ON THE IMPLEMENTATION OF THE NATIONAL STANDARDS FOR BEREAVEMENT CARE FOLLOWING PREGNANCY LOSS AND PERINATAL DEATH

JULY 2021

National Women & Infants Health Programme

Seirbhís Sláinte Níos Fearr á Forbairt | Building a Better Health Service

Come away, O human child!
To the waters and the wild
With a faery, hand in hand,
For the world's more full of weeping
than you can understand.

From *The Stolen Child* by W. B. Yeats (1865-1939)

Front cover photo by Louise Foott

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1. INTRODUCTION

Above (l-r): *Professor Keelin O'Donoghue, Ms Rióna Cotter*

Introduction

One of the criticisms often levelled at healthcare related documents, reports and standards published in Ireland is failure of implementation. While this is often not the complete story, it can be difficult to find a record of the work done to implement recommendations from these publications, as well as appreciate evidence of related changes in clinical practice. With this in mind we have prepared this report on the programmes of work undertaken to implement the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death, 2016 (the Standards).

Between 2017 and 2021, experts in perinatal bereavement care, bereaved parents and members of support organisations and voluntary groups came together to develop and improve perinatal bereavement care through the implementation of the Standards in all Maternity units. We hope this report does justice to all the work done.

Acknowledgements

The content of this 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. We acknowledge the work and commitment in each Maternity Unit to implement, or begin the implementation of infrastructural recruitment and practice recommendations.

In particular, we would like to acknowledge the support and assistance received from:

The National Women and Infants Health Programme
The Support Groups and Voluntary Organisations
The Bereavement Clinical Midwife/Nurse Specialist Group
The National Implementation Group for the Standards
The Parents Forum
The National Oversight Group for the Standards
All members of the Work Streams and Working Groups
Our colleagues in all 19 Maternity Units
Our colleagues in Cork University Maternity Hospital
Members of the Pregnancy Loss Research Group, University College Cork
The Irish Hospice Foundation

Finally, we are grateful to all the families who shared their experiences of pregnancy loss and perinatal death with us. Their experiences helped inform us of what is necessary to provide high quality bereavement care in our Maternity services.

2. BACKGROUND

This section consists of a number of papers which we hope serve as a comprehensive introduction to this report.

The first of these is reproduced with permission from Wordwell Press's *Birth and the Irish: a Miscellany*, due to be published this year. This chapter: 'Pregnancy Loss: A silent loss and challenging birth' from authors Daniel Nuzum and Keelin O'Donoghue based at the Pregnancy Loss Research Group in University College Cork, sets out the history of pregnancy loss in Ireland and brings us to the present day.

The second piece – on Stillbirth - was written by Keelin O'Donoghue on the occasion of the International Stillbirth Alliance's annual conference coming to Ireland for the first time in 2017. Over 400 hundred delegates from around the world attended the conference, of which one quarter were bereaved parents. This piece also reflects the hopes and plans early in the implementation project for the Standards.

Finally, we include the introduction to the revised Standards document, due to be published in its second edition in 2021.

2.1 Pregnancy Loss: A silent loss and challenging birth

"Pregnancy Loss: A silent loss and challenging birth" in Salvador Ryan (ed.), *Birth and the Irish: a Miscellany* (Dublin: Wordwell Press, 2021, forthcoming).

Introduction

The birth of a baby for most people is a happy event and is as much a social event as it is a familial one. In our current era where most pregnancies lead to the birth of a healthy baby it can be easy to forget that it is not always so. Alongside the excitement and celebration that accompanies most births, there is also the ever present and unwelcome shadow of pregnancy loss and perinatal death. Despite many modern advances in obstetric, midwifery and scientific understandings, up to one in four pregnancies will end in miscarriage, one in every two hundred and forty babies born in Ireland will die just before birth (stillbirth) and a smaller number will die shortly after birth (neonatal death). Globally 2.6 million babies are stillborn annually. The conflation of the high emotion of expectation and pregnancy with the devastatingly low feelings of death and grief leads to an unwelcome and bewildering experience which has a long lasting impact on parents, families, communities and wider society.

Historical situation

As a nation, the legacy of how we responded to the loss of a pregnancy or the death of a baby casts a long shadow over the individual, familial and communal experience of perinatal loss. The experience of this shadow continues to be felt today. The loss of a baby was shrouded in an unspoken cloak of silence and invisibility with little if any opportunity for shared grieving and support. A century ago infant mortality in Ireland was on average one death in every twelve births with the highest rate being one in six births in Dublin. In the early decades since the establishment of the State, infant mortality was almost double in large urban areas; a situation that continued until the 1960's. In a context of high infant mortality one simply cannot consider the history of birth without also recognising the reality and pain of loss. An examination of burial registers from this period presents a confronting and stark reality of this particular loss.

Society & Church(es)

In a context where infant mortality was high, the wider cultural and religious backdrop concerning birth, death and salvation (not unique to Ireland) played a significant role in the societal response to pregnancy loss and infant death. The reality for parents was that in addition to the pain of grief and loss there was a troubling spiritual/ecclesial shadow of invisibility and uncertainty concerning the very existence and status of infants who died before or shortly after birth. The unfortunate and narrow coupling of baptism of a living baby with salvation led to a devastating and yearning reality for parents faced with a disregarding approach to the life of their baby who died before birth or more particularly before or without baptism. The most tragic consequence of this was the denial of the usual and supportive rituals and rites of passage such as a baptism and a funeral to welcome and to say goodbye to a baby. A baby who died without baptism was denied burial in consecrated ground and in effect was disregarded by society. This led to a troubling tableau of burial sites outside consecrated ground, likewise with life-long impact and spiritual pain and uncertainty for parents and families. In a country that was predominately Catholic, concepts like 'limbo' ran deep in popular Catholic understanding and remained so to a greater or lesser degree until formally clarified by Pope Benedict XVI in 2007.

Faced with this harsh backdrop, parents buried their babies under the literal cloak of darkness and secrecy out with consecrated burial grounds or church yards and the usual comforts of religious and community support. Ireland is therefore scattered with the tender rebellions of parents who buried their babies in cilliní, consecrated not by formal religious ritual but by the intention, love and deeply felt and innate value of the life of each baby. In these places of burial there was no public memorial or gravestone and at best there were entries in the margins of burial registers; lives not worthy of their own entry or record. There have been many reclamations of these burial grounds in recent years and notable efforts to give them their place of honour in communities.

Civil Recognition

Civil registration of births has been a legal requirement since 1864. However, this only applied to live births and did not include babies who were stillborn. Civil registration of deaths was introduced a year earlier 1863 and likewise did not apply to stillbirths. The Central Statistics Office did however, begin to count stillbirths (from 28 weeks) for statistical purposes from 1957. Following much effort and campaigning by bereaved parents and support organisations it was not until 1995 that the Civil Registration of stillborn babies was enacted in the *Stillbirths Registration Act, 1994*. Civil registration confers a legal status and acknowledgement and for parents of babies who were stillborn this was a watershed moment in the societal acknowledgement of the life and death of their baby. The definition of 'stillbirth' was and continues to be "a child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who shows no sign of life".

However, with all definitions, the Act excludes earlier pregnancy loss and in particular miscarriage. It remains a painful reality that parents who grieve the death of their baby through late miscarriage and faced with the birth and burial/cremation of their baby will receive no legal recognition of their baby's life with neither a birth certificate, death certificate or a stillbirth certificate. The sensitive and challenging reality of complicated and crisis pregnancy also continues to evolve and has caused our society to reflect on the painful realities of abortion and reproductive rights. However the reality of pregnancy is that ethical complexities are ever-present and rarely manifest in black and white terms. For the purposes of this chapter, it is important to acknowledge that this has always been a painful if unspoken burden -another challenging reality when considering 'Birth and the Irish.'

Current developments

As the definition of stillbirth has evolved globally to include earlier gestations (varying from 20-22 weeks +) a recent study from University College Cork has recommended that the definition used in Ireland be lowered to twenty two weeks gestation and four hundred grammes. However, the reality is that definitions by their nature will always exclude. This raises the question of how then can society recognise and honour those who fall outside any given parameter of civil definition? The experience and practice of parents and families and indeed faith communities has contributed much in this regard. It is a comforting and reassuring fact that even if there is no formal civil recognition for early pregnancy loss, that the provision of ceremonies of blessing, naming and various other religious and secular rituals have responded meaningfully in recent years to publicly mark and honour these short lives. In addition all Irish Maternity units now hold annual ecumenical Services of Remembrance which includes all those who have experienced loss in the Maternity services, one such example is *www.cumhremembers.ie*

There has also been much development in the overall care of babies and families and their experience of care with the publication and implementation of the first ever *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* by the Health Service Executive in 2016.

Breaking the silence

Bereaved parents often remark 'How come I never knew this was a possibility until it happened?'. The very inclusion of a chapter such as this gives voice to what for so many over many generations was a silent and unacknowledged grief. Today, those of us who work in maternity services in whatever capacity wish to acknowledge the reality of loss alongside the joy of healthy newborn life. It is true to say that we consider our care of bereaved families amongst the most important and rewarding work in a maternity hospital. We will continue to work tirelessly through our research to eliminate all preventable stillbirth and we are proud at the Pregnancy Loss Research Group at the INFANT Centre at University College Cork to take our place alongside global colleagues in this regard as researchers.

Pregnancy loss and perinatal death will sadly always be a part of pregnancy and birth. We will not be able to prevent all loss in pregnancy; however, with good care, modern science, compassion and support we can make a difference. Bringing the conversation into the foreground is an important part of that.

2.2 Stillbirth Matters

Written on the occasion of the International Stillbirth Alliance Conference for 2017 which for the first time ever was held in Ireland in September 2017. Published in the Irish Examiner September 22nd 2017

Few complications in a maternity hospital are as emotionally devastating for parents and clinicians as the death of a baby during pregnancy or birth. In these days of modern healthcare, parents anticipate a normal pregnancy and a healthy baby, and their children surviving to adult life. They are deeply shocked and distressed by the loss of an expected child. Extended families and the wider community are also touched by this loss. Healthcare professionals too have come to expect good outcomes in a field of medicine dominated by happy endings, and often feel inadequate and unprepared in the face of parents' grief and distress.

Stillbirth is a major health burden. In the developed world, one in 200 infants is stillborn, meaning they are born with no signs of life. In Ireland, the 2015 Perinatal Mortality Annual Report from the National Perinatal Epidemiology Centre describes 294 infants who were stillborn. While these rates compare well with low and middle income countries internationally, and neonatal mortality continues to reduce, stillbirth rates are steady, and stillbirth remains up to 10 times more common than sudden infant death syndrome.

Stillbirth has relatively recently become an international focus of interest and concern as a preventable death, with the Global Alliance to Prevent Prematurity and Stillbirth (GAPPS) and the World Health Organization (WHO) naming reduction in stillbirth rates as key goals to improve pregnancy outcome. The investigation of causes of stillbirth as well as development of effective interventions to prevent stillbirth have now been classified as a specific global research priority. The 'Recall to Action' in 2016's Lancet Stillbirth series concluded that "ending preventable stillbirths can be achieved through improvements in the health status of women, through improvements in quality of maternity care, and with reductions in social inequities". In Ireland, the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death were also published in 2016, aiming to put bereavement care and parents' needs at the centre of maternity services.

Stillbirths should have the same systematic evaluation as any adult death. In general, the most common causes of stillbirth are investigated, as well as those conditions that might predispose parents to another stillbirth. Understanding reasons helps parents, but may also identify recurrence risks and even identifying a sporadic cause has merit as it can bring closure and provide reassurance. Several risk factors, including demographic and lifestyle factors, and medical or pregnancy disorders have also been associated with stillbirth, and understanding or modifying these can lead to effective interventions in future pregnancy. However, the study of specific causes of stillbirth has been hindered by the absence of uniform protocols of investigation, lack of agreement on classification systems for deaths, as well as public concerns about post-mortem investigations. It is accepted that unexplained deaths do occur, but sometimes these are simply un-investigated stillbirths, and the true rate of unexplained stillbirth should be under 10% overall. Clinicians should therefore continue to advocate for post-mortem examination of the baby and placenta, rather than inferring a cause, and the important role of specialist perinatal pathology within maternity services needs greater focus.

The economic, social, emotional, psychological and professional burden of stillbirth is well documented. The recognition of stillbirth as a significant bereavement is relatively recent, but the death of an infant is now acknowledged as a hugely stressful life event, which may have long-lasting effects on physical and emotional wellbeing. We know that the care parents receive at the time of stillbirth can shape their entire grieving process and affect their ability to cope. Creation of a caring environment, and strategies to enable the family to accept the reality of stillbirth, are now an accepted part of care. Good quality care cannot change what has happened, but bereavement care that does not meet parents' needs can have devastating consequences. The provision of support for parents following stillbirth is therefore a key part of overall care from the maternity services. This support should be initiated from the time of diagnosis and extend through the care provided in hospital and then following discharge. Dedicated bereavement teams contribute much to the support offered to parents, where trained professionals provide appropriate person-centred care and follow-up. While the specialised role of bereavement midwives in particular and other members of the bereavement team is highlighted, bereaved parents rightly expect understanding, kindness and sensitivity from all hospital staff.

For some, stillbirth remains a silent and unacknowledged grief which compounds the trauma of bereavement. Stigma and fatalism continue to hinder investigation of stillbirth, as well as attempts at stillbirth prevention. The lack of public discourse around stillbirth limits public awareness of the prevalence of stillbirth as a possible outcome of pregnancy. Given the extensive impact of stillbirth, there is a clear need for provision of public health information about risk factors for and causes of stillbirth that can help reduce the incidence of preventable deaths.

The International Stillbirth Alliance's (ISA) mission is to raise awareness of stillbirth and to promote global collaboration in the effective prevention of stillbirth and provision of appropriate care for parents whose baby is stillborn. The ISA is a diverse alliance of international organisations, ranging from parental groups and educational institutions to research groups who work together to support the goals of the organisation.

The International Stillbirth Alliance Conference for 2017 (ISA 2017) will for the first time ever be held in Ireland and is taking place this weekend. Organised in University College Cork (UCC), the conference will see around 380 delegates coming from all corners of the world, including Africa, Asia, Australia/New Zealand, Europe, South America, the USA and Canada. The Pregnancy Loss Research Group based within the Department of Obstetrics and Gynaecology and the INFANT centre at UCC and Cork University Maternity Hospital are hosting the conference.

I have been privileged to Chair the organising committee for ISA 2017, and lead a multi-disciplinary team involving obstetricians, midwives, social scientists, epidemiologists, services users, perinatal pathologists, chaplains, educators and researchers. For over a year, we have worked alongside our partners, including Féileacáin, the National Perinatal Epidemiology Centre and the INFANT Centre at UCC to host ISA 2017 and bring this conference to Ireland. The aim of the conference is to challenge healthcare professionals to constantly strive for excellence in stillbirth awareness, investigation, research and bereavement care. Our conference programme provides a blend of new research from various research centres around the world in addition to insight from world experts in stillbirth investigation and care. The human experiences of stillbirth bereavement from both bereaved parents and healthcare professionals will also be shared. We hope the programme meets the individual and professional needs of all our delegates, and facilitates future clinical and academic collaboration.

Research cannot happen without bereaved parents willing to share their experiences of stillbirth. Parents cannot hope for better outcomes for future pregnancies without research being undertaken. Doctors, midwives and the multi-disciplinary teams in maternity hospitals cannot provide the best care without parents to learn from, and evidence-based research to inform their practice. Support organisations need information to help bereaved parents and advocate for their needs. Coming together at ISA 2017 is a great opportunity to share our experience, discuss our research, reflect on our practice and gives us confidence that we are joined by many others, both nationally and internationally, in the pursuit of best practice.

The shared task for all of us attending ISA 2017 is to recognise the effects of stillbirth, ensure ongoing support for those affected by the death of a baby, strive to always improve the quality of care we offer to bereaved parents, and to promote research and training in this area.

As the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death are being implemented this year, it is additionally significant that this conference is being held in Ireland. The Standards clearly defined the care parents and families can expect to receive following stillbirth in our maternity hospitals. The conference is a step forward in our commitment to compassionate care for parents, as well as education and support for maternity staff, while raising awareness of stillbirth and recognising its wide impact.

2.3 Standards Introduction

From the Introduction to the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death, 1st published 2016, revised 2021

Dealing with the loss of a baby or pregnancy can be a difficult and devastating time for parents and families. Parents and families may need a range of immediate and longer term supports to help them with their bereavement. The role of family, friends and community is crucial in helping parents come to terms with their loss. There are a range of health and other support services that can play a positive and helpful role for parents during this time.

The purpose of the National Standards for Bereavement Care is to enhance bereavement care services for parents who experience a pregnancy loss or perinatal death. These Standards 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 for Bereavement Care following Pregnancy Loss and Perinatal Death are a resource for both parents and professionals. The Standards intend to 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. The Standards will guide and direct bereavement care staff on how to lead, develop and improve a hospital 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's response to the grief experienced by parents and their families. The Standards acknowledge the impact of perinatal loss on staff and the importance of having formal structures in place to support staff.

Providing bereavement care is an integral part of a Maternity service. It is important that such bereavement care is integrated with the hospital's overall medical and clinical care response to parents. All families have bereavement care needs. These needs are viewed as ascending from basic to more complex needs. Bereavement care is often described in terms of three levels and it is important that the Maternity setting has staff who can assess needs at each of these levels, provide care and/or refer to the most appropriate support.

At the most basic level (level one) mothers and families need reliable, accurate information given in a sensitive and supportive manner. They need to be able to express their responses in a safe environment. Level two bereavement care, also described as 'sensitive' care, is required by people potentially at risk of disenfranchised or complicated grief because of, for example, social isolation, demanding caring duties and reduced coping capacity. Level two care is provided by staff with a formal understanding of the grief process and who use the general skills of counselling including listening, affirming and clarifying. At level two, some people may benefit from an opportunity to talk to and receive more formal supports which are often provided by trained volunteers or convened by 'peers' who have had a similar bereavement experience. A minority of bereaved persons may experience significant or debilitating difficulties in their grieving, in which case they will be referred for professional and therapeutic support by the bereavement care staff. This is considered Level 3 support. In addition, in providing and integrating bereavement care, hospitals should be aware that there are a range of other professionals and services that may be involved with bereaved parents.

Advances in antenatal diagnosis of fetal anomalies, obstetric and neonatal care have increased the need for decision-making about end-of-life care for the fetus and neonate. These decisions also include the option of termination of pregnancy. This presents both Parents and Clinicians with new and difficult challenges. A perinatal palliative care approach is appropriate for Parents who continue their pregnancy after antenatal diagnosis of fatal fetal anomalies (FFA) / life- limiting conditions (LLC) as well as for those who opt for termination of pregnancy.

Maternity hospital staff (obstetric, midwifery, anaesthetic, paediatric, neonatology, nursing, chaplaincy, social work, and pathology and bereavement team) are responsible for providing care that incorporates anticipatory bereavement care and perinatal palliative care for the unborn baby, and for the parents and baby during the first week of the baby's life. Thereafter palliative care, provided in accordance with the Palliative Care for Children with Life-limiting Conditions National Policy, is transferred to the Paediatric Palliative Care Team. Bereavement care for the family continues to be provided by the Maternity hospital's bereavement team.

Pregnancy Loss and Perinatal Death – the numbers

The provision of bereavement care is based on the needs of the parents and not on the type of pregnancy loss. There were 381 perinatal deaths in Ireland in 2017, reported by the National Perinatal Epidemiology Centre's 2019 Perinatal Mortality Audit[1]. These included 235 stillbirths, 111 early neonatal deaths (within 7 completed days of birth) and 35 late neonatal deaths (after the 7th and within 28 completed days of birth).

On January 1st, 2019, the Health (Regulation of Termination of Pregnancy) Act 2018 was enacted, extending significantly the circumstances in which abortion care may lawfully be provided in Ireland. In 2019 there were 6,666 terminations of pregnancy carried out in the Republic of Ireland. There were 6542 terminations of pregnancy carried out before 12 weeks' gestation. One hundred were carried out following a diagnosis of a fatal fetal anomaly, with the remaining number carried out due to risk of the health or life of the mother. It is important to note, that those who do not meet the criteria within the legislation continue to travel outside of Ireland to avail of abortion services. While there was a decrease in the number of women travelling to England and Wales for abortions, from 2,879 in 2018 to 375 in 2019, a decrease of 87%, those under Ground E (substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped) rose from 3% to 17%.

There are over 100 molar pregnancies reported in Ireland each year to the National Gestational Trophoblastic Disease Centre; however data for these pregnancies has only recently been formally collected. In 2020, the centre reported 132 molar pregnancies notified to their service. It is estimated that 1-2% of all pregnancies end in ectopic pregnancy. Studies using the Hospital In-Patient Enquiry database have shown that the rate of hospitalisation for ectopic pregnancy is increasing over time. The Irish Maternity Indicator System (IMIS) National report for 2019[2] includes details on 978 ectopic pregnancies (a rate of 16.8 per 1000 pregnancies).

The number of miscarriages is not recorded officially in Ireland. The national guidance says that 14,000 early pregnancy miscarriages happen per year in Ireland, but this statistic is most likely based on an estimate of 20% of total births at the time that was written in 2012. While birth rates have fallen since then, the guidelines refers to 'clinically recognised' pregnancies, and a more accepted statistic is that 1 in 4 pregnancies end in miscarriage in the first trimester. Despite the burden of early miscarriage, information regarding trends in incidence rates of hospitalisations and type of management of early miscarriage is also limited. Studies using the Hospital In-Patient Enquiry database have shown that the rate of hospitalisation for miscarriage is decreasing over time. While this still under-estimates the overall numbers, as not all women attend hospital with a miscarriage, this change is likely due to access to early pregnancy clinics now within all 19 Maternity units, as well as options for medical management of early pregnancy loss.

[1] O'Farrell IB, Manning E, P Corcoran, Greene RA, on behalf of the Perinatal Mortality Group. Perinatal Mortality in Ireland Annual Report 2017. Cork: National Perinatal Epidemiology Centre, 2019.

[2] Irish Maternity Indicator System (IMIS) National report, National Women and Infants Health Programme, Clinical Programme for Obstetrics and Gynaecology, 2019

3. STANDARDS DEVELOPMENT

The National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death (the Standards) were developed in response to recommendations in the HSE's Investigation report into the death of Savita Halappanavar (2013)[3].

One of the recommendations of the HSE report following the investigation of the death of Savita Halappanavar stated:

'*Ensure that the psychological impact of inevitable miscarriage is appropriately considered and that a member of staff is available to offer immediate support and information at diagnosis. Members of staff should also advise of the availability of counselling services for women and partners at diagnosis. Care given, including counselling and support, should be documented. The availability of counselling services for women, partners and families who have suffered any incident or bereavement in childbirth should be reviewed, considered and developed as appropriate at each maternity site'.*

Following the 2013 report there were 9 recommendations for the HSE and one for the Department of Health. The HSE Clinical Programme in Obstetrics and Gynaecology, led by Professor Michael Turner, was tasked with implementation of these recommendations. A number of work streams were established, including bereavement care.

A number of other important reports over the following years also mentioned bereavement care in maternity services. The HSE Maternity Clinical Complaints Review which took place from 2014-2016 and was published in 2017 highlighted a common theme of a "*lack of bereavement support.*"[4] It recommended that "*each hospital should appoint bereavement counsellors trained to deal with perinatal deaths.*" One of the recommendations of the Health and Wellbeing chapter of the National Maternity Strategy (2016)[5] 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 Ciaran Browne, two years to research and develop the Standards. Following this two year development and review process the Standards were launched in August 2016.

The purpose of the Standards is to enhance bereavement care services for parents who experience a pregnancy loss or perinatal death. The Standards 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.

[3]Investigation of Incident 50278 from time of patient's self- referral to hospital on the 21st of October 2012 to the patient's death on the 28th of October, 2012, Health Service Executive, 2013.

[4]Maternity Clinical Complaints Review Final Report. Health Service Executive, 2017.

[5]Creating A Better Future Together - National Maternity Strategy, Department of Health, 2016.

The Standards are intended as a resource for both parents and professionals. They aim to promote multidisciplinary staff involvement in preparing and delivering an inclusive choice of bereavement care services that address the immediate and long-term needs of parents who experience pregnancy loss and perinatal death.

The Standards give guidance and direction to bereavement care staff on how to lead, develop and improve a hospital response to parents who experience the loss of a pregnancy or a baby. They also assist staff to develop and adapt care pathways that will assist the hospital's approach to caring for parents who are bereaved by pregnancy loss and perinatal death. Finally, the Standards acknowledge the impact of perinatal loss on staff and the importance of having formal structures in place to support staff.

The Standards were reviewed in 2020 and an updated version is to be published in 2021.

3.1 The Standards Development Group, 2014-16

The development group was composed of multidisciplinary staff from the HSE Clinical and Administrative Services, Staff from the Irish Hospice Foundation and Academic Staff.

Dr Ciarán Browne	Chair, General Manager, HSE Acute Hospital Division
Dr Anne Bergin	Project Manager, Coombe Women and Infants University Hospital
Ms June Boulger	National Lead, Patient and Public Involvement in Healthcare, HSE
Ms Helen Byrnes	Clinical Midwife Manager 2, University Hospital Galway
Dr Barbara Coughlan	Lecturer/Assistant Professor School of Nursing, Midwifery and Health Systems, University College Dublin (UCD)
Dr Joanne Fenton	Perinatal Psychiatrist, Coombe Women and Infants University Hospital
Ms Marie Hunt	Bereavement Clinical Midwife Specialist, University Maternity Hospital Limerick
Ms Orla Keegan	Head of Education, Research and Bereavement, Irish Hospice Foundation
Professor Máiread Kennelly	Obstetrician and Fetal Medicine Specialist, Coombe Women and Infants University Hospital
Ms Anne McKeown	Bereavement Liaison Officer, University Hospital Galway

Dr Mary Moran	Lecturer and Co-ordinator Obstetrics/Gynaecology Ultrasound Programmes, UCD
Ms Fiona Mulligan	Bereavement Clinical Midwife Specialist, Our Lady of Lourdes Hospital Drogheda
Ms Aileen Mulvihill	Senior Medical Social Worker, Specialist Palliative Care, Roscommon
Rev Dr Daniel Nuzum	Healthcare Chaplain, Cork University Maternity Hospital, Lecturer, University College Cork
Professor Keelin O'Donoghue	Consultant and Professor, Obstetrics and Gynaecology, Cork University Maternity Hospital
Ms Grace O'Sullivan	Hospice Friendly Maternity Units Programme Coordinator, Irish Hospice Foundation
Ms Sara Rock	Clinical Nurse Manager 2 (Neonatology), National Maternity Hospital
Ms Laura Rooney Ferris	Librarian, Irish Hospice Foundation
Ms Bríd Shine	Bereavement Clinical Midwife Specialist, Coombe Women and Infants University Hospital
Professor Martin White	Consultant Neonatologist, Coombe Women and Infants University Hospital
Ms Kathryn Woods	Bereavement Clinical Midwife Specialist, Midland Regional Hospital, Mullingar

3.2 Launch of the Standards

Mr Simon Harris, Minister for Health, launched the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death in Farmleigh House in August 2016. The launch of the Standards, attended by healthcare professionals from all 19 Maternity Units and parent representatives, was welcomed by both healthcare professionals and parents who have experienced pregnancy loss.

At the launch Mr Harris stated that he hoped the Standards would give grieving families "*the care and compassion they need*". At the launch it was further stated that: "*These new standards clearly define the care parents and families can expect to receive following a pregnancy loss or perinatal death. The standards will be implemented and applied across the health service in all appropriate hospitals and settings.*"

Standards Launch, Farmleigh House Dublin, August 2016.
Mr Tony O'Brien, Minister Simon Harris, Professor Keelin O'Donoghue.

Standards Development Group, Standards Launch, Farmleigh House Dublin, August 2016. **Back row (l-r):** *Ms Marie Finn, Ms Brid Shine, Ms Aileen Mulvihill, Dr Mary Moran, Ms Fiona Mulligan, Ms Kathryn Woods, Rev Dr Daniel Nuzum, Dr Barbara Coughlan, Ms Grace O'Sullivan, Ms Anne Mc Keown.* **Front row (l-r):** *Ms Marie Hunt, Dr Anne Bergin, Mr Tony O' Brien, Minister Simon Harris, Dr Ciaran Browne, Professor Keelin O'Donoghue.*

4. STANDARDS IMPLEMENTATION

The two year Implementation programme for the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death (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 bare in Irish Maternity Units. Implementation was supported by the National Women and Infants Health Programme (NWIHP) of the Health Service Executive (HSE). The NIG welcomed the input and support from the Parents Forum and the various Parent Support Groups and Voluntary Organisations who worked in partnership with the NIG in moving forward with the Implementation Programme.

Implementation was supported and further assisted by the Bereavement teams in all of the 19 Maternity Units in Ireland. Each hospital has a Bereavement team comprised of different healthcare professionals and is led by various disciplines in each hospital.

Professor Keelin O'Donoghue, Consultant Obstetrician and Gynaecologist in Cork University Maternity Hospital (CUMH) was appointed as National Implementation Lead in 2017.

Rióna Cotter, Midwife in Quality and Patient Safety in CUMH, was appointed, for a two year period, as Programme Manager in March 2017.

4.1 National Implementation Group

The Implementation process was facilitated by a 14 member National Implementation Group (NIG) made up of a multi-disciplinary team of healthcare professionals who have experience and expertise in the area of pregnancy loss and perinatal death.

The NIG first met in April 2017 and held 18 meetings over the two years of the implementation programme. (Appendix 1).

Purpose of the NIG

To develop structures to facilitate the implementation of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death in the 19 Maternity Units in the Republic of Ireland.

Objectives:

- To disseminate the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death.
- To collate the work and information from the 7 work streams in order to achieve the objectives of the group.
- To assist each Maternity Unit, where necessary to develop a bereavement care structure and where already established assist same to develop.
- To identify any updates to local clinical guidelines where necessary and to ensure dissemination of same.
- To determine integrated care pathways (ICPs) for the management of pregnancy loss and perinatal death in keeping with the Standards and develop key checklists within the ICPs.
- To assess staff education and support structures, and resource appropriate bereavement training.
- To identify and develop standardised resources that will contribute to the care of women and families requiring bereavement care.
- To develop standardised external referral pathways.
- To collate and assess all support agencies available to parents and healthcare workers.
- To develop an e-network for parents and healthcare professionals that will provide an interface between the groups and agencies which provide support for pregnancy loss.
- To collaborate with the National Neonatal Palliative Care Development Group.

Chair:

The National Implementation Group was chaired by Professor Keelin O'Donoghue.

Membership of National Implementation Group:

Ms Rióna Cotter	Programme Manager, Standards Implementation Programme Cork University Maternity Hospital
Dr Mary Devins	Consultant Paediatrician with a special interest in Palliative Medicine, Our Lady's Children's Hospital, Crumlin
Dr Anne Doolan	Consultant Neonatologist, Coombe Women and Infants University Hospital/Midland Regional Hospital Portlaoise
Dr Brendan Fitzgerald	Consultant Perinatal Pathologist, Cork University Hospital
Professor Mary Higgins	Consultant Obstetrician and Gynaecologist, National Maternity Hospital (2017-2018)
Ms Marie Hunt	Bereavement Clinical Midwife Specialist, University Maternity Hospital Limerick
Ms Orla Jennings	Senior Social Work Practitioner, Cork University Maternity Hospital (2018-2019)
Ms Marie Lynch	Paediatric Palliative Care Neonatal Nurse, Cork University Maternity Hospital
Professor Eleanor Molloy	Consultant Paediatrician, Our Lady's Children's Hospital, Crumlin, Consultant Neonatologist, Coombe Women and Infants University Hospital
Rev Dr Daniel Nuzum	Healthcare Chaplain, Cork University Maternity Hospital, Lecturer, University College Cork

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Dr Seosamh Ó Coigligh	Consultant Obstetrician and Gynaecologist, Our Lady of Lourdes Hospital Drogheda
Ms Stacey Power	Paediatric Palliative Care Nurse and PhD Student, INFANT Centre, University College Cork
Ms Dearbhla Ni Riordain	Manager of Social Work Department, Cork University Hospital (2017-2018)
Ms Anna Maria Verling	Bereavement Clinical Midwife Specialist, Cork University Maternity Hospital

4.2 Structures Around Implementation

The National Implementation Group carried out its work through six work streams.

- Quality and Service Improvement - chaired by Prof Keelin O'Donoghue
- Policies and Procedures - chaired by Ms Rióna Cotter
- Information technology - co-chaired by Prof Keelin O'Donoghue and Rióna Cotter
- Referrals and Integration - chaired by Rev Dr Daniel Nuzum
- Perinatal Palliative Care /TOPFA - co-chaired by Prof Keelin O'Donoghue and Dr Mary Devins
- Education, training and staff support - chaired by Prof Mary Higgins 2017-2018, Prof Keelin O'Donoghue 2018-2019

4.3 Implementation Work Streams

Each work stream had a chairperson and a working group comprised of healthcare professionals, recognised as experts in perinatal bereavement care.

The programme manager and the implementation lead worked with the chairperson of each group to choose members for their work stream, who was recognised as having expertise and relevant knowledge to work in the group. Each group was made up of representatives from different professions, working within perinatal bereavement care.

The following pages outline the membership and objectives of each work stream.

Quality and Service Improvement

Objectives for work stream:

- To assess bereavement care being provided in all 19 Maternity Units against the Standards.
- To reach a national consensus on the care to be provided
- To develop a national service user feedback tool
- To develop an audit tool for hospital review

Plan of work:

- Disseminate standards to all 19 hospital and group leads
- Involve group leads and identify their role and responsibilities
- Gather current guidelines, policies, pathways and share with policy group
- Organise site visits, staff meetings, site assessment and feedback process for site visits
- Review of current services and facilities and personnel to identify gaps and needs
- Develop quality audit tool for on-going assessment

FIGURE 1: Implementation work streams

Membership:

Prof Keelin O'Donoghue
Ms Rióna Cotter

Policies and Procedures

Objectives for work stream:

- To reach a consensus nationally on the policies, procedures and guidelines relating to pregnancy loss
- To produce a suite of national care pathways which reflect the Standards

Plan of work:

- Review and collect current policies and guidelines in all units to achieve consensus
- Facilitate development of local policies against the standards
- Review and identify change needed in national clinical guidelines on pregnancy loss
- Determine the referral pathways for pregnancy loss
- Determine integrated care pathways for pregnancy loss
- Make key checklists and proformas
- Update of medication protocols
- Disseminate pathways and updated protocols

Membership of Policies and Procedures Work Stream:

Ms Rióna Cotter	Chairperson
Ms Anna Maria Verling	Bereavement Clinical Midwife Specialist, CUMH
Dr Seosamh Ó Coigligh	Consultant Obstetrician and Gynaecologist, Our Lady of Lourdes Hospital, Drogheda
Ms Marie Lynch	Paediatric Palliative Care Neonatal Nurse, CUMH
Dr Anne Doolan	Consultant Neonatologist, CWIUH/Midland Regional Hospital Portlaoise
Dr Brendan Fitzgerald	Consultant Perinatal Pathologist, CUH
Ms Marie Hunt	Bereavement Clinical Midwife Specialist, UMHL
Dr Cathy Allen	Consultant Obstetrician and Gynaecologist, NMH
Ms Niamh Spillane	Midwife, CUMH
Ms Susan Dineen	Senior Medical Scientist, Perinatal Pathology, CUH
Dr Mendinaro Imcha	Consultant Obstetrician and Gynaecologist, UHML
Ms Katie Bourke	Practice Development Co-ordinator, CUMH
Ms Fiona Mulligan	Bereavement Clinical Midwife Specialist, Our Lady Of Lourdes Hospital, Drogheda

Information Technology

Objectives for work stream:

- To design and develop a national pregnancy loss website that will be a resource for healthcare staff and bereaved parents
- To work in collaboration with the MN-CMS team to ensure pregnancy loss documentation is streamlined on the Electronic Healthcare Record (EHR)

Plan of work:

- Design and develop a national pregnancy loss website
- Collate all the content for the national website
- Adapt the national care pathways for use on the EHR
- Reflect pregnancy loss in the EHR

Membership:

Prof Keelin O'Donoghue
Ms Rióna Cotter, Chairperson

In order to develop the national website a specific website development group was set up. This group was tasked with the design and content development for the national website. Membership of this group is described on page 17.

Referrals and Integration

Objectives for work stream:

- To identify and develop standardised resources that will contribute to the care of women and families requiring bereavement care
- To collate and assess all support agencies available to parents and healthcare workers
- To develop standardised external referral pathways
- To provide support/ education for support groups and voluntary organisations
- To prepare material to develop an e-network/portal for parents and healthcare professionals that will provide an interface between the groups and agencies which provide support following pregnancy loss

Plan of work:

- Identify and describe all the relevant support organisations
- Meet with larger support organisations
- Assess the external referral pathways and partner arrangements
- Liaise with parent organisations and advocacy groups regarding their services
- Assess support groups and voluntary organisations in relation to funding, structures, governance etc.
- Liaise with Palliative care and Outreach services to assess supports
- Collaborate with national Neonatology/Paediatrics programme

Membership of Referrals and Integration Work Stream:

Rev Dr Daniel Nuzum	Chairperson, Healthcare Chaplain, CUMH, Lecturer, UCC
Ms Rióna Cotter	Programme Manager, Standards Implementation Programme CUMH
Ms Dearbhla Ni Riordain	Manager of Social Work, CUH
Ms Marie Hunt	Bereavement Clinical Midwife Specialist, UMHL
Prof Eleanor Molloy	Consultant Paediatrician, Our Lady's Children's Hospital, Crumlin, Consultant Neonatologist, CWIUH
Dr Marie Christine de Tavernier	Consultant Obstetrician, Portiuncula Hospital
Ms Christina Kilpatrick	Neonatal Nurse, Rotunda Hospital
Ms Orla O'Connell	Bereavement Clinical Midwife Specialist, CUMH
Mr Tyrone Horne	Clinical Nurse Specialist, Children's Outreach Nurse, CUH
Ms Alice Anderson	Development Officer (Hospice Friendly Maternity Units Programme), Irish Hospice Foundation
Ms Niamh Brennan	Healthcare Chaplain, Portiuncula Hospital

Perinatal Palliative Care and TOPFA

Objectives for work stream:

To write a standardised care pathway for the provision of perinatal palliative care, including provision of TOPFA in all Maternity Units.

Plan of work:

- Review and collect current policies and working arrangements around PPC/TOPFA in all units helped by Quality & Service Improvement work stream
- Seek international guidance, policies and pathways
- Determine antenatal management and antenatal diagnosis care pathways for Life Limiting Conditions / Fatal Fetal Anomalies, incorporating care in Perinatal Palliative Care and Termination Of Pregnancy for Fatal Anomaly scenarios
- Consult re the above with fetal medicine leads in the 6 Groups
- Meet and consult with large support groups and voluntary organisations
- Review and agree work with the neonatal palliative care working group

Membership of Perinatal Palliative Care and TOPFA Work Stream:

Prof Keelin O'Donoghue	Chairperson
Dr Mary Devins	Consultant Paediatrician with a special interest in Palliative Medicine, Our Lady's Children's Hospital, Crumlin
Ms Rióna Cotter	Programme Manager
Dr Anne Doolan	Consultant Neonatologist, Coombe Women and Infants University Hospital/Midlands Regional Hospital Portlaoise
Prof Eleanor Molloy	Consultant Neonatologist, CWIUH, Our Lady's Children's Hospital, Crumlin
Ms Dearbhla Ni Riordain	Manager of Social Work, CUH
Ms Anna Maria Verling	Bereavement Clinical Midwife Specialist, CUMH
Ms Marie Lynch	Paediatric Palliative Care, Neonatal Nurse, CUMH
Ms Ann Charlton	Healthcare Chaplain Rotunda Hospital
Prof Joan Lalor	Associate Professor, School of Nursing and Midwifery, Trinity College Dublin
Ms Jane Dalrymple	Fetal Medicine Clinical Midwife Specialist, Rotunda Hospital
Dr Jennifer Donnelly	Consultant Obstetrician and Gynaecologist, Rotunda Hospital
Ms Stacey Power	Paediatric Palliative Care Nurse, PhD Student, INFANT Centre, UCC

Education, Training and Staff Support

Objectives for work stream:

- To examine the staff education programmes on perinatal bereavement care available to staff nationally
- To develop perinatal bereavement education standards
- To examine the staff support structures available
- To develop recommendations for a staff support programme
- Recommend staff education programmes for all groups of staff

Plan of work:

- Examine existing perinatal education workshops provided by national and international organisations
- Examine teaching methodologies and teaching aids
- Develop ideas for staff support workshops
- Facilitate staff networking through meetings and developing communication pathways
- Work with the Hospice Friendly Hospital network within the Irish Hospice Foundation
- Recommend best practice for Maternity Units in this area

Membership of Education, Training and Staff Support Work Stream:

Prof Mary Higgins	Consultant Obstetrician, NMH (Chair 2017-2018)
Prof Keelin O'Donoghue	Consultant Obstetrician (Chair 2018-2019)
Ms Rióna Cotter	Programme Manager
Dr Noirin Russell	Consultant Obstetrician, CUMH
Rev Dr Daniel Nuzum	Healthcare Chaplain, CUMH, Lecturer, UCC
Dr Barbara Coughlan	Lecturer/Assistant Professor, School Of Nursing Midwifery and Health Systems, UCD
Ms Clare Quinn	Lecturer, Programme Director, NUI Galway
Ms Orla Keegan	Head of Education, Research and Bereavement, Irish Hospice Foundation
Dr Karen McNamara	Specialist Registrar in Obstetrics and Gynaecology
Mr Breffni McGuinness	Training Manager, Irish Hospice Foundation
Ms Anna-Maria Verling	Bereavement Clinical Midwife Specialist, CUMH
Ms Brid Shine	Bereavement Clinical Midwife Specialist, CWIUH
Ms Christina Kilpatrick	Clinical Nurse Manager, Neonatal Unit, Rotunda Hospital

"It was the first time I had been involved in a group with such a diverse range of stakeholders. I really benefitted from hearing the perspectives of support groups and patient representatives - it really opened my mind to their point of view."
Member of National Implementation Group

"Seeing how so many maternity units and services have been able to address long-standing challenges in the provision of bereavement care has been inspiriting; in many cases being able to make significant changes within the limitations of older infrastructure."
Member of National Implementation Group

"The realisation of Clinical Midwife Specialists in every unit has been a tremendous success and paves the way for similar progress now in other disciplines."
Member of National Implementation Group

5. IMPLEMENTATION WORK STREAMS AND OUTPUTS

In this section of the report the outputs and achievements of each work stream, outlined in section 4, will be described in detail.

5.1 Quality and Service Improvement

Bereavement Clinical Midwife/Nurse Specialists

It was recognised by the authors of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal death (the Standards) that the development of Bereavement Specialist Teams (BST) in Maternity Units is fundamental to the successful implementation of the Standards. Critical to the establishment and function of the BST are the Clinical Midwife Specialists (CMS) in Bereavement.

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 needs of this very specific patient group. 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 patient care. The role of the CMS 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. It is a post very specifically focused on the maternity services.

An audit of the bereavement CMS group across all Maternity Units in Ireland was undertaken in 2015, and a whole time equivalent gap of 15.5 was identified nationally. Members of the Standards Development Group wrote the job description for the CMS posts after consultation with established CMSs in post and the Office for the Nursing and Midwifery Services Development in the HSE. It was then sent to the lead for the Acute Hospitals Division of the HSE for approval. Once the job description was approved, funding for resourcing these posts in all Maternity units was secured in the 2016 National Service Plan. The HSE stated in the 2016 plan that "the first priority" of the implementation of the Standards … "…is to ensure Clinical Midwife Specialist in Bereavement (CMS) availability in all Maternity Units". In August 2016, the HSE made funds available to ensure that each Maternity hospital had a bereavement CMS in post to support bereaved parents.

After establishing the National Implementation Group in March 2017 one of the group's first priorities was to ensure the recruitment and appointment of the midwife specialists. An audit was carried out on staffing with regard the CMS bereavement posts and vacancies were found to exist in the majority of units, with little progress noted to have been made since August 2016. Therefore, at the start of the implementation programme in March 2017 ten of the Maternity Units already had a Bereavement CMS or a partial whole time equivalent (WTE) in post, while the remaining 9 Maternity Units did not.

A national recruitment process was commenced in April 2017 and by December 2017, 13 of the 19 Maternity Units Bereavement Clinical Midwife/Nurse Specialists were recruited and in place, with the remaining six posts to be filled in 2018. By April 2019, following a long recruitment process, where the CMS job description and requirements to take up post were reviewed, all 19 Maternity Units had appointed a CMS/CNS in Bereavement. As of September 2020 the Clinical Midwife Specialists in Bereavement in post have established their roles and are working to ensure the implementation of the Standards in their respective units.

A number of the CMS/CNS have moved on to other roles. Unfortunately in some units replacement of the CMS has been problematic for a number of reasons. This has led us to recommending to hospital management teams to consider succession planning for the CMS group.

Table 1: CMS in Bereavement and Loss group, WTE

HOSPITAL NAME	2015 CMS WTE	2017 CMS WTE	2020 CMS WTE
Cork University Maternity Hospital	1.25WTE	1.5WTE	1.7WTE (approved for 2.5WTE)
South Tipperary General Hospital	0	0	1 WTE (vacant 2021)
University Hospital Kerry	0	0	1WTE
University Hospital Waterford	0	0	1WTE
University Maternity Hospital Limerick	1WTE	1WTE	2WTE
National Maternity Hospital	1.5WTE	1.64WTE	2.5WTE
St Luke's General Hospital Kilkenny	1WTE	1WTE	1WTE
Wexford General Hospital	0	0	1WTE
Midland Regional Hospital Mullingar	0	0.5WTE	1WTE
Coombe Women and Infants University Hospital	1WTE	1.5WTE	2WTE
Midland Regional Hospital Portlaoise	0.5WTE	1WTE	1WTE
Rotunda Hospital	1.5WTE	2WTE	1WTE (approved for 2WTE)
Cavan General Hospital	0.5WTE	1WTE	1WTE
Our Lady of Lourdes Hospital Drogheda	1WTE	1WTE	1WTE
University Hospital Galway	0	0	1WTE
Sligo University Hospital	0	1WTE	1WTE
Mayo University Hospital	0	0	1WTE
Letterkenny University Hospital	0	0	1WTE
Portiuncula University Hospital	0	0	1WTE

Bereavement Clinical Midwife/Nurse Specialists Network

A support network the CMS/CNS in bereavement group was set up and met for the first time in Cork in September 2017. The purpose of this group is to act as both a support network and a professional network where experience and professional knowledge will be shared. The CMS group met on 4 occasions throughout the 2 year implementation programme.

In the summer of 2018 it was decided by the National Implementation Group to run an education day for the CMS group. The CMS group were asked to identify areas that they would like to be addressed on the day. Topics such as self-care and conscientious objection were suggested and were included on the day. The education day took place in Cork in October 2018 and was positively evaluated by the group. At this stage the group were asked to elect a chairperson to continue the running of the network once the implementation programme had completed its work.

Bereavement Clinical Midwife Specialist Group, ISA Conference, UCC, 2017. **Back row:** *Ms Margaret Ryan, Ms Louise Dempsey, Ms Rita O'Brien, Ms Sarah Cullen, Ms Kathryn Woods, Ms Edel Ryan,Ms Fiona Mulligan, Ms Jill Whelan.* **Front row:** *Ms Louise Cooke, Ms Orla O'Connell, Ms Marie Hunt, Ms Trish Butler, Ms Anna Maria Verling, Ms Rióna Cotter, Ms Maria White, Ms Sarah Gleeson, Ms Brid Shine.*

CMS/CNS in Bereavement Education Day, Cork 2018. **Back row:** *Ms Marie Hunt , Ms Anne Brady, Ms Anna Maria Verling, Ms Carrie Dillon, Ms Kathryn Woods, Ms Margaret Ryan, Ms Fiona Mulligan, Ms Jill Whelan, Ms Sarah Cullen, Ms Louise Cooke, Ms Orla O'Connell, Ms Brenda Casey.* **Front row:** *Ms Maria White, Ms Sarah Gleeson, Ms Trish Butler, Ms Caroline Plunkett.*

BEREAVEMENT CLINICAL MIDWIFE/NURSE SPECIALIST DAY,

OCTOBER 19th2018

CLASSROOM B, 5th FLOOR, CORK UNIVERSITY MATERNITY HOSPITAL

TOPIC	SPEAKER	TIME
REGISTRATION & COFFEE 09.30-10.00		
Staff wellbeing- mini Schwarz round	Ms Juanita Guidera, Quality Improvement Division Lead Staff Engagement Ms Lisa Toland, Quality Improvement Microsystems Facilitator	10.00-12.00
LUNCH 12.15-13.00		
Every Life Counts- what services we offer parents	Ms Vicki Wall, Parent Advocate Every Life Counts	13.00-13.30
Overview of support groups providing support to parents bereaved through pregnancy loss and perinatal death in ROI	Dr Daniel Nuzum Healthcare Chaplain, Cork University Maternity Hospital	13.30-14.00
Leanbh Mo Chroí- what services we offer parents	Ms Jennifer Ryan, Parent Advocate Leanbh Mo Chroí	14.00-14.30
COMFORT BREAK 14.30-14.45		
Conscientious objection- professional issues around provision of termination of pregnancy	Dr Joan Mc McCarthy Lecturer in Healthcare Ethics in the School of Nursing and Midwifery, University College Cork, Ms Rióna Cotter, Programme Manager –for the Implementation of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death	14.45-15.45
Proposed legislation on provision of termination of pregnancy services- Q&A session	Dr Keelin O'Donoghue Consultant Obstetrician & Gynaecologist National lead for the implementation of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death	15.45-16.30
COFFEE 16.30		
Bereavement CMS/CNS meeting		16.30-18.00

FIGURE 2 - Programme

"This project brought focus and momentum to the need for standardised and improved bereavement care for women, parents and families along with a need for staff support and education in this very specific, niche area of care provision. Keeping parents and care at the centre of this work at all times. The commitment required to be part of this group was demanding at times while also maintain my role at hospital level."
Member of National Implementation Group

"Being involved in the Parents' Forum gave our baby a voice. It validated our experience and made it feel somewhat worthwhile. In our own small way, we were enacting positive change for others who may have similar experiences of loss down the line."
Member of Parents Forum

Following the completion of the implementation programme, the group has met a number of times in person and virtually. They continue to meet as a support network and as a way of sharing information and clinical expertise.

Throughout the Standards implementation and development programme the programme manager acted in a supportive and advisory capacity to the CMS/CNS group in relation to service development and service improvement.

Development of Audit tool for Maternity Units

To assess the perinatal bereavement care in each Maternity Unit an audit tool was developed. 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. The audit tool was given to the NIG for their feedback and approval before it was used. (Appendix 2).

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 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 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.

Once approved for use, the audit tool was used to audit perinatal bereavement care in all 19 Maternity units in the country. Every hospital was visited by Professor O'Donoghue and Rióna Cotter in 2017 and the tool was used during these visits to audit bereavement care. The feedback from the audit tool was presented to the Maternity Unit management teams in the three themes described above. Findings from the 2017 audit are presented in detail in Section 7.

5.2 Policies and Procedures

Care pathways

Care pathways for the different types of pregnancy loss were developed for use by this work stream. The work stream met in June 2017 to discuss the workload and to assign the different pathways to smaller subgroups. These sub-groups then met regularly to develop and agree the content of the pathways. Each pathway had input from various experts in the provision of perinatal bereavement care services. The members of the parents' forum (page 48), the NIG and a number of support organisations were asked for their input/comments. Six care pathways were published on the website in April 2019 and disseminated to all Maternity Units via the HSE's NWIHP.

The care pathways are presented in: Appendix 3-8

Ectopic Pregnancy Care Pathway
https://pregnancyandinfantloss.ie/ectopic-pregnancy-care-pathway/

First Trimester Pregnancy Loss Pathway
https://pregnancyandinfantloss.ie/first-trimester-pregnancy-loss-care-pathway/

Second Trimester Pregnancy Loss Pathway
https://pregnancyandinfantloss.ie/second-trimester-pregnancy-loss-care-pathway/

Stillbirth Care Pathway
https://pregnancyandinfantloss.ie/stillbirth-care-pathway/

Neonatal Death Care Pathway
https://pregnancyandinfantloss.ie/neonatal-death-care-pathway/

Perinatal Palliative Care Pathway
https://pregnancyandinfantloss.ie/perinatal-palliative-care-pathway/

All of the pathways are available on the *www.pregnancyandinfantloss.ie* website

Guidelines

In the absence of a national clinical guideline programme the National Clinical Care Guidelines relating to pregnancy loss published by the National Clinical Care Programme for Obstetrics and Gynaecology were reviewed to ensure that bereavement care was reflected in them.

The medication protocols (Appendix 9) for management of Miscarriage and Intra Uterine Fetal Death were identified as the most urgent issue to be attended to. They were reviewed and updated by Prof O'Donoghue in collaboration with Prof Brian Cleary, Chief Pharmacist Rotunda Hospital and National Medications Lead for the MN-CMS and Ms Elmarie Cottrell, Senior Clinical Informatics Pharmacist, CUMH and MN-CMS.

These protocols were disseminated to all 19 Maternity Units via the HSE's NWIHP and the Institute of Obstetricians and Gynaecologists in 2019.

https://pregnancyandinfantloss.ie/medication-protocol-for-medical-management-of-miscarriage/

https://pregnancyandinfantloss.ie/medication-protocol-for-medical-management-of-intrauterine-fetal-death/

5.3 Information Technology

National Pregnancy Loss Website Project

During the implementation programme the National Implementation Group (NIG) found that the information available to bereaved parents and healthcare providers alike differs greatly around the country. On examining the use of websites for sharing information with bereaved parents the NIG found that pregnant women routinely access information about pregnancy and childbirth from the internet.

It is accepted that increasingly pregnant women access online information about pregnancy and its complications. Although there is evidence that over 90% of women in high income countries use the internet to find information about pregnancy, previous research has illustrated that information related to pregnancy loss is scarce or not always easy to access online. This issue leaves women unprepared and uninformed, and can feed the stigma surrounding pregnancy loss. Availing of a reliable and user-friendly pregnancy loss website can serve as a tool to empower women to make informed decisions, break the silence around pregnancy loss and help preventive efforts.[6]

The Implementation Group for the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death in Ireland found that information available to bereaved parents and healthcare providers varies greatly.

The development of a pregnancy loss website with content for Ireland was therefore supported by the NIG, the Bereavement Clinical Midwife/Nurse Specialist group and the perinatal bereavement support groups and voluntary organisations. The website was agreed to be necessary to ensure that healthcare professionals delivering bereavement care have access to up to date, accurate information and advice. It was anticipated that the website would be a repository for patient information with links to all of the support groups and voluntary organisations working within the area of pregnancy loss. It was also planned that it would be a repository for documentation that staff can use e.g. patient information leaflets.

The Irish Hospice Foundation (IHF) worked with the NIG for the Implementation of the Standards, in the development and setting up of the website. The IHF provided funding for an agreed three year period. This funding covered the cost of the design and development of the website (to include the purchase of the domain name) and the annual maintenance fee for the three year period. A group was convened in September 2018 to work on the development and design of the website.

Website development group

The website development group was set up to develop an information website for parents and healthcare professionals to provide an interface between the groups and agencies which provide support for pregnancy loss. The group was tasked with planning and overseeing the development of the website to be used as a "hub" for perinatal bereavement care to be used by both parents and healthcare professionals.

Objectives:

- Contribute to the development and design of the website
- Decide and agree the content of the website
- Collate the final and approved work and information from the National Implementation Group work streams for the website
- Agree which parental support groups and voluntary organisations should be linked to website
- Liaise with the agreed parental support agencies in relation to links to website
- Agree which staff education and support structures will be available on website
- Oversee the development and management of the website
- Set timelines and monitor the progress of the development of the website
- Monitor the website to ensure suitability/accuracy of content/information is up-to-date
- Publicise and manage the launch of the website

Membership:

Professor Keelin O'Donoghue	National Implementation Lead
Ms Rióna Cotter	Chair, Programme Manager for Implementation
Rev Dr Daniel Nuzum	Healthcare Chaplain, Cork University Maternity Hospital, Lecturer, University College Cork
Ms Anna Maria Verling	Bereavement Clinical Midwife Specialist, CUMH
Dr Karen McNamara	Specialist Registrar Obstetrics and Gynaecology
Ms Kathryn Wood	Bereavement Clinical Midwife Specialist, MRHM
Ms Sarah Cullen	Bereavement Clinical Midwife Specialist, NMH
Ms Anne Finn	Parent Representative, NMH

This group met a total of 6 times during the development process, to agree content. The programme manager met with the designer and web designer a number of times to plan the design and format of the website. The design and content were agreed by the website development group.

Launch of the website

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.

At the launch of the website on April 19th 2019 Prof Keelin O'Donoghue said: "*The website is a step forward in our commitment to consistent quality care for parents, as well as education and support for Maternity staff while raising awareness of pregnancy loss and recognising its wide impact.*"

Ms Sharon Foley, CEO of the Irish Hospice Foundation which funded the design and development of the website said: "*Grieving parents should be able to access sensitive and consistent bereavement care at every stage of their journey and in every location throughout Ireland. Maternity hospitals play a vital role in*

[6]T Escanuela Sanchez; S Meaney; K O'Donoghue. Stillbirth and risk factors: an evaluation of Irish and UK websites. Journal of Communication in Healthcare 2021; 14 (1) 68-77. Published Online 6 September. DOI: 10.1080/17538068.2020.1807887

supporting parents whose child dies following pregnancy and post birth. It is vital we support staff with tools and information which will equip them to give this bereavement care to parents. This new website will play a major role, I believe, in providing vital information to parents and staff following pregnancy and perinatal death in our hospitals."

Launch of website, April 2019. **Above:** *Ms Rióna Cotter, Professor Keelin O'Donoghue*

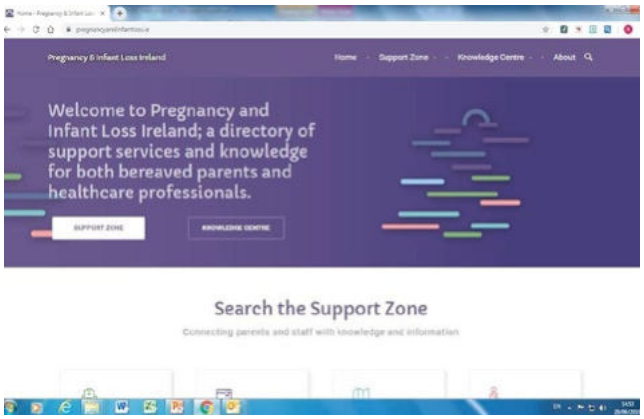

FIGURE 3 - Webpage

Following the launch of the website a management group was set up to oversee the running and management of the website.

Website management group

Purpose of the management group:

- To oversee the running of the website
- To update and change website content as necessary and work within the schedule of website updates in line with the agreed costs
- To recognise and manage urgent need for changes
- To report updates and changes to the Oversight Group

Objectives:

- Manage the website
- Ensure content is up to date
- Identify and include new documentation as it is produced
- Ensure that the links to the support groups and voluntary organisations are up to date
- Oversee the need for further development of the website

Membership of the Group:

Rióna Cotter	Chair, Programme Manager for Implementation
Prof Keelin O'Donoghue	Implementation Lead
Ms Sarah Cullen	Bereavement Clinical Midwife Specialist, NMH
Dr Anne Doolan	Consultant Neonatologist, Coombe Women and Infants University Hospital/Midland Regional Hospital Portlaoise
Ms Sarah Meaney	Research Officer NPEC
Rev Dr Daniel Nuzum	Member of NIG, Healthcare Chaplain, Cork University Maternity Hospital, Lecturer, University College Cork
Ms Christine O'Brien	Parent Representative
Dr Sioban O'Brien Greene	Irish Hospice Foundation
Ms Anna Maria Verling	Member of NIG, Bereavement Clinical Midwife Specialist CUMH

The management group meets every three months and reviews the website content to ensure information is accurate and up to date. This process is managed through the website development company as per the contract agreed in 2019, which is managed and overseen by the Irish Hospice Foundation.

Collaboration with the MN-CMS Project

The Maternal and Newborn Clinical Management System (MN-CMS) Project electronic health record (EHR) was designed and developed for all women and babies being cared for in maternity, newborn and gynaecology services in Ireland.

The commencement of Phase 1 occurred at Cork University Maternity Hospital (CUMH) in December 2016, at University Hospital Kerry (UHK) in March 2017, The Rotunda Hospital in November 2017 followed by the National Maternity Hospital in January 2018. The system will be rolled out to the remaining 15 Maternity Units in the next number of years.

The care of women who experience pregnancy loss and perinatal death is documented in the EHR. However, the specific aspects of care in relation to pregnancy loss were not streamlined. It was also acknowledged that there was a need for ongoing further education and training in navigating the MN-CMS, so that important information could be easily identified.

Issues with Pregnancy Loss documentation in the EHR were identified at an early stage by clinical staff using the system. A number of these issues were brought to the attention of NIG. These were escalated to the HSE's NWIHP, who informed the MN-CMS National Management Team of the issues.

The issues that were identified included:

- the need for pathways for first and second trimester pregnancy loss;
- the use of a specific pregnancy loss alert symbol;
- documentation of previous pregnancy loss;
- continuation of the pregnancy loss alert to subsequent pregnancy;
- use of a different colour banner to easily recognise pregnancy loss.

Following collaboration with Ms Fiona Lawlor, Business Manager for the MN-CMS National Project Team, Ms Katie Bourke, Director of Midwifery, CUMH and Ms Nilima Pandit, MN-CMS Local System Administrator, CUMH it has been possible to address some of the above issues.

The pathways for the different types of pregnancy loss were reviewed and while not compatible to be placed directly onto MN-CMS, the main components of the pathways were placed on the bereavement module of MN-CMS.

The alert notice to make staff aware of a pregnancy loss, which used to stay active for 60 days post pregnancy loss, is now active indefinitely on the chart and automatically carries forward to subsequent pregnancies.

Pregnancy loss is now included as a patient category on the inpatient whiteboard, allowing staff to easily identify women who have experienced a pregnancy loss.

Perinatal Mortality Multi-disciplinary team meeting (MDTM) forms, which are used to document the findings and discussions held at monthly MDT meetings, have been incorporated into the chart.

As of January 2021, it is now possible to use a hospital's own individual alert symbol on the EHR.

Tip-sheets and user handbooks have been developed to guide staff in the correct use of these new functions in the documentation of pregnancy loss in the EHR.

The need to update the medication protocols (Appendix 9) for management of Miscarriage and Intra Uterine Fetal Death, was identified in 2019. They were reviewed and updated by Prof O'Donoghue in collaboration with Prof Brian Cleary, Chief Pharmacist Rotunda Hospital and national medications Lead for the MN-CMS and Ms Elmarie Cottrell, Senior Clinical Informatics Pharmacist, CUMH and MN-CMS. The updated protocols were written for use on the EHR.

5.4 Referrals and Integration

Support Groups and Voluntary Organisations

The Referral and Integration work stream had amongst its stated objectives to identify and all relevant organisations providing support following pregnancy loss and perinatal death in Ireland. This scoping exercise sought to gather all relevant information concerning the services provided, the nature of the organisations, their governance structures, volunteer involvement and referral pathways.

An agreed template of requested information was drawn up for circulation to all support organisations to ascertain a comprehensive overview of services provided. Organisations were initially identified by the working group based on existing professional knowledge and engagement. These data were then supplemented by online searches of support groups and voluntary organisations. Each organisation was contacted and invited to provide information about their organisation, population served, volunteer involvement, governance structures, funding sources and referral pathways.

A total of twenty seven support groups and voluntary organisations were identified in this review (Appendix 10). The breakdown of the numbers of organisations providing support in the various areas of pregnancy loss and perinatal death served is illustrated in figure 4 (a number or organisations provide services/ support across a number of areas). The findings revealed a breadth of service provision ranging from parent advocacy groups, professional services (some publicly funded), parent-to-parent support groups and educational services. Of note, the type of service provided was potentially confusing to ascertain when accessing information or particular websites in addition to lack of clarity about the primary function/service available.

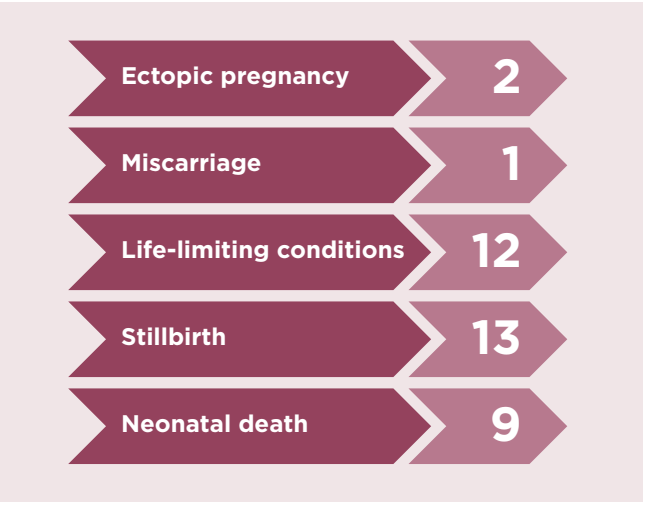

FIGURE 4: Breakdown of voluntary organisations/ support groups and areas of pregnancy loss

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The engagement of each group varied, however over time all groups did engage and participate in the overall shared endeavour of providing their information to be made available in the *www.pregnancyandinfantloss.ie* website as an initial signposting web portal where both parent and professionals can access information appropriate to their context in an accessible and timely way.

Individual support group meetings

The Implementation Lead and the Programme Manager met with a number of the larger organisations, who provide support in later pregnancy loss. These meetings took place in Dr Steevens Hospital in Dublin. Two hours was allocated to meet each group.

At these meetings the work of each group was discussed and the groups' needs were also explored.

Table 2: Support groups and voluntary organisations – meetings

GROUP	DATE
Every Life Counts	January 11th 2018
A Little Lifetime Foundation	January 11th 2018
Termination For Medical Reasons & Leanbh Mo Chroí	January 11th 2018
SOFT Ireland	January 11th 2018
Féileacáin	January 19th 2018
First Light	May 11th 2018
Nurture	May 11th 2018

There was ongoing collaboration with a number of the support groups and voluntary organisations on key issues that arose during the implementation process. Documents that were issued from the NIG were given to a number of the groups for their review.

Members of a number of support groups and voluntary organisations were involved in the Website development group and some of them remained involved in the website management group.

Education Day for Support Groups / Voluntary Organisations

There is a reliance on support groups and voluntary organisations to provide palliative and bereavement care services to families. While willing to fill these gaps in care, some groups told us when we met them that they did not always have the required knowledge or expertise to provide the level of care required by families. Following on from this it was decided to offer an education day to all of the support groups identified from the scoping exercise.

In order to identify the education needs of these groups, a Delphi approach was undertaken to explore what education was a priority for support groups who provide supports to parents who experience pregnancy/perinatal loss. The support groups were identified and asked to participate in two Delphi rounds.

SUPPORT GROUP EDUCATION DAY

RITA KELLY EDUCATION CENTRE, COOMBE WOMEN AND INFANTS UNIVERSITY HOSPITAL, DUBLIN
SATURDAY, DECEMBER 1ST, 2018

TOPIC	SPEAKER	TIME
REGISTRATION 09.30-10.00		
CHAIRS **DR SEOSAMH O'COIGLIGH, OBSTETRICIAN, OLOLH DROGHEDA** **MS RIÓNA COTTER, PROGRAMME MANAGER, STANDARDS IMPLEMENTATION**		
Welcome and Introduction	Dr Keelin O'Donoghue, (Maternal Fetal Medicine Specialist Obstetrician, CUMH) Ms Rióna Cotter (Midwife, Programme Manager, implementation of standards)	10.00-10.15
Prenatal diagnosis and screening; Fatal fetal anomalies/ life limiting conditions; Management of pregnancies	Dr Keelin O'Donoghue (Maternal Fetal Medicine Specialist Obstetrician, CUMH) Dr Jennifer Donnelly (Maternal Fetal Medicine Specialist Obstetrician, Rotunda Hospital) Ms Anna Maria Verling (Bereavement Clinical Midwife Specialist, CUMH)	10.15-11.15
Perinatal Pathology Postnatal care	Dr Brendan Fitzgerald (Perinatal Pathologist, CUMH) Ms Sarah Cullen (Bereavement Clinical Midwife Specialist, NMH)	11.15-12.15
LUNCH 12.15-13.15		
Neonatology Care of the Baby Palliative care	Dr Anne Doolan (Consultant Neonatologist, CWIUH) Anna Maria Verling (Bereavement Clinical Midwife Specialist, CUMH) Ms Stacey Power (Paediatric Palliative Care Nurse)	13.15-14.15
Bereavement Care; Pregnancy after Loss Supports for Bereaved Parents	Ms Anna Maria Verling (Bereavement Clinical Midwife Specialist, CUMH) Ms Fiona Mulligan (Bereavement Clinical Midwife Specialist, OLOH Drogheda) Rev Dr Daniel Nuzum (Healthcare Chaplain, CUMH)	14.15-15.15
Rights of women as patients in maternity hospitals	Ms Geraldine Keohane (Unit Manager of SIMS Clinic, Cork, Retired Director of Midwifery, CUMH)	15.15-15.30
Q & A SESSION FACILITATED BY MEMBERS OF NATIONAL IMPLEMENTATION GROUP FOR NATIONAL STANDARDS FOR BEREAVEMENT CARE FOLLOWING PREGNANCY LOSS AND PERINATAL DEATH		
CLOSE 15.45		

FIGURE 5 - Programme

"As a bereaved mother, I felt that my thoughts and opinions on the Bereavement standards were listened to and considered carefully when changes were being made."
Member of Parents Forum

"To have parents experiences and the professional expertise merged together was inspiring and gave me since of hope that babies that are born asleep in the future that parents will feel empowered from the knowledge of the professional and won't be afraid to talk about or ask any questions about their little baby."
Member of Parents Forum

"During the meetings, I was struck by the honesty of staff in acknowledging the challenges for them in providing bereavement care and the impact on staff when babies die. It became blatantly clear to me that meaningful support for staff and on-going education and training had to be central to the Bereavement Standards and must be prioritised by senior management as a non-negotiable."
Member of Parents Forum

Following the two rounds of the Delphi study the following topics were identified; antenatal diagnosis and management of pregnancy with a congenital anomaly, pathology, postnatal care, care of the baby at end of life, rights of women, and bereavement supports. These topics formed the basis of the content chosen for the Education Day.

In December 2018 members of the National Implementation Group facilitated an education day for a number of the support groups and voluntary organisations who provide support to parents bereaved by perinatal loss.

There were 85 attendees on the day, representing 15 of the organisations providing support to Bereaved parents. The education day was positively evaluated by those attending.

5.5 Parents Forum

Throughout the Standards implementation process we took a Public and Patient Involvement approach. Our past experiences have shown us that people are experts in their own care. By virtue of their own bereavement experience of grief parents have much to offer in shaping developments in bereavement care, policy and service provision. By involving bereave parents in decisions relevant to bereavement care, and acknowledging their experiences there can be an improvement in the quality of bereavement care being delivered.

The Standards Parents Forum was set up and had its first meeting in November 2017. It was comprised of ten parents who had experience of the different types of pregnancy loss, the NIG Clinical Lead, the NIG Project Manager and a Bereavement Clinical Midwife Specialist. 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 ensure that bereaved parents' views and opinions based on their experiences of pregnancy loss were represented in the implementation process.

The purpose of the Parents Forum was to:

- Represent the parent voice 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.

The Parents Forum met on five occasions during the two year implementation programme. The parents contributed to the implementation process in many ways, including reviewing pathways, reviewing the website content and giving their opinions on developments based on their experiences.

A number of parents attended the Bereavement Forums, both in 2018 and 2019. A number of parents assisted with publicising the work of the Standards implementation programme by engaging with National and regional media.

Participating parents contributed openly and creatively 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. The parents also gained new perspectives on the impact of perinatal bereavement on healthcare professionals thereby creating a deeper mutual understanding of the impact of perinatal death on both parents and healthcare professionals and thereby to establish a common goal to provide the highest quality compassionate bereavement care and support for all.

Members of Parents Forum at Bereavement Forum, Croke Park, 2018.
Above (l-r): *Ms Sue Mc Cabe, Ellie Mc Cabe, Professor Keelin O'Donoghue, Ms Rióna Cotter, Minister Simon Harris, Ms Anne Finn, Ms Rachel Rice.*

Members of Parents Forum at Bereavement Forum, UCC, 2019.
Above (l-r): *Professor Keelin O'Donoghue, Ms Sue Mc Cabe, Ms Collette O'Toole, Ms Jackie Prout, Mr Mikey Prout, Ms Rachel Rice, Ms Trish Clifford, Ms Rióna Cotter.*

"There are many different challenges and diverse groups and needs to be catered for when a baby is dying or has died and working on the oversight group has been very beneficial to learn of the different groups and their needs. It has been lovely seeing all the different work that goes on behind the scenes representing so many different people."
Member of Oversight Group

"We were delighted to be involved and we hope we added something to the standards. We sincerely hope that the high standards that you and your team set will continue across all hospitals on the island as it is imperative they do."
Member of Parents Forum

5.6 Perinatal Palliative Care and Termination of Pregnancy for Fatal Fetal Anomaly

This group worked in conjunction with the National Neonatal/Perinatal Palliative Care group (as part of the National Programme for Paediatrics and Neonatology).

A pathway was developed on perinatal palliative care which will feed into the pathway on neonatal palliative care. This pathway was published in April 2019.

Both Prof O'Donoghue and Rióna Cotter sat on and contributed to the National Neonatal/Perinatal Palliative Care group which collaboratively looked at developing care pathways for families requiring perinatal palliative care, starting in the Maternity Unit in the antenatal period and continuing on after the baby's birth and onto the Paediatric, Maternity units and the community.

Members of the group have advocated both nationally and internationally for the improvement in the provision of and access to prenatal diagnosis for all women using the Maternity Services in this country.

It is widely acknowledged that the provision of fetal anomaly ultrasound is an essential component of good antenatal care. A study undertaken in 2016 found that fetal anomaly ultrasound was offered to all women in 7 Maternity units, selectively to some women in 7 of Maternity units and was not offered at all in the remaining 5 Maternity units.[7]

In conjunction with the HSE's NWIHP this group have advocated for and encouraged universal access to fetal anomaly ultrasound for all women. As of March 2021 there is universal access to fetal anomaly scanning in all 19 Maternity Units.

5.7 Education, Training and Staff Support

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.

Six universities provide education to medical or midwifery students. Each were contacted individually order to establish what was their curriculum in perinatal bereavement.

Results of the review of teaching provided to midwifery (undergraduate/post graduate) and medical (undergraduate / post graduate) students on perinatal bereavement care in the Republic of Ireland are shown below as reported to the group by each University.

Development of a list of educational programmes covering perinatal bereavement available to staff at a local, national and international level were identified and listed. While not a definitive list, this gives an indication of the types of education available relating to perinatal bereavement. Some of this detail is shown in Appendix 11.

Perinatal Bereavement Education Standards

The "National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death" set out the expectations for care that families can expect to receive in all settings in Ireland (HSE, 2016).

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 sets out core domains relevant to All, Some and Few staff across six dimensions.[8] 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. (Appendix 12).

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 men and their families within a complex healthcare system.

With the assistance of the HSE Staff Workplace Health and Wellbeing Unit a staff support document (Appendix 13) was written and published in 2019. This document sets out key recommendations for the provision of staff support within the 19 Maternity 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/*

[7] D Hayes-Ryan, K McNamara, N Russell, L Kenny, K O'Donoghue. Maternity Ultrasound in the Republic of Ireland 2016; A Review. Irish Medical Journal 2017; 110 (7): 598. PMID: 29341510

[8] Palliative Care Competence Framework Steering Group. Palliative Care Competence Framework. Health Service Executive, 2014.

Table 3: Education content for Midwifery and Medical Students

	MIDWIFERY	MEDICINE
University 1	An introduction to loss and bereavement, a theoretical perspective. Key psychosocial issues associated with bereavement following pregnancy loss and perinatal death. Ectopic pregnancy, miscarriage, termination of pregnancy, recurrent miscarriage. Midwifery care for families who experience, stillbirth. Education and Training Workshop in Bereavement Care (1day)	Communicating Bad News Perinatal Loss Perinatal Bereavement Care Termination of Pregnancy Self-Care
University 2	Diagnosis of fetal anomaly and psychological adaptation Perinatal loss Coroners Cases	Ethics Communication and Professional Development Communicating Bad News in Paediatrics Bereavement Care in Miscarriage, Stillbirth, Neonatal Loss
University 3	Eight hours face to face contact -lectures, small group work and discussion groups. 1. Overview of types of loss within the maternity population. 2. Introduction to theories of grief and loss. 3. Caring for woman and her family on the diagnosis of fetal anomaly. 4. Preparing for birth in cases of loss including perinatal palliative care. 5. Care of woman and her family at the time of loss. Including memory making, spending time with babies. 6. Support for women and families in postnatal period. 7. Support for women and families in pregnancy after loss. 8. Broader issues relating to perinatal loss e.g. lack of societal recognition, the policy agenda of perinatal loss, global context.	Lecture on Recurrent Miscarriages and Perinatal loss Lecture on Epidemiology Breaking bad news Behavioural medicine and self-care
University 4	Perinatal Loss and Bereavement. Theoretical instruction in relation to care of women who experience miscarriage, stillbirth and infertility. Two-hour workshop on National Bereavement Standards.	
University 5	N/A	We teach Counselling skills to undergraduates, now in the newly opened Simulation Centre in where we have a Simulated Clinic environment that allows us to place Simulated Patients (bank of SPs that we use) in a virtual OPD suite and the students are filmed breaking bad news (e.g Miscarriage), or asking patients about a prior Stillbirth, etc. These consultations can be live-streamed into an adjacent tutorial room, where a faculty member and an additional small group of students get to watch the consultation, or, more typically, we video-record the consultations and re-convene in the tutorial room with the wider group to discuss counselling skill/ style, techniques, terminology etc and the SPs get to provide invaluable feedback to the students. This tutorial runs weekly throughout the academic year.
University 6	"Meets NMBI Standards" Lectures/topics on loss Clinical Experience in care of women bereaved through miscarriage, stillbirth, neonatal death or neonatal disability; care of women with early pregnancy problems and pregnancy loss.	Formal teaching (lectures, tutorials, and online Blackboard) and case presentations about perinatal loss, which includes the importance of bereavement counselling. In addition, students are familiar with the role of the Perinatal Bereavement Officer. Ethical and Legal Aspects of Termination of pregnancy

6. DEVELOPMENT AND OVERSIGHT PROGRAMME

6.1 National Oversight Group

To ensure the continuation of the work of the Standards Professor O'Donoghue received approval from the HSE's NWIHP to convene an oversight group, after the two year implementation programme came to an end.

The purpose of the Oversight Group is to oversee the continued implementation and ongoing development of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death in the 19 Maternity Units in the Republic of Ireland.

The Oversight Group meets twice a year.

Objectives:

- To review reports from the website management group
- To oversee the need for further development of the national website: www.pregnancyandinfantloss.ie
- To act as an advisory group for any review of the relevant HSE/RCPI/IOG National Clinical Guidelines in Obstetrics and Gynaecology
- To review and update the Standards care pathways and national patient information leaflets as necessary
- To act as an advisory group around matters of staff education relating to bereavement care
- To continue to foster links and working relationships between the support groups and voluntary organisations and the Bereavement teams in the 19 Maternity Units
- To review the results of the Standards audit tool and the associated hospital QIPs
- To act as an advisory group for any planned review and update of the Standards
- To collaborate with relevant National Clinical Care programmes
- To report all of the above to the HSE's NWIHP

Accountability:

The oversight group reports to the HSE National Women and Infants Health Programme. The HSE's NWIHP are responsible for providing the Oversight Group with resources and/or assistance to carry out their functions.

Membership:
Membership of the Oversight Group is composed of clinicians who are experts in bereavement care, parent representatives and representatives from the support groups and voluntary organisations who have engaged with the implementation of the Standards.

Prof Keelin O'Donoghue	Consultant and Professor, Obstetrics and Gynaecology, CUMH
Ms Rióna Cotter	Co-chair, Programme Manager
Ms Mary Jo Biggs	General Manager, National Women and Infants Health Programme
Ms Anne Brady	Bereavement Clinical Midwife Specialist
Ms Louise Brookes	NILMDTS representative
Ms Siobhan Canny	SAOLTA Group Director of Midwifery
Ms Brid Carroll	Irish Childhood Bereavement Network representative
Ms Marie Cregan	Féileacáin representative
Ms Barbara Coughlan	Midwifery Education (University)
Ms Mary Devins	Consultant Paediatrician with a special interest in Palliative Medicine, Our Lady's Children's Hospital, Crumlin
Ms Ann Doherty	Maternity Social Worker, Mayo University Hospital
Dr Jen Donnelly	Consultant Obstetrician/ Gynaecologist, Rotunda Hospital
Dr Anne Doolan	Consultant Neonatologist, Coombe Women and Infants University Hospital/Midland Regional Hospital Portlaoise
Ms Angela Dunne	Director of Midwifery, NWIHP
Dr Brendan Fitzgerald	Consultant Perinatal Pathologist, Cork University Hospital
Ms Patricia Grehan	SOFT Ireland
Ms Heather Hughes	Fetal Medicine Clinical Midwife Specialist, NMH
Ms Christina Kilpatrick	Neonatal Palliative Care Nurse, Rotunda Hospital
Mr Kilian Mc Grane	National Programme Director, National Women and Infants Health Programme
Ms Mary Mc Grath	A Little Lifetime Foundation representative
Dr Mary Moran	Midwifery Sonography (Education) UCD
Dr Deirdre Muller Neff	Perinatal Psychiatrist, CUMH
Rev Dr Daniel Nuzum	Healthcare Chaplain, CUMH, Lecturer, UCC
Ms Cathy O'Sullivan	Midwifery Education (Centre for Midwifery Education) CUMH
Ms Deirdre Pierce Mc Donnell	Miscarriage Association of Ireland representative
Ms Stacey Power	Paediatric Palliative Care Nurse, PhD Student, INFANT Centre, University College Cork
Ms Margaret Quigley	National lead for Midwifery, ONMSD

Dr Amanda Roberts	Bereavement Development Officer, IHF
Ms Rachel Rice	Parent representative
Dr Nandini Ravakumar	Consultant Obstetrician, MRHM
Dr Jennifer Ryan	Leanbh Mo Chroí representative
Dr Fionnuala Sheehan	First Light representative
Ms Anna Maria Verling	Bereavement Clinical Midwife Specialist, CUMH
Ms Vicky Wall	Every Life Counts representative
Ms Siobhan Whelan	Vasa Praevia Ireland representative

6.2 Work of the Development Programme

6.2.1 Standards Review

Review of the Standards

The National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death were published in 2016. At publication a review date of August 2019 was set. A group to review and update the Standards was convened in November 2019.

Terms of Reference:

The Group for the Review and Update of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death will conduct its work in line with the following terms of reference:

Purpose of the working group:

To review and update the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death.

Objectives:

- To review and update the Standards
- To circulate the updated Standards via NWHIP to all Maternity Units and Community Health Organisations (CHOs)

Membership:

Prof Keelin O'Donoghue	Consultant and Professor, Obstetrics and Gynaecology, CUMH
Ms Rióna Cotter	Programme Manager
Ms Anne Doherty	Maternity Social Worker, MUH
Ms Susan Dineen	Senior Medical Scientist ,Perinatal Pathology, CUH
Dr Brendan Fitzgerald	Consultant Perinatal Pathologist, CUH
Ms Anne Flynn	Perinatal Mental Health Nurse Specialist, CUMH
Ms Marie Lynch	Paediatric Palliative Care Neonatal Nurse, CUMH
Rev Dr Daniel Nuzum	Healthcare Chaplain, CUMH, Lecturer, UCC
Ms Stacey Power	Paediatric Palliative Care Nurse, PhD Student, INFANT Centre, UCC
Ms Anna Maria Verling	Bereavement Clinical Midwife Specialist, CUMH
Ms Jill Whelan	Bereavement Clinical Midwife Specialist, UHW
Professor Martin White	Consultant Neonatologist, CWIUH

This group undertook a review of the Standards, the relevant literature, clinical guidance and international literature to assist in the update of the Standards.

Following the rewriting of the Standards, the document was distributed to the review group for feedback, and it was then sent to the original development and writing group (2014-2016) for their review.

Once feedback from these groups was received it was shared for comments with the National Oversight Group and then finally sent to the HSE's NWIHP for approval prior to publication.

The updated Standards document will be published in 2021.

6.2.2 Information Technology

The website management group, comprised of members of the National Oversight group and two parent representatives continue to meet biannually to review the content of and oversee the management of the Pregnancy and Infant Loss Ireland website. This group prepares updates twice yearly to ensure that the information is up to date and accurately reflects the care available to parents, both in hospital and from the support organisations. The running and management of the website continues to be supported by the Irish Hospice Foundation. *www.pregnancyandinfantloss.ie*

The corkmiscarriage.com website was launched in March 2020. This website is a resource for parents and staff who want information about first trimester miscarriage. Members of the National Oversight group provided assistance and support to the group who developed this resource. *www.corkmiscarriage.com*

MyChild.ie is a new website for parents that was launched in December 2018. It contains information and advice on pregnancy and the first 3 years of a child's life. In November 2020 the HSE communication manager who has responsibility for the content of the website contacted Prof O'Donoghue to ask for assistance with the content relating to pregnancy loss. A small multidisciplinary group was convened to review and update the content on pregnancy loss on the website. This updated information is due to be published on the website later this year. *www.mychild.ie*

6.2.3 Education and Training

TEARDROP Perinatal Bereavement Education

The multidisciplinary, interactive TEARDROP (Teaching, Excellent, pArent, peRinatal, Deaths-related, inteRactions, tO, Professionals) workshop was developed, piloted, 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*.

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-wide compassionate culture by all staff caring for bereaved parents in the Maternity settings

The first TEARDROP workshop took place in Cork University Maternity Hospital (CUMH), Ireland on the 9th August 2019. It was attended by 42 members of staff from midwifery, obstetrics and allied health professions. Members (14 in total) of the multidisciplinary CUMH Bereavement team facilitated the teaching. The workshop consisted of six interactive 30 minute stations using an internationally-recognised teaching style (SCORPIO method) which is frequently used in the Maternity setting for multidisciplinary team learning. Each small multidisciplinary group of participants (7 people) rotated through all six stations. Topics covered included: Communication, Investigation and Management, Perinatal Pathology, Fatal Fetal Anomalies, Pregnancy after Loss and Risk Factors, Audit and Reporting. Each participant was asked to give structured feedback on the workshop and was then asked what topics they thought should be included in future workshops.

The second workshop took place in January 2020 and was run in the same manner as the earlier workshop. There were 53 staff members, from the 4 Maternity Units in the South/ South West Hospital Group, in attendance at the second workshop. This was also attended by external clinical and academic observers who assessed the programme for suitability for use. The workshop was again positively evaluated both by the attendees and the observers.

A paper describing the TEARDROP workshop for perinatal bereavement care training, an evaluation of its pilot and first workshop, and the teaching methods applied has been published in the journal *Midwifery* in March 2021.[9]

Given the positive evaluation of the two workshops that have been already run consideration is being given to rolling out these workshops nationally. A proposal has been presented to the National Women and Infants Programme on how to progress this rollout beyond 2021.

TEARDROP Education Day, CUMH, 2019. **Back row:** *Ms Eimear O'Shaughnessy, Ms Orla O'Connell, Rev Dr Daniel Nuzum, Ms Stacey Power, Dr Margaret Murphy, Dr Karen Mc Namara, Dr Noirin Russell, Ms Sue Dineen, Dr Aenne Helps.* **Front Row:** *Ms Claire Everard, Professor Keelin O'Donoghue, Ms Sam Manna, Ms Anna Maria Verling, Dr Jessica White, Ms Rióna Cotter.*

TEARDROP Education Day, CUMH, 2020. **Above (l-r):** *Ms Orla O'Connell, Ms Orla Jennings, Ms Anna Maria Verling, Dr Margaret Murphy, Ms Rióna Cotter, Professor Keelin O'Donoghue, Dr Sarah Meaney, Dr Jessica White, Dr Karen Mc Namara, Dr Aenne Helps, Dr Caoimhe Ni Healaithe, Ms Sue Dineen, Rev Dr Daniel Nuzum.*

[9]Leitao S, Helps A, Cotter R, O'Donoghue K; TEARDROP PLRG working group. Development and evaluation of TEARDROP - a perinatal bereavement care training programme for healthcare professionals. Midwifery. 2021 Mar 5;98:102978. doi: 10.1016/j.midw.2021.102978. Online ahead of print. PMID: 3374351

Dealing With Loss in Maternity Settings Workshop, Irish Hospice Foundation

Standard four of the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death (2016) states that all staff 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.

The Irish Hospice Foundation (IHF) have developed a one day workshop called Dealing With Loss in Maternity Settings which is based on the Standards.

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.

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 patients and families
- Understand the importance of good communication in times of crisis
- Develop their ability to support patients 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

The Irish Hospice Foundation provided a Train the Trainers course for the Dealing with Loss in Maternity Settings workshop that would enable suitable participants to deliver the workshop under licence in their own Maternity Units. It was decided that the Bereavement Clinical Midwife/Nurse Specialist group should be trained as facilitators for this workshop to allow it to be provided in all Maternity Units.

It has been agreed that the Irish Hospice Foundation (IHF) will have oversight of this training. This oversight will allow the IHF retain ownership of the Dealing with Loss in Maternity Settings programme content and material (PowerPoint presentation, handbook, video, etc.). It is important that the workshop is quality assured through the use of facilitator support meetings, a participant workbook and analysis of participant feedback.

This training was scheduled to take place in spring 2020, however due the COVID-19 pandemic and related restrictions this was delayed. The first group of Bereavement CMS/CNS attended this training virtually in January 2021. The remaining number will receive their training later in 2021.

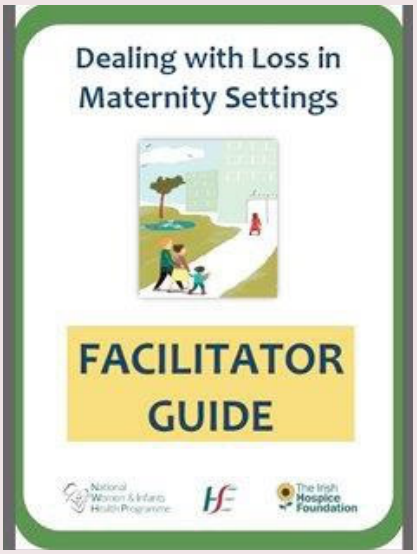

FIGURE 6: Booklet

Staff Induction Programme

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 (Appendix 14) itemising the suggested content for induction programmes has been developed. The topics contained within in this document include; explanation of Perinatal Bereavement, relevant legislation, communication skills, post mortem examination & management of fetal remains, family care, supports available for parents and staff, reporting requirements and contacts for staff and parent supports. This will be distributed to all the Maternity Units by the HSE's NWIHP.

"I think it has been a very positive experience. All members were given opportunity to speak to question or provide feedback. I feel there should be more active clinical members to provide feedback to the units providing the care."
Member of Oversight Group

"We all might have different opinions in some aspects and not agree on everything and that is good."
Member of Oversight Group

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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 Irish National Maternity Strategy acknowledges that there has been little confidence in the Maternity services and there is a need to regain the public's trust and increase staff morale.[10] The Strategy also 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. *www.hse.ie/eng/about/who/qid/staff-engagement/schwartzrounds/*

Schwartz Rounds are an intervention intended to develop compassionate and supportive cultures for staff working in health care settings, and in doing so, promote improvement in health care outcomes for patients and service users (Point of Care Foundation, 2017). 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.

We 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 has been recommended that all Maternity Units senior management teams give serious consideration to implementing them

It should also be acknowledged that the National Maternity Hospital introduced Schwartz Rounds in September 2019 and they have had a positive response from the staff who have attended. A number of Maternity Units located within large general hospitals have also participated in Schwartz rounds and have positively evaluated them.[11]

6.2.4 Audit Tool

The audit tool that was used to assess perinatal bereavement care in 2017 was reviewed and revised to reflect the improvements that had been made in practice since 2017.

From our knowledge of the services and of a certain amount of the improvements made since 2017 we were able to refine the audit tool to exclude questions about where women experiencing pregnancy loss are assessed in the hospital, what type of burial/cremation options are offered to parents, the use of bereavement alert symbols, availability of interpretation services etc. Among new topics covered we included questions about the provision of termination of pregnancy for fatal fetal anomaly, the provision of perinatal pathology services, and the availability of the perinatal mental health team. As we carried out the audits during the COVID-19 pandemic we also asked the teams about the impact the structures and restrictions in place to manage the pandemic was having on perinatal bereavement care.

The revised audit tool was presented to the National Oversight Group for approval before it was used. Findings from the 2017 audit are presented in detail in Section 7.

"A key element of the oversight group from my perspective is the wide membership including representatives from support groups, maternity units, service users, and education, local, regional and national leadership. This provided a 'bringing together' of the interested parties and enabled very balanced discussion/input at the meetings whilst keeping the bereaved woman/couples as the centre focus."
Member of Oversight Group

"The wealth of experience and knowledge of the group members, which included bereaved parents, will be valuable resource in aiding future developments and advocacy."
Member of Oversight Group

[10] Creating A Better Future Together -National Maternity Strategy, Department of Health, 2016.

[11] Cullen, S. (2020). Implementing Schwartz Rounds in an Irish Maternity hospital. Irish Journal of Medical Science, Feb;190(1):205-208. https://doi.org/10.1007/s11845-020-02268-6

7. MATERNITY UNITS BEREAVEMENT CARE AUDIT

7.1 Bereavement Care Audit 2015

In 2015 the Standards development group undertook an audit of perinatal bereavement care in all 19 Maternity Units in the country. This audit was carried out to get a baseline of perinatal bereavement care. An audit questionnaire was posted to midwifery and nursing staff, medical social workers and chaplains working in all Maternity Units in Ireland. There was an 82% response rate to the audit questionnaire, with responses received from each Maternity Unit.

This audit was not carried out by this group so the findings being presented are from a report received by this previous group. The findings will be presented according to "people, place and processes" as was done with the later audits carried out by implementation and development programmes.

Findings

PEOPLE

DISCIPLINE	NUMBER OF UNITS	WTE
Bereavement CMS	9 Maternity Units	6 full-time posts 3 part-time posts
Maternity Social Worker	10 Maternity Units	1 with specialist bereavement training
Chaplain	Available in all	Some hospital employed, some parish employed- (breakdown not specified)

PLACE

ACCOMMODATION	NUMBER OF UNITS THAT ANSWERED*
Single room available	98%
PL patients on Antenatal ward	76%
PL patients on Postnatal ward	59%

*It is noted that this was self-reported data by each Unit and the single room mentioned does not refer to designated inpatient bereavement accommodation.

PROCESSES

PROCESS	NUMBER OF UNITS
Bereavement Committee*	14 Maternity Units
End of Life Committee*	19 Maternity Units
Follow up pregnancy loss appointment	52%
Annual memorial service	17 Maternity Units
Provision of in-service training	Results unclear but it appears that MSW and chaplaincy have no access to training

*It is noted that this was self-reported data by each Unit and it is likely some of these committees were not maternity bereavement committees.

STAFF SUPPORT	STAFF	INFORMAL SUPPORT
Support for Bereavement Specialist Staff (n=32)	3 (<1%)	12 (38%)
Support for Staff involved in diagnosis of fetal demise (n=39)	11 (28%)	14 (36%)

Conclusion and Recommendations of the 2015 audit

There was underemployment of bereavement Clinical Midwife Specialists (CMS) in the Maternity services. Nine Maternity Units co-located within general Maternity Units did not have a medical social worker on their staff. Education in perinatal bereavement care was not available to all staff. Accommodation was inadequate and not all bereaved women had access to single rooms. It was also recommended that hospital management needed to address the impact on staff of providing bereavement support and put adequate interventions in place to ensure staff well-being.

These recommendations were fed back to the HSE Acute Care Division and also helped formulate some of the recommendations in the final Standards document.

7.2 Bereavement Care Audit 2017

In March 2017 Prof Keelin O'Donoghue and Rióna Cotter commenced working on the implementation of the Standards. As part of this an audit of all 19 Maternity Units was undertaken. An audit tool was developed from the Standards document and approved by the National Implementation Group. (Appendix 2).

Prof O'Donoghue and Rióna Cotter visited each Maternity Unit between May and August 2017.

ROUTE ACROSS IRELAND 2017

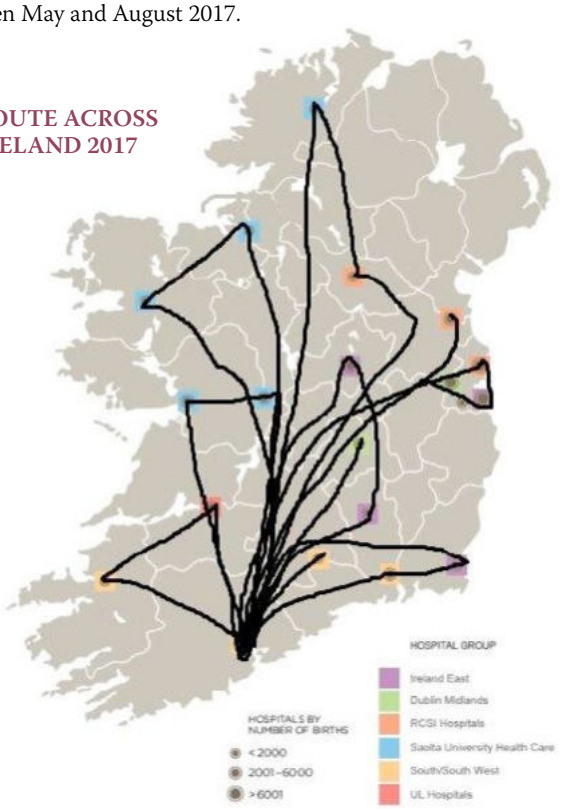

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TABLE 4: Example of feedback given to hospitals in 2017

FEEDBACK	NEED TO RESOLVE	TIMELINE FOR RESOLUTION & FEEDBACK	RESPONSIBLE PERSON
FAU - needs to be moved to maternity area and upgraded	Critical	3 Months	
Increase in Perinatal Pathology WTE & support for existing personnel needed	Critical	3 Months	
Perinatal Pathology Service needed	Urgent	3 Months	
Fetal anomaly scanning service for all women needed	Urgent	3 Months	
Clinical lead for pregnancy loss needed	Necessary	Quality Improvement Plan needed in 4 Months	
Administration support for bereavement team	Necessary	Quality Improvement Plan needed in 4 Months	
Direct admission card needed	Ideal	Quality Improvement Plan needed in 6 Months	
Dedicated book of remembrance for pregnancy loss needed	Ideal	Quality Improvement Plan needed in 6 Months	

The visits were pre-arranged with the Maternity Units with an invitation being sent to each Hospital Manager, Director of Midwifery/Nursing and Clinical Director. The senior management teams were asked to convene all the members of the bereavement team to meet with the auditors.

Each visit comprised of a meeting with the bereavement team and management team (attendees varied in each hospital). The auditors used the approved audit tool to ask questions about bereavement care in each hospital. This was followed by a tour of the bereavement facilities in each hospital.

Once all the Maternity Units audits were complete feedback was prepared for each hospital. This feedback which included individual recommendations with specified timelines for each hospital was presented to the HSE's NWIHP management team. Following this the individual feedback was presented to each hospital in October 2017, with a request for a quality improvement plan to be returned by the end of 2017 (Table 4). Quality Improvement Plans (QIPs) were received from all Maternity Units by early 2018. In July of 2018 all Maternity Units were asked for a progress report on their QIPs.

7.3 Bereavement Care Audit 2020

As part of the continuation and development of the Standards implementation programme, it was agreed that Prof Keelin O'Donoghue and Rióna Cotter would audit all 19 Maternity Units again. The audit tool that was used in 2017 was reviewed and revised to reflect the improvements that had been made in practice since 2017. This audit tool was presented to the National Oversight Group for approval before it was used. (Appendix 15).

Prof O'Donoghue and Rióna Cotter visited 17 of the 19 Maternity Unit between August 24th and September 24th 2020. One Unit had to cancel the visit due to enforced travel restrictions imposed to manage the COVID-19 pandemic. This meeting took place via an online platform. One of the Maternity Units was unable to facilitate a visit due to an issue with staffing. This audit was carried out over the phone with a senior member of the midwifery management team. As in 2017 the visits were pre-arranged with the Maternity Units with an invitation being sent to each hospital manager, Director of Midwifery/Nursing, Clinical Director and bereavement Clinical Midwife/Nurse Specialist. The senior management teams were asked to convene the members of the bereavement team to meet with the auditors.

In advance of the visit the audit tool was sent to the hospital bereavement team to be completed and returned to the auditors in advance of the visit. This allowed the auditor's time to discuss the findings and prepare targeted questioning based on the returned audit tool. Each visit comprised of a meeting with the bereavement team and management team (attendees varied in each hospital). The auditors discussed and clarified any issues that were identified on the audit tool. Due to COVID-19 pandemic precautions the auditors only directly visited clinical areas where improvements or developments had been made since 2017.

The feedback from each hospital was presented to the HSE's NWIHP management team, with recommendations for improvement. Summaries of the audit visit were also provided to each Maternity Unit.

ROUTE ACROSS IRELAND 2020

7.4 Hospital Reports Audit Results 2017-2020

Hospital Number 1

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	0	1WTE
Nominated Clinical Lead for Pregnancy Loss	No	No
Nominated Clinical Lead for Early Pregnancy Service	No	No
Neonatologist/Paediatrician assigned to bereavement care	No	No
Perinatal Pathologist	No- use locum perinatal pathology service	Service provided from within group
Social Worker	No	Maternity social worker- available to support bereaved parents if requested
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	No- service provided by radiographers	Yes- midwife sonographers and radiographer provide full service
Perinatal Mental Health Team	No	Perinatal Mental Health CMS in post supported by group hub
Administration Support for pregnancy loss team	No	Yes-
Allocated member of management team responsible for bereavement care	No	Yes- CMM3
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse and community palliative care team	Access to Childrens Outreach Nurse and community palliative care team
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	Yes
Quiet Room on Maternity Unit	No	No
Quiet Room in FAU/Ultrasound	No	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	No	Yes
Family Room in NNU	No	Access to quiet room on Maternity ward
Dedicated OPD space for follow up appointments	No-	No
Availability of Mortuary Facilities	Yes	Yes
CMS office	N/A	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	No	Yes
Direct Admission Policy and Card	No	Yes
Hospital Bereavement Symbol in use	Yes- IHF Symbol	Yes- IHF Symbol
Hospital Book of remembrance	No	Yes
Annual Service of Remembrance	No	Yes
Perinatal Pathology Service	Locum provided service	Service provided through group
Are national Clinical Guidelines/pathways in use?	Some	Yes- pathways adapted for use via group
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	HSE & Support Organisation information leaflets, group have developed a number of leaflets
Maternity Bereavement Committee	No- maternity representation on hospital committee	No- maternity representation on hospital committee
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	Yes- follow up miscarriage clinic held on Gynae ward	Yes- follow up miscarriage clinic held on Gynae ward
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Seen by Obstetric registrar or by named consultant with CMS	Seen by Obstetric registrar or by named consultant with CMS
Formal Staff support/wellness programme	No	Via EAP
Access to elective theatre list for ERPCs	No- access to emergency lists	No- access to emergency lists
Management of own Gynae and Maternity beds	No	No
Staff Education Sessions	No	Occasional

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Hospital Number 2

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	Vacant	1 WTE
Clinical Lead for Pregnancy Loss	No	Yes
Clinical Lead for Early Pregnancy Service	No	Yes
Neonatologist/Paediatrician assigned to bereavement care	No	Yes
Perinatal Pathologist	Use locum	Service provided within group from January 2021
Social Worker	No	No service in Maternity hospital
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	Use Community Psychiatric service	Perinatal Mental Health CMS post vacant
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes- DOM
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	No- plans in development
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	Yes	Yes- has been upgraded
Availability of Breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	No	No- refurbishment in progress
Dedicated OPD space for follow up appointments	No	No
Availability of Mortuary Facilities	Yes	Yes- upgraded mortuary with parent facilities
CMS office	N/A	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	No	Yes
Direct Admission Policy and Card	Yes	Yes
Hospital Bereavement Symbol in use	Yes- IHF symbol	Yes- IHF symbol
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Locum service	Service provided within group from January 2021
Are national Clinical Guidelines/pathways in use?		Adapted care pathways for use
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	HSE & Support Organisation information leaflets
Maternity Bereavement Committee	Hospital Committee with maternity representation	Hospital Committee with maternity representation
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No -seen as necessary by named consultant and CMS	No- seen as necessary by named consultant and CMS
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	No- seen as necessary by named consultant and CMS	No-seen as necessary by named consultant and CMS
Formal Staff support/wellness programme	Via EAP	Via EAP
Access to elective theatre list for ERPCs	No – emergency list only	No – emergency list only
Management of own Maternity and Gynae beds	No	No
Staff Education Sessions	No	Yes-regular

Hospital Number 3

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	1.5 WTE	1 WTE (0.5 WTE deficit)
Nominated Clinical Lead for Pregnancy Loss	No	Yes - locum
Nominated Clinical Lead for Early Pregnancy Service	Yes	Yes
Neonatologist/Paediatrician assigned to bereavement care	No	No
Perinatal Pathologist	Yes- full on site service	Yes- full on site service, providing full service within group
Social Worker	Yes- with dedicated bereavement sessions	Yes- with dedicated bereavement sessions
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	Perinatal mental health Psychiatrist and AMP	Full Perinatal Mental Health team in place as per National PMH Strategy, hub for group
Administration Support for pregnancy loss team	Yes	Yes
Allocated member of management team responsible for bereavement care	Yes- ADOM	Yes- ADOM
Availability of palliative care CNS/Service	Access to children's outreach nurse and paediatric palliative care consultant	Access to children's outreach nurse and paediatric palliative care consultant
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	No
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	Yes	Yes
Dedicated OPD space for follow up appointments	No	No
Availability of Mortuary Facilities	Yes	Yes
CMS office	Yes	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Yes	Yes
Direct Admission Policy and Card	Yes	Yes
Hospital Bereavement Symbol in use	Yes- use IHF symbol	Yes- use IHF symbol
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Full service	Providing full service within group
Are national Clinical Guidelines/pathways in use?	Yes	Yes- have adapted care pathways for use locally
Communication pathways with tertiary hospitals	No – need to be developed	No – need to be developed
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	
Maternity Bereavement Committee	Yes	No
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	Recurrent miscarriage clinic	Recurrent miscarriage clinic
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Twice weekly SpR with CMS- in CMS office or in OPD following Gynae clinic	Twice weekly SpR with CMS- in CMS office or in OPD following Gynae clinic
Formal Staff support/wellness programme	Yes- via EAP	Yes- via EAP
Access to elective theatre list for ERPCs	Yes	Yes
Management of own Maternity & Gynae beds	Yes	Yes
Staff Education Sessions	Yes- regular education sessions	Yes- infrequent

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Hospital Number 4

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	Vacant	Vacant
Nominated Clinical Lead for Pregnancy Loss	No	Yes
Nominated Clinical Lead for Early Pregnancy Service	No	Yes
Neonatologist/Paediatrician assigned to bereavement care	No	No
Perinatal Pathologist	Use service of locum perinatal pathologist	Service provided within group from January 2021
Social Worker	Yes- no perinatal bereavement sessions	Yes- no perinatal bereavement sessions
Hospital Chaplain	One chaplain on campus- Diocesan employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	No	Perinatal Mental Health CMS in post with support from group hub
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes- CMM3
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	No
Quiet Room on Maternity Unit	No	No
Quiet Room in FAU/Ultrasound	No	No
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	No	No- assessment room upgraded
Family Room in NNU	No	No
Dedicated OPD space for follow up appointments	No	No- seen in OPD at end of clinic
Availability of Mortuary Facilities	Yes	Yes
CMS office	No	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	No	Yes
Direct Admission Policy and Card	No	Yes
Hospital Bereavement Symbol in use	No	Yes- IHF symbol used
Hospital Book of remembrance	No	No
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Use locum	Group service will be available from January 2021
Are national Clinical Guidelines/pathways in use?	No	Some
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	HSE & Support Organisation information leaflets
Maternity Bereavement Committee	No – maternity representation on hospital committee	No – maternity representation on hospital committee
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No	No
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Seen as necessary by named consultant in OPD	Seen as necessary by named consultant in OPD
Formal Staff support/wellness programme	No	Via EAP
Access to elective theatre list for ERPCs	No- access via emergency lists	No- access via emergency lists
Management of own Maternity & Gynae beds	No	No
Staff Education Sessions	No	No

Hospital Number 5

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	1 WTE	1 WTE
Nominated Clinical Lead for Pregnancy Loss	No	Yes
Nominated Clinical Lead for Early Pregnancy Service	No	No
Neonatologist/Paediatrician assigned to bereavement care	No	No
Perinatal Pathologist	Use locum	Use locum
Social Worker	No- none on campus	No- none on campus
Hospital Chaplain	Use services of local parish	Use services of local parish
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	Access to psychiatry liaison CNS	Access to psychiatry liaison CNS- CMS post vacant
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes- DOM
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	Yes
Quiet Room on Maternity Unit	No	No
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	Yes	Yes
Dedicated OPD space for follow up appointments	Yes- not fit for purpose	Yes- not fit for purpose
Availability of Mortuary Facilities	Yes	Yes- currently being renovated
CMS office	Shared	Shared
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	No	Yes
Direct Admission Policy and Card	No	Yes
Hospital Bereavement Symbol in use	Yes- use IHF symbol	Yes- use IHF symbol
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	No	Yes
Perinatal Pathology Service	Use locum service	Use locum service
Are national Clinical Guidelines/pathways in use?	Yes	Yes- have adapted care pathway for use locally
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	Have developed own information leaflets
Maternity Bereavement Committee	No- Maternity representation on hospital committee	Yes
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No	No
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Patients seen by Obstetric consultant or specialist registrar and CMS	Patients seen by Obstetric consultant or specialist registrar and CMS
Formal Staff support/wellness programme	Via EAP	Yes- hospital run sessions
Access to elective theatre list for ERPCs	No- access to emergency lists	Yes- access to elective lists
Management of own Maternity and Gynae beds	Yes	Yes
Staff Education Sessions	No	Regular education sessions provided

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Hospital Number 6

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	1WTE	1WTE
Clinical Lead for Pregnancy Loss	No	No
Clinical Lead for Early Pregnancy Service	No	Yes- locum consultant
Neonatologist/Paediatrician assigned to bereavement care	No	No
Perinatal Pathologist	Use locum	Service provided from within group
Social Worker	No	Yes- provides perinatal bereavement support when requested
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	No- ultrasound performed by radiographers and registrars	No- ultrasound performed by radiographers
Perinatal Mental Health Team	No	Perinatal Mental Health CMS in post with support from group hub
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes- ADOM
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	Yes	Yes- awaiting upgrade
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	Yes	Yes
Dedicated OPD space for follow up appointments	Difficult to secure	Difficult to secure
Availability of Mortuary Facilities	Yes	Yes
CMS office	Shared	Shared
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	No	Yes
Direct Admission Policy and Card	No	Yes
Hospital Bereavement Symbol in use	Yes- IHF symbol	Yes- IHF symbol
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Service provide by locum	Service provided from within group
Are national Clinical Guidelines/pathways in use?	RCPI guidelines in use	Some of the guidelines are in use
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	Have developed own information leaflets
Maternity Bereavement Committee	No- maternity representation on hospital committee	No- maternity representation on hospital committee
Hospital provided mementoes	Yes	Yes- with community groups involvement
Pregnancy loss clinic/recurrent miscarriage clinic?	No -seen as necessary by named consultant and CMS	No- seen as necessary by named consultant and CMS
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	No- seen as necessary by named consultant and CMS	No-seen as necessary by named consultant and CMS
Formal Staff support/wellness programme	No	Use EAP and external programme facilitated in house
Access to elective theatre list for ERPCs	No- emergency lists only	Access to elective lists 2 days per week
Management of own Maternity and Gynae beds	Yes	Yes
Staff Education Sessions	No	Infrequent

Hospital Number 7

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	Vacant	1 WTE
Nominated clinical Lead for Pregnancy Loss	No	No
Nominated Clinical Lead for Early Pregnancy Service	No	Yes
Neonatologist/Paediatrician assigned to bereavement care	No	Yes
Perinatal Pathologist	Use locum service	Yes- provided by group
Social Worker	Yes- dedicated perinatal bereavement sessions	Yes- dedicated perinatal bereavement sessions
Hospital Chaplain	No- on call service from local parish	No- on call service from local parish
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	No	Perinatal Mental Health CMS in post with support from group hub
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	No
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	Yes
Quiet Room on Maternity Unit	No	Yes
Quiet Room in FAU/Ultrasound	No- small office used	No- small office used
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	No	No
Dedicated OPD space for follow up appointments	Yes	Yes
Availability of Mortuary Facilities	Yes	Yes
CMS office	N/A	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Limited	Yes
Direct Admission Policy and Card	No	No
Hospital Bereavement Symbol in use	Yes- use IHF symbol	Yes- use IHF symbol
Hospital Book of remembrance	No	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Locum provided service	Service provided within group
Are national Clinical Guidelines/pathways in use?	Some	Pathways adapted for local use by group
Use of written information leaflets for parents	HSE & Support Organisation information leaflets and have developed own information leaflets	HSE & Support Organisation information leaflets and have developed own information leaflets, , group have developed a number of leaflets
Maternity Bereavement Committee	Representation on General Hospital Committee	Representation on General Hospital Committee
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No	No
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Seen by Obstetric Consultant or Registrar with CMS	Seen by Obstetric Consultant or Registrar with CMS
Formal Staff support/wellness programme	No	Use EAP and external programme facilitated in house
Access to elective theatre list for ERPCs	No- access to emergency lists	No- access to emergency lists
Management of own Maternity and Gynae beds	No	No
Staff Education Sessions	Occasional	Occasional

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Hospital Number 8

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	Vacant	1 WTE
Clinical Lead for Pregnancy Loss	Yes	Yes
Clinical Lead for Early Pregnancy Service	Yes	Yes
Neonatologist/Paediatrician assigned to bereavement care	No	No
Perinatal Pathologist	Locum service	Locum service
Social Worker	No	0.5 WTE for all of maternity
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	No- radiographer provided ultrasound	Yes
Perinatal Mental Health Team	Access to community services	Perinatal Mental Health CMS in post with support from group hub
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes- CMM3
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	Yes
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	No	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	No	No
Dedicated OPD space for follow up appointments	Yes	Yes
Availability of Mortuary Facilities	Yes	Yes
CMS office	N/A	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	No	Yes
Direct Admission Policy and Card	No	Yes
Hospital Bereavement Symbol in use	Yes- own symbol	Yes- own symbol
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Locum service	Locum service
Are national Clinical Guidelines/pathways in use?	Some	Have adapted care pathways for use
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	Have developed own information leaflets
Maternity Bereavement Committee	Hospital Committee with Maternity representation	Hospital Committee with Maternity representation
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No seen as necessary by named consultant and CMS	No- seen as necessary by named consultant and CMS
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	No- seen as necessary by named consultant and CMS	No-seen as necessary by named consultant and CMS
Formal Staff support/wellness programme	Via EAP	Via EAP
Access to elective theatre list for ERPCs	No- emergency lists only	No- emergency lists only
Management of own Maternity & Gynae beds	No	No
Staff Education Sessions	No	Yes- regular

Hospital Number 9

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE	0.5 WTE	1 WTE
Nominated clinical Lead for Pregnancy Loss	No	Yes
Nominated clinical Lead for Early Pregnancy Service	No	No
Neonatologist/Paediatrician assigned to bereavement care	No	No
Perinatal Pathologist	Use locum	Use locum
Social Worker	No	No
Hospital Chaplain	Chaplaincy service on campus- Diocesan provided	Chaplaincy service on campus- Diocesan provided
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	No	No- waiting recruitment of Perinatal Mental Health CMS
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes- DOM
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse and local palliative care team	Access to Childrens Outreach Nurse and local palliative care team
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	No- plans in development
Quiet Room on Maternity Unit	No	Yes
Quiet Room in FAU/Ultrasound	No	No
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	Yes	Yes
Dedicated OPD space for follow up appointments	No	No
Availability of Mortuary Facilities	Yes	Yes- upgraded mortuary with parent facilities
CMS office	Yes	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Limited	Yes
Direct Admission Policy and Card	Yes	Yes
Hospital Bereavement Symbol in use	Yes- own symbol in use	Yes- own symbol in use
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Provided by locum perinatal pathologist	Provided by locum perinatal pathologist
Are national Clinical Guidelines/pathways in use?	Yes	Yes- care pathways adapted for local use
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	HSE & Support Organisation information leaflets
Maternity Bereavement Committee	No	Yes
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No	No
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Seen by named consultant with CMS	Seen by named consultant with CMS
Formal Staff support/wellness programme	No	Via EAP
Access to elective theatre list for ERPCs	Yes	Yes
Management of own Maternity and Gynae Beds	Yes	Yes
Staff Education Sessions	Regular sessions	Regular sessions (4 times per year)

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Hospital Number 10

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	1 WTE	2 WTE
Nominated clinical Lead for Pregnancy Loss	No	Yes
Nominated clinical Lead for Early Pregnancy Service	No	Yes
Neonatologist/Paediatrician assigned to bereavement care	On a rotational basis	On a rotational basis
Perinatal Pathologist	Onsite full service	Onsite full service- 0.5 WTE- 1WTE vacancy in the department covered by locums
Social Worker	Full service with dedicated bereavement care sessions	Full service with dedicated bereavement care sessions
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	All ultrasounds carried out by trained midwife sonographers	All ultrasounds carried out by trained midwife sonographers
Perinatal Mental Health Team	Perinatal mental health psychiatrist and CNS in post	Full Perinatal Mental Health team in place as per National PMH Strategy- hub for group
Administration Support for pregnancy loss team	No	Yes
Allocated member of management team responsible for bereavement care	No	Yes -Master
Availability of palliative care CNS/Service	Access to children's outreach nurse and paediatric palliative care consultant	Access to children's outreach nurse and paediatric palliative care consultant
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No-	No –plans in development
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	No	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	Yes	Yes
Is there a dedicated OPD space for follow up appointments	Yes	Yes
Availability of Mortuary Facilities	Yes- needs upgrade	Yes- mortuary upgraded with family facilities
CMS office	Yes	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Yes	Yes
Direct Admission Policy and Card	Yes	Yes
Hospital Bereavement Symbol in use	Yes- IHF symbol in use	Yes- IHF symbol in use
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Yes	Yes
Are national Clinical Guidelines/pathways in use?	Yes	Yes- have adapted pathways for use
Use of written information leaflets for parents	Own leaflets developed and HSE & Support Organisation information leaflets	Own leaflets developed and HSE & Support Organisation information leaflets
Communication pathways with tertiary hospitals	No– needs to be developed	No – needs to be developed
Maternity Bereavement Committee	Yes	Yes
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	Yes- dedicated pregnancy loss clinic	Yes- dedicated pregnancy loss clinic
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Monthly consultant led clinic for mid-trimester loss ,following stillbirth woman seen by named consultant	Monthly consultant led clinic for mid-trimester loss ,following stillbirth woman seen by named consultant
Formal Staff support/wellness programme	Yes	Yes- own programmes run
Access to elective theatre list for ERPCs	Yes	Yes
Management of own Maternity and Gynae beds	Yes	Yes
Staff Education Sessions	Yes- regular programme of perinatal bereavement education	Yes- regular programme of perinatal bereavement education

Hospital Number 11

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	1 WTE	1WTE
Nominated clinical Lead for Pregnancy Loss	Yes	Yes
Nominated clinical Lead for Early Pregnancy Service	Yes	Yes
Neonatologist/Paediatrician assigned to bereavement care	No	No
Perinatal Pathologist	Use locum	Service provided form within group
Social Worker	Yes- provides perinatal bereavement support when requested	Yes- provides perinatal bereavement support when requested
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	Access to Liaison Mental Health CNS	Perinatal Mental Health CMS in post with support from group hub
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes- DOM
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	Yes	Yes- with extra accommodation developed since 2017
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	Yes	Yes
Dedicated OPD space for follow up appointments	Yes	Yes
Availability of Mortuary Facilities	Yes	Yes
CMS office	Yes	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	No	Yes
Direct Admission Policy and Card	Yes	Yes
Hospital Bereavement Symbol in use	Yes- own symbol developed	Yes- own symbol developed
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Locum service used	Service provided from within group
Are national Clinical Guidelines/pathways in use?	Some	All in use
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	Have developed a number of own information leaflets
Maternity Bereavement Committee	Yes	Yes
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No	Yes
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Seen by Obstetric consultant or registrar with CMS as necessary	Seen by Obstetric consultant or registrar with CMS in pregnancy loss clinic
Formal Staff support/wellness programme	No	Via EAP, local programme EAP and external programme facilitated in house
Access to elective theatre list for ERPCs	Yes	Yes
Management of own Maternity and Gynae beds	No	No
Staff Education Sessions	Yes- occasional	Yes- occasional

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Hospital Number 12

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	Vacant	1WTE
Nominated Clinical Lead for Pregnancy Loss	No	Yes
Nominated Clinical Lead for Early Pregnancy Service	No	Yes
Neonatologist/Paediatrician assigned to bereavement care	Yes	Yes
Perinatal Pathologist	Use locum	Service provided from within group
Social Worker	Yes- with dedicated bereavement care sessions	Yes- with dedicated bereavement care sessions
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	No	Perinatal Mental Health CMS in post with support from group hub
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes- DOM
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse and local community palliative care team	Access to Childrens Outreach Nurse and local community palliative care team
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	Yes
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	Yes	Yes
Dedicated OPD space for follow up appointments	No	Yes
Availability of Mortuary Facilities	Yes	Yes
CMS office	N/A	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Limited	Yes
Direct Admission Policy and Card	No	Yes
Hospital Bereavement Symbol in use	Yes- use IHF symbol	Yes- use IHF symbol
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Locum service used	Service provided from within group
Are national Clinical Guidelines/pathways in use?	Yes	Pathways adapted for local use by group
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	HSE & Support Organisation information leaflets, , group have developed a number of leaflets
Maternity Bereavement Committee	Yes	Yes
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No	Yes
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	No- seen by named consultant as necessary	Yes- consultant led clinic set up in 2020 runs fortnightly
Formal Staff support/wellness programme	Yes- via EAP	Yes- via EAP and hospital provided wellness sessions weekly, and external programme facilitated in house
Access to elective theatre list for ERPCs	Yes	Yes
Management of own Maternity and Gynae beds	Yes	Yes
Staff Education Sessions	No	Regular staff education sessions

Hospital Number 13

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	1WTE	1WTE
Nominated clinical Lead for Pregnancy Loss	No	Yes
Nominated clinical Lead for Early Pregnancy Service	No	No
Neonatologist/Paediatrician assigned to bereavement care	No	Yes
Perinatal Pathologist	No-use locum	No-use locum
Social Worker	No social worker on- site	No social worker on- site
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	All ultrasounds carried out by trained midwife sonographers	All ultrasounds carried out by trained midwife sonographers
Perinatal Mental Health Team	Access to Liaison psychiatric CNS	Perinatal Mental Health CMS in post with support from group hub
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes- CMM3
Availability of palliative care CNS/Service	Access to children's outreach nurse	Access to children's outreach nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	No
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	No	No
Dedicated OPD space for follow up appointments	No	No
Availability of Mortuary Facilities	Yes	Yes
CMS office	Shared office	Shared office
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Limited	Yes
Direct Admission Policy and Card	Yes	Yes
Hospital Bereavement Symbol in use	Yes- IHF for current loss, Own symbol for previous loss	Yes- IHF for current loss, Own symbol for previous loss
Hospital Book of remembrance	No	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	No onsite service- use of locum service	No onsite service- use of locum service
Are national Clinical Guidelines/pathways in use?	Some- not all	All in use- have adapted pathways for use
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	HSE & Support Organisation information leaflets
Maternity Bereavement Committee	No- maternity representation on hospital committee	Yes- own committee and sit on hospital committee
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No-seen as necessary by named consultant and CMS	No-seen as necessary by named consultant and CMS
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Patients seen by Obstetric consultant or registrar with CMS	Patients seen by Obstetric consultant or registrar with CMS- dedicated appointment slots
Formal Staff support/wellness programme	No	Use EAP
Access to elective theatre list for ERPCs	No- placed on emergency lists	No- placed on emergency lists
Management of own Maternity and Gynae beds	No	No
Staff Education Sessions	No	Yes-regular sessions

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Hospital Number 14

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	Vacant	1 WTE
Clinical Lead for Pregnancy Loss	Yes	Yes
Clinical Lead for Early Pregnancy Service	Yes	Yes
Neonatologist/Paediatrician assigned to bereavement care	No	No
Perinatal Pathologist	Locum service	Service provided within group from January 2021
Social Worker	Yes- not dedicated to maternity	0.5WTE for Maternity
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	No	Perinatal Mental Health CMS in post with support from group hub
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	Yes- DOM	Yes- DOM
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	Yes	Yes- awaiting upgrade
Quiet Room on Maternity Unit	No	Yes
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	No	No
Dedicated OPD space for follow up appointments	No	Yes
Availability of Mortuary Facilities	Yes	Yes- upgraded mortuary with parent facilities
CMS office	N/A	Shared
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Yes	Yes
Direct Admission Policy and Card	No	Yes
Hospital Bereavement Symbol in use	Yes- IHF	Own symbol designed
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Locum service	Service provided within group from January 2021
Are national Clinical Guidelines/pathways in use?	Some	Care pathways in use
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	HSE & Support Organisation information leaflets
Maternity Bereavement Committee	Hospital Committee with Maternity representation	Hospital Committee with Maternity representation
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No	No
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	No- seen as necessary by named consultant and CMS	No- seen as necessary by named consultant and CMS
Formal Staff support/wellness programme	Use EAP	Use EAP
Access to elective theatre list for ERPCs	Yes	Yes
Management of own Maternity & Gynae beds	Yes	Yes
Staff Education Sessions	Yes- regular	Yes- regular

Hospital Number 15

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	1.5 WTE	2.5WTE
Nominated clinical Lead for Pregnancy Loss	Yes	Yes
Nominated clinical Lead for Early Pregnancy Service	Yes	Yes
Neonatologist/Paediatrician assigned to bereavement care	Yes	Yes
Perinatal Pathologist	2 WTE- full service	2 WTE- full service
Social Worker	Full service with dedicated perinatal bereavement care sessions	Full service with dedicated perinatal bereavement care sessions
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	Perinatal mental health Psychiatrist and AMP	Full Perinatal Mental Health team in place as per National PMH Strategy- hub for group
Administration Support for pregnancy loss team	No	Yes
Allocated member of management team responsible for bereavement care	Yes- ADOM	Yes- ADOM
Availability of palliative care CNS/Service	Access to children's outreach nurse and paediatric palliative care consultant	Access to children's outreach nurse and paediatric palliative care consultant
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	No - plans in development
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	No	Yes
Family Room in NNU	Yes	Yes
Dedicated OPD space for follow up appointments	No	Yes
Availability of Mortuary Facilities	Yes	Yes- plan for upgrade
CMS office	Yes	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Yes	Yes
Direct Admission Policy and Card	Yes	Yes
Hospital Bereavement Symbol in use	Yes- use IHF symbol	Yes- use IHF symbol
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Full Service	Full Service
Are national Clinical Guidelines/pathways in use?	Yes	Some- need to implement care pathways
Use of written information leaflets for parents	HSE & Support Organisation information leaflets and have developed own information leaflets	Have developed more information leaflets
Communication pathways with tertiary hospitals	Yes	Yes- needs to be improved
Maternity Bereavement Committee	Yes	Yes
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/ special follow up appointments	Consultant led designated recurrent miscarriage clinic	Consultant led designated recurrent miscarriage clinic
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	2nd trimester seen by SpR with CMS, 3rd trimester seen by lead for pregnancy loss service with CMS	2nd trimester seen by SpR with CMS, 3rd trimester seen by lead for pregnancy loss service with CMS
Formal Staff support/wellness programme	Yes	Yes- local programme and external programme facilitated in house
Access to elective theatre list for ERPCs	Yes	Yes
Management of own Maternity & Gynae beds	Yes	Yes
Staff Education Sessions	Regular education sessions run	Regular education sessions run

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Hospital Number 16

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	Vacant	1 WTE
Clinical Lead for Pregnancy Loss	No	Yes
Clinical Lead for Early Pregnancy Service	No	Yes
Neonatologist/Paediatrician assigned to bereavement care	Yes	Yes
Perinatal Pathologist	Locum service	1 WTE full onsite service providing full service within group
Social Worker	Yes- dedicated perinatal bereavement sessions	Yes- dedicated perinatal bereavement sessions
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	Access to psychiatry liaison CNS	Perinatal Mental Health team in place- hub for group
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes- DOM
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	No	Yes- early pregnancy and late pregnancy
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	No	Yes
Family Room in NNU	Yes	Yes
Dedicated OPD space for follow up appointments	No	Off- site facilities
Availability of Mortuary Facilities	Yes	Yes- upgraded mortuary with parent facilities
CMS office	N/A	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Yes	Yes
Direct Admission Policy and Card	Yes	Yes
Hospital Bereavement Symbol in use	Yes- IHF symbol	Yes- IHF symbol
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Locum service	Full onsite service
Are national Clinical Guidelines/pathways in use?	Some	Pathways adapted for local use by group
Communication pathways with tertiary hospitals	No	No – need to be developed
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	HSE & Support Organisation information leaflets, group have developed a number of leaflets
Maternity Bereavement Committee	Representation on hospital committee	Representation on hospital committee
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	Yes	Yes
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Seen in pregnancy loss clinic by Consultant and CMS	Seen in pregnancy loss clinic by Consultant and CMS
Formal Staff support/wellness programme	EAP	EAP and local staff support programme and external programme facilitated in house
Access to elective theatre list for ERPCs	No	Yes
Management of own Maternity & Gynae beds	Yes	Yes
Staff Education Sessions	Yes- infrequent	Yes- occasional

Hospital Number 17

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	1 WTE	2 WTE
Clinical Lead for Pregnancy Loss	Yes	Yes
Clinical Lead for Early Pregnancy Service	Yes	Yes
Neonatologist/Paediatrician assigned to bereavement care	Yes	Yes
Perinatal Pathologist	Locum service	Locum service
Social Worker	No	No
Hospital Chaplain	Use parish ministers	Use parish ministers
Midwife Sonographers	Yes	Yes
Perinatal Mental Health Team	Access to perinatal mental health psychiatrist	Full perinatal mental health team in place as per National PMH Strategy
Administration Support for pregnancy loss team	No	Yes
Allocated member of management team responsible for bereavement care	No	Yes- ADOM
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	Yes	No
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	Yes	Yes
Dedicated OPD space for follow up appointments	Yes	Yes
Availability of Mortuary Facilities	Yes	Yes
CMS office	Yes	Yes- upgraded with counselling space
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	No	Limited
Direct Admission Policy and Card	Yes	Yes
Hospital Bereavement Symbol in use	Yes- own symbol	Yes- own symbol
Hospital Book of remembrance	Yes	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Locum service	Locum service
Are national Clinical Guidelines/pathways in use?	Yes	Yes- have adapted care pathways for use
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	Have developed own information leaflets
Maternity Bereavement Committee	Yes	Yes
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	Yes	Yes
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Women seen at dedicated pregnancy loss clinic by Obstetric consultant or Specialist Registrar with CMS	Women seen at dedicated pregnancy loss clinic by Obstetric consultant or Specialist Registrar with CMS
Formal Staff support/wellness programme	Via EAP	Via EAP
Access to elective theatre list for ERPCs	Yes	Yes
Management of own Maternity & Gynae beds	Yes	Yes
Staff Education Sessions	Yes- regular	Yes- regular

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Hospital Number 18

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	1.25 WTE	1.7 WTE (vacancy of 1.3 WTE remains)
Nominated clinical Lead for Pregnancy Loss	Yes	Yes- succession planning should be considered
Nominated clinical Lead for Early Pregnancy Service	Yes	No
Neonatologist/Paediatrician assigned to bereavement care	Not assigned	Nominated Neonatologist on Bereavement Committee
Perinatal Pathologist	0.5 WTE- full service	Service increased to 1.5WTE- plan for group wide service from January 2021
Social Worker	Full service with dedicated sessions for bereavement care	As in 2017 and new dedicated post for NNU which includes bereavement support
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	All ultrasounds carried out by trained midwife sonographers	All ultrasounds carried out by trained midwife sonographers
Perinatal Mental Health Team	Perinatal Mental Health Liaison CNS in post	Full Perinatal Mental Health team in place as per National PMH Strategy – hub for group
Administration Support for pregnancy loss team	Yes	Yes
Allocated member of management team responsible for bereavement care	No	ADOM nominated
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse	Access to Childrens Outreach Nurse
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	Yes	Yes
Quiet Room on Maternity Unit	Yes- not protected for use	Yes- protected for use
Quiet Room in FAU/Ultrasound	Yes	Yes
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	Yes	Yes
Dedicated OPD space for follow up appointments	Yes	Yes
Availability of Mortuary Facilities	Yes	Yes
CMS office	Yes	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Limited	Yes
Direct Admission Policy and Card	No	Yes
Hospital Bereavement Symbol in use	Own symbol in use	Own symbol in use
Hospital Book of remembrance	No	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Yes	Yes- expanded since 2017
Are national Clinical Guidelines/pathways in use?	Yes	Yes
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	HSE & Support Organisation information leaflets
Communication pathways with tertiary hospitals	No-need to be developed	No-need to be developed
Maternity Bereavement Committee	Yes	Yes
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	Yes- dedicated pregnancy loss clinic	Yes- dedicated pregnancy loss clinic
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Seen at pregnancy loss clinic by Obstetric Consultant or Specialist Registrar	Seen at pregnancy loss clinic by Obstetric Consultant.
Formal Staff support/wellness programme	No – use EAP	No – use EAP
Access to elective theatre list for ERPCs	Yes	Yes
Management of own beds Maternity and Gynae beds	Yes	Yes
Staff Education Sessions	Infrequent sessions	Infrequent sessions

Hospital Number 19

People	2017	2020
Clinical Midwife Specialist Whole Time Equivalent (WTE)	Vacant	1 WTE
Clinical Lead for Pregnancy Loss	No	No
Clinical Lead for Early Pregnancy Service	No	No
Neonatologist/Paediatrician assigned to bereavement care	No	No
Perinatal Pathologist	Use locum	Service provided from within group
Social Worker	No	Yes- no dedicated perinatal bereavement sessions
Hospital Chaplain	Full chaplaincy service on campus- Diocesan and hospital employed	Full chaplaincy service on campus- Diocesan and hospital employed
Midwife Sonographers	Yes and obstetric sonographers	Yes and obstetric sonographers
Perinatal Mental Health Team	Access to liaison psychiatric CNS	Perinatal Mental Health CMS in post with support from group hub
Administration Support for pregnancy loss team	No	No
Allocated member of management team responsible for bereavement care	No	Yes - DOM
Availability of palliative care CNS/Service	Access to Childrens Outreach Nurse and palliative care consultant	Access to Childrens Outreach Nurse and palliative care consultant
Place	**2017**	**2020**
Dedicated in patient Bereavement Room	Yes	Yes
Quiet Room on Maternity Unit	Yes	Yes
Quiet Room in FAU/Ultrasound	No	No- plans in development
Availability of breaking bad news room in Admissions Room/Emergency Room/Assessment Room	Yes	Yes
Family Room in NNU	No	No
Dedicated OPD space for follow up appointments	No	No- off site facility used
Availability of Mortuary Facilities	Yes- with appropriate family facilities	Yes- with appropriate family facilities
CMS office	N/A	Yes
Hospital Burial Plot	Yes	Yes
Processes	**2017**	**2020**
Fetal anomaly scanning for all women	Limited	Yes
Direct Admission Policy and Card	Yes	Yes
Hospital Bereavement Symbol in use	Yes- IHF symbol	Yes- IHF symbol
Hospital Book of remembrance	No	Yes
Annual Service of Remembrance	Yes	Yes
Perinatal Pathology Service	Locum provided service	Service provided from within group
Are national Clinical Guidelines/pathways in use?	No	Pathways adapted for local use by group
Use of written information leaflets for parents	HSE & Support Organisation information leaflets	HSE & Support Organisation information leaflets, group have developed a number of leaflets
Maternity Bereavement Committee	Representation on hospital committee	Representation on hospital committee
Hospital provided mementoes	Yes	Yes
Pregnancy loss clinic/recurrent miscarriage clinic?	No	No
Follow up clinics for women following 2nd trimester and 3rd trimester pregnancy loss	Seen as necessary by named consultant and CMS	Seen as necessary by named consultant and CMS
Formal Staff support/wellness programme	Use EAP	Use EAP
Access to elective theatre list for ERPCs	No- emergency lists	No- emergency lists
Management of own Maternity and Gynae beds	No	No
Staff Education Sessions	Yes - occasional	Yes- regular

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7.5 Overarching Themes from the Hospital Audits

National Recommendations from 2017 Perinatal Bereavement Care Audit

It must be acknowledged that when the 2017 Perinatal Bereavement Care Audit was carried out, the 19 Maternity Units were at various stages of the implementation process. Some Units had established well-functioning bereavement teams that had been in place for many years. A number of Maternity Units had begun to organise their bereavement teams, in order to implement the Standards. Others were only starting to put together the components of a structured bereavement service.

Hereunder are the overarching national issues that needed to be addressed, as identified from the audits.

PEOPLE

Need for recruitment / provision of:
- Perinatal Pathologists at Hospital Group level
- Bereavement CMS/CNS in some units
- Clinical lead for pregnancy loss in some units
- Clinical Lead for Early Pregnancy Service in some units
- Perinatal psychiatry team at Hospital Group level
- Maternity Social Workers in some units
- Midwife sonographers in some units
- Access to children's outreach nurse for all units
- Clerical support for CMS/CNS and pregnancy loss clinics in all units
- Staff support structures in some units
- Formal staff debriefing programmes in all units
- Clinical supervision for members of bereavement team in some units.

PLACE

Need for development/upgrade of:
- Dedicated in-patient bereavement facilities in some units
- Access to quiet spaces in OPD /ED/FAU in some units
- Appropriate mortuary spaces in some units
- Maternity quiet room in some units
- Dedicated counselling rooms in some units
- Parent accommodation in NNU/SCBU in some units
- Appropriate clinic space for follow-up clinics in some units
- Hospital burial grounds in some units.

PROCESSES

Consideration to be given to:
- Provision of National Perinatal Pathology Services
- Developing a pathway for developing and approving policies/care pathways/checklists in some units
- Provision of parent information leaflets in some units
- Improvements in hospital - provide mementoes in some units
- Provision of hospital remembrance services in some units
- Streamlining of post-mortem practice and procedures in some units
- Providing assistance with burial arrangements in some units
- Transport of fetal remains off-site in some units
- Development of Staff education programme in some units
- Development of direct admission policy / card in some units
- Establishment of Maternity SIMT process in some units
- Provision of free hospital parking for bereaved parents in some units.

National Recommendations from 2020 Perinatal Bereavement Care Audit

When the 2020 re-audit of Perinatal Bereavement Care was carried out there were noticeable improvements in bereavement care in all 19 Maternity Units.

Hereunder are the overarching national issues that need to be addressed, as identified from the audits.

PEOPLE

Need for recruitment / provision of:
- Increased Perinatal Pathologists at Hospital Group level
- Clinical Lead for Pregnancy Loss Service in some units
- Clinical Lead for Early Pregnancy Service in some units
- Increased CMS WTE in some units
- Replacement of vacant CMS posts in some units
- Maternity Social Workers in some units
- Allocation of dedicated clerical support to bereavement team in some units.

PLACE

Need for development/upgrade of:
- 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.

PROCESSES

Consideration to be given to:
- Provision of National Perinatal Pathology Services
- Implementation of TOP for FFA service for women booked for antenatal care in each Maternity Unit
- Development of communication pathways with tertiary hospitals – most relevant for fetal medicine or neonatal transfers
- Discontinuation of the redeployment of Bereavement CMS/CNS to COVID-19 related roles interrupting Perinatal Bereavement Service
- Succession planning for CMS posts
- Provision of regular staff perinatal bereavement education programmes
- Introduction of Schwartz Rounds and/or other staff support / wellbeing programmes.

8. OTHER ACTVITIES, 2017-2020

8.1 Bereavement Forums

Bereavement Forum 2018

Minister Simon Harris opened the one-year progress meeting of the Implementation Programme for the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death held in Croke Park in April 2018. The day-long forum brought together national and international experts and members of the National Implementation Programme who discussed the progress of and international best practice one year on from the launch of the standards. The programme was varied and included presentations on updating the progress of the implementation programme. The Forum was attended by over 100 people including Maternity hospital clinical staff and management, members of parent support groups and voluntary organisations and the HSE's NWIHP.

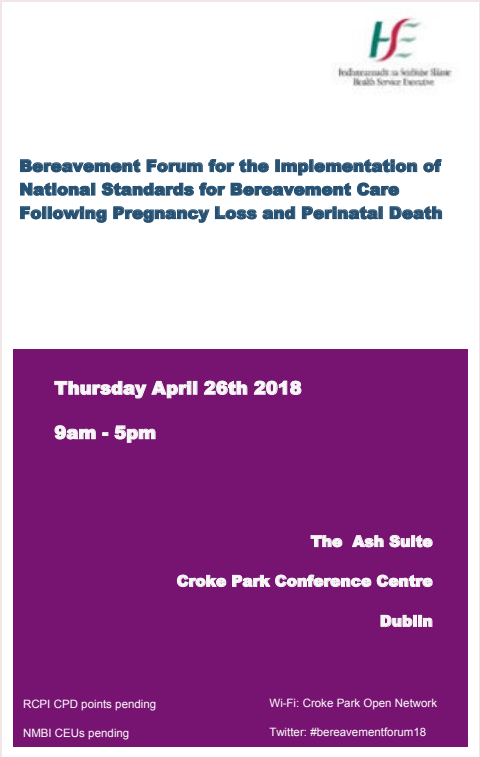

FIGURE 8: Programme

Professor Keelin O'Donoghue, Ms Rióna Cotter, Minister Simon Harris.

Bereavement Forum, Croke Park, 2018. **Above (l-r):** *Mr Kilian Mc Grane, Ms Rióna Cotter, Dr Niamh O'Rourke, Professor Keelin O'Donoghue, Rev Dr Daniel Nuzum.*

Bereavement Forum, Croke Park, 2018. Professor Keelin O' Donoghue, Ms Sharon Foley, Ms Rióna Cotter.

Bereavement Forum, Croke Park, 2018. Minister Simon Harris.

Bereavement Forum 2019

Mr Kilian McGrane, National Programme Director of the National Women and Infants' Health Programme, Health Service Executive, opened the Bereavement Forum marking the completion of the two year Implementation Programme for the 'National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death' in University College Cork in March 2019. The Forum hosted national and international experts along with healthcare professionals representing all 19 Maternity Units who discussed the work of the implementation programme. A member of the parents' forum also spoke of her experiences of being a parent involved with the implementation programme.

The development process of the *www.pregnancyandinfantloss.ie* website was presented, and it was officially launched.

FIGURE 9: Programme

Members of National Implementation Group, Bereavement Forum, UCC, 2019. **Above (l-r):** *Ms Anna Maria Verling, Ms Stacey Power, Professor Keelin O'Donoghue, Dr Seosamh O'Coigligh, Ms Orla Jennings, Dr Brendan Fitzgerald, Ms Rióna Cotter, Rev Dr Daniel Nuzum, Ms Marie Hunt.*

Bereavement Forum, UCC 2019. **Above (l-r):** *Professor Keelin O'Donoghue, Dr Peter Mc Kenna, Ms Rióna Cotter, Mr Kilian MC Grane, Ms Angela Dunne.*

Members of Parents Forum at Bereavement Forum, UCC, 2019. **Above (l-r):** *Professor Keelin O'Donoghue, Ms Sue Mc Cabe, Ms Colette O'Toole, Ms Jackie Prout, Mr Mikey Prout, Ms Rachel Rice, Ms Trish Clifford, Ms Rióna Cotter.*

Bereavement Forum, UCC, 2019. **Above:** *Ms Rióna Cotter, Professor Keelin O'Donoghue.*

8.2 Dissemination of Work

Members of the National Implementation Group and Development Group have presented work related to the Standards at National and International Conferences including:

National Conferences:

- Irish Hospice Foundation Maternity Bereavement Network, 24 March 2017
- South/South West Hospital Group Midwives Conference, Brookfield Health Sciences, University College Cork, 2 May 2017
- INFANT Centre Research Day 2017, Clayton Hotel Cork, 26 October 2017
- UCC School of Nursing and Midwifery Annual Conference, Brookfield Health Sciences Complex, 15 November 2017
- Ireland's 3rd International Children's Palliative Care Conference: Short Lives, Making a Difference, Farmleigh House Dublin, 24-25 November 2017
- Institute of Obstetricians and Gynaecologists Spring Study Day, Royal College of Physicians of Ireland, Kildare Street, Dublin 2, 9 March 2018.
- Junior Obstetrics and Gynaecology Society Annual Scientific Meeting, Royal College of Physicians in Ireland, Dublin, 23 November 2018
- Irish Hospice Foundation Maternity Bereavement Network, Aisling Hotel Dublin, 23 October 2018
- UCC School of Nursing and Midwifery Annual Conference, 29 November 2018
- Trinity Health and Education International Research Conference (THEconf2019), Trinity College Dublin School of Nursing and Midwifery, Wednesday 6 and Thursday 7 March 2019
- Reclaiming Conscience: Developing Ethical Frameworks for Reproductive Healthcare in Ireland. School of Law, University College Cork, 14 June 2019
- Institute of Obstetricians and Gynaecologists Study Day, Royal College of Physicians of Ireland, Kildare Street, Dublin 2, 28 September 2019
- Bereavement Clinical Midwife Specialist Forum Education Day, Cork University Maternity Hospital, Cork, 19 October 2019
- National Standards Support Group Education Day, Coombe Women and Infants University Hospital, 1 December 2019
- NPEC Study Day 2020: Investigations into Perinatal Mortality: Considerations and Lessons Learned, Kingsley Hotel, Cork, 17 January 2020
- Institute of Obstetricians and Gynaecologists Spring Study Day, Royal College of Physicians of Ireland, Kildare Street, Dublin 2, 9 March 2020.
- Directors of Midwifery Forum, 18 August 2020 (online)
- University Hospital Kerry Annual Perinatal Bereavement Day, 9 September 2020 (Online)
- Irish Hospice Foundation Maternity Bereavement Network,19 November 2020 (Online)
- Junior Obstetrics and Gynaecology Society Annual Scientific Meeting 27 November 2020 (Online)
- Institute of Obstetricians and Gynaecologists Study Day, Royal College of Physicians of Ireland 27 November 2020 (Online)

International Conferences:

- British Maternal and Fetal Medicine Society (BMFMS) 19th Annual Conference. Amsterdam, The Netherlands, 30 –31 March 2017
- Star Legacy Foundation Stillbirth Summit, Bloomington. MN, USA, 21-23 June 2017
- International Stillbirth Alliance, University College Cork, 22-24 September 2017
- British Maternal and Fetal Medicine Society 20th Annual Conference, Brighton, 19-20 April 2018
- 2018 Conference on Stillbirth, SIDS and Baby Survival; ISPID ISA International Conference. Glasgow, UK, 7-9 June 2018
- 22nd International Conference on Prenatal Diagnosis and Therapy, Antwerp, Belgium, 8-11 July 2018
- Society for Maternal and Fetal Medicine 39th Annual Meeting, Las Vegas, USA, 11-16 February 2019
- RCOG World Congress, London, 11-19 June 2019
- European Society of Human Reproduction and Embryology 35th Annual Meeting, Vienna, 23-26 June 2019
- International Stillbirth Alliance, Madrid, Spain, 3-6 October 2019
- European Society of Human Reproduction and Embryology 36th Annual Meeting, 5-8 July 2020 (Online)

Plenary Talks

Over the course of the standards implementation and develop work, Prof O'Donoghue has been invited to give plenary presentations at national and international meetings and conferences. These are detailed here.

"Awareness, Experience and Impact of Stillbirth"
Masterclass in Obstetrics and Gynaecology, Royal College of Physicians of Ireland, 18 November 2020

"The Experience of Pregnancy with Fatal Fetal Anomaly"
Ethics, Law and Pregnancy in Ireland Network (ELPIN) workshop (online) https://www.ucc.ie/en/elpin/
18 September 2020

"Evidence-Based Investigation of Perinatal Mortality"
NPEC Study Day 2020: Investigations into Perinatal Mortality: Considerations and Lessons Learned
Kingsley Hotel, Cork, 17 January 2020

"Access to first trimester ultrasound and service pathways in Ireland in 2020"
Dublin First Trimester Ultrasound Symposium
The National Maternity Hospital, Dublin 2, 11-12 January 2020

"Bereavement in the first trimester – a unique grief"
Dublin First Trimester Ultrasound Symposium
The National Maternity Hospital, Dublin 2, 11-12 January 2020

"Pregnancy Loss in Ireland: Research, Clinical Practice and National Standards"
INFANT Centre, Annual Study Day, UCC, 12 December 2019

"Communicating with parents: A multidisciplinary approach"
The International Stillbirth Alliance Annual Conference, Madrid, 4-6 October 2019

"Developing and Implementing Ireland's National Bereavement Standards"
The International Stillbirth Alliance Annual Conference, Madrid, 4-6 October 2019

"Pregnancy Loss in Ireland: Research, Clinical Practice and National Standards"
Gynaecological Visiting Society Meeting, University College Cork, 4 October 2019

"Evaluation of Using Applied Drama Techniques as part of Medical Training in pregnancy-related bereavement care"
Institute of Obstetricians and Gynaecologists Study Day, Royal College of Physicians of Ireland, Kildare Street, Dublin 2, 28 September 2019

"Awareness, experience and impact of Stillbirth: pathways of care and future directions"
North West Baby Loss Conference, Liverpool Women's NHS Foundation Trust, 16 July 2019

"Developing Ethical Frameworks in Ireland'
Reclaiming Conscience: Developing Ethical Frameworks for Reproductive Healthcare in Ireland
School of Law, University College Cork, 14 June 2019

"Bereavement Services in Maternity Care"
Tavistock and Portman NHS Foundation Trust HSE Ireland Perinatal Mental Health Training
Aisling Hotel, Dublin, 30th May 2019

"Awareness, Experience and Impact of Pregnancy Loss"
INFANT Research Seminar, Cork University Maternity Hospital, Cork, 15 June 2018

"Awareness, Experience and Impact of Pregnancy Loss"
Maternal and Fetal Health Grand Rounds, Institute of Human Development, University of Manchester, St Mary's Hospital, Manchester, 5 June 2018

"Facts around Fatal Fetal Anomalies"
Institute of Obstetricians and Gynaecologists Spring Study Day, Royal College of Physicians of Ireland, Kildare Street, Dublin 2, 9 March 2018

"Caring for the Mother when the outcome of Pregnancy is uncertain"
Ireland's 3rd International Children's Palliative Care Conference: Short Lives, Making a Difference, Farmleigh House Dublin, 24-25 November 2017

Welcome Address:
The International Stillbirth Alliance Conference, Cork, 22-24 September 2017

"Reflecting on the Conference: next steps for Ireland":
The International Stillbirth Alliance Conference, Cork, 22-24 September 2017

"National Bereavement Standards for Ireland"
SSWHG Annual Midwifery Conference
Brookfield Health Sciences, University College Cork, 2 May 2017

"Late Miscarriage and the Bereavement Standards for Ireland"
3rd Annual Prevention and Optimal Management of Pregnancy Loss Meeting
GMCA Maternity Network, Bolton NHS FT, Macron Stadium Bolton, 3 March 2017

8.3 Media Engagements

Members of the National Implementation Group and Development Group have also given interviews to both National and Regional media outlets to discuss the implementation of the Standards and to raise awareness of pregnancy loss.
See links to a selection of these below.

Irish Examiner, March 6th 2017.
http://www.irishexaminer.com/viewpoints/analysis/no-longer-alone-in-calling-for-fetal-anomaly-scans-for-all-444463.html

Irish Examiner, September 22nd 2017
http://www.irishexaminer.com/viewpoints/analysis/stillbirth-matters-research-is-key-to-mitigating-risk-459451.html

Irish Times, November 24th 2017
https://www.irishtimes.com/news/health/only-seven-out-of-19-irish-Maternity-units-offer-ultrasound-scans-to-all-1.3304414
Red FM, November 28th 2018
http://www.redfm.ie/news/cork/special-report-raising-awareness-about-stillbirth-two-cork-mothers-speak-out/

Business Post, December 9th 2018
https://www.businesspost.ie/opinion/safe-abortion-services-not-possible-january-2019-432488
Irish Examiner, February 28th 2019. https://www.irishexaminer.com/breakingnews/specialreports/a-caring-service-for-those-who-lose-a-baby-907876.html

Morning Ireland, March 1st 2019.
https://www.rte.ie/radio1/morning-ireland/programmes/2019/0301/1033646-morning-ireland-friday-1-march-2019/

RTÉ News, March 1st, 2019.
ttps://www.rte.ie/news/ireland/2019/0301/1033607-bereavement-maternity-Maternity Units/

Red FM, News Show, March 2nd- 4th 2019.
http://www.redfm.ie/news/cork/all-19-maternity-Maternity Units-in-ireland-now-have-bereavement-teams-specialising-in-pregnancy-loss/

Irish Medical Independent, March 21st 2019.
https://www.medicalindependent.ie/raising-the-standard-of-bereavement-care-in-Maternity Units/

University College Cork News, April 15th 2019.
https://www.ucc.ie/en/news/new-website-to-support-families-grieving-the-loss-of-a-baby.html

Carlow Nationalist, April 15th 2019,
https://carlow-nationalist.ie/2019/04/15/new-website-to-support-families-grieving-loss-of-a-baby/

Irish Examiner, April 15th 2019.
https://www.irishexaminer.com/breakingnews/ireland/new-website-to-support-families-grieving-loss-of-a-baby-917788.html

Laois Nationalist, April 15th 2019.
https://laois-nationalist.ie/2019/04/15/new-website-to-support-families-grieving-loss-of-a-baby/
https://www.ucc.ie/en/obsgyn/news/the-bereavement-forum-2019-.html

Roscommon Herald, April 15th 2019.
https://roscommonherald.ie/2019/04/15/new-website-to-support-families-grieving-loss-of-a-baby/

Waterford News, April 15th 2019.
https://waterford-news.ie/2019/04/15/new-website-to-support-families-grieving-loss-of-a-baby/

Kildare News, April 18th 2019.
https://www.kildarenow.com/news/new-website-parents-experience-pregnancy-loss-perinatal-death/275077

Echo, April 19th2019.
https://www.echolive.ie/corknews/New-website-launched-to-support-families-grieving-the-loss-of-a-baby-a4e5b81a-a197-4575-8f05-54b4d275df7c-ds

Irish Independent, April 25th 2019.
https://www.independent.ie/irish-news/health/new-website-launched-to-help-parents-who-suffer-a-pregnancy-loss-38016243.html

Breakingnews.ie, April 2019.
https://www.breakingnews.ie/ireland/new-website-to-support-families-grieving-loss-of-a-baby-917788.html

Her.ie April, 2019.
https://www.her.ie/news/theres-new-website-help-irish-parents-losing-baby-infant-459482

Herfamily.ie, April 2019.
https://www.herfamily.ie/news/theres-new-website-help-irish-parents-losing-baby-infant-347733

Business Post, 7th of July 2019
https://www.businesspost.ie/insight/doctors-left-high-and-dry-after-repeal-of-eighth-amendment-273f7225
Irish Examiner, October 25th 2019.
https://www.breakingnews.ie/lifestyle/healthandlife/meet-the-team-behind-infant-the-cork-based-centre-helping-mums-and-their-babies-959715.html

8.4 Collaborations

National Women and Infants Health Programme

The National Women and Infants Health Programme was established in January 2017, to lead the management, organisation and delivery of maternity, gynaecology and neonatal services. The Programme oversees the services currently delivered across primary, community and acute care settings. The implementation programme and the development programme for the Standards report to the HSE's NWIHP and gave them regular, formal updates on the progress of the programme from 2017-2021. The HSE's NWIHP have consulted the implementation lead and the programme manager on occasion when queries about perinatal bereavement care have arisen.
https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/

University College Cork /INFANT Pregnancy Loss Research Group

The Pregnancy Loss Research Group, led by Professor Keelin O'Donoghue was set up in 2012 and meets monthly at CUMH. The group is comprised of members of the clinical perinatal bereavement team, researchers, scientists, medical and midwifery students, medical and midwifery educators, masters and doctoral students. The group aims to examine the experiences of parents who have experienced early pregnancy loss, late miscarriage, stillbirth and neonatal death and thereby improve care for parents in the future. The group also works to increase public awareness of all types of pregnancy loss. A number of the group have been involved in the implementation programme and development programme.
https://www.ucc.ie/en/obsgyn/plrg

Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) in partnership with the Health Service Executive (HSE) rolled out the National Maternity Care Experience Programme in 2020. This programme seeks to improve the quality of Maternity care services in Ireland by asking women about their experiences of care and acting on their feedback. As part of the development of the National Maternity Care Experience Programme it was identified that bereaved parents should have their experiences recorded separately to highlight the specific care needs that they have. A programme to examine this groups experience has been set up. Professor O'Donoghue and Rióna Cotter have both engaged with members of HIQA and the HSE's NWIHP to discuss the specific needs of bereaved parents. Professor O'Donoghue is a member of the National Maternity Bereavement Experience Survey Programme Board.

Women's Health Taskforce

The Department of Health established the Women's Health Taskforce in September 2019. Following a recommendation from the Scoping Inquiry into the Cervical Check Screening Programme the taskforce was set up to help improve women's health outcomes and experiences of healthcare, and thereby ensure women's health issues be given more focused attention.

Prof O'Donoghue and Rióna Cotter made a submission to the taskforce in 2020 on behalf of the Standards development group. An opportunity was offered to present the ongoing work of the bereavement standards implementation and development programmes to the taskforce, and to engage with its members on these important aspects of women's healthcare. This presentation was scheduled to take place in March 2020 but was cancelled due to the national restrictions put in place to deal with the COVID-19 pandemic.
www.gov.ie/en/campaigns/-womens-health/

ELPIN

The ELPIN (the Ethics, Law and Pregnancy in Ireland) Network was established in 2020. This network, funded by the Wellcome Trust, aims to work with academics from different disciplines, women's health/reproductive rights advocates and health professionals. Its aim is to involve the members in the discussion of the complex issues related to pregnancy and childbirth. It aims to provide the members with the skills and knowledge to address emerging ethical and legal questions. Prof O'Donoghue and Rióna Cotter were invited to be members of this group and have attended all the meetings and workshops to date. Prof O'Donoghue presented a workshop on "Experiences of Fatal Fetal Anomaly" in September 2020.
https://www.ucc.ie/en/elpin/aboutelpin/

RE(AL) PRODUCTIVE JUSTICE

The Centre for Disability Law and Policy at NUI Galway, are conducting a research project called Re(al) Productive Justice on the experiences of disabled people in Ireland seeking reproductive justice. In this project the group are researching the law and policy that governs these decisions in Ireland and collecting oral histories from disabled people about their experience of making, or being denied the opportunity to make these decisions. The experiences shared in the project will then be used to develop a toolkit for health and social care practitioners. This toolkit will be designed to encourage good practice in respecting the rights of disabled people to make reproductive decisions, and providing appropriate support so that they can make informed choices. Prof O'Donoghue has been addressed this group and taken part in their discussion forums.
http://realproductivejustice.com/

COVID-19 Pandemic

In March 2020 the Irish Government announced restrictions to manage the COVID-19 pandemic. Included in these restrictions there was a visiting ban in all hospitals and various travel limitations. As a group we were aware of the impact this had on bereaved parents, who had difficulty accessing support from family and friends as well as the support groups and voluntary organisations.

To address this, a small number of the Oversight Group developed an information poster for parents experiencing pregnancy loss at this time. This was approved for use by the HSE's NWIHP and the HSE. This poster was shared with all 19 Maternity units, the support groups and voluntary organisations, via HSE websites and was shared on a number of social media platforms. (Appendix 17).

8.5 Research

Funding was provided within the Implementation Programme for the Standards in 2017 for a research fellow with the initial intention to base this work around the numbers of and needs of parents diagnosed with fatal fetal anomaly/ life limiting conditions during their pregnancy.

Following a completive interview process, Ms Stacey Power was successful in securing this PhD Studentship based at the Pregnancy Loss Research Group within the INFANT Centre at University College Cork and Cork University Maternity Hospital. She began work in July 2017 and her PhD supervisors were Prof Keelin O'Donoghue and Dr Sarah Meaney.

During this time Stacey was also a member of the National Implementation Group for the National Standards. Within this, she was a member of the Perinatal Palliative Care work stream and Referrals and Integration work stream. She implemented a Delphi survey to assess voluntary organisations who support families who experience a pregnancy loss or perinatal death, learning needs. With these results, alongside members of the NIG, an Education day was developed, implemented and evaluated responding to these learning needs. Stacey also contributed to the development of several care pathways for the NIPG work streams. She continues to contribute as a member of the Oversight Group for the National Standards.

Stacey contributed to the development and delivery of the TEARDROP workshop (A multidisciplinary team delivering pregnancy loss and perinatal death education to healthcare professionals) piloted in Cork University Maternity Hospital. She has also contributed to teaching perinatal palliative care to MSc Obstetrics and Gynaecology students.

Stacey submitted her PhD entitled: Experiences of pregnancy with major fetal anomalies" in July 2020. After a Viva in December 2020 her PhD was awarded in 2021.

Stacey's research was presented at:

Trinity Health and Education International Research Conference 2020, Dublin

19th Annual Nursing & Midwifery Research conference 2019, University College Cork

Trinity Health and Education International Research Conference 2019, Dublin

University College Dublin Children's Research Network PhD Symposium 2018, Dublin

Society for Social Medicine Annual Scientific Meeting 2018, Glasgow

22nd International Conference on Prenatal Diagnosis and Therapy 2018, Antwerp

Ireland's 4th International Children's Palliative Care Conference 2019

International Stillbirth Alliance Conference 2019, Madrid

National Perinatal Epidemiology Centre Annual Study Day 2019, Dublin

British Maternal and Fetal Medicine Society Annual Conference 2018, Bristol

Celebrating International Midwives' Week 2018 Midwives' Conference SSWHG 2018, Cork

International Stillbirth Alliance Conference 2017, Cork

School of Nursing, Midwifery and Health Systems Research Day, February 2017, Cork

23rd International Congress on Palliative Care, Montreal, October 2020, postponed 2022

Awards

- Awarded Travel Bursary from School of Medicine, University College Cork (2019) to attend the International Stillbirth Alliance Conference 2019, Madrid, with two posters commended
- Best 5X5 oral presentation at UCC 19th Annual Nursing & Midwifery Research conference 2019
- Third place for poster presentation at Ireland's 4th International Children's Palliative Care Conference 2019
- Best poster presentation at University College Dublin, Children's Research Network PhD Symposium 2018
- Best oral presentation of the Rapid Fire Round at Society for Social Medicine Annual Scientific Meeting, 5th-7th September 2018.

Publications in peer reviewed journals

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An assessment of the general public's knowledge of fatal fetal anomalies. Prenatal Diagnosis 2018. Aug 24 [ePub] doi: 10.1002/pd.5348

Published abstracts from conference proceedings

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S Power, S Meaney, K O'Donoghue
Knowledge of Perinatal Palliative Care following a Fatal Fetal Diagnosis. 22nd International Conference on Prenatal Diagnosis and Therapy, Antwerp, Belgium, 8-11 July 2018. Prenatal Diagnosis 2018; 38 (S1): 84

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S Power, S Meaney, K O'Donoghue
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9. ONGOING WORK

The development programme for the Standards concluded its work in February 2021. Professor Keelin O'Donoghue and Rióna Cotter were then asked by the HSE's NWIHP to provide oversight to the continued development of the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death, across the 19 Maternity Units. They will continue to supervise the ongoing implementation of the Standards and related developments.

Specific pieces of ongoing work include:

Managing the National Oversight Group - continuation and management of the National Oversight Group for the Bereavement Care Following Pregnancy Loss and Perinatal Death to include the review and update of the membership. It is proposed that this group will meet twice a year.

Managing the National Website - maintenance of and oversight of the pregnancy and infant loss website through the website management group, in partnership with the Irish Hospice Foundation.

Working with the Clinical Midwife Specialist Group - continued central support and point of contact for specialist bereavement midwives within maternity services.

Managing the Bereavement Care Audit - management of annual audit (people; place; processes, education) of bereavement services within maternity services.

Follow up of the education programme (Bereavement Care in Maternity Settings) for maternity hospitals in collaboration with the IHF.

Ongoing advocacy on pregnancy loss issues regionally and nationally.

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National Women & Infants Health Programme

Dublin Midlands Hospital Group
Academic Partner Trinity College Dublin

Grúpa Ospidéal Oirthear na hÉireann
Ireland East Hospital Group

UCD Dublin

RCSI Hospital Group
Grúpa Ospidéal RCSI

Ospidéil OL
UL Hospitals

Saolta
Grúpa Ollscoile Cúram Sláinte
University Health Care Group

Ireland South
Women & Infants Directorate

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

10. RECOMMENDATIONS

The Four Standards are the pillars of bereavement care following pregnancy loss and perinatal death and serve as the foundation for this report's recommendations.

1. Bereavement Care
Bereavement Care is central to the mission of the hospital 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.

2. The Hospital
The hospital has systems in place to ensure that bereavement care and end-of-life care for babies is central to the mission of the hospital and is organised around the needs of babies and their families.

3. The 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.

4. The Staff
All hospital staff 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.

Recommendations

These recommendations are based on the findings from the sequential national audits of perinatal bereavement care in the maternity services, expert opinion from multi- disciplinary healthcare professionals involved in the provision of bereavement care following pregnancy loss and perinatal death, the learning from the experiences of bereaved parents and families and best practice as identified from current literature.

The recommendations are presented as overarching subjects and within the themes of people, place and process that we have used throughout the implementation programme.

We acknowledge that, since the launch of the Bereavement Standards in 2016, there have been and continue to be improvements in bereavement care following pregnancy loss and perinatal death within the maternity services.

While some Maternity Units have addressed the majority of recommendations presented here, differences remain across the 19 Units. The recommendations are therefore general in tone and content, and should be a priority for every Maternity Unit.

Overarching recommendations

1. Public Awareness
The HSE's NWIHP in collaboration with the professional bodies and advocacy groups should implement an ongoing educational campaign to raise awareness and recognition of pregnancy loss in Ireland. This would include the role of bereavement care in helping women and their families come to terms with pregnancy loss, both early and late.

2. Public Health
The HSE's NWIHP in collaboration with the professional bodies should implement a public health education programme on late pregnancy loss and, in particular, how the risk of late pregnancy loss can be modified. This should be reflected in antenatal education websites and hospital information materials.

3. HSE Service Plan
HSE Annual Service Plan should make provision for the development and improvements in perinatal bereavement services, including expansion of perinatal palliative care services. The 2021 Service Plan does not make any reference to the provision of services for parents who experience pregnancy loss and perinatal death in Maternity Units.

4. Clinical Governance and Accountability
Each hospital 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.

5. Perinatal Mortality Reviews
The National Perinatal Epidemiology Centre should be supported in their recommendations around the establishment of a Confidential Enquiry for stillbirth and neonatal deaths, which should be considered in order to enhance the lessons which may improve care. An initial step would be the establishment of a standardised review of a case series of unexpected perinatal deaths associated with intrapartum events.

6. Adverse Events
Senior Management Teams in all 19 Maternity Units should have in place a system for reviewing adverse outcomes, which include those related to pregnancy loss or perinatal death. Parents should be included and/or consulted with for reviews of their care. The findings from these reviews should be shared appropriately with the woman and her family by a senior clinician and plans for any subsequent follow-up communicated.

7. Communication
Senior Management Teams in all 19 Maternity Units should ensure that there is a hospital 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.

8. Patient Care Experience Surveys
Each Maternity Unit should engage with HIQA on the National Maternity Bereavement Experience Survey which will be rolled out in 2021/2022. In addition, all units should seek feedback from those who have experienced pregnancy loss, which should be recorded and should inform future service developments.

9. Maternity Unit Annual Reports
Senior Management Teams in all 19 Maternity Units should reflect all of the perinatal bereavement care services being provided, and the activity and staffing levels in this service, in their annual reports.

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10. Annual Audit
The National Oversight Group will manage an annual audit of Bereavement Care services in each Maternity Unit on behalf of the HSE's NWIHP. Each Maternity Unit should take part in the audit to help drive improvement in Perinatal Bereavement Care in their own Unit.

11. National Clinical Guidelines on Pregnancy Loss
The HSE's NWIHP in collaboration with the Institute of Obstetricians and Gynaecologists of Ireland though their Clinical Guideline Programme should ensure that the National Clinical Guidelines for all types of pregnancy loss are updated in a timely manner. Auditable standards from the clinical guidelines should be regularly reviewed by each Maternity Unit.

12. Partnership with Support Groups
All Maternity Units should collaborate actively with local support groups for families bereaved after pregnancy loss and, in particular, should work to ensure consistency and clarity of communications.

13. Collaboration with Support Groups and Voluntary Organisations
Collaborative working between healthcare professionals and volunteers/support groups representing bereaved parents has been essential and beneficial during the implementation of the Standards and should continue through the work of the Oversight Group.

14. Screening for Fetal Anomaly
The HSE's NWIHP should work to establish a national screening programme for fetal anomaly in conjunction with the professional bodies and the Department of Health.

15. Research
Regarding pregnancy-related health, there is mounting evidence that more research is needed to improve outcomes for women and babies. Research Organisations and Health Service Funders should invest in and encourage research teams to work on original and multi-disciplinary research on the impact, experience and awareness of pregnancy loss and perinatal death, including the role of bereavement care, the prevention of pregnancy loss and follow-up care in subsequent pregnancies. Public and patient involvement in research also needs to be improved and should include the exploration of new research and/or research prioritisation processes.

The People

16. CMS- Succession Planning
All Maternity Units should put a succession plan in place to identify and develop midwives and nurses to be ready to fill the Bereavement CMS/CNS role in the event that the current post holder leaves the role.

17. Perinatal Pathologists
Perinatal pathology services should be provided for all Maternity Units. The resourcing of perinatal pathology services on a regional and national basis, as recommended by the Faculty of Pathology, would provide equal access to review for all perinatal deaths nationally and would facilitate an agreed approach to classification of autopsy, placental histology and cytogenetics.

18. Coroner
The HSE's NWIHP should 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 hospitals of provisional information on cause of death e.g., consideration to providing a draft autopsy report as per other jurisdictions, as well as facilitating communication between bereaved parents and Maternity Units.

19. Social Workers
All Maternity Units should recruit a Maternity Social Worker (MSW) to provide practical and psychosocial support to women who are receiving care in the hospital. Ideally, the MSW should have dedicated bereavement sessions.

20. Clinical Lead for Pregnancy Loss Services
A clinical lead for Pregnancy Loss services should be appointed in each Maternity Unit. The purpose of this post is to provide leadership to the multidisciplinary team and to take responsibility for the provision of a quality service.

21. Clinical Lead for Early Pregnancy Services
A clinical lead for Early Pregnancy services should be appointed in each Maternity Unit. The purpose of this post is to provide leadership to the multidisciplinary team and to take responsibility for the provision of a quality service.

22. Fetal Medicine CMS for each Hospital Group
Each tertiary unit (group hub) should have a fetal medicine CMS to co-ordinate their fetal medicine services. This would standardise communication between hospitals and facilitate transfer of care in complex pregnancies.

23. Perinatal Palliative Care CMS/CNS for each Hospital Group
Each tertiary unit (group hub) should develop a CMS/CNS to co-ordinate the delivery of Perinatal Palliative Care services in conjunction with the Nurse Co-coordinators for Children with life limiting conditions.

The Places

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

25. Dedicated Inpatient Bereavement Room
Each Maternity Unit should have one dedicated bereavement care room or suite where parents can be cared for following pregnancy loss or perinatal death.

26. Dedicated Quiet Room
Each Maternity Unit should have a dedicated 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.

27. Dedicated Quiet Room/Family Room for the Neonatal Unit
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.

28. Mortuary Facilities
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.

29. Early Pregnancy Assessment Units (EPAU)
All EPAUs must be staffed by a multidisciplinary team (medical, radiographer or specialist midwife or nurse) who are formally trained on a recognised training programme, to perform early pregnancy ultrasound. A senior obstetrician should lead the EPAU team.

The Processes

30. Adaptation of Care Pathways
The national care pathways for pregnancy loss should be adapted for use by each Maternity Unit.

31. Audit of Clinical Guidelines
Each Maternity Unit should develop tools to audit their compliance with National Clinical Guidelines on Pregnancy Loss and review their practice against the auditable standards.

32. Maternity Bereavement Committees
Each Maternity Unit should establish 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.

33. Bed Management
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.

34. Access to Dedicated Theatre Lists
Consideration should be given to allocating scheduled slots on elective theatre lists for women who require surgical management following pregnancy loss.

35. Implementation of Termination of Pregnancy Services for Fatal Fetal Anomaly
Women who receive a diagnosis of a fatal fetal anomaly in a tertiary fetal medicine specialist unit should be facilitated to return to the Maternity Unit where they booked for antenatal care (noting that in complex cases this may not be possible) and delivery.

36. Follow-up Arrangements for Pregnancy Loss/Perinatal Death
A standardised approach should be taken to the provision of appointments for follow up care to women who have had a pregnancy loss or perinatal death. A dedicated pregnancy loss clinic (or in smaller units, dedicated time slots) should be allocated for follow up care. A suitable, and where possible, dedicated space should be identified and used for these appointments.

37. Recurrent Miscarriage Clinics
All Maternity Units should streamline their provision of, or referral to, a dedicated recurrent pregnancy loss clinic for women who have experienced recurrent pregnancy loss. This clinic team should include a consultant obstetrician and specialist nurse(s)/midwife(ve)s in bereavement and loss.

38. Provision of Perinatal Bereavement Education
All staff who are involved in the care of families experiencing pregnancy loss and perinatal death should receive the necessary multidisciplinary training and education, relevant to their scope of practice, in line with the Perinatal Bereavement Education Standards. Maternity Units should include perinatal bereavement education in their annual education programmes and staff induction days.

39. Schwartz Rounds
All maternity senior management teams should give consideration to implementing or participating in Schwartz Rounds as a means of improving staff engagement and wellbeing.

40. Implementation of Staff Wellness Programmes
Maternity Units should collaborate with the Workplace Health and Wellbeing Unit of the HSE to develop appropriate staff wellbeing programmes. Hospital management should ensure that the staff support services provided within the hospital are fit for purpose through regular evaluation processes.

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12. GLOSSARY

ADOM	Assistant Director of Midwifery
BST	Bereavement Specialist Team
CHO	Community Health Organisation
CMS	Clinical Midwife Specialist
CNS	Clinical Nurse Specialist
CUH	Cork University Hospital
CUMH	Cork University Maternity Hospital
CWIUH	Coombe Women and Infants University Hospital
DOH	Department of Health
DOM	Director of Midwifery
ELPIN	Ethics, Law and Pregnancy in Ireland Network
FAU	Fetal Assessment Unit
FFA	Fatal Fetal Anomaly
HER	Electronic Healthcare Record
HCR	Healthcare Record
HFH	Hospice Friendly Hospitals
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IHF	Irish Hospice Foundation
IMIS	Irish Maternity Indicator System
INFANT	Irish Centre for Maternal and Child Health Research
IOG	Institute of Obstetricians and Gynaecologists (Ireland)
ISA	International Stillbirth Alliance
IT	Information Technology
IUFD	Intrauterine Fetal Death
LLC	Life Limiting Condition
LUH	Letterkenny University Hospital
MUH	Mayo University Hospital
MDT	Multidisciplinary Team
MN-CMS	Maternal Newborn Clinical Management System
MRHM	Midland Regional hospital Mullingar
MRHP	Midland Regional Hospital Portlaoise
MSW	Maternity Social Worker
NCEC	National Clinical Effectiveness Committee
NICE	National Institute for Health and Care Excellence
NIG	National Implementation Group
NILMDTS	Now I Lay Me Down to Sleep
NMH	National Maternity Hospital
NND	Neonatal Death
NNU	Neonatal Unit
NPEC	National Perinatal Epidemiology Centre
NWIHP	National Women and Infants Health Programme
OLOLD	Our Lady of Lourdes Hospital, Drogheda
ONMSD	Office of the Nursing and Midwifery Services Director
OPD	Out Patients Department
PHT	Palliative Healthcare Team
PMH	Perinatal Mental Health
PPC	Perinatal Palliative Care
PUH	Portiuncula University Hospital
QIP	Quality Improvement Plan
RCOG	Royal College of Obstetrics and Gynaecology (UK)
RCPI	Royal College of Physicians of Ireland
SB	Stillbirth
SOFT	Ireland Support Organisation for Trisomy 13/18 (Patau's/Edward's Syndrome)
STGH	South Tipperary General Hospital
SUH	Sligo University Hospital
TEARDROP	Teaching, Excellent, pArent, peRinatal, Deaths-related, inteRactions, tO, Professionals
TFMRI	Ireland Termination for Medical Reasons Ireland
TOP	Termination of Pregnancy
TOPFA	Termination of Pregnancy for Fetal Anomaly
UCC	University College Cork
UCD	University College Dublin
UHG	University Hospital Galway
UHK	University Hospital Kerry
UHW	University Hospital Waterford
UMHL	University Maternity Hospital Limerick
WHO	World Health Organisation
WTE	Whole Time Equivalent

13. APPENDICES

APPENDIX 1 - NATIONAL IMPLEMENTATION GROUP MEETINGS

APPENDIX 2 - 2017 AUDIT TOOL

APPENDIX 3 - ECTOPIC PREGNANCY CARE PATHWAY

APPENDIX 4 - FIRST TRIMESTER PREGNANCY LOSS PATHWAY

APPENDIX 5 - SECOND TRIMESTER PREGNANCY LOSS PATHWAY

APPENDIX 6 - STILLBIRTH CARE PATHWAY

APPENDIX 7 - NEONATAL DEATH CARE PATHWAY

APPENDIX 8 - PERINATAL PALLIATIVE CARE PATHWAY

APPENDIX 9 - MEDICATION PROTOCOLS

APPENDIX 10 - LIST OF VOLUNTARY ORGANISATIONS

APPENDIX 11 - LIST OF PERINATAL BEREAVEMNT EDUCATION PROGRAMMES

APPENDIX 12 - PERINATAL BEREAVEMENT CARE EDUCATION STANDARDS

APPENDIX 13 - STAFF SUPPORT DOCUMENT

APPENDIX 14 - STAFF INDUCTION PROGRAMME CONTENT

APPENDIX 15 - 2020 AUDIT TOOL

APPENDIX 16 – BEREAVEMENT FORUM 2018 & 2019 PROGRAMMES

APPENDIX 17 - COVID-19 PREGNANCY LOSS INFORMATION POSTER

A number of the appendices are published online and can be accessed through the following links:

APPENDIX 3
https://pregnancyandinfantloss.ie/ectopic-pregnancy-carepathway/

APPENDIX 4
https://pregnancyandinfantloss.ie/first-trimester-pregnancy-loss-care-pathway/

APPENDIX 5
https://pregnancyandinfantloss.ie/second-trimester-pregnancy-loss-care-pathway/

APPENDIX 6
https://pregnancyandinfantloss.ie/stillbirth-care-pathway/

APPENDIX 7
https://pregnancyandinfantloss.ie/neonatal-death-care-pathway/

APPENDIX 8
https://pregnancyandinfantloss.ie/perinatal-palliative-carepathway/

APPENDIX 9A
https://pregnancyandinfantloss.ie/wp-content/uploads/2019/11/MEDICATION-PROTOCOLS-IUFD.pdf

APPENDIX 9B
https://pregnancyandinfantloss.ie/medication-protocol-for-medical-management-of-miscarriage/

APPENDIX 11
https://pregnancyandinfantloss.ie/courses%e2%80%8b/

APPENDIX 12
https://pregnancyand.wpengine.com/wp-content/uploads/2019/03/Bereavement-Education-Standards.pdf

APPENDIX 13
https://pregnancyand.wpengine.com/wp-content/uploads/2019/03/STAFF-SUPPORT-DOCUMENT.pdf

APPENDIX 17
https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/bereavement-care/covid-19-pregnancy-loss-poster.pdf

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National Implementation Group Meetings- April 2017- March 2019

Date Of Meeting	Number in attendance
06/04/2017	13
04/05/2017	12
15/06/2017	9
07/09/2017	10
12/10/2017	11
16/11/2017	6
21/12/2017	10
22/02/2018	9
22/03/2018	9
26/04/2018	Bereavement Forum, Croke Park
28/06/2018	11
16/09/2018	11
16/10/2018	10
15/11/2018	11
20/12/2018	10
17/01/2019	10
21/02/2019	9
02/03/2019	Bereavement Forum, UCC
21/03/2019	9

Audit Tool

2017

Bereavement Care

Following

Pregnancy Loss and Perinatal Death

Maternity Hospital: **Hospital Group:**

Date:

In attendance:

People

Is there a Bereavement Clinical Midwife Specialist (CMS) in place?

What services does the CMS offer?

Is there a lead clinician for pregnancy loss and/or perinatal bereavement services?

Is there a Neonatologist assigned to perinatal bereavement care?

Is there a Paediatrician assigned to perinatal bereavement care?

Is there a dedicated social worker for pregnancy loss and/or perinatal bereavement care?

If yes, what grade are they?

Is there an assigned chaplain or a diocesan chaplain for pregnancy loss and/or perinatal bereavement care?

Is there access to spiritual care from faith groups outside the chaplaincy team?

Is a perinatal pathologist available?

If not on site- where? Transport arrangements?

Who looks after bereaved families in the Neo Natal Unit (NNU)?

Where are these parents cared for?

Who looks after families needing palliative care in the NNU/ ward?

Is there a midwifery lead for pregnancy loss on the dedicated ward?

Is there a referral pathway to a senior decision maker from Early Pregnancy Clinic (EPC)?

Are women given clear information of what to expect/ what to do/ who to contact from EPC?

Is there clerical support available to the BST / pregnancy loss clinics?

Who/ when follows up women with recurrent miscarriage?

Dedicated clinic?

Who/ when follows up women with 1st trimester miscarriage?

Dedicated clinic?

Who/ when follows up after women with ectopic pregnancy?

Dedicated clinic?

Who/when follows up women after 2nd trimester miscarriage?

Dedicated clinic?

Who/when follows up women after stillbirth?

Dedicated clinic?

Who/when follows up women after Neo Natal death?

Dedicated clinic?

Are there midwife sonographers/ dedicated obstetric sonographers?

Who looks after parents who receive an antenatal diagnosis of life-limiting condition/ fatal fetal abnormality?

What support is offered to parents who choose to discontinue pregnancy with life limiting condition/ fatal fetal abnormality?

Who follows these parents up?

Is an interpreter service available for parents whose first language is not English?

What support is available for parents for continuing care- private counselling rooms etc? Is space available on and off site?

What outside supports are available to the family?

What links are there with the outside support groups?

Is there a Bereavement Support Team (BST) in the hospital?

What is the membership of same?

How often do they meet?

How do they interact with the rest of the hospital?

Is there a pregnancy loss committee in the hospital?

What is the membership of same?

How often do they meet?

Is there a bereavement/ end of life care committee?

What is the membership of same?

How often do they meet?

Is there a perinatal mortality Multi-Disciplinary (MDT) group in the hospital?

What is the membership of same?

What is the agenda?

How often do they meet?

What cases are discussed?

Is there a template/ standardised method of documenting the cases?

Is there a fetal medicine/ neonatal MDT in the hospital?

What is the membership of same?

What is the agenda?

How often do they meet?

Who completes the NPEC stillbirth/ neonatal death enquiry form?

Reporting to CIS- who /when/how

Does hospital follow HSE serious incident management policy? Local policy?

Who are serious adverse events reported / escalated to?

Does the hospital have a Serious Incident Management Team (SIMT) for reporting unexpected intrapartum death etc?

Does the hospital practice Open Disclosure?

Staff attendance at Open Disclosure training

Staff training- what / who/ when/ how often/ what programme

What staff attend- clinical and non-clinical

Are staff facilitated to attend on duty or do they attend on their own time?

Is funding available for staff training?

Is bereavement care dealt with in hospital induction policy?

Staff attendance at workshops e.g breaking bad news

Care for staff dealing with bereavement care

Debriefing /peer support/referral to Employee Assistance Programme (EAP)

Staff have ability to seek support/advice in situations they find ethically difficult

Is there clinical/professional supervision/ support/ practical staff support in place for bereavement support specialist team?

If yes how often?

Who funds same?

Place

At what gestation do pregnant women attend the maternity hospital?

Do they attend general Emergency Department (ED)?

Are they seen on delivery suite/ assessment room/ admission room?

Early Pregnancy Clinic

Ultrasound facilities

Admission room (ER) facilities

Suitable rooms available for breaking bad news

Inpatient facilities

Dedicated pregnancy loss ward- gynae ward/ antenatal ward

Where are fetal remains kept in hospital?

Where are deceased babies kept on the ward?

Is there a facility for deceased babies to remain on the ward with parents?

Can parents freely access and visit deceased infant?

Do partners have open visiting/ stay overnight?

Single room- with availability of double bed for partner

Partner accommodation/overnight/refreshment facilities

Cuddle cot

Delivery Suite facilities

Theatre/ recovery facilities

Neonatal unit facilities

Family accommodation for neonatal unit

Is there a care by parent room when baby is palliative / parents unable to bring them home?

Prayer Room/ Chapel

Quiet room/ family room

Does the hospital provide mementoes? If so what are they?

Who takes responsibility for this?

Does the hospital provide mementoes of ritual (candle, blessing cert/booklet etc)?

Where do the follow- up clinics take place?

Parking facilities and payment arrangements

Facilities to transfer mother to be with infant when transferred to another hospital

Mortuary space

Are parents facilitated to spend time with their infant following post-mortem?

Burial pathway/ hospital burial pathway

Is there a pathway for the burial of fetal remains?

What burial options are available?

Has the hospital its own burial facility?

Information for parents around this

Pathway for parents leaving hospital with fetal remains

Are parents charged for hospital burial?

Are parents facilitated to attend hospital burial?

Is cremation offered?

Can repatriation of fetal remains be facilitated?

Is there a contract with a specified undertaker?

Clinic locations

Where does the follow up appointment for the following take place?

- Early Pregnancy
- Recurrent Miscarriage
- 2nd trimester loss
- Stillbirth
- NND

Are there special appointments/clinics for women known to have a pregnancy complicated by potential loss?

Who runs this clinic/ where?

Where does the Bereavement CMS meet people?

Does the Bereavement CMS have a dedicated office space?

Do other members of the BST have a dedicated office space?

Where does the perinatal mortality MDT take place (general hospital/maternity unit)?

Is there a dedicated meeting room available for the perinatal mortality MDT meeting?

Are there teleconferencing facilities available?

Processes

Policies & Guidelines

Policies/ Procedures/ Pathways/ Guidelines- process for developing/updating same

Is unit using National Guidelines for pregnancy loss?

- Have they developed their own guidelines?
- Are there checklists for patient pathways?
- Have they developed referral proformas?
- Is there a checklist for investigations?

Awareness of National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death - hard copies distributed/ PDF on desktop

How do guidelines get reviewed?

Is there a guideline development group or a local programme group?

Or do they get brought to a consultant meeting or directorate meeting

Patient Pathway

Are patient notes readily available?

Is there a direct/prompt admission policy?

Is there a defined, recognised symbol for those that experience pregnancy loss?

Is it possible to facilitate continuity of care giver? Where not possible is handover given?

What Clinician are patients admitted under?

Is there a named clinical lead for pregnancy loss services?

Who informs the CMS of the woman's admission/ need for care?

How is this done?

Investigation of Death

Is post mortem (PM) offered to everyone? (2nd and 3rd trimester loss and NND)

If not, to whom or what are the gestation limits?

In the absence of a post mortem:

- is a detailed examination of the stillborn infant carried out by a Neonatologist?

- is a skeletal survey offered to parents in the absence of a PM?
- Is the placenta sent for examination?
- Is cytogenetic testing offered?

What information re pm is given to parents?

Is written information provided to the parents?

Who obtains the consent from the parents?

Is there a pathway in place for organ retention/ return of same or burial?

In the case of a Coroner's PM who makes decision/ who communicates with coroner/ who communicates with parents?

Are PM's performed on site?

If not – what are the transfer arrangements in place?

Is there a pathway in place around the transfer of fetal remains to laboratory?

Who transports fetal remains?

In the case of organ retention who informs the parents? When are they informed?

Registration

Defined birth registration process in place for both Coronial and non- Coronial cases

Registration of pre-viable births- who decides- what criteria are followed?

Referral Processes

What is the referral process for the pregnancy loss / stillbirth/ miscarriage clinics?

Who informs the GP of the death/loss?

Who informs the PHN of the death/loss?

Neonatal Palliative Care

Is there a pathway in place for antenatal review by neonatologist to discuss care after delivery of infant with expected life-limiting condition?

Is there a defined process in place to identify, assess and develop care pathways for infants requiring end of life care?

Are there referral pathways in place for end of life care? Are they clearly defined?

Can the hospital facilitate a family to take their infant with a life limiting condition home?

Is there a pathway for referral to the local palliative care team/ Clinical Nurse Specialist (CNS) for children with a life limiting condition?

Follow-up Care

Is postnatal care and advice given in relation to physical and mental health to bereaved mothers prior to discharge?

Does the hospital have access to outside support for parents experiencing high levels of stress e.g mental health services?

Does the hospital hold a remembrance service for pregnancy loss and infant death?

Does the hospital facilitate public talks/ information sessions on pregnancy loss?

Does the hospital have a book of remembrance etc?

How does the hospital publicly acknowledge these deaths?

Can the hospital facilitate bereaved parents culture specific needs around death and dying?

Is there collaboration between the hospital and voluntary support groups e.g. NILMDTS
If yes, which ones

Clinical Governance

Does an allocated senior member of the management team have responsibility for bereavement care?

How are staff informed and updated on policies and guidelines?

How do they access them?

Is there a formal patient feedback process in place for parents?

Who deals with complaints about bereavement care?

How is the hospital collecting data on the provision of bereavement care?

What (if any) audit tools in use?

Examples of good practice

Your top 5 priorities for your unit

Appendices 3, 4, 5, 6, 7, 8 and 9 are published online. Refer to web links on page 65.

Organisations Identified*

Support following stillbirth is provided by a majority of the organisations surveyed, however many also provide support across the pregnancy loss continuum and others provide support for particular types of pregnancy loss.

Name of Organisation	Type of Pregnancy Loss Supported
Ectopic Pregnancy Ireland	Ectopic pregnancy
The Miscarriage Association of Ireland	Miscarriage & Ectopic Pregnancy
Well Woman Centre	Diagnosis of Life Limiting Condition
Marie Stopes (Dublin Office)	Diagnosis of Life Limiting Condition
Sexual Health Centre Cork	Diagnosis of Life Limiting Condition
IFPA	Diagnosis of Life Limiting Condition
CURA	Diagnosis of Life Limiting Condition
LIFE	Diagnosis of Life Limiting Condition
Leanbh mo Chroí	Diagnosis of Life Limiting Condition
Termination for Medical Reasons	Diagnosis of Life Limiting Condition
One Day More	Diagnosis of Life Limiting Condition
Every Life Counts	Diagnosis of Life Limiting Condition
SOFT Ireland	Diagnosis of Life Limiting Condition
A Little Lifetime Foundation	Stillbirth & Neonatal Death
Feileacáin	Stillbirth & Neonatal Death
Anam Cara	Stillbirth & Neonatal Death
Barnardos Bereavement Counselling	Stillbirth
Turas Le Chéile	Stillbirth
Now I Lay Me Down To Sleep	Second Trimester Miscarriage, Stillbirth & Neonatal Death
Bethany Bereavement	Stillbirth & Neonatal Death
Rainbows Ireland	Stillbirth & Neonatal Death
Bethany Bereavement Support	Stillbirth & Neonatal Death
Nurture	Stillbirth & Neonatal Death
First Light	Neonatal Death
Irish Hospice Foundation	Neonatal Death
Irish Childhood Bereavement Network	Stillbirth & Neonatal Death
Vasa Praevia Ireland	Stillbirth & Neonatal Death

*The above information was provided by each organisation as part of a self-report approach to the services provided, governance and role.

Appendices 11, 12 and 13 are published online. Refer to web links on page 65.

PROPOSED CONTENT FOR STAFF INDUCTION ON BEREVEAVEMENT CARE

This document has been prepared for clinical staff who will encounter parents and families who experience perinatal loss in Irish maternity hospitals. This document proposes the content relating to perinatal bereavement care that should be delivered to all new clinical staff when they commence employment in each Maternity hospital. This content should be included in a session on perinatal loss in the induction programme. It is important to note that it is recommended that these topics be discussed in the context of the practices in each individual hospital in as part of the overall staff induction programme.

"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. " (Health Service Executive, 2014.)

The purpose of induction is to support staff when they commence employment in a hospital. Good support structures, including a comprehensive induction programme, can help staff become fully integrated into the hospital as quickly and easily as possible. Induction has benefits for all involved in the process. Employees who settle quickly into their new job will become productive and efficient at an early stage and in turn will experience feelings of worth and satisfaction (NHS Scotland, 2013).

It is important to prepare an induction programme with attention given to specific areas/topics that are appropriate to the individual hospital/service, for example consideration of legislation relevant to the area/speciality.

Ideally all new clinical staff should have, as a minimum, a 2 hour session on perinatal bereavement care as part of their induction programme. This should be delivered by members of the hospital perinatal bereavement team. In the absence of a formal induction day consideration should be given to facilitating new staff attend an annual perinatal bereavement education study day, run locally and facilitated by members of the hospital perinatal bereavement team.

It is good practice to prepare a handbook/bereavement folder for all clinical areas as a resource for all staff (new and regular) with all the documents and information relevant to perinatal bereavement care. It would be beneficial to have a link to **pregnancyandinfantlossireland.ie** available on all desktops in the clinical areas. This Irish website, dedicated to perinatal bereavement, contains a lot of practical information that is useful for both staff and patients.

PERINATAL BEREAVEMENT TOPICS RECOMMENDED FOR INCLUSION

Perinatal Bereavement

- What is bereavement?

- What type of bereavement (losses) in the Maternity settings
- What to do for each type of loss: Pathways, National Clinical Guidelines, Medication Protocol

Legislation

- Coroners Act, 1962
- Coroners Amendment Act, 2019
- Stillbirth Registration Act, 1994
- Health (Regulation of Termination of Pregnancy) Act, 2018

Communication

- Communication- breaking bad news, what to/not to say
- Language
- Empathy
- Competent compassionate communication
- Personal and professional preparation
- Self care

Post Mortem Examination & Management of Fetal Remains

- Coroner directed post mortem examination
- Consented post mortem examination
- PM consent
- Placental investigations
- Maternal investigations
- Perinatal Pathology pathway
- Reason for time delay in PME reports
- Management of fetal remains- options for parents
- Organ retention- pathway

Family Care

- Partner and sibling support
- Memory making
- Practical advice for parents
- Use of dedicated bereavement rooms
- Follow up for parents
- Ways of acknowledging loss for parents

Supports- parents and staff

pregnancyandinfantlossireland.ie

Parents

- Hospital supports available
- External supports available

Staff

- Self care
    - What supports are available locally
    - Building resilience
    - What professional supports are available
- How to access further education
- Importance of research
- Raising public awareness of pregnancy loss

Reporting

- Local QPS office
- NPEC
- Coroner
- Management
- IMIS
- MPSS
- Local pathway for reporting

Local contacts

- Introduction to the local bereavement team with contact details
- What local team provide and to who

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Audit Tool

Bereavement Care Following Pregnancy Loss and Perinatal Death

Maternity Hospital: **Hospital Group:**

Date:

Completed by:

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HOSPITAL TEAM

Director of Midwifery:

Bereavement CMS/CNS:

Clinical Director:

Clinical Lead for Pregnancy Loss Service:

Hospital Manager:

Social Worker:

Bereavement Committee Chairperson:

Please note we are aware that some of the questions on this audit tool may not apply to smaller units, i.e. the provision of designated pregnancy loss clinics etc.

STANDARD	Y/N	COMMENTS
Is there a Bereavement CMS/CNS in post? What is the allocated Whole Time Equivalent (WTE)?		
Is there a lead clinician for pregnancy loss and/or perinatal bereavement services?		
Does an allocated senior member of the management team have responsibility for bereavement care?		
Is there a Neonatologist/Paediatrician assigned to perinatal bereavement care?		
Is there a dedicated social worker for pregnancy loss and/or perinatal bereavement care?		
Is there an assigned /diocesan chaplain for pregnancy loss and/or perinatal bereavement care?		
Is a perinatal pathologist available? Onsite/ within Group?		
Is there clerical / administrative support assigned to the Bereavement team?		
Who looks after Bereaved families in the NNU?		
Who looks after families requiring palliative care in the NNU?		
Is there a midwifery lead for Pregnancy Loss on the dedicated ward?		
Is there a named clinical lead for EPU/EPC?		
Is there a pregnancy loss (miscarriage, stillbirth) follow up clinic? Or designated follow up appointments with a named consultant? Where are these appointments held?		
Is there a Maternity bereavement/ end of life care committee?		
Is there a parent representative on the Maternity bereavement/end of life care committee?		
Is there a perinatal mortality Multi-Disciplinary (MDT) group meeting in the hospital?		
Is there a fetal medicine/ neonatal MDT group meeting in the hospital?		

STANDARD	Y/N	COMMENTS
Are there suitable rooms available for breaking bad news in Early Pregnancy Clinic?		
Does the Bereavement CMS/CNS have an office/ desk space?		
Where does the Bereavement CMS/CNS meet people?		
Are there suitable rooms available for breaking bad news next to Ultrasound facilities?		
Are there suitable rooms available for breaking bad news in admission room (Emergency Room) facilities?		
Where are pregnant women with emergencies (i.e. Reduced FM, PV Bleeding) seen?		
Where in the hospital are pregnancy loss patients admitted? Which ward?		
Are there designated inpatient rooms for pregnancy loss patients in the hospital?		
Are fetal remains kept in the hospital? If yes, where?		
Is there a facility for deceased babies to remain on the ward with parents?		
Can parents freely access and visit deceased infants?		
Do partners have open visiting / and can they stay overnight?		
Is there a designated single room with availability of a double bed for partner?		
Is there free car parking provided for the partner?		
Is there family accommodation in the neonatal unit?		
Is there a quiet room/ family room within the maternity unit? If yes, where is this room situated?		
Does the hospital provide mementoes? If so what are they?		
Does the hospital liaise with outside groups to assist with the provision of mementoes?		

STANDARD	Y/N	COMMENTS
Is there a pathway for the burial of fetal remains?		
What burial options are available?		
Has the hospital its own burial facility?		
Do you have access to a mortuary space?		
Are parents facilitated to attend hospital burial?		
Is cremation offered as an option to parents?		
Are coffins provided to parents free of charge?		
Is a departmental sonographer/radiographer provided **fetal anomaly ultrasound scan**, formally available to all women?		
Is a departmental sonographer/radiographer **provided fetal dating ultrasound scan** formally available to all women?		
Is the Bereavement team able to offer support to all families who require support?		
Is there a waiting list/ waiting time for the Bereavement CMS/CNS?		
Is Termination of Pregnancy facilitated in the hospital (post 12/40)? i.e. in interest of Maternal Health, Fetal Anomaly?		
If yes, is pre delivery and follow up support provided by the hospital Bereavement team?		
If no, is pre delivery and follow up support provided by the hospital Bereavement team following delivery/ discharge from delivering hospital?		
Who delivers the hospital perinatal palliative care pathway? For which infants?		
Who provides cover for the Bereavement CMS/CNS when on leave?		
Does the Bereavement CMS/CNS facilitate staff education?		
What types of education are provided and to whom?		
How often is staff education on Bereavement care provided in the hospital?		

STANDARD	Y/N	COMMENTS
Is there a formal staff support/wellness programme in place?		
Following an unexpected fetal death/intrapartum death/maternal death are staff debriefed?		
If yes, who facilitates the debriefing? Internal facilitator or external facilitator?		
Are the RCPI/IOG National Clinical Guidelines for all scenarios of pregnancy loss being used?		
Are the National Pathways for all scenarios of pregnancy loss being used/adapted locally?		
Are the updated National Medication protocols for IUFD and Miscarriage in use?		
Does the Bereavement team use/access the Pregnancy and Infant Loss Ireland website for information/guidance?		
Are the above named resources available for staff to access on ward desktops?		
Is there a hospital guideline development group?		
Is there a direct/prompt admission policy for pregnancy loss patients?		
Is there a defined, recognised symbol used for those that experience pregnancy loss?		
Is post mortem examination (PME) offered to all second and third trimester losses? If yes, from which gestation?		
In the absence of a PME is an alternative / external examination of the baby offered to parents?		
Is there a local pathway to inform the Coroner of all stillbirths/intrapartum deaths/infant deaths (Coroner Amendment Act, 2019)?		
Is there a pathway around managing externally provided PME, i.e. arranging times and transport?		
Is there a local pathway in place for managing organ retention/return to parents/burial?		

STANDARD	Y/N	COMMENTS
Can the hospital facilitate a family to take their baby with a life limiting condition home?		
Is the Perinatal Mental Health team easily accessible?		
Is there a pathway for referral to the local palliative care team/Clinical Nurse Specialist (CNS) for children with life limiting condition?		
Is there collaboration between hospital and local support groups? If yes, which groups?		
How does the hospital collect data on parents'' experience of bereavement care? Audit, Patient Experience etc.		
Who completes the NPEC Perinatal Mortality Forms?		
Is there a SIMT meeting held to discuss every unexpected IUFD/ (when; how often; Chair)		
Is Bereavement care included in the hospital Induction training for doctors and midwives?		

If there are any practices or issues, not covered in the audit tool that you would like to share with us, please do so.

Appendix 16

National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death

09.15-10.00	**Registration & Refreshments**	
Chair: Dr Keelin O'Donoghue, Implementation Lead		
Session	**Topic**	**Speaker**
10.00-10:15	**Opening Address**	**Mr Simon Harris TD** *Minister for Health*
10.15-10.30	**Update on work of National Women and Infants Health Programme**	**Mr Kilian McGrane**, *National Programme Director,* National Women & Infants Health Programme
10:30-11:00	**Service development: A Practical Approach to Evaluation**	**Professor Anne Marie Brady** *Head of School,* School of Nursing & Midwifery, Trinity College Dublin
11:00-11.30	**Coffee & Poster Viewing**	
Chair: Dr Brendan Fitzgerald, Perinatal Pathologist Dr Daniel Nuzum, Healthcare Chaplain		
11.30-12:00	**Update on Implementation Programme**	**Dr Keelin O'Donoghue** *Implementation Lead,* National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death **Ms Rióna Cotter** *Programme Manager,* National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death
12.00-13.15	**Bereavement CMS/CNS Breakout Session**	**Ms Rióna Cotter** *Programme Manager* , National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death
12:00-12:20	**Why the Bereavement Standards Matter**	**Dr Keelin O'Donoghue** *Implementation Lead,* National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death
12.20-12.40	**Using National Audit to Learn Lessons from Perinatal Mortality**	**Professor Richard Greene** *Director,* National Perinatal Epidemiology Centre, University College, Cork
12.40-13:00	**Role of Implementation Science**	**Dr Niamh O'Rourke** Clinical Effectiveness Unit, National Patient Safety Office

National Implementation Group Bereavement Forum Thursday April 26th, 2018

13.00-14.00	**Lunch and Poster Viewing**	
Chairs: Dr Seosamh O'Coigligh, Consultant Obstetrician & Gynaecologist Ms Anna Maria Verling, Bereavement Clinical Midwife Specialist		
Session	**Topic**	**Speaker**
14.15-14.45	**Pregnancy Loss in Ireland - Past, Present, Future**	**Professor Michael Turner** *Professor of Obstetrics and Gynaecology, Coombe* Women and Infants University Hospital, Dublin
14.45-15.45	**Work stream Updates**	**Dr Keelin O'Donoghue** *Implementation Lead,* National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death **Dr Barbara Coughlan** *Assistant Professor* School of Nursing and Midwifery, University College Dublin **Dr Daniel Nuzum** *Healthcare Chaplain*, Cork University Maternity Hospital **Ms Rióna Cotter** Programme Manager, National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death
15.45-16:00	**Bereavement Standards Implementation Programme: Year 2**	**Dr Keelin O'Donoghue** *Implementation Lead,* National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death **Ms Rióna Cotter** *Programme Manager* , National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death
16:00-16.30	**Caring for the Carers: Engaging Staff to Support Wellbeing**	**Ms Juanita Guidera** *Quality Improvement Division Lead* Staff Engagement, Health Service Executive
16.30-16.45	**Closing**	**Dr Peter Mc Kenna** ***Clinical Director,*** **National Women & Infants Health Programme**

National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death

09.15-10.00	**Registration & Refreshments**	
Chairs: Ms Rachel Rice, Parent Representative Dr Daniel Nuzum, Healthcare Chaplain		
Session	**Topic**	**Speaker**
10.00-10:15	**Opening Address**	**Mr Kilian McGrane** *National Programme Director, National Women & Infants Health Programme*
10.15-11.15	**Overview of Two Year Implementation Programme**	**Dr Keelin O'Donoghue** *Implementation Lead, National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death* **Ms Rióna Cotter** *Programme Manager, National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death*
11:15-11.45	**Refreshments**	
Chairs: Dr Anne Doolan, Consultant Neonatologist Dr Brendan Fitzgerald, Perinatal Pathologist		
11.45-12:30	**Working Towards Optimal Care after Pregnancy Loss – Experience from a UK Region**	**Professor Alexander Heazell** *Senior Clinical Lecturer in Obstetrics University of Manchester, Consultant Obstetrician St Mary's Hospital, Manchester*
12.30-13.00	**Bereavement Clinical Midwife Specialist Session**	
	Setting up a Clinical Midwife Specialist Support Network	**Ms Marie Hunt,** *Bereavement CMS, University Maternity Hospital Limerick*
	Setting up a Bereavement Service - Experience to Date	**Ms Anne Brady,** *Bereavement CMS, University Hospital Galway*
	Development and Usefulness of National Patient Information Leaflets	**Ms Brenda Casey,** *Bereavement CMS, National Maternity Hospital*

National Implementation Group Bereavement Forum Saturday March 2nd, 2019

13.00-14.00	**Lunch**	
Chairs: Dr Keelin O'Donoghue, Implementation Lead Dr Seosamh O'Coigligh, Consultant Obstetrician & Gynaecologist		
Session	**Topic**	**Speaker**
14.00-14.45	**From Stillbirth to National Charity: The Role of Civil Societies in Improving Bereavement Care and Providing Resources for Health Professionals**	**Ms Jillian Cassidy,** *Co-founder & President of Umamanita Stillbirth & Neonatal Death Society, Madrid, Spain. Chair of organising committee for International Stillbirth Alliance, Madrid 2019*
14.45-15.00	**Parental Experience of Implementation Process**	**Ms Christine O'Brien** *Parents Forum Member*
15.00-16.00	**Development of Perinatal Bereavement Education Standards**	**Dr Barbara Coughlan** *Assistant Professor. School of Nursing and Midwifery, University College Dublin* **Dr Margaret Murphy** *Lecturer, School of Nursing and Midwifery, University College Cork*
	Development of an Education Programme for Support Groups	**Ms Stacey Power** *PhD Candidate, INFANT, University College Cork*
	Development and Evaluation of a Parental Experience Feedback Tool	**Ms Anna Maria Verling** *Bereavement CMS, Cork University Maternity Hospital*
	Development and Evaluation of an Audit Tool for Hospital Audit of Bereavement Care	**Dr Jennifer Enright** *Obstetrics & Gynaecology, Senior House Officer Cork University Maternity Hospital*
16.00-16:30	**Website Overview**	
16.30	**Closing**	**Dr Keelin O'Donoghue** *Implementation Lead, National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death* **Ms Rióna Cotter** *Programme Manager , National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death*

Appendix 17 is published online. Refer to web link on page 65.

National Women & Infants Health Programme

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