National Standards for

Bereavement Care Following Pregnancy Loss and Perinatal Death

VERSION: 2

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BACKGROUND

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) .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*." 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) 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.

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.

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.*"

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.

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.

The purpose of the NIG was 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.

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

- Quality and Service Improvement - chaired by Professor Keelin O'Donoghue
- Policies and Procedures - chaired by Ms Rióna Cotter
- Information technology - co-chaired by Professor Keelin O'Donoghue and Ms Rióna Cotter

- Referrals and Integration - chaired by Rev Dr Daniel Nuzum
- Perinatal Palliative Care /TOPFA - co-chaired by Professor Keelin O'Donoghue and Dr Mary Devins
- Education, training and staff support - chaired by Professor Mary Higgins 2017-2018, Professor Keelin O'Donoghue 2018-2019

Each work stream had a chairperson and a working group comprised 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.

Oversight and Development

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 on-going 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.

A number of projects have been carried out as part of the development programme. These include this update of the Standards document, development and rollout of an annual national maternity bereavement care audit in all 19 maternity hospitals; development of and support for staff education programmes in all 19 maternity hospitals; the continued oversight and management of the pregnancyandinfantloss.ie website; support for the introduction of Schwartz rounds or other such staff support programmes in all 19 maternity hospitals.

Report on implementation

A report on the Implementation of the National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death was prepared to present the programmes of work undertaken to implement the Standards.

The content of the report, published in August 2021, 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. The report acknowledges the work and commitment exhibited in each Maternity Unit to implement the Standards.

Recommendations for continued development and improvement in perinatal bereavement care in Ireland are presented in the report. These recommendations are based on audit findings, expert opinion, best practice and the learning from experiences of bereaved parents and families, which should be a priority for every Maternity Unit.

The report is available at the link below:
www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/bereavement-care/hse-national-standards-for-bereavement-care.pdf

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In particular, the HSE would like to acknowledge:

- The Members of the Bereavement Standards Review Group who gave of their time to review and update the Standards. A list of the Group members are outlined below.
- The parents, voluntary organisations and health professionals, including members of the original authorship group who advised and informed the Bereavement Standards Review Group during their work.

The HSE would like to acknowledge parents and families who have experienced a pregnancy loss or perinatal death.

Membership of the Bereavement Care Standards Review Group (2019-2020)

The group was composed of multidisciplinary staff from the HSE, Academic Staff, the Irish Hospice Foundation and Parent representatives from number of the parental support organisations.

Chair

Professor Keelin O'Donoghue
Consultant Obstetrician & Gynaecologist, Fetal Medicine Specialist, Implementation Lead for Bereavement Standards

Programme Manager

Ms Rióna Cotter
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Ms Jill Whelan
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Membership of the Bereavement Care Standards Development Group (2015-2016)

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

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INTRODUCTION

Dealing with the loss of a baby or pregnancy can be a difficult and devastating time for parents and families (Nuzum et al. 2018; Meaney et al. 2017; Coleman, 2015; Murphy & Jones, 2014; Mulvihill & Walsh, 2013; Purandare et al., 2012; Malm et al., 2011). Parents and families may need a range of immediate and longer term supports to help them with their bereavement (Cullen et al. 2018; Spillane et al. 2018; Nuzum et al. 2018; Meaney et al. 2016; O'Connell et al. 2016). The role of family, friends and community is crucial in helping parents come to terms with their loss (Koopmans et al. 2013). 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.

These 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 (McNamara et al. 2018; Nuzum, 2014; Hill, 2012; McCready et al., 2009).

These Standards were developed in response to a recommendation in the HSE National Incident Management Team (NIMT) 50278 (2013) report which 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*'.

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.

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 (Institute of Obstetricians and Gynaecologists, 2020).

Maternity hospital staff (obstetric, midwifery, anaesthetic, paediatric, neonatology, nursing, chaplaincy, social work, pathology and other members of the 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 (*http://health.gov.ie/wp-content/uploads/2014/03/palliative_care_en.pdf*), is transferred to the Paediatric Palliative Care Team. Bereavement care for the family continues to be provided by the maternity hospital's bereavement team

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. The approach and skill of all professionals involved should be led by the principles and domains of competence as defined in the National Palliative Care Competency Framework. The framework will assist in providing an agreed and graded model for staff from different parts of the hospital and health system to understand the principles and types of skills required to be involved in a holistic and caring re-

sponse to parents. As the role of the Bereavement Team and the role of the Paediatric Palliative Care Team are distinct, this document does not prescribe for the responsibilities of the Paediatric Palliative Care Team or for Outreach Nurses or other services such as physiotherapy, pharmacy, etc.

Bereavement Care Standards and Other Policies

These Standards are intended for use in conjunction with current clinical guidelines, professional codes of practice, government policy and relevant legislation. The National Maternity Strategy (2016) was written with a focus on, women and their individual needs. This focus on individualised care has been central to the implementation and development of the Standards.

The National Women's Health taskforce (2019), the HIQA Standards for Safer Better Maternity Care (2016) among other national healthcare programmes have informed this update of the Standards. The Standards sit within the context of all the other policies that exist. Clinical guidelines are under continuous review and reflect contemporary research and current best practice. There is general and specific legislation that directly effects the practice of all healthcare professionals. This includes those working in the area of bereavement care and all health professionals applying these Standards. It is important that professionals comprehend legislative and other requirements when dealing with parents and undertake all interactions/consultations in line with appropriate legislation.

The HSE's Corporate Plan for Health Services (2015 – 2017) sets out the values of care, compassion, trust and learning.

www.hse.ie/eng/about/who/corpoperf/corporate%20plan%202015-2017.pdf

These Standards are a direct expression of these values and have been directly informed by them. These Standards contribute to the HSE's Goal (number 3) to foster a culture that is honest, compassionate, transparent and accountable.

In the HSE National Plan for 2020 (2019) the CEO of the HSE has set putting "the patient, service users and the public to the core of our thinking and planning" as one of the priorities for 2020. This prioritization is one of the principles that has underpinned the Implementation programme (2017-2019).

The HSE is committed to providing an open, timely and consistent approach to communicating with service users and their families when things go wrong in healthcare. This is called Open Disclosure (*www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/opendisclosure/*). It is important to recognise that openness and honesty when things have gone wrong form an important part of the bereavement and recovery process. This is not to suggest that openness and honesty are not integral to the bereavement process at all other times.

In particular, the Specialist Perinatal Mental Health Services model of care (2017) should be implemented and supported as pregnancy loss and perinatal death are potential triggers for mental health problems within the maternity service.

www.hse.ie/eng/services/list/4/mental-health-services/specialist-perinatal-mental-health/specialist-perinatal-mental-health-services-model-of-care-2017.pdf

A list of relevant guidelines, policies and pertinent legislation is available in Appendix 1.

Pregnancy Loss and Perinatal Death

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

There were 360 perinatal deaths in Ireland in 2019, reported by the National Perinatal Epidemiology Centre's 2018/ 2019 Perinatal Mortality Audit (National Perinatal Epidemiology Centre, 2021). These included 242 stillbirths, 118 early neonatal deaths (within 7 completed days of birth) and 32 late neonatal deaths (after the 7th and within 28 completed days of birth).

Of the deaths reported 35 (9.7%) involved multiple pregnancies, of which 30 deaths were twins and five deaths were triplets.

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%.

assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/891405/abortion-statistics-commentary-2019.pdf

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 data-

base have shown that the rate of hospitalisation for ectopic pregnancy is increasing over time. The Irish Maternity Indicator System (IMIS) National report for 2019 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.

It is important to note that the Standards apply to all parents who experience a pregnancy loss, diagnosis of fetal anomaly (with parents electing to continue or terminate the pregnancy) or perinatal death, irrespective of the source of that loss or the term used in these Standards. As a result all terms have been included in the glossary.

Use of Disputed Terminology in the Standards

During the Standards development process, a set of terms to describe parents with a baby who has a life-limiting condition; fatal/lethal fetal abnormality / fetal anomaly was the subject of discussion and consultation feedback. In writing and updating the Standards, it is acknowledged that there is no clear or universal term that can be used or is acceptable to the majority of parents. Any terms used in this area are subject to conceptual and practical challenges inherent in defining such terms (Wilkinson et al. 2012).

While the term, fatal fetal anomaly has gained popularity within the Irish social discourse, there is no universally agreed definition of what constitutes a fatal fetal anomaly or a list of conditions that belong to this term (Power et al. 2020). Widely accepted definitions includes Wilkinson et al. (2012), suggesting a fatal fetal anomaly is a condition that will inevitably lead to death of the fetus in utero or within the neonatal period. However, such descriptions do not accurately describe many of the conditions associated with this term, as known survivors are linked to many of these conditions. The Health (Termination of Pregnancy) Act 2018, avoids the use of any term and refers to a condition that will likely lead to death of the fetus in utero or within 28 days of birth.

With respect to this, the Standards will use the term 'life-limiting condition', a term consistent with the National Policy on Palliative Care for Children with Life-Limiting Conditions (DOH, 2009). We acknowledge that language is not neutral, however, it is important to note that although the term 'life-limiting condition' is used, the aim of the Standards is to provide bereavement care to all parents. Furthermore, the respectful terminology used needs to be person centered for all parents experiencing a pregnancy loss or perinatal death, meaning it must be directed by parents and their preference for terminology used regarding their diagnosis or their type of loss.

GLOSSARY OF TERMS

Anticipatory Grief
Anticipatory grief describes the normal grief response that occurs prior to death that includes sadness, sorrow, anger, crying and emotional preparation for death (Kehl, 2005). Anticipatory grief differs from conventional grief in so far as it is not infinitely prolonged since there is always an end-point in death (Sweeting & Gilhooly, 1990). Anticipatory grief is frequently experienced by the patient and his/her family. Anticipatory bereavement care plays an important role in lessening the intensity of the post- death bereavement (Duke, 1998).

Bereavement
Bereavement describes the entire experience of family members and friends in the anticipation of death and subsequent adjustment to living following the death of a loved one (Christ et al., 2003). It takes account of the unique individual experience of the bereaved person (National Clinical Programme for Palliative Care Glossary of Terms, 2012). Bereavement also refers to the objective situation of having lost someone significant through death (Stroebe et al., 2008).

Bereavement Care and Support
It is accepted by bereavement specialists that there are three levels of bereavement care for the general population (Keegan, 2013; Aoun et al., 2012; Currier et al., 2008; Walsh et al., 2008).

- Level 1 care, also described as 'universal' care, involves good end-of-life care, sensitive communication, reliable information and guidance (Aoun et al., 2012; Currier et al., 2008; Walsh et al., 2008). Level 1 care provides people with information on how to access up-to-date and useful information about the practical, emotional and other challenges associated with loss.
- Level 2 care, also described as 'sensitive' care, is required by people potentially at risk of disenfranchised or complicated grief because of social isolation, demanding caring duties and reduced coping capacity. At level 2, 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.
- Level 3 care, involves professional and therapeutic support and is required by only a minority of bereaved people and required by bereaved people who are experiencing significant or debilitating difficulties in their bereavement.

Two recent frameworks for bereavement care suggest a four-level model (Jones, 2016; IHF, 2020). The fourth level accommodates those who require a mental health intervention. For example, those who are diagnosed with Prolonged Grief Disorder (Boelen, 2017), those whose bereavement exacerbate a pre-existing mental health condition or when a bereavement results in an acute reaction that requires immediate support (e.g. self-harming behaviour, suicidal ideation).

Bereavement care staff are trained to assess the bereavement care needs of individuals; to identify people in need of extra support and/or therapeutic care and will have in place care pathways for referring parents to therapeutic services if necessary. Staff acknowledge that this group of people may also incur greater physical and mental health difficulties (Stroebe et al., 2007).

Bereavement Committee
The Bereavement Committee is multidisciplinary and may be composed of; a senior hospital administrator, clinical midwife specialist in bereavement, bereavement coordinator, medical social worker with responsibility for bereavement care, chaplain, clinical leads, hospital managers, clinical midwife specialist in mental health, service user and nominated representatives from midwifery management, obstetrics, paediatrics, neonatology, ultrasonography, psychiatry, pathology, laboratory, mortuary staff, clerical and household staff. The committee convenes on a regular basis as determined locally.

Bereavement Coordinator
The Bereavement Coordinator is responsible for the development, implementation and evaluation of the hospital's bereavement program. He/she works closely with the CMS in bereavement, Chair of the Bereavement Committee, associated professionals and hospital management, and is responsible for ensuring the hospital has capacity and referral systems in place for providing each of the levels of bereavement care. The Bereavement Coordinator has overall responsibility for the educating, training and upskilling of all hospital staff in bereavement care.

Bereavement Specialist Team (BST)
The BST is composed of staff members who have undertaken specialist and extensive education in bereavement care. The team includes; a bereavement coordinator, clinical midwife specialist in bereavement, chaplain and senior medical social worker. The team is supported in its work by the hospital chief executive officer (CEO), director of midwifery, clinical leads, obstetricians, paediatricians, neonatologists, perinatal psychiatrist, midwives, nurses, neonatal care nurses, chaplains, ministers of religions, palliative care teams, bereavement committees, end-of-life care committees, administrative and auxiliary staff – all of whom have received training appropriate to their role in bereavement care.

Care Pathway
A care pathway is a complex intervention for the mutual decision-making and organisation of care processes for a well-defined group of patients during a well-defined period (Vanhaecht et al., 2007). A care pathway is defined and documented in the patient's Healthcare Record (HCR) and is explicit in its goal statement. The care pathway is based on best practice and is discussed and agreed, in the case of a baby, with his/her parents.

Chaplain
The role of the Healthcare Chaplain in the maternity service is to provide spiritual and pastoral care and support to babies, parents and their families in the midst of illness or bereavement. This support is available to all and respects the personal, spiritual, religious and cultural expressions (or none) of the individual and family and is provided in accordance with the Association for Clinical Pastoral Education (ACPE Ireland Ltd.) training and in accordance with Healthcare Chaplaincy Board (HCB)/ Chaplaincy Accreditation Board (CAB) certification / accreditation requirements.

Clinical Nurse Co-Ordinator for Children with Life Limiting Conditions
The Clinical Nurse Co-Ordinator for Children with Life-limiting Conditions(formerly Children's Outreach Nurses for Life-limiting Conditions) provide a bridge between hospitals, community, statutory and voluntary services and are involved in supporting children with life-limiting conditions and their families in their homes.

Children's Palliative Care
Palliative care for children is a highly specialised field of healthcare. Palliative care aims to maintain quality of life for the duration of the child's illness which may be days, but can be months, and sometimes years. Children's palliative care is holistic in nature where the child and their family are viewed as one unit. Most children with palliative care needs will have these needs met by their family who are supported by locally provided services. This may sometimes, but not always, require the support of a specialist palliative care team.

Support for children with palliative care needs starts at the time of diagnosis, and for many children with life-limiting conditions this can be at birth. Palliative care support can be given alongside active treatments aimed at cure or prolonging life and should, where possible, be provided in the location where the child and family choose to be. Families vary in how strongly they wish to pursue treatments aimed at cure or prolonging life. Decisions about moving away from active care are difficult for both the family and staff and should only be made following full discussion. A care plan, once decided, should include details of what, if any, emergency treatment measures should be taken. The child's comfort should always be central to the decision-making process. Parents' wishes should be documented and care should be planned accordingly.

Clear communication between parents and all healthcare professionals involved in the care of the child is essential. (DOH, 2009. Palliative Care for Children with life-limiting conditions in Ireland – A National Policy). Available at: *http://health.gov.ie/wp-content/uploads/2014/03/palliative_care_en.pdf*

Clinical Midwife Specialist (CMS) in Bereavement
The Clinical Midwife Specialist (CMS) in Bereavement is recognised by the Nursing and Midwifery Board of Ireland as a specialist post. He/she is an experienced midwife who has undertaken specific training and education at level 8 or above in the area of bereavement. The CMS's role is to support and facilitate the loss and bereavement process in all areas of pregnancy loss. The CMS provides anticipatory bereavement support to those families whose baby is diagnosed with a life-limiting condition, working with the Multidisciplinary Team (MDT) within the Perinatal Palliative Care framework. He/she is an identifiable resource to bereaved mothers, partners and siblings around the time of loss, following discharge home and in subsequent pregnancies.

The CMS works within the framework of the NICE (2004) guidelines, being involved in the direct provision of level one support, signposting to level two supports in the community and adequately trained to recognise, treat and/or appropriately refer to level three support in the event of a complicated grief diagnosis (Kristjanson et al., 2006). The CMS demonstrates expertise in the aetiology of pregnancy, pregnancy loss and perinatal death and works collaboratively with his/her clinical colleagues in the formal follow-up care of bereaved parents. He/she is an advocate for bereaved families, provides education and training to staff, as well as being involved in audit and research aimed at enhancing bereavement care.

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

Coroner's Amendment Act 2019
The Coroners (Amendment) Act 2019 was signed into Irish law in 2019. The Act contains a number of key provisions which include:

- Express requirements for mandatory reporting and inquest in all maternal and late maternal deaths;
- Express requirements for mandatory reporting and inquest of a death occurring in a range of situations which constitute State custody or detention;
- Mandatory reporting to a coroner of all stillbirths, intrapartum deaths and infant deaths and, for the first time, a statutory basis for the coroner to enquire into a stillbirth where there is cause for concern (this normally arises from matters raised by the bereaved parents);

Culture
Culture can be defined broadly as the web of meaning in which humans live (Browning & Solomon, 2005). It is expressed through the characteristics and knowledge of a particular group of people, through their language, religion, cuisine, social habits, music and arts. Culture influences social interactions, cognitive constructs and understanding that are learned by socialisation.

Determinants of Signs of Life for births before 23+0 weeks gestation
Determination of signs of life for births before 23+0 weeks gestation where active resuscitation is not considered appropriate. A live birth is determined by the presence of one or more of the following signs of life for a period of **greater than 1 minute after birth**. (i) Spontaneous respirations and/or crying, (ii) Easily visible heartbeat, (iii)Visible cord pulsation and (iv) Definite movement of arms and legs (NWIHP, 2021).

Disenfranchised Grief
Disenfranchised grief occurs when the impact of a death is not recognised. It occurs when grief is not openly acknowledged, socially validated or publicly mourned (Doka, 2002). Circumstances that expose an individual to the risk of experiencing disenfranchised grief include:

- non-traditional relationships
- society failing to recognise that a significant loss has occurred
- society failing to recognise that a person such as a child or a disabled person is capable of grieving
- misunderstanding of an individual's response to their loss
- a bereaved person denying him/herself the right to grieve
- social isolation, demanding caring duties and reduced coping capacity
- social and psycho-social disadvantage e.g. domestic abuse, lone parent

Disenfranchised grief inhibits mourners' capacity to overcome suffering and live meaningfully again. Bereaved persons who experience disenfranchised grief may require specialised therapies to overcome their grief (Stroebe et al., 2007).

Ectopic Pregnancy
Ectopic pregnancy also called extra-uterine pregnancy, is when a fertilized egg implants outside the uterus, somewhere else in the abdomen (RCPI, 2014).

Electronic Healthcare Record (EHCR)
An electronic health record in the maternity services is a record of the entire obstetrical, medical and social history of a woman and the care she has been receiving from a multidisciplinary team in the hospital and in the community collected electronically and stored in a digital format.

End-of-life Care
For the purpose of these Standards the term end-of-life care is used to describe the perinatal palliative care of a baby during its first week of life (early neonatal period) when life expectancy is limited and death is imminent. It encompasses care of the baby from the time of diagnosis through to his/her death and care of the baby and parents following death.

Family
A family is defined as those closest to the patient in knowledge, care and affection and who are connected through their common biological, legal, cultural, and emotional history (National Clinical Programme for Palliative Care Glossary of Terms, 2012).

Fatal/Lethal Fetal Anomaly/Life Limiting Condition
Fatal fetal anomalies /life-limiting conditions include diagnoses that are highly likely to lead to death in utero or in the newborn period (28 days of life), although for some of these diagnoses, survival beyond 28 days has been reported. For these conditions, the diagnosis and prognosis are unequivocal. Estimates of prevalence range from 1 in 1000 (anencephaly) to 1 in 10,000 (Triploidy;Trisomy 13; Renal agenesis), (IOG, 2020).

Grief
Grief is the reaction to bereavement. It is a natural human response that is irrespective of culture and class and its expression varies considerably (Hooyman & Kramer, 2006; Gardner, 1999).

Health Care Record (HCR)
A Health Care Record in the maternity services is a record of the entire obstetrical, medical and social history of a woman and the care she has been receiving from a multidisciplinary team in the hospital and in the community.

Hospital
Hospital includes maternity hospitals and maternity units in general hospitals.

Intra Uterine Fetal Death
An intra uterine fetal death, also described as an intrauterine death (IUD), describes a baby who dies in the womb (RCPI & HSE Clinical Practice Guideline Number 4, 2011).

Levels of Palliative Care
- Level 1 care, also described as 'universal' care, involves good care from the point at which the potential for loss is identified; it can encompass end-of-life care and always includes sensitive communication, reliable information and guidance (Aoun et al., 2012; Currier et al., 2008; Walsh et al., 2008). Level 1 care provides people with information on how to access up-to-date and useful information about the practical, emotional and other challenges associated with loss. It is compassionate care and should be provided by all who come in contact with the family.
- Level 2 – At this level of practice, those providing palliative care will have additional training and expertise. This is viewed as an intermediate level of expertise, where engagement in palliative care is part of the health professional's caring role but does not define it.
- Level 3 – This level refers to those whose core activity is limited to the provision of palliative care. Caring for patients with complex and demanding palliative care needs requires a greater degree of training, staff and other resources.

(DOH, 2009. Palliative Care for Children with life-limiting conditions in Ireland – A National Policy). Available at: *http://health.gov.ie/wp-content/uploads/2014/03/palliative_care_en.pdf*].

Life-limiting Condition/Fatal/Lethal Fetal Anomaly
Life-limiting conditions/ fatal fetal anomalies include diagnoses that are highly likely to lead to death in utero or in the newborn period (28 days of life), although for some of these diagnoses, survival beyond 28 days has been reported. For these conditions, the diagnosis and prognosis are unequivocal. Estimates of prevalence range from 1 in 1000 (anencephaly) to 1 in 10,000 (Triploidy;Trisomy 13; Renal agenesis), (IOG, 2020).

Live Birth
Birth of an infant which, after complete separation from his/her mother, shows sign of life. Evidence of life includes breathing movements, presence of a heartbeat, pulsation of the cord or definite movement of voluntary muscles (RCPI & HSE Clinical Practice Guideline Number 4, 2011). HSE NWIHP, NPEC & NCICP, 2021 Determination of signs of life for births.

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

Miscarriage
Miscarriage is defined as the spontaneous loss of a pregnancy before the fetus reaches viability. The term therefore includes all pregnancy losses from the time of conception until 24 weeks of gestation. (RCOG, 2016).

First trimester miscarriage occurs in the first 12 weeks of pregnancy.

Second trimester miscarriage occurs after 12 weeks and before 24 weeks of pregnancy.

Recurrent miscarriage is defined as two consecutive first trimester miscarriages (Linehan et al, 2022).

Multidisciplinary Team (MDT)
The MDT is a team of health and social care professionals working together to provide holistic care. The MDT in a maternity hospital includes sonographers, fetal medicine consultants, obstetricians, neonatologists, anaesthetists, midwives, nurses, neonatal nurses, allied health professionals, bereavement care specialists, palliative care staff, bereavement care staff including chaplains, medical social workers and clinical midwife specialists, laboratory and mortuary staff. All staff play a central role in supporting and giving information to parents who receive bad news.

Neonatal
Refers to the period after birth up until the fourth completed week of life (National Perinatal Epidemiology Centre, 201).

Neonatal Death
Death of a baby occurring within 28 completed days of birth.

An early neonatal death describes a neonatal death occurring within 7 completed days of birth.

A late neonatal death describes a neonatal death occurring after the 7th and within 28 completed days of birth (National Perinatal Epidemiology Centre, 2021).

Next-of-Kin
The term next-of-kin has no legal definition in Ireland except for inheritance law (Succession Act 1965) where it is defined as the nearest blood relative to the deceased. For the purposes of this guideline, next-of-kin describes a spouse or nearest blood relative.

Parent
Parent is used to denote a mother, father or other parent.

Perinatal Bereavement
The experience of parents that begins immediately following the diagnosis of or loss of an infant through death by miscarriage, stillbirth, neonatal loss, or elective termination for fetal anomalies.

Perinatal Bereavement Care
For the purpose of this guideline, perinatal bereavement care refers to the care provided by the multidisciplinary maternity hospital staff to parents who experience pregnancy loss; parents who receive a diagnosis during pregnancy of a life-limiting condition; parents whose baby is stillborn and parents whose baby dies during the early neonatal period. Perinatal bereavement care includes physical, psychological, emotional and spiritual care following loss and is extended to siblings and grandparents.

Perinatal Palliative Care
Palliative care for the fetus, neonate or infant with life limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the neonate and support for the family. It includes the management of distressing symptoms and care through death and bereavement (Together for Short Lives, 2017).

Perinatal Pathologist
The perinatal pathologist ensures that within the pathology department the post mortem practice is viewed as parent-centred and that the baby and its parents are treated

with respect at all times. He/she is also responsible for ensuring;

- that post mortems are performed to a high standard, in keeping with national and international guidelines
- that members of the BST and others are educated about the post mortem process and placental pathology
- that the limitations of the post mortem examination are understood

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

Perinatal Mortality
Perinatal mortality refers to the death of babies in the weeks before or four weeks after birth. Perinatal mortality includes stillbirths (babies born with no signs of life after 24 weeks of pregnancy or weighing at least 500 grammes) and the deaths of babies within 28 days of being born (National Perinatal Epidemiology Centre, 2021).

Post Natal Care
Post-natal care includes the physical and emotional care of a woman after birth.

Post mortem
A post mortem is the examination of a body after death. It is also known as an autopsy.

Post Mortem Examinations are carried out by pathologists (doctors specialising in medical diagnosis), who aim to identify the cause of death.

Pregnancy Loss
Pregnancy loss is all types of loss, including spontaneous and medically supervised terminations that can occur during a pregnancy from the first to third trimester.

Prolonged Grief Disorder (formerly known as complicated grief)
Reactions to the loss of a significant person often includes temporary impairment of day-to-day functioning, withdrawal from social activities, feelings of yearning and numbness which can last for varying periods of time. Although grief is a natural process, it can lead to a more complex and prolonged* response, where symptoms are more disruptive, pervasive or long-lasting than in a normal grief response. Recent studies have reported a 10% prevalence rate for PGD in the bereaved population; however bereaved parents have been recognised as a high-risk group for prolonged grief (Kersting et al., 2011; 2012; Ellis et al., 2016; Lundorf et al., 2017).

*Prolonged Grief Disorder (PGD) is a new disorder added to the 11th edition of the International Classification of Diseases (ICD-11). It is also included in the section for disorders requiring further study in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as Persistent Complex Bereavement Disorder (PCBD).

Recurrent Miscarriage
Recurrent miscarriage is defined as two consecutive first trimester miscarriages (Linehan et al, 2022).

Staff
Staff describes all people who work in the maternity unit/hospital including all members of the multi- disciplinary team, reception staff, security staff, kitchen staff, midwifery and nursing students, nurse assistants, laboratory staff, mortuary staff, cleaning staff, porters and all other auxiliary staff in hospitals.

Stillbirth
A child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who shows no sign of life (Stillbirths Registration Act, 1994). Available at: *www.irishstatutebook.ie/1994/en/act/pub/0001/print.html#sec1*

Stakeholders
Stakeholders denote parents, siblings, grandparents, aunts, uncles, extended family, guardians, community health care personnel and voluntary support groups as well as hospital staff.

Symbol
A symbol that is recognised by hospital staff and the public is used in maternity units to indicate when an end-of-life issue is happening for a family and/or to indicate that a bereavement has taken place. The symbol selected for use in each hospital is agreed locally by staff and management. Parental consent for use of the symbol is necessary.

Termination of Pregnancy
A medical procedure which is intended to end the life of a foetus (Health (Regulation of Termination of Pregnancy) Act 2018). Available at: *www.irishstatutebook.ie/eli/2018/act/31/section/11/enacted/en/html#sec11*

STANDARD 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.

1.1 Bereavement Care at time of Diagnosis

Statement: All relevant hospital staff sensitively communicate bad news to parents in a quiet and private environment and with special consideration of individual needs and preparedness for the emotional and physical management of their diagnosis.

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Guidelines are in place for identifying the needs of and for supporting a parent experiencing bereavement in the maternity services. All relevant staff are aware of and use these guidelines where appropriate. Cacciatore and Bushfield (2007); SANDS (2007); ISANDS (2007); Hutti (2005); Cook et al. (2002); Catlin & Carter (2002).	✓	✓	✓	✓	✓	✓	✓	✓
Parents who experience bereavement in the maternity services are cared for compassionately, with dignity and with respect. Nuzum et al. (2014); RCPI/HSE Clinical Guideline No. 29 (2014); RCPI/HSE Clinical Guideline No. 4 (2011); Williams et al. (2008); Stratton and Lloyd (2008); SANDS (2007); ISANDS (2007); Callister (2006); Catlin & Carter (2002).	✓	✓	✓	✓	✓	✓	✓	✓
There is an acknowledgement on the part of the hospital that all hospital staff have an important role to play in ensuring effective and sensitive communication with parents. Hospital staff play an important role in the bereavement care provided to bereaved parents. Bereavement care training appropriate to their role in the hospital, is provided to all staff when commencing employment and bereavement training refresher courses are provided every three years. This is a core value of the hospital and is reflected in the decision and actions of the hospital. Ellis et al. (2016); McQueen (2011); Gold (2007); SANDS (2016); Fauri (2000); Helps et al (2020).	✓	✓	✓	✓	✓	✓	✓	✓
It is recommended that, with a woman's permission, a symbol denoting that a pregnancy loss or perinatal death has taken place is sensitively placed in a woman's Healthcare Record (HCR). RCPI/HSE Clinical Guideline No. 4 (2011); Gold (2007); SANDS (2016); ISANDS (2007, RANZCOG 2018	Optional	Optional	Optional	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
At commencement of employment, all hospital staff providing care to bereaved parents receive mandatory training, appropriate to their role in the hospital on how to communicate sensitively and how to break bad news. Rådestad et al. (2014); Roehrs et al. (2008); Lalor et al. (2007); Yee and Ross (2006).	✓	✓	✓	✓	✓	✓	✓	✓
Suitable rooms are available in the Admission Unit/ Ultrasound Department to facilitate discussion and provide support to the mother/parents when bad news is broken. Rådestad et al. (2014); SANDS (2016); Alkazeleh et al. (2004). PSANZ (2020).	✓	✓	✓	✓	✓	✓	✓	✓
If the mother is unaccompanied, staff always offer to contact her partner, a relative or a friend. Staff will strive to ensure that she does not leave the hospital alone. RCPI/HSE Guideline No. 4 (2011); SANDS (2016); Alkazeleh et al. (2004); Forest (1989).	✓	✓	✓	✓	✓	✓	✓	✓
Following the diagnosis of an ectopic pregnancy or first trimester miscarriage parents are given time to reflect on the diagnosis and discuss the woman's treatment options. RCPI/HSE Clinical Guideline No. 29 (2014); Spillane at al (2018); NICE (2019); Mc CARthy at al (2020).	✓	✓	✗	✗	✗	✗	✗	✗
Parents are given enough time after receiving a diagnosis of a baby with an unanticipated life-limiting condition to reflect upon the information and to discuss their preferences, wishes and plans. O'Donoghue (2019); O'Connell at al (2019).	✗	✗	✗	✗	✗	✓	✗	✗
Special consideration is given to the bereavement needs of families where there is a death in utero of a baby in a multiple pregnancy, e.g. staff acknowledge the complexity of the family's bereavement. Parents should be given the opportunity to discuss their concerns and wishes for the surviving baby. Richards et al. (2015).	✗	✓	✓	✓	✓	✓	✓	✗
Parents are offered access to the bereavement support team for support and guidance in relaying the loss to siblings. Involvement of the siblings is considered in accordance with the parents' wishes. Machajewski & Kronk (2013); Avelin et al. (2012); Torbic (2011); Riley (2003).	✓	✓	✓	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Parents are offered timely bereavement support following the diagnosis of an anomaly that is life-limiting or may be fatal. Aspects of this support, information provided or consultations with parents may need to be approached with due regard to provisions of relevant legislation such as the Health (Regulation of termination of pregnancy) Act, 2018. McNamara et al. (2013); O'Donoghue (2019).	✗	✗	✗	✗	✗	✓	✗	✓
Parents are given enough time after receiving an antenatal diagnosis of a baby with an unanticipated life-limiting condition to reflect upon the information and to discuss their preferences, wishes and plans. Any fears the mother may be experiencing are addressed in a timely and sensitive way. Parents are encouraged to articulate their concerns with staff. Consultations with parents and information provided should be in accordance with the Health (regulation of termination of pregnancy) Act, 2018; O'Donoghue (2019); Power, Meaney & O'Donoghue (2021).	✗	✗	✗	✗	✗	✓	✗	✗
Parents should always receive counselling from a fetal medicine specialist and in some cases, it would be helpful if the fetal medicine specialist and Neonatologist/Paediatrician met the Parents together for a consultation. (Together for Short Lives, 2013; (O'Donoghue, 2018). Consultations with parents and information provided need to be approached with due regard to provisions of relevant legislation such as the Health (Regulation of Termination of Pregnancy) act, 2018 Gibson et al. (2011); Malm et al. (2011); Henley & Schott (2008); RCOG (2008); Munson & Leuthner (2007); Mitchell (2004); Power, O'Donoghue, Meaney (2021).	✗	✗	✗	✗	✗	✓	✗	✗
Parents should have access to accurate and objective information and, if required, counselling and support. There should be local arrangements in place for providing value-neutral information to women about termination of pregnancy. (O'Donoghue, 2018). Information on accessing bereavement care is provided to all women registered at a maternity hospital. Irish Medical Council (8th ed., 2019) Guide to Professional Conduct and Ethics for Registered Medical Practitioner. Nursing and Midwifery Board of Ireland (2015). The Code of Professional Conduct for each Nurse and Midwife.	✗	✗	✓	✗	✓	✗	✗	✗

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
In the event criteria to terminate pregnancy under current legislation are not met, parents who chose to terminate their pregnancy should be provided with information on how to access the services in other jurisdictions. IOG (2020)	✗	✗	✓	✗	✓	✓	✗	✗
Parents who receive a diagnosis that their baby will be born with a life-limiting condition are referred to appropriate hospital and community specialist service providers. Coleman (2015); Munson & Leuthner (2007), Power at al (2021), O'Shaughnessy et al, O'Donoghue , Leitao (2021).	✗	✗	✗	✗	✗	✓	✗	✗
If the baby is likely to be admitted to a Neonatal Intensive Care Unit, and where feasible, the parents are offered an opportunity to visit the unit before the baby is born. SANDS (2016); Fowlie & McHaffie (2004).	✗	✗	✗	✗	✗	✓	✗	✗
Parents are offered information specific to the diagnosis of pregnancy loss (to supplement the discussions they have had with the relevant healthcare professionals) and information about the local, community and hospital specialist services available which should include the details of a named health professional and a phone number that they can contact if required. When required, information is translated. RCPI /HSE Clinical Guideline No. 24 (2011); SANDS (2016); Catlin & Carter (2002). Parents are directed to trusted online resources and local community services and local support services which provide safe, reliable and accurate information	✓	✓	✓	✓	✓	✓	✓	✓
Parents awaiting the spontaneous onset of labour or spontaneous miscarriage are given the details of a named health professional and a phone number that they can contact if required. A system of prompt admission to a ward such as the use of a direct admission card should be provided by hospitals and recognised by all staff. RCOG (2010); SANDS (2016); National Implementation Group (2018).	✗	✓	✓	✓	✓	✗	✓	✗

1.2 Treatment Options

Statement: All parents receive continuity of care with due consideration to minimising the stress of attending hospital and are given ample opportunities to discuss treatment options available in the hospital and provided within the framework of current legislation.

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
The medical and/or surgical treatment options available to the woman are clearly outlined with a full explanation of the advantages and disadvantages of each option. The woman is supported in making informed choices about her care and allowed time with her partner to consider her options. Appropriate explanations, supplemented with written information, are given to the parents. Staff should ensure sufficient time is made available to discuss any issues or concerns the parents may have during the course of the woman's care. Consultations with parents and information provided may need to be approached with due regard to provisions of relevant legislation. Ellis et al. (2016); RCPI/HSE Clinical Guideline No. 33 (2014); Malm et al. (2011); Henley & Schott (2008); Lalor et al. (2007); SANDS (2016); Fallowfield & Jenkins (2004). National Implementation Group (2019); IOG (2020).	✓	✓	✓	✓	✓	✓	✓	✓
When parents have chosen to continue their pregnancy, as part of a palliative care approach, they will meet with a member of the Bereavement Specialist Team for anticipatory care inclusive of; •placing emphasis on baby alive in utero •discussing memory making both of the pregnancy and following delivery •sibling involvement in accordance with parents' wishes and consent •counselling and support in managing the uncertainties of loss and life expectancy •preparation for birth inclusive of documented parental wishes/birth preferences as discussed with family and Palliative Healthcare Team (PHT) Ellis et al. (2016); Coleman (2015); van der Gest et al. (2013); Machajewski & Kronk (2013); Avelin et al. (2012); Branchett & Stretton (2012); Torbic (2011); Thames Valley Framework (2017), O'Donoghue (2018).	✗	✗	✗	✗	✗	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
A woman known to have a pregnancy complicated by potential loss, who attends for scanning or other out- patient procedure, should not have to wait alongside other pregnant women. Where resources do not permit such accommodation, the woman's appointment should be scheduled so as she will be the first woman seen by her sonographer, obstetrician or midwife on that day. Mulvihill & Walsh (2013); Branchett & Stretton (2012).	✓	✓	✓	✓	✓	✓	✓	✗
Multidisciplinary evidence-based pathways are utilized in providing care to parents. All relevant staff are aware of and use these care pathways and care plans where appropriate. Ellis et al. (2016); Gibson et al. (2011); Munson & Leuthner (2007); Gold (2007); Gold et al. (2007); National Implementation Group (2019).	✓	✓	✓	✓	✓	✓	✓	✓
There is a system in place to ensure that throughout her care a woman has continuity of care both as an out-patient and as an in-patient. The importance of continuity of care across health and social care services is paramount and is applied within the capacity of local resources. National Maternity Strategy (2016).	✓	✓	✓	✓	✓	✓	✓	✓

1.3 Preparing for Birth

Statement: In preparation for birth, parents are sensitively advised verbally and in writing of what to expect before, during and immediately after birth and are invited to meet with a member of the BST. A care pathway that takes in to consideration the cultural, religious and secular preferences of the parents is designed with the parents.

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Throughout a woman's care she and her partner are offered specific information in a sensitive manner, both verbally and in written format, regarding her diagnosis and treatment. Relevant information booklets/leaflets are provided for parents. SANDS (2016), National Implementation Group (2019).	✓	✓	✓	✓	✓	✓	✓	✓
The mother is offered individualised preparation for labour that is tailored to her and her partner's needs. Koopmans et al. (2013); RCPI /HSE Clinical Guideline No. 4 (2011); SANDS (2007); Sälfund & Wredling (2006); Catlin (2005).	✗	✗	✗	✓	✓	✓	✓	✓
Staff ascertain parental preferences for care during delivery and, based on these preferences, parents are supported in drawing up a care pathway for their baby. Kobler & Limbo (2011); Siddiqui & Kean (2009); Munson & Leuthner (2007); SANDS (2016).	✗	✗	✗	✓	✓	✓	✓	✓
Following pregnancy loss in the first trimester staff sensitively explain the processes and hospital policies around the management of the fetal remains National Implementation Group (2019).	✓	✓	✓	✗	✗	✗	✗	✗
Parents are often ill-prepared for the appearance of their baby, especially where death occurred several days before delivery. Staff, gently and sensitively, explain to the parents what their baby might look like after birth. RCPI /HSE Clinical Guideline No. 4 (2011); Trulsson & Rådestad (2004).	✗	✗	✗	✓	✓	✓	✓	✓
Following a diagnosis of a first-trimester and second-trimester miscarriage, the parents are sensitively informed that it may sometimes be difficult to determine the sex of their baby at birth. RCPI /HSE Clinical Guideline No. 29 (2014); National Implementation Group (2019).	✗	✓	✓	✓	✓	✗	✗	✗

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
All health professionals are aware of the psychological sequelae associated with pregnancy loss and perinatal death. Parents are made aware of the availability of the services of the BST. Nuzum et al. (2014b); Donovan et al. (2014); RCPI / HSE Clinical Guideline No. 4 (2011); Rowlands & Lee (2010); Badenhorst et al. (2006); Browne et al. (2005).	✓	✓	✓	✓	✓	✓	✓	✓
There is a system in place to cancel antenatal clinic appointments and all other antenatal-related appointments within one working day following the mother's diagnosis. Branchett & Stretton (2012); Williams & Datta (2012); SANDS (2016); Kean (2006).	✓	✓	✓	✓	✓	✓	✓	✓

1.4 Care Following Hospital Admission

Statement: Staff discuss with parents their options and choices and allow time for parents to reflect on their options and review their choices.

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Following admission/re-admission and resources permitting, the woman is cared for in a dedicated room with an ensuite toilet and shower. Each dedicated room has a double bed and/or a second single bed to facilitate the mother's partner or companion to stay overnight during her stay in hospital. Ellis et al. (2016); Branchett & Stretton (2012); RCOG (2010); Siddiqui & Kean (2009); RCOG (2008); SANDS (2016).	✗	✗	✗	✓	✓	✓	✓	✓
A woman admitted to hospital with a diagnosis of ectopic pregnancy or early pregnancy loss is accommodated in a Gynecological Ward or in an alternative non-obstetric ward. RCPI /HSE Clinical Guideline No. 29 (2014); Mulvihill & Walsh (2013); Jones & Pearce (2009).	✓	✓	✓	✗	✗	✗	✗	✗
Priority is given to scheduling elective surgical procedures for ectopic pregnancy and miscarriage at the beginning of a theatre list. HSE (2014).	✓	✓	✓	✗	✗	✗	✗	✗
A woman is advised of her choices in pain relief during management of pregnancy loss. Sagili & Divers (2007); Lozeau & Potter (2005).	N/A	✓	✓	✓	✓	N/A	✓	N/A

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
When one or more babies have died during a multiple pregnancy and one or more babies has also survived, staff should also offer parents opportunities before labour to discuss their concerns and how they are feeling. NBCP (2020).	✗	✗	✗	✓	✓	✓	✓	✓
Parents who choose to see/hold their baby at the time of birth are facilitated in doing so in a caring environment. Those parents who choose not to do so at birth are offered other opportunities at a later interval. Ellis et al. (2016); Kingdon et al. (2015); NICE, CG192 (2014); SANDS (2016); NBCP (2020).	✗	✗	✗	✓	✓	✓	✓	✓
Guided by the parents' wishes and consent, the midwife/doctor gently enquires how they would like to meet and parent their baby, for example would they like to; • have their baby delivered into the mother's arms • cut their baby's umbilical cord • have skin to skin contact with their baby • hold, touch, sit or lie beside their baby • take photographs of their baby • have photographs taken of their baby by staff which can be held in the HCR • if available, parents are offered the option of having a professional photographer take photographs of their baby • spend time (alone) with their baby • create memories of their baby for a memory booklet or memory box • in the case of a multiple pregnancy parents should be facilitated to make separate and joint memories for their babies • take a print of their baby's hand or foot • cut a lock of their baby's hair • keep their baby's ID bracelet and measuring tape • wash and dress their baby Inclusion of older siblings in memory making should be suggested to parents. Ellis et al. (2016); Kingdon et al. (2015) SANDS (2016), National Implementation Group (2019), RANZCOG (2019); NBCP (2020).	✗	✗	✗	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
If parents have chosen a name, the baby is referred to by name at all times. SANDS (2016); ISANDS (2007), National Implementation Group (2019), RANZCOG (2019).	✓	✓	✓	✓	✓	✓	✓	✓
In the event that a baby is born with a life-limiting condition that was not diagnosed before birth, a referral is made to the appropriate hospital and community specialist service providers. Balaguer et al. (2012); Sumner et al. (2006).	✗	✗	✗	✗	✗	✗	✗	✓
Consideration is given to the needs of mothers whose babies have been transferred to another hospital. All efforts are made to safely locate the mother with her baby. A copy of the baby's HCR accompanies the baby at the time of transfer. If medically unfit to travel, frequent updates on baby's condition are communicated sensitively to the mother and based on information from the clinical team in the other hospital. In consultation and with the permission of the parents a nominated family member is facilitated to be with the baby and where possible the parents are offered photographs of their baby. Marshall & Fanaroff (2013); Branchett & Stretton (2012); National Implementation Group (2019).	✗	✗	✗	✗	✗	✗	✓* refers to NND only	✓
All parents are invited to meet with a member of the BST (Clinical Midwife Specialist in Bereavement, Chaplain and Medical Social Worker Specialist in Bereavement). Parents are informed of the specific support services of each discipline and will decide what is most appropriate for them. Burden et al (2016); Queensland Maternity & Neonatal Guideline MN11.29-V3-R16 (2015); Nuzum et al. (2014); RCPI/HSE Clinical Guideline No. 4 (2011); D'Almeida et al. (2006).	✓	✓	✓	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
All parents are offered both verbal and written information in relation to funeral options and arrangements and are supported in organising a service, burial or cremation for their baby. Financial costs in relation to hospital and private burials are made clear. In accordance with their wishes parents are supported in the planning of their baby's funeral. It may be suggested and if parents wish they may; • lift their baby into the coffin • accompany their baby to the mortuary • write a goodbye note or place a toy, keepsake or drawing in the coffin if they so wish • do whatever is culturally appropriate for the family • include older siblings in service, burial/cremation. Woodroffe (2013); Gibson et al. (2011); RCPI /HSE Clinical Guideline No. 4 (2011); Brown (2009); SANDS (2016); ISANDS (2007).	✗	✗	✗	✓	✓	✓	✓	✓ if the baby goes on to die
Parents are offered mementoes from their time with their baby. Some may want such as a Certificate of Blessing (if or Certificate of Naming. Roose & Blanford (2011); SANDS (2016); ISANDS (2007); Capitulo (2005); Busch & Kimble (2001); National Implementation Group (2019).	✗	✗	✗	✓	✓	✓	✓	✓
A symbol that is recognised by all staff is visible on the ward/department. The symbol used in each maternity hospital is referred to as an end-of-life care symbol and is used to denote anticipatory loss as well as to denote that a bereavement has occurred. On seeing the symbol, staff should create an atmosphere of quiet and be prepared to meet people who are grieving. The INHA butterfly symbol should be used in a pregnancy loss in a multiple pregnancy with a surviving sibling. Ellis et al. (2016); RCPI /HSE Clinical Guideline No. 4 (2011); Williams et al. (2008); SANDS (2016);I National Implementation Group (2019; INHA (2020).	✓	✓	✓	✓	✓	✗	✓	✓
If a baby (fetus) is identified following an early miscarriage, the parents are offered the opportunity to see their baby. Mansell (2006). National Implementation Group (2019).	✗	✓	✓	✗	✗	✗	✗	✗

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
If a baby (fetus) is not identified following an ectopic pregnancy or early miscarriage; • this is clearly explained to the parents and recorded in the woman's HCR • the possibility of finding a fetus or fetal tissue in the histology specimens is discussed with the parents before discharge from hospital • there are clear procedures in place to inform parents if macroscopic fetal tissue is found in histology specimens. Parents are provided with the opportunity to collect and bury/cremate this fetal tissue if they so wish. If parents do not wish to collect this fetal tissue, and with their consent, it will be sensitively and ethically buried/cremated by the hospital in accordance with local practice and recorded in the mother's HCR. • in some cases only microscopic tissue may be identified in histology specimens. This may remain in the pathology department as part of the mother's medical record of the pregnancy or may be returned to parents for burial/cremation if they so wish. HSE Standards and Recommended Practices for Post Mortem Examination Services (2012); Limbo et al. (2010); National Implementation Group (2019).	✓	✓	✓	✗	✗	✗	✗	✗
Policies and guidelines are in place in relation to the retention of organs and/or tissue samples for histological examination. All relevant staff are aware of and use the guidelines where appropriate. Discussions are held with the parents as to the burial or cremation of the temporarily retained organs at a time distant from the baby's burial/cremation. Discussions with the parents are undertaken in a sensitive manner regarding their wishes for burial or cremation of organs/fetal tissue. The parent's wishes are documented in the mother's HCR. RCPI /HSE Clinical Guideline No. 29 (2014); HSE Standards and Recommended Practices for Post Mortem Examination Services (2012); SANDS (2007); ISANDS (2007); Mansell (2006); National Implementation Group (2019); Nuzum et al, (2021).	✓	✓	✓	✓	✓	✗	✓	✓ if the baby goes on to die
Staff offer parents the option of taking their baby home before burial/cremation takes place. Parental choice is respected in how parents wish to take their baby home (e.g. in an infant carrier, coffin or in their arms). The midwife/nurse ensures that the baby is sensitively escorted from the ward and hospital in a dignified manner. Limbo et al. (2010); Covington (2009); Kobler et al. (2007); PSANZ (2019).	Optional	Optional	Optional	✓	✓	✗	✓	✓ if the baby goes on to die

1.5 Post Natal Care

Statement: In addition to bereavement care, a woman's physical and social care is offered in accordance with her needs.

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
While emphasis is placed throughout these Standards on bereavement care to ensure the emotional and psychological recovery of the bereaved mother, it is important that her physical care, including her mental health are provided as for a non- bereaved post-natal woman. McGuinness et al. (2014); RCPI /HSE Clinical Guideline No. 4 (2011); ISANDS (2007); National Maternity Strategy (2016).	✓	✓	✓	✓	✓	✓	✓	✓
If one or both twins have died, a bereaved mother and her babies, should be cared for in a dedicated bereavement room with an en-suite toilet and shower. The dedicated bereavement room should have a double bed and/or a second single bed to give the father or other family members and friends the option to stay overnight, so that valuable memories can be created and also that families are together to support each other. The INHA butterfly symbol should be used in the cot of the surviving twin to alert staff to the death of the other baby .INHA(2019). National Implementation Group (2019); NBCP (2020).	N/A	✗	✗	✓	✓	✓	✓	✓
Lactation can be a distressing as well as painful experience for a bereaved woman. It is the responsibility of midwives caring for a bereaved post-natal woman to inform her that lactation may be initiated spontaneously after delivery. Midwives instruct and provide literature on options for managing and suppressing lactation. McGuinness et al. (2014); Gale & Brooks (2006). For women who have lost a baby in a multiple pregnancy with a surviving baby it is important that they are supported to breastfeed with a midwife individually rather than being offered a breastfeeding class. (NBCP, 2020).	✗	✗	✗	✓	✓	✓	✓	✓ if the baby goes on to die

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Management of expressed breast milk stores is sensitively discussed with the parents at an appropriate time. Welborn (2012). McGuinness et al. (2014).	✗	✗	✗	✗	✗	✗	✓	✓ if the baby goes on to die
In the event that a pregnancy has been terminated in another jurisdiction , post-natal clinical care and follow up bereavement care is made available as necessary. Kersting & Wagner (2012); Lalor et al. (2009); Kersting et al. (2009); O'Donoghue (2018); National Implementation Group (2019).	✗	✗	✓	✗	✓	✓	✓	✗

1.6 Preparing for Discharge from Hospital

Statement: Parents are advised on community and hospital health resources; on birth and death registration processes and are provided with appointments for follow-up care. They are also informed about the hospital's annual non-denominational Remembrance Service.

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
All staff are aware of the requirement for rapid communication with the woman's GP and appropriate community teams after discharge. A phone call to the relevant professional(s) is made on the day of the woman's discharge and followed up with written communication by post, or email within 1-2 working days. Queensland Maternity & Neonatal Guideline MN11.29- V3-R16. (2015); Kripalani et al. (2007); SANDS (2016); National Implementation Group (2018); ISANDS (2007).	✓	✓ Letter	✓ Letter	✓ Phone and Letter	✓ Phone and Letter	✓ Phone and Letter	✓ Phone and Letter	✓ Phone and Letter
The discharge letter should include; • the diagnosis • follow-up plan • services offered • information about the condition • the hospital plans for follow up • a list of the support services that have been offered to the woman and how to contact them Jones et al. (2007); Kripalani et al. (2007); SANDS (2016); Mansell (2006).	✓	✓	✓	✓	✓	✓	✓	✓
If a baby is diagnosed as having a life-limiting condition or diagnosed in utero with a life-limiting condition, the mother's GP is informed by phone on the day of diagnosis or the next working day. The phone call is followed up by a more detailed letter with information about the follow-up care plan including a list of supports available within the hospital and how the woman can contact these supports should she wish. Branchett & Stretton (2012); Kripalani et al. (2007); SANDS (2016); National Implementation Group (2019).	✗	✗	✗	✗	✗	✓	✗	✓

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
If early discharge is requested by the mother her GP, and when appropriate her Public Health Nurse, is notified on the day of the early discharge. All other members of the Community Health Care Team involved in on-going care of the mother are also contacted if necessary. Donovan et al. (2014); Rowlands & Lee (2010); Kripalani et al. (2007); SANDS (2016). National Implementation Group (2019).	✗	✗	✗	✓	✓	✓	✓	✓
Parents are provided with verbal and written information about the birth and death registration as well as stillbirth registration. Civil Registration (Certified Extract of Register of Deaths) Regulations (2014); RCPI/HSE Clinical Guideline No. 4 (2011); Williams et al. (2008); Stillbirths Registration Act (1994).	✗	✗	✗	✗	✗	✓	✓	✓
Prior to discharge from hospital, the woman is reviewed by a senior obstetrician. She is provided with verbal and written information in relation to her post-natal care. McGuinness et al. (2014); RCPI/HSE Clinical Guideline No. 4 (2011); SANDS (2016).	✓	✓	✓	✓	✓	✓	✓	✓
In the case of the death of ne twin it is important that the PHN and GP are informed of the death when discharging the surviving baby. Parents should be informed of the bereavement supports available to them following discharge.	✗	✓	✓	✓	✓	✓	✓	✗
Parents are provided with written details, as appropriate, of national and local sources of support and organisations and guided to relevant web sites. Donovan et al. (2014); Rowlands & Lee (2010); SANDS (2016); ISANDS (2007).	✓	✓	✓	✓	✓	✓	✓	✓
A follow-up medical appointment with a woman's obstetrician is recommended for all women who have experienced an ectopic pregnancy, second trimester miscarriage, termination of pregnancy, stillbirth or neonatal death. RCPI/HSE Clinical Guideline No. 29 (2014); RCPI/HSE Clinical Guideline No. 4 (2011); SANDS (2016); National Implementation Group (2019).	✓	✗	✗	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Healthcare professionals providing care for a woman with a history of recurrent miscarriage, ectopic pregnancy or who experienced complications during treatment will ensure that an appropriate follow-up appointment is arranged with a Consultant Obstetrician at a pregnancy loss clinic or gynaecological clinic. RCPI/HSE Clinical Guideline No. 4 (2014); Stratton & Lloyd (2008); SANDS (2016; ISANDS (2007).	✓	✓	✓	✓	✓	✓	✓	✓
It is mandatory to report all stillbirths and neonatal deaths to the Coroner in the jurisdiction in which the infant is born. Coroners (Amendment) Act (2019). http://www.irishstatutebook.ie/eli/2019/act/29/enacted/en/html								
When a hospital/consented post mortem examination has been carried out the parents are informed that they will receive an appointment, at approximately 3 months following discharge from hospital, to meet with their Consultant Obstetrician, Neonatologist/ Paediatrician and CMS who the family has built a relationship with to discuss the findings of the post mortem examination. All available results are collated and are to hand before the appointment. SANDS (2016); ISANDS (2007); Laing (2004). National Implementation Group (2019).	✗	✗	✗	✓	✓	✗	✓	✓
When a coronial post-mortem examination has been carried out, results should still be available to the parents in a timely manner. Parents are advised that results from the Coroner's post mortem can take an unpredictable length of time. The baby's death cannot be registered until these results are available from the Coroner. RCPI/HSE Clinical Guideline No. 4 (2011); Coroners Post Mortems. http://www.coroners.ie/en/CS/Pages/Coroners%20Pos t%20Mortems Birth, Deaths and Marriages Registration Act, 1972. http://www.irishstatutebook.ie/1972/en/act/pub/0025/in dex.html Stillbirth Registration Act, 1994. http://www.irishstatutebook.ie/1994/en/act/pub/0001/pri nt.html Coroners Amendment Act (2019). http://www.irishstatutebook.ie/eli/2019/act/29/enacted/en/html	✗	✗	✗	✓	✓	✓	✓	✓

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
Community-based medical, nursing and allied professionals, perinatal mental health team and social workers who are engaged in a woman's on- going medical or social care are, in certain circumstances, informed about the bereavement at the time of discharge. RCPI/HSE Clinical Guideline No. 29 (2014); Donovan et al. (2014); Rowlands & Lee (2010); Kripalani et al. (2007); SANDS (2016); ISANDS (2007), National Implementtaion Group (2019).	✓	✓	✓	✓	✓	✓	✓	✓
Parents are offered information and support following their baby's death and following discharge from hospital that responds to their individual bereavement needs. BST staff are sensitive to the social, religious and cultural values of individual parents. Donovan et al. (2014); RCPI /HSE Clinical Guideline No. 29 (2014); RCPI/HSE Clinical Guideline No. 4 (2011); Brier (2008); SANDS (2016); ISANDS (2007); Hutti (2005); PSANZ (2019); NBCP (2020).	✓	✓	✓	✓	✓	✓	✓	✓

1.7 Bereavement Care after Discharge

Statement: Parents are informed of the availability of hospital and community bereavement supports appropriate to their social, religious and cultural values.

	Ectopic Pregnancy	First-trimester Miscarriage	First-trimester Termination of Pregnancy	Second-trimester Miscarriage	Second-trimester Termination of Pregnancy	Baby diagnosed in utero with a Life-limiting Condition	Intra-uterine Fetal Death, Stillbirth and Early Neonatal Death	Baby born with a Life-limiting Condition
A parent returning to the hospital for a follow-up consultation with an obstetrician/fetal medicine specialist, paediatrician/neonatologist, bereavement specialist, chaplain or other staff member will be reviewed, where feasible, in a suitable room separate from mothers and babies and conducive to discussion and counselling. Flenady & Wilson (2008); SANDS (2016);PSANZ (2019); NBCP (2020).	✓	✓	✓	✓	✓	✓	✓	✓
Parents should be consulted regarding how they would like to receive sensitive documentation or personal belongings following their discharge from the maternity hospital. SANDS (2016).	✓	✓	✓	✓	✓	✓	✓	✓
Where possible and at parents' request, an opportunity is afforded to parents to meet the staff who cared for them and their baby when the baby died. Branchett & Stretton (2012); SANDS (2016).	Optional	Optional	Optional	Optional	Optional	✓	✓	✓
All hospitals should have a Book of Remembrance available to parents and all parents should be invited to have the baby included in the Book of Remembrance if that is their wish. Walsh et al. (2008); Platt (2004); National Implementation Group (2019).	✓	✓	✓	✓	✓	✓	✓	✓
Hospitals should schedule annual non-denominational Remembrance Services that are sensitive to the needs of parents of different religious faiths and none. All parents are welcome to attend. Walsh et al. (2008); Platt (2004); National Implementation Group (2019).	✓	✓	✓	✓	✓	✓	✓	✓
A woman with a history of recurrent miscarriage, stillbirth or perinatal death who is booked into the hospital on a subsequent pregnancy is offered access to the BST. Keegan (2013); Aoun et al. (2012); RCPI /HSE Clinical Guideline No. 4 (2011); Currier et al. (2008); Walsh et al. (2008); SANDS (2016); Catlin & Carter (2002); NBCP (2020); ESHRE (2017); Murphy et al (2021).	Optional	Optional	Optional	✓	✓	✓	✓	✓

STANDARD 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.

2.1 A Culture of Compassionate Bereavement Care

Statement: The Hospital Service Plan includes bereavement care as a core component.

Criterion	Source
There is a clear and transparent hospital ethos of bereavement care in place.	Donovan et al. (2014); SANDS (2016); ISANDS (2007); Catlin & Carter (2002).
The hospital acknowledges and promotes that all staff play a valuable role in ensuring a culture of compassion. Recruitment and retention of appropriately trained staff in relevant roles within the specialist bereavement team is prioritised. This is formally acknowledged by senior hospital management as a core value of the hospital and is reflected in the decision and actions of the hospital.	SANDS (2016); ISANDS (2007); Fauri (2000).
A designated member of the Hospital Group Management Team is allocated responsibility for bereavement care quality improvement across the hospital group.	SANDS Audit tool (2011); RCOG (2017).
A named member of the hospital management team e.g. Director of Midwifery, Hospital Manager or Lead Clinician is allocated responsibility and is accountable for developing the structures and processes necessary to implement the bereavement components of the Hospital Service Plan.	IHF Quality Standards (2010); SANDS Audit tool (2011).
The hospital has a committee with multi-disciplinary representation, including midwifery staff, that is responsible for overseeing quality improvements in bereavement care and end- of-life care. This committee reports directly to the senior management team in the hospital/hospital group.	Donovan et al. (2014); SANDS Audit tool (2011); IHF Quality Standards (2010); WHO (2006); Johnston et al. (2000).
Each maternity unit should have a multidisciplinary bereavement team in place.	IHF (2014).

2.2 General Governance Policies, Guidelines and Care Pathways

Statement: Governance policies and guidelines for bereavement care and/or care pathways are in place in the hospital to ensure best practice and that care is provided within the framework of current legislation and professional codes of practice.

Criterion	Source
All staff who provide bereavement and end-of-life care do so in accordance with the mission, vision and values of the hospital.	IHF Quality Standards (2010); SANDS (2016); Fauri (2000).
The National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death should be easily available and widely disseminated to all grades and disciplines to ensure awareness and appropriate use.	National Implementation Group (2019).
In accordance with their roles, all staff are educated to use and implement these Standards for Bereavement Care following Pregnancy Loss and Perinatal Death. The National Care Pathways for pregnancy loss should be adapted for use in each hospital.	Blood & Cacciatore (2014); Walsh et al. (2013); Weissman & Meier (2008).
Policy, standards and guidelines on bereavement care in the hospital are available and accessible to all hospital staff.	Catlin & Carter (2002); SANDS Audit tool (2011).
National Clinical Practice Guidelines should be available for use. It is expected that hospital would self assess against the Standards and audit clinical practice against the up-to-date National Clinical Guidelines.	National Implementation Group (2019).
There is a system in place for reviewing and updating all policies, guidelines and care pathways relating to bereavement care. Individual hospital policy incorporates relevant national policy and direction from external agencies.	IHF (2014); Gold et al. (2007); SANDS (2016); HSE (2016).
It is expected that each hospitals guideline group reviews guidelines. The member of the hospital management team allocated responsibility and accountability for developing the structures and processes necessary to implement the bereavement components of the Hospital Service Plan is also responsible for updating and reviewing the guidelines.	IHF (2014); Gold et al. (2007); SANDS (2016); HSE (2016).

2.3 Effective Communication with Parents

Statement: There is timely, clear and sensitive communication with the baby's parents and their families on all matters relating to dying, death and bereavement care.

Criterion	Source
Hospital staff work to the principle that good communication is fundamental to providing good patient care and is essential when communicating bad news.	Ellis et al. (2016); HSE Open Disclosure (2013); Harrison & Walling (2010); Rowlands & Lee (2010); Meyer et al. (2009); IHF Quality Standards (2010); Lalor et al. (2007); ISANDS: Guidelines for Professionals (2017).
All communication between hospital staff, parents and family members is governed by the expressed wishes of the parents.	Koopmans et al. (2013); IHF Quality Standards (2010); Sälfund & Wredling (2006); Gold (2007).
The hospital communications guideline is formulated according to evidence-based protocols for communicating prognostic information to parents of babies and is revised regularly to take account of parents' experiences.	Palliative Care Competence Framework (2014); IHF Quality Standards (2010); Rowlands and Lee (2010).
The hospital communications policy includes bereavement and end-of-life care and includes the importance of communication between departments, hospital and community/GP in relation to bereavement.	Donovan et al. (2014); Rowlands & Lee (2010); Jones et al. (2007); Kripalani et al. (2007); Säflund et al. (2004).
The use of recognised Translation Services are offered to parents who need them enables staff to provide high quality care and services through effective communication.	HSE (2009).
Expressed care preferences are clearly recorded in the EHCR/HCR.	IHF Quality Standards (2010); SANDS (2016); ISANDS (2007); Hammes et al. (2005).
There is an acknowledgement across the hospital that all staff parents may meet have an important role to play in ensuring effective communication with parents and their families in respect of bereavement care.	IHF Quality Standards (2010); Rowlands and Lee (2010); SANDS (2016); Fauri (2000).
The hospital bereavement symbol along with its explanation, is displayed in a public area to inform staff, parents and visitors to the hospital of its significance.	IHF Quality Standards (2010); Williams et al. (2008).

2.4 The Healthcare Record (HCR)/ Electronic Healthcare Record (EHCR)

Statement: The HCR/EHCR supports and enhances governance and communication in respect of bereavement care.

Criterion	Source
In cases where a woman does not have hand-held notes, her current HCR/EHCR is retrievable by all departments on a 24/7 basis. Historical HCRs may be stored off-site and may not be available for 24 hours.	IHF Quality Standards (2010).
The HCR/EHCR provides an accurate chronology of events and records all significant consultations, assessments, observations, discussions, parent's preferences, decisions, interventions and outcomes.	IHF Quality Standards (2010); SANDS (2016); ISANDS (2007).
A copy of a woman's HCR travels with her at the time of transfer for treatment to another hospital. Where the EHCR is in use a printed copy of same is provided on transfer to another hospital.	Irish Medical Council (2019).
If available, staff must consult a woman's current HCR/EHCR and become familiar with the woman's condition and medical history before seeing her.	Irish Medical Council (2019).
Members of the multidisciplinary team consult each other's notes within the HCR/EHCR on a regular and systematic basis.	IHF Quality Standards (2010); Lazaro et al (2021).
The National Clinical Care Pathways for Pregnancy Loss can be adapted for use in each Maternity Unit/Hospital in the HCR/EHR.	National Implementation Group (2019).

2.5 The Hospital Environment

Statement: The physical environment where end-of-life care and bereavement care is provided supports high quality care and facilitates privacy and dignity.

Criterion	Source
The hospital facilitates access to rooms and spaces where breaking bad news, end-of-life care and bereavement care can take place in a quiet, comfortable environment where privacy is ensured.	Parker et al. (2014); IHF (2014); Gibson et al. (2011); SANDS (2016); ISANDS (2007). www.designanddignity.ie
Make available appropriate spaces and surroundings, including accommodation, for parents whose baby has died or requires end-of-life care. The hospital facilitates parents with overnight rest and refreshment facilities.	Parker et al. (2014); IHF Quality Standards (2010); SANDS (2016); ISANDS (2007); National Implementation Group (2019).
Consideration is given to the provision of free or reduced-fee car parking for partners while a bereaved mother is admitted in the hospital.	SANDS (2016); Browning & Solomon (2005); Catlin & Carter (2002).
The hospital makes available dedicated theatre times for women undergoing surgical management of early pregnancy loss.	National Implementation Group (2019).
Make available theatre recovery spaces for parents experiencing pregnancy loss are not shared with other parents.	National Implementation Group (2019).
Protected beds for women experiencing pregnancy loss are prioritised and managed by midwifery management in each maternity unit.	National Implementation Group (2019).
Where applicable the Irish Hospice Foundation/HSE Design and Dignity guidelines and style book are followed for all capital projects, with specific adaptations relative to maternity settings including delivery rooms, waiting areas and mortuary spaces and movement through the hospital. The hospital service plan identifies and prioritises funding to improve areas of the hospital used for bereavement care.	IHF (2014); Siddiqui & Kean (2009); Branchett & Stretton (2012); Brown & Taquino (2001). www.designanddignity.ie

2.6 Monitoring and Evaluating Bereavement Care

Statement: Bereavement care in the hospital is continuously evaluated.

Criterion	Source
The hospital collects data on an ongoing basis that reflects the quality of provision of bereavement care. This information is recorded, reported and interpreted in order to direct changes where required.	SANDS Audit tool (2011); Irish Medical Council (2019).
Structures are put in place to encourage, collect and collate parents' feedback. This information is reported to the hospital's bereavement committee.	Palliative Care Competence Framework (2014); SANDS Audit tool (2011).
Complaints about bereavement care are recorded and are dealt with fully in a timely manner by the Hospital Risk Manager and in line with the Open Disclosure Policy.	IHF (2014); Health Act 2004; HSE (2013). www.hse.ie/opendisclosu re/
Stillbirths, neonatal deaths and second trimester miscarriages, are discussed and reviewed at regular perinatal mortality meetings. Input from a perinatal pathologist is central to the functioning of these meetings. Attendance at these meetings and clinical decisions made at them are recorded.	RCPI/HSE Clinical Guideline No. 29 (2014); RCPI/HSE Clinical Guideline No. 4 (2011); SANDS Audit tool (2011); ISANDS (2007); Drife (2006).
There is regular review of the bereavement care provided by the hospital.	IHF (2014); Irish Medical Council (2019); SANDS (2016); HIQA(2020).

2.7 Assessing and Responding to Baby's End-of-Life Care Needs

Statement: All babies who require end-of-life care are identified and provision for their individual care is made accordingly.

Criterion	Source
End-of-life care for each baby is guided by the Lead Paediatrician/Neonatologist and Multidisciplinary Team, and the principle of anticipatory bereavement care is put in place and included as part of an individual care pathway.	Coleman (2015); van der Gest et al. (2013); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007); Browning & Solomon (2006); Kehl (2005).
Policy and guidelines are available for communicating with parents of babies requiring end-of-life care.	Palliative Care Competence Framework (2014); IHF Quality Standards (2010); NICE (2016); Lago et al (2020).
There are effective mechanisms in place to identify babies who may require end-of-life care. The needs of the baby who require end-of-life care are identified, assessed and documented and care pathways are developed accordingly. Early referral is made to the local specialist palliative care team and local Outreach Nurse for Children with a Life-limiting Condition.	Branchett & Stretton (2012); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007); Catlin & Carter (2002).

2.8 Clinical Responsibility and Multidisciplinary Working

Statement: All babies who require end-of-life care are supported by a named Lead Clinician working in consultation/ partnership with the Multidisciplinary Team.

Criterion	Source
At birth the Paediatrician/Neonatologist responsible for the baby's care is identified, documented and communicated to the parents.	Lisle-Porter et al (2009); Munson & Leuthnen (2007); Mack & Wolf (2006).
Where care is being transferred within the hospital to another consultant, the consultant assuming care should be identified to the parents and clearly documented in the HCR. Similarly, when a baby moves to a different clinical environment within the hospital and the responsible Lead Clinician changes for a period, this change should be clearly communicated to parents and to staff.	Branchett & Stretton (2012); Yee & Ross (2006).
The clinical diagnosis that a baby's circumstances may require end-of-life care is communicated to the parents by the Paediatric/Neonatal Team. Verbal information may be supplemented with written information about what to expect and what supports are available. Consideration should be given to language and literacy difficulties.	Armentrout & Cates (2011); Gale & Brooks (2006); Catlin (2005); NICE (2016); Lago et al (2020).
Policy and guidelines should be in place for communication between disciplines, teams and service providers whether hospital based or community based in order to facilitate a planned approach to the baby's care and discharge/transfer out of hospital.	Palliative Care Competence Framework (2014); Donovan et al. (2014); Branchett & Stretton (2012); Rowlands & Lee (2010); Kripalani et al. (2007); Säflund et al. (2004).
The Neonatal Team responsible for discharge planning ensures that there is clear allocation and documentation of responsibility within and between clinical teams involved in the care of the parents and baby, particularly regarding discharge/ transfer out of the hospital. The Neonatal Team is also responsible for equipping parents with the skills to care for their baby.	Griffin & Abraham (2006).
The Neonatal Team responsible for discharge planning communicates directly with the family's GP and PHN when a baby dies. Messages communicating the death of a baby should not be limited to messages being left on an answering machine but there should be follow-up verbal and written communication with the GP and the PHN in due course. This communication should also include the Mother's Obstetrician and the referring hospital Paediatric/Neonatal team if the infant has been referred from another hospital.	Branchett & Stretton (2012); Henley & Shott (2008); Kriplanai et al. (2007); Jones et al. (2007).
The Neonatal Nurse Discharge Planner or the Neonatal Nurse caring for the baby at her/his time of death is responsible for notifying the baby's death to the CMS in Bereavement, Chaplain, Medical Social Worker, National Centre for Inherited Metabolic Disorders, the Hospital's Accounts Department, the hospital from which the baby was referred, and the Neonatal Out-Patient Appointments System.	Palliative Care Competence Framework (2014); Branchett & Stretton (2012); IHF Quality Standards (2010).
All paper/electronic health records and Patient Administration Systems should be updated with date and time of infants death to prevent automatic notifications for any routine child health surveillance communications being inadvertently sent.	IHF Quality Standards (2010).

2.9 Pain and Symptom Management

Statement: Effective pain and symptom management is provided as a key component of end-of- life care and staff education in the hospital.

Criterion	Source
A baby is referred to Palliative Care Services in a timely manner as soon as his/her needs and symptoms and other care factors indicate a need for such expertise, even if the baby is receiving life sustaining treatment. The plan for pain and symptom control may be planned before birth. The Association of Paediatric Palliative Medicine Mater Formulary (5th Edition 2020) is available as an important core resource to assist prescribers providing palliative care. This formulary brings together all available paediatric palliative prescribing information in a single volume , utilising up to date published research and consensus expert opinion.It is available as a digital copy free download from www.appm.org.uk	van der Geest (2014); Munson & Leuthner (2007); Gale & Brooks (2006); Sumner et al. (2006); APPM (2020).
There is a written hospital/departmental ethos regarding pain and symptom management that is evident through attitude, action and documentation.	Caitlin & Carter (2002); Kean (2006).
Anticipatory advice from the palliative care team can be helpful and can mean that symptoms may be prevented.	Lago at al (2020).
When assessing the extent of pain being experienced by a baby staff should employ the N-PASS or other pain assessment tool but must also take physiological symptoms into account.	Spence et al. (2005); Duhn & Medves (2004).

2.10 Clinical Ethics Support

Statement: Hospital management ensures that each staff member has access to clinical ethics support as appropriate to his/her role.

Criterion	Source
Hospital management promotes a climate within the organisation that promotes open discussion and provides a forum in which all employees feel comfortable raising and discussing ethical concerns.	IHF Quality Standards (2010); SANDS (2016); Corley et al. (2005).
The hospital actively promotes a climate where ethical concerns are routinely raised. Transparent processes and mechanisms for supporting ethical decision making are in place and may be used to resolve disagreements about the interpretation of policies or to address potentially difficult or contentious ethical issues that may arise in relation to bereavement care.	Palliative Care Competence Framework (2014); SANDS (2016); Cowley (2017)
Hospital staff consult with the parents to ensure that their wishes for their baby are respected. Parents are partners in their baby's care.	IHF Quality Standards (2010); SANDS (2016); ISANDS (2007).

2.11 Care after Death

Statement: Policies and guidelines for care after death are respectful of the parents' wishes and beliefs.

Criterion	Source
Policy and guidelines are in place for care of the deceased baby. All relevant staff use, and are trained in the use of, these.	RCPI/HSE Guideline No. 4 (2011); ISANDS (2007); Catlin & Carter (2002); Hughes et al. (2002); Lago at al (2020).
In cases where a woman does not have hand-held notes, her current HCR/EHCR is retrievable by all departments on a 24/7 basis. Historical HCRs may be stored off-site and may not be available for 24 hours.	IHF Quality Standards (2010).
A recognisable symbol or alert system that is recognised by all staff and by the public as indicating that a death has occurred should be clearly visible in the ward/department. This should be used with the mother's permission.	RCPI/HSE Guideline No. 4 (2011); IHF Quality Standards (2010); Gold (2007); SANDS (2016); PSANZ 2019.
Hospitals should also give consideration to the use of a symbol for the HCR and appointment cards to alert staff of previous bereavement e.g. on return to OPD.	SANDS (2016).
The hospital has clear written procedures for clear written procedures for examining the baby after birth. This examination includes the option of a skeletal survey regardless of whether post mortem examination is being done or not.	RCPI/HSE Clinical Guideline No. 4 (2011).
The hospital has clear and written procedures for the formal notification of death to the authorities.	SANDS (2016); RCPI (2011); Catlin & Carter (2002); Coroner's Amendment Act (2019).
Parents are advised that medical certification and registration is delayed when Coroner's post mortems have taken place. It is a legal requirement that all Stillbirths and Neonatal deaths are reported to the Coroner.	Coroner's Amendment Act (2019).

2.12 Post Mortem Examinations

Statement: The hospital manages all aspects of post mortem examination in a transparent, timely and sensitive manner and in accordance with the HSE Standards and Recommended Practices for Post Mortem Examination Services (2012).

Criterion	Source
The loss being experienced by the parents is recognised and acknowledged. Staff are sensitive to avoid the potential for further distress when communicating information about the post mortem examination.	RCPI /HSE Clinical Guideline No. 29 (2014); Breeze et al. (2012); RCPI/HSE Guideline No. 4 (2011); SANDS (2007); ISANDS (2007).
Staff are educated to understand what a post mortem entails and are able to answer parents' questions.	Heazell et al. (2012); SANDS (2007); ISANDS (2007); Rankin et al. (2002).
The hospital has policies and guidelines for post mortem examinations which address; • requesting informed consent for hospital/consented post mortem examination • the hospital/consented post mortem examination process • the role of the Coroner in some perinatal deaths • the Coroner's post mortem examination process.	IHF Quality Standards (2010); Putman (2007); SANDS (2007); ISANDS (2007); Coroners (Amendment) Act 2019
All staff are aware that post mortem policy is guided by statutory legislation and the *HSE Standards and Recommended Practices for Post Mortem Examination Services* and are familiar with how to access specific detailed information/expertise. The hospital policy is available in clinical areas and staff know how to access it.	HSE (2012); Coroners Acts (1962 & 2005); Coroners (Amendment) Act 2019.
Parents are offered a hospital/consented post mortem as appropriate. Where a death is reportable to the Coroner, in line with the *Coroners (Amendment) Act 2019*, the Coroner is notified and a post mortem is carried out with his/her authorisation where he/she deems necessary.	HSE (2012); RCPI/HSE Guideline No. 4 (2011); Coroners (Amendment) Act 2019.
Parents' written consent is not required for a post mortem directed by a Coroner. Clarity in relation to the potential for a Coroner's post mortem examination in individual cases should be achieved prior to discussing post mortem examinations with parents. This is so that parents aren't inappropriately asked for consent in a case where the Coroner may subsequently direct a post mortem under his/her jurisdiction.	HSE (2012); RCPI/HSE Guideline No. 4 (2011); Coroners Acts (1962 & 2005); Coroners (Amendment) Act 2019.
A senior clinician is always available to speak with bereaved parents where a Coroner's post mortem examination is to be carried out.	HSE (2012); IHF Quality Standards (2010); Coroners Acts 1962 and 2005; Laing (2004).
In the event that a Coroner's post mortem is required the parents are informed of the reason for this requirement and the Coronial legal process is clearly explained. The post mortem process itself is explained to the parents and written information is always provided. At the time of these discussions parents are informed about the possibility of organs being temporarily retained for further examination. Their wishes for the internment or cremation of these organs at a time distant from the baby's burial/cremation should be documented.	Ellis et al. (2016); HSE (2012); RCPI/HSE Guideline No. 4 (2011); SANDS (2016); ISANDS (2007); Laing (2004); Coroners (Amendment) Act 2019.
In the Coronial process Garda identification of the baby's remains may be required but this should be organized and managed sensitively to avoid parental distress.	National Implementation Group (2019).
A senior member of staff, neonatologist, pathologist or obstetrician known to the parents seeks informed consent for a hospital/consented post mortem examination. The discussion on consent includes discussion on the possibility of organs being temporarily retained for further examination. Their wishes for the burial or cremation of these organs at a time distant from the baby's burial/cremation should be documented.	Ellis et al. (2016); Breeze et al. (2012); RCPI/HSE Guideline No. 4 (2011); Irish Medical Council (2009); SANDS (2016); ISANDS (2007); Rankin et al. (2002); RCPI/Faculty of Pathology (2000).

Criterion	Source
All maternity units should have access to perinatal pathology services. A time frame for the availability of a perinatal pathologist to perform post mortem examination and a time frame for the availability of a standardised report in both hospital/consented and Coronial post mortems should be established and explained to the parents.	RCPI/HSE Guideline No. 4 (2011).
As perinatal post mortem facilities are not available in all hospitals, transfer of the baby may be required. Parents are sensitively informed of the necessity for transfer and kept informed of proceedings and timelines involved.	
Transport of the baby to and from the site of the post mortem examination (in the same unit or a different unit) should be performed with respect and dignity. There should be a hospital/hospital group policy in this regard.	
During the post mortem process the baby's time away from the parents should be reduced to the minimum possible allowed by local post mortem policy. If the mother is an inpatient at the time of the post mortem the baby should be returned to the mother after the post mortem examination, if at all possible. These steps recognise the importance of time spent by the parents with their baby.	
Families are provided with verbal and written information regarding a hospital/consented post mortem examination or a Coroner's post mortem examination using understandable and non-technical language. For a hospital/consented post mortem this information should include options for different types of examination (external only, limited or full).	RCPI /HSE Clinical Guideline No. 29 (2014); RCPI/HSE Guideline No. 4 (2011); SANDS (2016); ISANDS (2007); Rankin et al. (2002); PSANZ 2019.
Where a hospital/consented post mortem is declined, whether for personal, religious or cultural beliefs this decision should be respected. Less invasive options such as limited, external only or radiological examinations may be discussed in these circumstances.	Bakhbakhi 2017.
In accordance with their religious or spiritual tradition and wishes, all parents are offered the option of a ceremony or prayer service by the chaplaincy team or their own spiritual advisor prior to leaving the hospital for burial or cremation. Staff accept that for some parents it is important to hold the funeral within 24 hours of death.	Burden et al. (2016); IHF Quality Standards (2010); Chichester (2007); Gordijn et al. (2007); SANDS (2016); ISANDS (2007).
When discussing post mortem examinations cultural stereotyping and cultural based assumptions should be avoided as diversity exists in all cultural groups.	PSANZ 2019.
Meetings between parents and bereavement specialist staff may continue while awaiting the results of the hospital/consented or Coroner's post mortem.	SANDS (2016); ISANDS (2007); Laing (2004).
Effective and timely communication between all healthcare providers involved in the post mortem process is important for ensuring that a parent centred approach is maintained.	

2.13 Bereavement Care

Statement: The hospital provides assistance and support to parents in dealing with the death of their baby during the period approaching and following the death.

Criterion	Source
Bereavement care is resourced and managed in a multidisciplinary manner to ensure that all needs can be responded to effectively.	IHF Quality Standards (2010); SANDS (2016); ISANDS (2007); Hutti (2005); NBCP (2020).
Parents' questions about their baby's condition are answered fully and promptly by a senior staff member from the appropriate discipline. This support continues following discharge with appropriate onward referral as clinically indicated e.g. to a Geneticist.	Branchett & Stretton (2012); Henley & Schott (2008); SANDS (2016); ISANDS (2007); NBCP (2020).
Where there is a clear indication that death may be imminent parents and family members are alerted as appropriate.	IHF Quality Standards (2010); Henley & Schott (2008); SANDS (2016); NBCP (2020).
Where parents have differences of opinion, these are acknowledged and addressed sensitively. Staff must be responsive to gender differences in grieving and supportive of parents ensuring they have the opportunity to express themselves.	Meyer et al. (2009); Callister (2006); McGreal et al. (1998).
Parents who are experiencing a high level of distress are referred to the appropriate member of the Bereavement Specialist Team.	Kobler & Limbo (2011); IHF Quality Standards (2010); SANDS (2016); ISANDS (2007); RCPI /HSE Clinical Guideline No. 4 (2011).
If requested, the baby's parents can obtain further information or discuss concerns about the care and treatment of their baby with a member of the multidisciplinary team.	RCPI /HSE Clinical Guideline No. 29 (2014); RCPI/HSE Guideline No. 4 (2011); Hamilton et al. (2007); IHF Quality Standards (2010).
Parents, siblings and extended family are offered timely and appropriate bereavement supports from within hospital and/or community resources. Written information leaflets should be used to supplement/reaffirm verbal information. Parents are informed of what support is available to them from the hospital and in the community before and after the birth/death of their baby and how to access this support.	Avelin et al. (2012); Erlandsson et al. (2010); Redshaw & Hamilton (2010); Gold (2007); NBCP (2020).
Parents are assured of confidentiality and privacy when using bereavement services.	Roush et al. (2007); SANDS (2016).
Staff have an understanding of the range of responses to bereavement.	Machajewski & Kronk (2013); Kersting & Wagner (2012); Lang et al. (2011); Brier (2008); Dyer (2005).
Parents are offered timely appropriate bereavement supports including information regarding awareness and understanding of normal and expected grief reactions. This information may be offered on more than one occasion.	Williams et al. (2008); Gold et al. (2007).
Staff have an understanding of the types of risk factors that may result in complicated bereavement and refer parents to the appropriate services. Such factors may relate to the person (poor coping resources, mental ill-health, gender); to the circumstances of the death such as a twin(s) /triplet(s) in utero; termination of pregnancy or to their own particular circumstances (having other children, degree of emotional and social support available to the person). Consideration should be given to individual circumstances e.g. teen parents, psychosocial difficulties. Bereavement support should be provided in conjunction with support services already in place, e.g. Teen Parent Project, Mental Health Services.	Kersting & Wagner (2012); Shear et al. (2011); Roehrs et al. (2008); Kristjanson et al. (2006); Friedrichs et al. (2000).

Criterion	Source
Staff have information on and access to appropriate professional and peer support to address different types of risk factors and possible grief responses.	McGrath (2011); IHF Quality Standards (2010); Kene et al. (2010); Roehrs et al. (2008); National Implementation Group (2018).
Bereavement support is offered by the hospital. It is offered with reference to professional and voluntary providers.	RCPI/HSE Guideline No. 4 (2011); D'Agostino et al. (2008); Gold et al. (2007).
Access to bereavement services is guided by the families' bereavement needs.	IHF Quality Standards (2010); SANDS (2007); ISANDS (2007); Hutti (2005); Friedrichs et al. (2000).
The Bereavement Support Team organise hospital-funded events that facilitate the grieving process such as Remembrance Services and Public Talks.	Koopmans et al. (2013); Cacciatore (2007); Kavanaugh & Moro (2006).

STANDARD 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.

3.1 Communicating a Diagnosis of a Need for End-of-Life Care

Statement: There is timely, clear and sensitive communication with parents in respect of a diagnosis that their baby's circumstances may require end-of-life care.

Criterion	Source
The hospital has a policy and related guidelines to assist in communicating with the parents of a baby who requires end-of- life care. Staff use and are trained in accordance with their roles to use these guidelines.	Palliative Care Competence Framework (2014); Henley & Schott (2008); IHF Quality Standards (2010); Gold (2007).
The parents are facilitated to discuss the care of their baby with the Paediatrician/ Neonatologist/Palliative Care Consultant/Obstetrician/Fetal Medicine Specialist and are involved in the decision making process of care.	Gold et al. (2007); SANDS (2016); ISANDS (2007); Jones et al (2007); NICE (2016).
Staff are aware of parents' capacity for understanding and are aware of parents' specific religious, cultural and ethnic preferences.	RCPI/HSE Guideline No. 4 (2011); Laing & Freer (2008); Chichester (2007).
Confidentiality is always maintained in respect of any matters relating to diagnosis of a possible need for end-of-life care.	IHF Quality Standards (2010); Catlin & Carter (2002).
Opportunities are provided on an ongoing basis by the multidisciplinary team for the parents to clarify issues and concerns about their baby's well-being.	Malm et al. (2011); IHF Quality Standards (2010); Munson et al (2008); Leuthner & Jones (2007).
Opportunities are provided on an ongoing basis by the multidisciplinary team for the parents to clarify issues and concerns about their baby's well-being.	Malm et al. (2011); IHF Quality Standards (2010); Munson et al (2008); Leuthner & Jones (2007).

3.2 Clear and Accurate Information

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

Criterion	Source
As part of care, unexpected changes to the baby's condition or care plan are communicated to the parents in a timely manner.	Lisle-Porter & Podruchny (2009); Gold (2007); Jones et al (2007).
General information on end-of-life care and support services is provided to the parents both verbally and in written form.	IHF Quality Standards (2010); Flenady& Wilson (2008); Moro et al. (2006); Catlin & Carter (2002).

3.3 Parental Preferences

Statement: The parents are consulted to ensure their baby receives care in a manner and in a care setting of choice that is most appropriate for their baby.

Criterion	Source
Family-centered care facilitates that the baby is placed at the centre of care by supporting the parents as the primary representatives of the baby's best interest.	Redshaw & Hamilton (2010); Lisle-Porter & Podruchny (2009); SANDS (2016); ISANDS (2007); Lago at al (2020).
The baby is cared for in a manner that protects his/her rights and best interests after discussion with the parents. In end of life care, parents and all healthcare providers must recognise that in all cases, the best interests of the baby remain paramount at all times - this is the overriding medical, ethical and legal framework for provision of all care to the baby.	IHF Quality Standards (2010); Redshaw & Hamilton (2010); Hammes et al. (2005).
Decisions and choices that are important to the baby and parents are regularly assessed, optimised and reviewed by the multidisciplinary team. Open communication between parents and senior healthcare providers is essential to address concerns / dissenting opinions to fully address in a collaborative fashion what are the best interests of the baby.	Gibson et al. (2011); Williams et al. (2008); Munson & Leuthner (2007); ISANDS (2007); Fowlie & McHaffie (2004); NICE (2016).
Anticipatory bereavement support is offered to all families upon diagnosis of a life-limiting condition or a fetal anomaly that may prove fatal. This includes support to parents on how to communicate the diagnosis to extended family members. Any support or information provided may need to be approached with due regard to provisions of relevant legislation such as the Regulation of Information (Services Outside the State for Termination of Pregnancies) Act 1995.	Coleman (2015); van der Gest et al. (2013); Machajewski & Kronk (2013); Avelin et al. (2012); Torbic (2011); Williams et al. (2008).
Parents are offered age-appropriate advice in relaying the diagnosis to siblings.	Avelin et al. (2012); O'Leary & Gaziano (2011); Erlandsson et al. (2010); SANDS (2016); ISANDS (2007); Stokes (2004); Riley (2003); ICBN (2012); Avelin at al (2012).
In a case of multiple pregnancy with a surviving baby, parents must be assisted and supported to care for the surviving baby, while allowing them to spend time with the dying/deceased baby.	PSANZ (2019).
Designate a lead contact person with training in bereavement care to be available to the parents and other members of the care team to promote continuity of care. Ensure that more than one person is trained for this role to avoid compassion fatigue.	PSANZ (2019).
Consult parents about all decisions, with the understanding that they may not be ready to make decisions and may need more information and time	PSANZ (2019).
Consent by the parents for the care of their baby is easily and clearly identifiable in the HCR/EHCR.	Woodroffe (2013); IHF Quality Standards (2010); SANDS (2016); Yee & Ross (2006).
Should parents request a second opinion, this is facilitated in a timely manner.	Romesberg (2007).

3.4 Pain and Symptom Management

Statement: Pain and symptom management for each individual baby takes full account of the multifaceted nature of pain.

Criterion	Source
Comfort care measures such as skin to skin contact and non- nutritive sucking are employed with parental involvement as appropriate.	Mancini et al. (2014); Liu et al. (2010); NICE (2016).
There is documentation within the HCR of regular monitoring of the baby's symptoms and the effectiveness of interventions. Pharmacological and non-pharmacological methods should be considered.	Branchett & Stretton (2012); SANDS (2016); ISANDS (2007).

3.5 The Baby who is Dying

Statement: The particular needs of a baby whose death is imminent are assessed and provided for in a sensitive and culturally appropriate manner.

Criterion	Source
Where the parents wish their baby to die at home, or in another community setting, this is facilitated as far as possible. Information on logistical and financial issues; palliative care and community services are discussed with the Medical Social Worker and Palliative Care Team and the necessary arrangements are put in place prior to discharge.	Palliative Care Competence Framework (2014); Craig & Mancini (2013); IHF Quality Standards (2010); SANDS (2016); ISANDS (2007); NICE (2016).
Parents are advised as a matter of urgency when death may be imminent and are facilitated to be present with their baby.	Armentrout & Cates (2011); SANDS (2016); ISANDS (2007).
The needs of the dying baby are assessed and prioritised to ensure that, as far as possible, the best possible level of comfort is provided and the baby's parents' wishes are respected.	Mancini et al (2014); De Rooy et al. (2012); Hellmann (2012); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007): NICE(2016).
Staff allocation is structured so as to ensure that the nursing care and support of the baby/parents is in accordance with their needs. If the baby's parents are not present when the baby is dying, a staff member is allocated to ensure that the baby is always accompanied at this time.	Reid et al. (2011); IHF Quality Standards (2010); Flenady & Wilson (2008).
The dying baby is cared for in a private and dignified space and as far as possible in a single room unless otherwise requested by his/her parents. If death is to take place in an open plan ward activity is kept to the minimum and noise levels controlled as far as possible.	Laing & Freer (2008); IHF Quality Standards (2010); SANDS (2007); ISANDS (2007); NICE (2016).

3.6 Discharge Home/Out of Hospital

Statement: The parents are actively involved in discussions and decisions regarding admission, discharge home or transfer to another setting for end-of-life care for their baby.

Criterion	Source
Prior to discharge from hospital, the parents are given opportunities to discuss their baby's care plan with the Paediatrician/Neonatologist and the Multidisciplinary Team involved in their baby's care.	Parker et al. (2014); Kripalani et al. (2007); SANDS (2016); ISANDS (2007); Hummel & Cronin (2004); Craig & Goldman (2003); NICE (2016); Lago et al (2020).
Sensitively address mothers' postnatal physical care needs, including lactation, vaginal bleeding, wound care, contraception, and physical activity.	HSE, Clinical Care Pathways (2019); PSANZ (2019).
Parents are provided with information and advice both verbally and in writing on various aspects of caring for their baby at home.	SANDS (2016); ISANDS (2007); Griffin & Abraham (2006); Hummel & Cronin (2004); Craig & Goldman (2003).
Discharge home is facilitated as efficiently as possible. The hospital has a process of proactive admission and discharge planning that addresses the baby's and the parents' individual needs. a plan for any required emergency readmission shoudl be in place (an admission "passport" to facilitate quick and seamless access to inpatient care without the need for additional distress in A&E if either infant/family not managing with initial plans for care at home.	Parker et al. (2014); ISANDS (2007); Hummel & Cronin (2004); NICE (2016).
The primary care team (GP/PHN) should be included as early as is feasible in discussions with MSW/Palliative Care team to ensure an holistic family centred approach to the care of the infant after discharge from the hospital.	NICE (2016).
All legal /certiification/documentation/cremation requirements including communication with the Coroner are required for the infant who dies at home. Clear preparation and agreed assignment of roles across the healthcare teams prior to discharge can help prevent unnecessary distress to grieving parents after their baby has died.	HSE (2016).
The Neonatal Team communicates directly by telephone with the baby's GP, PHN, Outreach Nurse for Children with a Life-limiting Condition and Specialist Palliative Care Services to clearly outline the baby's care plan. Verbal communication is followed up on the same day with written communication.	DOH (2009); Henley & Schoot (2008); Kriplianai et al. (2007).
Written information provided to the GP and/or other service providers is formulated so that essential relevant information is shared. This should include: – relevant clinical information – the parents' awareness of prognosis – the parents' wishes regarding preferred place of death – any other non-clinical information that is important.	DOH (2009); Craig & Goldman (2003); Hummel & Cronin (2004); SANDS (2016); ISANDS (2007); HSE (2016).
If a baby dies at home the GP should notify the baby's hospital team.	DOH (2009); HSE (2016).
The Community Pharmacist is notified prior to discharge of all medication requirements and medical supplies.	IHF Quality Standards (2010); Kripalani et al. (2007); Levine et al. (2001).
The Medical Social Worker will expedite the processing of a Long Term Illness or Medical Card.	*http://health.gov.ie/future- health/reforming-primary-care- 2/medical-cards/*

3.7 Communication with the Parents in the Event of a Baby's Sudden/Unexpected Death or Sudden Decline in Health Leading to Death

Statement: In cases involving a sudden change in the baby's condition likely to lead to death and or in cases of sudden/unexpected death of a baby, the baby's parents are provided with prompt and clear information as appropriate.

Criterion	Source
The clinical decision that a baby may no longer be responding to treatment and may be dying is communicated clearly, sensitively and timely to the parents and documented in the HCR/EHCR.	Woodroffe (2013); Henley & Schott (2008); SANDS (2016); ISANDS (2007); Widger & Wilkins (2003); Kaempf et al (2008); HSE (2009).
In the event of a redirection of care being provided, the parents are consulted and any decisions required are made jointly with them.	Fowlie & McHaffie (2004); Roy et al. (2004); Kaempf et al (2008); PSANZ (2019).
The hospital has guidelines on consulting parents to ascertain the parents' known wishes in respect of resuscitation and organ donation.	Roush et al. (2007); Catlin & Carter (2002); Umana et al (2018).
Parents are provided with names and contact details of members of the healthcare professionals involved in the ongoing care of their baby.	SANDS (2016); ISANDS (2007); Hummel & Cronin (2004).
Validate parenthood and support memory making with parents.	PSANZ (2019).
The content of conversations between staff and the parents of a baby discharged home to continue end-of-life care are documented within the HCR/EHRC.	DOH (2009); Hummel & Cronin (2004); Heller & Solomon (2005).
Parents are provided with support and advice on supporting their other children/siblings during the baby's time at home.	Avelin et al. (2012); O'Leary & Gaziano (2011); Torbic (2011); Erlandsson et al. (2010); SANDS (2016); ISANDS (2007); ICBN (2020).

STANDARD 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.

4.1 Cultivating a Culture of Compassionate Bereavement Care among Staff

Statement: Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in bereavement care.

Criterion	Source
Each staff member ensures that he/she is familiar with and guided by the professional ethical code of conduct appropriate to his/her role.	Rådestad et al. (2014); McQueen et al (2011); IHF Quality Standards (2010); Catlin & Carter (2002).
The hospital ensures that there are education, training and staff programmes in bereavement care for hospital staff in accordance with the size, complexity and specialties of the hospital.	IHF Quality Standards (2010); Fenwick et al. (2007); SANDS (2007); Browning & Solomon (2005); Engler et al. (2004).
It is the responsibility of hospital management to outline the responsibilities of each member of the Bereavement Team and to ensure that all staff are adequately trained and educated at the point of recruitment (or within 3-4 weeks of commencing employment) and throughout their time as an employee. It is therefore the responsibility of hospital management to ensure that the education and training needs of staff are assessed, addressed and resourced to implement and sustain the Standards. Assessment should include local factors, but also ensure that contemporary developments are incorporated (e.g. competencies, findings from research).	Ellis et al. (2016); Rådestad et al. (2014); Blood & Cacciatore, (2014); Mancini et al. (2013); Walsh et al. (2013); Branchett & Stretton (2012); Roehrs et al. (2008); Yee & Ross (2006).
Hospital staff are trained to deliver high quality bereavement care in accordance with the HSE's Palliative Care Competence Framework (2014).	Palliative Care Competence Framework (2014); Mancini et al. (2013); Ferguson et al. (2012); IHF Quality Standards (2010); SANDS (2010).
Staff are educated to compassionately and sensitively communicate bad news to parents and to regularly update parents on their baby's health. This includes communicating changes in care such as the commencement of end-of-life care.	Palliative Care Competence Framework (2014); DOH (2009); Henley & Schott (2008); SANDS (2016); ISANDS (2007); National Implementation Group (2018).

4.2 Staff Induction

Statement: All newly recruited staff are inducted on the general principles and components of bereavement care in the hospital. It is important that all staff are aware of the culture of compassion within the hospital. It is critical that staff involved in direct patient care, and who are more likely to be involved in bereavement care, receive a more significant induction and training programme.

Criterion	Source
The hospital's general induction programme includes a component on bereavement care.	Donovan et al. (2014); Palliative Care Competence Framework (2014); IHF Quality Standards (2010); Fenwick et al. (2007); National Implementtiaon Group (2019).
Hospitals should ensure that the organisation and availability of Pastoral Care Services within the hospital are presented during the staff induction process. For key staff that are more likely to be involved in bereavement care, the induction process related to Pastoral Care and support services should be more extensive and include referral pathways and supports available to all.	Burden et al. (2016); Rosenbaum et al. (2011); Barletta and Thomsen (2001); Nuzum (2014).
Bereavement Care Pathways and National Clinical Guidelines form an essential part of the induction of new staff. Staff are informed and briefed on all new and revised care pathways that are easily accessible by all staff.	Donovan et al. (2014); Palliative Care Competence Framework (2014); IHF Quality Standards (2010); Gold (2007); Gold et al. (2007); HSE (2021).
The provision of information to staff on staff support and who is responsible for co-ordinating this within the hospital is provided as part of an induction/staff education/training day. Induction days and education/training days are regularly used to encourage all Staff to support their own health and wellness	National Implementation Group (2018).

4.3 Staff Education and Development Needs

Statement: The development needs of staff are assessed relative to their roles in bereavement care and underpinned by continual learning and according to emerging national consensus on competencies and standards.

Criterion	Source
A core group of hospital staff with the required expertise in bereavement care (Bereavement Team) are facilitated and supported to deliver bereavement care education and training to hospital staff.	Perinatal Bereavement Education Standards (HSE 2019); Mancini et al. (2013); Ferguson et al. (2012); Branchett & Stretton (2012); SANDS (2016); Flenady et al. (2020).
Staff members who would benefit from specialised education in bereavement care are identified and their participation in standard and accredited education programmes on an ongoing basis is facilitated by the hospital. Topics covered should include, but not be limited to respectful communication, professional requirements under relevant legislation, Post Mortem Examination and awareness of support groups.	McCool et al. (2009); Lalor et al. (2007); Engler et al. (2004); SANDS (2016); Flenady et al. (2020); Leitao et al. (2021); Power at al. (2020).
The hospital provides and maintains resources and facilities for education, training and continuous professional development in coordination with the regional education and training services, including access to computers, libraries, and the internet.	Mancini et al. (2013); Browning & Solomon (2005); SANDS (2007); ISANDS (2007); Flenady et al. (2020).
Staff who have a conscientious objection to certain treatments should inform their manager as soon as possible. The hospital should provide education for staff on conscientious objection.	Irish Medical Council (2019); NMBI (2021).

4.4 Education and Training Programmes for staff

Statement: Education and training programmes for all staff have defined objectives that reflect evidence-based best practice and legislation. These programmes must be delivered at an appropriate level for all staff relevant to the position they hold within their organisation following the "All, Some, Few" framework (HSE, 2014).

Criterion	Source
The design of staff education and training programmes involves stakeholders (state organisations, voluntary bodies, educational institutions and bereaved parents), with relevant experience and knowledge and includes both adult and children's bereavement care needs. The design of education and training programmes is provided at an appropriate national standard and relative to defined competencies and allows for the development of new competencies as the need arises.	Perinatal Bereavement Education Standards (HSE 2019); Palliative Care Competence Framework (2014); PARENTS 2 paper Bakhbakhi et al. (BMJ Open 2019); Mancini et al. (2013); Heazell et al. (2012); IHF Quality Standards (2010); SANDS (2016); Gandino et al. (2019); Emond, de Montigny & Guillaumie (2019); Rice et al. (2019); Flenady et al. (2020); Ratislavováa et al. (2019).
Staff education and training programmes are essential and should cover the key elements of these national standards specifically addressing how to support parents' or families' preferences and values.	Mancini et al. (2013); Mancini (2011); Flenady & Wilson (2008); AycWatson J, Simmonds A, La Fontaine M, Fockler ME (2019); Shakespeare et al. (2019); Ellis, A, Chebsey, C, Storey, C et al. (2016); Siassakos D, Jackson S, Gleeson K et al. (2018); Richards J, Graham RH, Embleton ND, Rankin J. (2016); SANDS (2016); Gandino et al. (2019); Boyle et al. (2020); Warland et al. (2020).
Competency statements are developed by heads of departments for different categories of staff in accordance with their individual roles. Performance management systems are uses to measure this aspect of care within their role.	Blood & Cacciatore (2014); Walsh et al. (2013); Catlin & Carter (2002); SANDS (2016)
Education and development programmes relating to bereavement care are revised annually. The impact of training is evaluated regularly.	Walsh et al. (2013); IHF Quality Standards (2010); Browning & Solomon (2005); Watson, Simmonds, La Fontaine, Fockler (2019); Shakespeare et al. (2019); Ellis, A, Chebsey, C, Storey, C et al. (2016); Boyle et al. (2020); Jackson S, Gleeson K et al (2018); NICE guideline [NG126] published date 17 April 2019. https://www.nice.org.uk/guidance/ng126/chapter/Recommendations
Staff are knowledgeable about and practice in accordance with current legislation for termination of pregnancy. Staff are alsoaware of relevant aspects of their codes of professional conduct in this area. Education on Termination of Pregnancy is included in relevant undergraduate and graduate curricula.	Guide to Professional Conduct and Ethics for Registered Medical Practitioner (8th ed., 2019); Mansell (2006); NMBI Code of Professional Conduct and Ethics (2014); Health (Regulation of termination of pregnancy) Act (2018); Kamranpour, Noroozi & Bahrami (2020); Hewitt and Cappiello (2015); Mainey, et al. (2020); O'Connor et al. (2019); O'Shea et al. (2020); Blackwell et al. (2020).
Public and parental involvement in provision of education should be considered.	Bakhbakhi et al. (BMJ Open 2019); Doherty et al. (2018); Rice et al. (2019); Merrigan, J. (2019); Emond, de Montigny & Guillaumie (2019); Martin, Robb, & Forrest. (2016); Patterson, Begley, & Nolan. (2016); Ratislavováa et al. (2019).
Staff are aware of and utilise the national Pregnancy and Infant Loss website both as a source of information and a support resource.	www.pregnancyandinfantloss.ie

4.5 Staff Support

Statement: Staff support services relating to Bereavement Care reflect the need for peer support and professional support systems.

Criterion	Source
A formal policy on staff support for those working in maternity settings is devised and resourced. This policy defines and addresses the efficacy of a range of support options (supervision, individual debriefing, time-out, peer group support, the services of a professional counsellor).	Larcher et al (2015); McCready & Russell (2009); Catlin & Carter (2002); National Implementation Group (2018); O'Riordan, O'Donoghue, McNamara (2020).
Reliable information is provided to each staff member so that staff are also encouraged to take individual responsibility for well-being and self-care.	Mancini et al. (2013); IHF Quality Standards (2010); Mancini (2011); Aycock & Boyle (2009); National Implementation Group (2018).
Hospital Management recognises the importance of providing debriefing for staff involved with trauma or sudden deaths and puts in place formal and informal systems to support staff who have been involved, directly or indirectly, in such events.	Larcher et al (2015); Hughes & Goodall (2013); Kene et al. (2010); Aycock & Boyle (2009); McCready & Russell (2009).
All clinical managers (particularly in the labour ward and neonatal unit) are trained to support staff around bereavement and to provide immediate debriefing to staff and that this training is designated as mandatory for clinical managers.	National Implementation Group (2018); HSE (2018).
The provision of information to staff on staff support and who is responsible for co-ordinating this within the hospital is provided as part of an induction/ staff education/training day.	National Implementation Group (2018).
Senior Management observe for signs of stress and difficulty in staff members and recognise the importance of support for staff involved in caring for bereaved parents.	Walsh et al. (2013); Keene et al. (2010); Catlin & Carter (2002); HSE (2018).
Staff are given the opportunity to meet with peers for support and that structures are put in place such as extra staff or the re organisation of work load to facilitate time away from the clinical area. Consideration must be given to the introduction of Schwartz rounds in each maternity hospital. Continued use of the 'Assist Me' model" (HSE, 2013) is recommended.	Nuzum et al. (2014); McNamara et al. (2013); National Implementation Group (2018).
Each staff member takes personal responsibility for her/his self- care and knows how to access structured debriefing services. She/he has access to the Employee Assistance Programme provided by Hospital Management.	Mancini et al. (2013); Mancini (2011); McGrath (2011).
Issues and challenges for staff arising from the delivery of bereavement care form part of team discussions and are addressed in reviews of bereavement care.	Hughes & Goodall (2013); Aycock & Boyle (2009); Rogers et al. (2008).
Staff who use support services to address issues that may arise during provision of bereavement care are facilitated to provide feedback on their appropriateness and value. These can be achieved through both formal and informal evaluations.	SANDS Audit tool (2011); Aycock & Boyle (2009); McCreight (2005).
Hospital Management ensure that the staff support services provided within the hospital are fit for purpose through regular evaluation processes. This evaluation should include (i) Peer to peer in immediate aftermath An evaluation process is implemented to include the use of staff survey, staff suggestion boxes, staff feedback forums. Hospital Management/HR Annual review 5 (ii) Management response (iii) Formal debriefing (iv) EAP.	National Implementation Group (2018).
Private space is available to enable staff to discuss and address issues that may arise when providing bereavement care and dealing with death.	McCreight (2005); IHF Quality Standards (2010); SANDS (2016); National Implementation Group (2018); Hartigan et al (2018).
Staff are aware of and utilise the national Pregnancy and Infant Loss website both as a source of information and a support resource.	www.pregnancyandinfantloss.ie

4.6 AUDIT

Criterion	Source
The Bereavement Service will be audited annually through the tools developed by the Oversight Group.	National Implementation Group (2019).
The audits, in conjunction with documented findings from the Multidisciplinary Perinatal Morbidity and Mortality meetings and with the confidential service user feedback, will be used to measure the quality of the bereavement service.	National Implementation Group (2019).
Multidisciplinary bereavement care pathways will be reviewed and revised as indicated through the audits and in keeping with national clinical guidelines and research based up-to-date best clinical practice.	National Implementation Group (2019).

APPENDICES

Appendix 1: National Guidelines, Policy, Legislation and Reports

- Department of Health (DOH) (2014). *National Clinical Guideline No. 5: Communication (Clinical Handover) in Maternity Services.* Available at *http://health.gov.ie/national-clinical-guideline-no-5-communication-clinical-handover-in-maternity-services/*
- Department of Health (DOH) (2009). *Palliative Care for Children with Life-limiting Conditions: A National Policy.* Available at (*http://health.gov.ie/wp-content/uploads/2014/03/palliative_care_en.pdf*)
- Department of Health. Slainte Care. 2019. Available at: *https://www.gov.ie/en/publication/0d2d60-slaintecare-publications*
- Health Information and Quality Authority (HIQA) (2012). *National Standards for Safer Better Health Care.* Available at *www.hiqa.ie/system/files/Safer-Better-Healthcare-Standards.pdf*
- Health Service Executive (HSE) (2012). *Standards and Recommended Practices for Post Mortem Examination Services.* Available at *http://www.hse.ie/eng/about/Who/qualityandpatientsafety/Standards/hseStandardsandguidance/PME_services/PM_services_docs/QPSD D0071.pdf*
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- Health Service Executive, National Implementation Group (2019). Medication protocol for management of intrauterine fetal death. Available at: *https://pregnancyandinfantloss.ie/medication-protocol-for-medical-management-of-intrauterine-fetal-death*
- Health Service Executive, National Implementation Group (2019). Medication protocol for management of Miscarriage. Available at: *https://pregnancyandinfantloss.ie/medication-protocol-for-medical-management-of-miscarriage*
- Health Service Executive, National Implementation Group (2019). Pathway For Care Of Women Experiencing Ectopic Pregnancy. Available at: *https://pregnancyand.wpengine.com/wp-content/uploads/2019/04/ECTOPIC-PREGNANCY-CARE-PATHWAY.pdf*
- Health Service Executive, National Implementation Group (2019). Pathway For Care Of Women Experiencing First Trimester Pregnancy Loss. Available at: *https://pregnancyandinfantloss.ie/first-trimester-pregnancy-loss-care-pathway*
- Health Service Executive, National Implementation Group (2019). Pathway For Care Of Women Experiencing Second Trimester Pregnancy Loss. Available at: *https://pregnancyand.wpengine.com/wp-content/uploads/2019/04/SECOND-TRIMESTER-PREGNANCY-LOSS-CARE-PATHWAY.pdf*
- Health Service Executive, National Implementation Group (2019). Pathway For Care Of Women Experiencing Stillbirth. Available at: *https://pregnancyand.wpengine.com/wp-content/uploads/2019/04/STILLBIRTH-CARE-PATHWAY.pdf*
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- Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and Directorate of Quality and Clinical Care, Health Service Executive (2014). *Clinical Practice Guideline 29: Management of Second Trimester Miscarriage.* Available at *https://www.rcpi.ie/wp-content/uploads/2016/05/24.-Management-of-Second-Trimester-Miscarriage.pdf*

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Appendix 2: Project Methodology for Review and Update

Under the direction of the National Women and Infants Health, the review group was convened to review and update the Standards since the original publication in 2016. Its membership reflects the multidisciplinary nature of bereavement care and includes a number of the members of the original development group. Its membership is comprised of experts in obstetrics, fetal medicine, paediatrics, ultrasonography, chaplaincy, medical social work, midwifery, neonatal nursing, palliative care and specialist bereavement care.

PHASE 1

- Conduct a literature review of the impact of ectopic pregnancy, miscarriage, a diagnosis of fetal anomaly, stillbirth and early neonatal death
- Evaluate current bereavement resources and services through hospital staff questionnaires
- Update the standards for bereavement care for parents bereaved by ectopic pregnancy, miscarriage, a diagnosis of fetal anomaly, stillbirth and early neonatal

PHASE 2

- Distribute draft of the updated *Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* to stakeholders for feedback and input
- Distribute draft of the updated *Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* to members who were involved in the development and writing of the 2016 Standards
- Distribute draft of the updated *Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* to the National Oversight Group for the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death
- Finalise the updated Standards for *Bereavement Care following Pregnancy Loss and Perinatal Death*
- Submit the *Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* to the National Women and Infants Health Programme for publication.

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Appendix 4: Support and Advocacy Groups

Association	Services	Contact
A Little Lifetime Foundation (was Irish Stillbirth and Neonatal Death Society [ISANDS])	• provides telephone, email, forum and Facebook support for parents and families whose baby has died or is expected to die • regular parent support meetings in Dublin, Cork, Limerick, Tralee, Athlone, Cavan, Drogheda, Wexford, Waterford and Kilkenny • baby clothes to hospitals • information leaflets • a Little Lifetime Foundation Memories Collection • inter-denominational services of remembrance • representation to groups of professionals such as doctors, nurses, midwives, clergy and other interested groups • provide training for support team volunteers • heighten awareness about perinatal death • provide bereavement counselling by counsellor with special interest in bereavement • creative workshops • publishes bi-annual newsletter	www.alittlelifetime.ie Telephone: 01 882 9030
Ectopic Pregnancy Ireland	• raise awareness on ectopic pregnancy amongst the general public and health professionals • provide information and support to those who have been affected by an ectopic pregnancy • offer support rather than counselling. • advocate for the long term needs of couples following ectopic pregnancy	Telephone: 089 436 5742 (8- 10pm) http://ectopicireland.ie/ Email: info@ectopicireland.ie
Every Life Counts	• offers a support network for parents who have received a diagnosis that their child may not live for very long after birth. Every Life Counts provides an outreach for parents to share their memories, their stories, their love and their pain. Every Life Counts seeks to secure support, information and services for families through the establishment of perinatal hospice care across Ireland.	Dominick Court, 41 Dominick Street Lower, Dublin 1 http://www.everylifecounts.ie Telephone: 01 879 2382 office@everylifecounts.ie
Fèileacàin (Stillbirth and Neonatal Death Association of Ireland)	• offer regular support meetings • provide a befriending service and support helpline • provide a safe and confidential setting, in which those bereaved through stillbirth or neonatal death can share their experiences • promote research into the causes of stillbirth, neonatal death and the effects of grief on the family • work in co-operation with support services and other support organisations • organise remembrance services and family events • provide hospitals with memory boxes for bereaved families	www.feileacain.ie Telephone: 085 249 6464

Association	Services	Contact
First Light (previously Irish Sudden Infant Death Association)	• offers bereavement group therapy for newly bereaved parents and children • befriending service • annual memorial service • book of remembrance • SIDS Model of Care and information hotline for professionals • regional information meetings • speakers for professionals and community groups • national Sudden Infant Death Register	First Light, Carmichael House, 4 North Brunswick Street, Dublin 7 Telephone: 01-8732711 24 Hour Helpline: 087 242 3777 Fax: 01-8726056 www://firstlight.ie
HSE Crisis Pregnancy Programme (previously Crisis Pregnancy Agency)	• provides training, education, information, research, communications and support • funds 34 agencies to provide sexual health projects, crisis pregnancy counselling, medical services, parenting support • provide post abortion counselling through 15 voluntary and statutory organisations	89-94 Capel Street, Dublin 1. Telephone: 01 8146292 www.crisispregnancy.ie
Leanbh mo Chroí	• a non-judgmental support group, run by parents who have experienced complex diagnoses including severe and fatal fetal anomaly during pregnancy. • support parents who choose to interrupt the pregnancy and those who chose to continue. • offer support by phone, text, email and face to face. We hold regular support group meetings in Dublin and Cork, and sporadically in the rest of the country. • hold creative workshops and have an active online community which welcomes new members.	http://lmcsupport.ie/
Miscarriage Association of Ireland	• organises and facilitates monthly support group meetings in Dublin • telephone support, email support, Internet forum • regional support groups • newsletters • leaflets for hospitals and elsewhere • annual remembrance service • book of remembrance • memorial stone • support not counselling • make representation to groups of professionals such as doctors, nurses, clergy, midwifery students and other interested groups • public awareness campaigning	www.miscarriage.ie Telephone: 01 873 5702 (Carmichael House) Tel: Volunteers available by phone two hours morning and evening (10am-12md and 8pm-10pm) Monday to Friday (see website for mobile numbers)

Association	Services	Contact
NILMDTS (Now I Lay Me Down To Sleep)	• trains, educates, and mobilizes professional quality photographers to provide beautiful heirloom portraits to families facing the untimely death of an infant	www.nilmdts.org Telephone: 083 377 4777 (open between 9am–9pm)
NISIG - National Infertility and Support & Information Group	• provides information about infertility • offer support • organise support meetings	Telephone: 1890 647 444 (Lo-call) Telephone line open up to 9pm. P.O. Box 131, Togher, Cork. Email: nisig@eircom.net www.infertilityireland.ie
One Day More	• provides a support group made up of parents who received poor pre-natal prognoses for their babies • offers support to any parent who has just received a difficult pre-natal prognosis for their baby	One Day More 6-9 Trinity St,Dublin 2 Telephone: 086 0220362 www.onedaymore.ie SOFT Ireland Contact Co-ordinator
Peas in a Pod	• A group of bereaved parents who have lost a baby (babies) in a multiple pregnancy. The mission of the group is to increase awareness and advocate on issues relating to loss of a twin(s) or triplet(s)	https://www.facebook.com/peasinapodireland/
SOFT Ireland Support Organisation for Trisomy 13/18 (Patau's /Edward's Syndrome)	• offers support for families with newly diagnosed babies • support for families caring for babies and children with these disorders • support for families experiencing bereavement • information on Trisomy 13/18 • fund bereavement counselling • fund respite assistance • publish the SOFT booklet Why Our Baby and a newsletter • organise conferences • fund raising • links with S.O.F.T. organisations worldwide	Telephone: 1800 213 218 Email: soft.contactme@gmail.com https://www.facebook.com/p ages/Soft-Ireland/1936036 40656322
TFMRI Ireland – Termination for Medical Reasons Ireland	• campaign group promoting the interests of couples who receive a diagnosis of lethal fetal anomaly a campaign group promoting the interests of parents who receive a diagnosis of Vasa Praevia	http://www.terminationforme dicalreasons.com/
Vasa Praevia Ireland	• a campaign group promoting the interests of parents who receive a diagnosis of Vasa Praevia	www.facebook.com/vasapraeviasupportand awarenessIreland/

Appendix 5: Additional Support Groups

Additional Support Group	Services	Contact
Anam Cara	• support for parents and siblings following the death of a child • information • on-line forums for parents, siblings and volunteers • support group • guest speakers • counselling	HCL House, Second Avenue, Cookstown Industrial Estate, Tallaght, Dublin 24 http://www.anamcara.ie/ Telephone: +353 (0)1 4045 378 Email: info@anamcara.ie
Bethany Bereavement Support	• voluntary support groups located in most counties and organised within parishes. • many Bethany members have themselves been bereaved and are trained to listen with understanding	www.bethany.ie See website for local contacts
Barnardos	• provides national bereavement counselling service specifically for children • provides information and advice through its helpline and counselling for bereaved children	Dublin Christchurch Square Dublin 8 Tel: 01 453 0355 Email: http://www.barnardos.ie/what-we-do/our-services/special ist-services/bereavement- counselling.html
Barretstown Camp	• offers bereavement weekends to support families when their child (aged infant to 17) dies from a serious illness • provides a sensitive and caring environment in which families can meet others who have suffered a similar loss, share their experiences and find ways to look to the journey ahead	Barretstown Castle, Ballymore Eustace Co. Kildare Telephone: 045 864 115 www.barretstown.org
Compassionate Friends Ireland	• non-profit charitable organisation established in 2008 to provide consolation and support during the grieving process to families in which a child dies.	http://www.compassionatefriendsireland.ie/ Email: compassionatefriends ireland@gmail.com Telephone: Mary 086 382 2624 Nick 087 254 0355
CrosscareTeen Counselling	• provides counselling service for 12 – 18 year olds • offers bereavement counselling to young people and their families	Crosscare, The Red House, Clonliffe Road, Dublin 3 Telephone: 01 836 0011 Web: www.crosscare.ie/teencounselling Email: info@crosscare.ie

Additional Support Group	Services	Contact
Irish Childhood Bereavement Network	• founded in 2012 to act as a hub for those working with bereaved children, young people and their families. • provides information about age appropriate literature for children*	Telephone: 01 679 3188 http://www.childhoodbereavement.ie/
Irish Family Planning Association	• Promote the right of all people to sexual and reproductive health information and dedicated, confidential and affordable healthcare services	https://www.ifpa.ie/
Irish Hospice Foundation	• a national charity dedicated to all matters relating to dying, death and bereavement in Ireland.	Telephone: 01 679 3188 www.hospicefoundation.ie
Irish Patients' Association	• Advocates for the needs of patients while working in partnership with health care providers and addresses various committees, working groups and public bodies on behalf of patients	Tel: 087 6594183 http://irishpatients.ie/
Nurture Health	• A counseling and training support service delivering immediate, timely and affordable well-being professional counseling supports surrounding conception, pregnancy, childbirth and other related difficulties	https://nurturehealth.ie/
One Family	• non- directive service provides practical information and support in all options when faced with a crisis pregnancy	https://onefamily.ie/
Patient Focus	• point of contact and other supports to patients who have been damaged by the Healthcare system • assists people to try and resolve difficulties as early as possible after they arise • seeks to ensure the preservation and enhancement of patient rights in all healthcare settings	Telephone: (01) 885 1611; 885 1617; 885 1633; 885 1658 http://www.patientfocus.ie/ site/index.php
Patients for Patients' Safety	• Patients for Patients Safety Ireland (PFPSI) is a World Health Organisation (WHO) initiative aimed at improving safety in healthcare. PFPSI is supported by the HSE Quality Improvement Division. The WHO believes that safety will only be improved if patients are placed at the centre of care and included as full partners. This initiative brings together patients, providers, policy-makers and those affected by harm who are dedicated to improving health-care safety through advocacy, collaboration and partnership. Members regularly speak at patient safety events, work with health care teams to promote and encourage improvements in patient safety and highlight areas of unsafe practice focused by their own experiences.	www.hse.ie/eng/about/Who/qualityandpatientsafety/nau/patientsafety/

*A list of age appropriate literature is available at:
http://www.childhoodbereavement.ie/top-10-childrens- books-on-death-and-bereavement-the-guardian/#.VOxhIfmsV28

Additional Support Group	Services	Contact
TUSLA (Child and Family Agency)	• child protection and welfare services • education welfare services • psychological services • alternative care • family and locally-based community supports • early years services • domestic, sexual and gender-based violence services	St. Stephens Green House, Earlsfort Terrace, Dublin 2. Telephone: (01) 611 4100 Email: info@fsa.ie www.fsa.ie

Appendix 6: Abbreviations

AIMS	Association for Improvements in the Maternity Services Ireland
BST	Bereavement Specialist Team
CMS	Clinical Midwife Specialist
DOH	Department of Health
HCR	Healthcare Record
HFH	Hospice Friendly Hospitals
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IHF	Irish Hospice Foundation
IUFD	Intrauterine Fetal Death
MDT	Multi-disciplinary Team
MHCT	Mental Healthcare Team
NCEC	National Clinical Effectiveness Committee
NICE	National Institute for Health and Care Excellence
NND	Neonatal Death
NPEC	National Perinatal Epidemiology Centre
OPD	Out Patients Department
PHT	Palliative Healthcare Team
PMH	Perinatal Mental Health
RCOG	Royal College of Obstetrics and Gynecology (UK)
RCPI	Royal College of Physicians in Ireland
SANDS	Stillbirth and Neonatal Death Society
SB	Stillbirth