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# 'Remember Me': An Exploration of the Impact of the Féileacáin Remembering Memory Box on Parents Bereaved Through Stillbirth or Neonatal Death.

## CARL Research Project

in collaboration with

## Féileacáin



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## Declaration of Originality

I hereby state that this research project titled *'Remember Me: An Exploration of the Impact of the Féileacáin Remembering Memory Box on Parents Bereaved Through Stillbirth or Neonatal Death'* submitted to the School of Applied Social Studies, University College Cork, in partial fulfilment of the requirements for the award of Master in Social Work is my own work.

Any work that is not my own has been acknowledged and referenced appropriately.

Name : \_\_\_\_\_

Date: \_\_\_\_\_

# Community Academic Research Links

## **What is Community-Academic Research Links?**

Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grass roots groups, single issue temporary groups, but also structured community organisations. Research for the CSO is carried out free of financial cost by student researchers.

## **CARL seeks to:**

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers ([www.livingknowledge.org](http://www.livingknowledge.org)).

## **What is a CSO?**

We define CSOs as groups who are non-governmental, non-profit, not representing commercial interests, and/or pursuing a common purpose in the public interest. These groups include trade unions, NGOs, professional associations, charities, grass-roots organisations, organisations that involve citizens in local and municipal life, churches and religious committees, and so on.

## **Why is this report on the UCC website?**

The research agreement between the CSO, student and CARL/University states that the results of the study must be made public through the publication of the final research report on the CARL (UCC) website. CARL is committed to open access and the free and public dissemination of research results.

### **How do I reference this report?**

O' Sullivan, R. (2019) *'Remember Me': An Exploration of the Impact of the Féileacáin Remembering Memory Box on Parents Bereaved Through Stillbirth or Neonatal Death* [online], Community-Academic Research Links/University College Cork, Ireland, Available from: <http://www.ucc.ie/en/scishop/completed/> [Accessed on: date].

### **How can I find out more about the Community-Academic Research Links and the Living Knowledge Network?**

The UCC CARL website has further information on the background and operation of Community-Academic Research Links at University College Cork, Ireland. <http://carl.ucc.ie>. You can follow CARL on Twitter at @UCC\_CARL. All of our research reports are accessible free online here: <http://www.ucc.ie/en/scishop/rr/>.

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“Listen for my footfall in your heart,  
I am not gone but merely walk within you”

- Nicholas Evans

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## Abstract

This research dissertation was completed as part of a CARL initiative in UCC. CARL promotes community-based research, allowing for the voices of small community organisations to be heard. This research was undertaken in collaboration with Féileacáin. Féileacáin, the Stillbirth and Neonatal Death Association of Ireland (SANDI), provides support to parents and families affected by the death of a baby during or after pregnancy. The Féileacáin Remembering Memory Boxes are supplied to each maternity unit and children's hospital in Ireland. The function of these boxes is to provide support to parents and families to care of and make memories with their babies before or after death.

In 2016, the HSE introduced *National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death*. The objective of these standards was to facilitate the delivery of a comprehensive range of bereavement care services for parents bereaved while under the care of the maternity service (HSE, 2016). Féileacáin was named as a support service under these standards. Féileacáin called for this research to be undertaken upon hearing of the experiences of parents whom they support. The overall aim of this research was to understand parents' experience of receiving a Féileacáin Memory Box.

The research applied an epistemological perspective of social constructivism which was underpinned by interpretivism and participatory paradigms. Primary research was carried out in the form of an online survey which captured responses from 29 research participants. These responses were analysed from which the broad concept of 'bonds' was extracted. The findings illustrate the significance of the Memory Box to parents and families as it allows them to remain connected with their baby after their passing. Findings demonstrate how the Memory Boxes ameliorates the grieving process for parents. Furthermore, the findings question the overall standardisation of bereavement care provided by the HSE under the national standards.

A number of recommendations were drawn from the research findings and were offered in the conclusion of this research piece. It is envisaged that these recommendations will act as a foundation for future research for Féileacáin to inform policies and practices in bereavement care.

## Glossary of Terms and Acronyms

The following are a key number of terms and acronyms that are used throughout the research:

<b>Stillbirth</b>	The birth of a baby with no life at or after 24 weeks gestation (WHO, 2018)
<b>Perinatal Death</b>	A stillbirth or death of a baby within the first 2 weeks of life (WHO, 2018)
<b>Neonatal Death</b>	The death of a baby within the first 28 days of life (WHO, 2018).
<b>CARL</b>	Community Academic Research Links
<b>EDD</b>	Estimated Date of Delivery
<b>HIQA</b>	Health Information Quality Authority
<b>HSE</b>	Health Service Executive
<b>INFANT</b>	Irish Centre for Fetal and Neonatal Translational Research
<b>SANDAI</b>	Stillbirth and Neonatal Death Association of Ireland
<b>SANDS</b>	UK Stillbirth and Neonatal Death Charity
<b>UCC</b>	University College Cork
<b>WHO</b>	World Health Organisation

It is important to note that the HSE *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* (2016), which is a focal point of this research study, will be referred to as the **NSBC (2016)** herein.

# Chapter One: Introduction

## 1.1 Introduction

No parent is prepared for a child's death. Stillbirth and neonatal death can be a life changing experience for parents and families. These experiences are encompassed in the background of this study which will be discussed within this chapter. The chapter will examine the aims and objectives of the research questions and provide the rationale behind them. Research collaboration will be documented through a discussion of the CARL initiative. Finally, it will provide a brief outline of the subsequent chapters within this research piece.

## 1.2 Background to Research

Féileacáin, the Stillbirth and Neonatal Death Association of Ireland (SANDI) is an organisation which provides support to those affected by the death of a baby during or after pregnancy. It was established in 2009 by a group of bereaved parents. Their aim was to support anyone who was affected by a stillbirth or neonatal death of a baby. Féileacáin works with the 19 maternity units and two children's hospitals in Ireland to provide support to bereaved families. Since 2014, Féileacáin has supplied each of these hospitals with their Remembering Memory Boxes which offer encouragement and support for families to avail of the opportunity for memory making during the short time that they have with their babies. The contents of the box includes (Appendix 1):

- A hand knitted blanket to wrap the baby in.
- Two teddies. The idea is that the parents or family members will have one bear within them and that the baby will have the other bear with them. it is suggested that before burial the bears are swapped so that each are left with a part of the other.
- Keepsake box to hold a lock of the baby's hair or identification bracelet.
- Gift of touch. This is a small jar of balm to help care for the baby's lips.
- Keepsake folder to hold all of the baby's details.
- Butterfly poem cards which also contain the contact details for Féileacáin.
- Support leaflet pack.

- Finger/foot printing kit.
- Candle to light and to remember the baby.
- Notebook to document thoughts and feelings. (Féileacáin, 2019).

In 2016, the HSE introduced the NSBC. These standards were established in an effort to improve bereavement services for anyone who has experienced a pregnancy loss or neonatal death. Within these standards, Féileacáin was identified as a support and advocacy group. The need for this research was identified by the organisation following feedback from parents and families with whom they have worked. This feedback has highlighted that despite the standardisation of bereavement care, there remains a variance in the offering of support services to families following the death of a baby. The areas highlighted relate to inconsistency and poor timing in the offering of bereavement services and support. Subsequently, Féileacáin put forward a research project to the UCC CARL initiative which I expressed an interest in undertaking. The aim of this research was to gather data in relation to how the Féileacáin Memory Boxes were offered and explained to parents and the timescale from which such services were offered post loss.

### 1.3 Research Rationale

Despite the implementation of the HSE NSBC (2016), parents and families who are supported by Féileacáin describe experiences from which inconsistencies in care can be drawn. It is reported that these inconsistencies have resulted in missed opportunities for parents to create memories with their babies. This research has been requested by Féileacáin following much feedback from families with whom they work. The organisation stands over the willingness of parents and families who want to speak out about their experience of their loss in order to improve the systems and services for those who will experience losses in the future.

In 2019 the death of a baby still remains to be a predominantly unspoken subject amongst Irish society. The uncomfortable silence from friends, family and professionals that surrounds such a loss only sets to reinforce the issue of the silent nature of grief. Research indicates that

parents want to have their baby acknowledged and to want to be able to share their grief in an attempt to make meaning from their loss. However, this can only be done if society offers a space to support that grief. As the researcher, I hope to help to bring both the subject of and the lived experiences of those who have experienced a stillbirth or neonatal loss out from the shadows. I aim to give parents an opportunity to tell the story of their child and explore how opportunities to make memories with them impacted them and their families.

This research was completed as part of a CARL project. CARL is an initiative provided by UCC to encourage collaborative research between students and community or voluntary groups. The initiative provides a platform from which the voices of such organisations can be heard. Completion of a CARL project provides the organisation with established information and data on the subject which may become a starting point for palpable changes to be made in the research area. On hearing about CARL, I was immediately drawn to completing a project for this dissertation. In my own life, I have been involved in voluntary work for over seven years. I enjoy sharing my time to give back in many ways to society. I saw the CARL projects as a further way of me contributing to this through my research. As a developing social worker, I see my role as an agent for change. I adopt a critical approach to my thinking and see this as an opportunity to bring about positive social change. In conducting this research, I envisage that this completed dissertation will be a starting point for Féileacáin in improving and modifying their Memory Boxes. Furthermore, it is hoped that a significant contribution will be made to the knowledge and understanding of professionals which may inform practice in this area.

#### 1.4 Research Aims and Objectives

The overall aim of this research is to elicit parents' experience of receiving a Féileacáin Memory Box following a stillborn or neonatal death. The core objectives of the research are as follows:

- 1) To understand the effectiveness of the Memory Boxes by gathering information on the most/least helpful aspects of the boxes at the time they were received.
- 2) To establish how the Memory Boxes are currently used by families.

- 3) To determine if there is a variance in practices regarding the use of the Memory Boxes in the different maternity units and children's hospitals around Ireland.

### 1.5 Research Questions

Based on the research aims and objectives, six research questions were developed in collaboration with Féileacáin:

- 1) Did participants receive a Féileacáin Memory Box? If so, when did they receive it?
- 2) What was the participants experience of receiving a Féileacáin Memory Box?
- 3) What did the Féileacáin Memory Box contain?
- 4) At the time of the loss, what was the most/least helpful aspects of the Féileacáin Memory Box?
- 5) What items of the Féileacáin Memory Box still remain significant to participants today?
- 6) How could the Féileacáin Memory Box be improved?

### 1.6 Summary of the Research Strategy

This research examines the experiences of parents bereaved through stillbirth or neonatal death. With a view to understanding parents experiences of receiving a Féileacáin Memory Boxes, an epistemological perspective of social constructivism was employed, underpinned by an interpretivist framework. As the research was undertaken as part of a CARL project, a participatory paradigm was adopted also from which a qualitative survey was developed. This survey was circulated to Féileacáin service-users with 38 responses were gathered, of which 29 were used for data analysis. The research methods and findings will be discussed in Chapters 3 and 4.

### 1.7 Chapter Outline

This chapter provided an introduction to the overall research project, setting out a rationale and the research questions which informed the research purpose. Chapter Two will undertake a review of the literature in relation to the research topic. It will explore concepts of grief and loss and will look to examine national standards in relation to bereavement care. Chapter

Three will discuss the methodological approach taken within this research piece. It will also look to outline the theoretical perspective and the process of primary research. It will include a detailed account of ethical considerations that were worked through to obtain approval for this research. Chapter Four will analyse and present the findings from the data collected as part of the primary research. Links between literature and findings will flow throughout this chapter. Chapter Five will conclude the research. This chapter will include detail of several recommendations that will be made on the basis of the research findings. To conclude, this chapter will detail a reflective piece relating to the research process.

# Chapter Two: Literature Review

## 2.1 Introduction

The aim of this chapter is to give the reader an in-depth understanding of the literature surrounding theories of grief. It will look to examine how these theories transpire in practice in relation to those who grieve the death of a child. This chapter will draw on academic literature and official reports with the view to establishing a well-rounded and relevant view of discussion in the area. Furthermore, it will present statistics of perinatal death in Ireland. Finally, this chapter will conclude by examining national standards which operate as a framework for bereavement care in Ireland.

## 2.2 Grief Theories

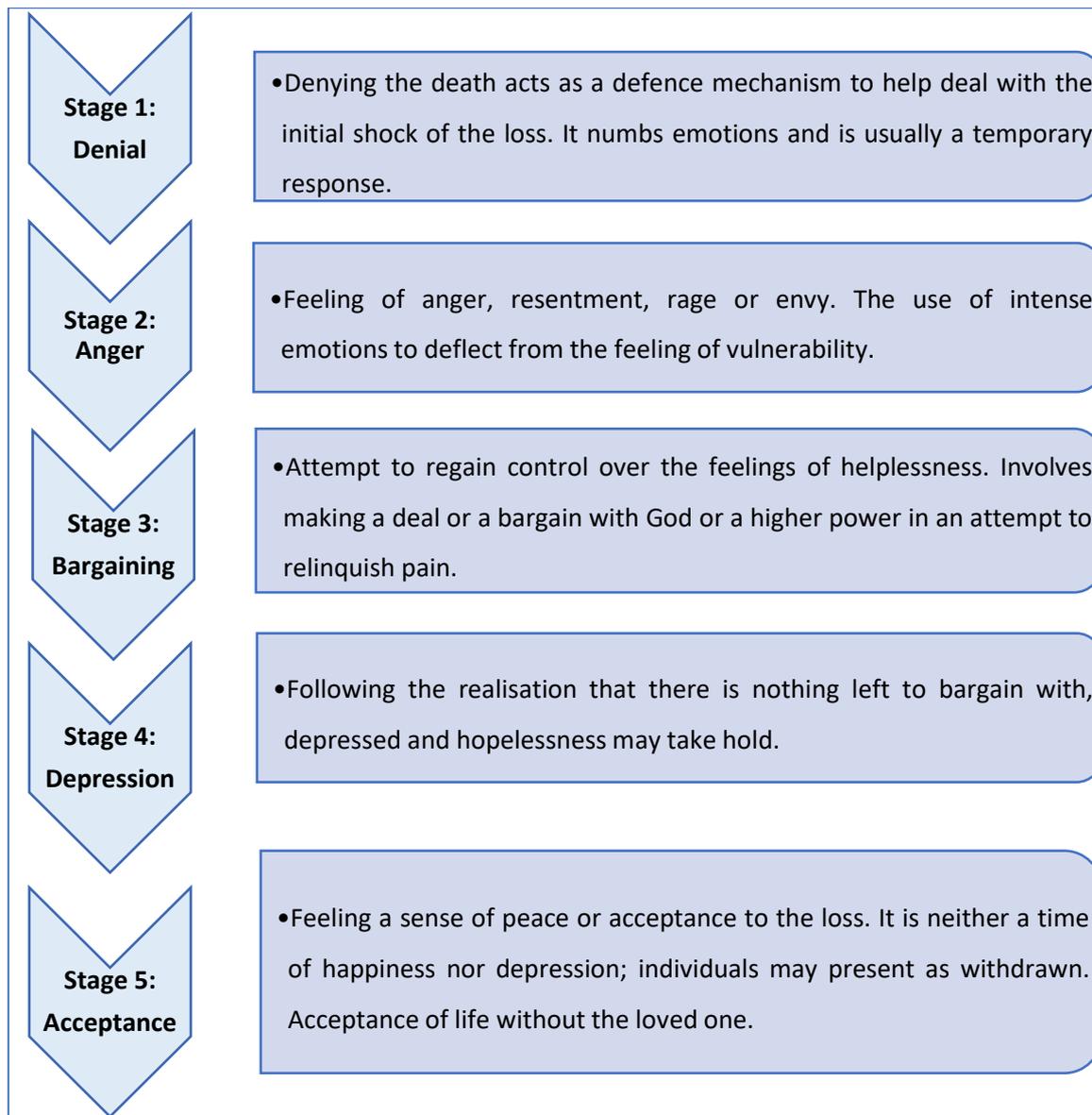
The overarching theory that is reflected in this area of research is that of grief. Bennett *et al*, (2008) describe perinatal loss as a profound and difficult event that can leave bereaved parents in a place of unknowing. Grief is a vastly complex and multidimensional process in the response to any significant loss, especially the loss of a child (Parkes, 1986). The grieving process can often be misunderstood or neglected by bereaved families and professionals around them. Grief has two purposes; to accept the death as real and to help deal with the social and emotional difficulties that come as part of the loss. Grief does not present as a linear progression in thoughts, emotions or behaviours but rather is a changeable phenomenon and a highly individualised process. According to Kaunonen (2000) there are many variables that have an effect on grief which include the type of death, the relationship to the deceased, social support systems, and the physical and mental health of the person experiencing the grief.

### 2.2.1 Traditional Grief Theories

Traditionally, it has been recognised that the journey through grief follows a path of adaptation to the loss of a loved one. Kubler-Ross (1969) saw grief as a series of phases through which individuals travelled. This theory encourages the individual to let go of the bond with the deceased and find a new way of living without them in their world in order to

move forward. Her theory consisted of the five stages of grief which are; denial, anger, bargaining, depression and acceptance.

Figure 1: Kubler-Ross Stages of Grief



### 2.2.2 Contemporary Grief Theories – Continuing Bonds

More contemporary theories of grief move away from the model of detachment and rebuilding a life that excludes any thoughts or feelings towards the loss. Recent theories emphasise the importance of the role of continuing bonds as essential to the adaptation of grief as discussed by Brennan *et al.* (2016). Notwithstanding the principals of traditional models of grief, there has been a wide recognition that the traditional perspectives do not in

capture the uniqueness of experiences of parental grief (Brennan *et al.* 2016). The emerging view is one of maintaining a connection with the loved one as opposed to surrendering ties. This model of grief challenges the idea of letting go or detaching from the deceased. 'Continuing bonds' refers to the many ways in which an individual can feel a sense of connectedness to the deceased (Jonsson and Walter, 2017). The process has been described by Stroebe and Schut (2005) as an ongoing dynamic relationship that is transformed rather than ceased, whereby the deceased is acknowledged. The memories of the deceased are kept alive by bringing them forward into the present and by incorporating them into relationships with others (Silverman and Klass, 1996). Normalising the loss and continuing bonds allow individuals to incorporate their loved one into family, community and social contexts. As discussed by Brennan *et al.* (2016), adjustment strategies such as memory making, taking photos and keeping physical items belonging to the baby all contribute to ameliorating the grief process. However, the question as emerged from Bremborg and Radestad (2013) regarding perinatal and neonatal deaths, is '*how do you make memories of and remember somebody who you did not have the chance to get to know?*' When a child did not get a chance to live in the world, parents are faced with limited direct memories and fewer opportunities to integrate them into their lives and thus parents are often faced with the struggle in bringing memories of their child forward in the world. Brennan *et al.* (2016) describes how validation by others of using the child's name played a key role in facilitating parents to bring their child forward in the world. A UK based study carried out by Larkin *et al.* (2015) found that five out of six participants recognised the importance of keeping a memory of their baby. Participants of this study highlighted the importance of taking photographs at the time that their baby died, noting their increased appreciation for the photographs with the passage of time. The photographs helped them in the healing process. Similarly, studies carried out by Hart (2014) emphasise the importance of keeping the memory of the baby alive and in memory by celebrating the birth, talking about them and recognising birthdays. While contemporary theories of grief, particularly those related to perinatal death of a child are under-researched, the perspective of the process of 'continuing bonds' serves as a useful starting point to understand the individual process for parents.

### 2.3 Anticipatory Grief

Anticipatory grief is a concept of bereavement which looks to explore the idea of expected loss. Overton and Cottone (2016) describe anticipatory grief as “a form of grief that occurs when there is an expectation of a significant impending loss or death” (p.430). The concept was coined by Lindemann (1944) who argued that anticipatory grief was experienced prior to the death of a loved one. It included the preparation for the emancipation of bonds and the planning of adjusting to new environments without them. This type of grief can be experienced by individuals whose child receives a life limiting illness prior to birth. A life limiting illness, as described by Irish Hospice Foundation (2019), is a condition or illness for which there is no reasonable hope or cure from which a person is expected to die. According to Nuzum *et al*, (2018), receiving a diagnosis that a baby will not survive or has already died in utero can bring with it an array of emotions. It can be seen as a collision of birth and death whereby parents move from a path of expectation to one of grief (Nuzum *et al*, 2018). Rando (1997) describes some of the feelings that are experienced with anticipatory grief as fear, confusion, uncertainty and powerlessness. The experience of anticipatory grief is one which can often be over looked. It can be as intense as that which occurs following the death of a loved one. Overton and Cottone (2016) argue that anticipatory grief can serve as an opportunity to prepare for death and allow a period of adjustment to the impending loss.

### 2.4 Silent Nature of Grief

Parental grief due to a perinatal loss has been recognised as an overwhelming and intense experience. The key issue of the silent nature of grief that underpins this research has been explored by Brennan *et al*. (2016). Understanding the uniqueness of the loss of a child is crucially important. A perinatal death brings with it numerous losses; the loss of new life, future plans and can often bring with it a loss of self-identity as a parent of that child (Callister, 2006). Studies have shown that parents’ grief can often be intensified by the silent nature of the loss, whereby opportunities to validate the loss are often overlooked by family, friends and professionals. Research carried out by Kelley and Trinidad (2012) found that parents struggle with the silence and taboo that surrounds perinatal death. All participants of the study identified that the silence and loneliness which followed the death of their baby, contributed to the awkwardness and discomfort felt by others when parents discussed or

attempted to normalise the experience by discussing their child (Kelley and Trinidad, 2012). Similarly, participants of a study by Brennan *et al.* (2016) described frustration and distress when their baby was not given a place in the world and they found that this impeded the healing journey for parents. The normalising of the loss is important to help parents feel authentic in bringing their baby forward in the world. Parents stressed the importance of receiving validation of their child from others by mentioning their name and acknowledging the birth. The validation and engagement of others in “saying my name” served as a dual function; for others to participate in bringing the baby forward and to help the mother to do so also (Brennan *et al.* 2012).

Silent grief is an issue which not only affects the parents who suffer a loss of a baby but can also affect professionals and how they work with these families. This body of people play a crucial role in supporting women and their families through a perinatal loss. The support offered by these professionals at the time of the loss should not be underestimated in how they encourage the mothers’ journey of healing and recovery. Research carried out by Fenwick *et al.* (2007) of midwives who provided perinatal loss care found that participants felt hesitant and lacked confidence. Midwives who participated in this study expressed feeling “unsure” as to the best course of action to take when they were faced with a loss of a baby, often not knowing what to say to parents (Fenwick *et al.*, 2007). Participants also expressed feeling confused, overwhelmed and also stated that they struggled with accepting the loss. As stated above, the validation of speaking about the baby and normalising the loss plays an integral part in the healing process for the family.

## 2.5 Bereavement Care – The Irish Context

According to WHO (2018), perinatal death is a global public health concern affecting over 2.6 million women and families each year. Pregnancy loss remains to be the largest complication of pregnancy and occurs in 20-25% of pregnancies (INFANT, 2019). Ireland is at the international forefront of bereavement care for parents who experience a perinatal death of a baby. Despite this, the area remains to be under researched within the Irish context. The

most recent statistics show that there were 407 perinatal deaths in Ireland in 2016 (Health Service Executive, 2018).

The variance in standards of bereavement care across maternity units in Ireland is an issue which is at the core of this research. The HSE NSBC were established to improve bereavement services for parents who experience a pregnancy loss or perinatal death (HSE, 2016). The implementation of these standards was seen as a resource for both parents and professionals. The development of the national standards was prompted following a recommendation outlined in the *HSE National Incident Management Team Report (2013)* following an investigation into the tragic death of a maternal patient. The aim of these standards is to:

*“...promote multidisciplinary staff involvement in preparing and delivering a comprehensive range of bereavement care services that address the immediate and long-term needs of parents bereaved while under the care of the maternity services” (HSE, 2016, p.6).*

The standards also act as a guide for bereavement care staff in leading, developing and improving hospitals responses to those who experience the loss of a pregnancy or a baby and will look to assist staff to devise care pathways in response to the loss experienced by parents and families (HSE, 2016). Féileacáin, the partner organisation of this research, were consulted with and are named in these National Standards as a support and advocacy group. Despite the standardisation of bereavement care, feedback from parents with whom Féileacáin has worked has highlighted the variance in the offering of such services following their loss. Parents and families have highlighted inconsistency and poor timing in the offering of bereavement services and supports. These inconsistencies alone can cause additional stress and upset to parents who feel they have missed opportunities to create memories with their baby. Similarities can be drawn from the accounts of these families experiences which come following the publication of the NSBC (HSE, 2016) to that of parents whose experiences were documented in the 2015 HIQA *Report of the investigation into the safety, quality and standards of services provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise*. The report highlighted the poor care that was offered at the Midland Regional Hospital to parents in the mist of their grief which was found to not reflect

good practice (HIQA, 2015). One such finding detailed how some babies' keepsakes were never returned to the family or were incomplete resulting in missed opportunities for memory making. The comparisons between these experiences leads to question how, if at all, the NSBC (HSE, 2016) have been implemented in the 19 maternity units and two children's hospitals across the country. It demonstrates that the issue runs deeper than an adverse systematic response to bereavement care. Is it possible that the inconsistencies can be linked to individual responses from those whose responsibility it is to provide on the ground care to parents? On the wider system, it poses a question for personal and professional accountability of hospital staff.

## 2.6 Conclusion

This chapter has provided the reader with an overview of the theories which flow through this research topic. It has presented both traditional and more contemporary theories of grief which are linked to this study. Also, it has explored bereavement care within the Irish context. It examined the NSBC (HSE, 2016), providing a contextual background from which these standards have emerged. Finally, it introduced the reader to the context from which this research stems by drawing a clear link between variations of these national standards and the said experiences of parents and families with whom Féileacáin has worked with. The above-mentioned content has provided a foundation from which an online survey has been devised to explore parents' experiences of receiving a Féileacáin Memory Box, the methodology of which will be presented in the subsequent chapter.

# Chapter Three: Methodology

## 3.1 Introduction

This chapter aims to provide an overview of the research process that was undertaken for this study. The epistemological and theoretical perspectives that were adopted will be presented along with a discussion of the overall research design and the chosen method of data collection and analysis. The chapter will conclude with a discussion of the ethical considerations and issues that were encountered in undertaking this research.

## 3.2 Epistemological and Theoretical Perspectives

According to Carey (2009), epistemology relates to the 'theory of knowledge'. It is utilised in research as a way of understanding and learning about the social world. The epistemological perspective that was applied to this research project was social constructivism. This approach works on the principle that there are multiple representations shared by people in specific contexts (Ormston *et al*, 2014). It ascertains that the knowledge of the social world can only be obtained through the representations people construct of their experiences (Onwuegbuzie *et al*, 2016). As this research aims to look at the experiences of parents who receive a Féileacáin Memory Box, I am of the view that the knowledge of the experiences of participants, while similar, can have multiple representations and therefore decided to adopt a social constructivism paradigm to the research. The data obtained in the research was through the experience of participants, from which each experience can differ, therefore it can be said to be socially constructed.

This research draws from a number of theoretical perspectives. The term theoretical perspective relates to the philosophical positioning which informs the methodology. An interpretivist positioning provided a useful framework to this research because it seeks to uncover how people make meaning of and interpret their experiences in the social world (Carey, 2009). This perspective was employed to support the aim of the research which is to endeavour to understand parents experience of receiving a Féileacáin Memory Box with a view to conceptualizing the views and experiences of the research participants.

As a CARL project, the research also adopted a participatory paradigm whereby the research study and questions were designed in collaboration between the researcher and Féileacáin. As the researcher, I felt that the epistemological perspective of social constructivism aligned well with the participatory paradigms and the principles of the CARL initiative because Féileacáin and the research participants were central to the study. According to Misra and Prakash (2012) the principles of social constructivism fosters trust and promotes dialogue. It also emphasises the recognition of 'other' on their terms. In adopting a social constructivism approach to the research, it promoted the development of a sense of trust with me as the researcher of such a sensitive topic.

### 3.3 Methodology

Establishing and defining a methodological positioning helps to bind, direct and guide research (Carey, 2009). Primary research was carried out within this study. The research design consisted of a questionnaire in the form of an online survey using the Google Forms platform (Appendix 2 and 3). The decision to conduct the research using an online survey was as a result of a number of research considerations and limitations which will be discussed hereafter. A literature review was undertaken which informed the structure, design and content of the survey that was devised. This involved defining the survey questions in collaboration with Féileacáin and deciding in advance what would be asked. The survey design consisted of a variety of question formats which included closed, open and multiple-choice questions. A provisional survey was then piloted with Féileacáin service users who gave feedback in relation to the structure of questions. As a result, the survey design was altered to include the answer option of 'other' to allow participants to give responses that were unanticipated. Furthermore, following consultation with the MSW Research Ethics Committee, the survey design was modified significantly to remove many multiple-choice questions and to include predominately open-ended questions throughout the survey. This request largely transformed the research study. While it added significant depth to the research and allowed for the fostering of an increased qualitative approach, it brought with it limitations in the number of responses the research could gather and analyse. These limitations will also be discussed in the subsequent sections below.

### 3.4 Sampling

Access to research participants was approved through the CARL initiative. Purposive sampling was used for the research process of which the aim was to gather sufficient data which would allow the research topic to be interpreted and explored (Carey, 2009). Participants were firstly selected to participate as they had availed of Féileacáin’s support services. Following this, inclusion and exclusion criteria was added for participants of the study. The description of and the rationale for each is as outlined below:

*Figure 2: Participants Inclusion and Exclusion Criteria*

Inclusion/Exclusion Criteria	Rationale
Participants had to have given birth in Ireland.	At the time of the study, Féileacáin solely provided Memory Boxes to maternity units and children’s hospitals in Ireland.
Participants had to have experienced a second trimester loss, stillbirth or neonatal death.	Féileacáin’s Memory Boxes are currently only fully established to support parents whose baby dies during these periods.
Participants must have been bereaved between the period of the 1 <sup>st</sup> of January 2016 and the 28 <sup>th</sup> of February 2018.	The HSE NSBC were established in 2016. One of the objectives of the research is to examine if variance exists in the care received by participants since the introduction of these standards. Also, the MSW Research Ethics Committee upheld the decision for participants be a minimum of 1 year bereaved before partaking in the study.

Féileacáin was provided with a copy of Google Forms link for the survey which they circulated to service users starting on the 4<sup>th</sup> of March 2019. From this, service users could access and read the research information sheet which gave in-depth details of the research being undertaken (Appendix 4). If consent was given to partake in the study, then these service users became research participants (Appendix 5). The survey remained open until the 18<sup>th</sup> of March 2019. A total of 38 responses were gathered, of which 29 were used for data analysis within this research. There were 9 responses obtained that could not be used in the study as participants did not meet the inclusion criteria of being bereaved between the specified dates.

### 3.5 Data Analysis

The survey responses were analysed using a mix of methods. The data gathered from closed ended questions to profile participants was analysed using the Google Forms software. This data is predominantly presented using graphs in Chapter 4. The remainder of the responses, which were largely open-ended questions, lent to the subsequent data being analysed thematically. Carey (2009) explains that this approach aims to unearth themes within the collected data which can include trends, patterns or outcomes that can be utilised to draw conclusions from. In relation to this study, it involved interpreting the material received through survey responses and looking to identify patterns across participants explanations of their own experiences. A system of coding was used to compile units of related data which fitted well together. Each unit was then further examined and analysed from which themes were then drawn. Once identified, these themes were examined and pieced together to provide a comprehensive picture of participants experiences. Themes were then linked back to the existing literature about memory making, 'continuing bonds' and national standards from which conclusions were then drawn. These conclusions will be presented in Chapter 5.

### 3.6 Ethical Consideration

Research ethics refers to the moral principles and guiding conduct that is to be upheld throughout a research process (Wellington, 2015). The ethical approval process for undertaking this research was both lengthy and thorough. An initial application was made to the MSW Research Ethics Committee in October 2018. This application was made for a joint research study. However, the study did not proceed as a joint piece and this application was disbanded in late December 2018.

A subsequent application for a revised individual project was made in January 2019 which outlined the research rationale, methods and the research questions. It also included a copy of the devised online survey which included the information sheet for participants. This application returned with a number of questions and recommendations from the committee in relation to the research project put forward. Due to the change in the research from a group to an individual project, the committee suggested that the research take an increased focus solely on the Féileacáin Memory Box. This involved the removal of questions relating to

the experience of interacting with members of hospital staff and the support participants received from same and the rewording of questions to a more general format to reflect this positioning. Permission to proceed was granted in February 2019 by the MSW Research Ethics Committee with the understanding that minor amendments be made (Appendix 6).

The following are the most pertinent areas of consideration that emerged from the overall approval process:

- The format of the questioning be changed to allow for predominantly open-ended questions. As the researcher, when initially designing the survey, I was conscious of getting a balance between gathering quality data and asking sensitive questions through the means of an online survey. This was a very progressive suggestion made by the committee as it allowed for much richer data to be collected by giving participants an in-depth opportunity to relay their experiences.
- The committee questioned the length of time that participants should be bereaved. They queried that the suggested timeframe of 12 months too soon for parents to partake. From the outset of the study, Féileacáin had assured that there was a hunger for their service users to be given an opportunity to have their say. This was further supported by research by Budd *et al.* (2018) which looked at women's experiences of being invited to partake in research relating to the death of their baby. The study drew on research conducted by Stacey *et al.* (2011) which reported that women within a six-week period of experiencing a stillbirth stated the desire to partake in the research with a view to helping others. They also welcomed the opportunity to talk about and to share their experiences (Stacey *et al.* 2018). The findings of this study were relayed to the committee who approved the 12-month timeframe.
- Language was a reoccurring feature in much of the ethical approval process. When developing the survey with Féileacáin a discussion was had in relation to the use of terminology of death. The organisation argued that the language used in the survey must be clear and direct and terms such as "loss of a baby" could be upsetting or offensive for participants. As the researcher I was initially uncomfortable with using terms that explicitly related to the death of a child as I felt it may be upsetting for

participants to be asked in such a direct way. I took on board the suggestions made by Féileacáin and opted to continually use these terms. Saleeby (1996) discusses how professional discourse on clients with whom we work are routed in relationship based social work. His bold statement that ‘words have the power to elevate or destroy’ is fitting with regard to the use of language within this survey (Saleeby, 1996). It is true also to say that as social workers we are indebted to examining our dictionary of helping (Saleeby, 1996).

The completed survey was piloted with Féileacáin service users who supported the use of clear and direct language. The survey was submitted along with the application for ethical approval. The use of the term death as opposed to loss throughout was initially queried by the committee who felt that the area of study was too sensitive to use such terms. The committee were informed that service users of Féileacáin had approved the use of language in this regard. After much consideration, approval was granted for the survey design and the language used therein.

Since the granting of this approval, a recent National Maternity Bereavement Forum discussing the Implementation of NSBC (HSE, 2016) was held at UCC. Part of the forum discussed the use of language following a diagnosis of a stillbirth. In her discussion O’Donoghue (2019) highlighted the importance of the use of language that is direct, accurate and understood. This further reinforces the decision to revise the language that was used within the research survey.

The process of obtaining ethical approval felt at times daunting, frustrating and unachievable. Through many discussions with my research supervisor I tried to uncover why I felt this way. I acknowledged that I was overly focusing on the research participants and their hunger to have their voices heard. In doing so, I was pushing aside the need for a rigorous ethical approval process to be undertaken. During this time, I had to take a step back from the research in order for me to reconnect with my positioning as the researcher with a view to remaining unbiased. While the process was long and testing, it improved the research design which resulted in a well-considered survey.

### 3.7 Reflexive Positioning as the Researcher

As the researcher, I recognise the need to acknowledge that all research carries probable bias on both the part of the researcher and the research participants. As this research topic is one of a sensitive nature, it was important that I recognised my positioning throughout the research process. It is for this reason, that I kept a reflective journal throughout. This allowed me to question my connectedness to the research in an effort to remain neutral and free of biases throughout the process. While according to Sword (1999) no research can be fully free of assumptions, bias or the personality of the researcher, it is anticipated that the use of reflection in this regard would increase the validity of the research findings.

### 3.8 Challenges and Limitations

There were a number of challenges and limitations to the study. The changing nature of research can bring with it many challenges. In the case of this study, the move from a joint research piece to a single project resulted in many changes needing to be made to the research method and design which in turn triggered further ethical consideration. It was initially envisaged that face to face interviews would be carried out with participants. However, changes in the project left a tight timeframe to carry out interviews. It was decided that the project would proceed conducting online surveys. The use of an online survey in researching a sensitive topic is not an automatic match. As the researcher, my preferred method would have been to conduct interviews from which participants could be de-briefed afterwards. The idea of conducting an online survey in relation to stillbirth and neonatal death did not fit well with me. The process challenged my preconceived conceptions of what a survey could and should be. My view was that it could only collect a large volume of quantitative data which I felt was not what the aim of this study. In an effort to maintain the research questions, the MSW Research Ethics Committee, Féileacáin, my research supervisor and I worked tirelessly to develop a survey design that would capture the experiences of participants using an approach that acknowledged the sensitive nature of the topic being discussed and that would be ethically sound. The direct support of Féileacáin to research participants allowed for a survey to be used in this regard. The development of an online survey that would be secure for participants to partake included formatting to direct participants towards certain questions depending on answers given. This was something I had

spent a lot of time planning and structuring as I wanted to ensure that participants were not asked questions that did not relate to their experiences. For example; participants who reported they did not receive a Féileacáin Memory Box were moved to a section of the survey which asked if they would have liked to receive a Memory Box as opposed to the next question which related to the contents of the box (Appendix 2). It resulted in a survey design that was sensitive, rigorous and allowed for a large volume of qualitative responses to be gathered. While the survey was a success, I feel that further research in this area would benefit from face to face discussion with participants.

The word count was a significant limitation of the study also. The recommendations, as outlined above by the MSW Research Ethics Committee, to alter the format of the survey questions to include a large number of open-ended questions limited the number of responses that could be obtained. It was suggested that the data gathered would be too much to analyse within the limited word count for this study. It was proposed that the study would take a two phased approach, whereby the remaining, unanalysed data would be used in a subsequent study or a second phase of analysis. This had to be relayed to participants within the survey information sheet and their consent had to be obtained.

A further limitation of this study was that all 29 participants of this study were female. While the study was open for all genders to partake, it was solely mothers who responded. This is reflective of much of the literature that surrounds the experience of stillbirth and neonatal death which focuses on women's experiences. Martin and Doka (1998) argue that traditionally, men are primarily inexpressive grievers and thus it is possible that men are not as comfortable as women in partaking in this type of research. The impact of pregnancy loss on men remains largely unexamined area within the literature.

### 3.9 Conclusion

This chapter has provided the reader with an in-depth discussion of the methodology used within this study. The epistemological and theoretical perspectives of social constructivism, interpretivism have been presented and linked to the research topic. A participatory

paradigm has been discussed which has remained at the centre of the research study. Research methods and sample have been discussed along with the rationale for the application of inclusion and exclusion criteria for research participants. The data analysis methods were discussed from which research findings and conclusions have been drawn and will be presented in the final two chapters. Finally, this chapter has not faltered in providing a lengthy and honest overview of the process of ethical approval, ethical considerations and challenges that were faced in undertaking this research study.

# Chapter Four: Findings

## 4.1 Introduction

This chapter is focused on presenting and discussing research findings that were gathered from data collected using the methods outlined in Chapter 3. The findings have been grouped together thematically into four key themes which centre on the concept of bonds. Findings have linked with literature to provide an informed analysis. It is important to note, that pseudonyms have been given to babies whose names have been eluded to in survey responses.

## 4.2 Demographic Information

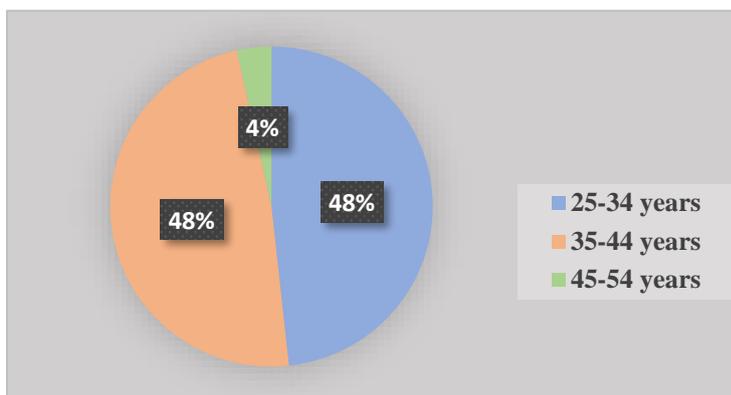


Figure 3: Age of Participants

As indicated, survey responses show an even split in age categories. The age cohort did not allow for the examination of parents under 25 years of age experience of the Féileacáin Memory Box.

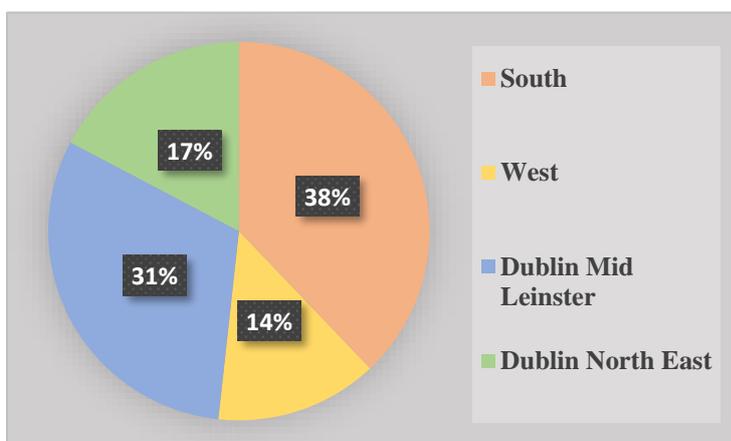
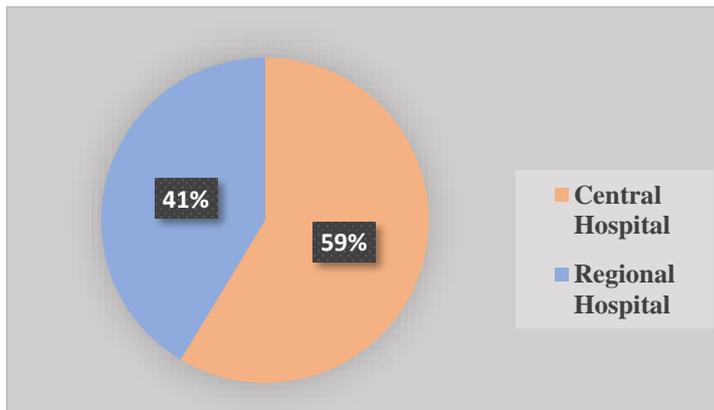


Figure 4: HSE Region

Participants were asked to indicate which HSE region they were living in when their baby died. Data was captured from all four of the HSE regions, proving a good representation of experiences from a national perspective. As

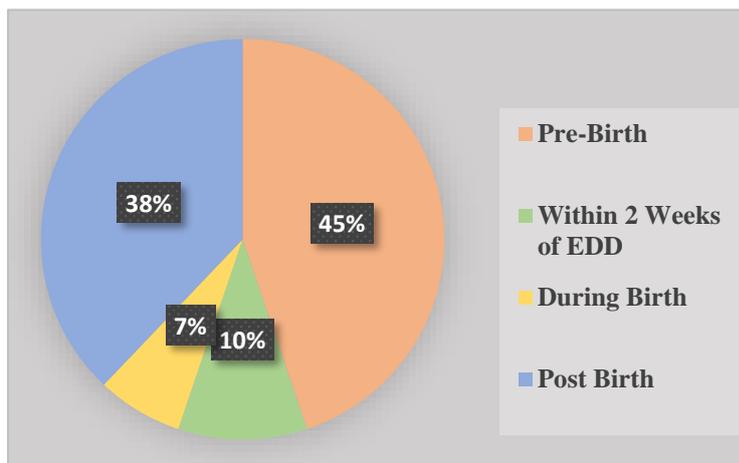
Féileacáin is a national service, it is positive to see responses from all areas as it gives an indication of the operation of its services within all regions.



*Figure 5: Classification of Hospitals*

Participants were asked to indicate where the birth of their child took place. The largest proportion of respondents (17) gave birth in a Central Hospital in Ireland while 41% (12) of respondents reported

giving birth in a Regional Hospital. This is reflective of the information provided in Figure 4. As nearly half of respondent's hail from the greater Dublin region. The description of the classification of hospitals can be seen in Appendix 7.

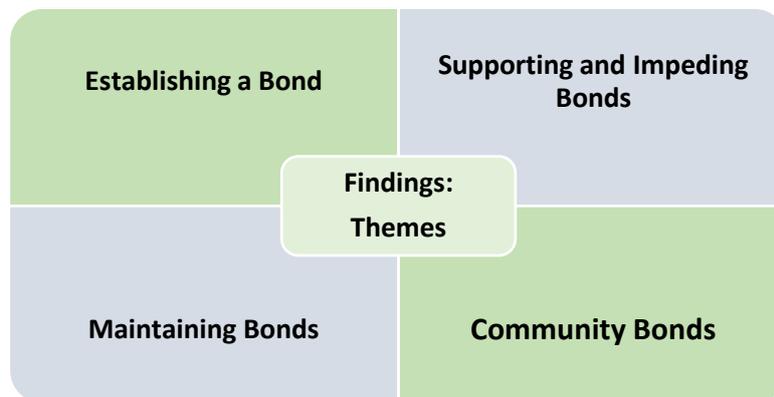


*Figure 6: Time of Death*

Research participants were asked to indicate when their baby died. This data shows a variance in the timing of death. Information gathered in relation to the timing of death allows for further exploration of difference in

experiences within themes below.

Figure 7: Themes



### 4.3 Theme One: Establishing a Bond

According to the information gathered in this study, 100% of participants received a Féileacáin Memory Box. A prominent theme that has emerged from the research relates to how the Memory Box helped participants to establish a bond and feel connected to their baby. Participants were asked questions in relation to their experience of receiving a Memory Box. The analysis of the data gathered from these questions will be presented through this theme.

#### 4.3.1 Memory Making:

When discussing their experiences of the Féileacáin Memory Box, each account centred on how the box helped them to make memories of their baby. Participants described how various items contained in the box facilitated this. 72% of participants included detail of the teddy bears in their accounts and discussed the meaning these had for them. For one participant these teddy bears enabled sensory memories to be made:

*“I swapped them daily so that my baby had me, and I could smell him” (P.2).*

The sense of touch was facilitated through the use of the lip balm contained in the boxes, as also seen from the accounts of participants:

*“...the lip balm as it’s something I use a lot, and everyone teases me about my addiction to it so it was lovely to share that with my baby girl and also made us laugh at such a sad time too” (P.4).*

*“I have beautiful memories of using the lip balm on my baby” (P.12).*

Participants reported that the teddies help to keep the memory of their baby alive and help them in continuing to feel connected. One participant describes how the teddy bear still remains a significant part of her life even after the passing of time:

*“The little bear continues to sleep in between mine and my husband’s pillow 16 months after our sons died” (P.4).*

The concept of connection was described by many participants also:

*“I have ‘Jake’s’ teddy that was in his coffin with him and he has the one that was with us. So, I have part of him with me” (P12).*

*“...we have a connection to baby ‘Luke’ after death with the teddy as we both have one each” (P.25).*

Responses also identified the significance that the bears held for siblings. Participants described how the use of the teddy bears are used daily by other siblings:

*“We hugged and kissed our bear until the day we had to say goodbye and then we swapped them...big brothers sleep with our little bear every night...we borrow the brown bear when we need a little cuddle too” (P. 18).*

#### 4.3.2 Acknowledgement of Life:

Findings of the research show that, for participants, the Féileacáin Memory Box served as an acknowledgement of their baby’s life. Participants spoke of how items contained in the box acknowledged that their baby existed and allowed for them to hold a physical representation of their baby:

*“Prints kit...it is the only physical piece of my son I will have here now” (P.7).*

Speaking of their experiences, participants also described how they have incorporated their baby’s prints into their lives:

*“I used the prints to have his handprint permanently tattooed over my heart” (P.25).*

*“The prints, I now have them tattooed on me, so my baby walks everywhere with me”*  
(P.28).

Similarities can be drawn from accounts of participants who found that the box promoted the opportunity to hold on to a physical part of their baby. Participants described how this would have not been possible without the Féileacáin Memory Box:

*“...clipping of his hair is very special and something without the box we would’ve never had”* (P.9).

*“The box for lock of hair (sic) was my most treasured piece because I never would have thought to take that myself only for the nurse showed me the box for it”* (P.15).

#### 4.3.3 Discussion

These findings demonstrate that the Féileacáin Memory Box facilitates the process of memory making through the various items contained within. The findings indicate also that the contents of the Memory Box allow for making and embedding of sensory memories. Memory-making has been seen as a central feature of the concept of ‘continuing bonds’ as described by Silverman and Klass (1996). The literature argues that this concept is an essential component to the adaptation of grief. Silverman and Klass (1996) describe the importance of parents keeping the memories of their baby alive by bringing them forward and incorporating them into relationships with others. Participants of this research described how the contents of the Memory Box has given them to opportunity to integrate memories of their baby into relationships with other siblings. The integration of the teddy bears into everyday life allows for the relationship with their baby to continue rather than be severed which promotes the idea of maintaining a connection with the baby after death. This indicates that the contents of the box centres on the idea of connectedness as a natural and adaptive experience to the death of a baby as described by Brennan *et al.* (2016). Furthermore, the findings indicate that the Memory Box is seen by participants as an acknowledgement of the life of their baby. The hair clippings and hand and foot prints were seen by participants as a physical representation that their baby existed. The concept of ‘continuing bonds’ can be seen throughout the accounts of research participants experiences of the Memory Box. The literature tells us that

the grieving process for parents is supported by making memories and maintaining a connection with their baby following death.

#### 4.4 Theme Two: Supporting and Impeding Bonds

The second theme that emerged from the findings relates to the factors which support or impede bonds. This concept was drawn from the disparity in participants experiences of care. This section will provide the reader with an understanding of the variance in participants experience of receiving a Féileacáin Memory Box and will describe how this impacted their experiences of memory making. While all 29 participants received a Féileacáin Memory Box on or before the death of their baby, findings indicate that there is a variance in the practices in the giving and communicating of the Memory Boxes.

##### 4.4.1 Timing

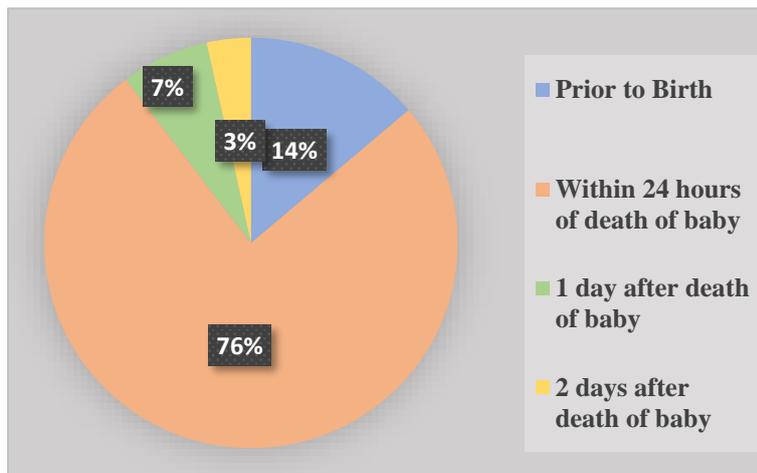


Figure 8: Time Memory Box Received

According to the information gathered in this study, 76% of participants reported receiving a Féileacáin Memory Box within 24 hours of the death of their baby. These findings appear to be consistent with the HSE NSBC

(2016). Standard 2.13, in relation to bereavement care, states that:

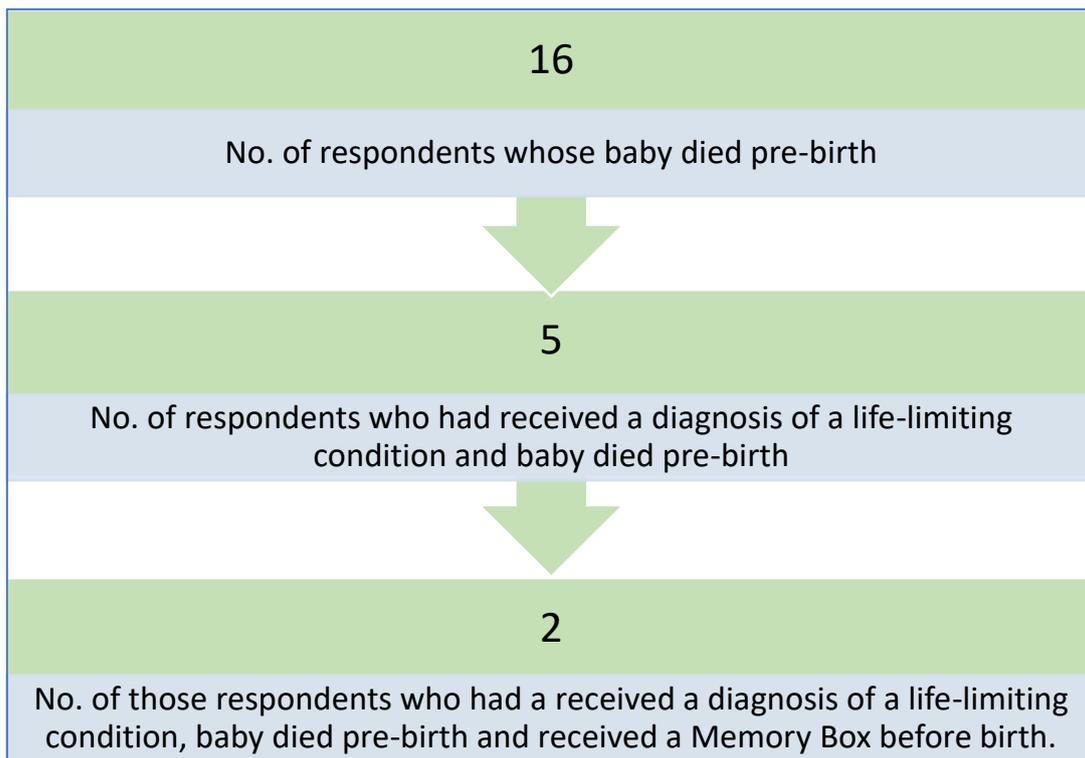
*“parents, siblings and extended family are offered timely and appropriate bereavement supports from within hospital and/or community resources”* (HSE, 2016, p. 45).

However, the term “timely” seems to be problematic as there is no defined timeframe stated within the standards to denote how long a parent should be waiting to receive any bereavement support. This observation is evidenced in the data gathered during this study

which shows that 10% of participants waited more than 24 hours after the death of their baby to receive a Féileacáin Memory Box, with one participant reporting waiting two days. In waiting two days to receive the box, it must be questioned if this mother missed opportunities to care for and make memories with her baby.

On analysing the responses, it was evident that participants experience differed depending on when they received their Memory Box. 16 (55%) respondents experienced the death of a baby pre-birth (Figure 6). The table below shows that 5 out of these 16 respondents received a diagnosis of a life-limiting condition for their baby. Further analysis of these responses shows that only 2 of these 5 received a Féileacáin Memory Box prior to giving birth (Figure 9).

Figure 9: Variance in Experiences for Diagnosis of Life-Limiting Condition:



Participants described the benefits of receiving their Memory Boxes before giving birth to their baby:

*“...the phone number as we rang Féileacáin and got great support there” (P.8).*

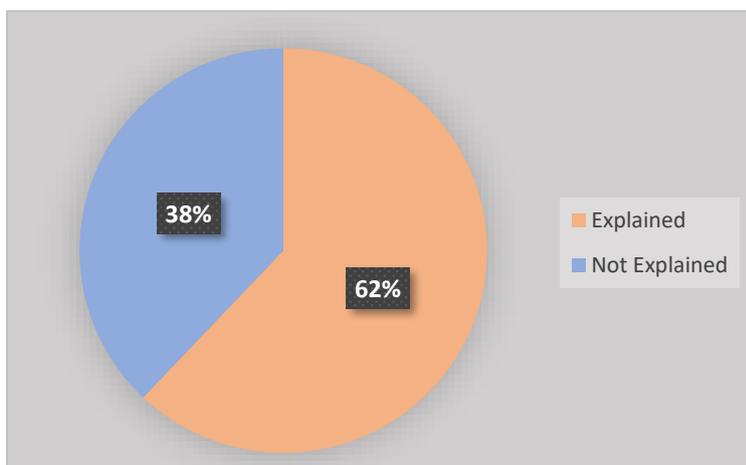
*“It was lovely, we were able to bring it home and go through it and prepare for ‘Ciara’s’ birth. It gave us something to have ready and we felt a bit less helpless in a situation we had no control over” (P.21).*

These accounts differ from the experience of another participant who, despite receiving a diagnosis that her baby had a life-limiting condition, did not receive a Memory Box until after she gave birth to her daughter:

*“I was begging for one from the minute I was told my baby would die...but they wouldn’t give me one until she was dead which was really wrong...I wanted to be making memories and saving them in it for the last few weeks that I was carrying her” (P.14).*

#### 4.4.2 Communication

When looking to examine if further variance existed in the bereavement care received by research participants, data in relation to communication was analysed. Findings show that there were a number of different responses reported by participants in relation to how the Féileacáin Memory Box was communicated and explained to them.



*Figure 10: Explanation of Féileacáin Memory Box*

This chart shows the percentage of participants who received an explanation of the Féileacáin Memory Box. While the data collected shows that almost two thirds of participants had the box

explained to them, the findings indicate that not all participants were communicated with.

Survey responses were further analysed to facilitate an exploration of the impact of this on participants.

The respondents who received an explanation of the Memory Box described a positive and supportive experience;

*“...seemed to know the right time and approach to sharing any information with us” (P.10).*

*“My clinical nurse went through everything that was in it very well and in a lovely manner I understood everything that was in it” (P.12).*

Furthermore, one participant described how the explanation of the Memory Box supported her in establishing a bond and facilitated the memory making process:

*“...the midwife explained to us that it was all about making memories, so we were keen to get it asap” (P.3).*

A considerably different picture is painted of the experiences of the respondents who reported not receiving an explanation of the Memory Box:

*“The need to tell you what it is and what it’s for. If the Féileacáin girl hadn’t come in about the clay prints we wouldn’t have swapped over the teddys and this makes me sad...they should explain it to you better in the hospital” (P.1).*

*“...it would be good to open it and go through it opposed to just being handed it. I had no idea what it was until I went through it about 6 weeks after the boys died” (P.5).*

*“I would have liked to have had the idea behind the teddy’s explained to us when we received the box instead, we found out 3 days later” (P.9).*

*“We didn’t know what it was. I thought it was one of those Bounty Bag type of products I got years ago when I had my other child” (P.26).*

Standard 2.3 of the HSE NSBC (2016) states that: “*There is timely, clear and sensitive communication with the baby’s parents and their families on all matters relating to dying, death and bereavement care*” (p. 35).

While 62% of participants received care that was reflective of this statement, it remains that 38% did not.

#### 4.4.3 Discussion

Despite the standardisation of care under the HSE *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* (2016) research findings demonstrate that variance existed in the care experienced by participants of this research. The first area examined related to the timing of receiving a Féileacáin Memory Box. The impact of the delay in receiving a Memory Box can have a resounding effect on parents and families. The purpose of the Memory Box is to give parents the materials to support and care for their baby and to make memories with them before or following their passing. Any delay in opportunities to make memories can impede on the opportunity to create bonds between a parent and their baby. In examining variance in timing, the research looked specifically at the experiences of participants who received a diagnosis of a life-limiting condition for their baby (*Figure 8*). Participants who reported receiving a Memory Box pre-birth, described a positive experience which supported them in their grieving process. Anticipatory grief refers to grief that is often experienced by those whose baby receives a diagnosis of a life-limiting condition prior to birth. The literature tells us that those who experience anticipatory grief often report feeling powerless and having no control (Rando, 1997). Findings demonstrate how the offering of a Féileacáin Memory Box prior to birth helped one particular participant in her grief as it allowed her to feel prepared and in control. Contrary to this, was the experience of a further participant who did not receive a box until after her baby died. When analysing participants responses against the HSE *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* (2016) it was evident that standards were varied. Examination of standard 1.2 indicates that in cases of a diagnosis of a life-limiting condition of an unborn child, the parents, as part of a palliative approach, will meet with a member of the Bereavement Specialist Team (BST) to “discuss memory making both of the pregnancy and following delivery” (HSE, 2016). As seen from the above accounts, this was not the experience

for all participants. Research findings, therefore, suggest a lack of standardisation in bereavement care under these National Standards.

The second area examined related to communication. Participants described an array of experiences of how the Féileacáin Memory box was explained to them. Findings show that these accounts were not consistent with the HSE *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* (2016). The absence of explanation of the Féileacáin Memory Box, in the above extracts, not only amounts to a missed or near missed opportunity for memory making but also contributes to the silent nature of grief, a concept which has been a prominent aspect within the literature. A study carried out by Brennan *et al.* (2016) documented how missed opportunities by professionals to validate the loss can intensify the grieving process for parents. The research findings demonstrate that there is a considerable variance in experiences of bereavement care as reported by participants. These findings question the overall implementation of the HSE *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* (2016).

#### 4.5 Theme Three: Maintaining Bonds

The concept of maintaining bonds emerged a prominent feature within the research findings also. Participants were asked to describe the significance the Féileacáin Memory Box held for them and their families currently. Responses demonstrate how the Memory Box helped participants to maintain a connection with their baby after death. They also described the importance that the box has for friends and family currently. The findings from this question will be presented and linked with relevant literature to provide the reader with an understanding of the meaning of the Memory Box in keeping a connection with the baby with the passing of time.

##### 4.5.1 Connecting Family and Friends:

It emerged from the findings that the Féileacáin Memory Box played a significant role for participants in keeping the memory of their baby alive. Responses demonstrate how the box

helped participants to bring their baby forward in the world to be kept within the memories of their friends and family:

*“It is a place I have all my memories of him in and it’s so nice to be able to open it and think about him. It is also something I can share with friends and family too” (P.9).*

*“If people come to visit and there is talk about ‘Kate’ the boys will take out the box and want to show off her little clothes and hand/foot prints” (P.18).*

Participants also described how they envisage using the Memory Box into the future:

*“I know I have all of ‘Ciara’s’ bits there that when I am able which is not very often that I can go there and look at them and if we have more children I can show them the bits belonging to their big sister” (P.21).*

Responses show that the Memory Box helps parents to keep a connection with their baby which can also be extended to friends and family members.

#### 4.5.2 Growing Memories:

Research findings have identified the significance the Féileacáin Memory Box holds for participants with the passing of time. Participants described how the box is the “centre of their world” (P. 26) which holds their treasured memories of their baby. Participants reported extending the use of the Memory Box to hold all other belongings of their baby:

*“It holds all the cards, photos and little bits we have to remember our son” (P.2).*

*“I often like to take the boxes out and go through them. I have added things to them, and it brings me comfort to know that even though ‘Cian and Daniel’ lived for a very short time, they have had a massive impact on our lives and it’s nice to be able to keep their memoirs in a box that was made for them” (P.4).*

*“The memory box holds so many precious moments with my baby girl. I added some of her belongings to the same box and I couldn’t be without it. I have recently bought a fireproof bag to store the memories in” (P.10).*

*“We treasure them and continue to add to them and look at them” (P.14).*

Responses show how the function of the Memory Box changes with time. By adding to the contents of the Memory Box, participants have identified how the box serves the function of remembering their baby after they have passed. In having a place to hold all belongings and memories of their baby, it allows parents to bring their baby forward in the world.

#### 4.5.3 Discussion:

Research findings show that the Féileacáin Memory Box allows the bond between a parent and baby to be maintained even with the passing of time. Furthermore, as seen from participants responses, the box helps to keep siblings, friends and families connected to the baby also after death. The literature identifies the importance of maintain an ongoing relationship after death (Stroebe and Schut, 2005). The findings show that continuing to use the Féileacáin Memory Box not only helps to keep the memory of the baby alive but also aids bringing them forward and integrating them into the present and into relationships with others (Silverman and Klass, 1996). We have seen from the literature that bringing a baby's memory forward into present and future life allows healing to occur for parents.

#### 4.6 Theme Four: Community Bonds

The theme of community bonds can be seen throughout the findings of this research. In describing their experience of the Féileacáin Memory Boxes, participants spoke of solidarity in grief from feeling part of a wider, collective community. For some, the idea of being part of a community originated from receiving a Memory Box. One participant described the comfort she felt when receiving a box and how this represented to her that she was not alone;

*“So mixed up...then I was so happy/glad (I don't know the right word) to know there were others out there like us” (P.8).*

For others the Memory box showed that they were supported by others even though they had never met:

*“...as we spent a few days in hospital I really appreciated that somebody had thought to put these things together for us, at a time when we couldn't think straight” (P.10).*

In relation to the contents of the Memory Box, participants described how they felt reassured, affirmed and at peace with making memories with their baby after they died:

*“It gives you peace as well...in real life you would never dream of taking photos of a dead person let alone a baby. It made it ok for us to gather our own memories” (P.25).*

*“When my older daughter went through it and she found the camera we felt well it must be ok to take pictures” (P.28).*

One participant describes feeling shared grief with others:

*“...everyone kept telling me I know how you feel when they couldn’t possibly know...I can remember a member of Féileacáin...saying to me what everyone else said, I know how you feel. At that point I was ready to shout HOW? HOW DO YOU KNOW HOW I FEEL AND WHAT I AM GOING THROUGH!!! And just as I was ready to shout, this lady said she lost her daughter and she understands...I felt an instant connection and thought somebody knows, somebody feels the pain I’m feeling” (P.16).*

#### 4.6.1 Discussion:

Findings show that the Féileacáin Memory Box joins together parents in grief. It can be said that it is representative of a wider collective of people who share the same feelings and experiences. The findings show that the sense of shared grief offers comfort for parents. Research findings also suggest that the Memory Box attempts to debunk social amnesia. Previously, parents and families were not given any opportunity to make memories with their baby after their passing; they were taken away and never acknowledged. These practices were underpinned by traditional theories of grief as seen in the literature. Kubler Ross (1969) theorised grief into a process which could only be overcome by letting go of bonds with the deceased and finding a new way of living without them. Findings show the Féileacáin Memory Box challenges these theories and practices by not only providing the tools to make memories with, but by offering a sense of solidarity in grief by acknowledging the life of a baby and supporting parents to live well with death in an attempt to help their grieving process.

#### 4.7 Conclusion

This chapter has presented the research findings that have been gathered from responses to the online survey. Findings have been categorised into four themes which emerged from participants responses. Each theme and discussion therein have been linked to the literature presented in Chapter 2. The findings highlight the significance that the Féileacáin Memory Box holds for participants. The research has shown how the box has allowed parents and families to maintain the memory of their baby. Furthermore, it has shown how the box represents being part of a wider community where solidarity in grief has been experienced. These findings also question the care received by participants as responses highlighted significant variations in the care received. The conclusions and recommendations drawn from these findings will be presented with the concluding chapter.

# Chapter Five: Conclusions and Recommendations

## 5.1 Introduction

Following on from the analysis of the findings in the previous chapter, this chapter sets out to draw conclusions arising from these research findings. The conclusions drawn from the research have informed the recommendations that follow. Recommendations will be representative of the opinions of research participants and the researcher. To conclude, this chapter will include a reflective narrative on the process of engaging in a primary research project.

## 5.2 Conclusions

The primary aim of this research was to understand the experience of receiving a Féileacáin Memory Box. Primary research was carried out in the form of an online survey which elicited responses from 29 participants. Following analysis of these responses the following conclusions have been drawn.

To conclude participants accounts, it can be said that the Féileacáin Memory Box is their most treasured possession. Participants felt that without the box, they would not have had the opportunity to make memories with their baby. By providing the tools to keep a physical part of their baby, participants have been able to keep the memory of their baby alive by incorporating the contents of the box into everyday life with friends and family also. Overall, the Memory Box has allowed participants to maintain a connect to their baby even after death. In keeping memories and connections alive, it can be said that the Féileacáin Memory Box aids the grieving process for parents and families who experience a stillbirth or neonatal death.

The Memory Box binds parents together in their grief. It has been seen from the analysis that the Féileacáin Memory Box challenges social perceptions of death and dying. It moves away from the traditional practices of masking stillbirth or neonatal death and instead offers ways

for parents to live well with the death of their baby. By acting as a symbol of solidarity in grief, the Memory Box aims to unite a community of bereaved parents who represent a contemporaneous experience of stillbirth and neonatal death.

The disparity of bereavement care is evident from the reports of research participants. This finding is particularly worrisome given the implementation of the HSE NSBC (2016). While limitations of this research only allowed for analysis of communication and timing of care, there is enough evidence from these findings to question the overall standardisation of bereavement care under the 2016 Standards.

### 5.3 Recommendations

The following recommendations are reflective of the data gathered and analysed in this research project:

It is recommended for Féileacáin to use the findings of this research as a starting point to begin to challenge policy and practice that surrounds bereavement care following stillbirth and neonatal death. This research has identified a variance in care which is in need of further investigation. A natural progression of this research is to undertake an in-depth mapping to identify where the variance in care has and is occurring and draw recommendations from these findings to further question, at a national level, the standardisation of care under the HSE NSBC (2016).

A recommendation for practice, which has emerged from the findings of this research, is to utilise bereaved parents in training all professionals involved in bereavement care within the maternity services. These parents are the experts in the field and can relay their experiences to improve practices.

In relation to policy, it recommended that a timeframe for bereavement support be established by the HSE and directly set down in a revised NSBC. The findings of this research demonstrate the importance of the timing of support care given and the impact that this has on parents. Following the death of a baby, parents have a small window of opportunity to

spend with their baby, making memories and caring for them. In consultation with Féileacáin, it is recommended that the HSE establish a timeframe for the offering of the Féileacáin Memory Boxes to parents.

This research calls for an increased role of social work in practices that surround the Féileacáin Memory Box. It is concerning to see no evidence of social work practice mentioned within any of the 29 responses of participants. Having completed this research, I feel that the giving and explaining of Féileacáin Memory Boxes would be best offered from a social work professional. This recommendation is rooted in client centred, relationship based social work practice and values. It is suggested that the role of social work in maternity bereavement care be examined to ascertain if there is opportunity for a specific role for social work to practice being established.

Finally, it is recommended that Féileacáin continue to work in collaboration with the CARL initiative. Areas for future research call for the examination of the experience of the Féileacáin Memory Box from a male's perspective.

#### 5.4 Research Reflection

When I first heard of the CARL initiative in May 2018, I was immediately drawn in. At the time the term research scared me. I felt unsure about what path I would like to take so hearing the collaborative approach that CARL operated from was music to my ears. Naively, I thought it was a little extra work but ultimately, they give the question and I research and return with an answer. However, it was not as simple as that! I had initially envisaged completing a single project but on hearing of the Féileacáin research project I agreed to undertake a joint research piece with a fellow student. I was both eager and excited to get started. Together with my research partner, I spent that summer completing a joint ethics approval application form for SREC and meeting with my tutor and the organisation to narrow down the research. It was time well spent, and while at the time I did not feel the project was building, looking back it was and I would see the benefit of this work in the weeks before submitting the final research piece.

I began my second practice placement. There were times I was envious of my peers who were not undertaking primary research. While I was juggling research, practice and my portfolio they had the opportunity to completely focus on their placement. I recall feeling frustrated about this at times and I questioned was it really worth all this extra work. Towards the end of the placement the research project took a turn and it was decided to proceed as a single piece. This was a hard and testing time for me. I felt overwhelmed, frustrated, angry and upset at how this had happened. I faced into the new year starting from scratch with a research project which had to change and the pressure of the final semester of the MSW. Again, I longed to be like my peers who could solely focus on assignments. Obtaining ethical approval was a long and challenging task also, one which at times I thought would not be possible. With growing frustrations from being set back time after time I wanted to throw in the towel. My supervisor was a great support to me through this time and allowed me the space to talk and held my frustrations when I could no longer hold them myself. I asked myself "what is it all for?". One answer was for a final mark at the end of your two years on the MSW. But those thoughts were superseded by remembering the people who called for this research. The organisation who supports parents and families. The parents who have experienced death of a child and who wanted to feedback about their experiences. With the help of my research supervisor, the organisation and with the valuable feedback from the MSW Ethics Committee we got the project over the line for ethical approval.

I feel I have learned a lot from undertaking this research. Firstly, I have learned that undertaking research isn't as bad as I once thought! I have learned that research is a process and part of that process is responding to change. I have seen how I am capable of juggling many balls in the air at one time, a skill that I hope to bring forward into my social work career. Importantly, I have learned a lot about myself throughout the process and on looking back I can see how much I have grown along with the research project. Finally, I have enjoyed the overall process of undertaking this research. I feel very fortunate that I was given the opportunity to undertake a project which has the potential to drive social change.

## 5.5 Conclusion

Having concluded on this primary research piece, the value of the Féileacáin Memory Box to participants cannot be denied. The memories of receiving and using the box and its contents has stood the test of time as seen from the clear accounts provided within this research. The Memory Box has joined together parents in their grief. The difference in bereavement care reported in this research cannot be refuted. Despite the introduction of the HSE NSBC (2016), it appears that little has changed from the findings of the *Report of the investigation into the safety, quality and standards of services provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise* (HIQA, 2015). It is hoped that the findings of this research along with the recommendations outlined within this chapter will be used and built on by Féileacáin to devise next steps to addressing these variations at a national level.

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# Appendices

## Appendix 1: Féileacáin Memory Box



## Appendix 2: Survey Design – Did Not Receive a Féileacáin Memory

### Féileacáin Remembering Memory Box Survey

\* Required

#### Survey

**What is your gender? \***

Your answer \_\_\_\_\_

**What is your age? \***

18-24 years

25-34 years

35-44 years

45-54 years

55-64 years

65+ years

**How long has it been since the death of your baby? \***

12 - 18 months

19 - 25 months

Other: \_\_\_\_\_

**Where was your baby delivered? \***

Central Hospital

Regional Hospital

Home birth

Other: \_\_\_\_\_

**Which HSE region of Ireland were you living in when your baby died? \***

South

West

Dublin Mid-Leinster

Dublin North-East

At what stage of the pregnancy did your baby die? Please specify one of the following: \*

- Pre-birth
- Within 2 weeks of estimated date of delivery
- During birth
- Post-birth

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If your child died pre-birth, please specify the time-period: \*

- Second trimester
- Third trimester

Did your baby receive a diagnosis of a life-limiting condition prior to birth? \*

- Yes
- No

If your baby had received a diagnosis of a life-limiting condition prior to birth, at what stage of the pregnancy were you notified? \*

- Second trimester
- Third trimester

Was the death of your baby unanticipated? \*

Your answer

Did you receive a Féileacáin Memory Box when your baby died? \*

- Yes
- No

If you did not receive a Féileacáin Memory Box, would you have liked to? \*

- Yes
- No
- Unsure

Do you have any recommendations in relation to the Féileacáin Memory Box? \*

Your answer

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## Appendix 3: Survey Design – Received a Féileacáin Memory Box

### Féileacáin Remembering Memory Box Survey

\* Required

#### Survey

**What is your gender? \***

Your answer \_\_\_\_\_

**What is your age? \***

18-24 years

25-34 years

35-44 years

45-54 years

55-64 years

65+ years

**How long has it been since the death of your baby? \***

12 - 18 months

19 - 25 months

Other: \_\_\_\_\_

**Where was your baby delivered? \***

Central Hospital

Regional Hospital

Home birth

Other: \_\_\_\_\_

**Which HSE region of Ireland were you living in when your baby died? \***

South

West

Dublin Mid-Leinster

Dublin North-East

At what stage of the pregnancy did your baby die? Please specify one of the following: \*

- Pre-birth
- Within 2 weeks of estimated date of delivery
- During birth
- Post-birth

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If your child died pre-birth, please specify the time-period: \*

- Second trimester
- Third trimester

Did your baby receive a diagnosis of a life-limiting condition prior to birth? \*

- Yes
- No

If your baby had received a diagnosis of a life-limiting condition prior to birth, at what stage of the pregnancy were you notified? \*

- Second trimester
- Third trimester

Was the death of your baby unanticipated? \*

Your answer

Did you receive a Féileacáin Memory Box when your baby died? \*

- Yes
- No

If you received a Féileacáin Memory Box how long were you waiting to receive it? \*

Your answer

Who gave you the Féileacáin Memory Box? \*

Your answer

Was the contents of the Féileacáin Memory Box explained to you? \*

- Yes
- No

What was it like for you to receive the Féileacáin Memory Box? \*

Your answer

What was included in the Féileacáin Memory Box? (Please tick all that apply) \*

- A blanket
- Two teddy-bears
- Keepsake box
- Camera
- 'Always Loved, Never Forgotten' card
- Butterfly poem card
- Finger/footprint kit
- Candle
- Gift of touch - balm for baby's lips
- Keepsake folder
- Support leaflets
- Other: \_\_\_\_\_

What aspect(s) of the Féileacáin Memory Box was the most helpful to you? Please explain why. \*

Your answer

What aspect(s) of the Féileacáin Memory Box was the least helpful to you? Please explain why. \*

Your answer

What is the significance of the Féileacáin Memory Box to you (and other family members) currently? \*

Your answer

Based on your experience of receiving a Féileacáin Memory Box, what would you recommend for practitioners in terms of discussing the Memory Box with a parent experiencing loss? \*

Your answer

Do you have any other recommendations or observations in relation to the Féileacáin Memory Box? \*

Your answer

Based on your experience of receiving a Féileacáin Memory Box, what would you recommend for practitioners in terms of discussing the Memory Box with a parent experiencing loss? \*

Your answer

Do you have any other recommendations or observations in relation to the Féileacáin Memory Box? \*

Your answer

BACK

SUBMIT

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## Appendix 4: Participant Information Sheet

### Féileacáin Remembering Memory Box Survey

THIS SURVEY WILL TAKE APPROXIMATELY 20 MINUTES TO COMPLETE.  
PLEASE READ THE INFORMATION BELOW AND INDICATE YOUR CONSENT ON THE NEXT PAGE.  
PLEASE COMPLETE THIS SURVEY ONLY ONCE.

**Title of the Study:**  
"Remember Me". An exploration of the impact of the Féileacáin Remembering Memory Box on parents bereaved through stillbirth or neonatal death.

**Purpose of the Study:**  
As part of the requirements for the Master of Social Work at UCC, I have to carry out a research study. This study is carried out as part of a Community Academics Research Links (CARL) Project in conjunction with Féileacáin. Féileacáin, the Stillbirth and Neonatal Death Association of Ireland, provide their Remembering Memory Boxes to 19 maternity units and 2 Children's Hospitals around Ireland. This study seeks to look at the impact that these Memory Boxes have on parents.

**What will the study involve?**  
In this initial phase of a broader study, participants are invited to partake in an online survey, which will take approximately 20 minutes to complete.

**Why have you been asked to take part?**  
You have been asked to participate in the study;  
(a) if you have availed of Féileacáin's services,  
(b) given birth in an Irish hospital and  
(c) have experienced a second tri-mester loss, still birth or neo-natal death between approximately 1st January 2016 and 28th February 2018.

**Do you have to take part?**  
Participation in this study is entirely voluntary. You are asked to read and consider this participant information in detail and decide if you would like to participate in the online survey. Should you agree to participate, you will be asked to indicate your consent to the study by ticking the relevant box on the next page. There is no obligation to participate, and should you choose to do so you can decide to withdraw from the study any time before submitting your answers.

**You maintain the right to withdraw from the study at any stage up to the point of data submission.**  
At this point your data will be collated with that of other participants and can no longer be retracted. IP addresses will not be collected at any point, meaning that the data you provide cannot be traced back to you.

**Will your participation in the study be kept confidential?**  
Yes. I will ensure as far as possible that no identifying information will appear in publications, presentations or reports that are linked to this study. Any extracts from the information you give that are quoted in this study will be entirely anonymous.

**What will happen to the information which you give?**  
The anonymous data will be stored on the University College Cork GoogleDrive system and subsequently on the UCC server. The data will be stored for 10 years after which it will then be destroyed. There may be more than one phase to the analysis of the data from this study and further phases of analysis may be carried out by a UCC student/staff member with the permission and collaboration of Féileacáin.

**What will happen to the results?**  
The results of the study will be presented as part of a postgraduate thesis, will be published on the CARL website (<https://www.ucc.ie/en/scishop/>) and will be drawn upon by Féileacáin in future service delivery. The data will be discussed with the research supervisor during the study. Publications may be in the form of articles in peer reviewed academic journals or book chapters in an edited book. Findings may also be disseminated via conference presentations.

**What are the possible disadvantages of taking part?**  
I do not intend to cause any distress to participants. Some of the topics broached in the survey, however, are of a sensitive and personal nature. Should you wish to do so, you can choose not to answer questions, or to withdraw from the survey. Should you experience distress arising from participating in the research, please contact Féileacáin directly on 085-2496464, who may be of assistance.

**Who has reviewed this study?**  
Approval for this research study to take place has been granted by the MSW Social Research Ethics Committee, School of Applied Social Studies, University College Cork.

**Any further queries?**  
If you need any further information, please do not hesitate to contact the researcher on the given information below: email: [redacted]@umail.ucc.ie  
Or alternatively the research supervisor: [redacted] (email: [redacted])  
or Phone: [redacted]

ON THE NEXT PAGE, YOU WILL BE ASKED TO INDICATE WHETHER OR NOT YOU AGREE TO PARTICIPATE IN THIS STUDY. PLEASE PROCEED.

NEXT

## Appendix 5: Participant Consent

### Féileacáin Remembering Memory Box Survey

\* Required

#### Consent

Please read the following statements:

The purpose and nature of the study has been explained to me.

I am participating voluntarily.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I UNDERSTAND THAT I CANNOT ASK FOR MY DATA TO BE WITHDRAWN AFTER I HAVE SUBMITTED MY RESPONSES, DUE TO THE FACT THAT DATA IS ANONYMOUS.

I understand that anonymous extracts from my responses may be quoted in a Master of Social Work thesis, in a published CARL report, conference presentations and academic publications.

I understand that there may be a second phase to the analysis of the data from this study. This analysis may be carried out by a UCC student/staff member with the permission and collaboration of Féileacáin if I give my permission below:

**I have read the above and I give my consent to for my anonymised data to be used as a part of the research: "Remember Me". An exploration of the impact of the Féileacáin Remembering Memory Box on parents bereaved through stillbirth or neonatal death. \***

Yes

No

Never submit passwords through Google Forms.

## Appendix 6: Ethical Approval



### MSW Research Ethics Committee

School of Applied Social Studies

<b>Applicant:</b>	[REDACTED], MSW2, 2018/2019
<b>Committee Dates:</b>	11 <sup>th</sup> February 2019
<b>Tutor(s):</b>	[REDACTED]
<b>Reference:</b>	2018-8

Dear [REDACTED]

Thank you for your application to the MSW research ethics committee.

The committee has reviewed your application. The decision of the committee is to grant ethical approval for your study with the following stipulations based on the research going from a group to an individual project with more focus on the Memory Box:

1. The order of the questions in the survey to change slightly;
2. The contents of the Memory Box question be changed to a please tick all that apply type of question;
3. Changing the wording of the questions about least and most comforting to helpful/least helpful;
4. The question about the any comments and recommendations about the components of the Memory Box should move to the last question and is made more general and open-ended by asking "Do you have any more comments or recommendations about the Féileacáin Memory Boxes?";

5. You consider changing the wording of the survey from loss to death, child to baby in consultation with Féileacáin;
6. The replacement of the of questions about emotional support with more open-ended questions about the process of getting the memory box and how that was facilitated, how the memory box was used since and what the memory box means to them now.

The Committee also suggest that there may be a lot of rich data gathered from this survey - so much that you may not have the space to report on it all; that another student/researcher may be in a position to analyse the data for some of the questions for another project in time. The suggestion then is that the information sheet and the consent form should include that as a proviso, allowing for the participants to give informed consent for this and for Féileacáin to work again with UCC on the data.

Please note that receiving ethical approval for your study does not absent you from also seeking ethical approval from external agencies, if this is required. Also, appropriate agency level / gatekeep permissions are also required in addition to this approval.

On the day of the submission of your MSW dissertation, you must provide UCC with a copy of the raw data (audio files, transcripts, completed surveys, etc.) and your data analysis files. All research data should be deleted from your PC and UCC cloud storage, and all paper documentation (consent forms, printed transcripts, etc.) given to UCC for confidential shredding. UCC will securely store electronic copies of all of the study data and consent forms for you for 10 years. This stipulation does not prohibit you from publishing your findings and presenting the data outside of UCC, once your informed consent process provides such permission.

We wish you the best of luck with your study. If you have questions, please contact your MSW tutor.

Best wishes,



**On behalf of the MSW Research Ethics Committee**

## Appendix 7: Classification of Hospitals

The term Central Hospital in relation to maternity care comprises of:

- Coombe Women’s Hospital, Dublin
- National Maternity Hospital, Holles Street, Dublin
- Rotunda Hospital, Dublin
- Cork University Maternity Hospital
- Galway University Hospital
- University Maternity Hospital, Limerick.

The classification of Regional Hospital in relation to maternity care comprises of:

- Kerry General Hospital, Tralee
- South Tipperary General Hospital
- St. Luke’s General Hospital, Kilkenny
- Waterford Regional Hospital
- Wexford General Hospital
- Letterkenny General Hospital
- Mayo General Hospital, Castlebar
- Portiuncula Hospital, Ballinasloe
- Sligo General Hospital
- Cavan/Monaghan Hospital
- Our Lady of Lourdes Hospital, Drogheda
- Midlands Regional Hospital, Mullingar
- Midlands Regional Hospital, Portlaoise.