (similar) terms of reference – largely advisory, reviewing materials for the NWIHP, and suggesting issues of importance for the programme to consider in improving bereavement care and pregnancy loss.
- Continue to advocate for additional investment required to deliver a high quality bereavement service throughout all 19 hospitals/units.
- Advocate through the Health Service Executive (HSE) annual estimates process for funding and resources to support the development and improvement of perinatal bereavement services, including expansion of perinatal palliative care services.
- Support maternity units to ensure that each of the 19 hospitals/units has dedicated Clinical Midwife Specialist (CMS) resource in Bereavement & Loss in post.
- Continue to develop a suite of National Clinical Guidelines on all types of Pregnancy Loss and support maternity hospitals/units to implement these and develop tools to audit their compliance and review their practice against the auditable standards.
- Develop a suite of standardised, evidence-informed, women's information leaflets for all types of pregnancy loss.
- Continue to further develop the workforce plan for perinatal pathology. This includes the consultant posts, and associated laboratory staff to ensure that the maternity services have access to timely perinatal pathology service across all 19 hospitals/units.
- Work with the six Maternity Networks and other key stakeholders to finalise and implement a framework for perinatal genetics as a component of the HSE's overarching Genetics and Genomics Strategy.
- Work collaboratively to deliver the recommendations arising from the Review of termination of pregnancy services due to fetal anomaly, in a timely, efficient and effective manner to help ensure that the complex clinical and emotional needs of women and partners seeking a termination of pregnancy are met.
- Support units to self-audit annually against the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death.

- In addition, the NWIHP will continue to collaborate with the Pregnancy Loss Research Group, University College Cork (UCC) on the following:

    1. Miscarriage and recurrent miscarriage (RM), e.g. developing women and staff information and support materials and resources in a variety of formats and languages, co-produced with knowledge user partners; plain language booklets for people experiencing recurrent miscarriage (printed and online).
    2. Leaflets, videos and online content about miscarriage and recurrent miscarriage (e.g. what is it, what to do, how to talk about pregnancy loss for public, family, friends and employers) and health services availability.
    3. Pre-appointment letter templates.
    4. Information checklist for healthcare staff with information for people who might be miscarrying and who need to attend hospital/maternity unit (notably emergency departments).
    5. Case studies (written information, photographs, videos) from different Irish units showcasing examples of good practice regarding appropriate physical environments and bereavement spaces within hospital/units.
    6. Evidence and policy briefs communicating key messages from various research projects on Pregnancy Loss.

The National Women and Infants Health Programme (NWIHP) and pregnancyandinfantloss.ie websites, accessible information/materials:

The NWIHP will continue to work with the Pregnancy Loss Research Group, UCC and the bereavement team at Cork University Maternity Hospital to update existing content on the NWIHP Bereavement webpage and the pregnancyandinfantloss.ie website, adding any new materials produced. The programme of work will include the staff videos to appear on pregnancyandinfantloss.ie and these YouTube can be embedded in any website or resource. The main purpose of these videos is to introduce people (primary audience: 'patients' and public; secondary audience: health care staff) to the different people involved in bereavement care in maternity hospitals/units and what they do. The entire website is being reviewed and content updated in early 2023, e.g. links, information leaflets and guidelines, list of Irish research papers, details of training and supports.

PILLAR 2

Hospital/unit

What we already know

Hospital/units should have systems in place to ensure that bereavement care and end-of-life care for babies is central to the mission of the hospital/unit and is organised around the needs of babies and their families.

The physical environment where perinatal bereavement care is provided throughout the hospital/unit should support high quality care and facilitate privacy and dignity.

The hospital/unit should facilitate access to rooms and spaces where breaking bad news, end-of-life care and bereavement care can take place in a quiet, comfortable environment where privacy is ensured.

The Standards[5] recommend that:

- Following admission/re-admission and resources permitting, the woman is cared for in a dedicated room with an ensuite toilet and shower. Each dedicated room has a double bed and/or a second single bed to facilitate the mother's partner or companion to stay overnight during her stay in hospital/unit.
- A woman admitted to hospital/unit with a diagnosis of ectopic pregnancy or early pregnancy loss is accommodated in a Gynaecology Ward or in an alternative non-obstetric ward.
- A parent returning to the hospital/unit for a follow-up consultation with an obstetrician/fetal medicine specialist, paediatrician/neonatologist, bereavement specialist, chaplain or other staff member will be reviewed, where feasible, in a suitable room separate from mothers and babies and conducive to discussion and counselling.

What we have heard

> Having a single room to ourselves with a beautiful picture on the wall was a comfort and also we couldn't hear other babies cry which would have been very difficult.

> I was put in the same room as other women who had already delivered their baby or who were on their way to delivery which made this even more difficult.

> When given initial explanation on the miscarriage it was in an area where routine scans were happening and behind a curtain in a very busy area. No privacy, sympathy or empathy shown on this occasion by the junior doctor. Midwives however did apologise for this treatment after it had happened

What we have learned

We learned that 60% said that they were accommodated in a single room, with a further 33% accommodated in a designated bereavement room.

We know that access to quiet spaces in Outpatients, Emergency Rooms and Fetal Assessment Units in some units is limited. We also know that in some units there are in-appropriate mortuary spaces.

What we have done

Bereavement Rooms

The NWIHP has provided significant investment in many aspects of bereavement services. In addition to funding specialist bereavement resource across the maternity hospital/unit network, non-pay funding has also been provided for bereavement rooms. These rooms provide a dedicated space for bereaved parents following the loss of a baby or end of a pregnancy. A number of bereavement rooms were funded under the Design & Dignity Grant scheme operated and co-funded by the Irish Hospice Foundation (IHF) and the Health Service Executive.

Questions about rooms and spaces have been part of the annual audit process for the Standards implementation programme. This process has also facilitated hospitals/units to both benchmark against each other and supported them to learn from each other in development of new facilities.

Overarching findings from the 2017 and 2020 audit included the need for:

- Continued development of dedicated inpatient bereavement facilities in some units
- Access to quiet spaces in OPD/ED/FAU in some units
- Appropriate clinic space for follow-up clinics in some units
- Appropriate mortuary spaces in some units
- Ring fencing of inpatient beds for Maternity and Gynaecology patients in some units.

What we will do

The HSE, with the support of the NWIHP will continue to advocate for funding for more dedicated spaces, designed to facilitate privacy and dignity to women and partners who have experienced a bereavement loss. This means:

- Each hospital/unit should have a quiet room in the antenatal clinic and or fetal assessment unit, ultrasound department which parents can use following a diagnosis of pregnancy loss or diagnosis of fetal anomaly.
- Each Maternity Unit should have one dedicated bereavement care room or suite where parents can be cared for following pregnancy loss or perinatal death.
- Each Maternity Unit should have a dedicated quiet room or family room on the Neonatal Unit which is available for parents and family when a baby is seriously ill, dying or following death.
- Maternity units should be allowed to manage their own bed allocation and protect these beds for use by Maternity and Gynaecology patients, which includes all women with pregnancy loss.

- Each Maternity Unit should have access to mortuary facilities which have a suitable area for families to receive and spend time with their baby following pregnancy loss and perinatal death. Consideration should be given to upgrade existing mortuary facilities to make them fit for purpose. Each maternity hospital/unit should have appropriate mortuary space.

These recommendations are reported in the Implementation of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death report published in 2022[5]. We plan to add this to the website – and NWIHP webpages – to show case studies and examples of good practice for other units to learn from.

PILLAR 3

Baby and Parents

Each baby/family receives high quality palliative and end-of-life care that is appropriate to his/her needs and to the wishes of his/her parents.

What we already know

The care parents receive at the time of perinatal bereavement can shape their entire grieving process and negative experiences can contribute to complicated grief for parents on top of what is already recognised as one of the most difficult bereavements. Lack of sensitivity or inappropriate language can leave a lasting impact, while good caring experiences are remembered in a positive and supportive way. The importance of communication skills for clinicians as highlighted in the literature on perinatal bereavement demonstrates the key role such interactions have in the overall experience of parents during a distressing time. Clinicians cannot change the news they must convey or the clinical situation of pregnancy loss that has happened, but they can change how this is communicated and how they express care.

Clear and accurate information must be provided to the baby's parents about their baby's condition, treatment options, and prognosis and care pathways in a timely and culturally appropriate manner and in accordance with the parent's preferences and the baby's best interests.

Communication skills are consequently core strands of healthcare professional training, postgraduate assessment, and ongoing professional development. The National Care Experience Programmes (NCEPs), first conducted in 2017, highlighted poor communication between patients and healthcare providers as one of its main findings. The Health Service Executive's response to the opportunities for improvement highlighted in the National Inpatient Experience Survey was to establish the National Healthcare Communication Programme (NHCP). The NHCP has been developed and are delivered in partnership with the International Association for Communication in Healthcare (EACH).

Partnership and Advocacy

Empowering women to be partners in their care is vital. We know from the results of the National Maternity Bereavement Experience Survey 20202 that service users want to be more involved in their healthcare and treated as full partners in their care. We also know this from the implementation programme for the Standard from 2017 to 2019. A Parents Forum and many Parent Support Groups and Voluntary Organisations worked in partnership with the implementation group. Past experience has shown that people are experts in their own care. By virtue of their own bereavement experience of grief, parents have much to offer in shaping developing in bereavement care, policy and service provision. By involving bereaved parents in decisions relevant to bereavement care, and acknowledging their experience there can be an improvement in the quality of bereavement care being delivered.

The Standards Parents Forum comprised of ten parents who had experience of the different types of pregnancy loss. The National Implementation Group (NIG) Clinical Lead, the NIG Project Manager and a Bereavement Clinical Midwife Specialist (CMS) also participated in the forum, which was established in 2017 and ran to 2019. Parents were advised that they could access bereavement support should this be required as a result of their involvement. The parents were asked to draw on their own experiences to consider the aim of the Standards for future bereaved parents.

The purpose of this forum was to:

- Represent parents voices and facilitate their opinions and experiences being taken into account when implementing the Standards.
- Provide opportunities for parents to contribute to developing guidelines, care pathways and services that aim to meet the needs of bereaved families in the future.
- Inform the National Implementation Group (NIG) about the needs of parents affected by pregnancy loss and perinatal death and provide feedback and constructive challenge to outputs from the NIG.

Participating parents contributed openly and actively with the overall process of review and implementation of the bereavement standards. Parents brought an important perspective from their experiences to guide the compassionate implementation of bereavement care and to shape the experiences for future care.

What we have heard

> The care we received was top class in really difficult circumstances. The staff were exceptional and their care, time and effort made a horrible time a little bit easier.

> Once discharged any follow-ups were to be instigated by me. I believe the bereavement team should check in on mothers in the early weeks, even just a phone call to see how they're coping.

> I think the hospital/unit did as much as they possibly could have for us, staff were compassionate towards us and helped us through a tough time.

> I was discharged with no support or information on emotional supports, grief or bereavement.

What we have learned

The most frequently occurring theme in the National Maternity Bereavement Experience Survey 2022 was 'Compassion and sensitivity' and 'Communication and information-sharing.

The care parents receive at the time of perinatal bereavement can shape their entire grieving process and negative experiences can contribute to complicated grief for parents on top of what is already recognised as one of the most difficult bereavements. Lack of sensitivity or inappropriate language can leave a lasting impact, while good caring experiences are remembered in a positive and supportive way. The importance of communication skills for clinicians as highlighted in the literature on perinatal bereavement demonstrates the key role such interactions have in the overall experience of parents during a distressing time. Clinicians cannot change the news they must convey or the clinical situation of pregnancy loss that has happened, but they can change how this is communicated and how they express care.

A culture of open, honest and transparent communication with bereaved women (and their families/ relevant person(s), as appropriate) when things go wrong in relation to their healthcare is very important.

Clear and accurate information must be provided, as appropriate to the baby's parent's needs and wishes, about their baby's condition, treatment options, and prognosis and care pathways in a timely and culturally appropriate manner and in accordance with the parents' preferences and the baby's best interests.

In the National Bereavement Experience Survey 2022, participants identified a need for greater information-provision at discharge, particularly in relation to physical recovery, mental health, grieving, and follow-up care and appointments. 38% of participants said that they were not given information about follow-up care plans and appointments before they were discharged from hospital/unit.

What we have done

The National Healthcare Communication Programme (NHCP) have directly addressed the findings of this survey and developed and delivered tailored communication modules across all 19 maternity hospitals/units.

A Framework for Promoting Empowerment Advocacy in Healthcare

The HSE together with the Department of Health, has developed a plan to provide training to staff and patient advocates on a competency based training programme in patient advocacy. This programme of work commenced in 2018 and was introduced across acute hospital/unit services in 2019, providing clear sign-posting for women and partners in relation to appropriate advocacy services in the community and the promotion of patient support services in local hospital/units. In 2019, the HSE welcomed the introduction of the new independent Patient Advocacy Service. The service was commissioned by the National Patient Safety Office in the Department of Health following a recommendation in the Health Information and Quality Authority's (HIQA) 2015 report on the Investigation into Maternity Care in Midland Regional Hospital Portlaoise[9].

Health information designed to empower women and partners to make informed decisions to be fully involved in the decision making about their health care was developed and promoted. This work will be advanced in partnership with service users and advocacy services. The Safer to Ask series of service users leaflets encouraging patients to be actively involved in the decision making about their care are available across hospital/unit sites and on the HSE website. Training for staff in healthcare communication skills encourages both doctors, nurses and all healthcare professionals to listen more to women and to encourage them to own their solutions, care plans and be more involved as shared experts in the decision making about their care.

The HSE has also rolled out training for staff on patient safety complaints advocacy. Many advocates and health service employees have to date, graduated with an accredited qualification (QQI level 7) as trained patient safety complaints advocates. This training programme addresses:

- Patients' rights in healthcare;
- Communication skills in healthcare;
- Resolving and learning from complaints;
- Handling patient safety complaints and advocacy related issues;
- The National Women and Infants Health Programme (NWIHP) and pregnancyandinfantloss.ie websites, accessible information/materials.

The NWIHP has worked closely with the Pregnancy Loss Research Group, UCC and the bereavement team at Cork University Maternity Hospital to update existing content on NWIHP Bereavement website and the pregnancyandinfantloss.ie website. A suite of information leaflets, spanning all types of pregnancy loss or perinatal death are available on the Pregnancy and Infant Loss website as a useful resource when providing bereaved parents with information specific to their situation.

What we will do

The National Healthcare Communication Programme (NHCP)

Talking to patients is often considered to be a 'natural' skill or an 'art'. However, it is well recognised that a clear set of skills for healthcare professionals can be identified, taught and learned with consequent benefits for women, their partners and for the staff themselves. Maternity services should ensure that arrangements are in place for staff to learn, develop and maintain core communication skills. The National Healthcare Communication Programme (NHCP) have reviewed the current communication modules and training based on the findings of the National Maternity Bereavement Experience Survey 2022 and continue to provide training for healthcare staff to enhance their communication skills in these areas.

Patient Safety Complaints Advocacy

The HSE will continue to roll out training for staff on patient safety complaints advocacy. The training programme is designed to build the capacity of both healthcare staff and patient advocates to respond to patients complaints and achieve better outcomes for patients.

The National Women and Infants Health Programme (NWIHP) and pregnancyandinfantloss.ie websites, Accessible Information/materials

The NWIHP will continue to work with the Pregnancy Loss Research Group, UCC and the bereavement team at Cork University Maternity Hospital to update existing content on the NWIHP Bereavement website and the pregnancyandinfantloss.ie websites, incorporating Guidelines, Research, Patient Leaflets, Education, Pathways and Reports.

Point of Contact for Parents

Senior Management Teams in all 19 maternity hospitals/units should ensure that there is a hospital/unit nominated point of contact for parents who have experienced pregnancy loss or perinatal death and have questions regarding their care, to guarantee that they can easily access information and have questions answered regarding their care. The NWIHP will monitor this through the oversight of the bereavement standards implementation.

Staff education and training which incorporates communication skills in bereavement care will be covered in the next section.

PILLAR 4

Staff

As set out in the Standards, it is critically important that a culture of compassionate bereavement care is cultivated amongst Staff. All hospital/unit staff must have access to education and training opportunities in the delivery of compassionate bereavement and end-of-life care in accordance with their roles and responsibilities and must also be supported through training and development to ensure they are competent and compassionate in carrying out their roles in bereavement care.

What we already know

Education and training programmes for all staff should have defined objectives that reflect evidence-based best practice and legislation. These programmes must be delivered at an appropriate level for all staff relevant to the position they hold within their organisation.

Staff Induction

During the course of the Standards development programme, it was found that perinatal bereavement care is not included in every maternity hospitals/unit's staff induction programme.

It is important that all staff should have access to education and training opportunities in the delivery of compassionate bereavement and end of life care in accordance with their role and responsibilities[10].

Staff Education

To ensure staff education is consistent and standardised, a document itemising the suggested content for induction programmes has been developed. The topics contained document include; explanation of Perinatal Bereavement, relevant legislation, communication skills, post mortem examination and management of fetal remains, family care, supports available for parents and staff, reporting requirements and contacts for staff and parent supports. This was distributed to all the Maternity Units by the HSE's NWIHP.

What we have heard

> Midwifes were very caring and neonatal specialist clearly explained my baby would not survive and took the time to investigate if they could intervene or not when he was born. He clearly explained all information to me.

> I wish I could have bathed and dressed my baby and I feel I was encouraged to use the cool cot and I did'nt hold my baby enough.

> Sonographer and consultant handled telling us the bad news very well, very empathetic and caring.

> The doctor who gave me the news about my baby could have been clearer about what was going to happen and what my delivery options were.

What we have learned

The National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death[3] state that staff support services relating to bereavement care should reflect the need for peer support and professional support systems, including self-care, peer support, debriefing, feedback and formal/informal support. The recent implementation report[10] noted the need for provision of regular staff perinatal bereavement education programmes and the introduction of Schwartz Rounds and/or other staff support programmes.

Staff induction is a process by which employees are received and welcomed to the organisation. It is a method of formally introducing the employee to their work location and colleagues. A clear understanding of their job, role and responsibilities and the mission and values of the wider organisation will be provided. An effective Induction process will ensure that the employee is supported in achieving expected performance levels. It will also ensure that the new employee is aware of the importance of team-working within the HSE and their role within the team.

Robust, targeted and standardised induction programme should be in place with attention given to specific areas and topics that are appropriate to the individual hospital/unit/service, for example consideration of legislation relevant to the area and speciality. As per the National Standards ideally all new clinical staff should have, as a minimum, a two hour session on perinatal bereavement care as part of their induction programme. This should be delivered by members of the hospital/unit perinatal bereavement team. In the absence of a formal induction day consideration must be given to facilitating new staff to attend an annual perinatal bereavement education study day, run locally and facilitated by members of the hospital/unit perinatal bereavement team.

What we have done

Staff induction programmes

During the course of the Standards development programme it was found that perinatal bereavement care is not included in every Maternity Unit's staff induction programme. It is a recommendation that this important subject be covered in regular staff induction programmes. To assist with this a document itemising the suggested content for induction programmes has been developed through 2021. The topics contained within in this document include; explanation of Perinatal Bereavement, relevant legislation, communication skills, post mortem examination and management of fetal remains, family care, supports available for parents and staff, reporting requirements and contacts for staff and parent supports.

Dealing with Loss in Maternity Settings Workshop, Irish Hospice Foundation

The Irish Hospice Foundation (IHF) has developed a one day workshop called *Dealing with Loss in Maternity Settings based on the Bereavement Standards.*

This workshop enables suitable participants to deliver the workshop under licence in their own Maternity Units. All Bereavement Clinical Midwife/Nurse Specialist were trained as facilitators for this workshop to allow it to be provided in all Maternity Units.

The National Implementation Group recommended that the IHF provided course be run in all Maternity Units in the country - thereby providing an opportunity to "all" staff to attend bereavement education. Following on from a recommendation from the Standards National Implementation Group funding was provided by the NWIHP to train the Bereavement Clinical Midwife Specialist (CMS) Group as facilitators of the Irish Hospice Foundation provided programme 'Dealing with Loss in the Maternity Setting'. This training will support the CMS group to provide bereavement education to staff within their own Maternity Units. This training was redesigned for online delivery due to COVID-19 restrictions, and the first group of Bereavement and loss Clinical Midwife Specialists (CMS) trained in January 2021. Subsequent to this, training has been provided both in person and online.

The Dealing with Loss workshop aims to address Standard 4 by helping all staff in Maternity settings to:

- Understand the importance and relevance of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death 2016.
- Understand the grieving process and how loss and death can impact on women and families.
- Understand the importance of good communication in times of crisis.
- Develop their ability to support women and families who experience loss and death.
- Develop their awareness of the importance of self-care when working with people who experience loss and death.

TEARDROP Perinatal Bereavement Education

The multidisciplinary, interactive TEARDROP (Teaching, Excellent, parent, perinatal, Deaths-related, interactions, to, Professionals) workshop was developed, piloted and evaluated to address the educational needs of all health professionals involved in maternity and neonatal care in managing perinatal death and pregnancy loss and is based on the Irish National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death[3]. It was designed, developed and facilitated by members of the Pregnancy Loss Research Group in UCC and members of the National Oversight Group with the overall objective of improving care to bereaved parents. The aim was to provide the teaching in blended multidisciplinary groups and to establish a consistent, hospital/unit-wide compassionate culture by all staff caring for bereaved parents in the Maternity settings.

TEARDROP workshop

The pregnancy loss research group at UCC developed, piloted, evaluated the multidisciplinary, interactive TEARDROP (Teaching, Excellent, pArent, peRinatal, Deaths-related, inteRactions, to, Professionals) workshop to address the educational needs of all health professionals involved in maternity and neonatal care in managing perinatal death and pregnancy loss. The workshop is based on the Irish National Bereavement Standards for Pregnancy Loss and Perinatal Death[3] and members of the National Oversight Group for the Implementation of the Standards were involved in its development.

Two workshops were held at CUMH in 2022, and staff from the SSWHG, Limerick, and Saolta hospital group attended.

Perinatal Bereavement Education Standards

The National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death[3] set out the expectations for care that families can expect to receive in all settings in Ireland. The standards are set in the context of a holistic clinical experience. They acknowledge that women and families will have a range of interactions at the time of diagnosis, intervention, at the time of death and following the death with a broad range of clinical staff including support staff, nursing, medical and other professional staff. While there was no established competence framework for this specific area of practice (perinatal bereavement care) this group built on a general platform accepted in palliative and bereavement care that ascending levels of understanding and skill are required relative to the roles, responsibilities and frequency of interactions with bereaved mothers and their families, to develop the Perinatal Bereavement Care Education Standards. The 2014 HSE palliative care framework[11] sets out core domains relevant to All, Some and Few staff across six dimensions. The Perinatal Bereavement Care Education Standards were written utilising the “All, Some and Few” framework to state what is required by each group of staff providing perinatal care. The six dimensions referred to for each group include palliative care approach, communication, optimising comport and quality of life, loss, grief and bereavement, and an ethical approach. The Perinatal Bereavement Care Education Standards were published on the www.pregnancyandinfantloss.ie website in April 2019.

Pregnancy and Infant Loss Website

The national pregnancy loss and perinatal death website has continued to receive increasing traffic in 2022. A management group continues to meet every 6 months to oversee the content of the website. The content of the website is updated bi-annually to reflect changes in clinical practice and to include relevant research in the area of pregnancy loss and perinatal death.

Bereavement Clinical Midwife/Nurse Specialists

With the implementation of a CMS/CNS post in all maternity units, a bereavement and loss CMS/CNS network was formed. This network met a number of times in 2022, with the programme manager for Bereavement Standards continuing to liaise with, advice and support this network in 2022.

Support & Advisory role

The Clinical Lead and Programme Manager continued to act in a supportive and advisory role to a number of maternity hospitals/units and individuals in the development and /or expansion of their bereavement services. They also supported the NWIHP team in responses to queries around implementation of the Standards or relating to bereavement care across the 19 maternity hospitals/units.

Quality Service & Improvement

Following on from the audit carried out in all maternity hospitals/units in 2020, a condensed audit tool was developed and sent to all 19 maternity hospitals/units in December 2021. Each hospital/unit bereavement team was asked to complete the audit tool. The results of the 2021 audit were presented to the NWIHP management team in April 2022, with accompanying recommendations.

Standards

The Standards document was edited and prepared for publication through 2021 and 2022. The revised version of the Standards was published in 2022.

The NWIHP would like to acknowledge: the members of the Bereavement Standards Review Group who gave of their time to review and update the Standards and the parents, voluntary organisations and health professionals, including members of the original authorship group, who advised and informed the Bereavement Standards Review Group during their work.

National Clinical Guidelines

Clinical practice guidelines synthesise the best available evidence to assist healthcare practitioners, service users, policymakers and other stakeholders to make informed decisions, with the aim of improving care quality and patient outcomes. Clinical guidelines can assist in the standardisation of care. Research on all areas of pregnancy loss has shown variation in access, provision and care quality.

A new clinical guideline programme was established by the HSE's National Women and Infants Health Programme in mid-2021. The older programme guidelines, including the Stillbirth guideline, required updating, and new guidelines were required for topics not previously addressed, including recurrent miscarriage. Prof O'Donoghue and Ms Cotter were involved in the development of both these guidelines, and the Oversight Group were asked to review the draft guidelines before approval by the National Expert Advisory Group of the Guideline Programme.

Staff Support Document

Standard 4 comes with many challenges as it seeks to ensure that staff support processes are put in place for all staff working within the Irish Maternity healthcare services. Most specifically, these recommendations support the necessity to address the needs of a diverse staff mix, with multiple backgrounds, experience, education and training who provide care to women and partners and their families within a complex healthcare system. With the assistance of the HSE Staff Workplace Health and Wellbeing Unit a staff support document was written and published in 2019. This document sets out key recommendations for the provision of staff support within the 19 maternity hospitals/units. The Staff support document is to be used in conjunction with HSE HR policies and procedures on staff support. See link to the staff support resources on the www.pregnancyandinfantloss.ie website https://pregnancyandinfantloss.ie/staff-support.

Schwartz Rounds

Occupational stress and emotional exhaustion in healthcare workers impact on their physical and psychological wellbeing and the quality of patient care and services provided.

The National Maternity Strategy[1] states that current changes in demands on Maternity services have a significant impact on staffing requirements and the need to prioritise wellbeing of Maternity Unit staff. There is a recognised need for interventions to raise emotional wellbeing, morale, teamwork and other non-clinical skills.

The introduction of Schwartz Rounds was one of several interventions explored in 2016 by the HSE Quality Improvement Division to support a positive culture of staff engagement across healthcare settings in Ireland.

According to a HSE review of various approaches to leading, fostering and engendering worthwhile staff engagement, Schwartz Rounds are a potentially powerful forum for organisational and cultural improvement and staff engagement. Schwartz Rounds are an intervention intended to develop compassionate and supportive cultures for staff working in health care settings and promote improvement in health care outcomes for patients and service users[15]. Schwartz Rounds are a multidisciplinary forum designed for all staff to come together, once a month, to discuss and reflect on the nonclinical aspects of caring for patients and families through sharing of emotional and social challenges associated with their work. Schwartz Rounds are comprised of highly structured one-hour, case/theme-based, interactive discussions. A trained Clinical lead and facilitator facilitate a discussion, which typically begins with an introduction from the Clinical lead, followed by each panellist verbally sharing their experiences under a previously agreed theme or case. The panel includes members drawn from clinical and non-clinical staff and discussions introduce multiple perspectives on selected themes. Schwartz Round participants and panellists join a facilitated group discussion, which follows a prescribed format and does not seek solutions, but instead encourages sharing of experiences, personal resonances and acknowledging feelings.

The National Bereavement Oversight Group reviewed Schwartz Rounds as a method of improving staff engagement, improving staff wellbeing and as a quality improvement tool. Following this review of Schwartz Rounds as a programme that could be implemented in all Irish Maternity Units, it was recommended that all Maternity Units senior management teams give serious consideration to implementing the rounds. A number of maternity units have introduced Schwartz Rounds and they have had a positive response from the staff who have attended. The NWIHP will continued to support maternity units to implement the rounds.

What we will do

The NWIHP will support maternity hospitals/units to ensure all staff who are involved in the care of families experiencing pregnancy loss and perinatal death receive the necessary multidisciplinary training and education, relevant to their scope of practice, in line with the Perinatal Bereavement Education Standards. Maternity Units will include perinatal bereavement education in their annual education programmes and staff induction days.

Dealing with Loss in Maternity Settings Workshop, Irish Hospice Foundation

The Clinical Midwife/Nurse specialist will continue to roll out the Dealing with Loss in Maternity Setting training thereby providing an opportunity to “all” staff to attend bereavement education.

The Dealing with Loss workshop aims to address Standard 4 by helping all staff in Maternity settings to:

- Understand the importance and relevance of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death[3] 2016
- Understand the grieving process and how loss and death can impact on women and families
- Understand the importance of good communication in times of crisis
- Develop their ability to support women and families who experience loss and death
- Develop their awareness of the importance of self-care when working with people who experience loss and death.

TEARDROP Perinatal Bereavement Education The multidisciplinary, interactive TEARDROP

In 2023, the TEARDROP Perinatal Bereavement Education workshop was rolled out the Saolta hospital group in a train the trainer format, with the first workshop supported in April. It is hoped to partner with another hospital group later in 2023 to roll the workshop out further.

Staff Education Review

The NWIHP will work with UCC Pregnancy Loss Research Group to build on the 2020 Audit of the Standards in the 19 maternity hospitals/units. A survey will be administered in Quarter 2 of 2023 to all 19 maternity hospitals/units seeking further information regarding education and training opportunities and support. This will enable us to examine what is current provided, and additionally any opportunities for sustaining and scaling up programmes and support nationally. This report will be completed by quarter three 2023.

The NWIHP and the Pregnancy Loss Research Group, informed by the scoping review, plan to develop education materials (e.g. short videos and animations, infographics, leaflets) identified within the review, in collaboration with knowledge users (e.g. hospital/unit staff, bereaved parents and other stakeholders).

Curriculum Review and Identification of Perinatal Bereavement Education

A review of what is available to date for perinatal bereavement education to medical and midwifery students in the Republic of Ireland was undertaken during Standards implementation from 2017-19. Six universities provide education to medical or midwifery students. This review identified that not all educational programmes were in line with the Bereavement Standards[5] and Perinatal Bereavement Care Education Standards[12].

Work done to date on this review: The NMBI Midwife Registration Programme Standards and Requirements have been reviewed for content relating to pregnancy loss/bereavement care; no such document exists for medical programmes. Details of eligible courses within Irish Higher Education Institution (HEI), and module details, have been gathered – this review is almost complete. Course leaders/directors will be contacted in April /May to confirm details gathered and a report provided to NWIHP and the new Bereavement Advisory group later in the year.

Staff Support and Wellbeing

The Pregnancy Loss Research Group, University College Cork plan to work on a project – to develop and pilot a psychosocial intervention for staff after critical incidents in maternity hospitals/units in Ireland. This will include identifying what psychosocial interventions for staff in maternity hospitals/units exist, and what the evidence is for their effectiveness and acceptability as well as investigating barriers and facilitators to implementing psychosocial interventions aimed at maternity care staff in the literature and an Irish context. Application has being made to the Irish Research Council Government of Ireland Postdoctoral Fellowship Programme for funding.

Section 2

Projects recently completed

PROJECTS RECENTLY COMPLETED

Dublin Midlands Hospital Group

Innovations & changes made in The Coombe during the survey period

The Solas Room

A dedicated Quiet Room has been refurbished and decorated in a sensitive manner. It is used by staff for breaking bad news, in the Early Pregnancy Assessment Unit of the Outpatient Department.

It allows women and partner to deal with unexpected bad news in a private room, and gives them the privacy needed in such a moment.

The Family Room

The Mortuary Area was extended to include an upgrade of the Spiritual Service room for all the family to be attend. It includes a dedicated room “Home from home” for the family, as well as a sitting room area where the extended family can visit, as well as the small kitchen area.

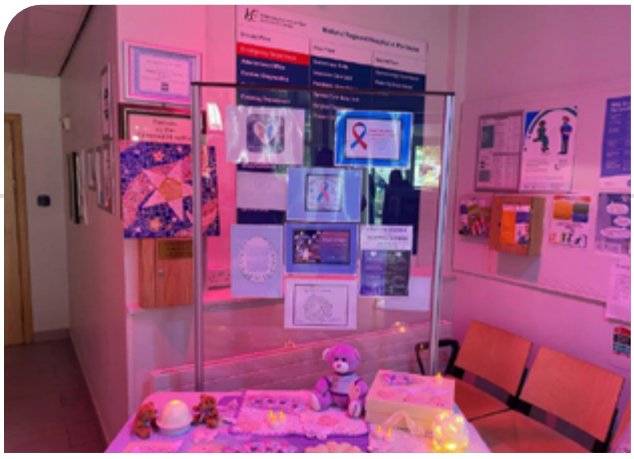
This allows the bereaved families to grieve in a private and sensitive manner.

During the survey period, the number of cool cots available to the women experiencing a pregnancy loss has also been increased allowing for more women to spend time with their baby after birth.

A Clinical Nurse Specialist (CNS) in Lactation has joined the Neonatal Intensive Care Unit (NICU) and is providing additional support to the women and families going through a neonatal death.

Information Pack - Féileacáin

Support for you when your baby dies
How you might feel, Grief and Grieving, Creating memories,
Taking photographs of your baby - A guide to helping you,
Deciding about a funeral for your baby, Deciding about a post mortem,
Rights and financial benefits, Registration,
Leaving hospital-going home, Follow-up appointments
The weeks & months ahead, Remembering… Memory Box,
Other mementoes,
Post Natal Support Leaflet - Following the Loss of a Baby.



Midland Regional Hospital Portlaoise

Annual Service of Remembrance

Our annual Service of Remembrance is held in Portlaoise in October. Bereaved parents, their families and friends are warmly welcomed to attend the service in remembrance of all babies who have died in pregnancy and shortly after birth, however recent, however long ago. As part of the service, mementoes including the service booklets, memorial candles and handmade heart keepsakes are offered. Throughout the service, parents and families are invited to place their baby's name on trees, to honour each life.

In 2021, the Clinical Nurse Specialist Bereavement and Loss was awarded funding from the Irish Hospice Foundation Quality Improvement awards to develop a bespoke information resource for bereaved women who will have an induction following the diagnosis of an intrauterine death. Information is also in included on labour and delivery options and care. This document is currently being processed to publishing.







PROJECTS RECENTLY COMPLETED

Ireland East Hospital Group

New Bereavement Suite in The National Maternity Hospital, Labour and Birthing Unit

The death of a baby during pregnancy or shortly after birth is a devastating experience for parents and their wider families. An appropriate environment is vital in order to provide high quality bereavement care that meets the standards set out by the HSE *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death*. The team in the National Maternity Hospital were aware of the need to develop a bereavement suite on the labour and birthing unit which would provide a private, peaceful and respectful room for bereaved parents to give birth to their baby, make precious memories and facilitate family members to visit them also.

The bereavement room was planned with the aim to provide a space where bereaved families can be cared for from admission through to discharge. This project aimed to provide continuity of care to parents and allow them uninterrupted time to spend with their baby.

The room also needed to function as a delivery room with all the required medical equipment while also providing a comfortable space suitable for bereaved families. The team consulted with bereaved parents to gain insights into the needs of parents who will use this space. Advice was also sought from a charity who has experience in renovating spaces for bereaved parents and combined their feedback into the design. This project was kindly supported by a bereaved family who raised funds for this project and donated to the NMH Foundation. The family's input was sought throughout the process and their baby's name was incorporated into the design.

Feedback from parents has been extremely positive and parents value having a private space to spend time with their baby. It has also been well received by staff caring for bereaved parents who appreciate being able to provide high quality compassionate care in a dedicated space. The woman and her partner are cared for by a midwife providing one-to-one care throughout their admission through to discharge. This provides much needed emotional support and continuity, while the corridor outside the room was also transformed into a space for family members to visit and has been decorated in a similar theme to the room.

The bereavement suite was completed in 2022 and we are aware that the majority of parents who completed the survey attended the hospital before this room was available.

PROJECTS RECENTLY COMPLETED

RCSI Hospital Group

The Rotunda Hospital

Beads of Courage

This initiative helps families to record, tell and own their stories of courage. When a premature baby is enrolled in the programme parents are given a bead bag, a piece of string and beads that spell out their baby's name along with a bead journal to document their baby's journey in the Neonatal Unit. The journal incorporates procedures, treatments and milestones that babies endure when born prematurely. Colourful beads are then given to parents, celebrating their baby's progress, no matter how small, each representing the different procedures, treatments and milestones.

The initiative has been found to be very helpful for parents in improving their awareness of procedures and understanding overall the care their baby received. Bereaved parents treasure this keepsake as it helps them to remember their baby's unique journey in the Neonatal Unit. This initiative is provided free of charge through the support of the Rotunda Foundation.

The Rotunda Hospital

Ceramic Hand and Foot Prints

With the agreement of bereaved parents, if it is possible, we take impressions of your baby's hand and/or foot. The imprint is an original impression of a hand or foot taken into very soft clay. About 12 weeks later, the bereaved parents will receive a very special gift of ceramic framed prints.

The initiative was introduced following fundraising for the Rotunda Foundation by Shane and Eleanor, parents of Aidan and Donnacha Ó Foghlú who were born alive at 23 weeks but sadly died. The initiative, named Aidan & Donnacha's Wings, provides bereaved parents with a beautiful individualised keepsake and it continues thanks to the ongoing donations received by the Rotunda Foundation.

Our Lady of Lourdes Hospital

Quality Initiatives in Bereavement Services

Maternity Unit

In the last 2 years, the staff in Our Lady of Lourdes Maternity Unit have initiated and completed a number of service improvements for those women and their families experiencing a pregnancy loss.

The Dove Room

A room dedicated to women who experience second trimester loss or women admitted for induction of labour following a diagnosis of intrauterine death was introduced, called The Dove Room. Situated on the Antenatal ward, this room complements The Dragon Fly Room, which is a quiet room suitable for parents to receive unexpected bad news, and The Butterfly Room, a self-contained home from home room for bereaved parents to spend time together with their baby. In the last two years, The Dove Room, was decorated to provide a less clinical, more welcoming and patient centred environment for those experiencing a pregnancy loss. Using warm colours for soft furnishing, en-suite facilities, and cleverly placed furniture to hide clinical equipment, this ward based room offers a respectful environment for families. Generously donated artwork from bereaved parents has been utilised within the room.

Comfort Packs Initiative

The Bereavement Support Midwife, working alongside the End of Life Coordinator has secured funding from the Irish Hospice Foundation through the Hospice Friendly Hospitals to commence a second initiative within the unit. This initiative is named *Comfort Packs*. The purpose of this project is to ensure women who are admitted unexpectedly, have access to toiletries and clothing, improving their comfort at this difficult time.

Ibraheem's Gift Packs

The maternity unit has been fortunate to receive *Ibraheem's Gift Packs*, from 4Louis, a Stillbirth Charity based in the UK. The packs contain items to help parents of the Muslim faith to prepare for the burial of their baby in a culturally appropriate way.

Memory Boxes

For patients experiencing a first trimester loss, The Simba charity, another UK charity have provided the hospital with a smaller memory box, to remember their loss. Similar to the Memory boxes, these are gifted to all our women, allowing an opportunity to acknowledge a life so short yet precious to them.

New Non-Denominational Burial Facilities

An additional quality initiative, recognises the changing demographics of the population of the North East.
A new burial facility, situated in a new multi-denominational cemetery, within a few kilometres from the hospital grounds has been completed. A headstone was carefully designed to reflect the final resting place for infants of different faiths. A database chronicling the name and burial position of all those interned in the plot was created, ensuring a record is kept for families who may wish to pay their respects. There is no charge for families who wish to avail of the angels plot. We have also developed an information leaflet for parents in relation to this new plot.

Annual Service of Remembrance

During COVID-19 restrictions, we continued to offer a Service of Remembrance for families who had experienced a pregnancy, infant or childhood bereavement, albeit virtually. However, in 2022, a face to face non-denominational ceremony, including teas and light refreshments for family and friends, was facilitated. Both families and staff were invited to participate in the service with volunteer readers and gift bearers. Light refreshments were provided by the catering staff of the hospital to allow families meet with staff after the service.

Staff Professional Development

The final initiative is continuous staff professional development. The Bereavement Support Midwife is currently undertaking an MSc in Bereavement and Loss. Her research topic relates to the facilitation of memory making. The research will pinpoint areas where staff feel they need more practical and emotional support. The aim of the research project is to develop a tool to enable staff to support women and their partners/families to create memories. The Bereavement Support Midwife has also completed the facilitators training for both *Dealing with loss in the Maternity setting* and *Final Journeys*. Training Programmes. This has led to the development of a staff training day to increase staff knowledge and skills in the care of women and their partners during pregnancy loss at all stages. The Bereavement Midwife's continuous professional development also included the completion of a *Gifts of Remembrance* study day, which has allowed her to enhance her skills in providing photographs, and hand and footprints moulding for parents, to remember their precious loss.

'The Quiet Room' 'An Cúinne Ciúin'

Cavan General Hospital

Women and Children's Services

1. The Quiet Path

'The Quiet Path' is a package of physical spaces and theoretical guidelines which ensure continuous, holistic and multidisciplinary care for families experiencing perinatal bereavement within the maternity department.

Evidence based care is delivered through our pathways which are drawn from national and international policies and from experiential feedback from families who have been through the system.

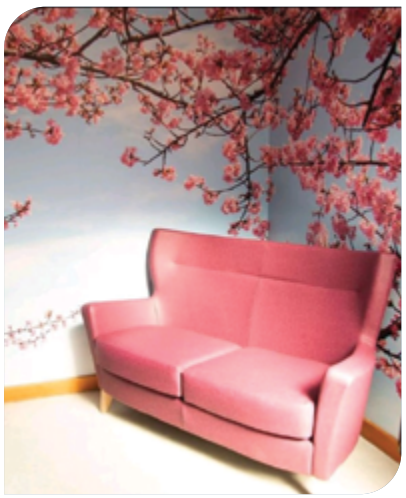
Care is also sympathetic to the perspectives and theories of grief aiming to normalise the grieving experience through continued bonds and memory making activities, the encouragement of coping mechanisms through narration and storytelling and a 'family-centred approach' through the understanding of family dynamics in grief.

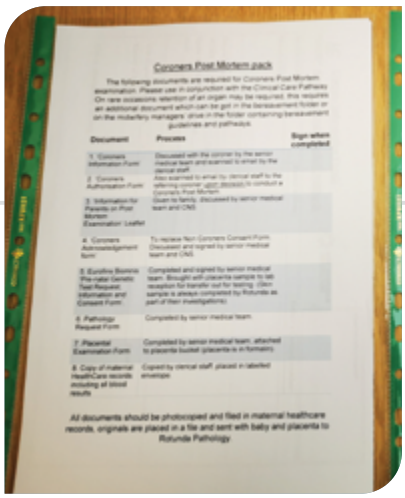
From *the Quiet Room, An Cúinne Ciúin* where consultation, forward planning and early initiation of treatments occur, to *the Quiet Blossom Room*, *An Seomra Bláth Ciúin*, the in-patient room located on the maternity floor where parents will stay for the duration of their care and finally to *the Quiet Path, An tSlí Chiúin* which is the discharge route which re-directs families to a quiet and gentle re-emergence from the hospital environment to discharge. These physical spaces of grief provide the privacy, safety and quiet for the journey which includes the learning of loss, the planning and processing of the care, labour and delivery of their baby, the holding space for the bonding, the honouring, the memorialising of baby and the planning and preparing for home.

The final step of the quiet path is *the Quiet Rest*, *An Codladh Ciúin* which is a new hospital burial plot in Cullies graveyard in Cavan Town. Families who have experienced perinatal loss have the options of private burial, hospital burial or cremation of their remains. This new burial plot replaces the old space in Annagh graveyard which is now at capacity. The Quiet Rest is currently at design stages.

'The Quiet Blossom Room'
'An Seomra Bláth Ciúin'

'The Quiet Path' 'An tSlí Chiúin'

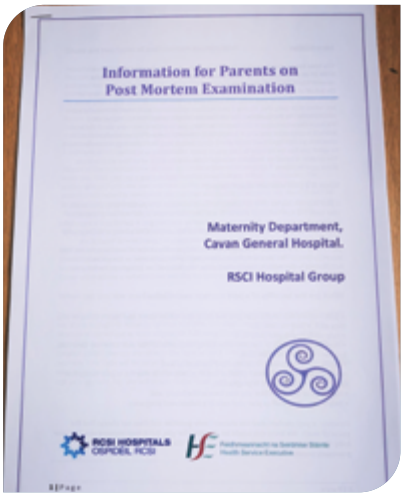




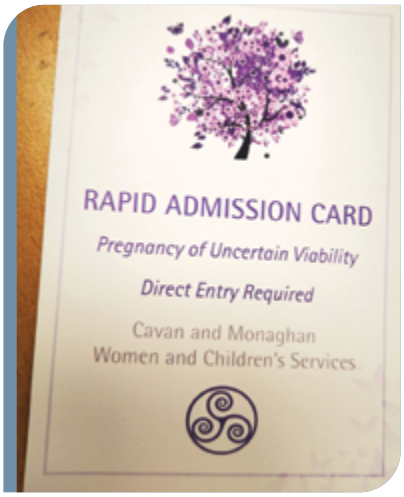
2. Coroners and Non-Coroners Post Mortem Pack

In addition and to complement our Clinical Care pathways we devised a suite of supportive materials to use in cases of coroners and non- coroners directed post mortem investigations.

- A revised and updated Standard Operating Procedure, reflective of the Coroners (Amendment) Act 2019, guides and directs the medical, midwifery and management team on the steps required to plan, organise and undertake this investigate the complex tasks of coroners and non-coroners post mortems.
- A pack with the specific documentation required for each type of post mortem and completion record. These packs are kept in duplicate the hard copies are in the 'Bereavement Folder' easily accessible to staff and the electronic copies are kept on the hard drive of each computer along with all policies, guidelines and documents.



Information for Parents on Post Mortem Examination booklet.



Quiet Awareness Week- Education, communication and information sharing sessions. Launch of Rapid admission card for pregnancies of uncertain diagnosis.

Coroners and Non-Coroners Post Mortem Packs

- Information for Parents on Post Mortem Examination booklet first written in 2019 is updated regularly and gives precise details for parents regarding all aspects of post mortem examination, from coroners input, information about pathology services, details around consent form, the transfer to and return back from Rotunda pathology and timeline for follow-up. This book is discussed with the Clinical Nurse Specialist Bereavement and Loss and consent is only collected when the family feel fully informed.
- 'Quiet Awareness: Perinatal Bereavement reflections on our practice' was a week long series of classroom training sessions, ward discussions and information sharing around perinatal bereavement. It ran from 9th-13th May 2022 and included a presentation at the multidisciplinary audit meeting about post mortem examination and which was attended by our local regional coroner. The training covered the post mortem processes described in the standard operating procedure, documentation guidance in the post mortem packs and how to communicate this delicate topic with families in the information booklet. A raffle was held with money gathered going to Féileacáin and The new 'rapid admissions card for pregnancies of uncertain viability' was launched as well as Casey's candles.

3. Casey's Candles

- Hand crafted candles made by a volunteer in the community using recycled and donated jewellery. These candles were initially made as part of a fundraising activity for Féileacáin in gratitude for all their input and support in perinatal loss. The initial fundraiser made €1,000 and candles were sold to those attending our Annual Remembrance Service in October 2019. Casey's Candles are designed with our 'Children's Remembrance Tree' in mind and our cherry blossom tree from 'the Quiet Path'. Candles are gifted to families who experience loss as a unique addition to the memory boxes in CGH.

The Children's Remembrance Tree

Casey's Candles

PROJECTS RECENTLY COMPLETED

Saolta Hospital Group

Developing Patient information booklets to support bereaved women and their partners

Within the Saolta Hospital Group we identified that women and their partners who have experienced loss in pregnancy needed to have high quality written information available to them. To date we have developed a booklet on *Information for Parents following the death of your Baby* and *A guide to perinatal post mortem examination for Parents*.

These patient information booklets were developed in collaboration with all five Maternity Units in the Saolta Hospital Group: Galway University Hospital, Portiuncula University Hospital, Mayo University Hospital, Sligo University Hospital and Letterkenny University Hospital. A wide range of stakeholders contributed to the development these include Midwives, Obstetricians, Neonatologists, the Bereavement Liaison Officer, Medical Social Worker and Service Users.

Information for Parents following the death of your Baby

The purpose of the booklet is to support women and their families whose baby has died. This booklet acknowledges the loss to families and gives written information about the care parents will receive. Details regarding the various staff parents will meet during their hospital stay, local contact details for the Bereavement team & voluntary organisations and practical information that will be beneficial in the difficult times ahead is also included in this booklet.

The booklet format and content has been informed by the feedback shared by women on their recent experience of our services which includes:

- information on physical symptoms e.g Breast care;
- birth registration;
- information on grief and loss;
- advice on how to support family members including siblings; *and*
- hospital specific Bereavement team contact card.

A guide to perinatal post mortem examination for Parents

The purpose of this booklet to provide women and their partners with clear information in relation to post mortem and its potential value in pregnancy loss. This booklet was also developed with input from the multidisciplinary team and a service users. This written information is designed to support the verbal discussion around the process of Post Mortem and includes:

- The role of the coroner and the coroners act;
- The post mortem process;
- Temporary organ retention; *and*
- The post mortem results.

This booklet is referenced in our new post mortem consent forms introduced in 2021 and provides staff and parents with clear information to assist in decision making.

Saolta Hospital Group Maternity staff who contributed to developing patient information booklets for women and their partners who have experienced pregnancy loss.

Mayo University Hospital

Rose Room for Perinatal Bereavement

Mayo University Hospital (MUH) has officially opened a designated room in the Maternity Unit for bereaved families. The Rose Room is named in memory of a much loved baby who sadly died at 9 days of age in 2017. Her parents and family who are from County Mayo have done significant fundraising which has allowed for the renovation of this space which will support the hospital in providing comfort and solace to families dealing with loss. This family have generously turned their personal experience of bereavement into an opportunity to help other grieving families by fundraising and supporting the hospital in providing a dedicated quiet space for bereaved families.

On Friday, 23 September the Rose Room was formally opened - the renovated room has been in use since 2019 but the official opening was delayed due to the COVID-19 pandemic.

Andrea McGrail, MUH Director of Midwifery said;

> “On behalf of Mayo University Hospital I want to thank you for your commitment to this project; for their fundraising and for engaging with the hospital so passionately to make the Rose Room such a beautiful place. It is a calm and quiet room, with a wonderful painted mural which depicts children releasing lanterns on a beach, evoking light and hope and the forever bond of siblings.

Unfortunately in the Maternity Unit, some families will experience pregnancy or infant loss and it is so important to have a quiet and comforting place in which families can prepare for the difficult journey they are on.

We also want to say a huge thank you to the community of Mayo and further afield, who have contributed to the various fundraising initiatives to renovate the Rose Room.

We wish to also acknowledge the incredible commitment our staff have shown to this project.

PROJECTS RECENTLY COMPLETED

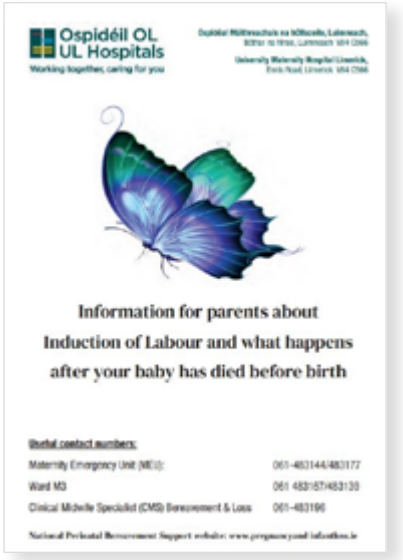
UL Hospital Group

Quality Improvements Progressed by Bereavement & Loss Department University Maternity Hospital Limerick

Development of induction of labour information booklet for parents whose baby dies before birth

Being told that your baby has died before birth is one of the most difficult experiences for parents. We are so sorry that this has happened to you. Midwifery & Obstetric team at University Maternity Hospital Limerick aim to provide compassionate care and support for you as parents. We will respect your individual wishes and support you on your journey to meeting your baby and creating memories of their short lives. We want to support you in making what is a very difficult experience into one filled with love and positive memories of your baby if possible. After receiving the diagnosis that your baby has died before birth is one of the most difficult experiences for parents.

To assist parents during this time the Clinical Midwifery Specialist Bereavement & Loss have developed a 10-page booklet outlining the pathway from diagnosis of pregnancy loss in providing an empathetic, sensitive and caring environment for family. This booklet aims to provide some information to support the discussions you have had with the doctor you met at the hospital. The information in this booklet is provided in a step-by-step approach and tries to address what questions you may have about what happens during this difficult time.



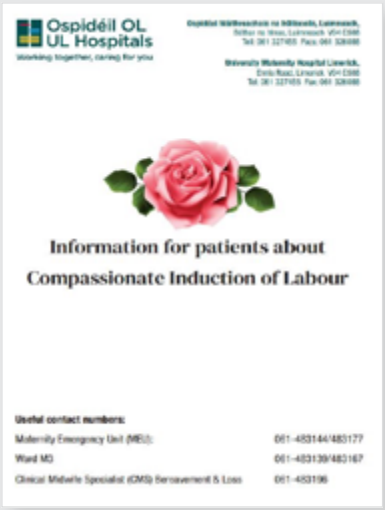
Baby diagnosed in utero with Life-Limiting Condition

Specific Q.I.P.

1. Pathway of Care for Women who experience Compassionate Induction of Labour
2. Information Booklet for Patients about Compassionate Induction of Labour

Finding out at any stage of pregnancy that an unborn baby has a fatal fetal abnormality or life limiting condition is a devastating shock. 'Fatal' is a word used to describe a condition that will result in a baby not being able to survive beyond the new-born period. 'Life Limiting' is a term used to describe any condition where there is no reasonable expectation of cure and will shorten the normal life expectancy of a person.

After the baby's diagnosis has been confirmed, it may be difficult for the woman and her partner to understand or accept what has happened or to remember what health care professionals are saying. The information booklet is not intended to replace the information and support that the staff will offer but will help to remember and prompt questions. For further information there are contact details at the front of the booklet.


Ospidéil OL
UL Hospitals

Information for patients about
Compassionate Induction of Labour

Useful contact numbers:

Excerpt from Information Booklet

Emotional effects; We acknowledge there can be complex emotions and grieving throughout the decision-making process, during, and after ending the pregnancy. Providing an empathetic, sensitive and caring environment to support you and your family is an integral part of our maternity service. You will be supported by your midwife, your medical team and by the CMS Bereavement. Some people may require further input from counselling services and the CMS Bereavement can advise you on these services.

What will improve

- Care of women and their partners following diagnosis of Fetal Life Limiting Condition who choose to undergo Compassionate Induction of Labour.
- Care form the time of diagnosis to follow up with Consultant postnatal and continuing emotional support from CMS Bereavement.
- Education of all staff meeting the woman and their partner at any stage in their journey of care.

Section 3

Listening, Responding and Improving

This section will provide an overview of local quality improvement initiatives which have and will be undertaken in response to both the National Bereavement Standards and the findings from the NMBES.

Dublin Midlands Hospital Group

Coombe Women and Infants University Hospital
Midland Regional Hospital Portlaoise

On behalf of the Dublin Midlands Hospital Group (DMHG) I welcome the results of the National Maternity Bereavement Experience Survey 2022. The DMHG hospitals in this survey include Midland Regional Hospital Portlaoise and the Coombe Hospital. These Hospitals provide maternity services across the geographical area delivering 8281 births in 2022.

We welcome the first ever National Maternity Bereavement Experience Survey and believe that it will be a vitally important tool to support women and their families to tell us about their experiences of bereavement in our maternity services.

I am delighted to note the positive feedback, in particular relating to the Bereavement Services and the high standard of care provided. The survey also identified areas for improvement. Our hospitals have been progressing a range of quality improvement initiatives in response to the survey findings to include; improved communication and bereavement education workshops, increased lactation support following bereavement, clear communication and information, updating of local policies and procedures to support staff and infrastructural improvements in facilities to ensure privacy and dignity.

The Dublin Midlands Hospital Group endeavours to support the hospitals with the development and implementation of the Quality Improvement Plans (QIPs) to address these key areas. I would like to acknowledge the care and compassion shown by staff across our Hospitals and their commitment to the provision of high-quality maternity care. I would also like to thank staff who engaged wholeheartedly with the survey by encouraging women and their families to participate and then by working diligently on quality improvement initiatives to improve services.

Finally, I wish to sincerely thank the women who use our services and their families who willingly gave of their time to provide insight into their experiences in relation to their maternity bereavement care.

Yours sincerely,

Trevor O'Callaghan
Chief Executive Officer, Dublin Midlands Hospital Group

OVERALL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Communication.	• Staff Training in relation to bereavement care.	• Train the Trainer - Irish Hospice Foundation facilitate the Course for Medical, Midwifery, Nursing and Health Care Assistant's. • Next steps: Videos on demonstration of memory making to be placed on the Intranet for easy access for all staff. • Encourage all staff to complete the HSE National Healthcare Communication Programme on HSeLanD.	• Staff will be better trained and informed, to support the families going through a bereavement. • The training applies to all staff. While the Bereavement team provides specific support, all healthcare professionals are aware of the importance of a supportive and caring communication.	2023
		• Participation in Bereavement & Loss Study Days, jointly with the National Maternity Hospital, Rotunda Hospital and the Coombe Women and Infant University Hospital.		1 day every 3 months throughout 2023
		• Training Programme *Dealing with Loss in Maternity Setting* commenced in 2022 with 25 staff facilitated through online and classroom learning, to continue with scheduled new session in October 2023.		Q3 2023
		• Student Midwives on Specialist Placement with the Clinical Midwife Specialist to be introduced to the video *Breaking bad news and neonatal death.*		2023

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
ER room and EPAU clinic situated in the middle of our out- patients department, which is very distressing for the women with early pregnancy loss.	• Restructure current facility while awaiting for new dedicated facilities.	• The restructuring the ER and assessment room on the ground floor, creating 5 single rooms, away from the out-patients department.	• The single rooms will ensure privacy for the women and streamline unscheduled care with Multi-Disciplinary Team (Obstetrician, Non-Consultant Hospital Doctors (NCHD), Midwives and candidate Advanced Midwife Practitioners (cAMP)).	Ongoing 2023
		• Building of a new dedicated Unscheduled Care Unit at the entrance to the Hospital. • Early Pregnancy Assessment Unit (EPAU) to move to new extension of the Womens Health Unit. • Plan for a new dedicated Bereavement Ward on the 3rd floor.	• Dedicated facilities with separate entrance will limit the encounters of bereaved mothers with other pregnant women.	Awaiting funding (on Coombe Strategy for 2022-2026).

POSTNATAL CARE				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Breast Feeding Support.	• Education for the Midwives & Nurses to increase the support for the women following bereavement.	• Continue individual support by Bereavement Specialist and Midwife. • Ensure access to Neonatal Intensive Care Unit CMS in Lactation & Midwifery CMS in Lactation support. • Neonatal Intensive Care Unit CMS in Lactation will engage with women who express the wish to express and donate their breast milk. • Ensure National Information Leaflet '*Breast Care Following the Loss of your Baby* is given to all bereaved women following a loss. • Reflection on a potential education programme for bereaved women including breastcare.	• Support and guidance for the women to be provided by staff specialised in lactation and sensitive to bereavement.	2023

OVERALL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Building and Maintaining Relationships, utilising Person-Centred care approaches.	• Cultivating a Culture of Compassionate Perinatal Bereavement Care amongst maternity staff. • MRHP Maternity Services are committed to fostering connections and maintaining learning opportunities with bereaved women, couples and parents.	• All staff are supported to attend HSE National Healthcare Communication Programmes. • Increasing the number of facilitators in the maternity unit of the National Healthcare Communication Programme, this will result in three trained facilitators. • Increase the number of bereavement education workshops to twice yearly for maternity staff. • Clinical Midwife Specialist Bereavement and Loss provides perinatal bereavement education at new staff inductions for midwives and NCHD's. • MDT Maternity unit bereavement committee oversees bereavement and End-of-Life care, inclusive of PPPG development. • Seeking for bereaved parents to join our committee and annual service of remembrance. Local volunteers and support members from the national support groups will also be invited to join our committee, annual service and educational workshops for the multi-disciplinary team. • Education and training for all members of staff regarding compassionate communication with bereaved parents and the chosen name(s) for their baby (documentation, healthcare records, using specific cot cards and using a baby's name on their identification bands). Specific care will be given to the spelling and pronunciation of each precious name.	• All staff will be confident and competent in delivering timely, evidence based care in an empathetic, compassionate and kind way, in line with national standards. • The staff within the maternity unit endeavour to increase the number of training opportunities and education sessions for staff to build and maintain therapeutic relationships in their provision of care. • To increase bespoke opportunities for maternity staff to embed person centred care for the baby, parents and families. • The maternity unit remains committed to the ethos of care, committed to delivering and maintaining bereavement standards of care, ensuring staff are well informed of their roles in the culture of compassionate care.	Q4 2023

POSTNATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Sensitive written information and imagery.	• Leaflet for women receiving anti-D.	• Development of an information leaflet for bereaved women who will receive Anti-D. • An audit of the national information leaflet used, revealed that the information was included on a leaflet with a background image of an in-utero fetus on an ultrasound image : new leaflet containing all the pertinent information and without the use of the fetal imagery.	• Bereaved women will receive information, with sensitive imagery.	Q1 2023

BEREAVEMENT CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Provision of Clear and Accurate Information, taking into account, parental preferences and choices in providing bereavement care.	• Maternity staff acknowledge the important role they have in collaborating with bereaved parents, to ensure effective, sensitive and timely communication processes.	• Education and training is developed, delivered and audited in line with national standards. Creating a culture of empathetic care is inclusive of effective and open communication with parents, families, MDT's, hospital and the community. • Education opportunities will be available to staff in breaking bad news at time of a diagnosis, and throughout bereavement care provision. • Specific training opportunities for staff to remain confident and competent in responding to the sensitive individual needs of bereaved parents for accurate and objective information and support.	• Maternity bereavement committee will develop initiatives to collaborate with bereaved parents in care and service delivery. • Continued commitment to infrastructure developments, thereby optimising appropriate spaces for breaking bad news with sensitivity, dignity and confidentiality. Maintain established links with Irish Hospice Foundation and Hospice Friendly Hospital projects. • Individualised and group training developed from local guidelines, will be appropriately responsive and designed to specific needs of staff. • Mentorship opportunities will be developed for new staff to work with senior midwives when providing bereavement care.	Q4 2023
Updating and Implementation of local IUFD PPPG, in line with national standards, practices and recommendations.	• Maternity staff recognise their individual responsibility, and are supported to engage in regular education and training. Implementation of guidelines fosters compassionate care cultures.	• Bereavement care is central to the maternity unit and hospital, embedded in the ethos of care. Processes will continue to be developed to organise care and parental needs. • Staff will confidently and competently promote MDT inclusion in preparing and developing a comprehensive suite of bereavement care guidelines. • National and Local Bereavement Care Guidelines cover all pregnancy loss that women and parents experience, from early pregnancy loss, perinatal death and the diagnosis of a fetal anomaly that may be life limiting and/or fatal.	• Carer choices and planning is accessible to women, parents and their families. Staff promote and advocate for such collaboration. • Core values of dignity, respect, compassion and kindness are embedded in the pillars of bereavement care and development in the maternity unit. • Maternity staff recognise that bereavement carer needs may ascend from basic to more complex needs. Staff are competent and confident in assessing parental needs, thereby providing individualised care and referral to supports as appropriate.	Q4 2023

POST-MORTEM EXAMINATION AND INVESTIGATIONS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Delay in provision of post mortem services.	• As there is no perinatal pathologist working in MRHP, babies who are required to undergo a post mortem, travel to the Coombe hospital.	• Comprehensive consideration has been explored and extrapolated into education and training workshops for staff in the maternity services in relation to post mortem care. • Continuous work with hospital senior management, our hospital group and NWIHP to contribute to changing the lengthy wait faced by bereaved parents for post mortem results and the return of retained organs. • A local undertaker is contracted by the hospital to provide the specialised transport between the unit and the Coombe.	• Acknowledgement and support the concern of bereaved parents and the reality of their experiences of the post mortem pathway. • Maintenance of high standards of communication with the pathology team in the Coombe.	Ongoing

DISCHARGE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Communication of information ahead of discharge about follow-up care.	• Coordinated information through a central contact point person.	• Timely verbal update to each woman's GP and PHN (with her permission). • Written discharge summary from team, including information to PHN. • Planned cover for days when the dedicated Bereavement Clinical Support person is not working • Discharge information for women includes written and verbal formats of contacts for the maternity ward, Clinical Midwife Specialist Bereavement and Loss, post natal OPD and maternity assessment unit. • Information is also offered for lactation specialist support, perinatal mental health specialist support, parental leave application, local civil registration office, county coroner's office and MRHP Freedom of Information office. • Designated attendance and visitor's card for bereaved parents during their attendance and admission. These cards can be used also at the postnatal follow up appointments in OPD. All maternity staff, and reception and security staff are regularly educated about the role and use of these specialised cards. Parking access is provided without charge during admission and for follow up visits. Bereaved parents are also signposted to www.infantandpregnancyloss.ie as an online resource.	• Better communication with community care. • Timely, accurate and cohesive information sharing process even when the dedicated staff isn't working (week-ends, leave). • Designated and facilitated pathway for admission, discharge and follow-up for bereaved parents.	Q1 2023

Ireland East Hospital Group

Grúpa Ospidéal Oirthear na hÉireann

Ireland East HOSPITAL GROUP

UCD DUBLIN

Wexford General Hospital
St Luke's General Hospital Kilkenny
Regional Hospital Mullingar
The National Maternity Hospital

On behalf of the Ireland East Hospital Group (IEHG), I would like to thank all the of the women and their families across the four hospitals in our Group for participating in the first National Maternity Bereavement Experience Survey.

Over the last 5 years, what matters to patients, women and their families is being consistently highlighted through the National Care Experience Programme. Ireland East Hospital Group are committed to learning and improving to meet the needs of all women using our maternity services, their families and the wider community.

This first Maternity Bereavement Experience Survey expands on this. The responses particularly reflect an appreciation of the kindness of our staff and the dignity and respect afforded to women and their families when they are coping with loss.

However, there are areas within our services which need to respond to the voices of women and their families, and, to this end, I am fully supportive of the detailed quality improvement plans which have been developed and the commitment of the staff in the maternity hospital and units of the Ireland East Hospital Group to engage and implement these improvements.

Amongst other targeted areas, our hospitals are committing to improving communications, both written and verbal, through the revision of existing information and providing information where this has been identified as lacking. In addition, follow up care has been identified as needing attention and all units have identified their commitment to improving this aspect of care.

As the National Care Experience Programme continues to expand into more areas of our healthcare service we will continue to respond and improve our services based on the experience of those who use them.

I would like to sincerely thank all our staff across the Group who encouraged the women who use our services to participate in the survey. Our staff are the core of our health service and their unwavering dedication to the women and families is seen in their willingness to adopt improvements wherever possible to ensure that women continuously receive the very best care and treatment in our maternity services.

My sincere thanks to all women and their families for providing this feedback and identifying areas of satisfaction and areas for improvement. I look forward to tracking all the identified improvements over the coming months to demonstrate our commitment to listening and responding to the feedback.

Yours sincerely,
Declan Lyons
Group Chief Executive, Ireland East Hospital Group

OVERALL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
To provide care sensitive to cultural and religious beliefs.	• Inform staff - education sessions. • Provide non-denominational space in the mortuary.	• Provide information folder for Religious and intercultural beliefs. • Ongoing 1 hour education sessions to update staff. • Upgrade of mortuary through the Design & Dignity programme of the Irish Hospice Foundation (IHF).	• This will increase awareness of the needs of all families from the diverse population we look after. • We will have a multifaith/ non-denominational room available in our newly upgraded mortuary.	Ongoing

POSTNATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
To provide information on lactation and breast care to all women who experience pregnancy loss from 13 weeks.	• To review information leaflet currently provided.	• Communicate the importance of breast care with staff, through education. • Remind staff about leaflet provided and to discuss with mother.	• All mothers experiencing a pregnancy loss from 13 weeks onwards, will be advised of what breast symptoms they may encounter and how to manage this.	Q2 2023
	• To highlight to staff the importance of breast care and lactation issues following pregnancy loss.	• Ensure staff know breastcare following pregnancy loss is included on our care checklist and must be completed.	• Written information will be provided and discussed, prior to discharge from hospital.	Ongoing

BEREAVEMENT CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Wexford's designated symbol of pregnancy loss to be used appropriately, to communicate to the multidisciplinary team, the sensitivity of a situation.	• To gain permission for our bereavement symbol to be displayed on the outside of the mother's chart, so staff are aware immediately of the sensitivity needed in caring for this mother/ family.	• To bring this concern to the End-of-Life-Care management team, and medical records for discussion on where we can display our bereavement symbol on the medical chart. • To inform and educate the multidisciplinary team on the symbol and its use.	• Our bereavement symbol will be made known to all staff and will be on display appropriately on the chart, to effectively alert staff to the sensitive needs of the situation.	Q2 2023

POST-MORTEM EXAMINATION AND INVESTIGATIONS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
The provision of a permanent postmortem service for Wexford.	• To have direct access to a post mortem service when required.	• To be able offer families rapid placental assessment, limited post mortem or full post mortem, without restriction.	• Families in Wexford will be offered all options in relation to postmortem as recommended by the National Bereavement Standards 2022.	Ongoing

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Communication.	• In house education on *Breaking bad news*.	• 2 doctors and 2 midwives are committed to become facilitators for the well established National Healthcare Communication Programme. • Focus on training doctors and midwives for *Breaking bad news* by providing updates and refreshers during Multi-Disciplinary Team (MDT) meetings. • Promote the *Breaking bad news* training programme for staff.	• It is envisaged that this will improve communication skills across the Multi-Disciplinary Team and promote sensitive and clear communication between staff and families.	Facilitators trained by Q2 2023
Information regarding diagnosis.	• Review current booklets.	• Review current information booklets and promote awareness of these booklets locally. • Audit newly set up bereavement follow up clinic an engage with bereaved parents to identify what specific information would be useful to them.	• Identifying women's needs for specific information will allow us to further develop information booklets currently in use.	Q2 2023
Location of scans in maternity.	• Development of ultrasound department within the hospital in an outpatient setting.	• Development of a new ultrasound department with access to appropriate services which will meet the needs of all pregnant women, being inclusive of those suffering loss.	• Ultrasound department within the hospital in an outpatient setting therefore couples will not need to attend maternity for routine scans. • This department will be designed with a separate waiting room for early pregnancy, a quiet space for breaking bad news if necessary or for parents to use following the delivery of bad news, a dedicated counselling room and access to the Perinatal Mental Health Midwife and Bereavement Clinical Midwife Specialist (CMS).	Q2 2023

NEONATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Parent involvement in decisions regarding their baby.	• Engage with Special Care Baby Unit (SCBU) to further discuss.	• Engage with staff through appropriate SCBU governance structure to discuss parents needs and how to meet these needs going forward.	• Create awareness of the importance of including parents in all aspects of their baby's care and decisions being made for their baby. This will further enhance the relationship between staff and families and ensure parents are at the centre of all decisions made for their baby.	Ongoing

POSTNATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Breast care and lactation.	• Addition of lactation education to our current bereavement study day and promote awareness of lactation after loss locally.	• Enhance awareness amongst staff at a local level of pre-existing information booklet and Standard Operation Procedure (SOP) on lactation following loss. We have invited lactation specialists to provide education during our planned bereavement study days for local staff.	• Reinforcing awareness around current information booklet available to bereaved couples locally will promote the use of this booklet on discharge and provide women with written information on suppressing lactation following loss. Education from the lactation specialists specific to bereavement and loss will support staff in providing this support to bereaved women postnatally.	Q4 2023
Mental Health support.	• Information leaflet on mental wellbeing following loss.	• Development of specific information leaflet on Mental Health following pregnancy loss and preparing for changes to emotional wellbeing. • CMS Perinatal Mental Health in post and CMS bereavement and PMH to continue to work together to improve services. • The patient representative (member of the Maternity Bereavement Committee) will be invited to review the leaflet and provide feedback.	• By introducing an information leaflet we can create awareness around the normal grief reaction and changes that you can expect with regards to your emotional wellbeing following loss. This will also serve as a platform to signpost support available both within the team and within the community.	Ongoing

FOLLOW UP CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Dedicated resource.	• Designated bereavement clinic.	• A specialised bereavement clinic has been established for follow up care. • Appointments will be discussed and co-ordinated by the Bereavement CMS. • Parents will be given written information about this appointment and any investigations that will be carried out.	• Continuity of care through the clinic with both consultants and Bereavement CMS. • Parents will be aware when they will attend this clinic and will have written information provided to them.	Started February 2023
Community support following discharge.	• Targeted Education/ study day.	• Plan to expand current bereavement study days and offer them to PHN and GPs within the community.	• It is envisaged that offering education to the wider community setting i.e. GP's and PHN's that this will improve the support they provide to bereaved couples following discharge from the hospital.	Q4 2023

OVERALL CARE				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Staff communication skills.	• Education on communication skills. • The hospital is committed to raising awareness amongst the entire healthcare team to improve communication with parents in a sensitive and respectful manner where a diagnosis of pregnancy loss is being given.	• Multidisciplinary team education is being delivered locally, using the National Healthcare Communication Programme provided by the trained trainers, and online resources with local updates provided by the training team. • The maternity department has commenced the roll-out of a dedicated module for Breaking Bad News (BBN) in the maternity setting *Dealing with Loss in the Maternity Setting*. (DWLiMS) • The education is targeted to specific healthcare workers in OPD/Women's health/antenatal inpatient/x-ray. • A joint educational initiative is under development in the midland region, to provide training to staff caring for women with a pregnancy loss; its impact on the parents and the steps that can be taken to improve the delivery of information and communication. The training will focus on assisting parents in the hospital; ensuring individual, sensitive and standardised care. • The hospital is targeting education for all staff caring for women with pregnancy loss and are prioritising staff in the outpatient dept/ antenatal ward/ultrasound and x-ray departments.	• Better staff awareness to the importance of actively listening and being sensitive, responding empathically to parent's needs. • Increase awareness around the sensitivity of the diagnosis and most importantly how to deliver the news of a fetal demise to parents.	In-house training is ongoing bi-monthly. BBN/ DWLiMS is quarterly Joint training Q3-'23

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Environment and dedicated space.	• Dedicated space for early conversation about bad news.	• The Quiet Room was specifically designed and is made available to families receiving bad news. • The quiet room was developed and designed as an important aspect of the care for women and partners who have received news of a pregnancy loss. • The department has included the availability of this room as part of the induction programme for new staff, obstetric/nursing/ midwifery health care assistant and administration staff. • The early pregnancy unit clinic is held as a separate clinic. The waiting area is located in a separate area to minimise any unintended distress to a woman receiving news of a pregnancy loss. We emphasise the importance of ensuring women are invited for appointment at this clinic amongst the entire team, which is held at a different time in the women's health department.	• Provide women and families with specifically designed rooms for private, quiet and sensitive to answer questions about the pregnancy loss.	Twice a year for medical staff. As part of orientation for all new midwifery/ nursing and admin staff.

POSTNATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Sensitive post-natal accommodation.	Development of a Bereavement suite.	• The maternity bereavement suite is located close to the antenatal unit which caters for the needs of parents and families, which is private and designed to create a sensitive, tranquil environment, respectful of their loss. The suite will have direct access for family. The suite will contain a hospital grade double bed to allow comfort for both parents. The kitchenette will provide tea/coffee and snack facilities.	• Women and partners will be accommodated in a specially designed room.	Ongoing build at time of reply; handover due May 2023.
		• The suite will facilitate parents to have time with their baby in supported surroundings.		May 2023
While you were in hospital, were you given enough care and support with your physical recovery after the birth of your baby.	• Providing Information and Planning.	• Encouraging quality conversations, emphasising whole person care (part of bereavement checklist for staff to walk through - ensured all individual needs are tracked). • The use of a checklist is in place to ensure standards of bereavement care are met. However, we also emphasise the importance of addressing individual care for parents, as each experience is personal and unique.	• Response to mothers physiological needs.	Education sessions Q1 & quarterly

BEREAVEMENT CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Memory making.	• Educate staff around memory making.	• Staff education workshops planned to increase knowledge and familiarity with memento making. This will also be included in joint training for staff in the midlands; with emphasis on the specific nature of pregnancy loss, its impact on the parents and the steps that can be taken to improve awareness.	• Increase staff knowledge and comfort, to support the families in making memories with their baby.	Q1 '23 & quarterly.
Family visits.	• Restoration of family visits post COVID.	• Currently family visits are encouraged and supported, if desired by the parents. Within the new maternity bereavement suite, parents will have a greater control over the visitor/support persons who can have access to the suite. Visits will be encouraged based on cues from parents.	• Bereaved parents are encouraged to be supported by their families and friends.	In place.
		• Security staff are contacted to ensure family members are facilitated with visits.		Additional capacity will be available on completion of bereavement suite May 2023.
Staff knowledge about options for funeral services.	• Staff education.	• Workshops are planned to outline the care we can and do offer to parents. This will increase staff familiarity with services available, and how to link families with their choices in arranging a service and funeral/cremation.	• Staff will be well informed and able to assist parents to make decisions.	Joint training Q3-'23.
If you wanted to, were you facilitated or supported to take your baby home prior to a funeral or cremation service?	• Providing Information and Planning	• Continuing the roll-out of staff education to ensure awareness of all facets of bereavement support	• Parental choice will be optimised.	Ongoing in-service training.

DISCHARGE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Information for hospital support services, counselling, or support organisations outside of the hospital.	Provide written information on supports women can access after leaving the hospital.	• We actively continue the ongoing review of the available hospital support services, counselling, & support organisations outside of the hospital, and updating as needed. • Parents are provided with information including; contact details for the national and local support groups specific to the loss of their baby. This is an integral part of the support, as is in the memory box from *Féileacáin, the Now I Lay me Down to Sleep* photography service, production of clay and ink prints, photographs, contact details for the miscarriage association (if appropriate). The information is presented to and discussed with parents during their stay, but the written leaflets for follow-up. Contact numbers for the Bereavement Support and antenatal ward are given.	• Family support following discharge from hospital.	Ongoing

FOLLOW UP CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Communication with community care providers.	• Communicate in a timely manner with GPs.	• Continue the ongoing liaison and communication between hospital & GP.	• Women will be better supported after discharge, through their GPs.	Q2 2023
		• The hospital will facilitate access to the roll-out of staff education to ensure trainee GPs awareness of all facets of bereavement support.		Q2 2023
	• Invite local GPs to take part in education sessions around bereavement.	• The maternity department will develop an information leaflet to be circulated to GPs, outlining: what the service entails, information given to parents, resources available in the community & contact details for hospital Bereavement service.		Q3 2023

ADMISSION CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Streamline the admission process for bereaved parents.	• Aim to improve the timing of elective admissions for bereavement care so that bereaved couples are not exposed to routine pregnancy care/admissions.	• Awareness communication with Consultants, NCHD's (junior doctors), Ward Managers, Admissions Office, Front Desk. Memo has been sent by the Master of the NMH to Consultant Group & NCHD's detailing specific elective admission times. • NCHD's education sessions at induction programmes outlining rationale for admission times. • Use dedicated Bereavement admission card to support the "direct admission pathway". • Continue the roll out of the National Healthcare Communication Programme for all staff, which includes a review of free text comments provided during the survey.	• A Seamless admission pathway for bereaved couples in order to mitigate any additional distress.	Ongoing
Improve the NMH facilities so that accommodation for bereaved parents is more sensitive to their needs.	• Provide an additional en-suite room for parents admitted for induction of labour.	• An en-suite bathroom is being added to a single room in the antenatal ward, allowing bereaved parents more privacy during labour. • The labour room is being redecorated with more 'homely' décor, added including lamps and art work.	• This was the last single room without an en-suite. Completion of works will offer more privacy and a more sensitive environment to bereaved parents.	Q1 2023

NEONATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Improve opportunities for parents to ask questions about their baby's care.	• To ensure parents feel included in decisions regarding their baby's care whilst in the neonatal unit.	• Facilitation of parents meetings at their baby's bedside or in a private room to ensure parents have the opportunity to ask questions and understand information regarding their baby's care and treatment. • A designated medical social worker for families with babies in the neonatal unit is working with families. For babies transferred from another hospital outside Dublin, the medical social worker can assist with securing an accommodation. • *Angeleye* cameras in use to offer parents separated from their baby to feel connected, although physically apart.	• Parents will have the opportunity to be more involved in decisions surrounding their baby's care.	Ongoing

NEONATAL CARE (CONTINUED)

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Improving visiting for parents with babies in the Neonatal Intensive Care Unit.	• To ensure parents feel welcome at all times when their baby is receiving end-of-life care.	• Where appropriate babies are moved to Neonatal Intensive Care Unit 2 for end-of-life care. This is a private and quiet space to ensure families have uninterrupted time with their baby. • The room has been fitted with new reclining chairs. Monitors can be silenced ensuring a peaceful environment whilst also providing the support of the Neonatal Intensive Care Unit team. • Extended family members are encouraged to visit. • Catering support is provided for families along with car park passes.	• Parents will be welcomed to stay in the neonatal unit with their baby for end of life care, in a supportive and caring environment. • They can also have the support of their extended family at this time.	Ongoing

DISCHARGE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Improve information given to bereaved parents about what they might experience when grieving or possible changes to their mental health.	• Need to improve information provided to bereaved parents regarding normal grief following pregnancy/ infant loss.	• Develop an information booklet regarding normal grief, mental health and support services. All leaflets are reviewed by the Patients Voice Group prior to finalisation. • Provide education to staff on the importance of providing this information to parents before discharge. • Bereavement and mental health teams will continue to collaborate to develop support services for bereaved families.	• Parents will receive more information regarding mental health following loss and how to access support services. • Written information (leaflet) will be available both in paper and on the website so parents can access information in their own time.	Q3/Q4 2023
Improve care and support around physical health following the birth.	• Need to improve information provided to bereaved parents regarding physical recovery, breast care & suppression of lactation following pregnancy/infant loss.	• A leaflet regarding suppression of lactation & physical recovery is currently given to parents following bereavement, prior to discharge. Provision and verbal discussion of the leaflet is part of the bereavement checklist. • Refresher education will be provided to staff to ensure this booklet is given and explained to all parents. Education sessions for staff on suppression of milk are currently provided in the hospital and also in the Centre for Midwifery Education (CME). • Bereaved parents will continue to be offered the services of a lactation consultant post delivery where appropriate.	• Mothers will have access to appropriate information and lactation support prior to discharge if required.	2023

DISCHARGE (CONTINUED)				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Improved contact information for hospital support services, counselling, or external support organisations.	• Parents requested improved written information about support and follow up care that will be offered to them following discharge from the Hospital.	• Currently the bereavement team make a follow up call 7-10 days following discharge. Parents are informed of this verbally prior to discharge. Parents in the survey have requested that information be provided in a written format. • We currently provide details of support services in a letter to parents and details of the scheduled follow up phone call will be added to this letter. During this phone call further support will be offered and information given again regarding support services in the hospital and the community. • All parents are offered a follow up appointment with an obstetrician and/or a paediatrician where appropriate. This appointment is given prior to discharge where possible (as some parents are discharged over the weekend).	• Parents will be more aware of the follow up care offered and available to them.	Q1 2023
Improve discharge advice following termination of pregnancy (TOP) in Ireland and UK.	• Insufficient advice in some cases for physical ailments following TOP.	• Development of a booklet *Ending a pregnancy in the UK following a diagnosis of a fetal anomaly*, with the fetal medicine therapist for TOP care including advice on breast care, vaginal bleeding and counselling services.	• The booklet will be provided to the women, allowing them to have written information of quality for reference after discharge.	End Q2 2023

RCSI Hospital Group

RCSI HOSPITAL GROUP
GRÚPA OSPIDÉAL RCSI

The Rotunda Hospital, Dublin
Cavan Monaghan Hospital
Our Lady Of Lourdes Hospital Drogheda

On behalf of the Royal College of Surgeons Ireland (RCSI) Hospital Group, I would like to thank all patients who participated in the National Maternity Bereavement Experience Survey.

Your feedback is invaluable in helping us to understand individual experiences and to assess our service performance against your expectations. Measurement of quality to drive improvement is one of the hallmarks of the RCSI Hospital Group and feedback has provided an additional and very important opportunity to enhance quality improvement initiatives which ultimately leads to an improvement in the quality of healthcare services provided by the RCSI Hospital Group.

Yours sincerely,

Ian Carter
Chief Executive Officer, RCSI Hospitals Group

ADMISSION CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Accommodation and facilities for bereaved parents.	• Develop the Solas Suite - tranquil rooms for families experiencing a pregnancy loss.	• Funding secured from Rotunda Foundation to upgrade the facilities.	• Facilities and inpatient accommodation for bereaved parents will be enhanced, affording them a more comfortable, peaceful and quieter environment.	Nov-2022
		• Upgrade an ensuite delivery room and two rooms on the Gynae Ward to provide homely, comfortable and peaceful accommodation for bereaved parents.		Q2 2023
		• Upgrade two counselling rooms in the Fetal Medicine Unit to provide a calm spare for discussions with expectant parents receiving bad news.		Q2 2023

NEONATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Care of parents who experience a neonatal death.	• Parents are supported throughout their journey in the Neonatal Unit to ensure they are fully informed, involved in decision making and memory making.	• Pre COVID-19 visiting has been reinstated for parents in the Neonatal Unit.	• The overall experience of parents will be enhanced as they receive holistic, individualised care. Parents can visit when/ for as long as they wish, which allows for better opportunities to meet with multidisciplinary team members and be included in discussions and decisions about their baby. Staff will be more conscious and mindful when they are communicating with parents and encourage them to make memories, which may bring comfort and healing in the future.	Nov-2022
		• Share the survey findings with the neonatal multidisciplinary team at staff handover and at departmental meetings over the coming months.		Apr-2023
		• Ensure parents and neonatal staff meet with the Palliative Care Consultant when developing a care plan. The Palliative Care Consultant attends our weekly multidisciplinary Fetal Medicine meetings.		Mar-2023 onwards
		• Refresher training for neonatal nursing staff on memory making in the Neonatal Unit. The Chaplain will provide these education sessions on a recurring basis until all neonatal nurses have received the refresher training.		Apr-2023
		• Provide specific information on lactation suppression to breastfeeding/expressing mothers following a neonatal death. Where possible, all bereaved mothers will be seen by our dedicated Neonatal Lactation Consultant to advise them appropriately. A complementary information leaflet on lactation suppression will also be available to mothers on the Neonatal Unit.		Feb-2023 onwards
		• All the neonatal multidisciplinary team to complete the HSeLanD module - making conversations easier.		Apr-2023

POSTNATAL CARE				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Postnatal care.	• Develop an information booklet which provides the specific information required by bereaved parents. (This will complement the bereavement booklet.)	• Review existing information provided.	• Parents will have access to practical, relevant information to address their physical needs and aid recovery. It will provide clarity on plans for their follow-up care and further information on dedicated support groups available.	Jan-2023
		• Include information on lactation suppression, postnatal exercises, pain management, contraception, follow-up care, support groups, role of GP and PHN.		Feb-2023
		• Obtain service user feedback on proposed content from previously bereaved couples who are known to the Bereavement Team.		Mar-2023
		• Translate the information booklet into Romanian, Arabic, Somali, Portuguese and Russian, which reflects the other main languages spoken by women availing of our maternity services. It will also be translated into Irish.		Apr-2023
		• Print booklet and upload onto website.		Apr-2023

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
A gap in practice relating to a woman's journey experiencing pregnancy loss through the Emergency Department was highlighted through comments from the NMBES.	• To update the clinical pathway for women experiencing pregnancy loss through the Emergency Department, aiming at improving respect and dignity.	• **Do:** Multidisciplinary group with key stakeholders will be developed to update clinical pathway acknowledging comments from NMBES. • **Measure:** An available updated pathway. Compliment and Complaints procedure.	• Will improve a woman's journey through the Emergency Department experiencing pregnancy loss by providing women-centred care. • Will enhance understanding of the psychological effect of communication on women through the Emergency Department when they are experiencing pregnancy loss. • Will enhance understanding of the different types of communication e.g. verbal, non-verbal, visual, written and interpersonal interaction.(Bereavement Education Standards HSE 2019) • Will build on and embed good practice already present.	Q1 2024
	• To assign a waiting area in the Emergency Department aimed at maintaining respect and dignity for woman experiencing pregnancy loss.	• **Do:** Multididciplinary group to reconfigure space within the Emergency Department to re-assign a single room. • **Measure:** The percentage of woman experiencing pregnancy loss and clinically suitable offered a single room in the Emergency Department.		
	• To provide an education and training programme for clinical staff in the Emergency Department on communication to support parents experiencing pregnancy loss.	• **Do:** This will involve a core group of hospital staff with the required expertise in bereavement care to facilitate and support delivery of bereavement care education and training to hospital clinical staff. • The design of the education programme will cover the key elements of the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death (2022): Clinical staff members who would benefit from specialised education in bereavement care identified as Non Consultant Hospital Doctors in Obstetrics and nurses from the Emergency Department and their participation for education and training programmes on an ongoing basis will be facilitated: Classroom based and Roadshow education sessions will be provided. • Communication champions will also be utilised to promote education and training. This quality initiative will be promoted within the hospital on education and notice boards. • **Measure:** An initial self assessment by clinical staff will measure knowledge prior to and after education. Participants will also rate the education provided. Also percentage of attendance will be measure. Compliments and complaints procedure.		

BEREAVEMENT CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
To improve written information provided to a woman experiencing pregnancy loss.	• To develop 2nd trimester and 3rd trimester pregnancy loss information booklets: with key information including information on making memories with photographs. Information regarding lactation and mental health. • To develop individualised Patient Information Leaflets relative to their individual needs which can be stored within the booklet.	• **Do:** Carry out a gap analysis by reviewing the current written patient information leaflet in relation to pregnancy loss against National Standards for Bereavement Care following Pregnancy Loss and Perinatal death, (2022). To seek input from women who have previously experienced pregnancy loss. Information to include choices available to women and support links available both in hospital and community. • **Measure:** Patient survey following discharge to measure: – Did all women receive a patient information booklet? – Compliments and complaints procedure.	• Some women gave positive feedback in relation to information received. • Written information will be compliant with National Standards for Bereavement Care following Pregnancy Loss and Perinatal death (2022). • Will provide written support to women following pregnancy loss. • Will provide individualised information for women following pregnancy loss. • Will demonstrate woman-centered care. • Will encourage autonomy in decision-making for the woman.	Q4 2023

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Communication and clear information sharing between families and the multidisciplinary team.	• We will update our Bereavement Information Booklets specifically for: *Miscarriage, Stillbirth, Death of a Newborn Baby and Babies who die in Hospice*. The Booklet will contain information about the physical, emotional and social needs of each group. – The information booklet will be given to families on diagnosis of the loss of their baby. We will go through this booklet with families at a pace that suits them. – We will also continue to give families *A Little Lifetime Foundation* journal. – Parents will be encouraged to use both books throughout their hospital stay and following discharge as a way of continuing the journey they started while in hospital.	• Information to be included in each booklet (specific to the type of loss) for example: 1. How we diagnose and confirm pregnancy loss or the death of a baby. 2. What happens next? Information about the options available; medical, surgical or conservative treatment ('wait and see') and induction of labour. 3. Information about where we will care for you along your journey and the steps we take to ensure you receive sensitive care at this difficult time (The Quiet Blossom Room, the Supportive Care Birthing Room and the use of the Bereavement Symbol). 4. Information about care during labour, birth and after the birth. 5. Supporting you to spend time with your baby, to make precious memories, such as foot and hand prints, photos, creating special momentos. 6. Advice about spiritual support, the chaplaincy team and cultural supports available to you. 7. Including your loved ones, sibling support, *Sibling Teddy Bears* and dealing with grandparent's grief. 8. Supporting you to register your baby. 9. Discussing options for private burial, hospital burial (the Quiet Rest burial plot) and cremation. 10. Care after birth, such as physiotherapy and lactation support following loss. 11. Ongoing emotional support from our Clinical Nurse Specialist (CNS) in Bereavement, access to our Mental Health Support Midwife, Social Worker, Counsellor, the annual Children's Service of Remembrance and contact details for local/national support groups. 12. GP and PHN support and follow-up when you go home. 13. Consultant Follow-up in CGH Women and Children's Services (Postmortem will be discussed in a sensitive manner if relevant and supported by a Parents Information Leaflet). – Specialists and multidisciplinary team will be involved in the contents of the booklet – Booklet will be planned and reviewed with the bereavement committee and the clinical lead for perinatal bereavement – A presentation of the planned booklet will be made to the clinical governance teams in women and children's services for input and support. – Service-User input will be used throughout the process.	• Families will be provided with information (in verbal and written format) on perinatal loss, support and resources available locally and nationally.	Q4 2023

DISCHARGE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Staff confidence and knowledge base in the care of families experiencing perinatal loss.	• A revision of our training programme for staff caring for Families experiencing Perinatal Loss. Aim – to enhance their understanding of the processes, perspectives and complexities of families at this difficult time.	• Using the recently developed Perinatal Bereavement Care toolbox, continue to provide multidisciplinary face to face and written support and education in the theoretical and practical elements of caring for families experiencing perinatal loss. **Perinatal Bereavement Care Toolkit** **Tool 1.** Clinical Care Pathways, a step by step guide to support the care of perinatal loss for the duration of their in-patient admission. **Tool 2.** Investigations and Post Mortem Examination, a detailed training guide outlining processes and rationale for all aspects of investigations used following perinatal loss. **Tool 3.** Resources and Theory Based Practices, this guide explains the use of all accessary support and links them to the theoretical frameworks. Topics covered include the importance of sensitive communication, memory making and the grief process. **Tool 4.** Perinatal Governance and Supports. This guide describes the National Bereavement Standards and the requirement to follow best practice guidelines. It also includes our reporting obligations to the Coroners department and the National Perinatal Epidemiology Centre. In addition there is information on the Local and National Supports available. – Staff will continue to participate in the Irish Hospice 'Final Journeys' programme available onsite; – As soon as available 'Dealing with Loss in the Maternity Settings' sessions will be made available to staff.	• Staff will be able to support the holistic needs of families experiencing perinatal loss including the more subtle complexities and perspectives of grief.	Q3 2023

FOLLOW UP CARE				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Family follow-up support following discharge.	• We will revise our bereavement follow-up programme, sensitive to the individual needs of each family.	• Families will be offered a 5 stage discharge follow-up plan with options to increase or decrease the interactions according to their individualised needs. **Stage 1.** Week 1. Cavan General Hospital designed card of condolence. **Stage 2.** Week 3. Clinical Nurse Specialist (CNS) Bereavement and Loss phone call. **Stage 3.** Week 5. CNS Bereavement and Loss phone call. **Stage 4.** Week 6. Consultant follow-up and death notification completion (increased to week 12 if awaiting post mortem report). **Stage 5.** Week 7. CNS Bereavement and Loss phone call. **Stage 6.** Week 8. Referral to hospital counsellor/psychotherapist (unless required more urgently). – A "Follow-up Record" will be added to the current bereavement referral and follow-up document. – Support calls will be recorded including agreed plans with parents for future support. – Support calls will include sign posting to national support networks – Families awaiting Post Mortem results will be seen by their consultant when the post mortem results are available, Parents are advised this takes a minimum of 12 weeks. – Parents will be made aware of the CNS Bereavement and Loss contact details and her open door policy of support. – Completed six stage follow-up documentation will be filed in the mothers healthcare record and any further contact will be recorded in CNS Bereavement and Loss communication file.	• Support following discharge will be more structured and formalised whilst allowing for the tailoring of support (additional phone or face to face support or the reduction of support if families feel they are coping well within their own support network) thus supporting individual family needs. – Families will be empowered throughout their experience to reach out to their personal support network and the local and national supports to enable a gentle transition through their grief.	Q2 2023

Saolta University Health Care Group

University Hospital Galway
Letterkenny University Hospital
Mayo University Hospital
Portiuncula University Hospital
Sligo University Hospital

We are very grateful to all the women and their families across the Saolta University Health Care Group for participating in this first National Maternity Patient Experience Survey.

The loss of a baby or pregnancy can be one of the most devastating and difficult experiences that a woman and her family will have to deal with. We recognise how important it is to have a comprehensive range of Maternity bereavement services available to women and their partners to ensure that their needs and the needs of their families are met.

This survey and the direct feedback from the women and their partners provide us with a measure of their experience of bereavement care following the loss of a pregnancy or baby.

It has provided us with an important opportunity to review our services from their perspective. We are committed to listening and fully engaging with the survey results.

In each Maternity unit, we have agreed and have commenced implementation of a detailed quality improvement plan to address the areas identified by our women and their partners where improvement is required. I thank each of them for sharing their experience with us. Their insights and commentary will help us to better meet the needs of women and their families in the future.

I would like to thank our staff across our Maternity services who have provided compassionate care in a skilled manner to all women who suffered a bereavement and their families at this difficult time.

Finally, I would like to once again thank all of the women and their partners who have shared their views and experiences with us and assure them of our commitment to continually strive to improve our services.

Yours sincerely,

Mr Tony Canavan
Chief Executive Officer, Saolta University Health Care Group

OVERALL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Staff bereavement awareness.	• Knowledge of National Standards for Bereavement Care following pregnancy loss and Perinatal Death (tests, investigations, paperwork). • Communication skills.	• Pilot *Teardrop* training in April 2023 with members of the Multidisciplinary team. • Training for all Maternity staff on the National Healthcare Communication Programme, Modules 1-4. • *Breaking bad news* HSE Training for all staff working in Maternity services. • Continuation of bi-monthly multidisciplinary departmental bereavement meetings to provide leadership and to oversee quality improvements in bereavement care.	• Staff working in Maternity services will have up-to-date training on best practises to care for women and families experiencing pregnancy loss. • Staff communication skills are developed to ensure bad news are delivered in a sensitive manner, and the overall care is conducted in a supportive way.	Apr-23
Written information for parents.	• Ensure women and partners have a written support to refer to in their journey of care.	• Updated information booklet for bereaved parents: *What happens when your baby dies*. • The booklet contains details of support groups and contact information for the Hospital, inclusive of the Hospital Chaplin and Medical Social worker. • The booklet is provided to all parents, for all types of losses including early miscarriages, in parallel of a discussion about their personal situation.	• Women and their partners are provided actively with information of the supports available to them throughout the hospital and support groups. • They can refer to this information in their own time, after a diagnosis, to prepare themselves to the next stages of their care.	Jun-23

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Physical Environment Waiting area for Ultrasounds in University Hospital Galway (UHG).	• Create a dedicated area close to the Maternity Scan Room.	• Review the clinical environment in the Maternity Scan room area to identify a separate private area for women who are experiencing pregnancy loss. This may be used as a waiting area and a quiet room. • Scheduled appointments for parents where it is known that their baby has died or has a known life-limiting condition so they can avoid wait times with other women and couples. • Offer to have a member of staff meeting the parents at the door and bringing them directly in the room for subsequent appointments, in order to avoid waiting times.	• Sensitive environment for women who have experienced a bereavement, maintaining dignity and respect for bereaved families.	Q2 2023

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS (CONTINUED)

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Communication Having written information available at the Fetal Medicine Clinic in relation to life-limiting conditions.	• Provide women and their partners with high-quality information regarding their baby's condition.	• Development of condition-specific information leaflets. • Leaflets are supplementing the verbal information and discussions taking place at the Fetal Medicine Clinic.	• Women and their partners have access to good quality information, enabling then to make informed decisions about their care and to identify and access support groups where appropriate. • The written support allows the families to reflect in their own time, and prepare for the next stages of care.	Q2 2023

POSTNATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Environment The Bereavement room in UHG is located on the Antenatal ward, hence creating possible encounters of bereaved women with pregnant women. The access and exit routes of the room need to be reviewed, and a dedicated separate route offered as a choice.	• Improvement of the Bereavement room and addressing its location with sensitivity.	• Environmental upgrade of the Bereavement Room to ensure that it is appropriate to the needs of bereaved women and their families. • Bereaved women who want to go for a walk will be offered access to areas off the antenatal ward. • Review and erect new signage in the Antenatal Ward to inform women and partners on alternative routes to access and exit the Bereavement room. • Include needs of bereaved women and partners in the design and building plans of the New Maternity Block.	• Improve the environment for women who have experienced a loss, by offering a private and sensitive room where partners and families can join in bereavement. • Women and families are given the choice of dedicated access and exit routes to lower the encounters with pregnant women or babies, with staff help and adequate signage in the ward.	Q2 2023
Education and Support for managing the physiological changes in the breast following a pregnancy and a perinatal loss.	• Information and education regarding breast care following a perinatal loss.	• Development of a condition-specific information booklet on breast care following pregnancy and perinatal loss. This will be available in written format, or through a QR code in different languages. • Referral pathway established for bereaved mothers, and service communicated to the MDT to promote appropriate referrals. • Training for all clinical staff on breast care following pregnancy loss (to include all methods of suppression of lactation for women following pregnancy and perinatal loss).	• Women provided with quality written information about lactation after a pregnancy loss, to support verbal discussions with the staff and educated decisions about options. • General staff knowledge improved and dedicated resources identified, to ensure continuity of high quality of care to women in relation to breast care.	May-23

POST-MORTEM EXAMINATION AND INVESTIGATIONS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Follow up on Investigations and Communicating Results.	• Improve the counselling provided in relation to investigations including post mortem examinations following pregnancy loss.	• Details of recommended investigations are readily available in all of the clinical areas and in the pregnancy loss care pathways. • Development of a detailed information booklet for women and partners in relation to Post Mortem examinations. • Review of process to ensure results are communicated to women and their partners in a timely and appropriate manner. • Strengthen coordination on results communication and follow up through the Bereavement Midwives, Consultant Obstetricians and Paediatrician. • Increase the uptake and availability of perinatal post mortems within our network.	• Women and partners will be supported into making an informed decision about post mortem examination. • Results will be communicated in a timely and coordinated manner to the women and their partner.	May-23

DISCHARGE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Registration of Birth of baby.	• Ensure that all parents, for which this is relevant, are provided with appropriate information and assistance on how to register their baby's birth and death.	• Written information and assistance to register their baby's birth and death provided to parents, if registration is possible. • If the baby cannot be registered, provision of a Certificate from the hospital acknowledging the birth for parents for inclusion in the memory of their baby.	• Ensure parents have a full understanding of when the registration is possible. • For babies who cannot be officially registered, the compassionate certificate support the inclusion for memory making.	Mar-23

FOLLOW UP CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Central role of the Bereavement Midwife.	• Ensure that women and their families are aware of the role of the Bereavement Midwife and how she can be contacted. • Liaison with community care.	• A Bereavement Midwife is in post. Women who have experienced pregnancy loss are systematically provided with contact cards for the Bereavement Midwife. • The Bereavement Midwife communicates and engages with Public Health Nurses and General Practitioners, in relation to pregnancy loss.	• Women and families have 1 central point of contact who coordinates all the information, and do not have to re-explain their story to multiple interlocutors. • The primary care team caring for women and their families will be informed of the case summary in a timely manner, so support after discharge can be provided.	Jun-23

FOLLOW UP CARE (CONTINUED)				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Communication Where women have had a history of a previous perinatal loss.	• "Previous loss indicator sticker" for subsequent pregnancies.	• Introduction of a "Previous loss indicator sticker" for use by staff. • Staff training in relation to the use and importance of the "Previous loss indicator sticker". • Regular audit of the use of the sticker.	• This will increase staff awareness of their previous loss which will help avoid women having to repeat their history unnecessarily. • It will ensure appropriate and consistent care, as well as emotional support during the new pregnancy.	Ongoing

OVERALL CARE				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Bereavement Support in hospital.	• Ensuring the Bereavement Support role is performed in line with Standards.	• Complete a gap analysis between Letterkenny University Hospital and the HSE National Standards for Bereavement Care following pregnancy and perinatal loss to strengthen governance, enhance bereavement culture, and identify additional areas for improvement.	• The Bereavement Midwife in Letterkenny University Hospital (LUH) will develop sustainable improvements in the care of women and their partners who have experienced pregnancy loss.	Q3 2023
Bereavement awareness and communication skills.	• Inform and thank staff at appropriate opportunities.	• Survey feedback shared and quality improvement plan shared with the Maternity Services Staff.	• Patient experience and staff morale.	Completed
	• Communication workshop.	• Training provided to all Maternity staff regarding the National Healthcare Communication Programme, Module 1-4. • Staff working in Maternity services to complete the HSE programme *Breaking bad news* (Target 80% of staff).	• Women and their families will have an improved experience of communication following pregnancy and perinatal loss, as staff develop on communication skills.	Q4 2023
	• Bereavement education.	• Creation of a Multi-Disciplinary Perinatal Bereavement forum specific to maternity to provide leadership and oversee quality improvements in bereavement care. This group will contribute to the Hospital End-of-Life Committee.	• To co-ordinate bereavement care and lead on quality improvement plans in maternity services.	Completed
Written information for parents.	• Ensure women and partners have a written support to refer to in their journey of care.	• Updated information booklet for bereaved parents: *What happens when your baby dies*. • The booklet contains details of support groups and contact information for the Hospital, inclusive of the Hospital Chaplin and Medical Social worker. • The booklet is provided to all parents, for all types of losses including early miscarriages, in parallel of a discussion about their personal situation.	• Women and their partners are provided actively with information of the supports available to them throughout the hospital and support groups. • They can refer to this information in their own time, after a diagnosis, to prepare themselves to the next stages of their care.	Jun-23

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Physical Environment.	• Create a dedicated area in the Gynaecology Unit/ Early Pregnancy Unit, including a counselling/quiet room.	• Room identified for use as counselling/quiet room for women who are experiencing pregnancy loss or have a baby with a life limiting condition. • Room furnished in a sensitive way, with possibility to accommodate partners or support persons and reserved for the use of mothers who are bereaved or have a baby with a life limiting condition.	• Mothers and families will benefit from dedicated sensitive rooms, allowing them dignity and privacy. • The rooms are permanently reserved for these families.	May-23
	• Create a dedicated area in the Maternity Assessment Unit.	• Area redesigned to create 2 assessment rooms, separated to accommodate women and partners receiving unexpected bad news in a private area. • Rooms furnished in a sensitive way, with possibility to accommodate partners or support persons and reserved for the use of mothers who are bereaved or have a baby with a life limiting condition. • Rooms will be able to accommodate partners or support persons.		May-23
Specialist services and pathways for pregnancies where the baby has been diagnosed with a life limiting condition.	• Improved access and pathways for women with life limiting conditions.	• Development of new Fetal Medicine service (October 2023) to ensure the pathways are available and meet the needs of women whose pregnancy is complicated by a life limiting conditions.	• Women will have an improved experience of bereavement care where their pregnancy is complicated by life limiting conditions.	Q4 2023

POSTNATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Education and Support for managing the physiological changes in the breast following a pregnancy and a perinatal loss.	• Information and education regarding breast care following a perinatal loss.	• Development of a condition-specific information booklet on breast care following pregnancy and perinatal loss. This will be available in written format, or through a QR code in different languages. • Referral pathway established for bereaved mothers, and service communicated to the Multi-Disciplinary Team (MDT) to promote appropriate referrals. • Training for all clinical staff on breast care following pregnancy loss (to include all methods of suppression of lactation for women following pregnancy and perinatal loss).	• Women provided with quality written information about lactation after a pregnancy loss, to support verbal discussions with the staff and educated decisions about options. • General staff knowledge improved and dedicated resources identified, to ensure continuity of high quality of care to women in relation to breast care.	May-23

POST-MORTEM EXAMINATION AND INVESTIGATIONS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Follow up on Investigations and Communicating Results.	• Improve the counselling provided in relation to investigations including post mortem examinations following pregnancy loss.	• Details of recommended investigations are readily available in all of the clinical areas and in the pregnancy loss care pathways. • Development of a detailed information booklet for women and partners in relation to Post Mortem examinations. • Review of process to ensure results are communicated to women and their partners in a timely and appropriate manner. • Strengthen coordination on results communication and follow up through the Bereavement Midwives, Consultant Obstetricians and Pediatrician. • Increase the uptake and availability of perinatal post mortems within our network.	• Women and partners will be supported into making an informed decision about post mortem examination. • Results will be communicated in a timely and coordinated manner to the women and their partner.	May-23

FOLLOW UP CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Post delivery care.	• Facilitation of follow up in the hospital and communication.	• Generic email set up for Bereavement Support service to ensure continuity of cover when the Bereavement Midwife is on leave. • Women systematically provided with contact details the Bereavement Midwife. • Improvement of communication post pregnancy loss to Public Health Nurses and General Practitioners. • Improvement of pathways for women and their families returning to the hospital post pregnancy loss for outpatient follow up. • External rooms for follow up meetings outside of the hospital setting (if preferred by the women and their families). • Creation of a recurrent miscarriage clinic to allow parents to be linked in with appropriate services.	• Women will have access to a dedicated member of staff with continuity of service and support during leaves of the Bereavement Support Midwife. • Trauma of returning to hospital for follow up will be lessened through separated setting. • The primary care team caring for women and their families will be informed of the case summary in a timely manner which will improve their ability to support the woman and their family.	Q2 2023
Subsequent pregnancies.	• Special pathways for women having experienced a loss who are pregnant again.	• Creation of dedicated pathways for early access to maternity services such as scans, mental health midwife, early antenatal classes for women who have had a previous experience of pregnancy loss.	• Women and their partners will be accompanied and supported through the subsequent pregnancy, by staff cognisant of their previous loss experience.	Q2 2023

OVERALL CARE				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Bereavement Support in hospital.	• Ensuring the Bereavement Support role is performed in line with Standards.	• Bereavement Midwife newly appointed in Mayo University Hospital (MUH) and supported in undertaking education and training. • Creation of referral pathways to the Bereavement Midwife for both inpatient and outpatient episodes of care.	• The Bereavement Midwife in Mayo University Hospital (MUH) will develop sustainable improvements in the care of women and their partners who have experienced pregnancy loss.	Ongoing
Bereavement awareness and communication skills.	• Inform and thank staff at appropriate opportunities.	• Survey feedback shared and quality improvement plan shared with the Maternity Services Staff.	• Patient experience and staff morale.	Completed
	• Communication workshop.	• Training provided to all Maternity staff regarding the National Healthcare Communication Programme, Module 1-4. • Staff working in Maternity services to complete the HSE programme *Breaking bad news* (Target 80% of staff).	• Women and their families will have an improved experience of communication following pregnancy and perinatal loss, as staff develop on communication skills.	Q4 2023
	• Bereavement education.	• Creation of a Multi-Disciplinary Perinatal Bereavement forum specific to maternity to provide leadership and oversee quality improvements in bereavement care. This group will contribute to the Hospital End-of-Life Committee.	• To co-ordinate bereavement care and lead on quality improvement plans in maternity services.	Completed
Written information for parents.	• Ensure women and partners have a written support to refer to in their journey of care.	• Updated information booklet for bereaved parents: *What happens when your baby dies*. • The booklet contains details of support groups and contact information for the Hospital, inclusive of the Hospital Chaplin and Medical Social worker. • The booklet is provided to all parents, for all types of losses including early miscarriages, in parallel of a discussion about their personal situation.	• Women and their partners are provided actively with information of the supports available to them throughout the hospital and support groups. • They can refer to this information in their own time, after a diagnosis, to prepare themselves to the next stages of their care.	Jun-23

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Physical Environment.	• Create a dedicated area in the Early Pregnancy Unit, including a counselling/quiet room.	• Room identified for use as counselling/quiet room for women who are experiencing pregnancy loss or have a baby with a life limiting condition. • Room furnished in a sensitive way, with possibility to accommodate partners or support persons and reserved for the use of mothers who are bereaved or have a baby with a life limiting condition.	• Mothers and families will benefit from a dedicated sensitive room, allowing them dignity and privacy. The room is permanently reserved for these families.	May-23
Specialist services and pathways for pregnancies complicated with life limiting conditions.	• Improved access and pathways for women with life limiting conditions.	• Development of new Fetal Medicine service (January 2022) to ensure the pathways are available and meet the needs of women whose pregnancy is complicated by a life limiting conditions.	• Women will have an improved experience of bereavement care where their pregnancy is complicated by life limiting conditions.	Jun-23

POSTNATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Education and Support for managing the physiological changes in the breast following a pregnancy and a perinatal loss.	• Information and education regarding breast care following a perinatal loss.	• Development of a condition-specific information booklet on breast care following pregnancy and perinatal loss. This will be available in written format, or through a QR code in different languages. • Referral pathway established for bereaved mothers, and service communicated to the MDT to promote appropriate referrals. • Training for all clinical staff on breast care following pregnancy loss (to include all methods of suppression of lactation for women following pregnancy and perinatal loss).	• Women provided with quality written information about lactation after a pregnancy loss, to support verbal discussions with the staff and educated decisions about options. • General staff knowledge improved and dedicated resources identified, to ensure continuity of high quality of care to women in relation to breast care.	May-23

POST-MORTEM EXAMINATION AND INVESTIGATIONS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Follow up on Investigations and Communicating Results.	• Improve the counselling provided in relation to investigations including post mortem examinations following pregnancy loss.	• Details of recommended investigations are readily available in all of the clinical areas and in the pregnancy loss care pathways. • Development of a detailed information booklet for women and partners in relation to Post Mortem examinations. • Review of process to ensure results are communicated to women and their partners in a timely and appropriate manner. • Strengthen coordination on results communication and follow up through the Bereavement Midwives, Consultant Obstetricians and Pediatrician. • Increase the uptake and availability of perinatal post mortems within our network.	• Women and partners will be supported into making an informed decision about post mortem examination. • Results will be communicated in a timely and coordinated manner to the women and their partner.	May-23

FOLLOW UP CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Post delivery care.	• Facilitation of follow up in the hospital and communication.	• Generic email set up for Bereavement Support service to ensure continuity of cover when the Bereavement Midwife is on leave. • Women systematically provided with contact details the Bereavement Midwife. • Improvement of communication post pregnancy loss to Public Health Nurses and General Practitioners. • Improvement of pathways for women and their families returning to the hospital post pregnancy loss for outpatient follow up. • External rooms for follow up meetings outside of the hospital setting (if preferred by the women and their families). • Creation of a recurrent miscarriage clinic to allow parents to be linked in with appropriate services.	• Women will have access to a dedicated member of staff with continuity of service and support during leaves of the Bereavement Support Midwife. • Trauma of returning to hospital for follow up will be lessened through separated setting. • The primary care team caring for women and their families will be informed of the case summary in a timely manner which will improve their ability to support the woman and their family.	Q2 2023
Subsequent pregnancies.	• Special pathways for women having experienced a loss who are pregnant again.	• Creation of dedicated pathways for early access to maternity services such as scans, mental health midwife, early antenatal classes for women who have had a previous experience of pregnancy loss.	• Women and their partners will be accompanied and supported through the subsequent pregnancy, by staff cognisant of their previous loss experience.	Q2 2023

OVERALL CARE				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Bereavement awareness and communication skills.	• Inform and thank staff at appropriate opportunities.	• Survey feedback shared and discussed with the Multi Disciplinary Team, as well as made available in each clinical area of Maternity. • Facilitation of sessions at multiple forums to present the feedback from the survey.	• Patient experience and staff morale.	Completed
	• Communication workshop.	• 5 additional staff supported to undertake *Train the trainer* programmes (National Healthcare Communication Programme Module). • Target of 50% of the multidisciplinary staff (clinical and non-clinical) trained in the first 6 months of 2023.	• Women and their families will have an improved experience of communication following pregnancy and perinatal loss, as staff develop on communication skills.	Q4 2023
	• Bereavement education.	• Bi-monthly multidisciplinary departmental bereavement meeting reinstated to provide leadership and to oversee quality improvements in bereavement care.	• To co-ordinate bereavement care and lead on quality improvement plans in maternity services.	Completed
		• Education sessions for all maternity staff led by Bereavement Support Midwife on relevant topics (training needs analysis conducted by a staff member undergoing the Higher Degree Programme in Bereavement care).	• Patient experience, through improved awareness of bereavement care for all staff.	Commenced Jan 2023. Ongoing.
		• Development of a local study day in relation to perinatal bereavement, in collaboration with the Centre for Nurse Midwifery Education (CNME).		Q2 2023
		• Bereavement Support Midwife undertaking education through the *Teardrop* initiative and the Perinatal Bereavement MSc module with University Limerick (UL).		Ongoing
Written information for parents.	• Ensure women and partners have a written support to refer to in their journey of care.	• Updated information booklet for bereaved parents: *What happens when your baby dies.* • The booklet contains details of support groups and contact information for the Hospital, inclusive of the Hospital Chaplin and Medical Social worker. • The booklet is provided to all parents, for all types of losses including early miscarriages, in parallel of a discussion about their personal situation.	• Women and their partners are provided actively with information of the supports available to them throughout the hospital and support groups. • They can refer to this information in their own time, after a diagnosis, to prepare themselves to the next stages of their care.	Jun-23

POSTNATAL CARE				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Physical environment.	• Enhancing women's and families' experience in relation to the environment where care is delivered.	• Midwives most suitable HCP to deliver high-quality maternity care and, as such, this care is provided in maternity ward setting to enhance patient safety and experience.	• Patient safety.	Ongoing
		• Upgrade of Bereavement Room: remodelling which will include improved sound-proofing, family facilities, and ensuite.	• Dedicated rooms allowing more privacy for the bereaved mothers and family. • Helpful and informative signage and possibility of dedicated access and exit route will offer the option to lower the encounters with pregnant women or babies, if this is the choice of the women and their families.	Apr-23
		• Review access and exit from the Maternity scan room and the Maternity Unit.		Ongoing
		• Review and erect new signage in both the antenatal and maternity areas.		Ongoing
		• Promotion of the availability of the Counselling room in the Maternity scan room.		Ongoing
Lactation care in pregnancy loss.	• Improve staff knowledge relating to lactation care and pregnancy loss. • Enhance written documentation available to women on lactation and pregnancy loss.	• Training for all clinical staff on breast care following pregnancy loss (to include all methods of suppression of lactation for women following pregnancy and perinatal loss). • Additional Breastfeeding Support Midwives appointed to increase the support available in order to meet women, antenatal and postnatal, to discuss all options including banking expressed breast milk and suppressing lactation etc. • Development of a condition-specific information booklet on breast care following pregnancy and perinatal loss. This will be available in written format, or through a QR code in different languages. • Referral pathway established for bereaved mothers, and service communicated to the MDT to promote appropriate referrals.	• Women provided with quality written information about lactation after a pregnancy loss, to support verbal discussions with the staff and educated decisions about options. • General staff knowledge improved and dedicated resources identified, to ensure continuity of high quality of care to women in relation to breast care.	Q2 2023

POST-MORTEM EXAMINATION AND INVESTIGATIONS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Follow up on Investigations and Communicating Results.	• Improve the counselling provided in relation to investigations including post mortem examinations following pregnancy loss.	• Details of recommended investigations are readily available in all of the clinical areas and in the pregnancy loss care pathways. • Development of a detailed information booklet for women and partners in relation to Post Mortem examinations. • Review of process to ensure results are communicated to women and their partners in a timely and appropriate manner. • Strengthen coordination on results communication and follow up through the Bereavement Midwives, Consultant Obstetricians and Pediatrician. • Increase the uptake and availability of perinatal post mortems within our network.	• Women and partners will be supported into making an informed decision about post mortem examination. • Results will be communicated in a timely and coordinated manner to the women and their partner.	May-23

FOLLOW UP CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Follow up care.	• Ensure a sensitive follow up care is provided within and beyond the hospital.	• Women systematically provided with contact details for the Bereavement Midwife. • Improvement of communication post pregnancy loss to Public Health Nurses and General Practitioners. • Improvement of pathways for women and their families returning to the hospital post pregnancy loss for outpatient follow up. • External rooms for follow up meetings outside of the hospital setting (if preferred by the women and their families). • Continuation of the two-weekly "Pregnancy Loss Clinic". • Women are referred to a Psychotherapy service where clinically indicated.	• Trauma of returning to hospital for follow up will be lessened through separated setting. • The primary care team caring for women and their families will be informed of the case summary in a timely manner which will improve their ability to support the woman and their family.	Q2 2023

OVERALL CARE				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Bereavement Support in hospital.	• Ensuring the Bereavement Support role is performed in line with Standards.	• Recruitment of a new Bereavement Support Midwife to fill the vacant position in Sligo University Hospital.	• The Bereavement Midwife in Sligo University Hospital (SUH) will develop sustainable improvements in the care of women and their partners who have experienced pregnancy loss.	Q1 2023
		• Complete a gap analysis between Sligo University Hospital and the HSE National Standards for Bereavement Care following pregnancy and perinatal loss to strengthen governance, enhance bereavement culture, and identify additional areas for improvement.		Q3 2023
Bereavement awareness and communication skills.	• Inform and thank staff at appropriate opportunities.	• Survey feedback shared and quality improvement plan shared with the Maternity Services Staff.	• Patient experience and staff morale.	Completed
	• Communication workshop.	• Training provided to all Maternity staff regarding the National Healthcare Communication Programme, Module 1-4. • Staff working in Maternity services to complete the HSE programme *Breaking bad news*.	• Women and their families will have an improved experience of communication following pregnancy and perinatal loss, as staff develop on communication skills.	Q4 2023
	• Bereavement education.	• Creation of a Multi-Disciplinary Perinatal Bereavement forum specific to maternity to provide leadership and oversee quality improvements in bereavement care. This group will contribute to the Hospital End-of-Life Committee.	• To co-ordinate bereavement care and lead on quality improvement plans in maternity services.	Completed
Written information for parents	• Ensure women and partners have a written support to refer to in their journey of care.	• Updated information booklet for bereaved parents: *What happens when your baby dies*. • The booklet contains details of support groups and contact information for the Hospital, inclusive of the Hospital Chaplin and Medical Social worker. • The booklet is provided to all parents, for all types of losses including early miscarriages, in parallel of a discussion about their personal situation.	• Women and their partners are provided actively with information of the supports available to them throughout the hospital and support groups. • They can refer to this information in their own time, after a diagnosis, to prepare themselves to the next stages of their care.	Jun-23

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Physical Environment.	• Create a dedicated area close to the Maternity Scan Room.	• Review the clinical environment in the Maternity Scan room area to identify a separate private area for women who are experiencing pregnancy loss. This may be used as a waiting area and a quiet room. • Scheduled appointments for parents where it is known that their baby has died or has a known life-limiting condition so they can avoid wait times with other women and couples. • Offer to have a member of staff meeting the parents and bringing them in the room directly for subsequent appointments, in order to avoid wait times.	• Sensitive environment for women who have experienced a bereavement, maintaining dignity and respect for bereaved families.	May-23
Specialist services and pathways for pregnancies complicated with life limiting conditions.	• Improved access and pathways for women with life limiting conditions.	• Development of new Fetal Medicine service (October 2023) to ensure the pathways are available and meet the needs of women whose pregnancy is complicated by a life limiting conditions.	• Women will have an improved experience of bereavement care where their pregnancy is complicated by life limiting conditions.	Q4 2023

POSTNATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Lactation care in pregnancy loss.	• Improve staff knowledge relating to lactation care and pregnancy loss. Enhance written documentation available to women on lactation and pregnancy loss.	• Additional Breastfeeding Support Midwives appointed to increase the support available in order to meet women, antenatal and postnatal, to discuss all options including banking expressed breast milk and suppressing lactation etc. • Referral pathway established for bereaved mothers, and service communicated to the MDT to promote appropriate referrals. • Development of a condition-specific information booklet on breast care following pregnancy and perinatal loss. This will be available in written format, or through a QR code in different languages. • Introduction of a referral pathway to a lactation specialist for women who require additional support regarding breast care. • Training for all clinical staff on breast care following pregnancy loss (to include all methods of suppression of lactation for women following pregnancy and perinatal loss).	• Women provided with quality written information about lactation after a pregnancy loss, to support verbal discussions with the staff and educated decisions about options. • General staff knowledge improved and dedicated resources identified, to ensure continuity of high quality of care to women in relation to breast care.	Q2 2023

POST-MORTEM EXAMINATION AND INVESTIGATIONS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Follow up on Investigations and Communicating Results.	• Improve the counselling provided in relation to investigations including post mortem examinations following pregnancy loss.	• Details of recommended investigations are readily available in all of the clinical areas and in the pregnancy loss care pathways. • Development of a detailed information booklet for women and partners in relation to Post Mortem examinations. • Review of process to ensure results are communicated to women and their partners in a timely and appropriate manner. • Strengthen coordination on results communication and follow up through the Bereavement Midwives, Consultant Obstetricians and Paediatrician. • Increase the uptake and availability of perinatal post mortems within our network.	• Women and partners will be supported into making an informed decision about post mortem examination. • Results will be communicated in a timely and coordinated manner to the women and their partner.	May-23

FOLLOW UP CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Post delivery care.	• Facilitation of follow up in the hospital and communication.	• Generic email set up for Bereavement Support service to ensure continuity of cover when the Bereavement Midwife is on leave. • Women systematically provided with contact details the Bereavement Midwife. • Improvement of communication post pregnancy loss to Public Health Nurses and General Practitioners. • Improvement of pathways for women and their families returning to the hospital post pregnancy loss for outpatient follow up. • External rooms for follow up meetings outside of the hospital setting (if preferred by the women and their families). • Creation of a recurrent miscarriage clinic to allow parents to be linked in with appropriate services.	• Women will have access to a dedicated member of staff with continuity of service and support during leaves of the Bereavement Support Midwife. • Trauma of returning to hospital for follow up will be lessened through separated setting. • The primary care team caring for women and their families will be informed of the case summary in a timely manner which will improve their ability to support the woman and their family.	Q3 2023
Subsequent pregnancies.	• Special pathways for women having experienced a loss who are pregnant again.	• Creation of dedicated pathways for early access to maternity services such as scans, mental health midwife, early antenatal classes for women who have had a previous experience of pregnancy loss. • Creation of bespoke “Rainbow Babies” antenatal classes for women and their partners.	• Women and their partners will be accompanied and supported through the subsequent pregnancy, by staff cognisant of their previous loss experience.	Q3 2023

South/South West Hospital Group

University Hospital Kerry
Cork University Maternity Hospital
University Hospital Waterford
Tipperary University Hospital

On behalf of the South/South West Hospital Group (SSWHG), I welcome the National Maternity Bereavement Experience Survey report and especially thank the parents who have taken the time to participate in the survey, share their experiences and their feedback. The loss of a baby during pregnancy, birth or afterwards is devastating and it is our intention that all bereaved parents receive consistent, compassionate care that is appropriate to their needs. The learning from the experiences of bereaved parents from this survey is essential to enable us to continuously improve our services and enhance the quality and experience of the care we provide.

I would like to acknowledge the work of all our staff in the Ireland South Women and Infants Directorate who have worked tirelessly across our four maternity units in the implementation of the National Bereavement Standards published in 2016. These standards have continually provided the necessary guidance to enhance our bereavement care services and are a vital resource for our staff in responding to parents who have experienced the loss of a baby during pregnancy, birth or afterwards.

Our four maternity units within the Ireland South Women and Infants Directorate have reviewed the results of the survey findings individually and collectively. The survey recognises areas of high-quality care within Ireland South Women and Infants Directorate as part of the SSWHG, achieving high quality ratings in areas such as, Admission Care, Labour and Birth, Care after Birth, Neonatal Care. This demonstrates the impact of the improvements in care following the National Bereavement Standards implementation leading to appointments of Clinical Midwife Specialists in Bereavement and the dedication of our staff in each of our maternity units.

This survey provided an opportunity for improvements to be identified by the parents and are welcome in assisting us to identify where further work is required. Areas highlighted include discharge planning and written information. Quality Improvement Plans have been developed and the Ireland South Women and Infants Directorate are committed to implementing the agreed actions over the coming months working with the National Women and Infants Health Programme, Health Information and Quality Authority and the Department of Health.

As CEO of the SSWHG, I am committed to improving our patients experience and we will continue to work in partnership with parents to improve the quality and experience of our Maternity Bereavement services.

Yours sincerely,

Dr Gerard O'Callaghan
Acting Chief Executive Officer, South/South West Hospital Group

OVERALL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Staff communication skills are of great importance to bereaved women and their partners.	• Women have two fundamental needs: the need to know and understand; and the need to feel known and understood.	• National Healthcare Communication Programme – Module 1 '*Making Connections*' and Module 2 '*Core Consultation Skills*' attendance.	• Information communicated in a manner that can be easily understood by women and their families (written/verbal). • Recognising and listening to women's worries and concerns.	Ongoing
'How' staff communicate with women is as important as 'what' they say.	• Women reported difficulties understanding professional 'jargon'; receiving too much or too little information; receiving information at the wrong time or information that undermined their confidence in the care they were receiving.	• National Healthcare Communication Programme – Module 4 '*Communicating with Colleagues and Supporting Teamwork*' attendance.		Q2 2024
		• Bereavement Education study day for multidisciplinary team – audited annually.		Ongoing
		• Open Disclosure e-learning.		Ongoing

BEREAVEMENT CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Staff knowledge and skills in the delivery of appropriate bereavement care.	• Management of delivery.	• Management of delivery: – Bereavement Education for appropriate clinical staff to include intrapartum and postnatal care.	• Improved management of delivery.	Ongoing
	• Feeling that you can hold baby for as long as you wish.	• Pathway and education in place to ensure service users feel that they can hold their baby for as long as they wish.	• Ensure parents have the opportunity to hold their baby for as long as they wish.	Ongoing
	• Offering Bereavement support.	• Care calls offered to all women by CMS Bereavement in place, initial care call within 1st week of discharge home and follow up care calls as deem appropriate (dependent on mother's needs).	• Offering Bereavement support (including timely care calls).	Ongoing
	• Opportunity to hold baby after post-mortem.	• Opportunity to hold baby after post-mortem – associated staff education to be scheduled.	• Opportunity to hold baby after post-mortem to be offered routinely.	Ongoing
	• Appropriate environment for follow up care/ appointments.	• Completion of new "Snow Drop" bereavement room.	• Appropriate environment for follow up appointments.	Q2 2023
	• Visitation of family and friends facilitated.	• Visitation limited during National COVID-19 restrictions only.	• Visitation of family and friends facilitated.	Depending on COVID context.

DISCHARGE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Information (both verbal and written) provided following diagnosis and prior to discharge.	• GP's awareness of baby loss prior to women attending. • Enriching information provided prior to discharge, especially around follow-up care and mental health awareness.	• Pathway operational to ensure GP's are informed verbally of baby loss, extending the pathway in place for stillbirths to 2nd trimester losses to include verbal communication.	• GP's are informed verbally of baby loss on mother's admission.	Ongoing
		• Intra Uterine Death University Hospital Kerry draft patient information leaflet to be reviewed and amended as appropriate for Maternity Services University Hospital Kerry(including services user input and approved by University Hospital Kerry Bereavement Committee).	• Provision of Intra Uterine Death Maternity Services University Hospital Kerry Patient Information Leaflet.	Q2 2023
		• Evaluation and development of information relating to follow up care (appointments). Perinatal deaths require considerable information – information set may include (verbal/written/web resources): – follow up care – mental health awareness.	• Availability of considerable information (written/ web based resources) to support in parallel with verbal information provided by healthcare staff: – follow up care – mental health awareness.	Q3 2023

OVERALL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Compassion and kindness.		• Implementation of National Clinical Care Pathways for Pregnancy Loss. • Continuing the provision of *Teardrop* Education in CUMH Commence education of Irish hospice Foundation for *Dealing with Loss in Maternity Services*.	• Awareness among staff through managed implementation of national guidelines. • Support for staff through national and local education sessions.	Q4 2023
Staff education in relation to bereavement.	• Developing staff training and education around bereavement care, especially in the immediate time after diagnosis.	• Develop/Review Education & Training for staff in *Breaking Bad News* maternity/neonatal specific. • Secure funding for local resource Fetal Medicine Coordinator. Recruitment in 2023. • Continuing the provision of *Teardrop* Education in CUMH with Clinical Midwife Specialist Bereavement & Loss leading in collaboration with the Centre of Midwifery Education (CME).	• Parents will be better supported, by staff educated and aware of bereavement care. • Designated resource for parents to liaise with directly on the diagnosis and management in pregnancy.	Q3 2023

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Suitable place for communicating bad news.	• Staff awareness of the importance of environment when breaking bad news.	• Staff awareness and reminders to utilise the dedicated spaces available when giving parents an unexpected diagnosis, such as the private counselling space allocated for breaking bad news in the CUMH fetal assessment area.	• Parents will be given bad news in a private and sensitive area.	Q2 2023
Written information at the time of diagnosis.	• Written information at the time of diagnosis.	• Develop an information leaflet with contact details and a nominated link for the patient to contact after they have received an unexpected diagnosis for diagnosis. • Audit of the fetal medicine service in relation to waiting times, standardisation of information and staff education by the fetal medicine coordinator.	• Women will have a dedicated person to support person, if they have questions returning home after an unexpected diagnosis. • Meet with expert midwifery staff in relation to communication and care following a diagnosis of pregnancy loss. • Audits to improve patient experience and targeted staff education.	Q4 2023

CARE AFTER BIRTH AND MEETING YOUR BABY

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Meeting your baby.	• Staff education to prepare and support parents in meeting their baby.	• Implementation of National Clinical Care Pathways for Pregnancy Loss. • Continuing the provision of *Teardrop* Education in CUMH with CMS Bereavement & Loss leading in collaboration with the CME. • Commence education of Irish hospice Foundation for *Dealing with Loss in Maternity Services*.	• Parents will be supported in a sensitive manner to meet with their baby. • Availability of Education for all staff who are working with parents who are dealing with a pregnancy loss including early neonatal death.	Q4 2023

POSTNATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Breast Care & Lactation Support	• While you were in hospital, were you given information and support with breast care and lactation	• Involve lactation consultants in breast care and lactation support in second and third trimester loss. • Create a referral route to the Lactation team. • Develop an information leaflet with contact details for parents on postnatal care after a pregnancy loss.	• Parents will be supported in a sensitive manner on what to expect after a loss on postnatal care. • Availability of education for all staff who are working within the pregnancy loss ward and lactation team.	Q4 2023

POST-MORTEM EXAMINATION AND INVESTIGATIONS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
		• Resource a link person working in the Bereavement & Loss service to regularly communicate updates to parents. • Implementation of recommendations in the stillbirth guidelines regarding timely follow up appointments for parents.	• Delegation within the Bereavement & Loss team to communicate regularly to parents following the loss of their baby.	Q4 2023

DISCHARGE				
AREA FOR IMPROVEMENT	**SPECIFIC QIP**	**QIP ACTIONS**	**WHAT WILL IMPROVE?**	**TIMELINE**
Dedicated exit route for bereaved families.	• Communication with the parents on the exit route.	• Parents expressed their dissatisfaction with exiting out the side entrance (Prayer room exit) of the hospital. • Explanation will be given to parents regarding the reason for exiting out via the prayer room to facilitate if they are having a service for the baby it is the easiest entry for family to attend, park and have privacy for a service/discharge.	• Information will be given to parents so that they can choose the exit pathway they wish to leave with their baby.	Q2 2023
Postnatal care information on discharge both verbal and written.	• Communication with parents on Physical and postnatal care.	• Develop information leaflets/ booklet/website on what to expect after a pregnancy loss e.g. Information should include: physical recovery, mental health and awareness, baby's death registration process following pregnancy loss in all trimesters. • Include a list of relevant hospital support and outside support group numbers. • Service user input to the booklet.	• Information provided early in the postnatal period should give parents an opportunity to question any of the information while in hospital. • Offering support services via an information leaflet/ booklet/website with contact details of a hospital liaison person should give additional support to parents following discharge. • Routine follow up with parents within a month of discharge via phone call or appointment with the pregnancy loss team.	Q4 2023

COMMUNICATION AND INFORMATION AT THE TIME OF DIAGNOSIS

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Understanding diagnosis.	• Information to all stakeholders around this is required including discussion prior to discharge.	• Multidisciplinary meeting/drills and skills education to inform the wider team.	• Overall improved understanding for staff on the use of plain English in the delivery of difficult diagnosis-including an understanding that there is often not a definitive diagnosis initially.	Q2 2023
Communication with kindness and sensitivity.	• Staff attendance at *Breaking bad news* delivered by RCNME. • *Final Journeys* course for Neonatal Intensive Care Unit staff.	• Use of the Haven Room to enhance a positive environment with privacy. • DOM/ADOM to determine staff to attend these courses (and others education forum) with priority for key staff.	• Better communication, supporting parents through their loss. • Positive impact on staff as more informed and confident.	Q4 2023
Written information on diagnosis and contact person for further questions.	• Review all written information available at this time. • Review contact information given at the time of diagnosis. • NB: diagnosis is often given by Fetal Medicine Department (external to UHW).	• Gather data. • Review contact details available on coordination of information to the women and families, to ensure consistency. • Discuss with external stakeholders.	• Quality written information and up-to-date contact details available to families and staff to support discussions around care.	Q2 2023

DISCHARGE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Information on physical care & recovery.	• Update information available.	• Update Breast care leaflet. • Update overall postnatal leaflet/ information.	• Understanding of breast changes. • Understanding of the changes in the weeks following delivery.	Q2 2023
Grief experience information prior to discharge.	• Leaflet available but information to all stakeholders around this is required including discussion prior to discharge	• Multidisciplinary meeting/drills and skills education to inform the wider team.	• Overall improved understanding for staff on grieving process, with emphasis on verbal communication. • The women and families will benefit by being more actively and sensitively supported.	
Mental Health information prior to discharge.	• Information to all stakeholders, including discussion that should be undertaken prior to discharge. • Acknowledgement of mental health potential needs during potential subsequent pregnancies.	• Multidisciplinary meeting/drills and skills education to inform the wider team. • Referral to perinatal mental health Clinical Midwife Manager 2 on subsequent pregnancies if required.	• Overall improved understanding for staff on the potential effect on mental health, with emphasis on verbal communication. • The women and families will benefit by being more actively and sensitively supported.	

DISCHARGE (CONTINUED)

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Contact person for physical or mental health concerns.	• Main contact is CMS Bereavement but education of wider team to be undertaken to ensure consistent information and care is provided.	• Multidisciplinary meeting/drills and skills education.	• Overall improved understanding for staff on processes, to support a consistent care of the families.	Q2 2023

PARTNER AND SUPPORT PERSON

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Decisions about baby's care.	• Build in time at all meetings for partner- include all stakeholders in education around this. • Timing of meeting to be flexible to include out of hours if required.	• Ensure Neonatal Intensive Care Unit care discussed if relevant. • Revisit Neonatal Intensive Care Unit alert sheet. • Ensure Senior Midwifery managers are aware of care plan (maximise staffing). • Ensure MSW involved as required.	• Overall communication to include partner. • Empowerment of the couple.	Ongoing
Opportunity to ask questions.	• Build in time at all meetings for partner to ask questions and get answers they can understand.	• Meet with multidisciplinary team to build awareness on building the time and creating the rights conditions for the partner to ask questions. • Communication is supported for a clear understanding: avoid medical jargon, organise for translator to be present if needed.		
Acknowledge needs of partner.	• Individual care plans to include specific requests/ requirements of partner e.g. physical/ cultural/spiritual needs.	• Inform the extended multidisciplinary team.	• Care pathway for partners, supporting their needs.	Q4 2023
Time with baby.	• Specific information to the family around time with baby potential interruptions e.g. post-mortems and investigations.	• Coordinated by the Clinical Midwife Specialist Bereavement. • Updated information for staff to include use of the Haven room out of hours.	• Better understanding of processes and occasional interruptions prior to discharge.	Ongoing

POSTNATAL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Care and support with physical recovery after the birth of baby.	• Provision of sensitive accommodation to mothers and support persons.	• Tipperary University Hospital have now available recliner chairs in two of the larger private rooms for family/ support person to provide extra comfort at this difficult time. These rooms are located at ward entrance, Labour Ward & SCBU are located at opposite end of corridor. • Staff awareness on the use of the end of life symbol on display at room entrance. Prior notice is given to the patient and support persons. • Refreshments, parking and meals are provided for mothers and support persons.	• Patients and support persons will benefit from sensitive accommodation allowing the support person to stay at the hospital.	Feb-23
Support with breast care and lactation.	• Written information and staff training on breast care.	• Development of a supportive information leaflet *Breast Care following the loss of your baby* with explanations, comfort measures, pain relief, supports in hospital, when at home and useful numbers to contact. • Leaflet reviewed by patient advocacy and patient representative from the Hospital Patient Service Users Representative Forum and Tipperary UH Inclusion Working Group. • Leaflet initial launch with hospital staff at Perinatal Monthly meeting to ensure staff education and awareness of contents. • Leaflet then made available to all staff. Second launch with Education and training by Bereavement Clinical Midwife specialist at Perinatal meeting.	• Information regarding breast care following the loss of their baby will be readily available as a supportive measure, this includes hand expression video links, hospital bereavement support midwife and supportive contact details. • All staff will be aware of the leaflet and knowledgeable on its content, to provide a consistent support to the women.	Feb-23

BEREAVEMENT CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Information and support for arranging a funeral (service) for baby.	Provision of information and 1-to-1 bereavement support.	• Development of an information leaflet *Final Journey Care* for bereaved parents and family. • This will provide information on options available for their loved one to include options for burial/ cremation and confidence for parents in their decision making for these precious last moments. • Leaflet launch, along with Education and training by Bereavement Clinical Midwife specialist at Perinatal meeting. • A Bereavement Clinical Midwifery Specialist commenced in post in June 2021.	• Information and support will be available to facilitate parental decision-making and reiterated by Tipperary University Hospital *Final Journey Care* leaflet. • All staff will be aware of this leaflet and its contents to assist with facilitating support. • Post COVID opportunities for family to meet your baby have returned.	Feb-23

DISCHARGE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Information about: – physical care; – experience when grieving; – who to contact if you had concerns or worries about your physical or mental health; – follow-up care plans and appointments.	• Provision of information and support by dedicated specialised staff.	• Development of a leaflet *What to expect when you are grieving*, inclusive of all areas of pregnancy loss. • In consideration of findings and comments from the NMBES Tipperary University Hospital, to coordinate and amalgamate information regarding physical care, experiences you may have whilst grieving, effects on your mental health and supports available, contact details for supportive personnel and hospital follow-up appointments. • This will include: physical, emotional and psychological care for the mother, her partner, siblings and family. • Facilitation of information and education sessions for ethnic minorities and vulnerable persons, in conjunction with the TUH Inclusion Working Group.	• Tipperary University Hospital has a Specialist Clinical Midwife in Bereavement available to support those that have experienced loss. • Holistic care given on a case by case basis. • Bereavement Midwife will be the link between patient/consultant/ results to optimise key relationships at this difficult time.	Jun-23

University Limerick Hospital Group

Ospidéil OL
UL Hospitals
Working together, caring for you

This is the first year of the National Maternity Bereavement Experience Survey, a national survey asking bereaved women and their partners about their experiences of maternity bereavement care in Ireland.

It forms part of the National Care Experience Programme (NCEP), a partnership between the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. The NCEP is now firmly established as a key driver of quality improvement across our hospitals in Ireland.

Over 50 of our bereaved parents participated and I would like to thank each and every one of them for sharing their experience with us and we acknowledge how painful and difficult it is to do this. We are very grateful for the invaluable feedback which we will use to improve the quality and safety of our maternity bereavement care and services.

We are committed to addressing those areas where our patients were dissatisfied with our services. The survey feedback has given us the opportunity to drive new quality improvement initiatives locally which are detailed in this document.

We were also pleased to hear the positive feedback and comments on the care provided by our doctors, midwives and staff at University Maternity Hospital Limerick (UMHL) and I would like to thank our staff who provided compassionate care in a skilled manner to bereaved women and their families at this difficult time.

Our staff continue to take a keen interest in the results of surveys conducted through the NCEP to help them improve our patients' experience in hospital. Now, with the addition of the National Maternity Bereavement Experience Survey, they can improve the experience for those using our maternity services at a difficult time of pregnancy loss.

We are looking forward to implementing these improvements in the months ahead.

Yours sincerely,

Ms Colette Cowan
Chief Executive Officer, UL Hospitals Group

OVERALL CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Communication. Service users identified the need to improve communication skills by multidisciplinary team in supporting women and their families.	• UMHL in partnership with National HR and CNME will continue to focus on the implementation of National Healthcare Communication Programme to promote best practice in communication skills and improved experience for women through bereavement care.	• All multidisciplinary team members in UMHL will participate in National Healthcare Communication Programme, building on Module 1 *'Making Connections',* Module 2 *'Core Consultation Skills'* to Module 3 *'Challenging Consultations'* & Module 4 *'Communicating with Colleagues and Promoting Teamwork'* (with compliance rate of 75% for Module 1 by Q3, 2023).	• Following training staff will be enabled to communicate skillfully on attitude, behaviour and communication with service users.	Q3 2023
		• University Maternity Hospital, Limerick will commence the roll out of the National recognised bereavement study day *Dealing with Bereavement and Loss in the maternity setting* will be available to all members of the multidisciplinary Team in UMHL. Four training dates will be available for 2023.	• Staff will have the knowledge and skills to break bad news in an appropriate manner.	Q4 2023

BEREAVEMENT CARE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Environment/ infrastructure. Services users identified the requirement for improved environment for families during bereavement journey.	• UMHL to engage with Irish Hospice Foundation design & dignity grant to submit an application for funding to upgrade current inpatient bereavement facilities. • UMHL currently upgrading bereavement & Loss department.	• To submit an application for funding to Irish Hospice funding, to enhance a single room for bereaved families in an the inpatient environment on antenatal ward. • To engage with HSE estates to support application. • To engage with service user on the design of the facility. • A new area has been identified for bereavement & loss department which will include a refurbished oratory and separate counselling department, which department will be nearer to hospital entrance.	• To provide a more supportive environment for bereaved families.	Q4 2023

DISCHARGE

AREA FOR IMPROVEMENT	SPECIFIC QIP	QIP ACTIONS	WHAT WILL IMPROVE?	TIMELINE
Discharge Care Service users identified the need for better information about: – Follow up care plans – Discharge advice – Support services	• UMHL in collaboration with the multidisciplinary team, service users and community partners will develop specific discharge information with corresponding QR codes to ensure service users. • Have access to health information specific to the physical, emotional and psychological needs and supports following a bereavement.	• Develop individualised care plans for service users for all pregnancy loss, still birth & neonatal death with a clear discharge and follow up pathway incorporating a follow up call from a member of the bereavement and loss team to parents within 7 days. • Develop a discharge booklet to provide comprehensive physical, emotional and psychological health information for bereaved parents incorporating QR codes and sign posting to additional supports available in the community. • The booklet will include information about breastcare. While there is no mandatory consultation with a lactation specialist, this will be facilitated either on recommendation of the Bereavement & Loss team or request of the women. • The booklet will be inclusive of all types of loss, at all stages of pregnancy, the booklet will be developed by Bereavement & Loss team in consultation with UMHL Perinatal steering committee. • The Perinatal steering committee, which involves services users and local representative of Féileacáin, will be involved in the design of the booklet. The first booklet will be produced in English language, and post pilot will be developed in other languages.	• This will facilitate for a seemless transition from the acute to the community setting with comprehensive health information and support service available on discharge. • A care plan specific to the individuals needs of each service user will ensure that care is family centered and appropriate.	Q3 2023

Appendices

Additional Messages of Support

Neonatology

The findings of the National Bereavement Experience Survey are welcomed by the National Clinical Programme for Neonatology. The feedback obtained from service user's experiences of neonatal services is of paramount importance in order to implement changes and create better experiences for bereaved parents. The Neonatal Model of Care is currently being updated and the lived experiences of parents in terms of neonatal services is implicit in the development of the Neonatal Model of Care whereby its key values seeks to ensure staff are approachable and that a culture of open disclosure with parents is fostered.

This survey was undertaken for the timeframe when the Irish Health service was under severe pressure in terms of the COVID-19 pandemic. Infants within the Neonatal Intensive Care Unit (NICU) are one of the most vulnerable cohorts of the population and COVID-19 further compounded their vulnerability rendering the necessity to restrict access to the NICU. Despite restricted access it is encouraging to note the positive experiences of bereaved parents within the NICU.

The NICU teams and the National Clinical Programme for Neonatology is continuously striving to improve the quality of services provided and note the survey results whereby there was a degree of dissatisfaction amongst respondents in terms of involvement of decisions about babies care and treatment. The delivery of end of life care is complex and very much differs from one experience to another as a result of varying presenting circumstances.

Since this survey was conducted funding has been invested in Neonatology in order to facilitate an multidisplinary team family centre care approach in the NICU with the funding of further Consultant Neonatology posts, Speech and Language Therapists, Occupational Therapists and Clinical Neonatal Psychologists. It is anticipated that the expansion of the MDT will contribute positively to the NICU experience.

Dr John Murphy
National Lead for Neonatology
National Women and Infant's Health Programme

Additional Messages of Support

Directors of Public Health Nurses Service (DPHN)

The Directors of Public Health Nurses welcomes the report of the National Maternity Experience Survey and thank the many women who contributed their feedback in the survey. It is important for the improvement of the health system that the voices and experiences of women and partners who have a pregnancy loss are heard.

The Directors of Public Health Nursing were delighted to be able to promote engagement with the National Maternity Bereavement Experience Survey in 2022 via the public health nurses (PHNs), and we fully endorse its findings. We will continue to actively promote engagement with initiatives that aim to make meaningful differences to women experiencing bereavement while attending the PHN service, such as the Perinatal Mental Health App for Healthcare professionals and Cascade Training, once it's designed, by the Specialist Perinatal Mental Health Programme (SPMHP). Women said:

> My PHN were amazing. PHN was also very available. She was sensitive and caring. She made herself available without intruding.

> I feel that more information relating to follow on services, support groups could have been given.

In response some work has progressed over the last year in the development of a National Guidance Document and associated Postnatal Record for use by the PHN Service. Also work has progressed in development of a National Standard Maternal and Infant Discharge Summary from Maternity Units to PHN's. Both documents are near completion and will be implemented over the next few months.

We welcome the National Women and Infants Health Programme comprehensive quality improvement plans in response to the survey and will actively participate in their implementation and evaluation nationally and within the community health organisations we are located.

Messages of Support

The Role of the Independent Advocacy Service

The Patient Advocacy Service (PAS) welcomes the HSE's response to the findings of the National Maternity Bereavement Experience Survey 2022. It is important for the improvement of the health system that the voices of patients are heard and form part of ongoing improvements.

Our service was commissioned by the National Patient Safety Office in the Department of Health following recommendation in the Health Information and Quality Authority's (HIQA) 2015 report on the Investigation into Maternity Care in Midland Regional Hospital Portlaoise. Since our launch in November 2019, we continue to develop the Patient Advocacy Service, supporting patients who wish to make a complaint about the maternity care they have received.

The HIQA Portlaoise 2015 report recognised the need for patient's reported experiences to be recorded, listened to and learnt from. It acknowledged the need for such learning to be shared between hospitals, within hospital groups, and nationally through the wider health system.

The ongoing active promotion of the Patient Advocacy Service by Maternity services will be a key action in driving quality improvement across all participating hospitals and community care areas.

We welcome collaboration with Maternity services and recognise that this opportunity to engage with the Hospital Groups will greatly enhance the experience of patients during labour, birth and post birth and will promote shared learning. Promotion of our service will also support and enhance best practice in how healthcare staff engage with women throughout their maternity care.

A key finding of the NMBES 2022 is that women would like greater involvement in the decision-making process during labour, birth and after birth. In addition, participants identified a need for greater information-provision at discharge, particularly in relation to physical recovery, mental health, grieving and follow-up care and appointments.

As 12% of our current caseload is in relation to maternity care, these findings mirror our findings around the importance of good communication, in particular, around discharge. We have experience and understanding of the added value of a fully independent advocacy service in supporting patients. We recognise the need for an empathetic and professional approach to advocacy support, given the difficult experiences that some women deal with through labour, birth and after birth.

The Patient Advocacy Service is delighted for the opportunity to improve support for women and to engage with the Hospital Groups. We look forward to sharing learning and enhancing the experiences of women during labour, birth and after birth.

Joanne Condon
Acting National Manager, National Advocacy Service for People with Disabilities (including the Patient Advocacy Service)

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(7) Government of Ireland. Health (Regulation of Termination of Pregnancy) Act 2018.
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(9) HIQA. Report of the investigation into the safety, quality and standards of services provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise. 2015 May.
(10) HSE. ON THE IMPLEMENTATION OF THE NATIONAL STANDARDS FOR BEREAVEMENT CARE FOLLOWING PREGNANCY LOSS AND PERINATAL DEATH. 2021 July.
(11) HSE. Palliative care competence framework 2014.
(12) HSE. PERINATAL BEREAVEMENT EDUCATION STANDARDS. 2019.
(13) Final Report of the Evaluation of the Introduction of Schwartz Rounds in Ireland.
(14) National Clinical Guidelines in Obsterics and Gynaecology.

Online Supplementary Material

Appendix 3	Ectopic Pregnancy Care Pathway https://pregnancyandinfantloss.ie/ectopic-pregnancy-care-pathway/
Appendix 4	First Trimester Pregnancy Loss Pathway https://pregnancyandinfantloss.ie/first-trimester-pregnancy-loss-care-pathway/
Appendix 5	Second Trimester Pregnancy Loss Pathway https://pregnancyandinfantloss.ie/second-trimester-pregnancy-loss-care-pathway/
Appendix 6	Stillbirth Care Pathway https://pregnancyandinfantloss.ie/stillbirth-care-pathway/
Appendix 7	Neonatal Death Care Pathway https://pregnancyandinfantloss.ie/neonatal-death-care-pathway/
Appendix 8	Perinatal Palliative Care Pathway https://pregnancyandinfantloss.ie/perinatal-palliative-care-pathway/
Appendix 9	Protocol for Medical Management of Intrauterine Foetal Death https://pregnancyandinfantloss.ie/wp-content/uploads/2019/11/MEDICATION-PROTOCOLS-IUFD.pdf
Appendix 10	Medication Protocol for Medical Management of Miscarriage https://pregnancyandinfantloss.ie/medication-protocol-for-medical-management-of-miscarriage/
Appendix 11	List of Perinatal Bereavement Education Programmes https://pregnancyandinfantloss.ie/courses/
Appendix 12	Perinatal Bereavement Care Education Standards https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/bereavement-care/230119-bereavement-education-standards.pdf
Appendix 13	Staff Support Document https://pregnancyand.wpengine.com/wp-content/uploads/2019/03/STAFF-SUPPORT-DOCUMENT.pdf
Appendix 17	COVID-19 Pregnancy Loss Information Poster https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/bereavement-care/covid-19-pregnancy-loss.pdf

Acknowledgements

National Care Experience Programme Steering Group

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Roisin O'Leary	Senior Patient Advocate, Sage Advocacy
Brian Place[6]	Patient representative
Joe Ryan	National Director of Operational Performance, HSE
Sean Egan	Director of Healthcare Regulation, HIQA
Marty Whelan	Head of Communications, HIQA
Orla Healy	National Clinical Director, Quality and Patient Safety, HSE
Yvonne O'Neill	National Director Community Operations, HSE
Mary Day	Interim National Director Acute Operations, HSE

National Maternity Bereavement Experience Survey, Programme Board

Rachel Flynn	Director of Health Information and Standards, HIQA (Chairperson)
Tracy O'Carroll	Head, National Care Experience Programme, HIQA
Conor Foley	Senior Analyst, National Care Experience Programme, HIQA
Anna Maria Verling	Project Lead, National Maternity Bereavement Experience Survey, HIQA
Deirdre Hyland	Patient Safety Surveillance Officer, Department of Health
Laura Mangan	Assistant Principal Officer, Patient Safety Surveillance and Performance Unit, National Patient Safety Office, Department of Health
Dr Cliona Murphy	Clinical Director, National Women and Infants Health Programme, HSE
Angela Dunne	National Lead Midwife, National Women and Infants Health Programme, HSE
Prof Keelin O'Donoghue	National Clinical Lead for the Implementation of Bereavement Standards in Pregnancy Loss & Perinatal Death, HSE
Krysia Lynch	Womens' Representative, AIMS Ireland
Rachel Rice	Parent Representative – Parent Forum, Implementation of National Standards for Bereavement Care
Louise Cooke	Clinical Nurse Specialist Bereavement & Loss Maternity Services, Midlands Regional Hospital, Portlaoise
Gavin Ashe	Administration Officer, Maternity & Gynaecology Policy Unit, Department of Health
Cara Regan Downey[7]	Business Manager, Operations, Performance and Integration, HSE
Denise Lawler	Regional Manager, Healthcare Regulation HIQA
Danny Smith	Assistant Principal, Maternity and Gynaecology Policy Unit, Department of Health
Mairie Cregan	Chairperson, Féileacáin
Aileen Killeen[8]	Senior Operations Manager, Partnering with Patients, Office of the National Director Operational Performance & Integration, HSE

1 Appointed CEO of HIQA and Chair of the Steering Committee in March 2022
2 Until December 2021
3 Until December 2021
4 Until December 2021
5 Until December 2022
6 The late Dr Brian Place was a patient representative on the steering group since its inception in 2017. He sadly passed away in November 2021.
7 Until August 2022
8 From September 2022

National Maternity Bereavement Experience Survey Team

Tracy O'Carroll	Head, National Care Experience Programme, HIQA
Anna Maria Verling	Project Lead, National Care Experience Programme, HIQA
Conor Foley	Senior Analyst, National Care Experience Programme, HIQA
Daniela Rohde	Analyst, National Care Experience Programme, HIQA
Trudi Mason	Project Officer, National Care Experience Programme, HIQA
Róisín Murphy[9]	Research Officer, National Care Experience Programme, HIQA
Donnacha O'Ceallaigh	Project Officer, Information Management, National Care Experience Programme, HIQA

NCEP – HSE internal Steering Group

Joe Ryan (Chair)	National Director, Operational Performance and Integration
Aileen Killeen (Deputy chair)	Senior Operations Manager, Partnering with Patients, Office of the National Director Operational Performance and Integration
Eileen Ruddin	Assistant National Director, Acute Operations, Unscheduled Care
Fidelma Browne	Assistant National Director, Strategic Communications
Kilian McGrane	National Director, National Women and Infants Health Programme
Mary Day	National Director, Acute Operations
Yvonne O'Neill	National Director, Community Operations
Sarah McBride	National Community Operations Team
Jennifer Martin	Clinical Lead, National Quality and Patient Safety Directorate
Patricia Heckmann	Assistant National Director, National Cancer Control Programme

NCEP – HSE Working Group

Aileen Killeen (Chair)	Senior Operations Manager, Partnering with Patients, Office of the National Director Operational Performance and Integration
Angela Dunne	National Lead Midwife, National Women and Infants Health Programme
Diarmuid O'Coimín	National Lead for End-of-Life and Bereavement Care
Laura Monaghan	Client Director, HSE Communications
Maurice Dillon	National Lead for Palliative Care, Operations Planning
Roisin Maguire	National Specialist, Office of the AND Services for Older People – Operations
Elizabeth Kinsella	Partnering with Patients, Office of the National Director Operational Performance and Integration
Hélène Tobin	Partnering with Patients, Office of the National Director Operational Performance and Integration
Orla O'Reilly	Partnering with Patients, Office of the National Director Operational Performance and Integration

HSE Hospital Groups and Maternity Units – National Maternity Bereavement Experience Survey

We acknowledge the work of the Directors of Midwifery, Clinical Obstetric Leads, Bereavement Teams and Quality Managers across all our Maternity Networks:

- Dublin Midlands Hospital Group (DMHG)
- Ireland East Hospital Group (IEHG)
- Royal College of Surgeons in Ireland Hospital Group (RCSI)
- Saolta University Health Care Group
- South South West Hospital Group (SSWHG)
- University Hospital Limerick (UL)

[9] Until November 2022

Glossary of Terms and Abbreviations

AIMS	Association for Improvements in the Maternity Services
BFI	Baby-Friendly Initiative
CHOs	Community Health Organisations
CMS	Clinical Midwife Specialist
CNS	Clinical Nurse Specialist
DOH	Department of Health
DOM	Director of Midwifery
EACH	European Association for Communication in Healthcare
ERCS	Elective Repeat Caesarean Section
FFA	Fatal Fetal Anomaly
HGs	Hospital Groups
HIQA	Heath Information and Quality Authority
HSE	Health Service Executive
ICGP	Irish Congress of General Practitioners
ICMS	Integrated Community Midwifery Service
IOG	Institute of Obstetrics and Gynaecologists (Ireland)
MDT	Multidisciplinary Team
MOC	Model of Care
NCEC	National Clinical Effectiveness Committee
NCEP	National Care Experience Programme
NCPPN	National Clinical Programme for Neonatology
NICU	Neonatal Intensive Care Unit
NND	Neonatal Death
NHCP	National Healthcare Communication Programme
NMBES	National Maternity Bereavement Experience Survey
NMES	National Maternity Experience Survey
NWIHP	National Women and Infants Health Programme
PAS	Independent Patient Advocacy Service
PHNs	Public Health Nurses
RAMP	Registered Advanced Midwife Practitioner
QIP's	Quality Improvement Plan's
SB	Still Birth
SCBU	Special Care Baby Unit
SPMHS	Specialist Perinatal Mental Health Services
YSYS	Your Service, Your Say

Notes

Feedback

All feedback in relation to this report is welcome.

Please send feedback to the report editor:

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