



**National Care
Experience
Programme**

**International
Review of
Maternity
Bereavement
Experience Surveys**

About the National Care Experience Programme

The National Care Experience Programme (NCEP) 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. The National Care Experience Programme is a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.

The National Care Experience Programme has a suite of surveys that capture the experiences of people using our services. The NCEP has successfully implemented the National Inpatient Experience Survey for three years, the National Maternity Experience Survey in 2020, and is currently developing three further surveys covering end of life care, older persons' care and maternity bereavement. These surveys will be ready for implementation by the end of 2021.

The National Inpatient Experience Survey is an annual survey providing patients with the opportunity to describe their experiences of public acute hospital care in Ireland. The purpose of this survey is to learn from patients' feedback to find out what is working well in our hospitals, and what needs improvement. "The HSE responds to the results of the National Inpatient Experience Programme by developing quality improvement plans at the national, hospital and hospital group levels. In addition, the results of the inpatient survey inform national policy and HIQA's healthcare monitoring programme.

The National Maternity Experience Survey offers women the opportunity to share their experiences of Ireland's maternity services. The aim of the survey is to learn from the experiences of women to improve the safety and quality of the care that they and their baby receive. The first National Maternity Experience Survey was completed in 2020, with over 3,200 women who gave birth on October and November 2019 sharing their maternity care experiences.

A National Care Experience Programme Survey Hub has been developed in order to provide support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.

Contents

1. Introduction	7
1.1 Aims and Objectives	9
1.2 Methodology	9
1.3 Structure	10
2. Summary of Findings	11
2.1 Objective	11
2.2 Governance arrangements	11
2.3 Resources	12
2.4 Legislative requirements for data protection	12
2.5 Ethical approval requirements	13
2.6 Communication	13
2.7 The Survey	13
2.8 Survey methodology	14
2.9 Outputs	16
2.10 Impact	16
3. England	18
3.1 Background	19
3.2 Objective	20
3.3 Governance Arrangements	20
3.4 Commitment	21
3.5 Data Protection	21
3.6 Ethical Approval	22
3.7 The Survey	22
3.7.1 The Sample	22
3.7.2 Distribution and Collection	22
3.7.3 Communication and Publicity	23
3.7.4 Response Rate	24
3.7.5 Analytical Methodologies	24
3.7.6 Outputs	25
3.7.7 Impact	25

3.8 Key Recommendations and Lessons Learned from the English survey.....	26
4. United States of America – Minnesota	28
4.1 Background	28
4.2 Objective	29
4.3 Governance Arrangements.....	30
4.4 Commitment	30
4.5 Data protection	30
4.6 Ethical Approval	30
4.7 The Survey	30
4.7.1 The Sample.....	31
4.7.2 Distribution and Collection	31
4.7.3 Communication and Publicity.....	31
4.7.4 Response Rate	31
4.7.5 Analytical Methodologies.....	31
4.7.6 Output.....	31
4.7.7 Impact.....	32
4.8 Key Recommendations and Lessons Learnt from the Evaluation of Care document.....	32
5. Australia.....	33
5.1 Background	33
5.2 Objective	35
5.3 Governance Arrangements.....	35
5.4 Commitment	35
5.5 Data Protection	35
5.6 Ethical Approval	35
5.7 The Survey	36
5.7.1. The Sample.....	37
5.7.2 Distribution and Collection	38
5.7.3 Communication and Publicity.....	38
5.7.4 Response Rate	38
5.7.5 Analytical Methodologies	39
5.7.6 Outputs	40

5.7.7 Impact.....	40
5.8 Key Recommendations and Lessons Learned from the ISA Lancet stillbirth survey.....	41
6. Canada	42
6.1 Background	43
6.2 Objective	43
6.3 Governance Arrangements.....	44
6.4 Commitment	44
6.5 Data Protection	44
6.6 Ethical Approval	44
6.7 The Survey	44
6.7.1. The Sample.....	45
6.7.2 Distribution and Collection	45
6.7.3 Communication and Publicity.....	46
6.7.4 Response Rate	46
6.7.5 Analytical Methodologies.....	46
6.7.6 Outputs	47
6.7.7 Impact.....	47
6.8 Key Recommendations and Lessons Learned from the Pregnancy and infant loss survey.	47
7 Spain	49
7.1 Background	49
7.2 Objective	49
7.3 Governance Arrangements.....	50
7.4 Commitment	50
7.5 Data Protection	50
7.6 Ethical Approval	51
7.7 The Survey	51
7.7.1. The Sample.....	52
7.7.2 Distribution and Collection	53
7.7.3 Communication	54
7.7.4 Response Rate	54

7.7.5 Analytical Methodologies.....	55
7.7.6 Outputs	55
7.7.7 Impact.....	56
7.8 Key Recommendations and Lessons Learned from the Spanish survey.....	56
8 Italy.....	59
8.1 Background	59
8.2 Objective	60
8.3 Governance Arrangements.....	60
8.4 Commitment	60
8.5 Data Protection	60
8.6 Ethical Approval	61
8.7 The Survey	61
8.7.1 The Sample.....	62
8.7.2 Distribution and Collection	62
8.7.3 Communication	62
8.7.5 Analytical Methodologies.....	62
8.7.6 Outputs	62
8.7.7 Impact.....	62
8.8 Key Recommendations and Lessons Learned from the Italian survey.....	63
9. Conclusion.....	64
9.1 Findings	64
9.2 Next Steps	64
Appendices.....	65
Appendix: 1. Participants and Organisations that contributed to this review.....	65
References: International Review.....	71

1. Introduction

Person-centred care has been a key domain of quality in healthcare for well over a decade.⁽¹⁾ The basic premise of focusing care around the person using the health and social care service and responding to their needs and preferences is well-established as a component of high quality healthcare.⁽²⁾

Measuring person-centred care involves the collection of feedback on the experiences of people who use health and social care services. This feedback is a key indicator in identifying where expectations in health and social care are being met and where they are falling short. Patient experience, or the experience of those who use health and social care services, is now recognised as one of the three pillars of quality in healthcare, alongside clinical effectiveness, and patient safety.⁽³⁾ Evidence has shown that the three pillars of quality should be looked at as a group and not in isolation.⁽⁴⁾

In recent years, health and social care experience surveys, which capture the experiences of those who use these services, have been implemented at a national level in several countries. Significant benefits have been gained for all stakeholders from capturing this experience, including service providers, people who use the services, the public and national policy developers and regulators. Care experience surveys or other methodologies can lead to informed choice for people who use services, enhanced recovery for patients, improved productivity and efficiency for healthcare providers, and lower staff turnover and absenteeism.^(5, 6) They provide a means by which patients and people who use services can be engaged, active and informed in their own care.

For healthcare providers, the data collected by care experience surveys helps to identify areas for improvement, provide assurance in the care being provided, and benchmark care experience both nationally and internationally. As care experience surveys are tools which inform healthcare management of the quality and safety of care provided, they drive accountability across the healthcare system.

Furthermore, they provide policy developers with definitive data to inform policy development and implementation. They also inform the development of national care standards in addition to monitoring and regulation programmes for care services.

In Ireland, national health policy highlights the importance of engaging with people who use health and social care services and capturing their care experiences to inform quality improvements in healthcare. The Department of Health's Statement of Strategy 2016-2019 commits to the creation of a more responsive, integrated and

people-centred health and social care service.⁽⁷⁾ It plans for the implementation of national strategies, which are underpinned by the engagement of people that use health and social care services, for example the *National Maternity Strategy 2016-2026*⁽⁸⁾ and the *National Cancer Strategy 2016-2026*.⁽⁹⁾ Similarly, Sláintecare, the ten-year, cross-political party strategy for healthcare and health policy in Ireland, advocates that “the voices of current service users and citizens must therefore be at the heart of healthcare reform, and success will be judged in terms of patient experience and outcomes and the overall health of our population.” Sláintecare explicitly sets out the development and expansion of systems to capture patient experience.⁽¹⁰⁾

In Ireland, the inaugural National Inpatient Experience Survey¹ was successfully conducted in May 2017, when over 13,000 patients, representing a 51% response rate, chose to share their experiences of care in Ireland’s public acute hospitals.⁽¹¹⁾ The findings helped to inform national and hospital-level quality improvements across the acute inpatient hospital sector.

At national level, the Health Service Executive (HSE) established an Oversight Group to review the findings of the National Inpatient Experience Survey and to develop a systematic plan for improving patient experience across acute hospitals. This led to the establishment of the National Healthcare Communication Programme. At local level, every hospital designed a quality improvement plan to address the findings.⁽¹²⁾

A commitment was subsequently made by HIQA, the HSE and the Department of Health to establish the National Care Experience Programme (NCEP), tasked with running the National Inpatient Experience Survey and expanding the Programme to cover other areas of health and social care. This expansion led to requests for care experience surveys across a range of other areas. In 2020, the first National Maternity Experience Survey (NMES) was successfully conducted throughout the 19 maternity hospital/units in Ireland, with over 3,200 women sharing their care experiences. During the development of the NMES, focus group participants identified that a dedicated survey was required to explore the experiences of bereaved parents, to capture meaningful information on their experiences of care in a sensitive and appropriate manner.

¹ The National Inpatient Experience Survey was previously known as the National Patient Experience Survey.

In recent years, several reports and reviews have highlighted service deficits and failings in Irish maternity services. The *National Maternity Strategy 2016-2026* was developed as a consequence, with the aim of providing a framework for a new and better maternity service in Ireland. Simultaneously, the *National Standards for Safer Better Maternity Services*⁽¹³⁾ were developed to support the implementation of this strategy. Following this the *National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death* were launched and implemented in 2019.⁽¹⁴⁾

1.1 Aims and Objectives

There is currently no nationally-standardised, comparable data on maternity bereavement care experiences being collected within Ireland.

This report identifies how international organisations and agencies collect and use maternity bereavement care experience data. Through identifying international best practice, this review is a step towards informing the National Care Experience Programme on the most advantageous approach to implement a national maternity bereavement experience survey in Ireland.

1.2 Methodology

The first step in determining the practicality of developing and designing a survey to capture bereaved parents' experience of care involved reviewing the provision of bereavement care services in maternity settings throughout the Republic of Ireland. This included identifying and reviewing national reports, investigations, policies, pathways, guidelines, strategies, and standards related to bereavement and perinatal loss.

Subsequently, a desktop review of international maternity bereavement care surveys was undertaken followed by interviews with the survey/research teams. It was considered likely that cultural variations in grief and bereavement, as well as hospital structures and healthcare provided would be evident, and would influence approaches to maternity bereavement surveys. As the focus was on parents' experiences, the inclusion criteria for selecting these surveys, and the affiliated national agencies/support organisations responsible for them was their expertise/experience in the area, access to key personnel and availability of technical documentation.

1.3 Structure

This document sets out a summary of the findings of the international reviews undertaken to inform the development of a national maternity bereavement experience survey for Ireland. Six international maternity bereavement experience surveys were selected from the scoping review for the current report.

The six international jurisdictions reviewed in this report are:

- England
- USA (Minnesota)
- Australia
- Canada (Ontario)
- Spain
- Italy.

Findings for this review were compiled from national documentation from each country and detailed discussions with key relevant personnel with responsibility for management of national/organisational maternity bereavement experience surveys within each country. Appendix 1 outlines the participants and organisations that contributed to this review.

Findings in relation to each jurisdiction are presented in this report under the following headings:

- objectives
- governance arrangements
- commitment
- data protection
- ethical approval
- the survey
- output
- impact
- key recommendations.

The review focuses on the methodology used in each jurisdiction, specifically:

- requirements from an operational perspective, specifically the model, methodology, resources, governance structures, information governance, administration, and development of survey model
- administrative requirements, that is communications and distribution
- outputs, that is what is reported, what happens with the results and how they are followed up by the service provider, policymaker, and regulator.

The survey questions are not considered in the current document, as these have been addressed in a separate development process.

2. Summary of Findings

A summary of the findings for the National Maternity Bereavement Experience Surveys is set out below. The main themes are:

2.1 Objective

The overall objective of conducting a maternity bereavement care experience survey within each of the countries reviewed was to listen to the voices of women as a recognised, essential tool to inform and improve the quality of maternity bereavement care provided.

2.2 Governance arrangements

Governance arrangements vary between countries, three of the surveys reviewed are carried out through formal academic research programs/units, involving national policy makers in their governance. One of the surveys reviewed is carried out at local service provider level and as such is governed within the service provider's structures.

Several of the surveys have adopted a partnership approach to governance, which included variations between the:

- survey team/research unit
- the bereaved parents support agencies/charities
- the policy maker.

Many of the surveys sought the support of a formal advisory group made up of parent representatives from support organisations in their survey design and development.

All surveys had an advisory group/team in place to agree on the design, development and delivery of the survey.

2.3 Resources

Of the surveys reviewed, the Italian survey was conducted as a component of a bereavement support agency and as part of their wider engagement with bereaved parents. The Australian survey was a global collaboration and was carried out by an academic research institute. The Canadian survey was undertaken through an amalgamation of a bereaved parents support charity, care provider and research team, while the UK survey was carried out by a national epidemiology unit. The Australian, UK and Canadian surveys had a team of staff assigned to the projects.

The Spanish survey was carried out by a PhD student in conjunction with a bereaved parent support organisation and university. The American survey was a local-level hospital survey. The US, Italian and Spanish surveys required a team of two to four often part-time volunteers/staff members to manage and support the maternity bereavement care survey.

Much of the knowledge, systems and tools used in maternity care surveys have benefited from the expertise gained and the resources developed from previous surveys of other healthcare sectors/support agencies.

Subcontractors are employed in only one of the six surveys to administer the survey in terms of collating the contact list, posting the survey and coordinating responses and reminder letters. Four of the six surveys are web based and administration is carried out by the surveying organisation.

2.4 Legislative requirements for data protection

The legislative requirements around data protection are a significant consideration for care experience surveys in light of the large amount of personal data required to conduct these surveys.

As the majority of the surveys reviewed were web-based, anonymity was protected but the option to leave personal details was offered in three of these surveys. In completing the survey consent was implied. In the case of the UK postal survey, participants are assigned a unique identification number to maintain anonymity. The

Minnesota hospital-level survey has an option to leave personal details but otherwise the replies are anonymised.

2.5 Ethical approval requirements

Four of the surveys received ethical approval from an ethics review board. The remaining surveys did not require ethical approval. The Spanish and Italian surveys were driven by bereaved parents support agencies and the USA survey was carried out by the service provider so ethical approval was not considered necessary.

2.6 Communication

The importance of promoting the survey to bereaved parents in order to increase response rates was noted. Due to the sensitive nature of the survey topic and acknowledging the vulnerability of bereaved parents, such surveys do not lend themselves to public promotion as would be the case with other surveys.

In the one global survey reviewed, the team used international support organisations and international contacts to promote participation through social media accounts.

In the case of the self-selecting web-based surveys, these were promoted by support agencies through their websites and various types of social media accounts.

The postal survey reviewed included an initial introductory letter to eligible participants in advance of the survey pack.

2.7 The Survey

Eligibility criteria

The eligibility criteria vary across the reviewed maternity bereavement experience surveys, with gestational age of the pregnancy, type of loss or time since loss being an exclusion criteria in some surveys.

Where participants had experienced more than one loss, they were asked to only answer with regard to the criteria set and or their most recent experience of loss.

The UK postal survey used the Office for National Statistics to identify the eligible prospective participants. Women who had registered a stillbirth or neonatal death during a specified time period were invited to take part. The American survey was

carried out at secondary/hospital level health care provision and so identified service users' details from inpatient activity.

Sampling

Selection of the survey sample varies amongst the surveys reviewed, with most utilising self-selecting web-based surveys, one using the country's available birth registers, either at national level or the level of the healthcare region and the other using details from the service provider/hospital.

Question pool

An international library of validated questions is not available for maternity bereavement experience surveys, as is the case for surveys of acute inpatient care. Most maternity bereavement surveys have developed, tested, and piloted their own questions or adopted some of those used in other maternity bereavement surveys.

The inclusion of questions requiring written, free-text comments is regarded as highly beneficial as these provide a rich source of data for quality improvement and for research purposes.

Translation

The global web-based survey reviewed in this document was translated into multiple languages, but the other surveys were generally not translated. The UK survey had a multi-language sheet leaflet in eighteen languages other than English, giving details on how to get help with the questionnaire in different languages in order to ensure that members of ethnic minority groups responded to the survey. A telephone translational service was offered in this survey and completion of the survey by telephone was made available. It was noted by the contact for this survey that uptake of this service was low.

2.8 Survey methodology

Mode of contact

Only two of the reviewed surveys used the postal system to contact survey participants. Women were contacted between one- and nine-months post-partum,

most commonly between 6 and 9 months. The web-based surveys recruited participants through social media and bereavement support agencies.

Being mindful of the time period of participants' loss and grief process when completing the survey questionnaire, contact details for support services were included in the postal pack and on the survey website.

Mode of response

All but two of the reviewed surveys utilised an online mode of surveying/ response, the two remaining used postal survey questionnaires which included completion of the anonymised survey via paper and return of responses by post in the prepaid envelope supplied.

Amongst care experience programmes the maternity cohort is predominantly young and familiar with online tools, of consideration for future surveys, participants may find it more convenient to complete the survey online rather than by paper.

The online mode of response has the advantage of being the most cost-efficient and time-efficient method.

While in the case of postal surveys reminder letters and packs sent out to non-responders can significantly increase the response rate. The national postal survey used approved survey contractors to distribute the survey packs to participants.

Response rate

The web-based surveys had responses varying from 600 to 4,200 women/partners as these were self-selecting surveys, with varying eligibility criteria and restrictions rates of response are not applicable. Many are created to review care experience without having national impact.

While the UK and USA postal surveys had response rates of 30% and 14% respectively.

Frequency

In contrast to surveys of acute inpatient care, or maternity care, maternity bereavement care surveys are not conducted routinely or on an annual basis or often not repeated at all after the initial survey.

2.9 Outputs

The UK survey results were published as a national report and were also available to download from the surveying organisation's website. Secondary analysis of the data led to other research papers and publications in international journals. The Australian global survey findings were published in a medical journal and were made available online through the researching organisation, findings were also presented at international conferences. The Spanish survey findings have been published in both an article and full report format. The survey teams in Canada, America and Italy have all published research papers on their findings.

No individual hospital-level results were reported or published for service providers for these surveys.

Research teams share their findings through local, national and international structures and work collaboratively with other research units/organisations nationally and internationally.

Bereaved parent advocacy support organisations use the findings to campaign on behalf of bereaved parents to emphasise the need for guidelines, policies, education and training for service provider in bereavement care.

2.10 Impact

The requirement to act on specific findings of maternity bereavement experience surveys varies amongst countries, with some focusing on creating national awareness of the incidence and impact of pregnancy loss on society and families. Others incorporate findings of care experience feedback into local and national quality improvement plans. In some cases, findings are used for education and training of healthcare providers. In general, the impact of maternity bereavement care experience surveys is not readily reported internationally.

Nevertheless, the benefits of maternity bereavement care surveys are regarded as significant for all those involved, this includes parents, families, service providers, regulators and policy developers.

Methodologies For International Maternity Bereavement Experience Surveys

3. England

The following is a review of the 2013 UK survey "*Listening to Parents after stillbirth or the death of their baby after birth*". This survey was carried out by **Dr Maggie Redshaw** and her team at the National Perinatal Epidemiology Unit (NPEU), University of Oxford. The report "*Listening to Parents after stillbirth or the death of their baby after birth*" was first published in 2014 by the Policy Research Unit in Maternal Health and Care, NPEU, Oxford. The National Surveys of Women's Experience of Maternity Care ⁽¹⁵⁾ which have previously been carried out by both the Care Quality Commission (CQC) and the NPEU, have excluded women whose babies have died. ⁽¹⁶⁾ While national maternity surveys have continued to be carried out by the Care Quality Commission along with NPEU in 2013, 2014, 2015, 2017, 2018 and 2019 bereaved parents have not been surveyed nationally since 2013.

The "Listening to Parents" survey ⁽¹⁷⁾ design followed the structure of the previous NPEU maternity care surveys of 2006 and 2010. However, some sections were removed and others added following discussion with representatives from Sands and Bliss support organisations to reflect the particular needs of the parents taking part in the survey. Two separate questionnaires were used, one for women who had a stillborn baby and another for women whose baby had died as a newborn, so that the questionnaires addressed appropriate issues for each group.

Support organisations such as Sands ⁽¹⁸⁻²³⁾ and Bliss ^(24, 25) have over the years developed best care standards and guidelines for professionals following feedback from bereaved parents. Sands also sought feedback from hospitals and as a result they developed an audit tool for maternity services to review the care they provide as well as evaluating staff training and educational needs.

While many specific areas of bereavement care had been evaluated in the UK, there was no national evidence of women and their partner's experience of their care. Surveying bereaved parents' experience of care and service provision forms a baseline for current practice and acts as a benchmark to determine the adherence of care providers to the bereavement care pathways on stillbirth and neonatal death which were designed to ensure consistent, compassionate provision of care ^(26, 27).

A survey in 2016 by Sands ⁽²⁸⁾ to identify if and how bereaved parents would like to feedback into maternity services led to a collaboration between the NHS England,

Sands and the London Maternity Clinical Network to develop the Maternity Bereavement Experience Measure (MBEM) questionnaire. The MBEM questionnaire is intended for use at Local Maternity Systems (LMS) level to support professionals in the collecting of information from bereaved parents about their experience of care and to make improvements where needed.

3.1 Background

The World Health Organization (WHO) recommends a definition of stillbirth as a loss after 28 weeks' gestation, whereas in the United Kingdom (UK) a stillbirth is classified as a baby born after 24 weeks or more, which did not at any time breathe or show sign of life. Losses prior to these gestations are considered a miscarriage. Neonatal death is defined in the UK as a death that occurs within the first 28 days after birth.

The statistics available from the MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK) – Perinatal Mortality Surveillance Report published in 2020 on UK Perinatal Deaths for Births from January to December 2018 reported 2,579 babies were stillborn and a further 1,199 babies died in the neonatal period (deaths under 28 days).⁽²⁹⁾ The death of a baby around the time of birth is the most common form of mortality in early life.

In England, as is the case in other countries, deaths under one year are a key indicator of a country's population health and quality of care services. Deaths occurring during the first 28 days of life in particular are considered to reflect the health and care of both mother and newborn.

As key care providers, the NHS accountability, transparency, performance, quality improvements and outcomes are monitored by the Department of Health and Social Care through a set of key indicators, the findings are reported in the NHS Outcome Framework document.^(30, 31)

3.2 Objective

The “Listening to Parents” survey/report was the first national survey to capture the care experiences of parents whose babies died before birth or in the neonatal period. The survey provided the NPEU with information on all aspects of parents’ experience of care during the antenatal period, diagnosis, admission to hospital, labour and birth, postnatal care, time spent with baby, making memories as well as support and follow up. The objective of this survey was to facilitate improvements in maternity services for women and families who experience such a loss.

3.3 Governance Arrangements

The study was funded by the Department of Health as part of the Policy Research Unit in Maternal Health and Care and was carried out by the National Perinatal Epidemiology Unit (NPEU) based in the University of Oxford.

The National Perinatal Epidemiology Unit (NPEU) is a multi-disciplinary research unit, which was established at the University of Oxford in 1978. Their work involves running randomised controlled trials, national surveillance programmes and surveys, confidential enquiries, aetiological studies and a disease register. The results of their research is connected to public and population health sciences, clinical care and health policy development.

“The NPEU’s mission is to conduct methodologically rigorous research to provide evidence to improve the care provided to women, babies and families during pregnancy, childbirth, the newborn period and early childhood as well as promoting the effective use of resources by perinatal health services”

The NPEU established the Listening to Parents survey programme in line with previous NPEU National Maternity Surveys in 2006 and 2010 and Care Quality Commission maternity surveys (CQC). Some sections were removed and other areas added so that appropriate experiences and issues for each group were surveyed. Questions from the wider maternity survey were deliberately included to allow for comparisons, bearing in mind bereavement care is carried out in conjunction with the broader maternity service care provided for all women.

In the design and development of this survey NPEU sought the support of a formal advisory group made up of parent representatives from the Sands, Bliss and National Bereavement Trust support organisations.

The Office for National Statistics (ONS) identified a nationally representative sample of women who had experienced a stillbirth or a neonatal death over two three-month periods in 2012 and 2013. ⁽³²⁾ There were two survey questionnaires; one for women who experienced a stillborn baby and the other for women whose baby died as a newborn.

3.4 Commitment

The survey was developed in association with the stillbirth and neonatal death charities Sands and Bliss in a supportive project advisory group. The ONS identified participants from birth and death registrations, all women over 16 years of age who registered a stillbirth or neonatal death between Jan – March 2012 and June – August 2012 in England.

The anonymised survey questionnaire feedback was returned to the research team at the NPEU where it was analysed and interpreted.

3.5 Data Protection

The Office of National Statistics (ONS) is a statutory body, created by the Statistics and Registration Service Act 2007⁽³³⁾, with the objective of promoting and safeguarding the production and publication of official statistics that serve the public good. The collection and use of data comes from powers found in this Act. The ONS complies with legislation governing how data is used

The Statistics and Registration Service Act (SRSA) 2007 allows the ONS to obtain information relating to births and deaths as well as NHS registration information.

This was a postal survey design with participant access to the survey website for information and FAQs. For this study, the ONS acted as the data controller and was responsible for identifying the sample group on behalf of the NPEU. The ONS coordinated sending out the initial letter of introduction followed by the survey questionnaire options, and data entry was carried out by an independent contractor and returned to NPEU. Anonymised information arising from birth and death registration was returned to the NPEU research team by ONS to be added to the dataset and used for analysis and interpretation. The NPEU research team were not aware of any personal details or identifying information of the invited participants.

The ONS has measures in place to protect the security and confidentiality of data during all stages of the survey. No personal identifying information was provided to

the study staff at the NPEU by the ONS. Any personal data collected by the ONS is not kept for a period longer than 12 months.

Data protection legislation requires that all processing of personal data by the ONS is undertaken under the following condition: "Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller."

3.6 Ethical Approval

National Health Service (NHS) Research Ethical approval for the study was obtained from the National Research Ethics Service Committee South Central – Oxford A on the 10th July 2012 (REC Ref.12/SC/0322). Completion and return of the questionnaire was taken as implicit consent to participate.

3.7 The Survey

3.7.1 The Sample

The Office for National Statistics (ONS) identified all women (excluding those aged under 16 years) who registered a stillbirth or neonatal death between 1st January and 31st March 2012 or between 1st June and 31st August 2012 in England.

3.7.2 Distribution and Collection

The "Listening to Parents" survey used a postal methodology. The main option for completion of the survey by respondents was via paper and return by post. Completion by phone and using Language Line with an interpreter was made available to all participants, and a multi-language leaflet was included with all questionnaires.

All identified women were sent an introductory letter and study information between six and nine months after the death of their baby, avoiding significant dates such as Christmas and birthdays/anniversaries.

Three weeks later women received a further letter consisting of:

- a covering letter
- an information leaflet about the study
- a questionnaire
- a multi-language sheet/ a leaflet in eighteen languages other than English, giving details on how to get help with the questionnaire in different

languages, in order to ensure that members of ethnic minority groups responded to the survey

- a freepost return envelope.

Women had the option to complete and return the questionnaire or to return it uncompleted if they did not wish to take part. An information leaflet was included in the pack to allow women to make an informed decision to opt out of participating in the national survey at any stage.

A reminder letter and a further copy of the questionnaire were sent to women who had not responded after a further four weeks to increase response rates.

Following advice from women who took part in cognitive interviews, mothers who had more than one baby who died were sent tailored information and sufficient questionnaires so that, if they wished, they were able to complete one questionnaire for each baby.

All letters and questionnaires were sent by the ONS so that the research team did not have the names and contact details of women invited to take part in the survey. Questionnaires were returned to the NPEU directly.

3.7.3 Communication and Publicity

A cover letter is included in the survey pack with information on why the survey is being conducted and the importance of patient feedback. A survey website was available for survey information details and FAQs.

Contact details of the research team at NPEU were provided with the mailed questionnaires and a dedicated study Freephone number enabled direct contact by participants if they chose for the duration of the study.

Information about the survey was posted on the websites of Sands and Bliss and on the Sands Facebook page. Sands representatives responded directly to women's concerns raised on their Facebook page.

In recognition of the potential for distress and concern caused by the survey women were also given information about support services offered by Sands, Bliss and other organisations. Sands and Bliss helpline staff were briefed about the survey and responded to calls accordingly.

3.7.4 Response Rate

In total 2,561 women were invited to take part in the survey, 1,668 who had a stillborn baby and 893 whose baby died as a newborn. Questionnaires for 154 women were returned by the Royal Mail as undelivered and 132 women returned blank questionnaires or contacted the research office to say that they did not want to take part in the survey. Overall 720 women completed the questionnaires, resulting in a 30% useable response rate. On average, women completed the survey questionnaire 9 months after their baby had died.

63 women invited to take part in the survey or others calling on their behalf contacted the research office directly by phone or email. Of these contacts 39 were from women not wanting to take part in the survey. Others were from women who wanted to talk or ask questions about the survey, or to give information of a change of address. Two women called to request help with the questionnaire in their own language and subsequently completed the questionnaire over the phone with the help of an interpreter.

3.7.5 Analytical Methodologies

The questions were mainly structured closed-ended questions but some questions allowed for open text responses where appropriate to capture qualitative and quantitative data. The open text responses were checked for over-arching themes and sub themes using a thematic content analytic approach. Extracts from women's responses to the open questions were included in the published report to highlight and illustrate findings.

The survey was designed in 12 sections, these included pregnancy, labour, birth, postnatal period, care at the time of baby's death and parental health and wellbeing. The questions on pregnancy/antenatal care were general and open ended, the answers were compared to questions asked in the National Maternity Survey in 2010 with similar satisfaction/response findings in both in this area.

Data were analysed descriptively using proportions and means or medians as appropriate. Raw percentages, cross tabulation and chi square statistics were used to test for associations between descriptors of the population and care, and gestational age at birth under the following groupings less than 28 weeks, 28 to 36 weeks, and 37 or more weeks.

Demographic data were provided by the ONS for the 1,687 non-responders to the survey. Compared to those who responded to the survey women who choose not to take part were statistically more likely to

- be born outside the UK
- to be aged less than 30 years old
- to live in more deprived areas.

All survey responses were analysed by the NPEU research team using STATA 13 SE.

3.7.6 Outputs

National Report: *Listening to Parents after stillbirth or the death of their baby after birth* was the first independent report to represent a national picture of the care experienced by parents of babies who died before birth or as a newborn in the UK.

The 57-page report was launched in 2014 by the NPEU and is available to download from the NPEU website or on request in hard copy format. The report presents the findings from the detailed questionnaires (107 questions per survey) in text layout as well as illustrating data comparisons using pie and bar charts. Quotations from women's responses to open questions in the survey are included in the report to reinforce and illustrate the results.

Throughout the report extracts from guidelines and standards are documented to identify best practice and to highlight evident gaps in care and services.

Responses were gathered in all from 720 women across England. Two questionnaires (stillbirth and neonatal death) were designed to capture and analyse separately the relevant data from each group's experience of care.

3.7.7 Impact

The results were used to identify and make necessary changes to improve the experiences of bereaved women who use maternity services. Bearing in mind bereavement care is carried out in conjunction with the broader maternity service care provided for all women.

Suggested improvements in care practices from the study included the adoption of policies, procedures and practices to address the psychosocial and practical needs of both women and their partners at the time of their baby's death and afterwards.

Following the survey, secondary analysis of the data led to other research papers being conducted by the NPEU research team:

- Parents Experience of post-mortem after stillbirth
- Impact of holding the baby after stillbirth on maternal mental health
- Care associated with stillbirth for the most disadvantaged women
- Impact of holding the baby after stillbirth on partner mental health
- Mothers' experience of maternity and neonatal care when babies die. (34-38)

3.8 Key Recommendations and Lessons Learned from the English survey

- Two separate questionnaires were used, one for women who had a stillborn baby and another for women whose baby had died as a newborn, so that the questionnaires addressed appropriate issues specific to each group.
- The researcher recommended that all identified women be sent an introductory letter and study information three weeks prior to receiving the survey material pack.
- The survey was carried out 6-9 months after their baby's death, a concern was the risk of recall bias. However, other research on childbirth confirms that the significant events of this time are generally well remembered by parents. (39, 40)
- The response rate of 30% (720 responses out of 2,561) is limited yet it is one of the largest surveys in this area. This study demonstrated that even in the most tragic of circumstances where their baby died through stillbirth or in the neonatal period, mothers were willing to take part in the survey and provide feedback.
- Qualitative interview data could have provided a fuller more in depth picture of the mothers' experience of care. However, by its nature this would have involved a smaller number of women.
- A strength of this study is the use of a national sampling frame identified by the Office for National Statistics (ONS) which sought to be representative of all women aged 16 years or more over the sampling period who had experienced a stillborn infant or newborn death. Using national sampling to

recruit participants in the survey avoided the bias of individual site or self-selection online-based responses.

- The pack sent to participants included a multi-language sheet/leaflet in eighteen languages other than English, giving details on how to get help with the questionnaire in different languages, in order to ensure that members of ethnic minority groups responded to the survey.
- The study also benefited from the involvement of bereaved parents and support groups working with parents at all stages of the design and development of the survey questionnaire.
- The sole option for completion of this survey by respondents was via paper and return by post. Of consideration for future surveys is that the maternity cohort is predominantly young and familiar with online tools, participants may find it more convenient to complete the survey online rather than by paper.
- The emphasis in this study was on the mothers' experience of care as the key respondent in the survey questionnaire. Fathers and partners grieve too and play a key support role in the case of stillbirth and neonatal death yet traditionally their care experience is less commonly the focus of research this is a key area that needs further investigation.⁽⁴¹⁾

4. United States of America – Minnesota

The information outlined in this review was obtained from **Susannah Hopkins Leisher**, Chair, International Stillbirth Alliance, Stillbirth Centre of Research Excellence, Mater Research Institute, University of Queensland. Co-chair, Stillbirth Advocacy Working Group, Columbia University, Dept. of Epidemiology and from **Sue Steen**, RN MS Perinatal Nurse Navigator, Maple Grove Hospital Maple Grove, MN, USA; Sue is also Assistant Professor of Nursing Adjunct, Bethel University, St Paul, MN, USA

4.1 Background

Traditionally in the US the focus on pregnancy loss has concentrated on infant mortality, with less focus on the incidence, aetiology, risk factors and prevention regarding fetal mortality.⁽⁴²⁾ As with many countries there have been longstanding concerns about data quality and completeness.⁽⁴³⁾ Often the lack of priority along with a lack of resources and commitment provided to collecting data or research on fetal deaths limits the quality of data collected.⁽⁴²⁾

In the United States 'fetal death' is an inclusive term encompassing stillbirths, spontaneous abortions, and miscarriages but excludes induced termination of pregnancy. It is estimated that in excess of 26,000 fetal deaths of more than 20 weeks gestation occur each year.⁽⁴⁴⁾

Infant deaths refers to all infants born alive who die in the 1 year of life, it is often divided into neonatal death (under 28 days of age) and post-neonatal death (28 days to under 1 year of life) this was reported in 2018 as 14,329 neonatal deaths and 7,169 post-neonatal deaths respectively giving a total of 21,498 infant deaths.

The registration of births, deaths and fetal deaths is solely a state responsibility. Each of the 50 states have their own mechanisms for data documentation, reporting and registration as well as their own classification of miscarriage and stillbirths. There is no national repository for detailed stillbirth data. In some states, reporting of fetal deaths occurs at all gestations and in other areas fetal deaths are only reported from 16 weeks gestation to the more commonly used 20 weeks gestation. When applying birth weight to the criteria for registration purposes a minimum birth weight of 350 grams is applied in the majority of areas, although other areas require a birth weight of at least 500 grams. Generally a combination of gestation and

weight is applied for registration purposes. ^(45, 46) These variations and inconsistencies can lead to underestimation of data figures.

For example in New York City both stillbirth and miscarriages are captured as 'spontaneous terminations of pregnancy' for data purposes.⁽⁴⁸⁾ Of note there are also differences among states in the reporting of fetal deaths between 20–27 weeks gestation.

According to the Centre for Disease Control (CDC) 2017, a miscarriage is defined as loss of a fetus/baby before the 20th week of pregnancy, and a stillbirth is the loss of a fetus/baby after 20 weeks of pregnancy. Stillbirth is further classified into early stillbirth 20-27 weeks of pregnancy, late stillbirth 28-36 weeks of pregnancy and term stillbirth from 37 weeks of pregnancy onward. Perinatal death and perinatal loss refer to the loss of a fetus/baby at any gestational age or the loss of a newborn before the age of 7 days.

Maple Grove Hospital, Family Birth Centre is the largest birth centre in Minnesota and has approximately 5,000 births per year and an average of 200 perinatal losses annually. The hospital developed a perinatal bereavement programme to provide compassionate care to all families who experienced perinatal loss at any time during their pregnancy. The perinatal bereavement programme which began in 2012 was developed based on global standards and guidelines from support organisations such as Sands.⁽⁴⁹⁾

Following on from the development of the perinatal bereavement programme an 'evaluation of care document' (survey) was designed to evaluate all parents' experience of care following a pregnancy loss in the hospital. This survey began in 2017 and is specific to Maple Grove Hospital. The document reflects the programme goals and acts as an evaluation tool for the programmes' impact and effectiveness.

4.2 Objective

The survey was designed to evaluate all parents' experience of care following a pregnancy loss in the hospital and to act as an evaluation tool for the perinatal bereavement programme in the hospital.

4.3 Governance Arrangements

There was no formal involvement of a regulator or policymaker in the project however, the survey was overseen by the director of the birth centre and the quality office, in keeping with the birth centre's agreed policies, practices and duty of care for all service users.

4.4 Commitment

The Perinatal Nurse Navigator with the support of the Director, Women and Children's Services at Maple Grove Hospital, Minnesota were responsible for developing and initiating this project.

4.5 Data protection

Completion of the survey and returning the survey implies that participants have given consent. The survey is anonymous but participants are given the option to sign their names at the end of the survey.

4.6 Ethical Approval

Ethical approval was not required, however, the survey was reviewed by the Director of the Birthing Centre and the quality department in Maple Grove Hospital.

4.7 The Survey

The survey pack is made up of an introductory letter, acknowledging the loss and goes on to explain that the hospital would like to learn from parents to provide the best care possible to others. The letter also recognises that parent input will assist the hospital in improving quality of care. A postage-paid envelope is enclosed for responses. The contact details for the perinatal nurse navigator is included if parents have any questions or require bereavement support or resources.

The survey itself is made up of 18 questions regarding care experiences in hospital and following discharge. The survey includes closed questions, and some free text boxes to elaborate on answers. Questions such as being offered choice, support in making memories, interaction with clinical staff, what was helpful and an option to document any other information.

At the end of the questionnaire parents are told that their feedback will be used to improve bereavement care and educate staff.

Parents have the option to remain anonymous or to sign their name/s at the end of the survey questionnaire.

4.7.1 The Sample

All families who experience a pregnancy loss in all areas of the hospital are given the opportunity to complete the survey.

4.7.2 Distribution and Collection

Distribution and collection of the survey is carried out by the Perinatal Nurse Navigator in the Birthing Centre.

Parents receive a survey in the mail one month after their loss. They are requested to return the survey in an included envelope and have the option to sign their name or remain anonymous.

4.7.3 Communication and Publicity

Parents are recruited following hospital admission following their experience of a pregnancy loss.

4.7.4 Response Rate

Currently, 100 survey responses from families with early and late loss that occurred in three different areas of the hospital have been returned and recorded from mid-2017 through 2020. However, approximately 200 surveys are sent out each year. As this was not a formal research project exact response rate are not available. 100 surveys returned out of a possible 700 surveys distributed gives a 14% response rate.

4.7.5 Analytical Methodologies

Data is recorded and reviewed occasionally to identify trends in families satisfaction with care received. Trends consistently show that families are extremely pleased with the care that they received.

4.7.6 Output

Over a one year period, 22 families who returned the evaluation identified that when birth planning was possible, 70% of families not only found value in having a plan,

but also felt that the staff followed the plan. Evaluations also showed that all parents believed that the nursing team offered compassion and guidance during their hospital stay.⁽⁵⁰⁾ Survey findings were published in 2019 in the International Journal of Palliative Nursing.⁽⁵¹⁾

4.7.7 Impact

The findings from the survey are used to educate and train staff in perinatal bereavement care. The survey feedback ensures consistent, high quality bereavement care and identifies the impact of care for families.

Data received shows that families value this care and find it extremely important to their health and healing.

4.8 Key Recommendations and Lessons Learnt from the Evaluation of Care document.

- The Perinatal Nurse Navigator undertook and processed this survey with full time work commitments and so, though valuable information on care experiences was received, it was a time consuming process that required significant support to maintain and sustain the program on an ongoing basis.
- The Perinatal Nurse Navigator aspires for the survey to be received by families around 4 weeks after the loss of their baby, so it is time sensitive.
- Perinatal Bereavement programs are not always present in hospitals in the USA and often are viewed as "extras". However, the survey responses show the positive impact that this program has on families and highlights how critically important it is.

5. Australia

Professor Vicki Flenady, Director of the Centre of Research Excellence in Stillbirth (Stillbirth CRE), Mater Research Institute, The University of Queensland and Associate Professor Fran Boyle, Bereavement Care Program Lead Stillbirth Centre of Research Excellence, Mater Research Institute, University of Queensland, provided the following survey review information.

This was an International Stillbirth Alliance (ISA)² web-based survey and was a collaboration between The Lancet Ending Preventable Stillbirths study group and The Lancet Stillbirths in High-Income Countries Investigator Group. It was published initially in the *Lancet* as part of the second Stillbirth Series - Stillbirths: recall to action in high-income countries. *Lancet* 2016; and it was published online in Jan 2018.⁽⁵²⁾

Three multi-language web-based surveys were developed to survey bereaved parents, care providers, and general community members to assess practices around stillbirth prevention, awareness of stillbirth risk factors, quality of antepartum and bereavement care, stillbirth investigations, audit and classification of stillbirths, priorities for research and action in stillbirth prevention and bereavement care.

The target audience for the parents' survey were parents in High Income Countries (HIC) who had had a stillborn baby at any time. With regard to the other two surveys; health-care providers included professionals in HIC providing maternity care and care to parents who had a stillborn baby (including maternity care professionals, pathologists, pastoral care and social workers, psychologists and others), and the 3 survey sought feedback from the general community population in HIC.

5.1 Background

The Lancet Series

The Lancet Stillbirth Series published in 2011 and 2016 aimed to draw attention to the significant psychosocial and economic burden that stillbirth places on families and society. The series aimed to keep stillbirth on the global agenda with an

² The International Stillbirth Alliance (ISA) objective is to raise awareness of stillbirth and to promote global collaboration in the prevention of stillbirth and provision of appropriate care for parents whose baby is stillborn.

emphasis on reducing rates, and prevention. It is estimated that 2.6 million stillbirths occur annually with 98% of these occurring in low and middle income countries

(LMIC). These figures highlight the inequalities in healthcare, funding and research with high income countries (HIC).

The first Lancet stillbirth series '*Call to action*' was published in 2011 providing a comprehensive assessment of global numbers and causes of stillbirths, identifying perceptions and beliefs of stillbirth around the world, and discussing the solutions to prevent stillbirth. It also highlighted the neglect of stillbirths by the global public health community. Despite progress the second stillbirth series showed that more needed to be done to keep stillbirth on the global agenda and bridge the gap to reduce the rate of stillbirths internationally.

The second series '*Ending Preventable Stillbirth*' launched in 2016, describes the huge impact this loss of life has on families, care-givers, societies and governments. This series builds on the Lancet Stillbirths Series published in 2011 by reviewing where progress has and has not been made since 2011.

The full second series includes five academic papers, two research articles, and four commentaries, written by over 210 authors from 43 different countries. ⁽⁵³⁾

The series papers are:

- [Stillbirths: progress and unfinished business](#)
- [Stillbirths: rates, risk factors, and acceleration towards 2030](#)
- [Stillbirths: economic and psychosocial consequences](#)
- [Stillbirths: recall to action in high-income countries](#)
- [Stillbirths: ending preventable deaths by 2030](#)

The fourth paper in this series on stillbirth - Ending preventable stillbirth: recall to action in high income countries includes the findings from a web based survey carried out by the International Stillbirth Alliance (ISA) to assess bereaved parents, care providers, and general community member's knowledge around stillbirth. ⁽⁵⁴⁾ For this review we will focus on the bereaved parent's survey.

5.2 Objective

The objective of the International Stillbirth Alliance (ISA) web-based surveys was to survey bereaved parents, care providers and general community members to assess practices in:

- stillbirth prevention
- awareness of stillbirth risk factors
- quality of antepartum and bereavement care
- uptake of stillbirth investigations
- audit and classification of stillbirth.

5.3 Governance Arrangements

The project was conducted and coordinated by the International Stillbirth Alliance (ISA) and was a collaboration between The Lancet Ending Preventable Stillbirths study group and The Lancet Stillbirths in High-Income Countries Investigator Group. Each participating country had a designated national leads as a contact person.

5.4 Commitment

The project was conducted and coordinated by the International Stillbirth Alliance (ISA) and was a collaboration between The Lancet Ending Preventable Stillbirths study group and The Lancet Stillbirths in High-Income Countries Investigator Group.

5.5 Data Protection

Under the Australian government The Privacy Act 1988 (The Act) is responsible for the protection of privacy around health data.⁽⁵⁵⁾

In the case of this survey all survey participants' data is anonymised therefore participants are unable to withdraw from the study once they have submitted their survey.

5.6 Ethical Approval

The study was approved by the Mater Health Services Human Research Ethics Committee, within the guidelines of the Australian National Statement on Ethical Conduct in Human Research 2007 (updated 2018) and the University of British Columbia Office Of Research Ethics.⁽⁵⁶⁾

As this is a self-selecting, voluntary and anonymous web-based survey, consent is implied through participation.

5.7 The Survey

The survey was web-based and was made up of three separate surveys designed for each category of participant:

- bereaved parents
- care providers
- general community members.

The surveys were developed in multiple languages and were available in English, Dutch, German, Italian, Spanish and Portuguese. The survey of care providers was also available in French and Japanese.

Surveys were developed in English and then translated by Translators Without Borders, a translation service available for non-governmental organisations.

Completed translations were checked for accuracy and appropriateness of language and tone by a member of the authorship team or the Lancet stillbirths in high-income countries investigator group.

Using mixed methods the parent survey questionnaire was divided into 11 sections and included 50 questions with 200 variables. The 50 questions were divided between 30 closed-ended/Likert scale agreement questions and 20 free-text boxes. The survey questions were developed by expert consensus and did not seek parental input in design or development.

The aim of including open-ended questions in the survey was to give parents an opportunity to elaborate on their responses or emphasise aspects they felt were not fully captured in the quantitative survey items. This approach allowed the research team to elicit comments and perspectives of events from parents around their experience of stillbirth and to illustrate and explain the survey data from their viewpoints.

The questionnaire began with an information page about the survey, inclusion criteria, acknowledging the emotional impact of the questions and contact details for support organisations if needed, the details of the research team and contact details

if any participant required further information about the project. The questionnaire was reported to take between 20-30 minutes to complete.

Parents were asked each question in relation to the care they themselves received in the pregnancy of their stillborn baby. If parents had experienced more than one stillborn baby, they were asked to answer the questions with regard to their most recent loss.

The initial questions in the survey were around demographics followed by chronological questions around care during pregnancy, care received after the baby was stillborn, care at home, investigations and post-mortem. In contrast to other surveys it then went on to ask about the financial costs to family, subsequent pregnancy, stillbirth views in your community, public awareness of stillbirth and finally the survey asked for suggestions around priorities for research and action to address stillbirth.

At the end of the questionnaire, participants were thanked for participating and the emotional impact of answering the survey was acknowledged and contact details for support organisations were included here again.

5.71. The Sample

The survey eligibility population were women who had experienced a stillborn baby and were over the age of 18 years of age.

The target audiences for the surveys were parents in High Income Countries (HIC), who had a stillborn baby at any time, health-care professionals in HIC providing maternity care and care to parents who had a stillborn baby (including maternity care professionals, pathologists, pastoral care and social workers, psychologists and others), and general community members in HIC.

The country income classifications provided by the World Bank was used to determine economic income and so differentiate between high and middle income counties.⁽⁵⁷⁾

The care provider survey was tailored to respondents' professional discipline with clinical questions around stillbirth restricted to midwives, obstetricians and/or gynaecologists and nurses who provide maternity care.

5.7.2 Distribution and Collection

The surveys were circulated between December 2014 and February 2015 via the International Stillbirth Alliance (ISA) member organisations.⁽⁵⁸⁾

The survey of care providers was also disseminated via the International Confederation of Midwives (ICM), International Federation of Gynaecology and Obstetrics (FIGO) and other national professional societies.

Participation in the study was voluntary and anonymous. If participants wanted to opt out of the survey after they had started it, they were advised to just stop and not submit the survey. However, participants were also informed that they could not withdraw from the study once their survey was submitted as all survey responses are anonymised.

5.7.3 Communication and Publicity

In the case of the bereaved parents' survey, participants were recruited through social media via the International Stillbirth Alliance (ISA) member organisations.⁽⁵⁶⁾ This organisation is made up of international bereaved parents support organisations and charities as well as Nursing organisations, Colleges of Obstetricians and Gynaecologists, Societies of Perinatal Medicine and Epidemiology centres.

5.7.4 Response Rate

Bereaved Parents: A total of 4,184 women and men completed the survey of bereaved parents, 3,504 were from HIC and 680 from middle-income countries (MIC). (Two ineligible participants who were not bereaved parents were removed).

Table 1. Characteristics of participants.

	Countries Responded	Response Rate	Gender (Female/Male)	% Age Range 30-39yrs
High Income Countries (HIC)	26	3,503	92/8 %	56%
Middle Income Countries (MIC)	18	679	97/3 %	53%

27% of HIC parent respondents were over 40 years age and 10% of MIC parent respondents were older than 40 years of age.

Due to the recruitment method adopted in the study, it was not possible for the research team to determine the number of men and women who were exposed to the study advertisement, and therefore the overall response rate is unknown.

Of the other two groups surveyed, care providers and general community members a total of 2,138 and 1,431 respectively (women and men) completed the survey.

5.7.5 Analytical Methodologies

Qualitative data were analysed using the software package NVivo. This software was used to organise and analyse responses based on the intent of the question.

The purpose of including open-ended questions in the survey was to give parents an opportunity to elaborate on their responses or emphasise aspects they felt were not fully captured in the quantitative survey items. This approach allowed the research team to elicit comments and perspectives of events from parents around their experience of stillbirth and to illustrate and explain the survey data from their viewpoints.

Following review of all qualitative responses, information-rich quotes were selected to complement and 'bring to life' key survey results.

Quantitative (closed ended questions) data was analysed using SPSS V22 (Version 22) and Microsoft Excel and only descriptive statistics were reported.

Quantitative data was weighted to allow for uneven distribution of responses across countries. Countries that contributed only a few responses <20 were omitted as the weights derived from small numbers were unreliable. In total 1-5% of responses were omitted depending on the survey question.

Following sensitivity analyses on the un-weighted results it was found that omission of responses from countries with low responses made no material difference to the results.

5.7.6 Outputs

The survey findings were published initially in the second Lancet Stillbirth series 'Ending Preventable Stillbirth' - Stillbirths: recall to action in high-income countries. *Lancet* 2016; and it was published online in Jan 2018. ⁽⁵²⁾

The 2 Lancet Stillbirth Series was presented at The International Stillbirth Alliance (ISA) Conference in Amsterdam in 2016.

In conjunction with the ISA and Lancet Research team, research papers and collaborations have been published following the Lancet Stillbirth Series.

The ISA/CRE research team share their findings and work in collaboration with other research units nationally & internationally.

5.7.7 Impact

This global survey identified gaps in health care systems internationally whereby they are not equipped or resourced to provide respectful stillbirth care and highlights a need for service improvement.

The research findings are used to educate all healthcare staff. The survey identified the need for specific care guidelines, education, training and support for healthcare workers challenged with such losses.

The Lancet Stillbirth series (published in 2011 and 2016) is working towards keeping stillbirth on the global agenda which is focused on ending preventable stillbirth by 2030.

5.8 Key Recommendations and Lessons Learned from the ISA Lancet stillbirth survey

- The research team describe finding it difficult to recruit dads/partners and younger women. They noted that when surveys are open to both parents, 98% of responses are from mother.
- In Australia pregnancy losses <20 weeks are not surveyed as these are not registered within states.
- The research team acknowledged the challenge of deciding/agreeing the defined survey group, gestational cut offs and timelines but consensus is necessary as for any survey.
- The use of web-based surveys where participation is through self-selection does not provide a representative sample and therefore can be a limitation to gaining insight into the wider population's experience.
- The process of self-selection can lead to a smaller response rate.
- The research team also recommended using previously validated survey questionnaires/questions. They highlighted the benefit of developing a standardised instrument to compare experiences internationally.
- The research team advised us to consider investigating the mental wellbeing of mothers in our survey questionnaire. It is widely recognised internationally that good bereavement care has psychosocial benefits for women and their families while poor care can have long term negative impact.⁽⁵⁹⁾

6. Canada

Megan Fockler RN, MPH, Advanced Practice Nurse, DAN Women and Babies Program and Education Coordinator of the Pregnancy and Infant Loss Network, at the Sunnybrook Health Sciences Centre, and a Practice-Based Researcher at Sunnybrook Research Institute, Sunnybrook Health Sciences Centre and an Adjunct Lecturer at the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, provided the information and insight into the Canadian survey model.

The survey was developed as a result of legislative action (Bill 141) that mandated for research and analysis to take place on pregnancy loss and infant death in the province of Ontario to support those who experience such a loss, and to inform the establishment or expansion of programs related to such losses. ⁽⁶⁰⁾

This was the first survey of its kind to survey a large population of families who experience all type of pregnancy and infant loss to be conducted in Canada. Prior to this survey, little was known about how families in Ontario accessed and experienced existing perinatal bereavement care and supports, and their views on system gaps needed to be identified, captured and improved upon.

The purpose of this survey was to collect and report comprehensive data on people's experiences of perinatal bereavement supports in Ontario, and to inform the development of a strategic plan to improve and expand services provided across Ontario, as well as developing training and support for healthcare and service professionals.

The target audience for the survey was people who lived and had experienced a pregnancy loss in Ontario at any gestation of pregnancy (the person who carried the pregnancy or their intimate partner(s)), or who had experienced the death of an infant, were all eligible to complete the survey about their experiences with the healthcare system and community supports at the time of the loss and during follow up. They were also asked their thoughts on current gaps within the system and to identify priorities for action.

6.1 Background

Ontario is a Canadian province with over 13.5 million residents and approximately 141,000 births annually.⁽⁶¹⁾

Between April 1, 2016 and March 31, 2017, there were approximately 38,665 recorded visits to emergency departments in Ontario related to pregnancy losses (under 20 week's gestational age) and their associated complications.⁽⁶²⁾

Between 2012 and 2016, there were 6904 reported stillbirths⁽⁶¹⁾ and 3283 reported infant deaths in Ontario.⁽⁶³⁾

In December 2015, Bill 141: The Pregnancy and Infant Loss Awareness, Research, and Care Act was enacted by the Legislative Assembly of the Province of Ontario into law.⁽⁶⁰⁾ Bill 141 was the first time any province in Canada has succeeded in passing legislation that mandated for research and analysis on pregnancy loss and infant death that would assist those who experience such loss and that would inform the establishment or expansion of programs related to such loss. Bill 141 was intentionally broad in mandate, which allowed program analysis and expansion to incorporate all experiences of pregnancy and infant loss, regardless of gestational age.

As a result of Bill 141, the Pregnancy and Infant Loss (PAIL) Network at Sunnybrook Health Sciences Centre in Toronto, Ontario, Canada, was given the funded responsibility, via the Ministry of Health and Long-Term Care, to provide free peer support services to bereaved parents and their families across Ontario, regardless of the nature of their loss, and has as their mandate the improvement and expansion of support services in Ontario.

6.2 Objective

The objective of this survey was to:

- collect and report comprehensive data on people's experiences of perinatal bereavement supports in Ontario
- to inform the development of a strategic plan by PAIL Network to improve and expand services provided across Ontario
- to providing training and support for healthcare and service professionals.

6.3 Governance Arrangements

The project was initiated and funded under the instructions of the Ministry of Health and Long Term Care and was conducted and coordinated by the Pregnancy and Infant Loss (PAIL) Network at Sunnybrook Health Sciences Centre in Toronto, Ontario.

6.4 Commitment

The survey was designed, conducted and coordinated by the Pregnancy and Infant Loss (PAIL) Network at Sunnybrook Health Sciences Centre.

6.5 Data Protection

No identifiable information was collected from respondents. Informed consent was implied through independent completion and submission of the survey.

6.6 Ethical Approval

Ethics approval was received from the Sunnybrook Health Sciences Centre Research Ethics Board (Approval Number: 443–2016).

As this is a self-selecting, voluntary and anonymous web-based survey consent is implied through participation.

6.7 The Survey

The anonymous, web-based survey was designed following a review of the literature and discussion amongst the researchers, which included clinicians and a person with lived experience of pregnancy loss. The draft survey was reviewed by an expert in online survey development and piloted by a group of women (n=5) who had experiences of pregnancy loss (miscarriage, stillbirth, neonatal death and infant death). Parents were accessed through the Sunnybrook Health Sciences Centre. These bereaved parents were asked about their thoughts on the length, content, ease of online completion, and wording of the survey and whether they were able to express what they wanted to express. Minor survey revisions were made based on their feedback.

The final survey included 59 closed-ended multiple choice questions (Likert, partial, and unordered) that focused on care and supports discussed or accessed both at and after the time of the loss, as well as current gaps in care and services and the experience of a pregnancy after loss.

The format of the final survey included skip-logic such that respondents were directed through different paths based on their responses and loss experience. In addition, one free-text question was included to allow respondents to express any thoughts or experiences considered important that they were unable to express in the rest of the survey and to further describe their experiences in their own terms. It was felt that allowing respondents to describe their experiences in their own terms would highlight elements of a complex issue and would also function to redress the power imbalance between researchers and participants by giving voice to the respondents' opinions in a way that is unconstrained by the researchers' agenda. ^(64, 65)

Participants who had experienced more than one loss were asked to respond to the full survey thinking about only one of their losses using the Canadian definitions for timing of loss options to select from which included:

- miscarriage (pregnancy loss under 20 weeks gestational age)
- stillbirth (loss over 20 weeks gestational age)
- neonatal death (death of baby within 28 days of life)
- infant death (death of baby after 28 days of life, but within one year)
- pregnancy termination for medical or other reasons.

The survey was developed in English only.

6.71. The Sample

The survey sample included people who lived in Ontario and had a pregnancy loss at any gestation of pregnancy (i.e. the person who carried the pregnancy or their intimate partner(s)), or who had experienced the death of an infant.

6.7.2 Distribution and Collection

The web-based survey was available for completion online for two months during January and February 2017. Participation in the study was voluntary and anonymous. No identifiable information was collected from respondents.

6.7.3 Communication and Publicity

Advertisements inviting people to participate were placed on the public Bill 141 Facebook page and PAIL Network website, with a link to the survey, information about the purpose of the study, and contact details for the primary investigator and the chair of the research ethics board for questions related to participation.

6.7.4 Response Rate

A total of 607 people completed the survey between January and February 2017. Respondents whose loss took place outside Ontario ($n=5$) or participants who did not progress past question three ($n=6$) were removed from the survey.

This left 596 responses for further analysis. Of the 596 respondents, 79 did not complete the entire survey; 21 responded to less than 25% of the survey questions. If a respondent did not answer a question, they were not counted in the denominator for calculations. For participants who answered the question about relation to the loss or losses ($n=515$), 501 had experienced the loss themselves, while 14 reported that their partner had the loss or losses. In total, 269 (52%) respondents completed the open-ended question.

In their survey responses 55% of respondents talked about a loss of under 20 weeks gestation ($n=330$). Fifty percent of the losses remembered by the respondents had taken place between 1-5 years previously. Other responses included 7% occurring in the previous 3 months and 10% had occurred over 10 years prior to survey completion.

6.7.5 Analytical Methodologies

Descriptive statistics were used to analyse the multiple-choice survey questions. The responses were summarized numerically by Survey Monkey, and then placed in tabular format.⁽⁶⁶⁾

For the open-ended question, a qualitative inductive approach using thematic analysis was used as a means of condensing raw textual data into categories and themes to achieve a more in-depth understanding of the experiences described within the participant responses.⁽⁶⁷⁾

Thematic analysis was undertaken through a systematic process that included close reading of the raw data, coding, and developing themes related to families' experience of loss. Data extracts for each theme were considered to determine whether the themes accurately reflected the voices of participants.⁽⁶⁸⁾ Four themes

were identified in the qualitative data. Review of qualitative responses, provided information-rich quotes which supplemented key survey results.

Peer debriefing and reflexive writing was carried out throughout the process to guarantee commitment with the data and establish credibility.⁽⁶⁸⁾

6.7.6 Outputs

The survey findings were published in 2019 in the BMC Pregnancy and Childbirth Journal.⁽⁶⁹⁾

6.7.7 Impact

The survey responses indicated a clear gap in healthcare systems and the need for improved bereavement care for those experiencing the loss of a pregnancy or the death of an infant in Ontario.

The research findings are used to educate all healthcare staff. As part of their mandate, PAIL Network offers workshops around Ontario to professionals who provide services or care to families experiencing pregnancy and infant loss. The findings from the study are both presented at the workshop and are used to inform the content of the workshop.

The survey respondent's findings helped to prioritize the development of other resources for families and professionals, which included videos, online learning modules, and downloadable resources translated into the seven most popular languages in the province.

The research findings also informed the development of PAIL Network's next Strategic Plan.

6.8 Key Recommendations and Lessons Learned from the Pregnancy and infant loss survey.

- This study collected information via an internet survey, which has the potential limitations of self-selection, sampling and coverage bias.
- The survey was only promoted in two online locations in the perinatal bereavement community and most of the survey respondents would have seen the invitation to participate in locations where they were already actively involved and connected.

- People without online access were excluded from this study, as were those who could not complete a survey in English which can lead to a smaller response rate.
- Having thematic analysis of the open-ended question facilitated understanding of the experiences of families in their own words. However, having only one open-ended question limited the extent to which the research team were able to understand in-depth the lived experience of perinatal loss.
- A limitation of the study included a lack of diversity in race, gender, and economic backgrounds of participants in the survey, which restricts a broad overview of the findings.

7 Spain

The information outlined below was obtained from the principal researcher of the survey, **Paul Richard Cassidy** BBS MPhil, Doctoral Student, Universidad Complutense de Madrid and a researcher with Umamanita (Stillbirth Charity) Madrid.

This was the first national-level survey in Spain for mothers on their experience in the Spanish healthcare system following an intrauterine fetal death. The Perinatal Bereavement Care Project was initiated by Umamanita and managed in a voluntary capacity by Paul as part of a masters and doctoral research programme at the Universidad Complutense de Madrid. The survey is part of a broader project that also includes qualitative interviews and participant observation of an online support forum

The aim of the study was to capture women's views on the quality of care they received after perinatal bereavement in Spanish hospitals and consequently develop data on healthcare practices.⁽⁷⁰⁾ The online survey was carried out from June 2013 to June 2016.

7.1 Background

The population in Spain in 2018 was 46,937,060 (as of 1st January 2019) there was 372,777 births documented that year. In 2018 the recorded numbers of Stillbirths (≥ 28 weeks) was 968³ and Neonatal deaths (≤ 28 days) was 711.

With regard to fetal deaths in Spain registration is required only in cases where the gestation is greater than 180 days (approx. 26 weeks). Because registration is required only for deliveries that take place after 26 weeks of gestation, underreporting of shorter pregnancies is likely to exist.

7.2 Objective

The "Umamanita Report: Survey on care quality following cases of intrauterine death" [*Informe Umamanita: Encuesta Sobre La Calidad de La Atención Sanitaria En Casos de Muerte Intrauterina*] survey was the first national survey to capture the care experiences of women/parents who experienced a perinatal bereavement.⁽⁷³⁾ The survey provided information on all aspects of parents' experiences of care

³ This is an estimate because statistics on pregnancy loss in Spain are limited and in 13.4% of cases the gestational age (from 22 weeks to birth) is missing. Based on an analysis of data from 2015 it was estimated by the researcher (using average birth weight data data) from available data that 84% of the 13.4% related to fetal deaths ≥ 28 weeks^(71, 72).

during the antenatal period, diagnosis, admission to hospital, labour and birth, postnatal care, time spent with baby, making memories as well as support and follow up. The objective of the survey was to gain insight into women's experiences of care, look at care practices in Spanish hospitals and compare them to the standards in other high income countries. Compiling national data provides a benchmark for quality and identifies areas where hospitals could make improvements to care practices to support women and their families who experience such a loss.

7.3 Governance Arrangements

This project was undertaken on a voluntary basis without subsidy or funding. The project was part of a masters and doctoral research programme under the supervision of the University Complutense de Madrid and in conjunction with Umamanita's (Stillbirth Charity) research programme.

There was no formal involvement of a healthcare provider, regulator or policymaker in the project, although Umamanita and the researcher made attempts to do so through the National Ministry of Health.

7.4 Commitment

The survey development and research was undertaken as a project driven by the support association Umamanita (Stillbirth Charity) and within a masters and doctoral student project in the Universidad Complutense de Madrid.

7.5 Data Protection

The national authority responsible for data protection in Spain is the Spanish Data Protection Agency (referred to as AEPD by its acronym in Spanish).

The Spanish Organic Law 3/2018, of December 5, on the Protection of Personal Data and the Guarantee of Digital Rights states that the fundamental right to data protection of natural persons, under Article 18.4 of the Spanish Constitution, shall be exercised under both EU GDPR and legislation.

The Guarantee of Digital Rights Law limits the use of information technology to allow citizens exercise their right to personal and family privacy, and guaranteeing their reputation as citizens.

In the case of this survey all information gathered was treated with absolute confidentiality and the stored data was held on a password-protected computer. Of note, this data was only available to the principal researcher. Participants were aware of this prior to commencing the questionnaire.

Participants were informed that the information they shared was only used for statistical purposes and never individually. Confidentiality was guaranteed in accordance with the Spanish Organic Law of Data (Personal) Protection Law 15/99.

7.6 Ethical Approval

Ethical approval for the survey was not required by the principal researchers' institution, Universidad Complutense de Madrid. The institution only required ethical approval in the case of clinical trials.

Consent was given through informed participation in the online questionnaire.

7.7 The Survey

This was the first national-level survey of this type conducted in Spain. There was no local literature or other mechanisms to assist in the development of the questionnaire, consequently extensive research into hospital protocols and research literature was required.

The survey questionnaire design, development and piloting took place over an 18 month period and went through numerous stages with the support of a panel of experts which included bereaved parents recruited through the stillbirth charity, relevant healthcare professionals and the support organisation Umamanita.

The development process included:

- literature review
- exploratory interviews and participant observation
- draft questionnaire phase
- content validation phase
- cognitive interviews on a paper version of the questionnaire
- development of the digital version of the questionnaire
- pilot interviews phase 1
- adaptation of the questionnaire based on phase 1 pilots
- pilot phase 2

- launch.

The questionnaire included 107 questions with 400 variables and was tested to take an average of 45 minutes (range 22mins - 90mins) to complete. The questionnaire began with an information page about the survey, inclusion criteria, acknowledging the emotional impact of the questions, time to complete survey, and contact details if any participant had queries about the survey questionnaire or methodology.

The initial questions were around demographics, so as not to start with details related to the loss, followed by a series of sections each of which dealt with an aspect of care, which followed, insofar as possible, a chronological order through care (diagnosis, admission, labour, and birth, seeing and holding baby, making memories, psychological support, care providers, hospital stay, investigations and post-mortem, burial and rituals, partner, social supports and follow up care). The questionnaire mainly used closed-ended questions which were categorical/nominal (yes/no/ don't know), ordinal (Likert scale agreement), continuous (age) and some free text qualitative variables.

Finally, at the end of the questionnaire, information about sources of support for perinatal grief were provided if respondents thought that they needed to contact someone for support.

The survey was designed in Spanish only. While a translated English version of the survey is available it was not tested in this format.

7.7.1. The Sample

The survey eligibility population was defined as women who had experienced an intrauterine death (stillbirth or termination of pregnancy for medical reasons) from 16 weeks gestation up to and including an intra-partum death within the Spanish national healthcare system within a 60 month time frame of survey completion. The 60 month restriction limit was set in terms of memory recall and to reduce errors. The lower gestation of 16 weeks was decided following consultation with bereaved parents, support organisations and pilot testing.

Termination of pregnancy for medical reasons (fetal anomaly, threat to the mother's life or selective reduction in multiple gestation pregnancies) were included. It was felt that though the clinical aspect of the diagnosis were different, care practices for

both stillbirth and termination of pregnancy are similar. It was also felt by the promoting organisation and the participants in the consultation process that parents who go through a termination are often stigmatised and misunderstood.

Neonatal deaths were excluded from this study as it was felt it would require a more complex questionnaire to study both stillbirth and neonatal death care practices in detail. It was also felt that neonatal bereavement care in Spain was more advanced than stillbirth care with significantly more practice-based development of care in NICU's , as well as a greater level of publications in this area.

The study questionnaire was designed to track the care procedures of women who experienced an intrauterine death (from 16 weeks to birth) from diagnosis, inpatient care to discharge/follow up and to benchmark care quality.

Women's partners were not invited to participate in the study as it was felt that a second separate questionnaire would have been necessary to capture and measure this data accurately with regard to comparison and practices of care. There is also a risk of distorting data by doubling up on single cases. However, some questions in the survey do ask about the objective experiences of partners, collective completion was not recommended though it was suggested that it may be necessary to get some help in relation to some aspects of care, such as asking a partner to help inform the answers if the mother didn't know the answers herself.

The online survey questionnaire was available for participants from June 2013 to June 2016

7.7.2 Distribution and Collection

This was an anonymous online self-selecting, self-completion survey questionnaire, participants were not required to leave any contact details, but had the option to do so at the end of the questionnaire if they wanted to receive information about the research results. The survey was advertised as an opportunity for women to "tell your story".

Participants were recruited using the snowballing technique (non-probabilistic convenience sampling) online through support websites, Facebook pages, contact lists, blogs, web pages, and contact with health professionals, as well as national and regional press publications.

The online version of the questionnaire was developed on the Lime survey platform which allowed IP access control (which prohibits double completion from the same device), the use of skip logic, as well as an ordered presentation of questions. Participants could also save their responses and return at a later time if they were unable to complete the survey in one sitting, although they were encouraged to do it in one sitting.

The option of recruitment through a hospital based population study though ideal was found to be problematic and impractical in terms of ethics, access to patient lists, cost and coordination requirements.

7.7.3 Communication

The survey was promoted online through support websites, Facebook pages, contact lists, blogs, web pages, and contact with health professionals as well as national and regional press publications.

At the end of the questionnaire participants were also asked to pass the survey details on to other bereaved mothers that they might know.

Included in the questionnaire was the email contact details of the principal investigator if any information was required by participants.

During the course of the 3-year recruitment time line (2013-2016) regular ongoing advertising/promotion took place through social media, support websites and with healthcare professionals to maintain recruitment.

Information about perinatal grief and support was acknowledged and the contact details for support organisations were included on all promotional sites as well as at the end of the questionnaire.

7.7.4 Response Rate

A total of 796 women whose baby had died within the previous 60 months were deemed to have validly completed the questionnaire. Data purification included screening out participants from outside the Spanish national territory (Latin America), early neonatal deaths and insufficiently completed questionnaires.

Non-completion

In total 632 interviews were initiated but not completed. 59% of incomplete interviews were abandoned before 5 minutes and 75% before 10 minutes.

Abandonments may be related to three factors: a) the emotional and sensitive nature of the survey, although this is purely speculative; b) the length of the questionnaire, although as most abandonments were early, this may not have been that influential; c) mismatch between care processes outlined in the survey and the experience of care in second trimester losses. For example, of the 632 interviews that were not completed 293 participants got as far as question 12 – number of weeks gestation at which the death occurred. Analysis of those cases show they were significantly associated with earlier losses (16 -19 weeks gestation) compared to the completed sample.

7.7.5 Analytical Methodologies

The questionnaire mainly used closed-end questions which were categorical/nominal (yes/no/don't know), ordinal (Likert scale agreement), continuous (age) and some free-text qualitative variables.

Survey analysis was carried out by the researcher using SPSS. The method of analysis varied according to nature of the objectives of the analysis and the dependent variable i.e. cross-tabulations, multiple regression (relationship between variables), binary logistical regression (yes/no answers) or segmentation (age, race, gender, occupation, education).

7.7.6 Outputs

A full report ([Infome Umamanita](#))⁽⁷¹⁾ with 10 chapters, including an introduction, summary and eight chapters each dealing with an aspect of care was published in 2018. Apart from the research results, the introduction to each chapter contains an outline of best-practice care.

Additionally, an article, containing some comparative data, was also published in 2018. A thesis has been finished and will be defended by the end of January 2021. One article is currently in review and five other articles are in the process of being written, they deal with: interactive aspects of disenfranchised grief, sedative administration, vulnerability and ethics of care, post-mortem contact decision-making, autonomy and agency during care, and practices related to the disposition.

Participants were informed of the publication of the first article and the report, but will not be informed of future publications as their details have been deleted from the database for data protection reasons (they were informed of this in the last communication).

Findings have also been disseminated through press releases to national and regional media (TV, newspapers and radio) and on social media. Coverage was widely achieved in all national newspapers, on a number of national TV channels and in regional press.

The research team have shared their findings and work in collaboration with other research units and this research is cited internationally.

This research work has been presented at national and international conferences.

All findings will be used in education and training courses for healthcare providers and stillbirth charity workers.

7.7.7 Impact

The survey work has had considerable impact. It is widely presented in seminars and conferences within Spain, and also widely used as reference material in training courses (by Umamanita and other associations).

It has been covered extensively in the press, helping to create increased awareness about stillbirth in Spain and is also cited in national research.

It is influencing regional health authorities, who are slowly beginning to introduce protocols and care guidelines for perinatal bereavement care.

The principal researcher along with the Stillbirth Charity Umamanita plans to continue to explore aspects highlighted in the survey data analysis and is considering running the survey again for comparison.

Both the researcher and the charity, plan to continue to use the findings to seek to influence government policy.

7.8 Key Recommendations and Lessons Learned from the Spanish survey

- The study, though structured, provided an opportunity for parents to tell their story which they greatly appreciated, highlighting the willingness of bereaved parents to share their experience in order to acknowledge and improve perinatal bereavement care experiences.

- Though it was a difficult decision, partners were not invited to participate in the survey as the primary objective of the study was to benchmark care quality. It was felt that there could be duplication of cases which could not be differentiated against. The questionnaire design wasn't suitable for partners' experience because of the way it tracked care procedures from diagnosis to follow up. It was felt that two distinct survey questionnaires would have been necessary if partners were included. Some questions did include data on the partner but answers are based on the mother's testimony/recall.
- The study population encompassed both stillbirths and termination of pregnancy for medical reasons (fetal anomaly) it was felt that much of the subjective experiences are similar in these groups. The lower gestational age of 16 weeks was determined following consultation with parent support associations and pilot testing.
- Neonatal deaths were excluded from this study firstly because it would entail the need for a complex questionnaire to study both stillbirth and neonatal care practices in detail and secondly it was felt that neonatal bereavement care in Spain was more advanced than stillbirth.
- Limiting the scope of the participants will likely create issues for the excluded bereaved community but this is not a reflection of lack of interest often it is limited by data, research or processes.
- The researcher relied on a panel of experts and carried out interviews with bereaved parents and healthcare professionals with experience in perinatal bereavement to design and validate the questionnaire. Along with cognitive and pilot interviews the use of free text questions are useful for providing a rich source of data which was critical to the survey; respondents often relay more detail when replying to these.
- Conducting surveys online can have advantages and disadvantages. Self-selection by participation lead to errors in confidence levels in the data, as the sample is non-probabilistic. On the other hand, the snowballing technique is useful in reaching people that are normally difficult to locate especially those in low socio economic groups. However, online surveys may have the opposite effect for some low-income groups or immigrants if they don't have internet access or are outside the principal reference chains for snowballing.

- The survey was advertised as “tell your story”, which the research team thought was a successful way to communicate with women and something that they wanted to do because nobody had ever asked them before.

8 Italy

The information below was obtained from communication with **Dr Claudia Ravaldi** Psychiatrist and Psychotherapist, President and founder of CiaoLapo Onlus, Charity for Stillbirth and Perinatal Grief Support, Adjunct Professor of the University of Florence along with **Dr Alfredo Vannacci**, Associate Professor of the NeuroFarBa Department, University of Florence, Vice President of CiaoLapo Onlus.

CiaoLapo a non-profit organisation which was founded in 2006 by both Claudia and Alfredo and its aim is to provide support and assistance to families who are bereaved by the death of a child during pregnancy or after birth for any reason or any gestational age.

This was the first study of its kind in Italy and was developed to gain insight into bereavement care in Italy from parents' perspective. The aim of the study was to gather data from women following a perinatal bereavement on their experience of care and healthcare practices in Italian hospitals.

This was not a survey questionnaire, instead parents were asked to share their experience "to recall their narrative story" through writing or an interview process. No boundaries or guidelines were set for participants around the time interval since their loss or the type of pregnancy loss they had experienced.

The target audience for the study were women who experienced a pregnancy loss in Italian healthcare settings.

8.1 Background

Italy has a population in excess of 60 million people. The birth rate in Italy in 2018 was 439,747. Stillborn babies and neonatal deaths account for 3,000 events per year.⁽⁷⁴⁾ In Italy fetal deaths before 180 days of gestation (25 weeks and 5 days) are not registered, they are considered to be spontaneous abortion. Stillbirth is therefore defined as a fetal demise at or after 26 weeks of gestation.⁽⁷⁵⁾

The national framework for perinatal bereavement in Italy is different to other High Income Countries. There is no formal training for professionals in universities in the area of perinatal bereavement.⁽⁷⁶⁾ No formal clinical guidelines on perinatal bereavement care exist in Italy. Culturally there is stigma and silence around

perinatal loss in Italy. Stillborn babies do not receive societal or family recognition, they are rarely named or have funeral rites or even held or seen by the mother or family. Geographically care is inconsistent, hospital perinatal bereavement care varies and the gap between theory and practice is very different.

8.2 Objective

The objective of this survey was to:

- The aim of the study was to gather data from women following a perinatal bereavement on their experience of care and healthcare practices in Italian hospitals.
- To identify training and support needs for healthcare and service professionals. There is no formal training for professionals in Universities in the area of perinatal bereavement.

8.3 Governance Arrangements

There is no formal government involvement in this study however the Ciaolapo Foundation was responsible for its governance and oversight.

The CiaoLapo Foundation for Healthy Pregnancy and Perinatal Loss Support provided infrastructure for the realization of the study (documents, material, software, web platforms, open access).

CiaoLapo as a charity receives economic support from government taxes paid by residents/employee. Five euro from every 1,000 euro earned can be assigned by employees to a charity of their choice.

The study was not funded; no researcher received grants, salary or reimbursements for the realization of the study.

8.4 Commitment

The Narrative study was initiated, conducted and coordinated by the support association CiaoLapo a Charity Organization for Stillbirth and Perinatal Loss in Italy.

8.5 Data Protection

No identifiable information was collected from respondents. This is a self-selecting, voluntary and anonymous web-based study consent is implied through participation. Participants were advised to use a pseudonym to protect their identity

8.6 Ethical Approval

In order to use the findings from this large study for publication of research papers ethical approval was granted by the University of Florence, Viale Pieraccini 6, 50139 Firenze, Italy.

Participants sign an agreement to privacy and consent prior to commencing the web-based study.

Participants are also advised to assign themselves a pseudonym to protect themselves from recognition.

8.7 The Survey

This was not a formal survey questionnaire, instead parents were asked to share their experience “to recall their narrative story” through writing or an interview process. No boundaries or guidelines were set for participants around the time interval since their loss or the type of pregnancy loss they had experienced.

The aim was to categorise information and identify themes documented in parents’ stories when compared to best international practice guidelines to identify the presence or absence of good practice in bereaved parents’ experience of care.

It was an anonymous, online, self-selecting, self-completion study.

Participants were recruited through social media such as support websites. The study was carried out over a 3 year period from 2007 to 2010, and 1,000 stories were collected from parents over this time period. Of these participants, 700 experienced a stillbirth and 300 had either a miscarriage or a termination of pregnancy. The completion rate was 5:1 for mothers versus fathers, often both parents completed the survey together and approximately 20% of fathers completed the survey independently.

At the time of the study the website was developed in Italian only (but has since been translated to English as well). This initial study was an open answer questionnaire.

8.7.1 The Sample

The survey eligibility population were women who experience pregnancy loss in Italy.

8.7.2 Distribution and Collection

The study was available for completion online over a 3 year period 2007 -2010.

8.7.3 Communication

The study was designed in Italian only.

The web-based study was promoted through the CiaoLopa, Stillbirth Charity along with other support organisations.

Participants were recruited through social media and support websites.

8.7.4 Response Rate

As this was an open-ended narrative study it was not possible to calculate a response rate. Nonetheless a 1,000 stories were collected from parents over the 3 year time frame.

8.7.5 Analytical Methodologies

Qualitative and quantitative data was analysed by the researcher, a statistician and member of CiaoLapo, Stillbirth Charity and for comparison and reliability an independent group of statisticians were also used to compare findings. Main themes were identified through thematic analysis.

8.7.6 Outputs

The survey findings were not formally published in journals, but the themes identified were used to create guidelines for bereavement care and staff education.

Findings were disseminated through social media and at regional level.

Research team share their findings and work in collaboration with other research units.

8.7.7 Impact

Findings from the study were used to create guidelines for bereavement care practices in Italy.

Feedback from parents identified and informed the need for training for professional clinical staff (nursing/medical) in universities and hospitals in Italy.

Following on from this study, healthcare professionals were surveyed to investigate their behaviours and practice in bereavement care during both the acute phase of loss and the grieving process. The *Lucina* study was carried out from 2009 to 2015.
(76)

Other specific areas such as post-mortem examination and making memories “memory box questionnaire” were surveyed from the evidence identified in the initial study.

CiaoLapo plan to survey professionals next and compare the findings in the two studies.

8.8 Key Recommendations and Lessons Learned from the Italian survey

- This study was the first of its kind in Italy and was web-based. This was not a formal survey questionnaire, instead parents were asked to share their experience “to recall their narrative story” through writing or an interview process. No boundaries or guidelines were set as a result the responses resulted in long detailed text to explore and identify themes. The team identified the need for more specific, closed questions in future surveys.

9. Conclusion

9.1 Findings

The findings of this review are set out in Section 2, Summary of Findings.

9.2 Next Steps

The National Care Experience Programme will roll out Ireland's first national maternity bereavement care survey to explore the experiences of bereaved parents in maternity care, the *National Maternity Bereavement Experience Survey*, in October 2021. The methodologies outlined in this paper will be adapted for Ireland's purposes.

Appendices

Appendix: 1. Participants and Organisations that contributed to this review

The Project Lead on behalf of the National Care Experience Programme would like to thank the below participants and organisations for generously giving of their time and knowledge to inform this international review.

Table 2: Conference call/Email contact, participants and organisations

Date of contact	Name/Title	Organisation	Country
30 September 2020	Dr Maggie Redshaw	National Perinatal Epidemiology Unit (NPEU), University of Oxford.	England
1 October 2020	Professor Vicki Flenady Director of the Centre of Research Excellence in Stillbirth. Associate Professor Fran Boyle, Bereavement Care Program Lead Stillbirth CRE	Centre of Research Excellence in Stillbirth (Stillbirth CRE), Mater Research Institute, The University of Queensland	Australia
13 October 2020	Paul Richard Cassidy BBS MPhil, Doctoral Student	Universidad Complutense de Madrid and a researcher with Umamanita (Stillbirth Charity) Madrid Non Profit Advocacy Group	Spain
2 November 2020	Susannah Hopkins Leisher	Chair, International Stillbirth Alliance, Stillbirth Centre of Research Excellence, Mater Research Institute, University of Queensland. Co-chair, Stillbirth Advocacy Working Group, Columbia University, Dept. of Epidemiology.	USA

Date of contact	Name/Title	Organisation	Country
9 November 2020	Claudia Ravaldi & Alfredo Vannacci	CiaoLapo Onlus, Charity for Stillbirth and Perinatal Grief Support Non Profit Advocacy Group	Italy
20 November 2020	Sue Steen	Perinatal Nurse Navigator, Maple Grove Hospital Maple Grove, MN Assistant Professor of Nursing Adjunct, Bethel University, St Paul, MN	USA
26 November 2020	Megan Fockler	RN, MPH, Advanced Practice Nurse, DAN Women and Babies Program and Education Coordinator of the Pregnancy and Infant Loss Network, at the Sunnybrook Health Sciences Centre A Practice-Based Researcher at Sunnybrook Research Institute, Sunnybrook Health Sciences Centre and an Adjunct Lecturer at the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto.	Canada

Table 3. International Review Summary

	Survey Methodology	Participant Eligibility	Language Options	Pregnancy Loss options surveyed	Timing of experience of Loss	Recruitment period	Response Rates
Australia	Web based- Retrospective Questionnaire Self-selecting	All women over 18years	Multi language	Stillbirth.	No time restriction of experience of loss.	3 months	4,184 responses received
Spain	Web based- Retrospective Questionnaire Self-selecting Snowballing	All women	Spanish	Termination of pregnancy (for medical reasons) or stillbirth from 16 weeks upward.	Loss experienced in a 60-month time frame prior to survey completion.	3 years	796 women completed survey
Italy	Web based- Retrospective Self-selecting Narrative	Option of Women & Partners	Italian	Stillbirth, Miscarriage and Termination of Pregnancy – but not specified as a requirement.	No time restriction of experience of loss.	3 years Open forum ongoing	1,000 Stories collected

UK	Postal Questionnaire	Over 18 years	Multi language option	Stillbirth and Neonatal death.	6-9 months after loss.	Two 3 month periods in 1 year	720 responses out of 2,561
USA	Postal Questionnaire	Service Users	English	All losses.	1 month after loss.	Annual ongoing	22 responses out of 200
Canada	Web based Questionnaire Self-selecting	All women/partners who had experienced a pregnancy loss/infant death in a specific province	English	Miscarriage, SB, Neonatal Death, Infant death and Termination of Pregnancy for medical reasons.	No time restriction of experience of loss.	2 months	607 people responded

Table 4. International Definitions of Miscarriage, Stillbirth and Neonatal death:

	UK	Australia	Spain	USA	Italy	Canada	Ireland
Definition							
Miscarriage	Pregnancy loss up to 23+6 weeks gestation.	Pregnancy loss with no cardiac activity documented at < = 20 weeks gestation.	The involuntary loss of a developing fetus before the 20th week of pregnancy.	The loss of a baby before the 20th week of pregnancy.	The loss of a pregnancy before 180 days of gestation (25 weeks and 5 days), are considered spontaneous abortions.	The loss of a pregnancy before 20 weeks gestation of pregnancy.	Pregnancy loss < 23+6 weeks gestation
Stillbirth	When a baby is born dead after 24 completed weeks of pregnancy.	A baby born with no heart beat or respiration, or other signs of life with a birth weight > = to 400 g or gestation at birth > = to 20+0 weeks gestation.	In Spain registration of fetal deaths is required only in cases where the gestation is > than 180 days Stillbirth is a baby born dead at or after 26 weeks gestation.	A baby born with no signs of life from 20 weeks gestation. Early SB :20 to 27 weeks Late SB: 28 to 36 weeks	Italy does not register fetal deaths before 180 days of gestation (25 weeks and 5 days). Stillbirth is defined as fetal demise at or after 26 weeks of gestation.	Loss of a pregnancy over 20 weeks gestation with a birth weight of 500 grams or more	A baby born with no signs of life with a birth weight > = to 500g or gestation at birth > = to 24 weeks gestation.

				Term SB: from 37 weeks completed pregnancy*			
Neonatal Death	A baby born at any time during the pregnancy who lives, even briefly, but dies within four weeks birth.	Death of a newborn baby of any gestation or birth weight within 28 days of live birth, when heart beat or respiration or other signs of life were observed after the birth is completed.	In Spain registration of fetal deaths is required only in cases where the gestation is greater than 180 days.	Live born baby who dies in the first 28 days of life.	A baby born alive who dies in the first 28 days of life. Early NND – 1 st 7 days of life Late NND – after 7 days up to 1 st month of life.	Death of a baby within 28 days of life.	Live born baby who dies in the first 28 days of life. ENND – first 7 days of life LNND – after 7 days up to 28 days of life.

References: International Review

1. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press, 2001.
2. Gerteis, M., Edgman-Levitan, S., Daley, J., Delbanco, T. Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care. San Francisco: Jossey-Bass, 1993.
3. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press, 2001.
4. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013;3:e001570. doi:10.1136/bmjopen-2012-001570
5. Coulter A, Fitzpatrick R, Cornwell J. The point of care - Measures of patients' experience in hospital: purpose, methods and uses. The King's Fund, 2009.
6. Luxford K, Sutton S. How does patient experience fit into the overall healthcare picture? *Patient Experience Journal*. 2014;1(Inaugural issue).
7. Department of Health Statement of Strategy 2016-2019
<https://health.gov.ie/wp-content/uploads/2016/12/DoH-SoS-2016-2019-Final-En.pdf>
8. Creating a better future together. The National Maternity Strategy, 2016-2026
<https://health.gov.ie/wp-content/uploads/2016/01/Final-version-27.01.16.pdf>
9. The National Cancer Strategy, 2017-2016
<https://health.gov.ie/wp-content/uploads/2017/07/National-Cancer-Strategy-2017-2026.pdf>
10. Sláintecare Implementation Strategy
<https://health.gov.ie/wp-content/uploads/2018/08/Sl%C3%A1intecare-Implementation-Strategy-FINAL.pdf>

11. National Patient Experience Survey
<https://www.patientexperience.ie/app/uploads/2018/02/NPES-National-Report-2017- WEB.pdf>
12. HSE Listening, Responding and Improving. The HSE response to the findings of the National Patient Experience Survey 2018
https://www.patientexperience.ie/app/uploads/2018/11/NPES_National_QIP_2018.pdf
13. National Standards for Safer Better Maternity Services
<https://www.hiqa.ie/reports-and-publications/standard/national-standards-safer-better- maternity-services>
14. Health Service Executive. National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death. 2016. Available online from:
<https://www.hse.ie/eng/services/list/3/maternity/bereavement-care/national-standards-for-bereavement-care-following-pregnancy-loss-and-perinatal-death.pdf>
15. NPEU Maternity Survey Reports <https://www.npeu.ox.ac.uk/maternity-surveys>
16. Care Quality Commission
<https://www.cqc.org.uk/publications/surveys/surveys>
17. National Perinatal Epidemiology Unit (NPEU), Listening to parents after stillbirth or the death of their baby after birth (2014)
www.npeu.ox.ac.uk/downloads/files/listeningtoparents/Listening%20to%20Parents%20Report%20-%20March%20 2014%20-%20FINAL%20-%20PROTECTED.pdf
18. Sands /Stillbirth and neonatal death charity www.sands.org.uk
19. Henley A, Schott J. The death of a baby before, during or shortly after birth: good practice from the parents' perspective. Seminars In Fetal & Neonatal Medicine. 2008;13(5):325-8.

20. Schott J, Henley A, Kohner N. Pregnancy loss and the death of a baby: guidelines for professionals. London: Sands (the UK Stillbirth and Neonatal Death charity); 2007.
21. Henley A, Schott J. The Sands Audit Tool for maternity services. Caring for parents whose baby has died. London: Sands, 2011.
22. Sands. Sands 17 principles of care. London: Sands, 2007.
23. Henley A, Schott J. Bereavement care report 2010. Survey of UK maternity units and the care they provide to parents whose baby dies before, during or shortly after birth. London: Sands, 2010.
24. Bliss for babies born sick or premature <https://www.bliss.org.uk/>
25. Bliss. The Bliss Baby Charter Standards. London: Bliss, 2009.
26. National Bereavement Care Pathway. Stillbirth bereavement care pathway: NBCP; 2020 [Available from: <https://nbcpathway.org.uk/pathways/stillbirth-bereavement-care-pathway>
27. National Bereavement Care Pathway. Neonatal death bereavement care pathway: NBCP; 2020 [Available from: <https://nbcpathway.org.uk/pathways/neonatal-death-bereavement-care-pathway>
28. Sands, *Audit of bereavement care provision in UK maternity units* (2016) www.sands.org.uk/sites/default/files/Bereavement%20Care%20Audit%20Report%202016%20DIGITAL%20-%2010.01.17.pdf
29. MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK) <https://www.npeu.ox.ac.uk/mbrance-uk/reports>
30. Department of Health. The NHS Outcomes Framework 2020. London: Department of Health; 2020.

31. Department of Health. National Service Framework for Children, Young People and Maternity Services. Standard 11: Maternity Services. London: Department of Health, 2004.
32. Office for National Statistics GB <https://www.ons.gov.uk/>
33. Statistics and Registration Service Act (SRSA) 2007
<http://www.legislation.gov.uk/ukpga/2007/18/contents>
34. Henderson J, Redshaw M (2017) Parents' experience of perinatal post-mortem following stillbirth: A mixed methods study. PLoS ONE 12(6): e0178475. <https://doi.org/10.1371/journal.pone.0178475>
35. Redshaw M, Hennegan JM, Henderson J. Impact of holding the baby following stillbirth on maternal mental health and well-being: findings from a national survey. *BMJ open*. 2016 Aug 1;6(8).
36. Redshaw M, Henderson J. Care associated with stillbirth for the most disadvantaged women: A multi-method study of care in England. *Birth*. 2018 Sep;45 (3):275-285. doi: 10.1111/birt.12335. Epub 2018 Feb 13. PMID:29436049
37. Hennegan JM, Henderson J, Redshaw M. Is partners' mental health and well-being affected by holding the baby after stillbirth? Mothers' accounts from a national survey. *J Reprod Infant Psychol*. 2018 Apr;36(2):120-131. doi: 10.1080/02646838.2018.1424325. Epub 2018 Jan 19. PMID:29517345
38. Redshaw M, Henderson J. Mothers' experience of maternity and neonatal care when babies die: a quantitative study. *PLoS One*. 2018;13(12):e0208134.
39. Quigley MA, Hockley C, Davidson LL. Agreement between hospital records and maternal recall of mode of delivery: evidence from 12 391 deliveries in the UK Millennium Cohort Study. *BJOG*. 2007; 114 (2):195–200. <https://doi.org/10.1111/j.1471-0528.2006.01203.x> PMID: 17166217
40. Bat-Erdene U, Metcalfe A, McDonald SW, Tough SC. Validation of Canadian mothers' recall of events in labour and delivery with electronic health records. *BMC Pregnancy Childbirth*. 2013; 13 Suppl 1:S3.

41. Obst KL, Due C, Oxlad M, Middleton P. Men's grief following pregnancy loss and neonatal loss: a systematic review and emerging theoretical model. *BMC pregnancy and childbirth*. 2020 Dec;20(1):1-7.
<https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-019-2677-9.ris>
42. Stillbirth Collaborative Research Network Writing Group. Causes of death among stillbirths. *JAMA* 306(22):2459–68. 2011.
43. Flenady V, Wojcieszek AM, Middleton P, Ellwood D, Erwich JJ, Coory M, et al. Stillbirths: Recall to action in high-income countries. *Lancet* 387(10019):691–702. 2016.
44. Save the Children. Stillbirths-The global picture and evidence based solutions. An executive summary for the BMC Pregnancy and Childbirth Supplement. Available from: <https://www.healthynewbornnetwork.org/hnn-content/uploads/Stillbirth-ExecSumm.pdf>
45. Infant Mortality in the United States, 2018: Data from the Period Linked Birth/Infant Death file; Danielle M Ely, PhD., and Anne K. Driscoll, PhD.
https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_10-508.pdf
46. The national fetal death file: Joyce A.Martin, Donna L.Hoyert
<https://doi.org/10.1053/sper:2002.29834>
47. MacDorman MF, Kirmeyer SE, Wilson EC. Fetal and perinatal mortality, United States, 2006. *National vital statistics reports*; vol 60 no 8. Hyattsville, MD: National Center for Health Statistics. 2012.
https://www.cdc.gov/nchs/data/nvsr/nvsr60/nvsr60_08.pdf
48. New York City (NYC) ESTOP Data Entry Guidelines Health
<https://www1.nyc.gov/assets/doh/downloads/pdf/vr/vr-estop-data-entry-guidelines.pdf>
49. Sands Guidelines
<https://www.sands.org.uk/professionals/sands-guidelines-4th-edition>
50. Mediocre or excellent-where does your facility stand?

Becoming a perinatal loss gold standard hospital
<https://doi.org/10.1186/1471-2393-15-S1-A13>

51. Steen SE. Raising the bar: development of a perinatal bereavement programme. *International Journal of Palliative Nursing*. 2019 Dec 2;25(12):578-86.
52. Stillbirths: recall to action in high-income countries. *Lancet* 2016; published online in Jan 2018. [http://dx.doi.org/10.1016/S0140-6736\(15\)01020-X](http://dx.doi.org/10.1016/S0140-6736(15)01020-X)
53. International Stillbirth Alliance: Ending Preventable Stillbirth Series
https://www.stillbirthalliance.org/wp-content/uploads/2019/10/ISA-Lay-Summary_EPS_English_final-2.pdf
54. Stillbirth 2016: ending preventable stillbirths -Lancet
<https://www.thelancet.com/series/ending-preventable-stillbirths>
55. Australian Government Privacy Act 1988:
<https://www.legislation.gov.au/Series/C2004A03712>
56. Australian National Statement on Ethical Conduct in Human Research 2007(updated 2018): <https://www.nhmrc.gov.au>
57. World Bank Country and Lending Groups –World Bank Data:
<http://data.worldbank.org/about/country-and-lending-groups>
58. International Stillbirth Alliance (ISA) member organisations:
<http://stillbirthalliance.org/about-us/member-organisations>
59. Care following stillbirth in high-resource settings: Latest evidence, guidelines, and best practice points <https://doi.org/10.1016/j.siny.2017.02.008>
60. Bill 141, Pregnancy and Infant Loss Awareness, Research and Care Act, 2015. Legislative Assembly of the Province of Ontario; Ministry of Health and Long-Term Care. 2015. <https://www.ola.org/en/legislative-business/bills/parliament-41/session-1/bill-141>

61. Live births and fetal deaths (stillbirths), by type of birth (single or multiple). Statistics Canada Table 13-10-0428-01, 2018. Statistics Canada; 2018. <https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310042801>
62. Northwest Health Alliance. Conditions related to Threatened/Missed/Spontaneous/Social Abortion Cases (CIHI case mix groups 548-551) in Ontario from April 1, 2016 to March 31, 2017. Ontario Ministry of Health and Long-Term Care: IntelliHEALTH ONTARIO; 2018
63. Infant mortality, by birth weight. In: Canada S, editor. Statistics Canada; 2018. <https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310036801>.
64. Frey J. Open ended question. In: Lewis-Beck M, Bryman A, Ruting Liao T, editors. The Sage Encyclopedia of Social Science Research Methods. <http://sk.sagepub.com/reference/socialscience>.
65. O'Cathain A, Thomas KJ. "Any other comments?" open questions on questionnaires - a bane or a bonus to research? *BMC Med Res Methodol*. 2004;4:25.
66. Survey Monkey 1999–2018 [Available from: <https://www.surveymonkey.com/>]
67. Thomas DR. A general inductive approach for analysing qualitative evaluation data. *Am J Eval*. 2006;27(2):237–46. ISSN 1098-2140.
68. Nowell L, Norris J, White D, Moules N. Thematic analysis: striving to meet the trustworthiness criteria. *Int J Qual Methods*. 2017;16(1–3):1–13.
69. Watson, J., Simmonds, A., La Fontaine, M. *et al*. Pregnancy and infant loss: a survey of families' experiences in Ontario Canada. *BMC Pregnancy Childbirth* **19**, 129 (2019). <https://doi.org/10.1186/s12884-019-2270-2>
70. Cassidy PR. Care quality following intrauterine death in Spanish hospitals: results from an online survey. *BMC Pregnancy Childbirth*. 2018 Jan 10;18(1):22. doi: 10.1186/s12884-017-1630-z. PMID: 29321000; PMCID: PMC5763533

71. Number of Births in Spain 2006-2019 –Stastica:
<https://www.statista.com/statistics/449295/number-of-births-in-spain/>
72. Mortality Rates in Spain
https://www.ine.es/en/daco/daco42/sanitarias/metodologia_00_en.pdf
73. Cassidy, Paul Richard, Jillian Cassidy, Ibone Olza, Ana Martín Ancel, Sara Jort, Diana Sánchez, M. Àngel. Claramunt, Gabriella Pi-Sunyer, Maria Teresa Bianco, and Paloma Martínez Serrano. 2018. Informe Umamanita: Encuesta Sobre La Calidad de La Atención Sanitaria En Casos de Muerte Intrauterina. Girona: Umamanita. ISBN: 978-84-09-03812-1
74. Italian National Institute of Statistics: (Istituto Nazionale DI Statistica)
www.istat.ie
75. *A critical analysis on Italian perinatal mortality in a 50-year span*
<https://doi.org/10.1016/j.ejogrb.2005.12.021>
76. Stillbirth and perinatal care: Are professionals trained to address parents' needs? <https://doi.org/10.1016/j.midw.2018.05.008>



National Care Experience Programme

