



National Maternity Bereavement Experience Survey

Anna Maria Verling
Project Lead

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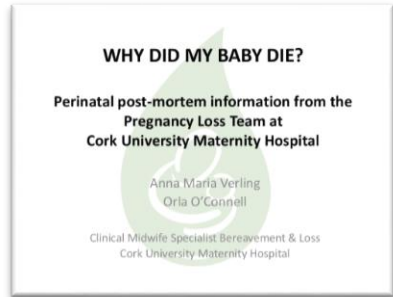


An Roinn Sláinte
Department of Health

Parent Advocate- improve quality, safety and experience of care



Passionate, support, caring, honored to be with parents in their grief, witnessing human vulnerability is very humbling



1 IN 4 PREGNANCIES END IN FIRST TRIMESTER MISCARRIAGE

The website provides medically accurate, helpful and user-friendly information on:

- Pregnancy
- Pregnancy Concerns
- Miscarriage Symptoms
- Types of Miscarriage
- Management and Services
- Feelings and Emotions
- Pregnancy after Miscarriage

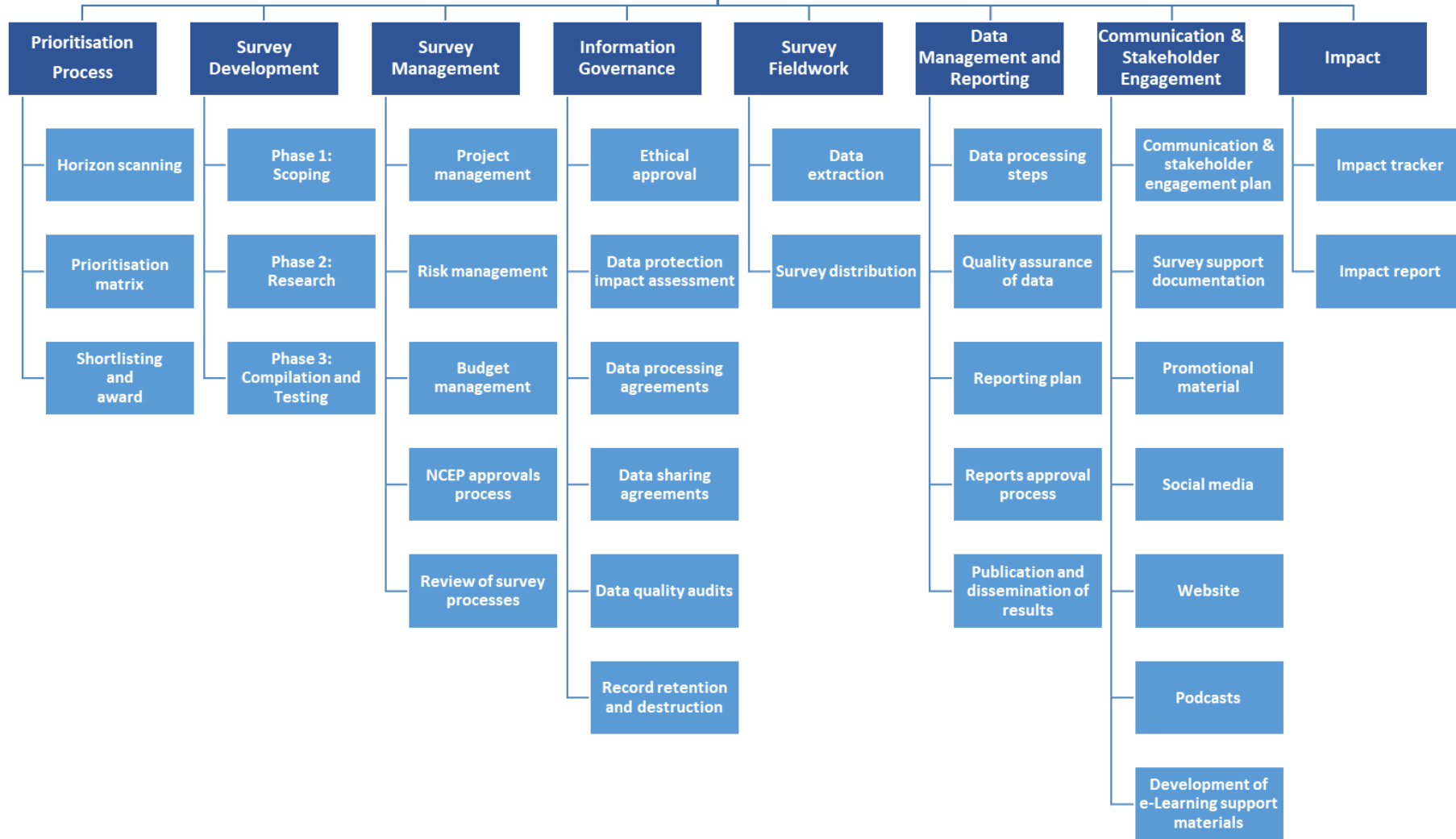
National Care Experience Programme

The National Care Experience Programme seeks to improve the quality of health and social care services in Ireland by asking people about their experiences of care and acting on their feedback

We're committed to excellence in healthcare

Quality Assurance Framework(QAF)

National Care Experience Programme Quality Assurance Framework



National Maternity Experience Survey





National Maternity Bereavement Experience Survey (NMBES)

- Bereaved women needed a stand alone survey, more appropriate and sensitive to their needs and so the National Maternity Bereavement Experience Survey came about.

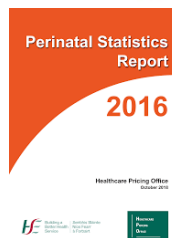
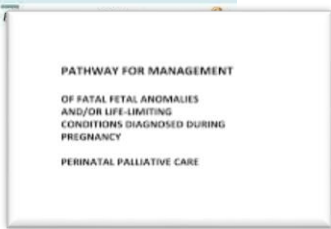
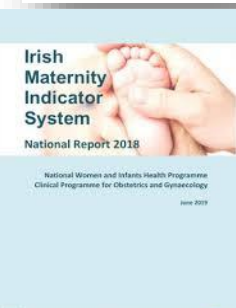
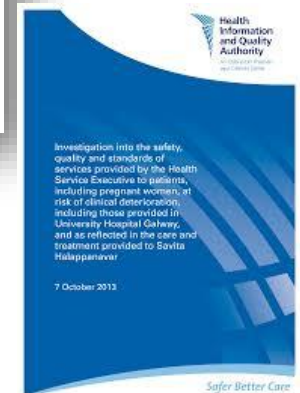
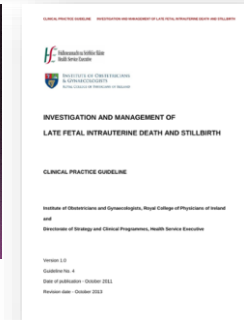
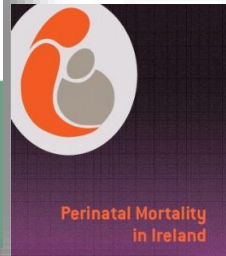
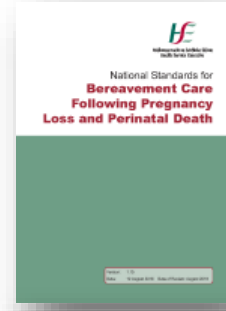
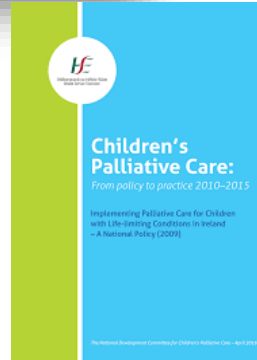
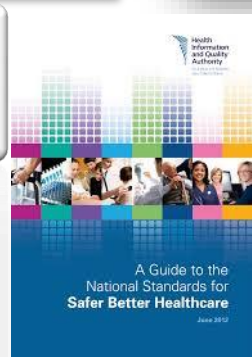


Introduction to NMBES

- The National Maternity Bereavement Experience Survey will be the first national survey of bereaved parents' experiences of Irish maternity healthcare.
- The aim of the survey is to capture meaningful information on bereaved parents experiences of care in a sensitive and appropriate manner. Experiences of care includes diagnosis, outpatient and inpatient care following the loss of their baby as well as support and follow up care.
- Learning from the lived experience of parents will acknowledge what was good about their care and what we can do better.
- Identifying areas for quality improvement, to help ensure appropriate, consistent care is provided to all bereaved parents in the future.

National Review

List of relevant HSE and HIQA Reports carried out between 2007-2016 (17)



Health Service Executive. Report into the circumstances pertaining to the death of Mrs. Tania McCabe and her infant son Zach at Our Lady of Lourdes Hospital, Drogheda on Friday 9 March, 2007 (2008)
Health Information and Quality Authority. Report of the investigation into the circumstances surrounding the provision of care to Rebecca O'Malley, in relation to her symptomatic breast disease, the Pathology Services at Cork University Hospital and Symptomatic Breast Disease Services at the Mid-Western Regional Hospital, Limerick. 2008.
Health Information and Quality Authority. Report of the investigation into the provision of services to Ms. A by the Health Service Executive at University Hospital Galway in relation to her symptomatic breast disease, and the provision of Pathology and Symptomatic Breast Disease Services by the Executive at the Hospital. 2008.
Health Information and Quality Authority. Report of the investigation into the quality and safety of services and supporting arrangements provided by the Health Service Executive at the Mid-Western Regional Hospital Ennis. 2009
Health Information and Quality Authority. Report of the investigation into the quality and safety of services and supporting arrangements provided by the Health Service Executive at Mallow General Hospital. 2011
Health Service Executive. National Miscarriage Misdiagnosis Review 2011
Health Information and Quality Authority. Report of the investigation into the quality, safety and governance of the care provided by the Adelaide and Meath Hospital, Dublin incorporating the National Children's Hospital (AMNCH) for patients who require acute admission. 2012
Health Service Executive. National Incident Management Team (NIMT) 50278 Report (2013)
Health Information and Quality Authority. Report of the investigation into the safety, quality and standards of services provided by the Health Service Executive (HSE) to patients, including pregnant women, at risk of clinical deterioration, including those provided in University Hospital Galway (UHG), and as reflected in the care and treatment provided to Savita Halappanavar. 2013
Prime Time. Fatal Failures. Electronic Recording. Dublin: RTÉ Investigations Unit; 30 January 2014 ¹
Holohan, T. (2014) HSE Midland Regional Hospital, Portlaoise Perinatal Deaths (2006-date). Dublin: Department of Health.
Flory Report. Health Service Executive Commissioned –Independent Review – Cavan and South Tipperary Maternity Units, 2015
Health Service Executive. Baby Molloy Report 2015
Health Service Executive. Systems Analysis Review Report: Review of Care of Shauna Keyes. 2015.
Health Information and Quality Authority. Report of the investigation into the safety, quality and standards of services provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise. ¹ May 2015
Health Service Executive. "A Review of 28 Maternity Case Notes" - A Clinical Review Report 2015

Type of Pregnancy Loss	Prevalence	Care options/ Hospital admission	Data collected	Limitations of data
Artificial Reproductive Technology (ART)	Limited national data collected – NPEC. Local level data in individual units not shared	Yes if medically indicated	Limited data available	Mode of conception not documented. Outcome of pregnancy depends on data collected.
Molar Pregnancy	1:650-700 per birth rate approx.	Yes if medically indicated. Otherwise managed in outpatient setting	If referred to GTD Centre. ¹ (hospital local level registers)	Referred to GTD Centre. ¹ Is not compulsory
Ectopic	14.4 per 1000 maternities 863 in 2018 – (IMIS report)	Yes if medically indicated. Otherwise managed in outpatient setting	Yes (If admitted to hospital)	Only captured if admitted for hospital care
Termination of pregnancy (TOP)	In 2019 - 6,666 TOP 6,542 were in early pregnancy 100 – for FFA 22 – Under Section 9 of Act 3 – Under Section 10 of Act	Early TOP under GP care, not hospitalised unless medically indicated. All other cases would take place in hospital setting.	Yes Under Section 20 of the Act of 2018 all TOP must be notified to the Minister for Health (no identifying information included)	Report completed by the Department of Health
Miscarriage -1st Trimester (up to 12wks gestation)	1:4 pregnancies Estimated 14,000 per annum	Yes if medically indicated Many 1 st Trimester losses occur at home	Yes –HIPE – HPO report (if admitted to hospital)	Only captured if admitted for hospital care
Miscarriage – 2nd Trimester (after 12 and up to 24 weeks gestation)²	No national data collected, some local level data available	Yes 2 nd Trimester losses managed in hospital setting	Yes – HIPE – HPO report Using ICD-AM-10 coding. ²	ICD-AM-10 coding uses ranges of gestational weeks different to the definitions used in Ireland
Multiple Pregnancy/Loss³	In 2016, there were 61,706 singleton births, 2,387 twin births, 72 triplets and 8 quadruplets reported to the NPRS	Yes –for continuing pregnancy or if medically indicated in a pregnancy loss	Yes – if later loss HIPE, NPRS,NPEC,CSO	If one of a multiple pregnancy ends in miscarriage it's not always captured ³
Fatal Fetal Anomaly/Life Limiting Condition	A diagnosis may end in a TOP, 2 nd Trimester Miscarriage SB or E/L NND	Yes for medical care	Yes –HIPE,NPEC,NPRS,CSO ⁴ (once admitted to hospital) (hospital local level registers)	Outcome of pregnancy determines where data is collected
Stillbirth	2017 – NPEC report 235 - SB Perinatal Mortality Rate 5.6 per 1,000 births.	Yes for medical care	Yes –HIPE,NPEC, NPRS,CSO ⁴ (hospital local level registers)	Data is not linked between the various organisations
Neonatal death –Early (in the 1st week of life)	2017 – NPEC report 111 - ENND	Yes for medical care	Yes – HIPE, NPEC, NPRS,CSO ⁴ (hospital local level registers)	Data is not linked between the various organisations
Neonatal death – Late (in the first month of life)	2017 –NPEC report 35 - LNND	Yes for medical care	Yes – HIPE, NPEC, NPRS,CSO (hospital local level registers)	Data is not linked between the various organisations

Data collection systems

Hospital In-Patient Enquiry (HIPE)

Hospital In-Patient Enquiry (HIPE) is a database that collects clinical and administrative information on patients each time they are discharged from a public hospital in Ireland. Using the disease classification system ICD -10-AM diagnostic and procedural codes are assigned to each inpatient hospital event. All patients who experience a pregnancy loss and are admitted to hospital are captured in this data set



Irish Maternity Indicator System (IMIS)²

A standardised data-based management tool that is designed as a quality assurance assessment to capture and measure individual maternity hospital activity against 33 multidisciplinary metrics for national comparison and benchmarking. Data are collected within hospitals and reviewed monthly. Data collected includes maternal deaths, perinatal deaths, serious obstetric events i.e. Ectopic Pregnancy



Maternity Patient Safety Statement (MPSS)² (MSS)

Initiated by the Department of Health, the MPSS is published for all maternity hospitals/units on a monthly basis and is intended to provide assurance that maternity services are delivered in an environment that promotes open disclosure and safe care. Information is gathered under the broad headings of hospital activity, major obstetric events, modes of delivery, and clinical incidents reported.



National Perinatal Epidemiology Centre (NPEC)

NPEC collaborates with maternity services and publishes annual data on perinatal mortality and severe maternal morbidity using a range of research methodologies and drawing on the HIPE data submitted to the HPO1.



National Perinatal Reporting System (NPRS)

Based on data derived from the birth notification form (BNF01), the NPRS provides national statistics on perinatal events, details of every birth in Ireland are submitted to the NPRS. Information on pregnancy outcomes, perinatal mortality, and important aspects of perinatal care are also included.



Central Statistics Office (CSO)

In the context of maternity information, the CSO collects data on infant mortality, stillbirths and maternal mortality based on death certification.



International Review



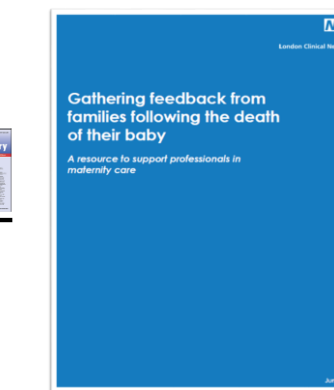
Stillbirth and perinatal care: Are professionals trained to address parents' needs?

Claudia Ravaldi, MD, MSc^{a,b}, Miriam Levi, MD, PhD^c, Elena Angeli, MSc^d, Gianpaolo Romeo, MMathStat^e, Marco Biffino, MMathStat^e, Roberto Bonati, MEng^d, Alfredo Vannacci, MD, PhD^{b,d,*}

^a Gasko Onlus, Charity for Stillbirth and Perinatal Grief Support, Prato, Italy
^b International Stillbirth Alliance, Bristol, UK
^c GORMP Regional Centre for Occupational Disease and Injury, Tuscany Region, Florence, Italy
^d Department of Neuroscience, Psychology, Drug Research and Child Health (NeuroFARMA), University of Florence, Viale Pisaneschi 6, 50139 Firenze, Italy



Listening to Parents
after stillbirth or the death of their baby after birth



Gathering feedback from families following the death of their baby
A resource to support professionals in maternity care

Aust NZ J Obstet Gynaecol 2018; 58: 185-191
DOI: 10.1111/ajog.12684

ORIGINAL ARTICLE

Bereaved parents' experience of care and follow-up after stillbirth in Sydney hospitals

Diana Bond^{1,2}, Camille Raynes-Greenow³ and Adrienne Gordon^{1,4}

¹RPA Newborn Care, Royal Prince Alfred Hospital, Camperdown, New South Wales, Australia
²Alenczky Centre for Health Policy, Kolling Institute of Medical Research, University of Sydney, Sydney, New South Wales, Australia
³Sydney School of Public Health, University of Sydney, Sydney, New South Wales, Australia

Background: Despite stillbirth being identified as one of the most traumatic events a woman can experience, there is a lack of evidence on which to inform best practice in hospital and follow-up care.
Aims: The aim of this study was to identify which strategies are most valued by parents regarding care following stillbirth in order to improve the support and management of grieving families.



Casidy BMC Pregnancy and Childbirth (2018) 18:22
DOI: 10.1186/s12884-017-1630-2

RESEARCH ARTICLE

Care quality following intrauterine death in Spanish hospitals: results from an online survey

Paul Richard Casidy^{1,2}

Abstract
Background: The objective of the study was to evaluate practices in Spanish hospitals after intrauterine death in terms of medical/technical care and bereavement support care.



Midwifery 64 (2018) 53-59

Contents lists available at ScienceDirect

Midwifery

journal homepage: www.elsevier.com/locate/mid

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Watson et al. BMC Pregnancy and Childbirth (2018) 18:22
DOI: 10.1186/s12884-017-1630-2

RESEARCH ARTICLE

Pregnancy and infant loss: a survey of families' experiences in Ontario Canada

J Watson^{1,2}, Anne Simmonds², Michelle La Fontaine¹ and Megan E. Fokier^{1,2}

Background: Pregnancy and infant loss has a pervasive impact on families, health systems, and communities. During and after loss, compassionate, individualized, and skilled support from professionals and organizations is important, but often lacking. Historically, little has been known about how families in Ontario access existing care and supports around the time of their loss and their experiences of receiving such care.
Methods: An online cross-sectional survey, including both closed-ended multiple choice questions and one open-ended question, was completed by 586 people in Ontario, Canada relating to their experience of care and support following pregnancy loss and infant death. Quantitative data were analysed descriptively using frequency distributions. Responses to the one open-ended question were thematically analysed using a qualitative inductive approach.
Results: The majority of families told us that around the time of their loss, they felt they were not adequately informed, supported and comforted by healthcare professionals, and that their healthcare provider lacked the skills needed to care for them. Almost half of respondents reported experiencing stigma from providers, supporting their experience of loss. Positive encounters with care providers were marked by timely, individualized, and compassionate care. Families indicated that improvements in care could be made by providing information and explanations, discharge and follow-up instructions, and through discussions about available supports.
Conclusions: Healthcare professionals can make a positive difference in how loss is experienced and in overall well-being by recognizing the impact of the loss, minimizing uncertainty and isolation, and by thoughtfully working within physical environments often not designed for the experience of loss. Ongoing supports are needed and should be tailored to parents' changing needs. Prioritizing access to specialized education for professionals providing services and care to this population may help to reduce the stigma experienced by bereaved families.
Keywords: Perinatal loss, Stigma, Miscarriage, Stillbirth, Infant death, Pregnancy loss, Neonatal death, Perinatal care, Ontario, Healthcare professionals

Journal of Obstetrics and Gynaecology
Volume 37, 2017, Issue 7

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Abstracts

Assessing the quality of bereavement care after perinatal death: development and piloting of a questionnaire to assess parents' experiences

Esther Aylagaagbe, Rebecca E. Scott, Victoria Holmes, Emma Lane & Alexander E. P. Heazell

Pages 931-938 | Received 21 Mar 2016, Accepted 18 Mar 2017, Published online 21 Jun 2017

Abstract
 Understanding parents' experience of care is essential to develop high-quality perinatal bereavement services. This study aimed at developing a questionnaire to identify

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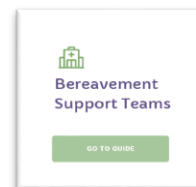
Survey Development

- Focus Groups – to include:
 - Bereaved parents
 - Healthcare professionals who engage with and provide care to bereaved parents
 - Representatives of bereavement support organisations
 - Representatives of special interest groups
 - Policy makers
- To identify and generate topics, ideas and themes for the purpose of developing the survey questionnaire

Themes

- Diagnosis – Breaking bad news
- Communication/Language/words
- Choice/Person centered care/respect parents wishes
- Continuity of care/feeling heard/feeling safe
- Relationships/consistency/trust/people
- Contact person
- Compassion/kindness /humanness
- Environment/Privacy/space
- Information –verbal/written –clear
- Prepared to meet baby –Parenting baby
- Spiritual care/Cultural inclusiveness
- Time /care quality/support from staff
- Staff knowledge /education

- Making memories
- Postnatal care –medical & emotional
- Partners/support person
- Extended family
- Investigations
- Post-mortem –consent/coronial/inquest
- Follow up appointment /waiting time
- Community supports – PHN - GP
- Hospital Bereavement Support
- Support Organisations
- Professional Counselling
- Perinatal mental health
- Weekend care can be different–be standardised
- Private V Public care & information



Gap analysis /Delphi study/ Cognitive Interview

- Gap analysis
- 2 Rounds of a Delphi Study
- The Picker Institute review
- Cognitive Interviews

Gap analysis

Themes identified were mapped against the

- Surveys we reviewed internationally
- The National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death

	Survey objective	Questions	Free text box Q's	Open ended Q's	Variable option Q's	Initial inclusion in NMBES Questionnaire
UK –NND	Improve maternity services for women /families'	171	8	22	141	}
UK –SB		138	11	12	115	
Spain	Gain insights into women's experiences, compare practices in Spain with international	107	10	5	92	32
Australia Lancet	Assess practices – stillbirth prevention, risk factors, care, investigations and audit	50	19		30	18
USA	Evaluate hospital care for their bereavement Programme	17	4		13	6
Canada – PAIL	Collect and report data on experiences of supports, strategies to expand services, staff education and training	67	1	1	65	12
NMB Standards	Enhance bereavement care services for all types of pregnancy loss					90

Delphi Study

This was followed by:

- 2 Rounds of a Delphi Study (120 participants)
- Picker Review

Final Picker Questions (123)	Round 2 Delphi Study (129 Q)	(R 1 -136 Q)
Section headings (13)	Number of questions for Picker review (124)	Free Text questions (14)
Opening Questions	4	
Breaking Bad News	18	1
Communication & Information	4	1
Admission Care	4	1
Labour & Birth	14	1
Neonatal Care	10	1
Postnatal Care	11	1
Bereavement Care	9	1
Post-mortem & Investigation	11	1
Discharge Care	10	1
Follow up Care	9	1
Overall Care	8	3
Partner	10	1

Cognitive Interview:

6 – parents who had experienced each of the different losses

- 2nd trimester miscarriage
- Stillborn infant
- Early neonatal death of a baby
- Antenatal diagnosis
- Ended pregnancy journey early
- Unexpected event in labour

Cognitive Interview testing		
Section headings (12)	Number of questions for Cognitive testing (112)	Free Text questions (8)
Opening Questions	7	
Communication & Information at the time of diagnosis *	17	1
Admission Care	3	
Labour & Birth	12	
Neonatal Care	6	
Postnatal Care	13	
Bereavement Care	8	1
Post-mortem & Investigation	9	
Discharge Care	10	1
Follow up Care	9	1
Overall Care	8	3
Partner	10	1

Survey Questionnaire

- **13 sections**
 - Opening Q's (7)
 - Communication & Information- diagnosis (15)
 - Admission care (3)
 - Labour & birth (14)
 - Care after birth and meeting your baby* (4)
 - Neonatal care (6)
 - Postnatal care (14)
 - Bereavement care (8)
 - Post-mortem examination (11)
 - Discharge care (10)
 - Follow up care (9)
 - Overall care (7)
 - Partners/support person (10)
- **118 Questions**, to include 10 Free text boxes

MATERNITY BEREAVEMENT EXPERIENCE SURVEY



What is the survey about?

The National Maternity Bereavement Experience Survey is the first national survey asking women, their partners or support person with them during their care about their experience of bereavement care in Ireland's maternity units or hospitals. Please use this survey to provide feedback about your experience of maternity bereavement care.

34 Thinking about the care you received during your labour and birth, did you feel that you were treated with respect and dignity?

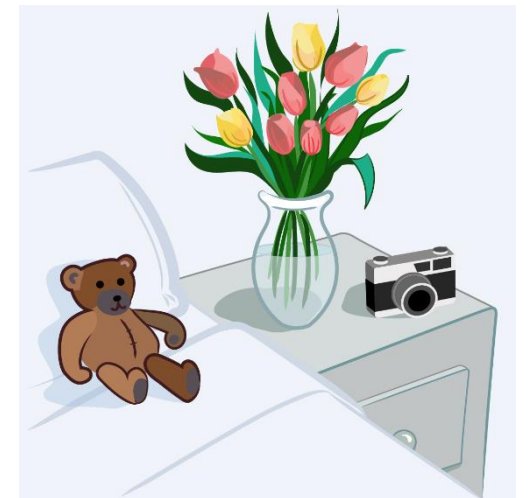
- Yes, always
- Yes, sometimes
- No
- Don't know or can't remember

75 Were your cultural, spiritual and religious needs respected and facilitated by healthcare professionals?

- Yes, always
- Yes, sometimes
- No

Hope, Aim, Focus

- That this survey will give parents who experience late pregnancy loss in Ireland an opportunity to voice their opinions and to tell their story
- Their experiences will provide a rich source of information that will acknowledge what is good and highlight areas for improvement in maternity bereavement healthcare services



Currently

- Finalising the survey implementation plan
- Survey roll out later in 2022

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THANK YOU

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Department of Health