


TFMR

Parents' Healthcare Needs

Key Messages from the Bluebell Study

2022





Thank you to the parents who took part in the *Bluebell Study* and who shared their stories in the hope it that would make a difference to other parents in these circumstances. To all your beautiful babies. This work is for them. May they shine brightly.

Thanks to the healthcare professionals who participated, shared their experiences and identified how TFMR services could be improved.

Introduction

The Bluebell Study was a research project carried out at Queen's University Belfast between 2019–2022. The research aimed to understand the healthcare experiences and needs of parents who had a termination of pregnancy following a diagnosis of a fetal anomaly. This is referred to as "*termination of pregnancy for medical reasons*" (TFMR). The qualitative study includes the perspectives of parents from Northern Ireland (NI) and the Republic of Ireland (IE), as well as the perspectives of healthcare professionals from both jurisdictions who provide TFMR care.

A summary of the key messages and recommendations from the research are presented in this paper. These will be of interest to all those who participated in the study as well as healthcare professionals, policy-makers and voluntary organisations.

There was a strong correlation between the views of parents and healthcare professionals about the nature of TFMR care provided and needed. This is reflected in the key messages and recommendations

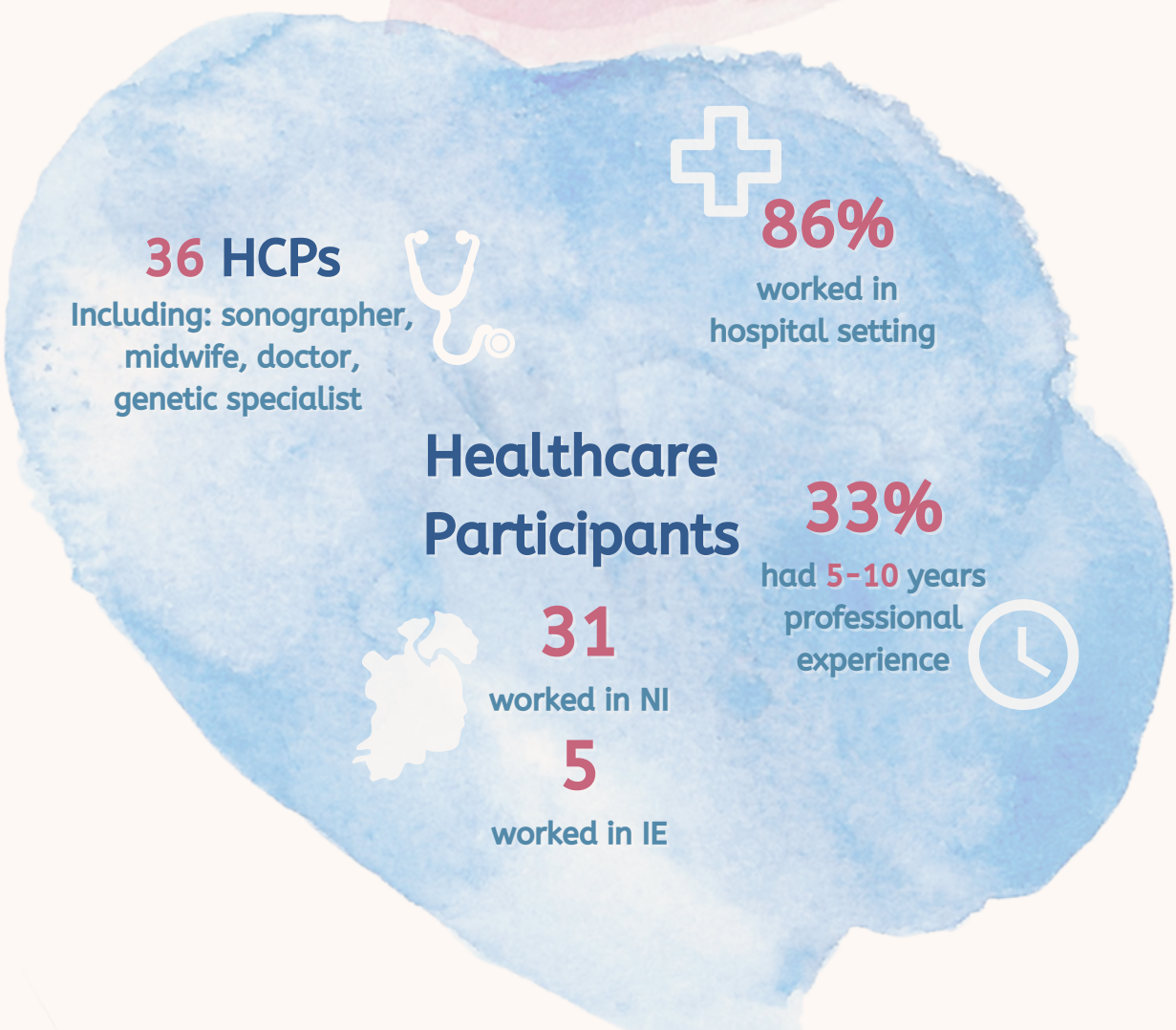
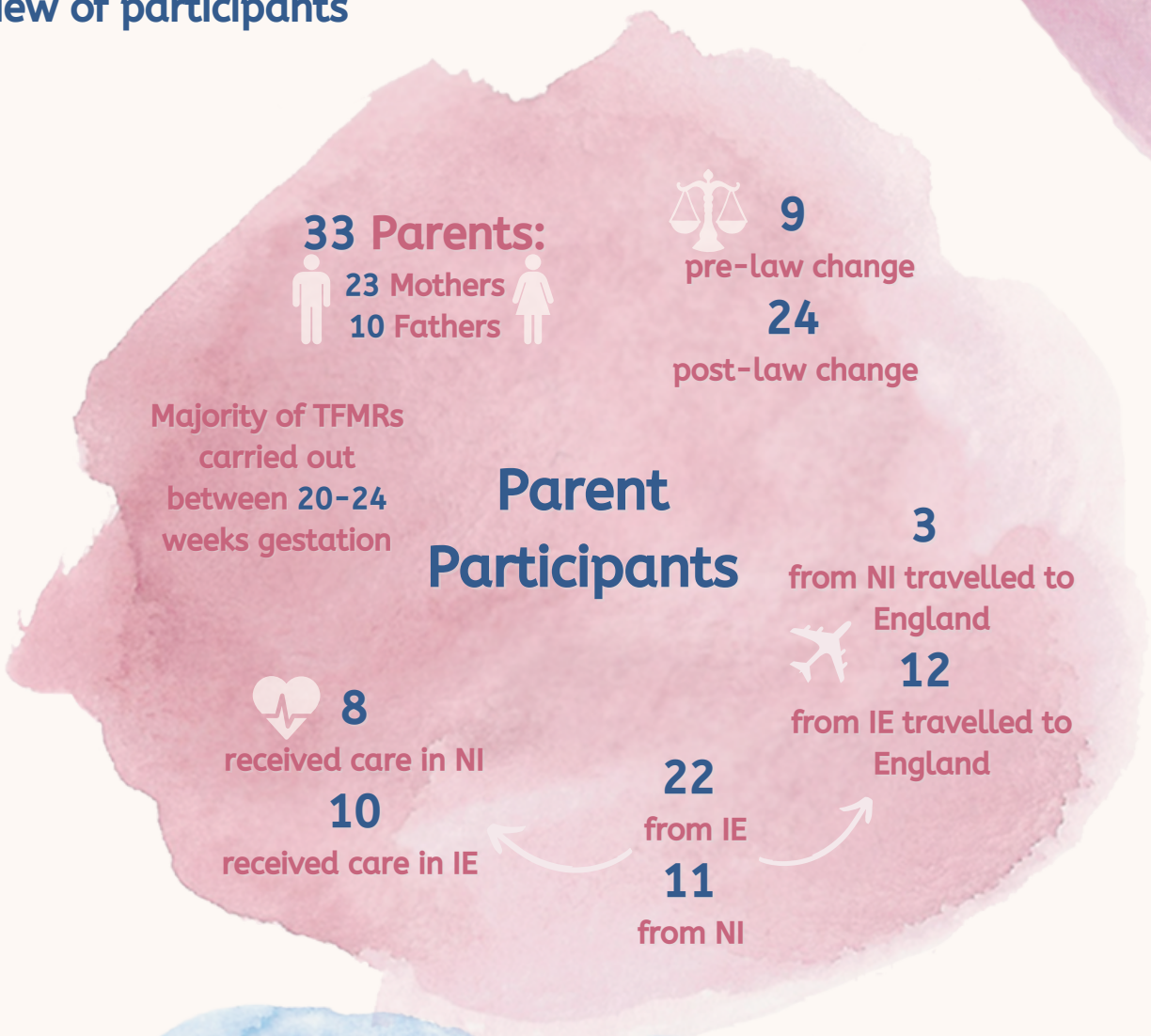
Legal Context

Legislative changes made TFMR legally available in IE from 2018 and in NI from 2019. This study included parents' experiences of TFMR carried out in NI, IE and England, both pre and post changes to the law.



Please see the back cover for the contact details of the researchers and how to access further information about this research.

Overview of participants



Background

The majority of parents found out the devastating news that their unborn baby had a serious fetal anomaly at a routine scan in pregnancy. They spoke of how they were catapulted into a state of shock, uncertainty, and fear and faced the hardest decision of their lives.

While each parent's account of their TFMR experience was unique, every parent was devastated at the prospect of losing their much wanted and loved baby. The decision to have a TFMR was described as 'Sophie's choice'.

Many parents felt judged by the actions and words of those involved in their healthcare, which they found distressing. Many felt unable to share their experience and loss with others which made them feel alone and unsupported.

Parents described their experience of changing from being an expectant parent to a bereaved parent as life-altering. Their TFMR healthcare experience was not experienced as a clinical, time-bound event but as a complex and traumatic journey of grieving and mourning that continued following their discharge from hospital. For many, their experiences were exacerbated by the lack of recognition of their loss by others. TFMR is a unique type of baby loss and parents wanted their baby and loss to be acknowledged by those around them.

All quotes to represent the messages are words from parents and healthcare professionals who participated in The Bluebell Study and are attributed to parents as 'PP' and to healthcare professionals as 'HCP'.

"It's the loneliest journey in pregnancy that any family will ever make" (HCP).

"The arrogance of having two healthy pregnancies, you never think something could be wrong" (PP).

"The duration of the pregnancy does not equate to the amount of loss that you feel" (PP).

"It was like a bomb had exploded in my body, in my mind, in my heart, and I was still alive – that was the pain" (PP).

"Anyone who has children will understand the bond and connection you build before you even meet them, it's something I certainly didn't appreciate until now" (PP).

Key Messages

1. Compassionate Care

Compassion shown by HCPs was identified as the most important attribute that impacted on whether parents experienced their healthcare positively or negatively. A kind word or gesture, being shown empathy and respect were remembered and valued more than clinical competence and helped support parents through their healthcare experience, heartbreak and grief.

“This isn’t about judgment, it has to be about care” (HCP).

“It was such a relief to finally be treated like I was losing a child and not ending a pregnancy” (PP).

“I’m afraid if I make a phone call are they going to say ‘no we don’t deal with people like you’. I feel I’ve had enough rejection, enough hurt, enough loss, enough grief, that if I pick up a phone I need the person to be compassionate and kind and inclusive of my loss” (PP).

“The midwives were so special, the amount of love they showed us” (PP).

“The Consultant took my hand and said, ‘I won’t let you down’” (PP).

“I will never do them justice with my words, the midwives who held me together when I was so afraid” (PP).

2. Non-judgmental Care

The diagnosis of a fetal anomaly and poor prognosis presented parents with a heart breaking situation and decision. Parents who had been looking forward to the birth of their baby were now preparing for its loss. Parents wanted HCPs to respect their choice without judgement and to recognise and acknowledge this was a loss of a much loved baby.

Many parents perceived HCPs actions and words, spoken or unspoken, as judgement about their choice to have a TFMR which compounded any feelings of guilt or shame they may have been feeling. HCP participants also recounted examples of actions or words of colleagues which they believed were judgemental and had a negative impact, directly or indirectly, on parents and the healthcare provided.

Parents expressed their respect of the right of HCPs to exercise conscientious objection in relation to TFMR care. However, parents believed that there should be greater clarity and more active management of conscientious objection in practice. This would help ensure parents receive care without judgement.

“I don’t think we should judge anybody, when a woman arrives to us, they are pregnant and we need to look after them” (HCP).

“Staff have a personal opinion, but when you put on your uniform you’ve got a professional opinion and sometimes people’s personal opinion supersedes their professional opinion and that is not ok” (HCP).

“The vast majority of women, they Google this, Dr Google is the answer, that’s appalling” (HCP).

“You’re treated like a vessel, so the discussions are all about your uterus, but not actually including you in the conversation, I found that very tough” (PP).

3. Information and Effective Communication

Information was important at every stage of parents’ TFMR journey, from diagnosis to aftercare. Information was fundamental in helping parents understand the diagnosis and prognosis, what choices they had, what decisions were needed and when. Information helped them feel a greater sense of control in a situation that was beyond their control.

Parents wanted information about the cause of the anomaly and implications for future pregnancies. Parents who had a more ambiguous prognosis wanted specialist geneticist input to more fully understand the situation and ensure their decision was fully informed. They also wanted to be included in discussions with clinicians.

HCPs also identified their need for access to better information so they were better equipped to provide or signpost parents to reliable sources of information.

Parents valued clear and honest communication from healthcare professionals delivered in language they could understand and absorb. They appreciated when information was delivered in manageable chunks, repeated and given both verbally and in writing. Parents also valued information that was communicated with compassion and sincerity by staff who were open to discussion and answering questions.

“They told me as much as they could in the clearest terms that they could” (PP).

“Honesty, bare facts go a long way” (PP).

I really appreciated that continuity, because I never had to give my story, everybody knew” (PP).

“I wish I had someone who would say I’m going to walk with you the whole way. We had so many different hospitals, so many different doctors” (PP).

4. Continuity of Care

Parents reported increased satisfaction with their healthcare when they experienced continuity of care. Parents who did not receive continuity of care reported a more disjointed, confusing and overwhelming experience, having to repeat their story, not just during their TFMR journey but also in subsequent pregnancies. Lack of continuity of care was particularly challenging to those parents who travelled to England, where they had to navigate a new health system and build new relationships with healthcare professionals.

“We had an anchor around us, a consistent anchor of people” (PP).

5. Person-Centred Care

There was consensus among HCPs that the design and development of TFMR services should be informed by parents' wishes and needs. Healthcare professionals highlighted that to be able to offer person-centred care they needed to be able to offer choices and options relating to care and treatment, which were not always available.

"It needs to be parent focused, this has to go parent led" (HCP).

"There is no point being one way with one parent and trying to be the same with everybody, because they are all different. Parents have different needs and they want to deal with it differently" (HCP).

"That was the most horrendous part of the experience, the abandonment, to be able to access the service here in your own Trust with the same team of people who were giving you such good care up to then and not feel this awful abandonment" (PP).

"This is legal now but there's no real guidelines for it" (HCP).

"They did not seem to know how to deal with it" (PP).

6. Pathway of Care

Parents wanted a clear TFMR care pathway that sets out a step-by-step process about what would happen from diagnosis to post-TFMR to ensure an equitable service. The lack of a consistent regional approach, guided by policies, pathways and guidelines was identified as a barrier in providing effective, high quality TFMR care to parents. All parents wanted care close to home, and felt where this was not possible, there should be a care pathway that ensured care between hospitals was consistent, structured and effective.

"It's not something we are used to doing so we need to be sure that we are doing it the best way we can for these parents" (HCP).

7. Sensitive Care Environment

Being cared for in a mainstream maternity service when losing a baby was distressing for many parents. While many acknowledged a maternity hospital was probably the most appropriate setting for them clinically, some expressed distress being surrounded by newborn babies.

Parents were positive when there was forethought in how the service was managed. For example, reception staff being aware of their circumstances and arrangements made to take them to an appropriate space away from mainstream maternity waiting areas. This privacy was appreciated.

Regarding the birthing environment key priorities were to have space so a partner could stay, self-contained facilities and an appropriate area for their baby.

“They knew we were coming but I still had to walk through the maternity ward, navigating new babies as I was losing my own” (PP).

“There was a flower symbol which signalled there had been a loss” (PP).

“They had a nursery, it was so beautiful and I had him with me in the room” (PP).

“The midwife was really inclusive and gave me things to do” (PP).

“We’re having counselling sessions together and it’s really inclusive, the support for me has been great” (PP).

8. Partner Involvement

The majority of partners wanted to be involved and included in the process. Partners were often the main support for the woman, but they were also grieving parents. Participants wanted partners roles to be acknowledged and supported by healthcare professionals but some had poor experiences.

“Fathers are completely forgotten about, there’s nothing there for them” (PP).

9. Support for Making Memories with Baby

All parents who saw their baby described it as a positive experience. Seeing, holding and spending time with their baby enabled parents to make physical and psychological memories. Parents were positive about the emotional and practical support provided by the midwives to make memories with their baby.

"The midwives gave me precious time with my angel" (PP).

"I needed to see that she was real and that she existed" (PP).

"The nurses dressed her in a beautiful little outfit and took hand and footprints and photos, things we will treasure forever" (PP).

"I remember feeling completely at a loss, you had all this support and appointments and then all of a sudden nothing" (PP).

"When you're in that tunnel of darkness, you need people with experiential knowledge" (PP).

"A lot of people are afraid because they don't want to upset you, but for him to be remembered is just the nicest feeling" (PP).

10. Importance of Support Networks

Emotional and bereavement support were identified as important factors in effective TFMR care. Aftercare was identified by the majority of parents as a service gap and there was unanimity that this should be an integral part of a TFMR care pathway.

Community support networks also need to be strengthened with many parents identifying the need and benefit of peer support from other parents with lived experience as well as a TFMR specific baby loss group.

Family and friends were identified as important supports, however some parents felt there was a need for more public awareness about TFMR as there continues to be silence and stigma attached to having a termination, irrespective of the circumstances

Recommendations

A number of recommendations for healthcare policy, practice and education have been made based on the research findings to ensure parents get the TFMR healthcare they need and are entitled to.

Policy

Recommendations for policy are designed to address identified gaps in service provision and variations in the quality and consistency of TFMR care. In summary the recommendations are as follows:

- An independent review of the implementation of the legislation and TFMR services in IE and NI;
- Development of an agreed regional and/or national TFMR pathway to promote consistency, co-ordination and quality in professional practice and TFMR care;
- Workforce planning for TFMR services including a focus on recruitment, deployment and management of staff that ensures conscientious objection is managed effectively;
- Service development to consider continuity models of care.
Consideration should be given to establish dedicated posts to help parents navigate their TFMR journey;
- Collaborative approach to improve TFMR services through co-design with service-users and service-providers;
- Standardise and improve trend data collection to inform TFMR service development and workforce planning.

Practice

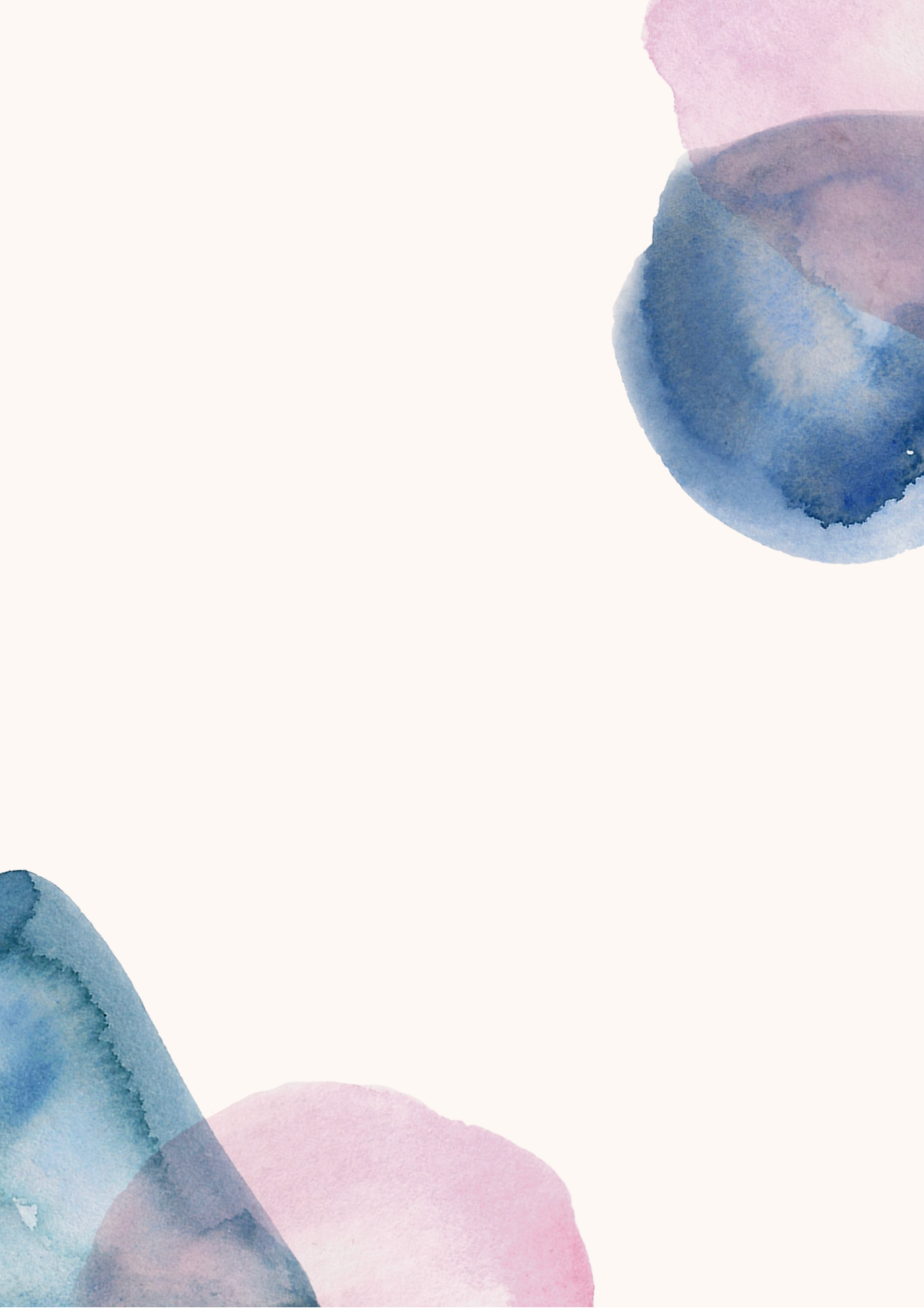
The following recommendations are suggested to strengthen practice and improve the healthcare experiences of parents:

- Embed a person-centred care approach in TFMR care based on the values of dignity, compassion, respect and compassion;
- Improve access to and availability of information for parents who receive a fetal anomaly diagnosis and HCPs who care for them;
- Develop structured emotional support and aftercare pathways for parents who have a TFMR;
- Support the role and needs of partners of women who have a TFMR.


Education and Training

A range of education and training needs have been identified to address the knowledge and skills required by HCPs working in TFMR care. They can be delivered as stand-alone courses or modules for those who input to TFMR care. Recommendations are as follows:

- Awareness training for all staff involved in the delivery of a TFMR service;
- Enable and support parents who have had a TFMR to share their stories with HCPs and relevant others as an integral part of professional training;
- Training in person-centred care for key HCPs involved in care of parents and provision of TFMR. Such training to include the impact of baby loss through TFMR and how to communicate effectively, compassionately and empathetically with parents;
- Enhance training on ethical issues, professionalism and the importance of respect and non-judgemental care;
- Include training on TFMR at an appropriate level in the initial professional education of all nurses, midwives, medical practitioners and specialists.



If you would like any more details about this research or are interested in future work in this area, please contact:

Mrs Suzanne Heaney
Queen's University Belfast
School of Nursing and Midwifery
sheaney22@qub.ac.uk
 @thebluebellstudy

Dr Áine Aventin
Queen's University Belfast
School of Nursing and Midwifery
a.aventin@qub.ac.uk
 @aineaventin