Tuituia te Kahu: A national Bereavement Care Pathway for Perinatal Loss

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Te Kāwanatanga o Aotearoa
New Zealand Government

Health New Zealand
Te Whatu Ora

Co-Chairs' Foreword

Tuia ki runga

Tuia ki raro

Tuia ki waho

Tuia ki roto

Tuia te here tangata

Ka rongo te ao, ka rongo te pō

Tūturu whakamaua

Kia tina! Tina!

Haumi e , hui e. Taiki e!

We, as the co-chairs, welcome you to this report and to Tuituia Te Kahu, the National Bereavement Care Pathway for Perinatal Loss. As this report begins with a simple, but meaningful karakia, so the pathway begins the same. The ingoa, Tuituia Te Kahu, emerged within a dream, recognised as a tohu pai by the co-chair (and dreamer). The pathway is designed upon a concept of whāriki (woven mat), with each strand being a standard interwoven with one another to enable strength, interconnectedness, adaptability, and balance. Each kupu (word) provides insight of the purpose and architecture of the pathway.

The kupu, *tuituia,* derives from the kupu *tuia* or *tuitui*, which are verbs that means to sew, to bind, to thread (repeatedly). It depicts the weaving of each strand within this whāriki. It captures that weaving notion of the many strands, and the many dualities that we see and face within pēpi loss (for example, the dualities of tapu and noa, te ao marama and te ao wairua, unjust and justness). The opening karakia is also an illustration of tuia whereby there is an acknowledgement of binding and connecting all things above, below, within, out, the hunga ora (living), and the hunga mate (passed).

The next kupu, *kahu*, is another example of a kupu with multiple, interconnected meanings. Kahu is used as a nod to Kahu Taurima, the maternity and early years framework that we recognise as being the shelter to which this pathway may sit within. This pathway fits the aspirations of Kahu Taurima, that include protecting and nurturing the pēpi and whānau. Kahu is also a term used for a pēpi who dies. A further reason the kupu *kahu* was included in the ingoa is to mean (kā)kahu and round back to the concept of weaving the whāriki. It is also a way of acknowledging the significant role kākahu hold in death practices across multiple cultures.

As such, Tuituia Te Kahu carries with it not only the hopes and aspirations for a holistic pathway that offers care for pregnant women, pregnant people, whānau and families, but it also carries with it whakapapa, mana, and intentional thought through its ingoa. We, the co-chairs, also stress that this ingoa is an accountability tool. It requests whānau remain at the forefront of perinatal bereavement care. It requires not repeating harm to communities already burdened by harm, and it insists on upholding the mana of mātauranga Māori, relationships, and whānau experiences.

Tuituia Te Kahu includes nine standards, each of which has emerged from deep listening, honest reflection, and commitment to a future where every woman, person, whānau and family experiencing baby loss receives compassionate, competent, consistent care.

E tū ake ana mātou i raro i te maru o Tuituia Te Kahu, he kahu kua whatuhia ki te wehi o te aroha, ki te mātauranga tuku iho, kia ruruhau ai te ngākau e tangi ana, kia tau ai te mauri i te wā o te mamae. We now stand beneath the cloak of Tuituia Te Kahu, a garment woven with the awe of love, with ancestral knowledge, to shelter grieving hearts, and to settle the life force in times of sorrow.

This mahi is much needed and long overdue. Calls have been made for support for bereaved whānau following the loss of a precious baby for many, many years by caring and selfless individuals who provided care to many, despite no promise of change in the future. We embrace their dedication and offer this report in honour of those who have come before us. We also thank those who took up the wero and carried this mahi forward. We needed allies with voice and courage who would continue to name what was missing despite resistance and antipathy. Ngā mihi ki a koutou.

Now is the time for change- we are calling for action.

Contents

How to read this report

This report is structured to guide you through the development of Tuituia Te Kahu: the national bereavement care pathway for perinatal loss. It is a comprehensive report: it reviews our system, identifies where it needs to change and how to ensure equitable, culturally safe and compassionate care for all individuals, whānau and families experiencing perinatal loss, while also having a focus on the health and maternity workforce.

Chapter One: Terms of Reference, Membership and Approach

This chapter sets the foundation for the report. It explains the purpose of the project, introduces the members of the Technical Advisory Group (TAG), and outlines how information was gathered, ensuring the process was inclusive of pregnant women/people, whānau and family voices. It also provides insight into the strategic values and principles that guided the work.

Chapter Two: Strategic Case for Change

Here, you will find a thorough discussion on the need for change. It focuses on the current gaps in perinatal bereavement care, especially the inequities in care for our whānau who experience the highest rates of perinatal mortality in Aotearoa - Māori, Pasifika and Indian communities. For Indian communities, these disparities are particularly complex due to the remarkable diversity within this population, encompassing multiple religious traditions (Hindu, Sikh, Muslim, Christian, Jain, Buddhist) and regional cultures (North, South, East and West Indian). Additionally, it is further diversified with a number of regional cultural practices and languages. Chapter 2 examines how current services often fail to recognise this diversity, leading to one-size-fits-all approaches that do not meet the specific cultural, spiritual, and linguistic needs of different Indian families experiencing perinatal loss. It presents a compelling case as to why these changes are necessary, including the urgent need for culturally competent care and enhanced mental health support.

Chapter Three: Tuituia Te Kahu: The National Bereavement Care Pathway for Perinatal Loss

This chapter introduces the nine core standards that will form the woven foundation of Tuituia Te Kahu, the national bereavement care pathway for perinatal loss. It explains how these standards work together and highlights their potential impact on the lives of individuals, whānau and

families. It also outlines the measures for success and the improvements we expect to see in care delivery.

Chapter Four: Scope and Scale of Change

Here, the focus shifts to the scale of the changes required. This chapter defines the scope of the national bereavement care pathway, from the services that will be impacted, to the high-level business requirements necessary for implementation. This section provides a detailed look at the logistical and systemic changes that must occur. The TAG understands that delivery is important, so has used this chapter to offer its first and best advice on implementation.

Chapter Five: Assumptions and Dependencies

This chapter identifies the key assumptions behind the proposed changes, as well as the legislative and policy updates required. It also looks at how this pathway connects to other health initiatives, ensuring that efforts are aligned for a cohesive approach to perinatal bereavement care.

Chapter Six: Options for Implementation

This chapter explores the different options for how the pathway can be rolled out, comparing gradual, phased, and immediate approaches. It considers the pros and cons of each and provides recommendations on the best approach for achieving long-term success. Much like Chapter Four, it is the TAG's first and best advice on how to successfully implement Tuituia Te Kahu in a way that integrates with the other Kahu Taurima initiatives and the wider goals the government has for the health system.

Technical Advisory Group

The development of the first national bereavement care pathway for perinatal loss in Aotearoa represents a pivotal moment in addressing one of healthcare's most sensitive and critical areas. At the heart of this transformative initiative stands the Technical Advisory Group: thirteen individuals whose collective wisdom, lived experiences, and professional expertise form the foundation for creating equitable, culturally responsive care for bereaved whānau across Aotearoa.

The Advisory Group: A Tapestry of Knowledge and Experience

Leadership and Clinical Excellence

Co-chairing this distinguished group are Dr Vicki Culling, a leading advocate in perinatal loss with qualifications spanning education, social work, and clinical supervision, whose personal journey with stillbirth led to decades of supporting bereaved whānau through Sands NZ; and Dr Kendall Stevenson (Ngāti Awa, Ngāti Kurī, Ngāpuhi), a Senior Research Fellow whose research centres on the oranga of whakapapa and wellbeing of wāhine, pēpi Māori, and whānau through a Kaupapa Māori lens.

Clinical Expertise and Frontline Care

The group brings together exceptional clinical practitioners including Dr Kay Jones, a midwife with 26 years of dedicated bereavement care experience whose PhD research has profoundly influenced how health providers support women through loss; Dr Jaynaya Marlow, a respected Obstetrician and Maternal Fetal Medicine specialist serving as National Clinical Director of Aotearoa's Maternal Fetal Medicine Network; and Nerissa Walters (Ngāi Tamanuhiri, Rongomaiwahine, Ngāti Mihiroa, Rotuman), a highly respected midwife and Tairāwhiti Perinatal Mortality Review Committee Coordinator who advocates tirelessly for culturally appropriate care.

Cultural Leadership and Community Advocacy

Indigenous and cultural perspectives are powerfully represented through Fay Selby-Law (Ngāti Porou, Ngāti Raukawa ki te tonga), General Manager of the National SUDI Prevention Coordination

Service with Hāpai Te Hauora, who brings both clinical expertise and personal understanding of baby loss; Rose Torau Martin, a Cook Island/Māori midwife at Hapū Wānanga ki Taranaki, whose own experience of losing her son Bailey inspired her journey into midwifery and bereavement care; and Joy Sipeli, Executive Director of NET Trust and daughter of the Niue community, who ensures Pasifika families receive culturally appropriate, compassionate care.

Lived Experience and Advocacy

The group's strength is amplified by members who bring profound personal experience alongside professional expertise. Melanie Tarrant, Chair of Sands NZ, who lost her daughter Kate at 19 weeks and son Zac at 27 weeks, has transformed her grief into advocacy for bereaved whānau. Claire Turnham, founder of Birth and Beyond and recipient of an MBE for her services to consumers, has pioneered community-based death care practices while drawing from her own experiences of pregnancy trauma.

Community Points of View

Ensuring comprehensive representation are Frankie Karetai Wood-Bodley, a passionate advocate for LGBTQIA+ and disability rights who identifies as disabled, non-binary and gay, bringing vital perspectives on intersectional advocacy; Poonam Rishi, an artist, and project coordinator at The Asian Network Incorporated (TANI) bought a deep understanding of the cultural, linguistic, and systemic barriers faced by Indian families navigating healthcare systems: Poonam and The Asian Network (TANI) advocates for culturally responsive care that acknowledges the diverse religious, regional, and linguistic traditions within Indian communities; and Rāwā Karetai (Waitaha, Kāti Māmoe, Kāi Tahu, Ngāti Maniapoto), a respected advocate for Indigenous, Tāngata Whaikaha Māori, and LGBTQIA+ human rights with international leadership experience.

A Collective Vision for Transformation

Together, these thirteen individuals represent far more than a collection of expertise: they embody the lived realities, cultural wisdom, and professional excellence necessary to transform perinatal bereavement care in Aotearoa. Their diverse backgrounds spanning clinical practice, research, community advocacy, cultural leadership, and personal experience with loss create a powerful foundation for developing a pathway that truly serves all bereaved whānau. Through their guidance, Tuituia Te Kahu a National Perinatal Bereavement Care Pathway promises to

become not just another framework, but a compassionate bridge toward healing, equity, and hope for families navigating one of life's most profound challenges.

Glossary

Nau mai haere mai ki tēnei pātaka kupu. Kua whakatakoto ēnei kupu hei awhina i te marama me te manaaki o tēnei ao. Me āta pānui, āta marama ngā kupu, ngā reo whānui o tēnei ara hou – Tuituia Te Kahu | the National Bereavement Care Pathway for Perinatal Loss.

We welcome you to this glossary as an introduction and foundation of the language specific and integral to our new pathway, Tuituia Te Kahu, the National Bereavement Care Pathway for Perinatal Loss.

Each term and word hold definitions that honour the many communities impacted by perinatal bereavement in Aotearoa.

A

Active parenting: engaging in acts of caregiving, such as holding, washing and dressing, reading and singing to, and spending time with their baby in either the hospital, at home or outside settings. These may be included as part of memory-making. (Also referred to as Affirmation of Parenthood).

Acute Care: The provision of appropriate, timely, acceptable, and effective management of conditions of sudden onset and rapid progression that require attention.

Āiga: A significant term for people of Samoan cultural heritage; in this context, meaning immediate/extended family.

All Losses: The loss of a baby from conception through the first year of an infant's life, no matter the gestation period or how the baby died.

Antepartum Haemorrhage (APH): Any bleeding from or into the genital tract, occurring from 20 weeks of pregnancy and prior to birth. One of the leading causes of maternal/perinatal morbidity and mortality. Women/people who have an APH are at significant risk of a postpartum haemorrhage (PPH). APH complicates 2-5% of all pregnancies.

Antim Sanskar: The final rites or funeral ceremonies in Hindu tradition. For Indian families experiencing perinatal loss, elements of antim sanskar may be important for spiritual closure, even when adapted for the loss of a baby.

Aotearoa: New Zealand.

Asherman Syndrome: An acquired condition, which develops when scar tissue is present inside the uterus (womb) or cervix. Most likely to occur after multiple surgeries or infection following miscarriage and/or dilation and curettage (D&C) or caesarean section (C-section).

At Risk: In the context of the perinatal bereavement pathway, "at risk" refers to pregnancies (current or subsequent), in which a newborn or infant may have a heightened likelihood of dying. Care should be tailored to provide additional monitoring, intervention, and support, where needed.

Autopsy (also known as postmortem): A procedure carried out by a specialist perinatal pathologist (surgeon) for gathering information about why a baby has died. There are three options: full postmortem (surgery), limited (surgery), and external examination (no surgery).

B

Baby Loss: In the context of this perinatal bereavement care pathway, baby loss refers to when a baby dies, in utero or after birth, up to one year old. This term may include the loss of a pēpi (baby) during pregnancy, and due to miscarriage, stillbirth, neonatal or infant death, or termination for medical reasons (TFMR).

Baby Loss NZ: A registered charity that provides support to whānau and families who have experienced baby loss. They are located in South Auckland and have branches in Hauraki/Piako and Christchurch. Their main service is the provision of care bags and memory-making services.

Bed-sharing: Sharing the same sleeping surface. See also co-sleeping.

Bereavement Midwife: A midwife who specialises in supporting families experiencing baby loss.

Bereavement Care Pathway for Perinatal Loss: A structured and compassionate approach to providing care and support for individuals, whānau and families experiencing pregnancy or baby loss. This pathway ensures that bereaved individuals, whānau and families receive timely, equitable, and personalised support that aligns with their cultural, emotional, and spiritual needs. It is not a clinical pathway. Traditionally, clinical pathways primarily focus on diagnosis and time-limited treatment, whereas this pathway prioritises holistic care, incorporating psychological, social, and bereavement support. It emphasises individual, whānau and family-led decision-making, continuity of care and access to specialist bereavement services. It has been designed to create an environment where grief and mourning are acknowledged, respected and supported, irrespective of where the pregnant woman/person, whānau and family are on their journey.

C

Co-sleeping: A term used to describe sharing the same sleeping surface. See also bed-sharing.

Congenital Abnormality/Anomaly/Difference: A condition present at or before birth that can cause health challenges or may be life-limiting for the baby.

Continuing Bonds: The ongoing emotional connection and enduring relationship a bereaved parent has with their baby. It may help to keep their child present in the lives of their whānau and family through memories, rituals and thoughts. This is a way of integrating their loss and finding meaning in their grief.

Coroner's Investigation: A legal process that occurs in some perinatal and infant deaths to determine the cause and circumstances of a sudden and unexpected death. A coroner is called if a doctor has been unable to determine the cause of death of a baby, or if a death has occurred in violent or unnatural circumstances.

Cremation Certificate: A legal document required for cremation in Aotearoa.

Culturally Safe, Whānau-Led, and Spiritually Appropriate: An approach that ensures bereavement care and services are directed by the preferences and needs of individuals, whānau, āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmili - immediate/extended family, for example, rather than being assumed or dictated by healthcare professionals. This often means creating a space where pregnant women/people, whānau, and families determine the cultural, spiritual, and personal aspects of their care. It is also crucial that professional support is consistent, respectful, responsive, and adaptable to the individuals, whānau and families' values, traditions and grieving processes.

D

Death Literacy: The knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end of life and death care options. An important aspect of death literacy is being able to talk about death, dying, and loss. It directly shapes the decisions we make about the care we receive, as well as our ability to care for others.

Determinants of Health: The range of personal, social, economic, and environmental factors that determine the health status of individuals or populations.

Dilation & Curettage (D&C): A surgical procedure, in which the cervix is expanded and the baby or retained placenta is removed using a suction device and curette placed through the vagina and cervix into the uterine cavity.

DIA: Department of Internal Affairs. Te Tari Taiwhenua - The Department of Internal Affairs serves and connects people, communities and government to build a safe, prosperous and respected nation.

Doula – A person who provides non-medical support and guidance during birth and perinatal loss.

E

Early Anatomy Scan: A scan optimally performed at 12-13+6 weeks gestation. It can be used to date pregnancy if an earlier scan was not done, conduct early anatomy assessments, detect multiple pregnancies, and screen for chromosomal anomalies and other conditions. It may include Nuchal Translucency (NT) assessment, as combined screening (MSS1) for Down's Syndrome.

Early Pregnancy Scan: An ultrasound examination performed when the baby is less than 12 weeks: typically, when there are indications of bleeding or pain in early pregnancy; concern about

pregnancy loss; consideration of termination; trauma; previous ectopic pregnancy; pregnancy with an intrauterine contraceptive device (IUD); requirement for early dating; requirement for early viability confirmation; or complex medical conditions.

Ectopic Pregnancy: Occurs when a fertilised egg implants and grows outside the uterine cavity (womb), most commonly within the fallopian tubes between the ovary and uterus. Usually occurs within the first 10 weeks of pregnancy and always results in pregnancy loss. An ectopic pregnancy can be a medical emergency.

Ethic of Restoration: As explained by Moana Jackson, an ethic of restoration recognises that, like colonisation, restoration is a process; a process that seeks to restore our tikanga (practices), which is a values-based system of what ought to be, to help sustain a balance of relationships. The ethic of restoration was an integral design principle of Tuituia Te Kahu. This indicates that the pathway has been designed from a holistic position, seeking balance and care for all. Furthermore, it indicates the commitment to restore health and wellbeing as an ongoing process.

F

Family-Led Care: Family-led decision-making and care, recognising cultural, social, and spiritual needs. A reminder that it is not culturally safe to try and impose one's cultural norms on the pregnant woman/person, whānau or family's grief and journey. This is consistent with the midwifery standards of practice, including Turanga Kaupapa.

Follow-up: In the context of this pathway, the Lead Perinatal Bereavement Coordinator ensures appropriate follow-up, as defined within the Nine Standards of Care articulated in Tuituia te Kahu: the National Bereavement Care Pathway for Perinatal Loss.

First Trimester Miscarriage: Loss of a baby during the first 12-14 weeks of pregnancy. Most miscarriages (95%) occur at this time.

First Trimester Ultrasound: Ideally offered between 12- and 13+6-weeks' gestation for optimal assessment of fetal anatomy and nuchal translucency (NT). Used to confirm viability, accurately assess gestational age, and determine the number of viable fetuses. (See also Early Pregnancy Scan).

Fetal | Foetal Anomalies/Differences: Unusual or unexpected conditions in a baby's health, development or genetics, which occur during pregnancy. May also be known as congenital disorders, birth defects, and abnormalities. (See also Congenital Abnormality (Anomaly/Differences)).

Fetal | Foetal Anomaly Scan (Second Trimester Anatomy Scan): An ultrasound scan optimally performed at 19+ weeks of pregnancy to assess the physical development of the unborn baby (fetus) and used to detect fetal anatomical differences/abnormalities and placenta location.

Fetal Biometry: Measurements taken during ultrasound examination, which are used to assess the growth of the baby.

Fetal Movements: A well-recognised indicator of fetal wellbeing. Movements may vary depending on the time of day and gestational age. Reduced fetal movements are linked with adverse perinatal outcomes. More than half of pregnant women/people, who present with a stillbirth identify a decrease in fetal movements before the diagnosis of fetal death.

Fetus | Foetus: An unborn baby that develops in the uterus of a woman or pregnant person.

Fāmili: A significant term for people of Tongan cultural heritage, in this context meaning immediate/extended family.

G

Gestational hypertension: New onset hypertension occurs after 20 weeks gestation (in a pregnant woman/person who had normal blood pressure before 20 weeks gestation).

Grief: Intense sorrow, a natural emotional response, especially caused by the death of someone. Grief is often a healthy and necessary step of bereavement.

Gurdwara/Mandir/Masjid: Places of worship (Sikh temple, Hindu temple, mosque respectively) that serve as community centres and sources of spiritual support for Indian families of different faith traditions during times of loss.

H

Hauora: A Māori concept of health, including physical, mental, social, and spiritual wellbeing. Hauora is noted to be when these four domains are in a state of balance.

Health Equity: Health equity in Aotearoa means ensuring that all individuals, whānau, families, in the context of their chosen communities, have a fair and just opportunity to achieve their highest level of health and wellbeing, regardless of their socioeconomic status, ethnicity, geographic location or social determinants of health. This requires ensuring health care services are accessible, efficient, effective, and safe. Health equity is not just about equal access to healthcare but also about achieving equal health outcomes, particularly for those who live in communities that are underserved and who experience systemic disadvantage.

Health New Zealand (Te Whatu Ora): Health New Zealand (Te Whatu Ora) is the organisation established in 2022 to lead the day-to-day running of the health system across Aotearoa, with functions delivered at local, district, regional, and national levels.

Health Outcomes: A change in the health status of an individual, group or population, which is attributable to a planned programme or series of programmes, regardless of whether such a programme was intended to change health status.

I

Integration: Combine into a whole or complete programme by the addition of parts. In the context of this pathway, it means integrated care between all parts of the hauora (health and social services) system.

Intrauterine fetal death or stillbirth: When a baby dies in utero after 20 weeks of pregnancy or weighing more than 400 g at birth.

K

Kahu Taurima: This is the maternity and early years approach of Health New Zealand (Te Whatu Ora). The name is symbolic of the intention whereby Kahu is a protective layer and Taurima speaks to the nurturing and caring for pēpi (baby), whānau and families.

Kōpū tangata: A significant term for people of Cook Island Māori cultural heritage, in this context meaning immediate/extended family.

Kāiga A significant term for people of Tokelauan cultural heritage, in this context meaning immediate/extended family.

Kaihautū: leader.

Kaiwhakatere The lead perinatal bereavement coordinator is the kaiwhakatere: they navigate the whānau - āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmili - and family along the pathway.

L

Late Miscarriage: Also known as a second trimester loss. This occurs when a pregnancy ends after 15 and before 20 completed weeks' gestation.

Lead Perinatal Bereavement Coordinator: A role, and a professional, responsible for organising and overseeing bereavement support services, ensuring individuals, whānau and families receive care following a loss. They may work within healthcare, community or charitable organisations to

coordinate support and ensure easy access to the services articulated in Tuituia Te Kahu - the National Bereavement Care Pathway for Perinatal Loss.

M

Manaaki Mats: Specialist cooling mats used to support whānau and families in caring for their baby after death. Allows individuals, whānau, aiga, families more time to be with and hold their baby in hospital and/or at home.

Magafaoa A significant term for people of Niuean cultural heritage, in this context meaning immediate/extended family.

Maternal Sepsis: A life-threatening condition that arises when the immune system of a woman or person who is pregnant or has recently given birth responds to a severe infection. It is the third most common cause for maternal admission to ICU/HDU.

Medical Certificate Cause of Death of Fetal and Neonatal Death HP4721: A medical practitioner or nurse practitioner can complete the HP4721 Form for a liveborn baby who dies within 28 days of birth and stillbirth, as set out in the Burial and Cremation Act 1964. If no medical practitioner was present at the birth of a stillborn baby, a midwife may complete this form instead. The certificate records information about the mother, pregnancy, and delivery. It also includes the baby's birth weight, gestation, and cause of death.

Memory-Making: Creating tangible and intangible memories, such as handprints, footprints, photos, keepsakes or experiences, such as washing and dressing baby. Having time for bereaved whānau and families to hold, be with, and care for a baby if they wish. Participating in memory making can often enable parenting choices and opportunities, and support whānau- and family-led care.

Miscarriage: When a baby dies in pregnancy before 20 completed weeks' gestation. In Aotearoa, it is estimated by Health New Zealand (Te Whatu Ora) that between one to two of every 10 pregnancies ends in miscarriage. Legal definition: the issue from its mother before the 21st week of pregnancy, of a dead fetus weighing less than 400g (BDM).

Molar Pregnancy: A molar pregnancy, also called a hydatidiform mole or gestational trophoblastic disease, is one where an abnormally fertilised egg implants in the uterus (womb). The cells that should become the placenta grow far too quickly and take over the space where the embryo

would normally develop. About one in 600 pregnancies is a molar pregnancy. A molar pregnancy can be 'partial' or 'complete'.

Morbidity: Illness or disease prevalence.

Mortality: The rate of death within a population.

N

National Minimum Data Set: A national collection of public and private hospital discharge information for inpatients and day patients, including clinical information.

National Public Health Service: The National Public Health Service brings together functions from Te Hiringa Hauora, the Ministry of Health, and public health units into a unified operational service.

National Screening Unit (NSU): The National Screening Unit (NSU) is responsible for the safety, effectiveness, and quality of organised screening programmes in Aotearoa.

Neonatal Death: The death of a liveborn baby at any gestation. An early neonatal death is defined as a baby who dies from birth to seven days; a late neonatal death is defined as a baby who dies from eight to 28 days old. Also referred to as newborn death.

Neonatal Encephalopathy (NE): A clinically defined syndrome of disturbed neurological function within the first week of birth in the term (≥37 weeks) infant, manifested by difficulty in initiating and maintaining respiration, depression of tone and reflexes, subnormal level of consciousness, and often seizures (PMMRC).

Noa: The antithesis of tapu, whereby noa is the state lifted of (necessary) sanctions and restrictions.

Non-binary: A term for people who do not identify exclusively as male or female. It refers to those who fall outside the gender binary.

O

Oranga Tamariki: Also known as the Ministry for Children and previously the Ministry for Vulnerable Children, is a government department in Aotearoa responsible for the wellbeing of children, and specifically children at risk of harm, youth offenders, and children of the State.

P

Paediatric Palliative Care: a system of care that focuses on comfort, improving quality of life and supporting the pregnant women/people, whānau and family when a baby has a terminal or life-

limiting diagnosis. For the National Bereavement Care Pathway for Perinatal Loss, a baby is a newborn or infant.

Pae Ora: The Pae Ora (Healthy Futures) Act 2022 took effect on 1 July 2022. The Act's purpose is to protect, promote, and improve the health of all New Zealanders. It aims to achieve equity by reducing health disparities among population groups in Aotearoa, particularly for Māori.

Parivar: A Hindi term meaning family, encompassing not just immediate family but extended family networks that play crucial roles in decision-making and support during times of loss. In Indian communities, the parivar often includes grandparents, aunts, uncles, and cousins who provide emotional, spiritual, and practical support during bereavement.

Pasifika: In Aotearoa, Pasifika is a term for people who are descended from the indigenous peoples of the Pacific Islands.

Passed Away (Died): Death is indicated when the baby in utero or after birth does not show any evidence of life. Although 'passed away' is a euphemism for died/death/dead/deceased, it is a commonly understood term and is often referred to by whānau and is used interchangeably in this report.

Perinatal Bereavement: The grief and mourning process experienced by individuals, whānau and families following the loss of a baby at any stage of pregnancy or infancy. The grief and mourning process can also be experienced for an indefinite period. Perinatal bereavement care within the context of this pathway applies to **all losses** (across all gestations and includes TFMR (Termination for Medical Reasons)), and ensures comprehensive, compassionate support tailored to the needs of grieving individuals, whānau and families of babies up to 12 months of age.

Perinatal Death/Mortality (Te Mate Pēpi): The death of any fetus or baby from 20 weeks gestation, or over 400g if gestation is not known, until 28 days of age. (While 'perinatal' is clinically understood as from 20 weeks' gestation, in this report we are referring to all losses as perinatal).

Perinatal and Maternal Mortality Review (PMMR): A workstream that is part of Te Tāhū Tauhora/Health Quality & Safety Commission's He Mutunga Kore/National Mortality Review Committee (NMRC), which focuses on the deaths of babies from 20 weeks gestation to 28 days old, and pregnant or postnatal mothers until 42 days after birth. It builds on the work of the previous Perinatal and Maternal Mortality Review Committee (PMMRC). We refer to the PMMRC through the report, as the data we accessed came from PMMRC reports.

Perinatal Mental Health Services: Specialised health professionals skilled in helping families struggling with grief and trauma. Their team offers support services, assessment, treatment, and

advice to those who have a mental illness during the perinatal period or who have an ongoing or previous need for mental health services.

Perinatal Palliative Care: Compassionate care for babies in utero diagnosed with life-limiting conditions, focusing on maximising quality of life, comfort, and dignity. Sometimes referred to as 'hospice in the womb'.

Perinatal Pathologist: A specialist who examines a baby's body during a postmortem (autopsy) for signs of infection, disease, and/or cause of death.

Period of Care: The period of care covers the time from when the presenting referral is accepted through to the closure of the presenting and all other related referrals. For example, a multi-trauma patient arriving at the emergency department becomes an inpatient, may have surgery, follow-up treatments, and rehabilitation. If another condition is discovered (e.g., diabetes), this should be treated as another presenting referral, and thereby another period of active care.

Pharmac (Pharmaceutical Management Agency) Te Pātaka Whaioranga: An agency that secures, for eligible people in need of pharmaceuticals, the best health outcomes that are reasonably achievable from pharmaceutical treatment and from within the amount of funding provided.

Primary Health Organisation (PHOs): PHOs encompass the range of primary care and practitioners and are funded by DHBs to provide a set of essential primary healthcare services to those people who are enrolled in that PHO.

Postmortem (also known as Autopsy): A procedure carried out by a specialist perinatal pathologist (surgeon) for gathering information about why a baby has died. There are three options: full postmortem (surgery), limited (surgery), and external examination (no surgery).

Pasifika Peoples (PP): The population of Pacific Island ethnic origin (for example, Tongan, Niuean, Fijian, Samoan, Cook Island Māori, and Tokelauan), incorporating people of Pacific Island ethnic origin born in Aotearoa, as well as overseas. (Also see Pasifika)

Preeclampsia: A serious condition where high blood pressure with systemic dysfunction develops during pregnancy after 20 weeks gestation and up to 2-3 weeks after birth, affecting both the mother and baby. Estimated to affect 3-8% of pregnancies in Aotearoa.

Primary Birthing Facility: A facility providing inpatient services for labour, birth, and the immediate postnatal period.

Primary Care: The first level of contact with the health system. It consists of essential healthcare based on practical, scientifically sound, culturally appropriate, and socially acceptable methods. It

is universally accessible to people in their communities, involves community participation, and is integral to, and a central function of, the country's health system.

Public Health: The science and art of preventing disease, prolonging life, and promoting health and efficiency through organised community effort. A collective effort to identify and address the unacceptable realities that result in preventable and avoidable health outcomes, and it is the composite of efforts and activities that are carried out by people committed to these ends.

Q

Quintile: A division of areas into five groups based on deprivation levels, with Q1 being the least deprived and Q5 being the most deprived.

R

Rainbow Baby: A baby born subsequent to a miscarriage, stillbirth, baby loss, termination, or the death of a newborn or infant.

Rainbow Communities: Rainbow is a broad umbrella term that covers a diversity of sexual orientations, gender identities and expressions, and sex characteristics. Rainbow communities, rather than rainbow community, indicates that this is not a homogenous group and that there are multiple communities woven into the rainbow umbrella term. Rainbow communities means inclusive of people from various sexual diversities and gender identities and expressions. We assert the position that Tuituia Te Kahu is inclusive of our rainbow communities, and when people, whānau and family are mentioned throughout the report, we are inclusive of rainbow communities.

Return on Investment (ROI): A financial metric used to evaluate the efficiency or profitability of an investment, calculated as the ratio of net profit to the initial investment cost.

Ring Fence: A term relating to mental health funding, ensuring that surplus funds are not transferred outside of mental health services.

Ritual: A particular action, movement, the recitation of certain words or any other defined process that has meaning and significance to those involved.

S

Sands NZ: A voluntary organisation throughout Aotearoa that provides meaningful support to parents and whānau who have experienced the death of their baby. They provide baby loss

support information packs and resources, in-person and online support, Baby Loss Awareness Week activities, education to health professionals, and a biennial national conference.

Sangha/Samaj: Community support structures within Indian communities that provide collective care and assistance during times of crisis. These community networks are essential for understanding how Indian families access support beyond immediate family.

Sanskar: Life cycle rituals and ceremonies in Hindu tradition that mark important transitions, including birth, marriage, and death. In the context of perinatal loss, understanding sanskar helps healthcare providers appreciate the spiritual significance of rituals that may be important to Indian families during their grieving process.

Secondary Birthing Facility: This is a hospital that provides inpatient and outpatient services for women and their babies who need additional maternity care involving obstetricians, paediatricians, and other specialists.

Secondary Care: Specialist care that is typically provided in a hospital setting.

Sepsis: A life-threatening condition that arises when the body's severe response to an infection result in organ failure and shock. It can happen during pregnancy, childbirth, following termination, or in the postpartum period.

Social Investment: An approach where funds are allocated with the expectation of generating positive social and financial returns over time.

Shradh: Memorial rituals performed to honour deceased family members in Hindu tradition. Understanding shradh practices helps healthcare providers support Indian families in their ongoing remembrance and connection with their lost baby.

SIDS (Sudden Infant Death Syndrome): The sudden death of a child less than one year of age, which cannot be explained even after investigation. Previously known as "cot or crib death". Due to being unexplained, it cannot be predicted or prevented.

Spiritual Care: Provided by practitioners to appropriately meet the individual's spiritual and emotional needs. It may include presence, conversations, ritual, ceremonies, and the sharing of sacred texts and resources.

Stillbirth: The loss of a baby in utero after 20 completed weeks' gestation. In Aotearoa, a stillbirth is legally defined as: a dead fetus that:

(a) Weighed 400g or more when issued from its mother, or

(b) Issued from its mother after the 20th week of pregnancy (BDM, Births, Deaths and Marriages).

Sudden Unexpected Death of an Infant (SUDI): The unexpected loss of a baby under 12 months old, often requiring specialist investigation, bereavement care, and family support. It includes unexplained deaths of babies under one year (SIDS) and sleep-related deaths, which may occur from asphyxia or suffocation.

System Signal: In the context of this perinatal bereavement pathway, a system signal refers to healthcare data that signals to healthcare providers that targeted grief and mourning, as well as bereavement services, may be needed by a particular pregnant woman/person and their whānau and family.

T

Tāngata whaikaha: people who are determined to do well, and an active removal of using the term 'disabled people'. Tāngata whaikaha are incredibly resilient and adaptable, particularly in systems that often marginalise them. Tuituia te Kahu is inclusive of our tāngata whaikaha whānau.

Tangihanga: Traditional Māori mourning and funeral process to honour the baby or person who has died. Also known as Tangi, which means to weep.

Tapu: Sacredness or spiritual restriction, often applied to the baby or person who has died and their care.

Te Whatu Ora (Health New Zealand): the organisation established to lead the day-to-day running of the health system across Aotearoa, with functions delivered at local, district, regional, and national levels. This now includes the functions from the disestablished Māori Health Authority. We are mindful, however, that some of those functions are now shared with the Iwi Māori Partnership Boards.

Turanga Kaupapa: Guidelines for cultural competence developed by Nga Maia o Aotearoa in 2006 and formally adopted by both the Midwifery Council of Aotearoa and the Aotearoa College of Midwives.

Termination: A medically induced end of pregnancy, which may occur for various reasons, including fetal anomaly, maternal health concerns, or personal choice.

Termination for Medical Reasons (TFMR) / Termination of Pregnancy for Fetal Anomaly (TOPFA): A medically advised termination due to severe fetal anomalies, often following diagnostic screening and ethical counselling.

Tertiary Care: Very specialised care, often only provided in a smaller number of locations.

Third Trimester Scan: also referred to as a Growth Scan, performed where there is high clinical risk of SGA (small for gestational age), FGR (fetal growth restriction) or another obstetric indication.

Threatened Miscarriage: Any bleeding in or from the genital tract of a pregnant person under 20 weeks gestation is defined as a threatened miscarriage.

Tikanga: Correct procedures and/or practices, reason, purpose.

Transgender: An umbrella term for people whose gender identity differs from their gender/sex assigned at birth.

Transmasculine Individual: People who were assigned as female at birth but identify more as male than female. Their anatomical birth sex does not match their inner sense of gender identity and can include non-binary and gender fluid individuals.

Te Tiriti o Waitangi: Aotearoa's founding document. It establishes the relationship between the Crown and Māori as tangata whenua and requires both the Crown and Māori to act reasonably toward each other and with utmost good faith.

Tuituia Te Kahu: The story of Tuituia Te Kahu is captured in the Co-Chairs' Foreword.

Tūpāpaku: A deceased person's body.

U

Urupā: A Māori burial ground.

V

Vuvale A significant term for people of Fijian cultural heritage, in this context meaning immediate/extended family.

W

Wahakura: A traditional woven harakeke (commonly known as flax) bassinet for infant sleeping. Providing a defined sleep space for pēpi to bed-share.

Well Child / Tamariki Ora Programme: A program providing eight core health checks for children from birth to 5 years.

Whāriki: A woven mat.

Whaikaha (Ministry of Disabled People): The ministry responsible for leading the disability support system in Aotearoa.

Whakapapa: Genealogy and ancestral heritage.

Whānau: Extended family and community, which may include close friends, is central to Māori culture and decision-making in bereavement. The connected “family” group includes physical, emotional, and spiritual relationships and is based on a Te Ao Māori worldview. Whānau is used throughout the report, and within that term we are inclusive of all of those who are within the rainbow communities, and tāngata whaikaha. Whānau is another kupu meaning birth. When we mention whānau in this report, we also note the Pasifika references to family and whānau as well - āiga, kāiga, magafaoa, kōpū tangata, vuvale, and fāmili.

Whānau-Centred Care: The concept of Whānau-Centred care is valuable, if it does not involve the policy and managerial state imposing what is considered "right" from their own perspective. This does not mean that clinical and professional expertise is not important – it certainly is. However, it should not come at the expense of the pregnant women/people, whānau and family’s own processes. This pathway prefers whānau- and family-led care.

Whānau-Led Care: Whānau-led decision-making and care, recognising cultural, social, and spiritual needs. A reminder that it is not culturally safe to try and impose one’s cultural norms on the whānau grief and journey. This is consistent with the midwifery standards of practice, including Turanga Kaupapa. Tuituia Te Kahu asserts the position of bereavement care being whānau-led care. Whānau have mana motuhake.

Whānau Ora Commissioning Agencies: Organisations responsible for commissioning Whānau Ora services.

Whānau Ora Navigation: A service providing support and guidance to pregnant women/people, whānau and family to access health and social services.

Whānau Ora: A holistic Māori healthcare approach focusing on pregnant women/people, whānau and family wellbeing.

Whetūrangitia: An online government service that provides information and support to pregnant women/people, whānau and family following a perinatal or infant loss, or the loss of a child. The site is operated by the Department of Internal Affairs (DIA) with links to other agencies involved in the services, including Inland Revenue, Ministry of Health, Ministry of Social Development and Ministry of Justice.

CHAPTER ONE: TERMS OF REFERENCE, MEMBERSHIP AND APPROACH

SUMMARY

This chapter introduces the background and development of the report; explaining how it was created and by whom.

It starts by describing the Terms of Reference (TOR). The TOR explain that the goal was to improve support for pregnant women, pregnant people, whānau and families experiencing perinatal loss, and it was created by Health New Zealand (Te Whatu Ora). The TOR outlines the main questions that needed to be answered and highlights the values that guided the project, such as respect, cultural safety, and fairness.

The chapter then introduces the Technical Advisory Group (TAG), a team of experts from various fields who helped design the pathway. These experts brought a variety of perspectives to the table. Everyone understood the experiences of individuals, whānau and families who had faced perinatal bereavement. Many had experienced bereavement themselves. Their combined knowledge helped shape the pathway for better bereavement care.

Next, the Approach section explains how the TAG gathered the information that would form the basis of the report. This wasn't just about research. The TAG used the voice of whānau and families who had experienced loss, looked at service delivery gaps, considered expert opinions, and reviewed international best practice. The TAG made sure the process was thorough, ensuring that the needs of everyone were considered. The chapter also outlines the timeline for the work, showing that the project was planned to start and end with clear stages.

Finally, the How to Read This Report section guides readers on how to navigate the document. It explains the structure of the report and where to find the most important information, ensuring that anyone reading it can easily understand and use this information.

TERMS OF REFERENCE (TOR)

The TOR were developed by Health New Zealand to guide the development of a national perinatal bereavement care pathway. The purpose being to recruit experts to design a pathway that ensures equitable access to high-quality care, and cultural safety for bereaved families.

The **Technical Advisory Group (TAG)** was tasked with:

- Examining current service gaps.
- Engaging with whānau and families.
- Recommending improvements based on best practices.

Health New Zealand asked the Technical Advisory Group (TAG) to look at the journey pregnant women, pregnant people, whānau and families go through, from primary and maternity services to community care. They also asked the group to think about care in future pregnancies. This pathway was designed to take a broad approach, considering all stages of care, not just clinical settings. Furthermore, the TAG was tasked with designing a pathway, not a service.

The TAG's role was advisory. They used their specialist knowledge to help shape the care pathway. They were tasked with exploring different options and providing high-level advice on how the pathway could be implemented. The final report, which is their advice, was submitted in June 2025; it included advice on the implementation and practical implications of the pathway.

The work was guided by key values, such as respect, excellence, empathy, and a commitment to Te Tiriti o Waitangi and equity. The members of the TAG were expected to work collaboratively, meet deadlines, and make sure their advice helped shape a care pathway that met the needs of bereaved women/people, whānau and families.

The budget for the TAG's activities, including fees and expenses, was capped by Health New Zealand.

THE APPROACH

The TAG designed Tuituia Te Kahu using a collaborative, evidence-based approach. The process involved:

- **Online Workshops and Engagement**: Wānanga with experts, pregnant women, pregnant people, whānau and families.
- **Research and Evidence Review**: Drawing from national and international best practices.
- **Service Gap Analysis**: Identifying challenges in current perinatal bereavement care.
- **Perinatal Mortality Data**: Reviewing statistics from PMMRC.

The TAG participated in a series of online workshops, consultations, and discussions to ensure that the pathway would be comprehensive, culturally responsive, and practical to implement.

How the TAG Gathered Information

The TAG used a combination of evidence-based research, case studies, expert opinions, and feedback from whānau to inform their work. Key resources included:

- **Whānau and Family Voice Reports**: These reports provided valuable insights from families who had experienced perinatal loss, ensuring the pathway reflected their needs and concerns.
- **Service Gap Analysis and Environment Scan**: This helped identify areas where services were lacking and highlighted the need for improvement in the current care system.
- **Perinatal and Maternal Mortality Review Committee (PMMRC) Reports**: These reports offered important data on the challenges faced by different demographic groups in Aotearoa, particularly in relation to maternal and perinatal health.
- **Literature Review**: A review of research on perinatal loss, bereavement care, and cultural competence in healthcare, with a specific focus on Māori and Pasifika health outcomes, helped guide the pathway's design.
- **International Best Practice**: The TAG also looked at best practices from other countries to learn from their experiences in developing perinatal bereavement care pathways.

What Information Was Used

Several types of information were central to shaping the pathway:

- **Statistical Data**: Reports from the PMMRC, along with the service gap analysis, provided the data necessary to understand the current state of perinatal care and where improvements were needed.
- **Personas**: Focusing on the lived experiences of families who had experienced perinatal loss was crucial in shaping a pathway that would be truly responsive to their needs.
- **Cultural Frameworks**: Insights from Māori, Pasifika and Indian representatives ensured that the pathway was culturally sensitive and addressed the unique needs of different communities.

Timeline of The Work

The work of the TAG followed a clear timeline:

- **August 2024**: The TAG was formed and had its initial orientation. Early discussions focused on the scope of the work, objectives of the pathway, and high-level design principles.
- **September – November 2024**: A series of workshops were held to complete the current and future state personas, helping to define the needs of whānau and families.
- **December 2024 – February 2025**: The draft pathway was developed, incorporating feedback from the workshops and refining all the elements of the approach.
- **June 2025**: The final report was submitted to Health New Zealand (Te Whatu Ora), providing a comprehensive plan for the implementation of the pathway.

CHAPTER TWO: STRATEGIC CASE FOR CHANGE

SUMMARY

This chapter talks about the need to improve care for individuals, whānau and families whose baby dies either during pregnancy or soon after birth.

It explains that many do not get the right support during this very sad time.

There are many problems in the current system, such as differences in the care different people receive, depending on where they live and/or their culture.

Some pregnant women/people, and families feel they are not listened to, especially Māori, Pasifika and Indian families.

Two key reports (The Perinatal Bereavement Support Environmental Scan Report and The Triennial Maternity Consumer Survey reports) show that a lot of people are unhappy with the care they get, and many feel abandoned after their loss.

Many also do not get the grief support they need, and healthcare workers are often not trained to help grieving pregnant women, pregnant people, whānau and families properly.

This chapter says that urgent changes are needed to make the system better.

This includes making sure that everyone gets help that is caring, respectful of their culture, and available when they need it. It also talks about the importance of providing better training for healthcare workers to help them give the best support possible.

Lastly, it highlights the need for a national pathway that will ensure everyone across Aotearoa can get the help they need, no matter where they live or their background.

WHĀNAU AND FAMILY VOICE

In 2021 Manatū Hauora (now Te Whatu Ora) commissioned Research New Zealand to conduct a maternity survey to better understand the experiences of individuals, whānau and families with maternity care, including the experiences of bereaved whānau.

The resulting reports provide in-depth insights into the current state of maternity and perinatal bereavement care in Aotearoa, shedding light on critical service gaps, particularly for some groups, and not others. Both reports strongly advocate for urgent reforms.

Findings from Technical Reports

The first report, Technical Report 1, based on a survey of 4,355 respondents, evaluated the overall satisfaction with maternity services, spanning antenatal, labour, birth, and postnatal care.

While 79% of respondents reported being satisfied with their overall experience, the percentage of those who were “very satisfied” has significantly decreased: from 48% in 2014 to 41% in 2022. This decline signals a troubling trend in the quality of care. Furthermore, disparities in satisfaction are evident among different demographic groups. While Māori, Pasifika and young mothers reported satisfaction levels similar to the general population, disabled pregnant women/people showed notably lower satisfaction, at just 69%.

These disparities point to ongoing challenges in ensuring equitable access to high-quality care and underscore the need for targeted improvements in service delivery, particularly for Māori, Pasifika and disabled women/people.

The second report, Technical Report 2 focused specifically on the experiences of individuals, whānau and families who have experienced perinatal loss, and surveyed 118 respondents who had suffered the loss of a pēpi or baby.

It found that only 53% of bereaved families were satisfied with the care and support they received; a significant decrease from 74% in 2014.

Many bereaved pregnant women, pregnant people, whānau and families described feeling unsupported in the aftermath of their loss, with 14% reporting that they received no follow-up visits, leaving them to cope without the necessary emotional or practical support.

A further 30% of respondents expressed a desire for additional support, particularly from their Lead Maternity Carer (LMC) or other healthcare professionals. This finding highlights a critical gap in ongoing care, with many families feeling neglected and left without the guidance and comfort they needed during an already difficult time.

The qualitative data collected from the second report reveals that, beyond the lack of follow-up visits, many individuals, whānau and families felt that their emotional needs were not met, particularly in terms of mental health support.

While 57% of bereaved respondents were offered counselling, only 46% of those who were offered it actually received the support. This gap in mental health provision is concerning, as the emotional impact of perinatal loss requires immediate and ongoing support.

The shortage of accessible mental health services for grieving pregnant women, pregnant people, whānau and families is a recurring issue, reporting that, when counselling was provided, it often came too late or was insufficient in addressing their needs.

Additionally, there was a strong call for culturally appropriate bereavement care, particularly for Māori and Pasifika pregnant women/people, and equally urgent for Indian families, who reported feeling that their diverse cultural and spiritual needs were not being understood or accommodated. Indian families specifically highlighted the lack of understanding among healthcare providers about the importance of extended family involvement in decision-making, the need for culturally appropriate spaces for prayer and ritual, and the challenges of navigating healthcare systems when English is not their first language. Many Indian families expressed feeling isolated from their cultural support systems during their most vulnerable moments, with healthcare providers often unaware of the significance of community networks and religious practices in their healing process.

One of the most frequently cited issues by pregnant women, pregnant people, whānau and families was poor communication from healthcare professionals, both in terms of the delivery of the news of their loss and the support provided afterwards.

Several pregnant women, pregnant people, whānau and families reported that the news of their baby's death was delivered insensitively, with little regard for the emotional toll it would take. This lack of empathy and support in such a sensitive situation was said to have exacerbated their grief.

Furthermore, many pregnant women, pregnant people, whānau and families felt pressured to make decisions quickly, without being given enough time or information to make fully informed choices. This lack of clear, compassionate communication, both during the initial loss and throughout the bereavement process, contributed to feelings of abandonment and frustration.

The findings from both reports underscore the urgent need for improvements as to how perinatal bereavement care should be delivered. Key areas for improvement include enhancing communication between healthcare providers, pregnant women, pregnant people, whānau and

families; ensuring that follow-up care is not only offered but actually provided; and making mental health support more accessible and timelier. Additionally, there was a strong call for culturally appropriate bereavement care, particularly for Māori and Pasifika, pregnant women/people but also for Indian families, who reported feeling that their cultural needs were not being addressed. Both reports emphasise that the system must do more to integrate cultural competence into its bereavement support services, to ensure that all pregnant women, pregnant people, whānau and families receive the care and respect they deserve during one of the most difficult times in their lives.

These findings have played a crucial role in informing the design of the national perinatal bereavement care pathway. The insights gained from the voices of individuals, whānau and families will guide the development of a more compassionate, culturally safe, and effective system for supporting those affected by perinatal loss.

CURRENT SERVICE GAPS

In March 2023, Health New Zealand commissioned an environmental scan to assess the state of perinatal bereavement support across Aotearoa (the Perinatal Bereavement Support Environmental Scan Report).

The focus of this scan was to better understand the experiences, service inconsistencies, and challenges that individuals, whānau and families face when accessing perinatal bereavement care. The findings reveal a stark contrast between the care available to parents of living babies and those experiencing perinatal loss.

Parents of living babies meet the criteria for support after birth, through services such as maternal mental health; those who experience perinatal bereavement often find that because they do not have a living child, they do not meet the required criteria. This gap in service provision has left many families feeling unsupported and abandoned in the most difficult time of their lives.

The environmental scan identified a range of systemic issues that contribute to these service gaps. One of the most significant findings is that perinatal bereavement care in Aotearoa operates as a fragmented system. This fragmentation leads to significant disparities in the level of support families receive, depending on factors such as location, timing of the loss, and the available resources in their area. For example, while approximately 700–900 pregnant women/people experience stillbirth annually, and an additional 13,000 experience miscarriage before 20 weeks, the care these pregnant women, pregnant people, whānau and families receive varies

dramatically. Some regions offer high-quality services with dedicated bereavement support, while others lack even the most basic resources.

The hospital environment presents immediate challenges for bereaved whānau and families. Most facilities lack dedicated bereavement spaces, which forces grieving parents to navigate maternity wards filled with newborns and whānau and families celebrating the birth of their babies. The contrast between the joy of other whānau and families and the grief of those who have experienced a loss only adds to the emotional burden.

Counties Manukau stands out in Australasia as an exception, with its comprehensive bereavement support team and dedicated facilities. Their practices, such as the "pink slip" system that alerts staff to a bereavement situation, provide a model for how thoughtful protocols can significantly improve care. However, these exemplary practices remain isolated and are not standard across the country, further exacerbating the gaps in support.

Another critical issue highlighted by the scan is the arbitrary 20-week gestation threshold, which creates a troubling divide in the care provided to pregnant women, pregnant people, whānau and families, based on the timing of their loss. Whānau and families experiencing losses before 20 weeks often receive clinically focused care, which can be less compassionate and more disjointed. They are frequently managed in gynaecology wards, which do not have the necessary bereavement support services or resources, further underscoring the disparity in care, based on the timing of the loss.

Healthcare professionals also face significant challenges in providing appropriate care to bereaved pregnant women, pregnant people, whānau and families. Many staff members have minimal formal training in bereavement support, leaving them ill-equipped to handle such sensitive situations.

Sonographers, for example, who are often the first to deliver the devastating news of a loss, are typically not trained in grief counselling. Similarly, junior doctors, who rotate through various services, often lack the expertise needed to support bereaved pregnant women, pregnant people, whānau and families. Even experienced midwives report feeling underprepared for providing bereavement support, and there is insufficient institutional support for staff dealing with the emotional toll of supporting grieving pregnant women, pregnant people, whānau and families. Professional supervision and pastoral care remain limited, leaving healthcare workers without the necessary resources to cope with the emotional burden they face.

The system particularly fails to provide culturally competent care for Māori, Pasifika and Indian families, highlighting significant cultural safety gaps. For Indian families, these gaps are compounded by the diversity within Indian communities, where healthcare providers often lack understanding of the different religious, linguistic, and cultural needs of Hindu, Sikh, Muslim, Christian, and other Indian families. The absence of culturally appropriate spaces for prayer and ritual, limited access to interpreters for the many languages spoken within Indian communities, and insufficient understanding of extended family decision-making processes create additional barriers to culturally safe care. Many Indian families report feeling that their spiritual and cultural practices are not understood or accommodated, particularly around death rituals and the important role of community support systems in their grieving process.

When cultural support is available, it often comes too late to be fully effective. The shortage of Māori, Pasifika and Indian healthcare professionals in specialist roles further compounds these issues, as these families are not always able to access culturally appropriate care.

Regional disparities also create significant inequities in care. While some urban centres provide specialist services, rural areas often lack even the most basic resources, such as cooling resources or dedicated bereavement rooms. The concentration of perinatal pathologists in just four centres nationwide creates additional barriers for pregnant women, pregnant people, whānau and families seeking answers about the cause of their loss. Coronial investigations can take up to three years, and often receive results by post, with no support or explanation, adding further trauma to an already devastating situation.

Mental health support within the system shows serious gaps. There is limited access to free counselling sessions, long waiting lists for specialist perinatal mental health support, and minimal assistance for partners and siblings, who are also affected by the loss. The transition from hospital care to community support is often poorly managed, with inconsistent handover to GPs, variable LMC support post-discharge, and poor connection to community services. Pregnant women, pregnant people, whānau and families report that the support they receive is fragmented and not coordinated, leaving them to navigate the system alone during a time of immense grief.

Non-governmental organisations (NGOs), such as Sands NZ and Baby Loss NZ, play a vital role in filling these system gaps, providing essential support services. However, these organisations face their own challenges, including volunteer workforces and unstable funding models. While these community partners offer invaluable services, their geographic coverage is patchy, and their integration with healthcare systems is often weak.

The environmental scan strongly advocates for a national perinatal bereavement care pathway to address these systemic issues. A coordinated, standardised approach is necessary to ensure equitable access to services, consistent staff training, and the effective integration of cultural practices across Aotearoa.

This report suggests that a **properly resourced and culturally grounded national framework could transform the bereavement journey for individuals, whānau and families, while also providing healthcare professionals with the support and training they need to deliver comprehensive care**.

These findings echo and support the voices of individuals, whānau and families, as described in the previous section, reinforcing the need for urgent changes in how perinatal bereavement care is delivered across Aotearoa.

WHY CHANGE IS URGENTLY NEEDED

The findings from both the whānau voice research and the environmental scan are echoed in the Perinatal and Maternal Mortality Review Committee (PMMRC), which underscores the urgent need for reform in perinatal bereavement care, particularly in addressing the persistent failures and inequities that continue to affect individuals, whānau and families.

Where the environmental scan highlighted gaps in service provision, the PMMRC's detailed mortality data paints a much more concerning picture of systemic failures and the stark inequities faced by Māori, Pasifika and Indian populations, including young people, often living in isolated and difficult circumstances.

The PMMRC's most recent report reveals a disturbing stagnation in perinatal mortality rates over the past decade, despite some efforts to reduce stillbirths and preventable deaths.

This lack of progress suggests systemic failures within the healthcare system to address the needs of those at greatest risk. The review highlights that Māori, Pasifika and Indian populations continue to face disproportionately high rates of perinatal mortality.

This inequity is compounded by broader social determinants such as poverty, housing conditions, and access to care, but the review highlights that these disparities are primarily due to the failings within the health system itself.

These findings make it clear that targeted efforts to address these inequities have been insufficient, and that urgent reforms are required to ensure equitable outcomes for all.

In addition to the broader findings on mortality rates, the PMMRC report identifies specific failures in clinical care that contribute to poor outcomes for vulnerable groups. These include inadequate

monitoring of at-risk pregnancies, delayed interventions, and inconsistent application of clinical guidelines. For example, the report notes that, while there are established guidelines for managing pregnancies at risk of stillbirth, these are not always consistently followed, leading to what would otherwise be preventable deaths.

This likely reflects the systemic issues identified in the environmental scan, where fragmented services and inconsistent care practices contribute to gaps in support for pregnant women, pregnant people, whānau and families experiencing perinatal loss.

The PMMRC also highlights significant challenges in providing culturally appropriate care. This mirrors the two previous reports. Māori and Pasifika pregnant women, pregnant people, whānau and families continue to report feeling that their cultural needs are not being adequately addressed, leading to feelings of alienation and lack of support during critical times.

The ongoing failure to integrate cultural safety into care practices is a major concern, with both the environmental scan and the PMMRC finding that cultural incompetence within the healthcare workforce is a key barrier to effective perinatal care.

The PMMRC confirm that many whānau and families often report feeling unsupported in their grieving processes, particularly when cultural rituals are disregarded or when there is insufficient cultural competence among healthcare providers. These findings reinforce the importance of addressing cultural safety as a central tenet of the design of the bereavement care pathway for perinatal loss.

The PMMRC's findings on mental health support further emphasise the need for change. Mental health services for bereaved pregnant women, pregnant people, whānau and families are consistently inadequate, with long-wait times, insufficient coverage, and a lack of appropriate follow-up care.

Many whānau and families who experience perinatal loss report that their emotional and mental health needs are not met, leaving them to cope with their grief without adequate professional support.

The environmental scan concurs, highlighting that bereaved whānau and families often struggle to access timely counselling and support services. The PMMRC stresses that the mental health needs of these pregnant women, pregnant people, whānau and families must be a priority, and that timely, ongoing, and culturally appropriate counselling services must be integrated into the perinatal care pathway.

The PMMRC also reveals that healthcare professionals remain underprepared for managing perinatal bereavement. Many professionals, including midwives, obstetricians, and sonographers, report feeling ill-equipped to provide the necessary emotional and psychological support to grieving pregnant women, pregnant people, whānau and families.

This is consistent with the findings of the environmental scan above, which identified gaps in bereavement training and professional development. Both reports highlight that healthcare workers must receive comprehensive training in grief literacy, communication, and cultural safety, to ensure that they can provide compassionate and competent care during such a sensitive time.

The combination of the PMMRC's findings and the environmental scan makes it clear that Aotearoa's perinatal bereavement care system continues to fail. The disparities in clinical outcomes, the failure to provide culturally appropriate care, and the lack of mental health support all point to systemic issues that require immediate and comprehensive reform.

To better understand these critical gaps, the section following examines the peer-reviewed literature on inequity, cultural safety, pregnant women, pregnant people, whānau and families' needs, workforce development, and international best practice.

The literature provides important insights into how other healthcare systems have tackled similar challenges and can inform the design of a national bereavement care pathway for perinatal loss. By reviewing the evidence from global best practices, we can develop a pathway that ensures that all pregnant women, pregnant people, whānau and families, particularly those in greatest need, receive the compassionate, equitable, and culturally safe care they need.

The peer-reviewed literature also reinforces the need to build a workforce that is not only clinically competent but also equipped to provide compassionate, culturally safe, and emotionally supportive care.

It is through such informed, evidence-based approaches that we can address the ongoing failures in the system and create a pathway that meets the needs of all individuals, whānau and families experiencing perinatal loss. It is also the gaping silence within the literature that calls us to action. There is limited research that has been undertaken about the experiences of LGBTQIA+/takatāpui and tangata whaikaha/disabled whānau in perinatal bereavement care. Thereby, there are no specific support services run by and for these communities who experience perinatal bereavement. This silence/invisibility/exclusion calls for urgent reform.

WHAT THE LITERATURE SAYS

The peer-reviewed literature on perinatal bereavement care offers critical insights that both support and extend the findings outlined in the previous sections, particularly in areas that remain under-explored or inadequately addressed.

The whānau voice, environmental scan and PMMRC reports provide valuable data on the experiences of pregnant women, pregnant people, whānau and families, and the gaps in service provision. The literature offers a detailed understanding of these issues, particularly in terms of international best practices, workforce training, and the integration of mental health and cultural safety.

Below, we explore what the literature contributes beyond the findings of the previous sections.

Inequity and Systemic Failures

Consistent with the environmental scan and PMMRC, the literature highlights inequities in perinatal care. It offers further clarification of the systemic nature of these issues and the need to be mindful of other reasons. Pollock et al. (2020) and Brierley-Jones et al. (2018) offer evidence that socioeconomic factors and systemic biases in healthcare often prevent marginalised groups from accessing adequate care. These studies underscore that the failure to address the intersection of social determinants, such as housing, income, and access to healthcare, exacerbates health inequities. In contrast to the PMMRC's focus on mortality rates, the literature takes a deeper dive into the broader social, cultural, and institutional barriers that prevent equitable access to bereavement care. It argues that a multi-sectoral approach, engaging healthcare and social services, and communities is crucial to addressing these root causes of inequity.

Cultural Safety and Competency

Both the environmental scan and the PMMRC found significant gaps in cultural safety, particularly for Māori, Pasifika and Indian families. However, the literature goes further, by offering specific frameworks for integrating cultural safety into perinatal care. Pollock et al. (2024) and Brierley-Jones et al. (2018) discuss models of care that ensure cultural practices are not only respected but are embedded within the care process.

These models provide examples of how to incorporate culturally specific mourning rituals and support mechanisms into the healthcare system, such as providing space for whānau and aiga rituals and supporting traditional grieving practices.

The literature also stresses that cultural safety should be more than just a matter of awareness; it requires structural changes to healthcare systems, including workforce diversity and the integration of indigenous knowledge and values. While the PMMRC and the environmental scan highlight these gaps, the literature offers actionable models for transforming cultural care practices, which could be used to inform the development of a culturally grounded perinatal bereavement care pathway.

Family Needs and Mental Health Support

The environmental scan and PMMRC both highlight the inadequacy of perinatal mental health services for bereaved families, pointing to delays and a lack of timely support. What the literature adds is a deeper exploration of the mental health needs of grieving families, particularly in terms of the psychological and emotional support required immediately after the loss and in the months following.

Studies, such as those by O'Connell et al. (2016) and Thornton et al. (2020) emphasise the importance of immediate emotional validation and ongoing mental health support, not just clinical care. The literature suggests that bereavement care should be framed as a long-term support system, where pregnant women, pregnant people, whānau and families are consistently followed up and offered tailored support, based on their unique needs.

Memory-making practices, such as offering keepsakes, photographs, or memory boxes, have also been shown to significantly aid the grieving process, helping pregnant women, pregnant people, whānau and families maintain a connection with their child and affirming the child's life. These insights suggest that mental healthcare should be embedded into the entire care pathway – not treated as a separate or secondary service, and be available earlier, rather than later.

Workforce Development and Training

While the previous sections highlight gaps in workforce preparedness for bereavement care, the literature adds depth to this issue, by stressing the importance of integrating bereavement care training throughout healthcare curricula and professional development programmes.

Research by Laing et al. (2020) and Qian et al. (2021) notes that many healthcare professionals, including midwives and sonographers, report feeling overwhelmed by the emotional demands of perinatal bereavement care.

The literature highlights that bereavement training should not only focus on technical aspects but also emotional resilience, communication skills, and cultural competence. The studies argue that healthcare workers must be equipped with the tools to manage the emotional complexity of supporting grieving pregnant women, pregnant people, whānau and families, as well as the skills to engage in sensitive communication, both in delivering the news of their loss and in providing follow-up support.

Furthermore, institutional support for staff, such as regular supervision and mental health support, is often overlooked. The literature advocates for integrating this type of emotional and professional support into the broader healthcare system, which is largely missing from current practices highlighted in the environmental scan and PMMRC reports.

International Best Practices

International best practices provide valuable lessons that can inform the development of a perinatal bereavement care pathway in Aotearoa.

The UK's National Bereavement Care Pathway (NBCP), for instance, has been successful in standardising bereavement care across multiple loss pathways, ensuring that families receive consistent, high-quality care. The literature highlights that implementing national bereavement pathways, as seen in the UK and Ireland, can significantly improve the quality of care and consistency of services, ensuring that no family is left without support, regardless of their geographical location.

In addition, countries like Australia and Canada have integrated culturally competent care into their perinatal services, demonstrating how a culturally sensitive approach can be successfully implemented in bereavement care. These international models underscore the importance of adopting a systems approach to bereavement care, which incorporates comprehensive support, cultural safety, and professional training.

The literature also emphasises the value of integrating memory-making practices as a standard aspect of perinatal bereavement care. This approach has been widely adopted in countries like the UK and Australia, where families are given the opportunity to create lasting memories of their child. Research by Cacciatore and Flint (2012) shows that these practices have profound psychological benefits for families, offering them a means to process their grief and keep a tangible connection with their baby. Implementing such practices in Aotearoa could help bridge

the gap identified in the environmental scan, where pregnant women, pregnant people, whānau and families often report feeling disconnected or unsupported in the aftermath of loss.

STRATEGIC ALIGNMENT

The need for reform in perinatal bereavement care, as outlined in the previous sections, aligns strongly with several key strategic frameworks and priorities in Aotearoa. These include the overarching goals of improving health and maternity outcomes, ensuring healthcare is culturally safe, and addresses the needs of individuals, whānau and families.

First and foremost, the findings from both the environmental scan and PMMRC support the government's commitment to reducing health inequalities. As highlighted earlier, Māori, Pasifika and Indian communities continue to experience significantly worse outcomes in perinatal mortality. Addressing the gaps identified in the reports will be critical in ensuring that these strategic objectives are met.

Ensuring healthcare is culturally safe is important to the government. Based on the evidence in this chapter, the perinatal bereavement care pathway will need to ensure culturally appropriate and sensitive care for all New Zealanders. This directly supports the government's strategy that care should be needs-based and appropriate to the context of the individual.

Furthermore, the findings from the reports align with the strategic priority to improve mental health outcomes across the population. The mental health needs of individuals, whānau and families following perinatal loss are critical, yet they remain insufficiently addressed in the current system. The call for enhanced mental health support within the reports echoes the goals of the government's Mental Health and Wellbeing Commission, which seeks to provide comprehensive and accessible mental health services to all New Zealanders. Integrating robust mental health services into the perinatal bereavement care pathway is not only a response to the gaps identified but also a necessary step towards fulfilling these broader strategic priorities.

Additionally, the need for workforce development aligns with the objectives outlined in various workforce strategies. As discussed, healthcare professionals often feel ill-equipped to provide bereavement care, and there is a clear need for specialised training in this area. The perinatal bereavement care pathway will need to advocate for a workforce that is skilled, supported and capable of responding to the diverse needs of the population. The implementation of mandatory bereavement education and training, and the integration of emotional support and cultural

competence into healthcare curricula will be crucial to building a workforce that is ready to meet the challenges identified in this report.

Finally, the call for a national perinatal bereavement care pathway for perinatal loss aligns with the broader goal of transforming Aotearoa's health system into one that provides consistent, high-quality care across all areas. As identified in the environmental scan, the lack of coordination and consistency in perinatal bereavement care across regions creates inequities in service provision. The development of a coordinated, standardised approach to perinatal bereavement care, supported by national guidelines and protocols, is an essential step in creating a health system that truly meets the needs of all New Zealanders.

CONCLUSION

The findings presented in this report, derived from whānau voices, the service gap analysis and environmental scan, the PMMRC and the peer-reviewed literature, make a clear and compelling case for a national bereavement care pathway for perinatal loss in Aotearoa.

As outlined above, systemic gaps persist that leave many individuals, whānau and families without the consistent, compassionate, and culturally appropriate support they need following perinatal loss. Māori, Pasifika, and other communities are particularly affected, facing disparities in care that reflect broader systemic issues within the healthcare system.

The evidence points to the need for a national bereavement care pathway for perinatal loss that can address these gaps, ensuring that every pregnant woman/person, whānau and family, regardless of their background or location, receives equitable access to high-quality care.

Importantly, the literature calls for a **multi-faceted approach to address these challenges, including integrating mental health support into the care pathway, providing comprehensive training for healthcare workers, and ensuring that cultural safety is embedded** within the healthcare system.

A well-designed, coordinated pathway can bring about the changes necessary to ensure that pregnant women, pregnant people, whānau and families affected by perinatal loss are supported from the moment of getting the bad news and throughout their grieving process.

This section has made a case for change and it is clear that moving forward with a national approach will ensure that the care provided is equitable, culturally responsive, and compassionate.

CHAPTER THREE: TUITUIA TE KAHU A NATIONAL BEREAVEMENT CARE PATHWAY FOR PERINATAL LOSS

SUMMARY

Tuituia Te Kahu is a nation-wide approach to supporting individuals, whānau and families who experience the loss of a baby during pregnancy, around birth or as a newborn or infant (up to 12 months).

It is based on nine important standards that work together to ensure individuals, whānau and families receive the care, help, and support they need during this difficult time. In short, those standards are:

1. **Early and Compassionate Care**: Whānau and families will receive immediate and caring support as soon as a loss (expected or diagnosed) is identified. This includes help with mental health and physical care.
2. **Consistent Care and Clear Handovers**: Whānau and families will receive continuous support with clear communication between doctors, nurses, and other care providers, to avoid gaps in care.
3. **Early Mental Health Integration**: Mental health services will be available from the start to help with grief and emotional challenges.
4. **Culturally Responsive, Whānau-Led and Spiritual Care**: Support will be tailored to each individual, whānau and family's cultural and spiritual needs, ensuring they feel respected and understood.
5. **Memory-Making and Bereavement Support**: Whānau and families will have the opportunity to create memories of their baby, such as taking photos or making handprints, if they wish. This helps families honour their child.
6. **Follow-up Care in the Community and Subsequent Pregnancy Support**: After the loss, pregnant women, pregnant people, whānau and families will receive ongoing support. This includes emotional and psychosocial support and help with future pregnancies (if wanted).
7. **Clear Information and Decision-Making Support**: Whānau and families will be provided with easy-to-understand information to help them make decisions about their care.
8. **Well-Supported Staff and Bereavement Education**: Healthcare workers will receive education and support to ensure they can care for grieving whānau and families with compassion and understanding, and that they, too, are cared for.

9. **Regular Review and Continuous Improvement**: The pathway will be regularly reviewed to ensure it continues to meet the needs of pregnant women, pregnant people, whānau and families and is improved, where and when necessary.

The pathway is like a woven mat, where each part works together to create a strong, supportive structure that helps whānau and families through every stage of their grief journey. We also stress that people with lived experience from LGBTQIA+/takataapui and tangata whaikaha/disabled communities were actively involved in developing Tuituia Te Kahu, bringing forward intersectional perspectives that reflect the diverse realities of whānau who experience perinatal bereavement. Tuituia Te Kahu aims to highlight these gaps and advocate for more responsive, equitable, and inclusive perinatal bereavement care. This is important to note because as outlined in earlier chapters, there is limited research that has been undertaken about the experiences of LGBTQIA+/takatāpui and tangata whaikaha/disabled whānau in perinatal bereavement care. Thereby, there are no specific support services run by and for these communities who experience perinatal bereavement. Tuituia Te Kahu aims to provide care that is timely, respectful, and adaptable to the needs of each and every individual, whānau and community.

TUITUIA TE KAHU

1 EARLY AND COMPASSIONATE ENGAGEMENT

People should be met with kindness, not confusion. From the moment someone realises something is wrong, they deserve quick, gentle, and clear care: no cold language, no long waits, no being left alone in the dark.

2 CONSISTENT CARE AND CLEAR HANDOVER

Care should not fall through the cracks. Whether it's the midwife, the hospital team, the GP, or the social worker: everyone needs to be on the same page. Families should never have to repeat their story over and over again. The lead perinatal bereavement co-ordinator uses a care plan tool to navigate the whānau and family through the system.

3 EARLY MENTAL HEALTH INTEGRATION

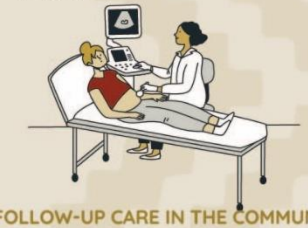
Grief is real. Sadness can turn into deep pain if it's ignored. Mental health support should begin straight away: not weeks later when whānau and family are already struggling.

4 CULTURALLY RESPONSIVE, WHĀNAU-LED AND SPIRITUAL CARE

No one should have to fight to have their culture or beliefs respected. This standard says: whānau and family know best what they need. The system should follow their lead, not the other way around.

5 MEMORY-MAKING, BEREAVEMENT AND GRIEF SUPPORT

Every family should have the chance to make memories. While not every family will want to, photos, footprints, karakia, holding the baby: whatever feels right will be offered. Support doesn't stop at the door. It follows the family home and keeps checking in.

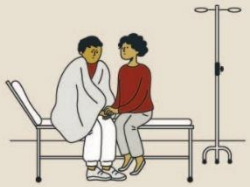


6 FOLLOW-UP CARE IN THE COMMUNITY AND SUPPORT IN NEXT PREGNANCY

Grief doesn't end when you leave hospital. Neither should care. Follow-up means someone checks in. And if someone gets pregnant again, they need extra support: not just "see you at 12 weeks."

7 CLEAR INFORMATION AND DECISION-MAKING SUPPORT

People have the right to good information. No jargon. No rushing. No hiding things. This includes understanding what happens next, what their choices are, and what support is available. The lead perinatal bereavement co-ordinator has a key role to play in this standard.



8 WELL-SUPPORTED STAFF AND BEREAVEMENT EDUCATION

Staff are hurting too. But they need to know how to help. This standard says they need proper training, supervision, and space to process grief too: so they can show up well for everyone, including themselves.

9 REGULAR REVIEW AND CONTINUOUS IMPROVEMENT

This isn't a "set and forget." Services need to keep learning, keep improving. We listen to whānau, measure what's working, and change what's not. Accountability matters.

HOW EACH STANDARD IS WOVEN AS A UNIQUE INDIVIDUAL THREAD

Each standard begins with a **Description**, which outlines the scope and overarching aim of the standard.

Why it Matters explains the importance of the standard, illustrating how it can positively influence care and contribute to long-term improvements in maternity and health outcomes.

The **Improvements Required** section addresses the health system, identifying areas that need development over the next three-to-five years.

Improvement Actions provide a set of practical steps to help relevant decision makers start to shape concrete actions for the years ahead.

The **Establishment Priorities** focuses attention on immediate tasks that need to be completed, particularly before June 2026.

Year One Priorities specifies the key actions for the initial implementation year of Tuituia Te Kahu.

Success Measures outlines the key metrics and targets that will help gauge the effectiveness of the interventions in Years Two and Three.

The **Metric** section delves deeper into how success will be tracked, acknowledging that these processes will need to be tested and piloted.

Finally, the **Target Actions** offers guidance to those responsible for the system, identifying lead indicators of success.

The **Personas** aim to bring the 'Why It Matters' section to life, drawing on the experiences of the Technical Advisory Group, while ensuring privacy and confidentiality are maintained by making them fictionalised.

STANDARD	KEY FOCUS	OUTCOME FOR WHĀNAU
1. Early and compassionate engagement	Early identification of perinatal loss	Immediate emotional and practical support
2. Consistent care and clear handovers	Continuity between hospital and community care	Seamless transitions with no gaps
3. Early mental health integration	Immediate access to psychological support	Reduced long-term grief impacts
4. Culturally responsive, whānau-led care	Ensuring care aligns with cultural values	Whānau and spiritual needs respected
5. Memory-making & bereavement support	Opportunities to create memories	Options for parents to honour their baby
6. Follow-up care in the community	Ongoing whānau-centred support	Grief services remain accessible
7. Information & decision support	Clear, plain-language information	Pregnant women, pregnant people, whānau and families feel informed and in control
8. Well-supported staff	Training for healthcare providers	Compassionate, skilled and supported workforce
9. Continuous improvement	Regular service reviews	System adapts based on feedback

Table 1: Outline of standards, their key focus and the anticipated outcomes for whānau.

STANDARD ONE: EARLY AND COMPASSIONATE ENGAGEMENT

Description:

Early, compassionate and comprehensive support will be provided to pregnant women, pregnant people, whānau and families at every stage of their journey. The goal is to identify loss (expected[i] or diagnosed) and acknowledge previous loss early and offer timely and targeted assistance, with support including tools, such as notification systems to signal loss or subsequent pregnancies following a previous loss. Comprehensive early support systems, once a perinatal loss or pregnancy loss is identified, will activate coordinated care pathways and build whānau - āiga, kāiga, magafaoa, kōpū tangata, vuvale, familia-family trust, through timely and high-quality engagement.

Why it Matters:

Early and compassionate engagement is crucial to avoiding complications and enhancing overall care, ultimately fostering a more supportive environment for pregnant women, pregnant people, whānau and families. Early identification of perinatal loss, and notification of previous loss, with compassionate communication significantly impacts whānau - āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmili - and families' grief journey and long-term mental health outcomes.

Improvements Required:

An early system signal is needed to identify loss, and subsequent pregnancy after loss, to ensure that pregnant women/people, whānau - āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmili - and families receive immediate and appropriate support. Clinical teams must be able to act upon the signal swiftly and effectively. Comprehensive tools, capable of supporting different types of loss must be deployed and integrated into practice.

Improvement Actions:

- Trial the identification/notification systems within selected maternity units to monitor the effectiveness of the early identification of perinatal loss and the timely activation of coordinated care pathways.
- Gather feedback from healthcare teams, whānau - āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmili - and families regarding the clarity and utility of tools used to support different types of perinatal loss.

- Refine the systems based on trial results, before proceeding with a wider rollout.

Establishment Year Priorities:

- Conduct a feasibility study to assess the integration of a national notification/identification system into current systems.
- Bring together key partners and stakeholders to ensure alignment with existing practices and protocols for delivering news of perinatal loss, and to identify the most appropriate tools and training required.
- Design a testing framework to guarantee that the tools are user-friendly and effective for clinical teams.

Year One Priorities:

- Begin a formal rollout of notification/identification system in selected regions.
- Implement 'compassionate conversations' protocols to ensure whānau and families are compassionately informed about risks and available support. Provide education and training for healthcare teams to ensure proper and compassionate use of the new tools.

Success Measures:

By Year Three, assuming Year One is carefully scaled in Year Two, success will be measured by:

- The percentage of pregnant women, pregnant people, whānau and families who have experienced a loss, who receive support within 24 hours.
- A target of 90% satisfaction from pregnant women, pregnant people, whānau and families regarding the timeliness and effectiveness of the support provided.
- A 90% satisfaction rate from healthcare teams in terms of confidence in identifying and compassionately addressing loss or previous loss appropriately.

Metric:

The success of the early engagement process will be tracked by ensuring that 90% of pregnant women/people who have experienced a loss receive support within 24 hours of identification. Feedback will also be gathered to assess the clarity, compassion and timeliness of the communication.

Target Actions:

Achieve this target by ensuring that clear identification protocols are implemented and that healthcare teams have the resources necessary to intervene quickly. Real-time feedback from whānau and families will be used to track the effectiveness of interventions.

Personas

Angela and Priya arrived at the emergency department just before midnight. Angela is bleeding. The pregnancy is at eleven weeks. They were told to wait. The chairs were hard. Angela was worried about the amount of bleeding. No one spoke to them. No one acknowledged them. When they were finally seen, a nurse told them they were likely miscarrying and handed them a sanitary pad and some papers. They were told to see their GP in the coming weeks. That was it. No explanation. No kindness. Under Tuituia Te Kahu, Angela and Priya would be taken straight into a quiet room. A calm voice would explain what is happening. They also bring water and tea. A nurse then explains the physical process of miscarriage and reassures them that their feelings are valid. The couple is offered follow-up support and shown the community support that is available. They are not alone in the worst moment of their lives.

Molly and Mark had already been through more grief than most. They lost baby after baby, each time filled with hope, then heartbreak. When Molly became pregnant again, they held their breath. But at nine weeks, she miscarried once more. The GP gave them a form to get tests. No one called. When the results finally came through, Molly was told over the phone that her miscarriages were likely caused by scarring from earlier surgeries. There was no follow-up appointment. No face-to-face conversation. No one asked how they were coping. They were left alone to carry the weight of another loss, and the fear that there might never be a next time.

Under Tuituia Te Kahu, Molly and Mark would be met with care from the start. The miscarriages would have been acknowledged gently. The local perinatal bereavement co-ordinator calls a few days later, not just to book tests but to see how they are emotionally. When the results come, Molly and Mark are invited in to talk through them. A perinatal bereavement care plan is prepared. A family counsellor is at the heart of the plan. A specialist is also looped in. Molly and Mark are not left to make hard decisions alone. They are seen, held, and given time to find their footing again.

Te Rina is eighteen. She lives rurally on the coast. She carries the name of her kuia. When she noticed her baby wasn't moving, she caught a ride into town and waited for hours at ED. No one looked her in the eye. Eventually a doctor came in and told her he was sorry but there was no heartbeat. He left the room. No one stayed. She didn't know what to do. She sat there alone, in a thin gown, crying, waiting for someone to come back. Under Tuituia Te Kahu, when Te Rina arrives, she's taken into a quiet space straight away. Someone will sit with her. Her whānau will be contacted, if that is what she wishes. She's not left to wonder. The staff take their time. They say her baby's name. They make space for karakia. She feels like a person, not a problem. When she leaves, she knows who will follow up and when they will call.

STANDARD TWO: CONSISTENT CARE AND CLEAR HANDOVERS

Description:

Pregnant women/people, whānau, and families will receive coordinated and integrated support services, ensuring that care remains consistent throughout their journey. Clear handovers (also known as referrals) between clinical and healthcare teams, as well as community-based services are essential to avoid gaps in care. Every healthcare provider, from clinicians to community support teams, needs a shared understanding of the needs of pregnant women, pregnant people, whānau and families and of trauma-informed care, ensuring that transitions between services are seamless.

Why it Matters:

Consistent care and clear handovers are key to reducing stress and improving mental health and general health outcomes. Effective communication between care teams ensures that no essential information is missed, and the care pathway remains coherent, leading to a smoother experience for grieving women/people, their whānau and families facing perinatal loss. It also ensures that whānau do not have to repeat their story continually as they interact with various clinicians.

Improvements Required:

A dedicated Lead Perinatal Bereavement Coordinator will be assigned to ensure that the grieving person, their whānau and families experiencing loss receive consistent care and clear handovers. The Lead Perinatal Bereavement Coordinator is the kaiwhakatere: they navigate the whānau - *āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmili* - and family along the pathway, with care and compassion that is trauma focused and grief literate. The grieving woman/person, whānau and family remain the kaihautū: they set the pace and speed of the journey. A standardised system for handovers must be established to guarantee that critical information is transferred without delay. The kaiwhakatere is not necessarily a health worker, let alone someone currently working in a hospital setting.

Improvement Actions:

- Pilot the dedicated Lead Perinatal Bereavement Coordinator role, with a view to understanding its purpose and value, and how it fits with other roles.

- Pilot new handover protocols to ensure critical information is communicated effectively between service providers.
- Gather feedback from both healthcare teams and community grief supporters, as well as whānau and families on the effectiveness of handovers, refining the protocol based on that feedback.

Establishment Year Priorities:

- Define roles and responsibilities within care teams to ensure clarity on duties and the services provided. A focus needs to be on trialling the dedicated Lead Perinatal Bereavement Coordinator.
- Reconfirm the gap analysis completed in 2023.
- Design and implement protocols for handovers that can be applied consistently across different services. This could be included in the birth-plan.
- Ensure that a system is in place for identifying when handovers should occur, and that pregnant women/people whānau and families are informed at each stage of their care.

Year One Priorities:

- Subject to the success of the dedicated Lead Perinatal Bereavement Coordinator role, scale this nationally.
- Begin implementing structured handover protocols in selected regions.
- Train all healthcare staff involved in care on the importance of communication and how to effectively execute handovers.
- Set up a system for monitoring the effectiveness of handovers, tracking both the accuracy of the information shared and the satisfaction of pregnant women, pregnant people, whānau and families.

Success Measures:

By Year Three, assuming Year One is carefully scaled in Year Two, success will be measured by:

- An evaluation confirming the value of the dedicated Lead Perinatal Bereavement Coordinator role.
- The percentage of whānau and families reporting seamless, well-communicated handovers.

- A 90% positive response rate from whānau and families regarding the handover process, focusing on clarity and communication.

Metric:

The effectiveness of handovers will be measured by ensuring that 90% of whānau and families report positive experiences. Healthcare staff and community partners will also be surveyed, with 80% of respondents indicating that the handover process has improved care coordination.

Target Actions:

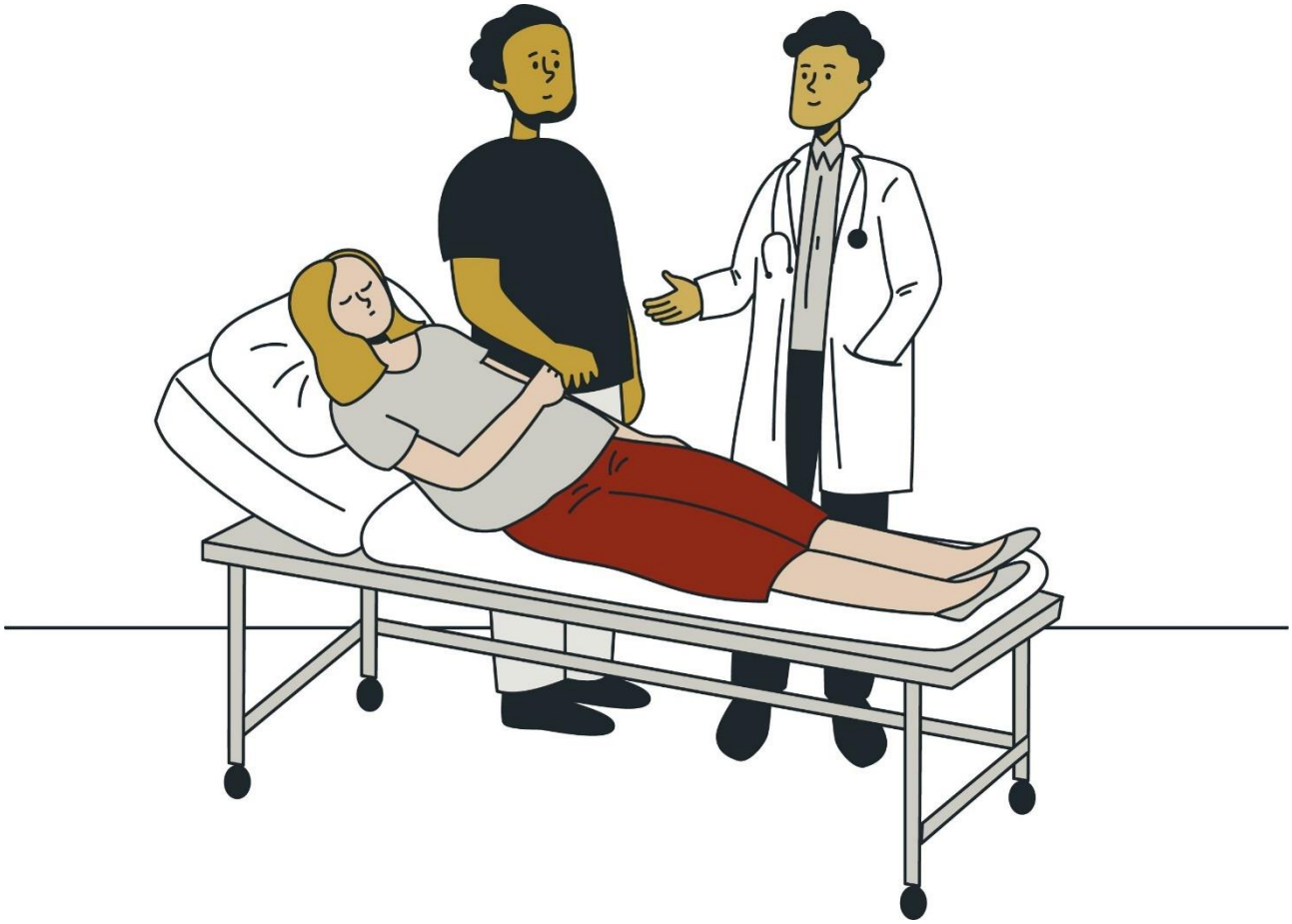
Achieve this target by ensuring that roles are clearly defined, communication protocols are in place, and all care team members are trained in effective handover procedures. Regular audits will track the effectiveness of handovers, and feedback will be used to further refine the process.

Personas

Hana gave birth to her baby boy, born still. She had to tell her story again and again: to the registrar, the hospital midwife, the social worker, the GP, the pharmacist and then her smoking cessation kaimahi. No one seemed to know what the others had said. Each time she spoke, the pain was opened again. She started avoiding appointments because she was tired of explaining why she had no baby in her arms. Under Tuituia Te Kahu Hana's story is captured once. It's written down, carefully, with her permission, and handed over with compassion. Her midwife already knows what happened. Her GP calls to check in, not to ask what went wrong. Her smoking cessation support worker is there at every step. Hana is happy to meet her as someone already seen and understood.

Jo had everything ready for her first baby. Hunter arrived after a hard labour, and he was beautiful. Six days later, Jo rushed him to hospital. Something was wrong. No one had seen it coming. He passed away at ten days old from complications no one had picked up. Jo was devastated. Every conversation with staff felt rushed and inconsistent. Some didn't know who she was. Notes hadn't been shared. She kept getting asked what had happened. She didn't have the words. She wanted to scream. With Tuituia Te Kahu in place, Jo and Hunter's journey is tracked carefully. When Jo arrives at the hospital, staff already know her birth story. The team speaks to each other. Jo doesn't have to explain. After Hunter dies, her care is coordinated by her perinatal bereavement co-ordinator. Every handover includes her name, her grief and a full understanding of her needs and her families' needs. No one treats her like a stranger. The pain is still there, but the confusion and chaos are not.

Lucy and Jack were excitedly preparing to meet their son, Tom, when Lucy noticed a change in his movements. At the hospital their worst fears were confirmed – Tom had passed away. They were told to prepare for the birth of their still born son. Communication lacked any compassion. Jack felt ignored through the entire process. The hospital discharged Lucy with a pile of pamphlets. They assumed the GP would follow up, but when Lucy and Jack arrived at the clinic a week later, the GP hadn't even seen the hospital letter. Jack had to explain. Lucy sat in stunned silence. It felt like they were starting from zero again. With the new pathway, the hospital treats Lucy and Jack with care and compassion. The hospital sends a summary and alerts the GP, and ensures they receive it. When Lucy turns up, a room is ready. Jack is offered support too. They don't have to explain. The GP introduces Lucy and Jack to the local perinatal bereavement co-ordinator. The care continues, as if someone carried them forward.



STANDARD THREE: EARLY MENTAL HEALTH INTEGRATION

Description:

Mental health and wellbeing interventions will be made available early in the pathway. Mental health and wellbeing services will also integrate into the overall care pathway, ensuring that support is not treated in isolation but as a core part of holistic care for the individual, their whānau and family.

Why it Matters:

Early mental health and wellbeing support for bereavement and grief reduces the risk of further long-term complications. For clarity, this includes the pregnant woman/person, as well as their whānau and family. Addressing mental health concerns promptly can lead to better overall health outcomes, reducing the likelihood of issues escalating and affecting both the individual and the whānau and family unit. Integrated scalable mental health care ensures that wellbeing is prioritised and supported during critical moments.

Improvements Required:

Mental health services must be expanded to provide timely and accessible support for pregnant women, pregnant people, whānau and families who experience perinatal loss. Mental health and wellbeing professionals need to be embedded within healthcare teams, and the services must be culturally and spiritually responsive to the needs of all whānau and families.

When the pathway refers to mental health services being expanded, it means in both capacity as well as scope. Access needs to be improved to specialist services, alongside access to services that take a wellbeing approach and understand mental health in the widest sense: emotional, psychological and social wellbeing needed to cope with the normal stresses of life, realise potential, work productively and contribute to whānau, family and community.

For this standard, mental health is also about maintaining balance and resilience in the face of grief and bereavement - the ethic of restoration in practice. Grief is a natural and healthy response to loss. Mental health in this standard is not simply the absence of mental illness, but a broader state of wellbeing that enables individuals to thrive in all areas of life, even in times of loss and adjustment.

Improvement Actions:

- Implement a pilot project to integrate mental health and wellbeing for professionals into selected maternity care teams.
- Evaluate the impact of this integration through feedback from healthcare staff, community partners, whānau and families.

Establishment Year Priorities:

- Establish partnerships with mental health and wellbeing providers to ensure that services are available from the early stages of all perinatal loss.
- Develop assessment tools and referral protocols for mental health and wellbeing services, ensuring that whānau and families have clear and accessible pathways to support.

Year One Priorities:

- Roll out early access to mental health and wellbeing interventions in selected regions, ensuring that healthcare teams and community partners are educated and trained to understand the grief associated with baby loss. Ensure frontline emergency workers are included in the training.
- Establish clear referral protocols for mental health and wellbeing support, ensuring timely access for individuals, whānau and families.

Success Measures:

By Year Three, assuming Year One is carefully scaled in Year Two, success will be measured by:

- The percentage of pregnant women/people and their whānau and families who access mental health and wellbeing support early in their loss journey, especially within the first trimester.
- A decrease in reported cases of anxiety and clinical depression during and after perinatal loss.
- A decrease in reported anxiety for pregnant women/people in their subsequent pregnancies, following their perinatal loss.

Metric:

A year-one trial measure will be that 80% of pregnant women, pregnant people, whānau and families receive early one-on-one mental health and wellbeing support within four weeks of seeking assistance. Whānau and family feedback on the accessibility and timeliness of mental health and wellbeing services will be gathered, with a target of 85% positive responses.

Target Actions:

To meet this target, mental health and wellbeing services will be integrated into birth and care plans, with healthcare teams trained to identify early signs of mental health concerns. Bereavement coordinators will develop a care plan that details the support available to individuals, whānau and families, so that they receive the necessary support promptly.

Personas

Fa'amolemole lost her twin daughters at 22 weeks. She asked for help. The social worker gave her a number for counselling. She rang. No one called back. When they finally did at six weeks later, Fa' had already shut down. She told them she was fine. She wasn't. Under the new pathway, someone would sit with Fa'amolemole before she even asks. A referral is made while she's still in hospital to the local Pasifika health provider. The Pasifika health worker calls the next day and speaks gently and carefully. The support begins before the grief hardens. Fa' doesn't have to pretend.

Lini was a young Pasifika mother, full of joy as she waited for her baby. When her pēpi was born still, her whole world collapsed. She chose to grieve within her family, drawing close to her elders and her church. But when she looked outside that circle, there was nothing. No outreach. No space where she could speak in her own language. No one offered culturally grounded support or spiritual guidance. The silence from the health system was deafening. Lini carried her heartbreak alone. Under the Pathway, Lini is met with gentle, culturally appropriate care. A Pasifika health worker is introduced before she leaves the hospital. They speak softly, respectfully, and check what Lini needs. Grief support is offered that includes her aiga and her pastor. The service doesn't just hand her a pamphlet — they walk with her, step by step. She is not left to navigate the silence on her own.

Mo miscarried after being assaulted by their partner. The staff were kind but rushed. No one asked about home. No one asked how they were coping. Mo left with a pamphlet and a numb kind of silence. They didn't know how to ask for help, so they didn't. Under the new Pathway, someone notices. The lead perinatal bereavement co-ordinator asks Mo about their safety. A warm handover is made to a local rainbow-inclusive support service. Mo doesn't need to tell the whole story again. Their grief is seen. The trauma is held with care. Mo's care plan takes care of all her safety and wellbeing needs.

Sarah had migrated for a better life. Her pregnancy had been high risk, but she held onto hope. When her baby was born with severe abnormalities, the room fell silent. Hours later, her baby died in her arms. No one checked in on her, beyond the basics. She was given papers to sign and told to call if she needed anything. She didn't understand the system and she didn't know who to call. She had no family in Aotearoa. Her grief was heavy, and there was no space in the system to carry it with her. Bills piled up. No one asked how she was coping, emotionally or spiritually. With Tuituia Te Kahu in place, Sarah is never left alone in that first darkness. A perinatal bereavement co-ordinator sits with her after the birth. Together they work on Sarah's care plan. A mental health worker follows up the next day. The care plan connects Sarah to a culturally aware grief support group. The perinatal bereavement co-ordinator helps Sarah to navigate her entitlements. They also help Sarah contact family overseas. Sarah doesn't have to explain why it hurts: they already understand.

Suz adored her 3.5-month-old son. Every night, she fell asleep with him beside her. One morning, he didn't wake up. The ambulance came fast, and then the police. Their home was sealed off, and Suz was asked questions she could barely understand, let alone answer. It felt like she was being blamed. While all the official people were kind, there was no gentle voice, no one to walk her through the shock. It felt like she was being blamed. Everyone was kind but also focused on their job. Someone from Victim Support sat with them and then left a card in case she wanted to talk further. Suz was in shock and hardly remembered the person. Suz was told there would be an investigation but didn't understand what that involved. After the investigation, they just received a letter. Suz and her partner were left alone in their grief, afraid, broken, and unsure how to keep going. With Tuituia Te Kahu in place, emergency services are trained in compassionate response. Suz is treated with care, not suspicion. A perinatal bereavement co-ordinator is notified immediately. They come to the house, explain the process, and stay connected throughout. The process takes a number of years. The co-ordinator provides continuity across the whole process. Their role is to co-ordinate the counsellor and family mental health support. Whetūrangitia now has easy to understand information on the coronial process, so Suz and the co-ordinator know what is happening next. Tragedy will still happen. But under Tuituia Te Kahu families are not abandoned in it. Someone walks with them as they walk through other state processes.

STANDARD FOUR: CULTURALLY RESPONSIVE, WHĀNAULED AND SPIRITUAL CARE INTEGRATION

Description:

Cultural, spiritual, and whānau-led practices will be integrated into the care of pregnant women, pregnant people, whānau and families. This ensures that services are responsive to the diverse cultural needs of New Zealanders, respecting their traditions, beliefs, and practices. Spiritual care, whether for emotional support, rites, or rituals, will be embedded within this pathway, empowering whānau and families to engage with their cultural and spiritual needs in ways that support their wellbeing.

Why it Matters:

Culturally responsive care improves both the experience and the outcomes for pregnant women/people, their whānau and families. Recognising and respecting cultural and spiritual needs fosters a sense of inclusion, dignity, and support. Whānau- and family-led care ensures that the family unit remains central to decision-making, enhancing their autonomy and comfort throughout the care process. Particular attention is paid to Māori, Pasifika and Indian peoples, as well as young people under 20, being our population groups who experience the highest perinatal mortality rates.

Improvements Required:

Maternity healthcare settings need to be equipped with resources, such as bereavement rooms and spiritual support services, to provide a culturally and spiritually safe environment. The inclusion of cultural and spiritual leaders in care teams is essential for delivering care that aligns with whānau and families' values and practices.

Improvement Actions:

- Conduct an audit in hospitals to assess current gaps with respect to perinatal bereavement rooms – then address those gaps as part of capital improvement projects.
- Build partnerships with cultural and spiritual leaders to ensure that their expertise is integrated into care teams.
- Integrate perinatal bereavement into cultural competency and cultural safety education and training programmes.

Establishment Year Priorities:

- Update cultural competence training programmes to account for perinatal bereavement and make it available to all healthcare providers, including community partners.
- Take advice from Iwi Māori Partnership Boards (IMPBs) on how they wish to be included in the Year One implementation, noting that this will not be a priority for all IMPBs.
- Ensure that hospital spaces are equipped for spiritual and cultural practices, such as designated areas for prayer or reflection.

Year One Priorities:

- Establish partnerships with iwi, spiritual, and cultural leaders to integrate their perspectives into care models.
- Implement cultural competence education and training for all staff involved in perinatal bereavement and trauma-informed care.
- Introduce systems to monitor satisfaction with cultural and spiritual care.

Success Measures:

By Year Three, assuming Year One is carefully scaled in Year Two, success will be measured by:

- The percentage reporting satisfaction with the cultural and spiritual care they received.
- The number of healthcare facilities offering appropriate and dedicated perinatal bereavement rooms and spaces for grieving individuals, whānau and families.

Metric:

85% of whānau and families report that their cultural and spiritual needs were met during their care. Additionally, 80% of healthcare staff, including community partners report increased confidence in providing culturally safe perinatal bereavement and grief care.

Target Actions:

Ensure that cultural safety is embedded in all service provisions. Regular training sessions will be held to enhance staff awareness and competencies in delivering culturally responsive bereavement and grief care.

Personas

Mihi was a first-time mum, excited and nervous about becoming a mother. When she started bleeding at 18 weeks, she went straight to the hospital. She told them something wasn't right. But her worries were brushed off. She was told to wait. Hours passed before anyone properly assessed her. By then, it was too late. She delivered her stillborn baby alone, in the emergency department, behind a thin curtain. No one asked if she wanted karakia. No one called her whānau. The next day, she was discharged with a packet of leaflets and no further contact. Her grief was deep, but the silence around it was deeper. She felt abandoned by the very system meant to care. Under Tuituia Te Kahu when Mihi raises concerns, she's listened to straight away. She's brought into a quiet space where her fears are taken seriously. When she births her baby, a Māori health worker stays by her side. Karakia is offered. Her whānau are welcomed in, not kept away. She is given time, space, and cultural support that acknowledges the sacredness of her loss. After discharge, she's contacted by a perinatal bereavement co-ordinator who speaks her language and understands her world. She is held in her grief, not left to carry it alone.

Naveen and Asha's daughter died during birth. Asha wanted to wash her baby and dress her in clothes bought in from home. Staff said there was limited time and no one available straight away to help her do that. The next day, their baby had already been sent away for post-mortem. They were told that they could still wash and dress their baby when she came back, but for them the rituals were missed. Asha cried for days. It didn't feel complete. Now, under Tuituia Te Kahu staff would ask Asha and Naveen what they and their family need and how much time that would take. They would also have all the tangi options explained and be asked whether they would like to use a funeral director or make the arrangements themselves. Cultural assumptions are not made. Rather, time is made to ensure care is culturally responsive. Carers are aware that Indian communities living in Aotearoa require recognition of the remarkable diversity within the population and the development of flexible approaches that can accommodate different religious, linguistic, and cultural needs. This means an understanding that Indian families may draw upon Hindu, Sikh, Muslim, Christian, Jain, Buddhist, or other spiritual traditions when facing perinatal loss, each offering different perspectives on death, afterlife, and appropriate mourning practices. Under Tuituia Te Kahu, whatever the family decides, the facilities are prepared to accommodate the various religious practices that may be important. This might include providing space for prayer, allowing for specific ritual requirements, facilitating access to religious leaders from appropriate traditions, and understanding that different families may have different needs based on their specific faith background. It most definitely includes ensuring access to professional interpreters who can communicate not just in the appropriate language but with cultural sensitivity about grief, loss, and spiritual concepts that may not translate directly into English.

Sala gave birth to twin babies. One arrived without breath, and the other passed away months later. Sala's grief was layered and crushing. In her culture, there are rituals for loss, ways to honour pēpi, ways to help a mother move through sorrow surrounded by her family and community. But none of that was offered. The hospital was kind, but unsure. There was no Pasifika liaison person, no space made for her language, her faith, her family. No one guided her through the spiritual weight of what had happened. After the funeral, the system went quiet. Sala grieved alone. Under Tuituia Te Kahu when Sala gives birth to her twins, a Pasifika health worker is there. They speak her language and ask who should be involved. The hospital makes space for prayer, singing, family, community and church. The team understands that cultural care is not an extra: it's essential. When her second baby passes, the same care is there again. The system stays with her. She's guided through grief by people who know what it means in her world, and why that matters.

STANDARD FIVE: MEMORY-MAKING AND BEREAVEMENT AND GRIEF SUPPORT

Description:

Pregnant women, pregnant people, whānau and families who experience perinatal loss will be supported in processing grief and creating lasting memories. Memory-making options and supported farewell rituals, will be offered to help individuals, whānau and families honour their loss in a way that is meaningful to them. Bereavement and grief support will be personalised to meet the individual needs of each whānau and family, providing the emotional support required during this challenging time.

Why it Matters:

Supporting pregnant women, pregnant people, whānau and families through grief and providing opportunities for memory-making can help people acknowledge their loss, honour the life of their child, and find meaningful ways to move forward. It is important to acknowledge that the offer of memory-making is valuable, while also recognising that not all individuals, whānau and families wish to create memories.

Personalised bereavement support and trauma-informed care ensures that whānau and families receive care that aligns with their emotional needs, providing the necessary space to grieve and heal.

Improvements Required:

Bereavement rooms should be equipped with the necessary resources for whānau and families to create memories and spend time with their child. Additionally, all healthcare providers should be educated in trauma-informed care and grief, so they are able to recognise and support the emotional needs of grieving whānau - *āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmili* - families. It is essential to offer pregnant women, pregnant people, whānau and families a variety of options for memory-making (for example, photographs, hand and footprints, or keepsakes) and to ensure these options are offered sensitively, noting that not every individual, whānau or family will want to make a memory or memories.

Improvement Actions:

- Ensure that all pregnant women, pregnant people, whānau and families experiencing baby loss are offered the option, information, support and provision of effective cooling resources to care for and actively parent their baby in hospital and/or at home.
- Train midwives and nurses nationwide to confidently provide resources that allow for whānau- and family-led care, such as cooling resources, or memory making resources.
- Ensure that bereavement rooms are equipped with the necessary tools, and space to facilitate memory-making and emotional support.
- Gather feedback from whānau and families and community support organisations regarding the usefulness and emotional impact of memory-making options, and what items/materials might make up a memory-making kit to be provided to pregnant women, pregnant people, whānau and families.
- Pilot memory-making kits in select hospitals to gather feedback and adjust these, as needed.

Establishment Year Priorities:

- Design and fund memory-making resources for hospitals that include tangible mementoes, as identified by whānau - *āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāmili* - and families. Ensure that these resources can be used by community partners, at their discretion.
- The integration of bereavement support into the continuity of care model must be prioritised, with clear procedures for when and how to offer memory-making opportunities to pregnant women, pregnant people, whānau and families.
- Ensure clarity in relation to funding required to make initiatives (such as memory-making or cooling resources) available in both hospital and community settings to provide continuous support.
- Ensure all staff have a good knowledge and thorough understanding of options and choices available to fully inform bereaved pregnant women, pregnant people, whānau and families.
- Include information/education on memory-making, and how to approach the topic with whānau and families, in training offered to staff. Include memory-making information on Whetūrangatia.

Year One Priorities:

- Standardise the provision of memory-making resources across all healthcare settings, ensuring that they are available to whānau and families experiencing loss.
- Train staff in trauma-informed care and grief literacy so that they can offer memory-making options in a compassionate and timely manner, ensuring that individuals, whānau and families are supported through the process.
- Strengthen a network of bereavement support services to ensure whānau and families have access to long-term support. Ensure all maternity and frontline emergency workers know about these services, especially NZ Police.

Success Measures:

By Year Three, assuming Year One is carefully scaled in Year Two, success will be measured by:

- The level of engagement with memory-making opportunities, with at least 90% of whānau and families offered memory-making options.
- The satisfaction with the bereavement and grief support they received, with a target of 90% reporting that the support met their emotional needs.

Metric:

90% of whānau and families experiencing perinatal loss will be offered memory-making options and will report satisfaction with the bereavement support they received. Additionally, feedback will be gathered from families at three and six months, to track the ongoing emotional impact of memory-making support. This feedback will be used to improve the programme.

Target Actions:

Achieve this target by ensuring that memory-making options are available in all hospitals, that staff are adequately trained to offer them, and that pregnant women, pregnant people, whānau and families receive sensitive and empathetic support throughout the process.

Personas

Aria was 20, alone, and unsure. No one told her she could hold her baby. She thought maybe she wasn't allowed. By the time she asked, it was too late. Her silence was misinterpreted, and she left with nothing. The silence has followed her for years. Under the new pathway, Aria would be guided slowly. A midwife or lead perinatal bereavement co-ordinator explains what's possible and she would be gently asked again; she would know she could change her mind. They would be offered time to hold her baby, to name him, to have photos taken. There is no pressure: just gentle, loving invitations. Aria, under Tuituia Te Kahu would leave with something real to carry.

Brooke and Niko were offered a memory-making box. But no one knew how to use it. The plaster didn't set. The ink smudged. There was no one to take photos. They left with a broken cast and deep regret. It felt like they lost their baby twice. With Tuituia Te Kahu, staff are educated. Memory-making is not a bonus or add-on: it's part of care. Photos are taken gently. Footprints are pressed with care. Brooke and Niko leave with a box that holds their son's presence, not just his absence.

Hailey and Cody had been counting the days until their son Kyrei arrived. At 38.5 weeks, he stopped moving. He was born still. They knew they wanted to take him home to be with his siblings and whānau, to hold him, dress him, and grieve together before the funeral. None of the staff were trained in how to support a whānau taking their pēpi home. There were moments of care, but also panic, delays and quiet confusion. With the Pathway in place, the team knows what to do. The Manaaki Mats are ready. Staff have been trained and guide Hailey and Cody through each step with sensitivity and confidence. They're offered death care options and cooling resources early: not as an afterthought. A memory box is also prepared, and a lead perinatal bereavement co-ordinator helps with photos and handprints. His parents wash and dress Kyrei, they actively parent their son and remain in control of his care. This time belongs with them. Their choice to take him home for five days to be cared for by whānau is respected and supported, not met with hesitation. The farewell begins with love, not uncertainty. It begins with support, not uncertainty.

Hana and Tāne were excited for their first baby. Everything was ready. But at 20 weeks, a scan showed their baby had passed away. The news came like a wave that flattened them. In the days that followed, no one was consistent. Some staff were kind, others rushed. No one asked if they wanted to hold their baby or give them a name. No one offered memory-making or explained how to create a taonga to honour the loss. Their baby was treated like a clinical event, not a person. Hana and Tāne were left with nothing: no photos, no footprints, no rituals and no recognition. Their grief sat in silence, heavy and unfinished. With Tuituia Te Kahu in place, the team walks gently with them.

Their baby is acknowledged with mana. They are offered time to hold and dress their baby, to name them, to cry freely. Memory-making is normal. Not something they have to ask for. The lead perinatal bereavement co-ordinator finds a cultural advisor they both know who can support them to follow practices that reflect their whakapapa. They leave the hospital with mementos and a sense that their baby's life mattered. The grief is still deep, but they are not left with emptiness. They are ready to join the tangi for their first baby.

Cultural Memory-Making for Indian Families:

Memory-making practices for Indian families should acknowledge the diverse religious and cultural traditions within this community while respecting individual family preferences. Healthcare providers should understand that different Indian families may have different approaches to creating memories and honoring their baby based on their specific religious and cultural background.

Religious Considerations: Hindu families may appreciate the opportunity to perform simple prayers or ceremonies, while Sikh families might value the reading of sacred texts. Muslim families may have specific preferences about handling and remembering their baby that align with Islamic teachings, while Christian Indian families may seek pastoral care and prayer from their specific denominational tradition.

Cultural Artifacts: Memory-making might include culturally significant items such as religious symbols, traditional clothing, or items that reflect the family's regional heritage. Healthcare providers should be open to incorporating these elements into memory-making activities when families express interest.

Photography and Keepsakes: While many Indian families appreciate photographs and physical keepsakes, providers should be sensitive to any religious or cultural considerations that might affect these practices and should always follow the family's lead in determining what types of memories they wish to create.

Community and Extended Family Involvement: Memory-making activities should accommodate the extended family structure common in Indian communities, allowing grandparents, aunts, uncles, and other relatives to participate in creating memories and saying goodbye to the baby when families desire this involvement.

STANDARD SIX: FOLLOW-UP CARE IN THE COMMUNITY AND SUBSEQUENT PREGNANCY SUPPORT

Description:

Follow-up care will be personalised and provided in the community, ensuring continued support after discharge from hospital or from any other clinical environment. This care will focus on both the immediate and long-term needs of whānau and families, offering emotional - *alofa/aro'a/fakaalofa/ofa* - and practical support, as they adjust to their new circumstances. Additionally, support will be available for individuals, whānau and families planning subsequent pregnancies, ensuring that their physical and emotional needs are addressed with sensitivity and understanding.

Why it Matters:

Structured follow-up care reduces isolation and improves mental and physical health outcomes for pregnant women, pregnant people, whānau and families following a pregnancy loss. It is essential that the individual, their whānau and family impacted by the loss receive continuous support after their immediate care needs are met, as the emotional and psychological impact of perinatal loss can be long-lasting.

The community sector plays a crucial role in this follow-up care. As whānau and families navigate the complex emotional terrain of grief, community partners, like Sands NZ, provide a network of support that extends beyond clinical care, offering a sense of connection, understanding, and shared experience. These services are often more accessible and flexible than formal healthcare systems, providing ongoing support long after clinical care has ended. It is time to acknowledge and invest in that unpaid work.

Offering support for subsequent pregnancies ensures that individuals, as well as whānau and families are prepared and supported in a way that respects their previous experiences.

Improvements Required:

Tailored follow-up care must be provided beyond the immediate aftermath of the loss, including regular check-ins with mental health professionals, healthcare providers, and social workers. While it is likely the Lead Perinatal Bereavement Coordinator will still be acting as a navigator, it is crucial to acknowledge that the community sector plays a vital role in supporting mental health and wellbeing, particularly in the context of perinatal bereavement.

As families navigate the complex emotional terrain of grief, the community sector provides a network of support that extends beyond clinical care, offering a sense of connection, understanding, and shared experience. Community-based services, such as support groups, and peer networks and memorial events, create familial and warm spaces for individuals, whānau and families to express their grief, gain insights from others facing similar challenges, and receive emotional and practical assistance.

These services are often more accessible and flexible than formal healthcare systems, providing ongoing support long after clinical care has ended. The community sector also ensures that mental health and grief supports are culturally relevant and responsive to diverse needs, offering tailored resources that align with whānau and family values and traditions.

In this way, the community sector is vital to better maternity and perinatal mental health outcomes. They are providing a safety-net that helps pregnant women, pregnant people, whānau and families heal and reintegrate into daily life after a loss, while also ensuring whānau and families are supported in their decision-making for subsequent pregnancies and that any physical or emotional concerns are addressed in a timely manner. Funding of community partners so that they can continue to provide the invaluable support they do is also necessary. Targeted support for individuals, whānau and families preparing for a subsequent pregnancy is also essential.

Improvement Actions:

- Develop clear protocols for identifying individuals, whānau and families that need ongoing support and ensure that they receive timely follow-up from their dedicated Perinatal Bereavement Coordinator.
- Create an investment fund for the community partners who provide follow-up care and peer support for perinatal bereavement and loss, ensuring a focus on approaches that resonate with populations most impacted by loss.
- Clarify how subsequent pregnancies will be supported.
- Consider the role and feasibility of a national perinatal bereavement service.

Establishment Year Priorities:

- Explore IT solutions to track follow-up support and ensure that whānau and families continue to receive care after they transition back into the community.
- Integrate follow-up services with community organisations to ensure ongoing support.

- Clarify the role of the Lead Perinatal Bereavement Coordinator in the follow-up care: three, six and 12 months down the track.

Year One Priorities:

- Implement protocols for regular follow-up care and check-ins, ensuring pregnant women, pregnant people, whānau and families are consistently supported in the long-term.
- Pilot a time-limited investment fund for community partners for curriculum and capability development.
- Begin providing targeted emotional support for pregnant women, pregnant people, whānau and families considering subsequent pregnancies.
- Consider the role of a national perinatal bereavement service to provide ongoing support for pregnant women, pregnant people, whānau and families, ensuring access to resources and counselling for grief processing and subsequent pregnancies. This includes content updates to Whetūrangtia. Information on Whetūrangitia can be simplified and expanded, especially coronial information.

Success Measures:

By Year Three, assuming Year One is carefully scaled in Year Two, success will be measured by:

- The continuity and effectiveness of follow-up care, with at least 80% of pregnant women, pregnant people, whānau and families receiving regular follow-up and reporting satisfaction with the support provided.
- Whānau and families who plan subsequent pregnancies will report that their needs, as the pregnant woman/person, whānau and family define it, are met.

Metric:

Eighty percent of individuals, pregnant women, pregnant people, whānau and families will receive follow-up care in the community and report satisfaction with the ongoing support they receive. Individuals, whānau and families planning subsequent pregnancies will also report satisfaction with the support provided for their next pregnancy journey.

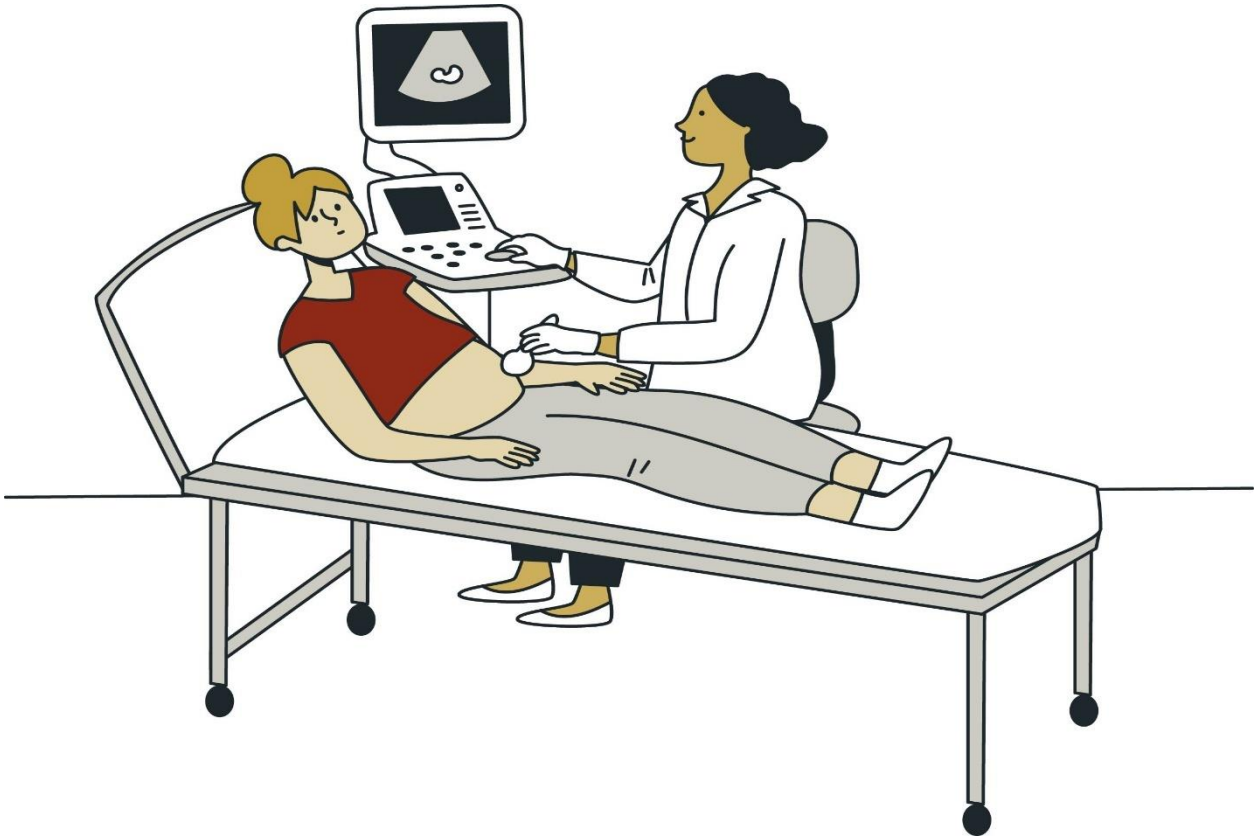
Target Actions:

Achieve this target by establishing regular follow-up schedules, integrating care pathways with

community providers, and ensuring that all pregnant women, pregnant people, whānau and families are offered tailored emotional and practical support.

Personas

Renee birthed her baby at 19 weeks, she was stillborn. The hospital staff were kind, but after discharge, she was told to follow up with her GP: no one booked it. She wasn't given any information, let alone a care plan. When she became pregnant again, her anxiety was constant. But the new midwife had a large caseload, was time-pressured and stressed so hadn't read all her notes, therefore was no indication she needed extra support. She was treated like any other person. The weight of her previous loss sat silently between her and every health professional she saw. Under Tuituia Te Kahu, Renee's loss is acknowledged and carried through the system. It is clear her current midwife has received a full handover by her previous midwife. At her first visit, she's offered extra time, additional scans and reassurance. She's connected with a counsellor and specialist support so she can speak openly with professionals who've assisted others who have been through similar grief and anxiety. The local Sands supporter stays in touch throughout her pregnancy, and she attends a Pregnancy After Loss support group with other bereaved parents. Renee doesn't need to explain herself over and over: the care is joined up, consistent and seamless.



Kauri and Lee buried their baby girl last year. They received one call from the hospital, and then nothing. They grieved alone. When Lee became pregnant again, they expected things might be different. But at her first appointment with a new midwife, she had to tell the story of their daughter and her death. Lee thought ‘the system’ would know about her daughter but it felt as though she had never existed. Under the Pathway, their grief is not forgotten. Their Lead Maternity Carer has already been briefed by their Lead Perinatal Bereavement Co-ordinator. She then welcomes them gently and speaks their daughter’s name. She explains the supports available, including a local Māori grief support worker and access to whānau-focused services. Kauri and Lee are invited to participate in pregnancy-after-loss sessions that connect them with others. Their care reflects both their sorrow and their hope: a continuity that honours the full shape of their current and future whānau.

STANDARD SEVEN: CLEAR INFORMATION AND DECISION-MAKING SUPPORT

Description:

Information systems will be implemented to ensure seamless data sharing and communication between healthcare professionals, pregnant women, pregnant people, whānau and families. The aim is to provide clear, timely, and accessible information that supports informed decision-making throughout the pregnancy and post-pregnancy journey. This means individuals, whānau and families will be provided with all the necessary resources to understand their care options and make choices that best suit their needs and circumstances.

Why it Matters:

Clear, timely information enables informed decision-making, which is critical for ensuring that pregnant women/people and their whānau and families receive the right care at the right time. When whānau and families are well-informed, they can make decisions that align with their values, needs, and preferences, leading to better outcomes and a greater sense of agency over their care. Information systems that are effective and easy to use empower people to navigate the healthcare system more confidently.

Improvements Required:

Clear, accessible written materials and digital resources should be made available to all pregnant women, pregnant people, whānau and families to support their decision-making. There must be a focus on simplifying medical terminology and ensuring that information is culturally appropriate and inclusive. Healthcare teams should also be trained to provide personalised, trauma-informed, decision-making support to help pregnant women, pregnant people, whānau and families understand their options in a compassionate and supportive way.

Improvement Actions:

- Develop a birth plan that integrates questions about perinatal bereavement.
- Develop a digital information platform that consolidates all decision-support resources in one place.

- Harmonise all of the regulations and rules with respect to perinatal bereavement. Have this information available on one platform. Ensure it is in plain language, with translations. Make use of the existing information service, Whetūrangitia, developed by DIA.

Establishment Year Priorities:

- Explore the development of information systems to enable seamless data sharing between healthcare providers, ensuring that all involved parties have access to up-to-date information.
- Collaborate with communication specialists to ensure that all written and digital materials are accessible, clear, and culturally relevant. Update Whetūrangitia and consider how it might be better utilised.

Year One Priorities:

- Provide training for staff on how to deliver information in a way that is compassionate, informative and empathetic, particularly when addressing sensitive issues.
- Keep updating Whetūrangitia.

Success Measures:

By Year Three, assuming Year One is scaled in Year Two, success will be measured by:

- Ability to access and understand the information they need to make informed decisions, with a target of 90% positive feedback on the clarity and usefulness of the information provided.

Metric:

Ninety percent of individuals, whānau and families will report that the information and decision-making support provided was clear, timely, and helpful in guiding their choices.

Target Actions:

Achieve this target by ensuring that information systems are integrated into the overall care pathway and providing consistent access to clear and accessible information. All healthcare providers will be trained to deliver decision-making support in a way that is compassionate, inclusive, and sensitive to the needs of pregnant women, pregnant people, whānau and families.

Personas

Salote sat quietly as the doctor spoke. Her baby had a rare condition, one that meant she would not survive. The doctor said, “You have options.” But the words that followed were full of medical terms, spoken quickly and clinically, without warmth or clarity. Salote nodded, overwhelmed. She agreed to a termination, not because she understood, but because she didn’t know what else to do. Later, she would sit with her grief and wonder whether there had been another way. She didn’t feel like she’d been given the space to find out. Under Tuituia Te Kahu, Salote’s care slows down. The doctor explains things simply, and a Pasifika health worker joins them to help bridge understanding and emotion. Salote is given time to speak with her partner, her family and her church. She’s supported to consider her spiritual and cultural beliefs. Her decision, when it comes, is one she can live with: made with care, not confusion.

Jay and Tama sat in a fog after their baby was born still. Their LMC offered them the option of a postmortem. It sounded clinical, cold. No one explained what it involved or why it might help. They were too numb to ask questions. They said no, as they did not want their baby to be ‘cut up’. Weeks later, as the grief settled and questions surfaced, they wondered if a post-mortem may have provided some answers. But it was too late. Now, under the Pathway, when the offer is made, it’s done with patience and care. The Lead Perinatal Bereavement Co-ordinator sits with them, gently explains what a postmortem means, and answers their questions. There is no pressure. They are also given time to talk with a support worker from Baby Loss NZ. Their choice, whether yes or no, is theirs: and it’s made with understanding, not regret.

Jessie and John had decorated the nursery. They had chosen a name. They were counting down the weeks. At 30 weeks, a scan revealed their baby had severe heart anomalies. Then Jessie became seriously unwell. She was diagnosed with sepsis. The specialists gave them time, but not much. The decision to terminate the pregnancy wasn't really a choice: it was presented as a matter of survival. Far from their family on the other side of the world, without familiar faces or guidance, they made the decision and entered a fog of loss. After the hospital stay, there were no follow-ups, no wraparound care, no space to process what had happened. John went back to work the next week. Jessie couldn't. They both felt they'd walked off a cliff and were expected to carry on. Under Tuituia Te Kahu, Jessie and John are supported the moment the diagnosis is made. The Lead Perinatal Bereavement Co-ordinator builds their care plan with a navigator and grief specialist at the heart of their process. Their shared focus is to help Jessie and John to deconstruct and understand their options. After the termination, their care continues: not just physically, but emotionally. They are linked with Sands and a regional mental health team. A bereavement coordinator arranges online counselling and connects them with a local pregnancy loss circle when they're ready. Family back home is looped in. When Jessie returns for follow-up care, the team knows her story. When John needs time off work, the Lead Perinatal Bereavement Co-ordinator supports them with paperwork. They are not left to "get back to normal" after something that changed them forever: they are given time to rebuild in their own way.

STANDARD EIGHT: WELL-SUPPORTED STAFF AND BEREAVEMENT EDUCATION

Description:

Staff working with pregnant women, pregnant people, whānau and families will receive education, training, and wellbeing-support to ensure they can provide the highest level of care. This includes training in bereavement support, emotional resilience, trauma-informed care, and cultural competence. Staff will be equipped to manage the emotional and psychological challenges of supporting individuals, whānau and families during perinatal loss, ensuring they can provide compassionate and empathetic care.

Why it Matters:

Well educated and supported staff are better able to provide the care that pregnant women, pregnant people, whānau and families need, especially during difficult times, such as pregnancy and baby loss. When staff receive adequate training and emotional support, they are more confident and effective in their roles and can sustain their emotional wellbeing through the consequent care of families and whānau who experience perinatal loss. This leads to better outcomes for whānau and families, as staff are equipped to manage the complexities of grief and emotional support with sensitivity and professionalism. Ongoing wellbeing-support ensures staff can cope with the emotional toll of their work and maintain their own mental health. This latter point is key to retaining the maternity workforce, in particular.

Improvements Required:

Training for staff must be comprehensive and cover areas, such as bereavement care, communication skills, trauma-informed care, and cultural competence. Comprehensive includes undergraduate level and professional development. Staff must be supported emotionally and given the resources they need to handle the challenges of working in this field. Ongoing professional development and support should be prioritised, with a particular focus on building resilience and coping strategies for staff members who may be continually exposed to emotional and distressing situations.

Improvement Actions:

- Pilot a resilience-building programme for teams in selected hospitals to assess its impact on wellbeing.

- Develop and implement a standardised education and training curriculum that includes perinatal bereavement and grief education, communication skills, trauma-informed care and cultural competence, as part of undergraduate education for all professions that interact with bereaved whānau, as well as ongoing professional development.

Establishment Year Priorities:

- Ensure that all healthcare providers and community partners involved in care are trained in bereavement and grief support and emotional resilience.
- Establish a support network for maternity staff by providing access to counselling, supervision (professional support) and/or peer support to discuss the emotional challenges of their work.

Year One Priorities:

- Implement a core perinatal bereavement training programme for all staff and carers, including midwives, nurses, sonographers and doctors, and ensure it is accessible to community partners. Encourage some community partners to develop their own training specific to their community context, as well as whānau and family needs.
- Establish clear support pathways for staff and carers, including access to wellbeing resources and peer networks.
- Offer training on recognising and addressing burnout to help staff and carers maintain their mental health.

Success Measures:

By Year Three, assuming Year One is scaled in Year Two, success will be measured by:

- Staff satisfaction and wellbeing, with at least 90% of staff reporting feeling supported and confident in providing bereavement care.
- A high percentage of families (90%) reporting that staff provided compassionate and empathetic care throughout their experience.

Metric:

Ninety percent of staff will report feeling well-supported in their roles and confident in providing bereavement care. Additionally, 90% of families will report that staff provided compassionate and empathetic care throughout their experience.

Target Actions:

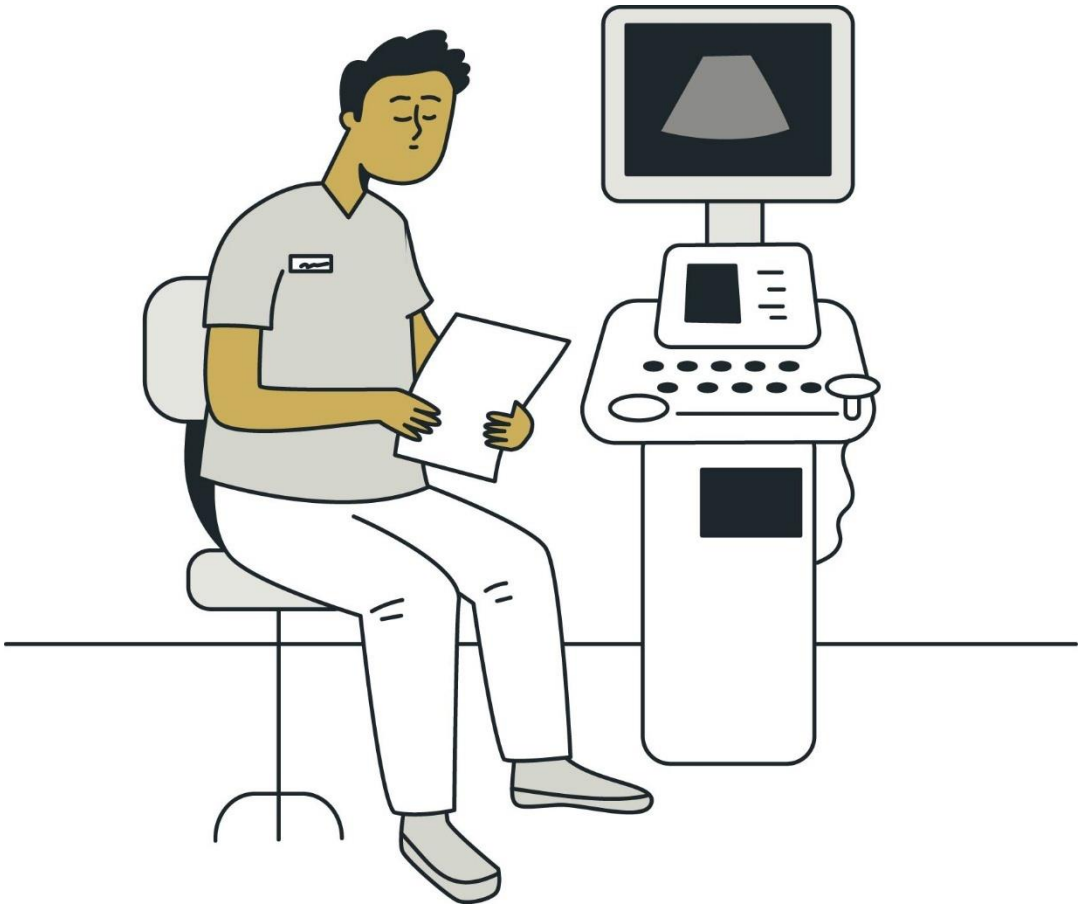
Achieve this target by ensuring that all staff receive comprehensive education and training in bereavement support and emotional resilience and provide regular wellbeing resources and support to create a positive work environment.

Personas

Alex, a transmasculine individual, hadn't planned to get pregnant: but when it happened, they felt a surprising sense of hope. At 11 weeks, they miscarried. The grief was sharp, but what hurt just as much was how unseen they felt. The forms didn't fit. The language didn't match. Staff stumbled over pronouns or avoided them entirely out of awkwardness. No one asked who their support people were. The miscarriage was treated clinically — the rest of Alex's identity was ignored. They left the hospital feeling erased, with no follow-up and nowhere to turn. Under Tuituia Te Kahu, Alex is cared for as a whole person. Staff are trained in inclusive practice. The intake form reflects who they are. The lead perinatal bereavement co-ordinator makes sure their identity is respected and affirmed. The team checks in about whānau and family support, and what language feels right for Alex. Alex is offered follow-up counselling with someone who understands LGBTQIA+ grief and loss. They leave the hospital feeling seen and as someone who matters.

Emma was the core midwife when the baby was born still. She stayed late to support the family. She made cups of tea, helped with memory making, called the funeral home. This beautiful baby and the family's grief profoundly affected her. She cried in the toilet, wiped her face, and went back to her next shift the following day. Other staff asked how she was, but they were busy. There was no debrief, no space to speak. She carried the sorrow home, where it sat quietly in her body. It began to change how she worked. She was more distant. More guarded. The pain stayed. Under Tuituia Te Kahu, Emma is not left alone with it. After the birth, there is a team debrief. She has access to supervision (professional support) and a peer support circle. She can speak openly, without shame, about what it meant to care for a grieving family. Her grief is recognised as part of the job: not something to hide. She comes back to work lighter, not hardened. Emma and her team also have easy access to training to support grieving families.

Sam, the sonographer, found no heartbeat. The room was quiet, too quiet. He didn't know what to say. He froze, then stumbled through the scan. He told the parents he had to get the radiographer and left them alone in the room, with concerned looks and unanswered questions. He kept seeing their faces. He wanted to talk about it with them, but it was not part of the process. No one had trained him for this part of the job. He never brought it up again, but it stayed with him. Now, Sam has completed bereavement care training. He's learned how to break the news gently and stay present. He has a guide to follow, a simple template to fill in and a colleague he can call if he needs support. When a baby has died, he knows what to do and what not to say. He's no longer alone in the silence. He carries the sadness with care, but it doesn't weigh him down the same way it used too.



STANDARD NINE: REGULAR REVIEW AND CONTINUOUS IMPROVEMENT

Description:

This pathway will undergo regular review and continuous improvement to ensure that care standards are consistently met and that services remain responsive to the evolving needs of pregnant women, pregnant people, whānau and families. Regular audits and feedback mechanisms will be implemented to evaluate the effectiveness of the services provided. This ongoing evaluation will ensure that improvements are made in response to the needs and experiences of pregnant women, pregnant people, whānau and families, enabling better care outcomes.

Why it Matters:

Regular reviews and continuous improvement are essential to maintaining the quality and relevance of care services. By continuously assessing the effectiveness of care pathways and making necessary adjustments, services can better meet the needs of pregnant women, pregnant people, whānau and families, leading to improved health outcomes and family satisfaction. Feedback loops that include input from pregnant women, pregnant people, whānau and families, healthcare providers, and staff ensure that the pathway remains relevant and responsive to changing needs. In addition, and most importantly, it is critical that bereaved individuals, whānau and families have visibility of the actions being undertaken to ensure transparency and impact preventable deaths.

Improvements Required:

Routine audits of perinatal bereavement care services will be carried out to assess their effectiveness and identify areas for improvement. Key performance indicators (KPIs) need to be developed to measure the impact of interventions and the overall quality of care. Each standard in this pathway has its own set of measures of success. But there must be clear systems for incorporating feedback from pregnant women/people, whānau, families and staff to drive improvements, ensuring that services evolve in line with changing needs and expectations. An important improvement is the inclusion of miscarriage as a clinical maternity indicator. Currently, pregnant women and people who are miscarrying are effectively told their baby's life does not count and their physical experience of miscarriage does not matter. Including miscarriage as a

clinical indicator changes this and gives us the data to review, follow up, and better understand the experience of early pregnancy loss.

Improvement Actions:

- Set up a pilot audit of bereavement services in selected hospitals to gather initial data and insights, which includes miscarriage as a clinical indicator.
- Test and then rollout the KPIs that reflect the goals of improving care and support.
- Ensure that feedback is systematically incorporated into care practices, enabling ongoing adjustments to services.

Establishment Year Priorities:

- Confirm the KPIs that will guide the review process and ensure alignment with the overall goal of improving pregnant women/people, whānau and family care and support.
- Establish mechanisms for gathering feedback to inform the review processes.
- Explore data collection tools and IT systems that can support auditing and provide real-time insights into care effectiveness.
- Confirm that there are processes in place to ensure accurate, timely and publicly accessible data is collected, and that reviews on perinatal mortality are being undertaken.
- Incorporate recommendations from the PMMRC into the Tuituia Te Kahu review and improvement process.
- Confirm the input and outputs costs of this pathway. Take the high-level cost-benefit analysis into detailed analysis.
- Miscarriage needs to be included as a clinical maternity indicator in the establishment year. This action is necessary for early loss to be included in the bereavement care pathway, most notably in standards six and in this standard.

Year One Priorities:

- Based on findings, develop and implement a framework for continuous improvement.
- Engage all staff in the review process, encouraging their input and developing solutions that are responsive to the feedback received.

Success Measures:

The success of this standard will be measured by the following:

- *Annual Reviews:*

  All care services, including bereavement support, will undergo a formal review process at least once a year. This review will involve:

  - A comprehensive audit of all care protocols, including the availability and quality of resources, and support provided to families. This will be done by Health New Zealand in the first instance and overseen by an independent advisory group in the second.
  - Gathering feedback from all relevant stakeholders (pregnant women/people, whānau, families, healthcare providers, community partners, and staff) to assess satisfaction and areas needing improvement.

- *Family Feedback:*

  At least 85% of families who have experienced care will be invited to provide feedback. This feedback will cover areas, such as:

  - The quality and timeliness of support received.
  - How well their cultural, spiritual, and emotional needs were met.
  - Overall satisfaction with the services provided.

- *Implementation of Improvements:*

  A key measure of success will be how effectively feedback is incorporated into practice. This will be measured by:

  - At least 80% of the suggested improvements from the review with pregnant women/people, whānau and family feedback being implemented within six months of receiving the feedback.
  - Tracking the specific changes made, such as adjustments to service protocols, staff training, resource allocation and/or communication improvements.

- *Impact on Care Outcomes:*

  The long-term goal is to assess whether improvements have led to measurable improvements in care outcomes. This will be tracked by:

  - Reduced instances of negative family experiences or gaps in care, based on their feedback.
  - Increased pregnant women's/people's, whānau and families' satisfaction, as measured by follow-up surveys at regular intervals (3-6 months, 12 months, etc.).

Metric:

The review process will be evaluated, based on the percentage of services that undergo an annual review, the proportion of families who provide feedback, and the percentage of feedback-based improvements implemented. Pregnant women, pregnant people, whānau and families will report satisfaction with the changes made, and follow-up surveys will assess improvements in care outcomes.

Target Actions:

Achieve this target by establishing a structured review system, incorporating regular audits, and developing robust feedback mechanisms that allow pregnant women, pregnant people, whānau and families and staff to share their experiences and suggestions. Ensure that improvements are acted upon promptly and systematically.

Personas

Amelia and Chris were overjoyed to be expecting their first child. At 18 weeks, their daughter Sophie died. The hospital was busy. Amelia was told she'd have to birth the baby on the ward. There was no private room, no clear information, no one assigned to stay with them. One nurse was kind, but she looked unsure, like she hadn't done this before. Amelia and Chris felt invisible. Sophie was born in silence. No one explained what had happened or offered to talk it through. They left with questions, with grief, and with the feeling that the system didn't know how to care for parents like them. Months on, they still don't know what went wrong or if anyone ever asked. With Tuituia Te Kahu in place, Amelia is moved to a quiet space as soon as staff realise what has happened. A midwife trained in bereavement care stays with her until the lead perinatal bereavement co-ordinator arrives. A care plan is prepared. Chris is included in the plan. He is also supported, not left to the sidelines. The room is calm. Staff know what to do, and what not to say. After Sophie is born, they are offered memory-making, support, cooling resources and time. All their options and choices are explained so they can make informed decisions. A senior clinician follows up with them and talks through the clinical details with care and honesty. The system doesn't just care in the moment, it reflects, learns, and stays accountable. Amelia and Chris are not left with silence. They are met with presence, knowledge and kindness.

The Pasifika perinatal bereavement co-ordinators have been walking alongside grieving families for years. They worked from churches, community halls, and kitchen tables: guiding rituals, offering prayer and holding space. But their mahi was invisible to the system. They had no contract, no formal recognition, no consistent funding. When the health reforms came, their modest contract disappeared. No evaluation was done. No one asked what would be lost. One day they were there. The next, they were gone. Families kept grieving, but with fewer hands to help. Now, under Tuituia Te Kahu, their role is recognised as essential. They are funded, supported, and evaluated alongside clinical services. Their stories, their impact, are part of the national picture. Reviews capture the difference they make. Their wisdom is shared across regions. The community knows where to turn, and the team is no longer at the edge: they are at the heart of bereavement care.

For years, Parliament asked questions about perinatal loss and bereavement care, and got vague answers. There were no national figures on how many parents were being supported. No consistency in care. No formal reviews after deaths. The system operated in fragments, tucked inside DHBs, hidden in local practices. When things went wrong, no one could say why — or whether anything had changed. Grieving families were lost in the system, and those in power couldn't see the full picture, let alone improve it. Now, under Tuituia Te Kahu, the system is visible. Every region reports on bereavement care. The data is clear — not just on clinical outcomes, but on cultural safety, whānau satisfaction, and staff wellbeing. Reviews after loss are routine, not rare. Lessons are shared across services. Parliament can see what is working, where gaps remain, and how care is improving over time. Investment is no longer a shot in the dark: it's guided by evidence and driven by accountability. The system is learning, and Parliament can finally see it.

Rosa manages a busy maternity ward. In one awful month, four babies died. Each case was different. Each one weighed on her team. But there was no time. Staff wiped their tears and went back to work. No reviews were done. No space was made to talk. Rosa tried to grab a moment with staff when she could. The same issues kept surfacing: miscommunication, rushed handovers and unclear protocols. The grief didn't just belong to families. It soaked into the staff too. But nothing changed. Everyone just kept going. Under Tuituia Te Kahu, Rosa calls for a review hui after every loss. The room is quiet, then full of kōrero. Staff speak openly. They share what was missed, what worked, and what must be done differently next time. The process isn't about blame: it's about learning. When new staff join, they are trained in what the team has already lived through. The ward doesn't carry the same weight. The system gets better: not just busier.

CONCLUSION

This pathway, like a carefully woven whāriki, integrates nine essential standards that come together to provide pregnant women, pregnant people, whānau and families with a resilient, compassionate and responsive care journey. Each standard, from early engagement to follow-up care and continuous improvement, acts as a critical thread, supporting whānau and families at every stage, from grief to integration and potential healing. The interconnectedness of these standards ensures that pregnant women, pregnant people, whānau and families experience care that is seamless, culturally responsive, and always evolving to meet their needs. As the journey of perinatal bereavement is deeply personal and ever-changing, the pathway adapts and grows, continually improving through feedback and review.

Just as a whāriki holds its form while adapting to the needs of those it shelters, this pathway ensures that every pregnant woman/person, whānau and family is provided with the strength, support, and care they need to heal, integrate their experience of loss and move forward with dignity, respect, and hope.

Tuituia Te Kahu is more than a pathway; it is a commitment to ensuring that every whānau and family experiencing perinatal loss receives compassionate, consistent, and culturally safe care. It is a call to action. By embedding these nine standards into practice, we can create a healthcare system where no grieving woman/person, whānau or family is left behind.

CHAPTER FOUR: SCOPE AND SCALE OF CHANGE

SUMMARY

This chapter outlines the changes needed to improve perinatal bereavement care, focusing on the scope, scale, and risks involved in implementing these changes.

Scope of Change:

The changes will affect three main areas: people, places, and processes.

- **People**: Bereavement services for pregnant women, pregnant people, whānau and families will be better coordinated through roles like the Lead Perinatal Bereavement Coordinator. Healthcare professionals will receive education and training in emotional support, mental health, trauma-informed care and cultural sensitivity, to provide compassionate care. There will also be stronger partnerships with community groups, such as Sands NZ, to offer continuous support.
- **Places**: Healthcare facilities will create or improve private spaces for people to grieve, with areas designed to respect cultural practices.
- **Processes**: New guidelines will be introduced to ensure consistent, compassionate care across healthcare settings. These include standard operating procedures for delivering care, improved communication, and the integration of technology to track cases and share information.

Scale of Change:

The changes will be significant but manageable.

- **People**: A more coordinated approach to bereavement care, with specific support, particularly for Māori, Pasifika and Indian families, will require significant shifts in how services are delivered. The workforce will need to be trained in these new approaches, including mental health support and cultural sensitivity.
- **Workforce Education and Training**: Education and training are required to ensure that the workforce is prepared to offer the right care at the right time. This education and training will need to cover bereavement, mental health, and cultural sensitivity.
- **Community Support**: There will be a shift in how healthcare services and community groups collaborate. This will require new referral processes, strengthened relationships and extra funding to ensure ongoing, coordinated care for grieving pregnant women, pregnant people, whānau and families.

- **IT Systems**: A new IT system will be developed to facilitate better communication and data-sharing between healthcare providers. This will require significant investment in technology and training to ensure effective implementation.

Risks and Mitigations:

Several risks could affect the successful implementation of these changes, but each risk has strategies in place to manage them.

- **Risk: Lack of Planning**

  Without a clear, structured timeline, the implementation of these changes could face delays and confusion, leading to mismanagement of resources.

  Mitigation: The implementation will be broken into phases, each with its own timeline and goals. A detailed project management plan will track progress, with flexibility to adapt, as needed. Regular oversight will ensure deadlines are met and any problems are addressed quickly.

- **Risk: Insufficient Funding**

  The changes require significant funding but without sufficient financial support, essential elements, such as training or IT systems may not be fully implemented.

  Mitigation: A thorough cost-benefit analysis will be conducted to assess financial needs. A range of funding sources, including government and private sector partnerships will be explored. Contingency funds will be set aside for unexpected costs, with ongoing financial reviews to ensure resources are used efficiently.

- **Risk: Lack of Stakeholder Engagement**

  If healthcare professionals, whānau and families, and community organisations are not properly involved, the changes may not meet their needs or there may be resistance to the new system.

  Mitigation: A multi-stakeholder advisory group will be established to ensure diverse representation from all relevant groups. Regular consultation and feedback loops will be built into the project to ensure the pathway meets the needs of whānau and families, healthcare professionals, and community partners.

- **Risk: No Clear Performance Metrics**

  Without measurable performance indicators, it will be difficult to evaluate whether the changes are successful.

Mitigation: Clear performance metrics will be established to assess success, including the timeliness and effectiveness of care, staff competency, and stakeholder satisfaction. These metrics will be monitored regularly, and pilot programmes will be used to test and refine them, before full-scale implementation.

- **Risk: Insufficient Workforce Readiness**

  If healthcare workers are not properly educated and trained or prepared for the changes, the quality of care could suffer.

  Mitigation: A comprehensive education and training plan will be rolled out, starting with pilot programmes for key healthcare professionals. The plan will include specialised training in bereavement care, grief counselling, and cultural competency. Ongoing professional development will ensure staff remain well-prepared for the demands of the new system.

- **Risk: Poor Public Communication**

  If the public is not informed about the changes, it could lead to confusion or resistance.

  Mitigation: A detailed public communication plan will ensure that everyone is informed about the changes. Information will be shared through multiple channels, including social media, community outreach, and informational websites. Regular updates will help keep the public informed, building trust and reducing uncertainty.

- **Risk: System Conflicts**

  The new changes could conflict with other healthcare reforms, causing inefficiencies or confusion.

  Mitigation: The new pathway will be aligned with other health system initiatives. A coordination team will be established to ensure that Tuituia Te Kahu, the perinatal bereavement pathway, fits smoothly with broader healthcare reforms. Regular communication between stakeholders will help resolve any issues before they become significant problems.

The change management challenge lies in effectively coordinating and implementing these wide-ranging changes across multiple sectors, ensuring that all stakeholders are engaged, trained, and resourced appropriately, while managing risks, such as funding shortages, lack of planning, and workforce readiness, to ensure the pathway delivers consistent, compassionate, and culturally sensitive care. By addressing these risks, with careful planning and targeted strategies, Tuituia Te Kahu can be successfully implemented, providing better care and support for grieving pregnant women, pregnant people, whānau and families.

SCOPE OF CHANGE: SERVICES

To understand the scope of change, the services that are **likely** to be affected have been grouped into three categories: people, places, and processes. This distinction helps to provide an initial assessment of the scope of change, which feeds into the final assessment of the change-management challenge.

People - Individuals, Whānau and Families

- **Bereavement support services**: Centralised and coordinated through the role of the Lead Perinatal Bereavement Coordinator will ensure that individuals, whānau and families receive timely, consistent, and compassionate care.
- **Mental health services**: These will be integrated into the care process, offering ongoing support for individuals, whānau and families, particularly at the start of their grieving journey.
- **Culturally responsive services**: Specific cultural needs for Māori, Pasifika and Indian whānau and families will be formally addressed, including memory-making and rituals, as part of the care process.
- **Improved access to information**: Plain-language and digital resources will be made more readily available through the Whetūrangitia website.

People - HR and Workforce Education and Training

- **Bereavement care education and training**: All healthcare professionals will receive education and training in providing compassionate and responsive care in grief, emotional support, and mental health assistance.
- **Cultural competency training**: Healthcare workers will be trained to offer culturally sensitive support, ensuring the needs of various communities are met.

- **Supervision (professional support) and emotional resilience programs**: These will be established for healthcare workers, to help manage the emotional demands of supporting grieving pregnant women, pregnant people, whānau and families. Resources will be developed to support workers in this area.

People - Community Partners and Providers

- **Integration with community organisations**: Partnerships between healthcare providers and community organisations, such as Sands NZ, will be formalised to ensure continuous, coordinated care for pregnant women, pregnant people, whānau and families.
- **Expansion of peer support networks and counselling services**: These will provide ongoing emotional support to pregnant women, pregnant people, whānau and families immediately after their loss and in their period of adjustment to living with the loss of their baby.
- **Enhanced mental health resources**: Access to mental health professionals and grief counsellors will be expanded to ensure pregnant women, pregnant people, whānau and families receive comprehensive, ongoing support.

Places - Buildings and Healthcare Facilities

- **Bereavement rooms and culturally sensitive spaces**: Healthcare facilities will create or enhance private spaces for pregnant women, pregnant people, whānau and families to grieve; designed to meet cultural needs, particularly for Māori, Pasifika and Indian families. These spaces may also become available for care providers if they're in need of space to process the perinatal loss and the grief associated with that loss for all people impacted.
- **Spiritual care and memory-making areas**: Areas will be established in healthcare facilities to support mourning rituals and memory-making, ensuring that pregnant women, pregnant people, whānau and families have the space they need to honour their loved ones.

Processes - Operational and Policy Changes

- **Standard Operating Procedures (SOPs) and Protocols**: These will be introduced to guide providers in delivering consistent, compassionate care, with clear communication protocols and handover systems.
- **Integration of cultural safety and mental health**: SOPs will incorporate cultural safety and mental health considerations throughout the care process, ensuring that the diverse needs of pregnant women, pregnant people, whānau and families are met at every stage.

- **Care Plan:** The Lead Perinatal Bereavement Coordinator will develop a care plan with the individual, whānau and family. The plan will outline specific services and support tailored to each party's needs, covering bereavement care, mental health services, cultural considerations, and community partners.

Processes - Systems

- **Centralised Signal**: An IT solution will be developed to track perinatal loss cases, ensuring all healthcare providers are aware of the grieving context of the pregnant women/people, whānau and family.
- **Continued development of Whetūrangitia**: This digital platform will be improved to provide grief resources, guidance, and support, making it easier for pregnant women, pregnant people, whānau and families to access the help they need. The support of Internal Affairs will be crucial in this development, which provides an opportunity for inter-agency collaboration.
- **Standardised data-sharing protocols**: These will enable seamless communication between healthcare providers, mental health professionals, and community support teams, ensuring that pregnant women, pregnant people, whānau and families receive coordinated care.

Summary of Scope of Change: Services

The changes outlined in this section highlight the wide-reaching impact on people, places, and processes within the national bereavement care pathway for perinatal loss. From improved training for healthcare professionals to enhanced community partnerships and culturally responsive spaces in healthcare facilities, these changes aim to provide more coordinated, compassionate, and culturally aware support for grieving pregnant women, pregnant people, whānau and families. The introduction of standard operating procedures, improved IT systems, and centralised support structures will further ensure that these services are effective and timely, ultimately leading to a more integrated and supportive care system.

SCALE OF CHANGE: CURRENT TO FUTURE STATE

It is clear from the previous section that changes are necessary across various service areas to address past and current gaps and to create a timelier, more coordinated, compassionate, and culturally responsive pathway. The following section looks at each area in detail, by examining the current state versus the future state, and then assesses the scale of the change. This is broken down into people, places, and processes.

People: Individuals, Whānau and Families

- **In the Past**: Pregnant women, pregnant people, whānau and families experiencing perinatal loss often found themselves navigating a fragmented healthcare system with inconsistent support. Māori, Pasifika and Indian communities, in particular, faced challenges in receiving culturally appropriate care. The system lacked integrated mental health and emotional support, leaving them to grieve in isolation.
- **In the Future**: Tuituia Te Kahu, the national bereavement care pathway for perinatal loss, will introduce comprehensive services and protocols to address these gaps. Healthcare providers will be trained to deliver culturally responsive care, incorporating memory-making and cultural rituals into the care process. Mental health professionals, grief counsellors, and culturally competent support workers will be integrated into the care team, ensuring continuous support for pregnant women, pregnant people, whānau and families throughout their journey.
- **Scale of Change**: This change will be significant. A coordinated and culturally sensitive approach to care will require the creation of new services, such as tailored grief counselling and whānau- and family-led decision-making processes. Healthcare providers will need to adopt new protocols for culturally responsive care, mental health integration, and the support of spiritual practices. This systemic shift will require substantial commitment from healthcare providers, policymakers, and community partners.

HR and Workforce Training

- **In the Past**: Healthcare professionals were often ill-prepared to address the needs of grieving pregnant women, pregnant people, whānau and families. Bereavement care education and training was not standardised, meaning opportunities to offer sensitive and compassionate care were often missed.
- **In the Future**: New education and training protocols will ensure that all healthcare professionals involved in perinatal bereavement care are equipped with confidence and skills to provide culturally sensitive and compassionate support. These protocols will include detailed bereavement care education and training, mental health support strategies, and cultural competency. Specific care pathways will be developed to help guide healthcare professionals through complex grief scenarios, ensuring that they deliver the right care at the right time.
- **Scale of Change**: The scale of change is moderate to-large. This will involve a significant overhaul of education and training programmes, requiring healthcare workers to undergo specialised bereavement training. The challenge will be ensuring consistency in training delivery and making sure the training translates into compassionate, effective care for grieving pregnant women, pregnant people, whānau and families. Structured implementation and significant resources will be required to support ongoing professional development in the sector.

Community Partners and Providers

- **In the Past**: Community organisations, such as Sands NZ and Baby Loss NZ, played an essential role in supporting grieving pregnant women, pregnant people, whānau and families but were often underfunded and disconnected from healthcare systems. Pregnant women, pregnant people, whānau and families, particularly those in rural areas or those with specific cultural needs, faced barriers in accessing these services. There was also limited integration between healthcare providers and community organisations, resulting in fragmented care.
- **In the Future**: The pathway will introduce formal protocols to integrate community organisations with healthcare providers, ensuring seamless referrals and continuous support. These organisations will be better resourced and aligned with healthcare teams, allowing for more efficient collaboration. Peer support networks, mental health services, and grief counselling will be expanded to ensure pregnant women, pregnant people, whānau and

families receive ongoing care throughout their grief journey, with regular check-ins from community support workers.

- **Scale of Change**: The scale of change is moderate. Strengthening the relationship between healthcare providers and community organisations will require a shift in service delivery, with new referral processes and funding mechanisms. Specialised training will also be necessary to ensure all partners are aligned and working towards the same goal of providing continuous, comprehensive support to grieving pregnant women, pregnant people, whānau and families.

IT Systems

- **In the Past**: IT systems were fragmented and disconnected, making it difficult for healthcare providers to share critical information about perinatal loss cases. This lack of integration has resulted in delays and miscommunication, leaving pregnant women, pregnant people, whānau and families without timely care or support.
- **In the Future**: A fully integrated IT system will be developed to enable seamless communication and data sharing between healthcare providers, mental health professionals, and community support teams. This will include new protocols for tracking perinatal loss cases to ensure that pregnant women, pregnant people, whānau and families receive timely, coordinated care. Healthcare providers will have access to a centralised case management system, and all will be able to access a digital platform with resources, grief guidance, and virtual support services.

- **Scale of Change**: This change is large. Developing and implementing a new IT system will require significant investment in technology, infrastructure, and training. New policies will need to be implemented to ensure secure data sharing and that all parties follow the same protocols for patient confidentiality and care coordination. Once established, this system will streamline the care process for both healthcare teams and pregnant women, pregnant people, whānau and families.

Places: Buildings and Healthcare Facilities

- **In the Past**: Many healthcare facilities lacked dedicated spaces for grieving families. Bereavement rooms or culturally sensitive spaces for mourning rituals were often unavailable, which compounded the grief families experienced when coping with loss.
- **In the Future**: Healthcare facilities will be required to incorporate culturally responsive bereavement rooms, designed to allow pregnant women, pregnant people, whānau and families to engage in mourning rituals. These spaces will be private and comfortable, offering families a safe place to grieve. Healthcare providers will follow new guidelines to ensure these spaces are used respectfully and that pregnant women, pregnant people, whānau and families are supported during their time there.
- **Scale of Change**: This change is moderate. While some facilities may already have bereavement rooms, adding culturally specific elements will require capital investment and design changes. New standards will need to be established for facility design and the use of these spaces. While the physical changes may be moderate, the emotional and cultural impact on grieving pregnant women, pregnant people, whānau and families will be profound.

Processes: Operational and Policy Changes

- **In the Past**: The processes surrounding perinatal bereavement care were not standardised and were inconsistent. Pregnant women, pregnant people, whānau and families often lacked clear information on available resources, and there was little coordination between healthcare providers and support services.
- **In the Future**: New standard operating procedures (SOPs) will ensure that healthcare providers deliver consistent, compassionate care. These SOPs will include clear communication protocols, handover systems, and policy guidelines to ensure pregnant women, pregnant people, whānau

and families receive coordinated, high-quality care. Cultural safety and mental health integration will be embedded in these processes, and healthcare providers will follow specific procedures for offering grief support and memory-making opportunities.

- **Scale of Change**: This change is large. Implementing SOPs across healthcare settings will require substantial changes to existing policies, staff training programmes, and interdepartmental collaboration. The integration of these new SOPs into existing workflows will require significant commitment from both healthcare teams and policymakers.

Summary of Scale of Change: Current to Future State

The shift from the current to the future state of perinatal bereavement care represents a large-scale transformation. The most significant changes will occur in how healthcare services are delivered, focusing on culturally responsive care, integrated mental health support, and comprehensive bereavement services. This transformation will involve creating new services, enhancing workforce training, upgrading IT systems, and developing culturally sensitive spaces within healthcare facilities. While the scale of change varies, the overall goal is to provide pregnant women, pregnant people, whānau and families with the timely, compassionate, and coordinated support they need and deserve.

RISKS AND MITIGATION STRATEGIES

While the introduction of the national bereavement care pathway for perinatal loss is essential, as designed, it comes with a range of risks that could affect its successful implementation. Identifying these risks early-on and developing strategies to address them effectively is key to ensuring the pathway's success. Below is a detailed breakdown of the primary risks associated with the implementation of the new pathway, along with strategies to mitigate these risks.

Risk: Lack of a Detailed Timeline and Phases of Implementation

One of the most significant risks is the absence of a clear, structured timeline for the rollout of this new pathway. Without a detailed plan and phased implementation, there is a danger of delays, mismanagement, and confusion, which could lead to ineffective deployment of resources.

- **Mitigation:** To address this, the implementation should be divided into clear phases, each with its own timeline and specific objectives. A detailed project management plan should be developed, outlining each phase and expected outcomes. The plan should be regularly reviewed to track progress and adjust, where necessary. Flexibility should be built into the timeline to allow for changes, but the focus must remain on achieving key milestones. Regular oversight by a dedicated project management team will help ensure deadlines are met, and any issues are addressed promptly.

Risk: Insufficient Funding and Financial Resources

The introduction of a national bereavement care pathway for perinatal loss requires substantial funding, not just for initial development but for ongoing support, training, and resource allocation. There is a risk that the pathway may not receive enough financial backing, which could result in cutbacks or incomplete execution of critical elements, such as workforce education and training and/or IT system upgrades.

- **Mitigation:** A comprehensive cost-benefit analysis should be conducted to assess the financial implications of the pathway. This analysis should cover all aspects, including training, IT infrastructure, and support for community partners. A range of funding sources should be explored, including government allocations, private sector partnerships, and philanthropic contributions. Additionally, contingency funds should be set aside to address unforeseen costs.

Ongoing financial review will ensure that funds are allocated efficiently throughout the implementation phases.

Risk: Lack of Stakeholder Engagement and Buy-In

Successful implementation of the new pathway depends on the involvement of all relevant stakeholders, including healthcare professionals, community organisations, whānau and families. If these groups are not properly engaged, the pathway may not meet the needs of those it is designed to support, and/or there could be resistance to change.

- **Mitigation:** A multi-stakeholder advisory group should be established early in the process, ensuring diverse representation from all key groups. This group will provide input and feedback throughout the development and implementation process. Regular consultation and feedback loops should be built into the project plan to allow stakeholders to influence the direction of the pathway. Cultural and spiritual experts should be consulted early-on to ensure the pathway respects the cultural needs of Māori, Pasifika and other communities. Involving stakeholders early and often will reduce resistance to change and help ensure that the pathway meets the needs of all parties.

Risk: Failure to Establish Effective Performance Metrics and Accountability

Without clear performance metrics, it will be difficult to measure the success of the pathway and identify areas for improvement. Lack of accountability could result in a lack of focus and insufficient monitoring of the pathway's progress.

- **Mitigation:** It is crucial to develop clear, measurable key performance indicators (KPIs) that align with the pathway's goals. These KPIs should cover a range of areas, including the timeliness and effectiveness of care delivery, staff competency, and stakeholder satisfaction. Regular monitoring and evaluation should be part of the implementation plan, assessing performance against these metrics. Pilot programmes could be used to test and refine these KPIs, before full-scale implementation. A robust monitoring and evaluation framework will ensure that the pathway is meeting its objectives and allow for adjustments, if necessary.

Risk: Challenges in Risk Management and Unforeseen Disruptions

Large-scale changes often face unforeseen disruptions, such as policy conflicts, and delays or coordination issues between different agencies. If not effectively managed, these disruptions can undermine the success of the initiative.

- **Mitigation:** A comprehensive risk-management plan should be created, which anticipates potential issues and outlines strategies for managing them. This plan should include risk assessments at each phase of implementation, with designated teams responsible for identifying, monitoring, and managing risks. Contingency plans should be in place to address any disruptions promptly, ensuring that the broader pathway continues to progress smoothly. Regular risk assessments and updates to the risk-management plan will help keep the project on-track.

Risk: Insufficient Workforce Readiness and Capacity

The success of the pathway relies heavily on the preparedness of the healthcare workforce. If staff are not adequately trained and educated in bereavement care, mental health support, and cultural competency, the quality of care provided to grieving pregnant women, pregnant people, whānau and families may fall short of expectations.

- **Mitigation:** A comprehensive training and development plan should be implemented, starting with pilot programmes for key healthcare professionals. This plan should include specialised training in bereavement care, grief counselling, and cultural competency. Ongoing professional development should be provided to ensure staff stay up to date with best practices. Leadership roles should be created for those overseeing perinatal bereavement care, with clear career pathways to support retention and long-term commitment. Sufficient time and resources should be allocated to training to make it an integral part of the pathway.

Risk: Poor Public Communication and Lack of Transparency

If the public is not adequately informed about the pathway, there may be misunderstandings or confusion, which could lead to resistance or dissatisfaction. Clear and transparent communication is essential to gaining public support and ensuring the success of the pathway.

- **Mitigation:** A comprehensive public communications plan should be developed, outlining how information will be shared with the public and stakeholders. Multiple channels, such as social media, community outreach, and informational websites, should be used to communicate the benefits of the pathway, the timeline, and what to expect. Transparency should be maintained

throughout the process, with regular progress reports shared with the public and stakeholders. This approach will help build trust and reduce uncertainty, encouraging greater support for the pathway.

Risk: Integration Challenges with Broader Health System Changes

There is a risk that Tuituia Te Kahu could conflict with or fail to integrate smoothly with other health system changes, resulting in inefficiencies and confusion.

- **Mitigation:** Tuituia Te Kahu should be closely aligned with other health system initiatives, such as maternal health and mental health care programmes. A coordination team should be established to ensure smooth integration with other changes. Regular communication between stakeholders will help identify potential conflicts early-on, and resolve them, before they become significant issues.

Risk: Sustainability and Long-Term Impact

Even if the pathway is successfully implemented, there is a risk that it may not be sustainable in the long-term. Without ongoing funding, training, and support, the pathway could lose momentum and become less effective.

- **Mitigation:** A sustainability plan should be developed from the outset, outlining how the pathway will be supported in the long-term. This plan should include provisions for ongoing funding, training, and adjustments to policy. Embedding the pathway into national legislation and ensuring that future budgets account for its need will help sustain the programme. Long-term monitoring and evaluation should be in place to track the pathway's effectiveness and identify areas for improvement.

Summary of Risk and Mitigation Strategies

The risks associated with the introduction of Tuituia Te Kahu, the national bereavement care pathway for perinatal loss is significant but manageable, with proper planning and resources. By identifying risks, such as insufficient funding, lack of stakeholder engagement, and workforce readiness early-on, mitigation strategies can be put in place to address these challenges. A detailed project plan, clear performance metrics, and robust risk management strategies will be key to the success of the pathway, ensuring that it delivers effective, compassionate, and culturally responsive care to grieving pregnant women/people whānau and families in the long-term.

THE CHANGE MANAGEMENT CHALLENGE

The introduction of Tuituia Te Kahu, the national bereavement care pathway for perinatal loss represents a significant change within the context of perinatal care, and indeed the entire health care system of Aotearoa New Zealand. It addresses crucial gaps in how pregnant women, pregnant people, whānau and families experiencing loss are supported, focusing on coordination, cultural sensitivity, and workforce readiness. Within the maternal-perinatal care sector, the changes are substantial, as they require a shift in practice, the integration of new systems, and enhanced support for healthcare professionals.

However, while the changes are considerable within this specific area, they are relatively modest in the context of Aotearoa's broader healthcare system. The adjustments needed are primarily around improving existing processes, systems, and training, rather than a complete overhaul of the healthcare infrastructure. The changes are also not as expansive as those required for systemic health reforms or large-scale shifts in public management. Yet, it will create a significant impact. The pathway's implementation is a focused and targeted effort, which will be significant in terms of its impact on those affected by perinatal loss, but not disruptive to the overall healthcare or public management systems. With proper planning and risk mitigation, it is well within capacity to implement this pathway successfully, addressing an important need (and current failure), without overwhelming the wider system.

CHAPTER FIVE: ASSUMPTIONS AND DEPENDENCIES

SUMMARY

This chapter talks about the things that need to happen for Tuituia Te Kahu to work. It looks at what changes might be needed in laws, rules, and policies to make sure the pathway works well. It also explains how Tuituia Te Kahu is connected to other projects, such as maternity care and mental health services, which all need to work together.

The chapter explains that we need to make sure there are enough resources, like money, training for healthcare workers, and support for pregnant women, pregnant people, whānau and families, to make the pathway work. It also says that the pathway will need to be rolled out in steps, and that some laws or rules might need to change.

Finally, it talks about how the pathway should work with other projects, to make sure families get the support they need, from pregnancy to when they experience a loss.

KEY ASSUMPTIONS

This section outlines the assumptions that underpin the development and potential implementation of Tuituia Te Kahu. These assumptions are based on the current understanding of services, the future needs of pregnant women, pregnant people, whānau and families, available resources, and the expected timing for the implementation of Tuituia Te Kahu. Each assumption is a critical building block that informs the overall design and expected outcomes of the pathway.

About Current Services

Current perinatal bereavement services are varied across regions and often lack the integration and consistency necessary to ensure that all individuals, whānau and families receive appropriate support following perinatal loss.

Services in place today are fragmented, with significant disparities, depending on geographic location, cultural needs, and access to mental health support.

In some regions, support is insufficient, and the quality of services can differ dramatically from one area to another.

These gaps highlight the need for a more coordinated, nationwide approach to bereavement care, where all pregnant women, pregnant people, whānau and families can access high-quality, consistent support, no matter where they live. That said, such an approach needs to be whānau- and family-led, based on regional and local needs.

About Future Needs

As the demand for perinatal bereavement services grows, there is an increasing need for support that is not only compassionate and timely but also culturally sensitive and mentally supportive. The current system does not fully meet the needs of Māori, Pasifika and Indian communities, and bereaved parents under 20 years of age, who experience higher rates of perinatal loss. These groups require targeted care that addresses their needs, including their unique cultural practices and mental health needs.

To create a fit-for-purpose health system, Tuituia Te Kahu accounts for these disparities, by ensuring every pregnant woman/person, whānau and family, regardless of their background, location or health needs receives the care and support they need during their time of grief.

About Resources

To implement Tuituia Te Kahu effectively, sufficient resources will be required.

This includes funding for community-based support services, integration of mental health support into the pathway, and training and education for healthcare workers to provide culturally responsive care.

Healthcare facilities will also need to establish culturally responsive spaces to ensure that pregnant women, pregnant people, whānau and families feel supported and respected throughout their journey. In addition, up-to-date and accessible information for both healthcare providers and whānau and families is essential, to ensure a smooth process from start-to-finish.

The necessary infrastructure, including IT systems for case management and data-sharing, must also be in place to support the pathway. Most importantly, the establishment of a Lead Perinatal Bereavement Coordinator is essential for managing care, overseeing the pathway's implementation, and ensuring that each pregnant woman/person, whānau and family receives tailored support.

About Timing

Tuituia Te Kahu will require a phased implementation approach.

The initial rollout will focus on specific areas or regions, with the expectation that the pathway will expand over time.

This phased approach allows for gradual adjustments and improvements based on real-time feedback and lessons learned.

As the pathway evolves, it must be flexible enough to meet the diverse needs of all pregnant women, pregnant people, whānau and families, healthcare professionals, and community partners.

The implementation schedule will need to align with the broader healthcare priorities to avoid delays and ensure that the pathway integrates smoothly with existing services.

What These Assumptions Mean

These assumptions are essential to understanding the structure and objectives of Tuituia Te Kahu. They have guided the planning, success measures, and return on investment analysis.

- **Risks and Mitigations**: While these assumptions are critical to the design of the pathway, risks associated with their accuracy must be carefully managed. The potential risks related to these assumptions, such as insufficient resources or an unanticipated increase in demand, are

discussed in detail in Chapter Four. There, the strategies to mitigate these risks are outlined, ensuring that any challenges can be addressed promptly to avoid setbacks.

- **Evidence Base**: The assumptions about current services, cultural needs, and resource requirements are informed by evidence, which is further explored in Chapter Two. This evidence includes data on current service provision, health outcomes, and feedback from key stakeholders. The evidence-base is central to validating these assumptions and ensuring that the pathway is built on a solid foundation.
- **Cultural Competency and Cultural Safety**: Assumptions regarding the specific needs of Māori, Pasifika and Indian communities have been informed by the composition of the TAG and the evidence gathered is outlined in Chapter Two. The TAG, which includes experts from diverse backgrounds, has provided invaluable insights into these cultural needs, ensuring that the pathway is inclusive and equitable. Additionally, the cultural perspectives provided by these experts will continue to shape the pathway's evolution, ensuring it meets the unique needs of different communities.
- Along the way, the TAG has developed the following assumptions in respect of how it understands the role of the new Perinatal Bereavement Coordinator in the context of whānau- and family-led care.
- **Whānau- and Family-led care** is a model of care that places the needs, preferences and decisions of the individual, whānau and family at the centre of the care process. In this model, individuals, in the context of their whānau and families are recognised as the primary support system and decision-makers, and their leadership is crucial in determining the course of care, and what needs to be in the care plan. Whānau- and family-led care emphasises the importance of treating whānau and families as active partners, acknowledging that their knowledge, beliefs and values are key to an individual's wellbeing. Whānau- and family-led care integrates Cultural Competency and Cultural Safety; specifically in the context of Tuituia Te Kahu, cultural competency and cultural safety are essential for creating an inclusive, respectful and effective healthcare environment. Cultural competency refers to the healthcare provider's ability to consistently reflect on their practice and interact effectively with people from diverse cultural backgrounds. It involves having the knowledge, skills, and attitudes needed to provide care that is respectful of cultural differences. Cultural safety goes beyond just understanding different cultures. It is about creating an environment where people feel safe to live their culture. This involves healthcare providers actively considering their own

power, biases, and assumptions, and taking steps to ensure that their actions do not marginalise or alienate the pregnant women/people, their whānau and family. In practice, this means the Lead Perinatal Bereavement Coordinator is expected to adapt the care plan to meet the specific needs of each pregnant woman/person, whānau and family. It means encouraging, and sometimes requiring, healthcare providers to be flexible and open to adjusting their ways of working, based on what is important to those involved. It also means:

  - **Listening actively** to understand the needs and beliefs of the whānau and family, noting they may differ from conventional practice. This ensures that all involved feel their voices are heard and valued.
  - **Engaging whānau and families as equal partners** in the decision-making process. This means the ensuring all healthcare providers offer guidance, while respecting the autonomy and cultural preferences of each pregnant woman/person, whānau and family, ensuring all decisions align with their values and priorities – not the coordinator's.
  - **Adapting services to cultural contexts**, integrating cultural practices where appropriate. This might involve supporting the use of cultural healing practices based on the pregnant women/people, whānau and family needs.

- **Feedback Loops**: The assumption that the pathway will evolve based on feedback is critical. This feedback mechanism has been built into the standard and is designed to ensure that the pathway remains responsive to the needs of pregnant women, pregnant people, whānau and families. By integrating regular feedback from healthcare providers, , the pathway can adapt and improve over time to meet the changing landscape of perinatal care.

Summary of assumptions

In summary, the assumptions that guide the development of Tuituia Te Kahu, the national bereavement care pathway for perinatal loss, are grounded in the understanding of current service provision, future needs, available resources, and the timing for implementation. These assumptions have been informed by evidence, cultural insights, and stakeholder input, ensuring that the pathway is both inclusive and responsive to the diverse needs of individuals, whānau and families. Risks related to these assumptions are acknowledged, with strategies for mitigation outlined in Chapter Four, and the evolving nature of the pathway is supported by feedback mechanisms integrated into the standards. By accounting for these assumptions and actively

managing them, the pathway aims to provide a comprehensive, equitable, and culturally competent system of care for perinatal bereavement support.

LEGISLATIVE CHANGES NEEDED

This section examines the legislative changes required to ensure the national perinatal bereavement pathway is successful. Based on current information, no legal changes are required at this time. Existing laws and regulations already support the care needed to address the emotional, cultural, and mental health needs of pregnant women, pregnant people, whānau and families experiencing perinatal loss.

Current Laws Affecting Service

The existing laws and regulations related to healthcare are adequate in supporting the scope of cultural competence, mental health integration, and the comprehensive care required for perinatal bereavement. Current legal frameworks provide a solid foundation for the pathway to address the critical aspects of perinatal care, including emotional support, cultural safety, and mental health needs.

Proposed Changes

At present, no significant legislative changes are needed to ensure the successful implementation of Tuituia Te Kahu. The existing legal framework already supports the integration of mental health services, cultural safety measures, and the roles of Lead Perinatal Bereavement Coordinators. This includes laws governing healthcare workers' roles, mental health integration, and safety at work. There are also no changes required to the Health and Safety at Work Act.

Future Legislative Considerations

While no immediate legal changes are necessary, it is important to recognise that, as the pathway evolves, certain roles and services may require legislative backing. For instance, the introduction of new roles, such as Lead Perinatal Bereavement Coordinators or culturally specific care providers, could require formal recognition. Additionally, as healthcare technologies advance, changes may be needed to ensure data privacy laws remain in line with innovations in care.

Alignment with Broader Legislation

Tuituia Te Kahu aligns with existing health and social legislation and, to the extent possible, reflects the principles of the Te Tiriti o Waitangi. This ensures that the pathway is consistent with

the broader legislative framework of Aotearoa, which prioritises accessible, equitable care for all communities, including Māori and Pasifika whānau, as well as Indian people.

What This Means for the Pathway

The current legislative framework provides a strong base for Tuituia Te Kahu. This means that, for now, efforts can focus on the implementation and coordination of services, without the need for significant legal reform. However, it is essential to keep monitoring the legal landscape to ensure the framework remains relevant and continues to meet the evolving needs of perinatal care. While changes to the law are not immediately necessary, any future adjustments or additions will need to be considered in the future, to ensure the pathway remains effective and adaptable.

Summary of Legislative Changes Needed

In conclusion, the existing legislative framework is sufficient to support the national bereavement care pathway for perinatal loss, and no immediate changes to laws are required . The current legal structures already address the key elements necessary for the pathway, including mental health integration, cultural safety, and support for healthcare professionals. However, ongoing monitoring of the legal landscape is essential to ensure that any future legislative changes can be quickly implemented, if necessary, allowing the pathway to remain responsive to the needs of individuals, whānau and families.

POLICY, REGULATION AND RULES UPDATES

This section discusses the updates needed in the policies, regulations, and rules that guide perinatal bereavement care services. These updates are crucial for ensuring that the national bereavement care pathway for perinatal loss is fully integrated into the healthcare system and is in line with the broader goals of providing comprehensive, compassionate care to pregnant women, pregnant people, whānau and families facing perinatal loss.

Ministry of Health | Manatū Hauora Guidelines

To ensure consistent, high-quality care, the existing Ministry of Health | Manatū Hauora guidelines should be updated to include a national standard for bereavement care for perinatal loss. These updated guidelines will set clear expectations for service providers, ensuring that all professionals involved in the care of pregnant women, pregnant people, whānau and families experiencing perinatal loss adhere to the same high standards of compassion, trauma-informed care, cultural safety, and mental health integration.

Updating these guidelines will also help ensure that healthcare providers across regions are equipped to deliver the same level of care, reducing disparities and ensuring that all individuals, whānau and families receive equitable support, no matter where they live.

Professional Standards

Relevant health workforce regulatory and professional bodies need to consider necessary changes to their professional standards to ensure alignment with the pathway. These standards will include training in mental health support, cultural competency, and specific guidance on perinatal bereavement care. By ensuring that healthcare professionals are equipped with the necessary knowledge and skills, the pathway can better meet the needs of individuals, whānau and families during their time of grief.

The update of professional standards will not only ensure consistency in the quality of care provided but will also foster a culture of compassion and understanding, which is critical to supporting pregnant women, pregnant people, whānau and families through this difficult time.

Delegations

Health New Zealand will need to determine the delegation of responsibilities, particularly in relation to the new roles of Lead Perinatal Bereavement Coordinators and mental health professionals. These professionals will play a central role in ensuring pregnant women, pregnant people, whānau and families receive consistent care and follow-up support. Clear delegations will ensure that each professional understands their role and responsibilities, facilitating smoother coordination of services and reducing the risk of fragmented care.

Commissioning Frameworks

The Maternity Commissioning Framework will need to reflect these new standards as part of the essential services list. This will ensure that perinatal bereavement care is officially recognised as a critical part of maternity services. Incorporating these standards into commissioning frameworks will help ensure that perinatal bereavement services are adequately funded, resourced, and integrated into the wider maternity care system.

Regional and Local Policies

Regional and local health providers will need to align their policies with national standards to ensure consistency in care across different regions. While the national pathway will set the overarching framework, local providers will need to tailor their services to meet regional needs. Local policies should reflect the specific cultural, social, and geographical needs of their communities, while still adhering to the national standard.

Additionally, regional commissioners will play a vital role in assessing local needs and ensuring that the pathway is adapted to meet those needs effectively. This ensures that care remains responsive to the unique circumstances of each community.

Documentation Requirements

Standardised documentation processes must be established to track perinatal loss cases, ensuring that all relevant parties are informed and that whānau and families receive timely and coordinated support. Consistent documentation will allow for better communication between healthcare providers, making it easier to track care plans and ensure that follow-up services are provided, as needed.

Moreover, standardised documentation will help to identify any gaps in care and allow for ongoing improvements in the delivery of services. Clear and consistent records are essential for monitoring

the effectiveness of the pathway and ensuring that pregnant women, pregnant people, whānau and families receive the support they need in a timely and coordinated manner.

Simplification and Plain Language Project

Once these policy updates are complete, it will be essential to make them accessible to all healthcare providers and individuals, whānau and families dealing with baby loss. The Simplification and Plain Language Project will run over the Establishment and Year One phases, with updates available on Whetūrangitia. This project will ensure that the policies and guidelines are communicated in an accessible and understandable way, making it easier for healthcare providers pregnant women/people, and whānau and families to navigate the system.

Summary of Policy, Regulation and Rules

In conclusion, updating policies, regulations, and rules is essential to ensuring that Tuituia Te Kahu functions as intended. These updates will provide a clear, standardised approach to perinatal bereavement care, ensuring that pregnant women, pregnant people, whānau and families receive consistent, high-quality support across regions. The alignment of professional standards, the commissioning framework, and regional policies within the national standards will further strengthen the pathway's implementation, while the Simplification and Plain Language Project will make these changes accessible to all stakeholders. By updating policies and regulations, the pathway will be better integrated into the healthcare system, providing comprehensive, compassionate care for pregnant women, pregnant people, whānau and families experiencing perinatal loss.

LINKS TO OTHER PROJECTS

The success of Tuituia Te Kahu is closely linked to several other projects within the healthcare system. These include the Maternity Commissioning Framework, changes to maternity services, mental health initiatives, the paediatric palliative model of care, and the Turanga Kaupapa rollout. Effective coordination between these projects will ensure that whānau and families receive continuous and comprehensive support across different stages of care.

Maternity Commissioning Framework

Tuituia Te Kahu must be aligned with the Maternity Commissioning Framework to ensure that bereavement care is integrated into the broader maternity care system. This alignment will create clear referral pathways, ensuring that whānau and families have access to consistent support during and after perinatal loss. By embedding bereavement care within the framework, the pathway will be seamlessly incorporated into the services offered by maternity providers, ensuring that women/people, whānau and families receive the support they need throughout their pregnancy journey.

Additionally, the framework will provide a structure for the ongoing development and funding of perinatal bereavement services, ensuring they are prioritised as an essential part of maternity care. This integration will also help reduce fragmentation in services, making it easier for healthcare providers to coordinate care and provide consistent, compassionate support.

Maternity and Early Years Service Changes

Any changes to maternity and early years' services, particularly those related to perinatal loss, must be in alignment with the standards outlined in Tuituia Te Kahu. This ensures that the care provided to families experiencing perinatal loss is consistent with the national standards, no matter the service they access. For example, changes in maternity care, such as the introduction of new models of care or the reorganisation of services, should consider the needs of pregnant women, pregnant people, whānau and families facing perinatal loss to ensure they are not overlooked during periods of change.

By ensuring that changes in maternity services are aligned with the bereavement pathway, we can guarantee that pregnant women, pregnant people, whānau and families receive seamless and

continuous care during this challenging time. This alignment will help healthcare providers respond effectively to perinatal loss, ensuring that services are available at every stage of care.

Mental Health Initiatives

The integration of mental health support is critical to the success of Tuituia Te Kahu. Mental health initiatives, particularly those focused on perinatal mental health, must be linked with the bereavement pathway to ensure that pregnant women, pregnant people, whānau and families receive comprehensive care. This includes providing pregnant women, pregnant people, whānau and families with the tools and resources they need to cope with grief and loss, while also offering specialised mental health support, when necessary.

By integrating and ensuring access to maternal and whānau mental health services early in the bereavement process, pregnant women, pregnant people, whānau and families will be better equipped to deal with the emotional and psychological impacts of perinatal loss. This integration will also ensure that mental health services are consistently available, reducing the risk of pregnant women, pregnant people, whānau and families experiencing delays in care or being unable to access the support they need.

Turanga Kaupapa

The Turanga Kaupapa framework, developed by Nga Maia, provides a culturally grounded approach to midwifery practice and is a vital component of the national perinatal bereavement pathway.

This framework emphasises the importance of cultural values, such as Whakapapa (acknowledging the wahine and her whānau), Karakia (the use of prayer), and Whanaungatanga (the involvement of whānau, family and the community). It also underscores the importance of Mana (maintaining dignity), Hau Ora (holistic wellbeing), and Manaakitanga (care and respect).

By exploring where Turanga Kaupapa and Tuituia Te Kahu can integrate the cultural needs of Māori whānau will ensure that these will be respected and met throughout the baby loss journey. This inclusion reflects the broader commitment to upholding Te Tiriti o Waitangi, ensuring equitable, culturally appropriate care for Māori whānau. The framework's emphasis on Te Reo Māori, Tikanga Whenua, and Te Whare Tangata ensures that Māori traditions and practices are honoured, promoting a sense of safety and cultural connection during a vulnerable time.

This integration will help ensure that Māori whānau experience culturally relevant and timely support, further strengthening the pathway's effectiveness and inclusivity.

Summary

In summary, the success of Tuituia Te Kahu depends on its integration with several key projects in the healthcare system. The Maternity Commissioning Framework, changes to maternity services, mental health initiatives, and the Turanga Kaupapa rollout all play a vital role in ensuring pregnant women, pregnant people, whānau and families receive continuous, comprehensive care. By aligning the pathway with these projects, we can guarantee that perinatal bereavement care is seamlessly incorporated into the wider healthcare system, providing pregnant women, pregnant people, whānau and families with the support they need at every stage of their journey. Effective coordination and integration of these projects will ensure that pregnant women, pregnant people, whānau and families receive consistent, culturally appropriate, and compassionate care, regardless of where they access services.

CHAPTER SIX: IMPLEMENTATION OPTIONS

SUMMARY

This chapter looks at different ways to roll out Tuituia Te Kahu, a national plan to improve care for pregnant women, pregnant people, whānau and families affected by perinatal loss.

It explores different speeds of change, from taking time to implement it slowly, to making changes right away.

The chapter focuses on making sure the health system is ready, that care is culturally appropriate, and that the changes will last in the long-term.

Key points include balancing the need to act quickly with making sure the plan works well and fits the needs of different regions.

OPTION ANALYSIS

In this section, the various options for implementing Tuituia Te Kahu are explored, with a focus on the scope of change, the potential scale of rollout and the resources required for successful delivery.

The options were developed based on the findings from Chapters Two, Four and Five, which together address some of the key challenges related to readiness, cultural competency and system integration.

Each option provides a distinct approach to achieving equitable, culturally competent and sustainable perinatal bereavement care.

1. DO NOTHING

The option was immediately ruled out, due to the significant gaps in perinatal bereavement services, as outlined in Chapter Two. Maintaining the status quo will perpetuate systemic inequities, particularly for Māori, Pasifika and Indian families, as well as Tāngata Whaikaha, who are disproportionately affected by inadequate care. The lack of culturally safe, consistent and compassionate care means that failing to act would leave these issues unresolved.

- Pros:
    - No immediate financial outlay or resource allocation required.
    - No disruption to current services.
- Cons:
    - Perpetuates the inequities in bereavement care identified in Chapter Two, particularly for Māori, Pasifika and Indian communities.
    - Leaves pregnant women, pregnant people, whānau and families unsupported during a deeply challenging time, exacerbating grief and potentially mental health outcomes.
    - Fails to address systemic issues, such as lack of culturally responsive care and inadequate workforce training, highlighted in Chapter Two and discussed in Chapter Four.
    - Fails to address the cost of doing nothing (see Appendix One).

Maintaining the status quo would hinder any attempts to improve the quality and accessibility of perinatal bereavement care and will fail to address the urgent need for reform.

2. GO-SLOW (GRADUAL IMPLEMENTATION WITH CAREFUL DESIGN)

This option suggests a more cautious approach to reform, with a gradual, step-by-step rollout of Tuituia Te Kahu. This approach allows time for careful design, identification of risks and integration of feedback. As highlighted in Chapter Four, a slower approach would enable the system to address workforce readiness, particularly by ensuring that healthcare workers are adequately educated and trained, and culturally competent, before full implementation.

- Pros:
    - Allows for in-depth testing and risk assessment before full implementation.
    - Provides time to address workforce training and the integration of cultural competency.
    - Reduces the likelihood of widespread disruption by testing key elements of the pathway before scaling-up.
    - Enables careful engagement with whānau, families and the health and hauora professions, including discussions within Health New Zealand to align the pathway's design and establish yearly tasks.
- Cons:
    - Delays the benefits of reform, potentially frustrating pregnant women, pregnant people, whānau and families, and the community partners, who are eager to see urgent and overdue improvements in the bereavement care provided to whānau and families.
    - Progress may feel slow and be difficult to sustain without visible milestones or quick wins.
    - The gradual nature of the approach may not fully address the urgent needs identified in Chapter Two, where care gaps are most severe.

While the Go-Slow approach provides a measured and thoughtful pace, there is a risk that it could be perceived as insufficiently urgent, particularly in regions or for populations with the greatest need.

3. GO GRADUAL (MODERATE SPEED, PHASED IMPLEMENTATION)

The Go Gradual option proposes a moderate pace, where the pathway is introduced in phases. Initial interventions could begin in key regions or areas of care, with lessons from these early phases informing broader implementation. This phased approach ensures that the system can

adapt based on real-time feedback, which allows for a more responsive and flexible implementation process.

- Pros:
    - Ensures a steady pace of progress, while providing room for adjustments, as needed.
    - Allows for flexibility, by piloting the pathway in different regions, testing its effectiveness and cultural appropriateness, before expanding.
    - Builds momentum in the system, with early successes helping to fuel further efforts.
    - Enables the phased integration of new components, such as mental health support and culturally safe care pathways, as discussed in Chapter Four.
- Cons:
    - While progress would be steady, it may still feel slow to stakeholders who are eager for quicker, system-wide change.
    - There may be missed opportunities to make an immediate impact in the most underserved regions, as noted in Chapter Two.
    - A gradual approach might not address all the urgent needs identified in Chapter Two, particularly in areas where disparities in care are most prominent.

The Go Gradual option strikes a balance between the need for urgent change and the caution necessary to ensure that the pathway is integrated thoughtfully and sustainably. It offers the flexibility to adapt the pathway based on feedback from early phases.

4. GO SLIGHTLY FASTER, TESTING MULTIPLE THINGS

This approach suggests a slight acceleration of the pace, allowing different components of the pathway to be trialled in parallel. This would provide an opportunity to test across a range of tasks, while still allowing for ongoing evaluation and adjustment. This test-and-learn-fast-fail approach could offer valuable insights, enabling the pathway's components to be refined in real-time.

- Pros:
    - Facilitates faster delivery of key services, such as increasing the number of Lead Perinatal Bereavement Coordinators or establishing community-based support in year one.
    - Allows for the testing of different whānau- and family-led models in parallel, leading to faster identification of effective strategies.

- Helps to address urgent needs in high-demand areas, ensuring that whānau and families in these regions benefit from the pathway sooner.

- Cons:
  - Without careful management, there is a risk of fragmentation or lack of coordination between different elements of the system.
  - Some components may be poorly tested or rushed, which could lead to inefficiencies or gaps in services.
  - Requires robust monitoring and oversight, as discussed in Chapter Five, to manage risks effectively.

The Go Slightly Faster option offers a more immediate response to the urgent need for change, but it requires careful oversight and management to avoid risks associated with rushed implementation. The ability to go faster will rely on the progress being made in wider commissioning system, particularly the Maternity Commissioning Framework.

5. GO ALL OUT AND DO IT NOW

The Go All Out option proposes a swift, nationwide implementation of the entire pathway, with minimal testing or phased rollout. While this option might appear appealing, due to its potential to deliver rapid systemic change, it presents significant risks, particularly regarding the health system's capacity to absorb such a large-scale change. The workforce challenges and the need for cultural sensitivity, would make this option difficult to implement effectively.

- Pros:
  - Immediate, national rollout of services across Aotearoa, addressing systemic issues quickly.
  - Potential for a rapid response to the urgent need for reform, particularly in the areas of cultural safety and bereavement care.

- Cons:
  - Overwhelms the system, particularly in terms of workforce readiness, with insufficient time to train staff and integrate new services.
  - High risk of failure if key components of the pathway are not fully developed or tested, before implementation.
  - Resistance from healthcare workers and local providers, who may feel unprepared for such a large-scale shift in practice.

While Go All Out could yield immediate results, the associated risks, particularly the lack of preparation and the scale of the required changes, make this approach less feasible.

Summary

The options for implementing Tuituia Te Kahu present varying levels of risk, urgency, and resource allocation. The Go Gradual approach, implemented via a phased strategy, is the most balanced solution, offering flexibility, cultural integration and effective risk management, while allowing steady progress. This option provides the necessary groundwork for long-term, sustainable reform, with an emphasis on engagement, preparation and adaptability. However, the TAG notes that the Go Gradual approach could be expedited, if an establishment phase were funded to carefully plan the implementation and oversee the rollout of specific projects as part of a wider programme.

IMPLEMENTATION OPTIONS

The successful delivery of Tuituia Te Kahu will depend on the chosen method for its implementation. Once Health New Zealand decides on its preferred option, the Establishment Year will be dedicated to planning, engagement and preparing the system for broader rollout. During this phase, decisions will need to be made about the preferred delivery model with a focus on ensuring that the pathway can be scaled effectively, while meeting the unique needs of different regions, and whānau and families and the context in which they live.

For clarity, while the previous section focused on the strategic analysis of implementation options, this section outlines the specific delivery methods for rolling out the pathway, including the phased, regional, national, and hybrid approaches.

It is important to note that Chapter Three of the report provides a comprehensive framework for the pathway's Establishment Year tasks, the Year One tasks and the likely success measures. This section outlines everything required to ensure the pathway is successfully integrated into the health system, including the key actions, milestones and success indicators for each phase. The tasks and measures laid out in Chapter Three serve as the foundation for the implementation of the pathway and will guide the actions in the establishment year.

The following delivery options, remind decision-makers that they will have to rollout Tuituia Te Kahu, balancing the need for gradual implementation with the urgency for reform. These options were developed based on the analysis of system readiness, workforce training, and cultural integration, all of which were explored in previous chapters.

1. PHASED APPROACH

The Phased Approach involves implementing the pathway in manageable stages, with each phase focusing on specific regions or services. This approach ensures that the system can adapt to each new element, before moving on to the next, providing opportunities to address challenges as they arise.

- Key Characteristics:
    - Implementation is rolled out gradually, with each stage allowing for evaluation and adjustments.
    - Initial phases may focus on high-priority areas, such as cultural training or increasing the availability of bereavement support services.

- The phased approach allows for testing specific components of the pathway, gathering feedback, and refining the model, before expanding to other regions.

- Advantages:
  - Reduces the risk of overwhelming the system by introducing changes in stages.
  - Provides a more controlled environment in which to test and refine the pathway, ensuring that the needs of local populations are met.
  - Aligns with the establishment year focus, where the groundwork can be laid for the first phases of rollout.
- Challenges:
  - Delays full system-wide implementation, which may frustrate whānau and families and key stakeholders who are eager to see improvements in care.
  - While it addresses the need for gradual adaptation, it may still not fully address the most urgent needs of pregnant women, pregnant people, whānau and families in the areas of greatest demand.

The Phased Approach provides the flexibility to tailor the implementation to the needs of each region, ensuring that the pathway is built in a way that is culturally competent and adaptable to local contexts.

2. REGIONAL ROLLOUT

A Regional Rollout focuses on introducing the pathway in specific regions first, before expanding to others. This method allows for the tailoring of services to meet regional needs and ensures that the pathway is integrated into the health system, based on the local context. This reflects the regional commissioning models that are currently being developed.

- Key Characteristics:
  - Initial rollout is concentrated in selected regions, often with the highest need or readiness for change.
  - The regional approach allows for the pathway to be adapted to the needs of local populations, including Māori, Pasifika and Indian communities, as well as Tāngata Whaikaha.
  - Regional pilot programmes can help to assess the effectiveness of the pathway and make adjustments before scaling-up nationally.

- Advantages:
    - Offers a more targeted approach that focuses on high-need areas first.
    - Ensures that regions can implement the pathway, based on their unique challenges and resources, making it more likely to succeed.
    - Provides valuable insights into the pathway's effectiveness, before national expansion.
- Challenges:
    - Could lead to inequities, if some regions are prioritised, while others are left behind.
    - May delay the benefits for pregnant women, pregnant people, whānau and families in regions outside of the initial rollout areas.
    - Requires careful coordination between regions to ensure consistency and prevent fragmentation of services.

The Regional Rollout method offers a tailored approach, addressing the needs of specific areas and providing the flexibility to refine the pathway based on local conditions.

3. NATIONAL ROLLOUT

A National Rollout would involve the immediate implementation of the pathway across all regions, delivering services throughout the country simultaneously. While this approach may appeal to those seeking rapid, nationwide change, it is not recommended at this stage, due to the significant risks outlined in previous chapters; particularly the challenges related to workforce readiness and system integration. However, it is important to acknowledge that the National Rollout could be revisited once the pathway has been successfully tested and refined through phased or regional approaches. For example, a National Perinatal Bereavement Service might replace the pathway.

- Key Characteristics:
    - Nationwide implementation from the outset, with the same pathway rolled out across all regions.
    - Minimal flexibility to adapt to regional or local needs.
    - Immediate large-scale delivery of services, aiming for system-wide change.
- Advantages:
    - Immediate impact on the entire country, which could address systemic issues quickly.
    - Rapid response to the urgent need for reform in perinatal bereavement care.
- Challenges:

- Overwhelms the system, particularly in terms of workforce training and infrastructure, which could lead to delays and implementation failures.
- Lack of regional flexibility may cause the pathway to be less effective in areas with specific local needs or challenges.
- High risk of fragmentation and inconsistency in service delivery, particularly if regions are unprepared for large-scale change.

Given the challenges discussed in Chapter Four, the National Rollout is not advisable at this stage. However, it could be reconsidered in the future, once the pathway has been successfully tested and refined. The TAG anticipates this would take another three to five years and not be ready until the detailed business case on a National Perinatal Bereavement Service was decided to be necessary.

4. HYBRID APPROACHES

A Hybrid Approach combines elements of both the phased and regional rollouts, allowing for flexibility, while maintaining overall system coherence. This approach could involve regional testing in certain areas, while other components are tested at a national level or in a specific community.

- Key Characteristics:
  - Regions with high readiness or high need could begin with local implementations, while other areas may focus on testing specific components.
  - This approach balances the benefits of a gradual rollout with the need for faster implementation in key areas.
  - Provides the flexibility to address specific regional needs, while ensuring alignment with the broader national framework.
- Advantages:
  - Offers a balanced solution, by combining the best of both phased and regional approaches.
  - Ensures that urgent needs are addressed, while allowing for flexibility and adaptation.
  - Provides opportunities for learning across regions, ensuring the pathway is refined based on real-world feedback.
- Challenges:

- Requires significant coordination to ensure that different components of the pathway are integrated effectively.
- Potential for complexity in managing multiple types of rollouts simultaneously, which could stretch resources and create inconsistencies.

The Hybrid Approach allows for rapid action where needed, while ensuring that regions can adapt and tailor the pathway, based on local needs.

Summary

The delivery options explored in this section provide multiple pathways for implementing Tuituia Te Kahu. The Phased Approach and Regional Rollout are the most suitable methods for ensuring a gradual, adaptable implementation that meets local needs, while maintaining national coherence. The Hybrid Approach offers additional flexibility, combining the strengths of the phased and regional methods to accelerate certain components, while ensuring broader integration. The National Rollout, while appealing for rapid change, is not recommended at this stage, due to the system's lack of readiness and the risks involved.

ESTABLISHMENT YEAR TASKS

The Establishment Year is a critical phase in the implementation of Tuituia Te Kahu, and it is important to note that the tasks for this phase are entirely at the discretion of Health New Zealand.

As designed in Chapter Three, the Establishment Year focuses on laying the groundwork for the pathway's broader rollout, ensuring that the health system has all the necessary resources, support and guidance to implement the tasks successfully.

The TAG could continue to play a key role during this phase, ensuring that Health New Zealand has everything it needs from the TAG to move forward. This includes providing ongoing advice, expertise and guidance to help execute the establishment year tasks effectively and ensure the pathway is designed to meet the diverse needs of all pregnant women/people, whānau, families and communities.

MONITORING AND EVALUATION FRAMEWORK

A comprehensive monitoring and evaluation (M&E) framework is essential for assessing the impact and effectiveness of Tuituia Te Kahu. Chapter Three provides detailed metrics for evaluating the pathway's success, while the Ninth Standard guides the development of this framework, ensuring it aligns with Te Tiriti o Waitangi principles and Te Ao Māori perspectives.

RECOMMENDED APPROACH

After considering the pros and cons of each option and reflecting on the implementation challenges and risks outlined in previous chapters, the Go Gradual approach, implemented via a Hybrid Approach, is recommended. This offers the most balanced solution, addressing the urgent need for reform, while managing the significant risks identified in Chapter Four. This approach is fitting also for the underpinning concepts and aspirations of Tuituia Te Kahu.

A whāriki is not woven in a single day, but rather is woven over time, following intentional steps to ensure each strand or section is correct, before moving on to the next.

The end result is a flexible, yet balanced, structure. This is what we envision when we recommend the **Go Gradual approach via a Hybrid Approach.**

RISK MANAGEMENT

While the recommended approach offers a clear path forward, it is crucial to consider the risks associated with each phase of implementation. Careful attention will need to be paid to the identification of emerging risks during each phase of implementation, with mitigation strategies in place to address them promptly. The risks associated with system fragmentation, workforce readiness, and cultural safety—highlighted throughout the report—will be carefully monitored to ensure the pathway remains effective and sustainable.

SUMMARY

This chapter discusses several ways to implement Tuituia Te Kahu and the pros and cons of each. The options range from moving slowly to making quick changes. The best approach, according to the TAG, is to move at a steady pace (Go Gradual) but also to use a flexible approach (Hybrid) that combines gradual steps with testing in different areas. This balance allows time for the health system to adjust, while still making progress. The focus is on making sure the system is ready and that the changes meet the needs of all communities. This chapter stresses the importance of planning during the Establishment Year, to ensure the pathway is effective and sustainable in the long run.

Closing Message

As part of the engagement with the sector on Tuituia Te Kahu, Hōkai Tahi shared a story with us. Hōkai Tahi is a Wairarapa-based community service supporting whānau journeying through pregnancy or baby loss. We have included the story here to close our report, and we acknowledge and thank Lochlan's family for permission to include it.

We close with Lochlan's journey because his story demonstrates how the nine standards practically work. The story of Lochlan and his parents illustrates the pathway in action and reminds all of us that interconnected services can provide compassionate, culturally responsive care from diagnosis through long-term healing. It is offered here, as a reminder to Health New Zealand, that good work is already being done, and there is no justification to spend another decade wondering what to do. We thank Hōkai Tahi for this story.

The Beginning: Early Engagement and Hope

When we first met Lochlan's parents at Hōkai Tahi, they had already travelled a long and difficult journey. But their story began, as so many do, with hope and excitement. In February 2024, they discovered they were expecting their first child. New to the maternity care system in Aotearoa, they took the important first step of enrolling with a community midwife and scheduling their early scans. This early engagement with healthcare services would prove to be the foundation stone of the care pathway that would later support them through unimaginable challenges.

The couple's decision to keep their baby's gender a surprise reflected their joy and anticipation. Their 7 and 12-week scans proceeded smoothly, with no concerns identified. At this stage, the first standard of Tuituia Te Kahu - Early and Compassionate Engagement - was already at work. Their LMC midwife had established a relationship built on trust and care, creating the foundation that would prove essential when difficult news emerged later in their pregnancy. This early phase demonstrates how Tuituia Te Kahu begins not with crisis, but with the establishment of caring relationships that can weather any storm. The pathway recognises that compassionate care must be woven into every interaction, from the very first appointment through the most challenging moments that may lie ahead.

The First Signs: When Routine Becomes Complex

At 21 weeks gestation, what should have been a routine anatomy scan became the first indication that this pregnancy would take an unexpected turn. The sonographer struggled to obtain clear images and asked the family to return in a few weeks. Even after second and third attempts, she couldn't fully visualise the baby's heart, though she did note a ventricular septal defect - a hole in the heart - while offering reassurance that such conditions were often not serious.

This moment illustrates the delicate balance that healthcare providers must maintain when uncertainty emerges. The sonographer's approach demonstrated the compassionate communication that is central to Tuituia Te Kahu's first standard. Rather than dismissing concerns or providing false reassurance, she acknowledged the limitations of what could be seen while maintaining hope and ensuring appropriate follow-up care.

The family's midwife, recognising the need for specialist expertise, made a referral to Wellington Maternal Fetal Medicine (MFM) for a more detailed scan. This seamless transition from community-based care to specialist services exemplifies the second standard of Tuituia Te Kahu - Consistent Care and Clear Handovers. The midwife didn't simply make a referral and step back; she remained an integral part of the care team, ensuring continuity and support throughout the process.

This phase of the journey demonstrates how the pathway's emphasis on clear communication and appropriate escalation can work effectively. The family wasn't left to navigate the system alone or to wonder about the significance of the findings. Instead, they were supported by professionals who understood both the medical complexities and the emotional impact of uncertainty during pregnancy.

The Diagnosis: Compassion in the Face of Devastating News

At 26 weeks gestation, the family travelled to Wellington MFM for what they hoped would provide reassurance. Instead, after multiple scanning attempts, they received news that would change their lives forever. The sonographer's words - "I am so sorry to tell you that your baby only has half a heart" - delivered devastating news with the compassion and directness that families need in such moments.

The specialist's explanation of Hypoplastic Left Heart Syndrome (HLHS) was thorough and honest. This severe congenital defect, where the left side of the heart is underdeveloped, presented the family with three heartbreaking options: pursue multiple surgeries at Starship Hospital, continue

the pregnancy with palliative care, or terminate for medical reasons (TFMR). Each option carried its own complexities, risks, and emotional weight.

This moment exemplifies several standards of Tuituia Te Kahu working in concert. The compassionate delivery of difficult news reflects the first standard, while the clear presentation of options demonstrates the seventh standard - Clear Information and Decision-Making Support. The family wasn't rushed into a decision or given incomplete information. Instead, they were provided with comprehensive details about each option, allowing them to make an informed choice that aligned with their values and circumstances.

The immediate provision of additional testing, including amniocentesis, showed how the pathway's emphasis on thorough assessment can provide families with the information they need. The coordination with Starship Hospital for case review demonstrated the second standard in action - ensuring that specialist expertise was available when needed, with clear communication between services.

Support in Decision-Making: The Whāriki Begins to Form

Over the following two weeks, the family received support from multiple sources as they grappled with their impossible decision. A termination counsellor provided professional guidance, while organisations like Sands and Heart Kids offered the invaluable perspective of others who had faced similar situations and decisions. This multi-faceted support system illustrates how Tuituia Te Kahu's third standard - Early Mental Health Integration - can work in practice.

The involvement of these various support services wasn't coincidental or haphazard. Instead, it reflected the pathway's understanding that families facing perinatal loss need different types of support at different times. Professional counselling provides clinical expertise and emotional support, while peer support from organisations like Sands offers the unique understanding that comes from lived experience. Heart Kids brought specific knowledge about congenital heart conditions and the realities of surgical interventions.

During this period, the family's case was reviewed at Starship Hospital, where the HLHS diagnosis was confirmed. This additional layer of specialist review provided both medical confirmation and the assurance that all options had been thoroughly explored. The coordination between Wellington MFM and Starship demonstrated how the pathway's emphasis on consistent care can ensure that families receive the best possible medical expertise while maintaining continuity of support.

The two-week timeframe for decision-making reflects the pathway's recognition that families need time to process devastating news and consider their options carefully. This wasn't a rushed process driven by medical convenience, but rather a family-led approach that honoured their need for time and space to make one of the most difficult decisions any parent can face.

A Loving Decision: Family-Led Care in Action

After careful consideration and with the support of their care team, the family made the difficult decision to proceed with TFMR. This choice, made with love and in the best interests of their baby, demonstrates the fourth standard of Tuituia Te Kahu - Culturally Responsive, Whānau-led and Spiritual Care Integration. The pathway recognises that families are the experts on their own values, beliefs, and circumstances, and that healthcare providers must support whatever decision families make.

The scheduling of the feticide for August 14th provided a concrete timeline while allowing the family to prepare emotionally and practically for what lay ahead. Before the procedure, they requested one final scan, hoping against hope for a miracle. This request was honoured without question, demonstrating the pathway's commitment to family-led care. The scan confirmed the absence of blood flow to the left side of their baby's heart, providing final confirmation that their decision was indeed the most loving choice they could make for their child.

This phase of the journey illustrates how Tuituia Te Kahu's emphasis on family autonomy doesn't mean leaving families to make decisions alone. Instead, it means providing comprehensive support while respecting their ultimate authority over their own care. The healthcare team's willingness to accommodate the family's request for an additional scan, even when the medical outcome was unlikely to change, showed deep respect for their emotional needs and their role as parents making decisions for their child.

Preparing for Goodbye: Memory-Making and Bereavement Support

Following the procedure, the family returned home to prepare for the induction that would bring their son into the world. Their midwife's visit during this time exemplified the continuity of care that is central to Tuituia Te Kahu. She didn't simply provide medical information about the induction process; she helped organise clothing through the hospital and coordinated photography with Heartfelt, ensuring that the family would have precious memories of their time with their baby.

This preparation phase demonstrates the fifth standard of Tuituia Te Kahu - Memory-Making and Bereavement and Grief Support - in action. The pathway recognises that even in the face of loss, families need opportunities to create meaningful connections with their babies. The coordination with Heartfelt, an organisation that provides free professional photography for families experiencing loss, ensured that these precious moments would be captured with sensitivity and skill.

The midwife's role during this phase illustrates how the pathway's emphasis on consistent care can provide stability during a time of profound upheaval. Rather than handing care over to hospital staff, she remained actively involved, serving as a bridge between the family's established relationship with community-based care and the hospital environment where their baby would be born.

On August 16th, the family was admitted to the hospital. After a long induction but a fast labour, their beautiful son Lochlan was born the following morning. The speed of the labour, following the extended induction, created its own emotional complexity - a mixture of relief that the physical process was complete and the profound sadness of meeting their son in circumstances they had never imagined.

Precious Time: The Gift of Memory-Making

Heartfelt's photography captured precious images of Lochlan, creating tangible memories that the family would treasure forever. These photographs serve multiple purposes within the Tuituia Te Kahu framework. They provide immediate comfort during the acute phase of loss, create lasting memories for the future, and offer a way for family members who couldn't be present to feel connected to the baby.

The family spent two nights with Lochlan in a cuddle cot, a specialised cooling system that allowed them extended time with their son. This technology, which has become an important tool in perinatal bereavement care, enabled the family to hold, care for, and bond with Lochlan in a way that honoured and affirmed their relationship as his parents. The two nights provided time for the reality of their loss to settle while creating precious memories of their time together as a family.

The hospital staff's offer to allow the family to take Lochlan home in the cuddle cot demonstrated the pathway's commitment to family-led care. While the family ultimately decided that this would be too emotionally difficult for them, the fact that the option was offered shows how Tuituia Te Kahu's emphasis on individualised care can accommodate different family needs and preferences.

This phase of the journey illustrates how memory-making within the Tuituia Te Kahu framework goes beyond simply taking photographs or creating keepsakes. It encompasses the creation of meaningful experiences that honour the relationship between parents and their baby, regardless of how brief that relationship may be. The time spent with Lochlan allowed his parents to fulfil their role as caregivers, even in the context of loss.

Saying Goodbye: Honouring Individual Choices

The family's final goodbye to Lochlan at the funeral home and their choice of cremation reflected their personal preferences and cultural background. The pathway's fourth standard - Culturally Responsive, Whānau-led and Spiritual Care Integration - recognises that there is no single "right" way to say goodbye to a baby. Instead, families must be supported in making choices that align with their own values, beliefs, and circumstances.

The transition from hospital to funeral home represents another handover point where the pathway's emphasis on consistent care becomes crucial. The family needed to feel supported and informed throughout this process, understanding their options and feeling confident in their decisions. The respectful handling of these arrangements, while deeply personal, also reflects the broader community's recognition of Lochlan's significance as a member of his family and society.

This phase demonstrates how Tuituia Te Kahu's approach to bereavement care extends beyond the immediate medical context to encompass the full range of decisions and experiences that families face after loss. The pathway recognises that saying goodbye is a process, not a single moment, and that families need support throughout this extended period of transition.

The Journey Continues: Follow-Up Care and Community Support

In the weeks following Lochlan's birth and death, the family's midwife continued to provide crucial support through weekly visits for the first six weeks. This ongoing care exemplifies the sixth standard of Tuituia Te Kahu - Follow-Up Care in the Community and Subsequent Pregnancy Support. The pathway recognizes that the immediate period following loss is often when families feel most isolated and vulnerable, making consistent professional support essential.

These weekly visits served multiple purposes. They provided medical monitoring to ensure the mother's physical recovery was progressing normally. They offered emotional support during the acute phase of grief. They maintained the therapeutic relationship that had been established throughout the pregnancy. And crucially, they provided a bridge to longer-term support services. It was during one of these visits that the midwife connected the family with Hōkai Tahi, beginning a relationship that would provide ongoing counselling support for almost ten months. This

connection illustrates how the pathway's emphasis on follow-up care can create seamless transitions between different types of support services. The midwife's knowledge of available resources and her ongoing relationship with the family enabled her to make this crucial connection at the right time. During the weeks that followed, Sands was also able to provide community support to the extended whānau, reflecting the need for care to continue into the weeks and months after a loss.

Long-Term Healing: The Ongoing Journey with Hokai Tahi

The family's engagement with Hōkai Tahi represents the longer-term dimension of Tuituia Te Kahu's approach to perinatal bereavement care. Their nearly ten months of counselling demonstrates how the pathway recognises that grief is not a problem to be solved quickly, but rather a natural response to loss that requires ongoing support and understanding.

At Hōkai Tahi, the family found a space where their grief was normalised and their ongoing need for support was understood. The counselling provided through our service offered them tools for managing their grief, opportunities to process their experience, and connection with others who understood their journey. This long-term support reflects the pathway's understanding that healing from perinatal loss is measured in months and years, not days and weeks.

The family's recent participation in a Hōkai Tahi care-package session marked a significant milestone in their healing journey. This session, which they described as "profoundly healing," provided them with an opportunity to give back to others walking a similar path. This transition from receiving support to providing support for others represents a powerful form of healing that benefits both the giver and the receiver.

The care-package session also illustrates how Tuituia Te Kahu's ninth standard - Regular Review and Continuous Improvement - can work in practice. By engaging families who have experienced the pathway in supporting others, services can benefit from their insights and experiences while providing meaningful opportunities for continued healing.

Reflections on the Pathway: What Worked and What We Learned

The family's reflection on their experience provides valuable insights into how Tuituia Te Kahu can work effectively when its standards are implemented with skill and compassion. Their statement that they "feel fortunate to have had access to services like Hōkai Tahi" highlights the importance of accessible, ongoing support services in the community.

Their observation that "baby loss is tragically common, and free, ongoing, accessible support should be available everywhere" reflects both their personal experience of effective care and their

recognition that not all families have access to the same level of support. This insight speaks directly to the equity goals that are central to Tuituia Te Kahu's vision.

The family's understanding that "the grief of losing a baby is life-altering, and ongoing support is essential for families to heal" demonstrates their deep appreciation for the long-term nature of grief and recovery. This perspective, gained through their own experience, provides valuable validation for the pathway's emphasis on sustained, community-based support.

From the perspective of Hōkai Tahi, this family's journey illustrates several key elements that made their care effective. The early establishment of trusting relationships provided a foundation for navigating later challenges. Clear communication and comprehensive information enabled informed decision-making during crisis. Respect for family autonomy ensured that their choices were honoured throughout the process. Coordinated care between multiple services prevented gaps or duplications in support. Memory-making opportunities created lasting connections with their baby. And ongoing community-based support provided a pathway for long-term healing.

The Whāriki Revealed: How the Standards Wove Together

Looking back on Lochlan's journey, we can see how the nine standards of Tuituia Te Kahu wove together to create a strong, supportive whāriki (woven mat) of care. Each standard contributed essential elements, but it was their integration and interconnection that created the comprehensive support this family needed.

The early and compassionate engagement established through their midwife's care provided the foundation for everything that followed. When difficult news emerged, the trust and relationship that had been built enabled honest, caring communication. The consistent care and clear handovers between services ensured that the family never felt abandoned or lost in the system. The early integration of mental health support provided professional guidance during decision-making and ongoing counselling for long-term healing.

The culturally responsive, whānau-led approach honoured the family's autonomy and supported their decisions throughout the journey. Memory-making opportunities created precious connections with Lochlan that will last a lifetime. Follow-up care in the community provided sustained support during the vulnerable period following loss. Clear information and decision-making support enabled the family to make informed choices that aligned with their values. And the ongoing relationship with services like Hōkai Tahi created opportunities for both continued healing and contributing to the support of others.

Looking Forward: Lessons for Implementation

This case study demonstrates that when the standards of Tuituia Te Kahu are implemented effectively, they can create a comprehensive, compassionate response to perinatal loss that supports families from diagnosis through long-term healing. However, it also highlights several factors that were crucial to the success of this family's care.

The availability of skilled, compassionate professionals at every stage of the journey was essential. The midwife who maintained continuity throughout the process, the specialists who delivered difficult news with care, the counsellors who provided emotional support, and the community organisations that offered peer and whānau support all played crucial roles. This highlights the importance of workforce development and training in implementing Tuituia Te Kahu effectively.

The coordination between services was seamless, preventing the family from falling through gaps or having to navigate complex systems during their most vulnerable time. This level of coordination requires strong relationships between services, clear protocols for communication, and shared understanding of each organization's role in supporting families.

The availability of specialised resources like cuddle cots, professional photography, and ongoing counselling services made crucial differences in the family's experience. This highlights the importance of ensuring that all communities have access to these resources, not just those in major urban centres.

Perhaps most importantly, the family's experience demonstrates that effective implementation of Tuituia Te Kahu requires more than just having the right services available. It requires a culture of care that prioritises family needs, respects individual choices, and recognises that healing from perinatal loss is a long-term journey that requires sustained support.

Conclusion: The Promise of Tuituia Te Kahu

Lochlan's story, while heartbreaking, also offers hope. It demonstrates that when healthcare and community services work together with skill, compassion, and coordination, they can provide families with the support they need to navigate even the most difficult circumstances. The family's journey from devastating diagnosis to long-term healing illustrates the potential of Tuituia Te Kahu to transform the experience of perinatal loss in Aotearoa.

Their experience also reminds us that behind every statistic about perinatal loss is a family whose world has been forever changed. Lochlan may have lived for only a brief time, but his impact on his parents, his extended family, and even on the services that supported them, will last forever. Through sharing their story, his parents have contributed to the development and understanding

of Tuituia Te Kahu, helping to ensure that other families will receive the compassionate, comprehensive care that they experienced.

As we work to implement Tuituia Te Kahu across Aotearoa, Lochlan's journey serves as both inspiration and guidance. It shows us what is possible when the pathway's standards are implemented effectively, while also highlighting the ongoing work needed to ensure that all families, regardless of their location or circumstances, have access to the same level of care and support.

The whāriki of care that supported Lochlan's family was woven from many strands - professional expertise, community support, family strength, and the love that connects parents to their children regardless of how brief their time together may be. As we continue to develop and implement Tuituia Te Kahu, we carry forward the lessons learned from their journey, working to ensure that every family facing perinatal loss can experience the same level of compassionate, comprehensive care.

In honouring Lochlan's memory and his family's courage in sharing their story, we commit to continuing the work of building a healthcare system that truly serves all families during their most vulnerable moments. Their journey reminds us that while we cannot prevent all loss, we can ensure that no family faces that loss alone.

This case study was developed by Hōkai Tahi in collaboration with Lochlan's family, who generously shared their experience to help others understand how Tuituia Te Kahu can work in practice. We are grateful for their courage in sharing their story and their ongoing commitment to supporting other families facing similar journeys.

Unuhia, unuhia
Unuhia ki te urutapu nui
Kia wātea, kia māmā, te ngākau, te tinana,
Te wairua I te ara takatā
Koia rā e Rongo, whakairia ake ki runga
Kia tina! Tina! Hui e, taiki e!

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Perinatal Bereavement Support Environmental Scan Report

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Inequity

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This study investigates a care model providing increased continuity of care for pregnant women/people after stillbirth or neonatal death, highlighting barriers, such as leadership changes and service pressures.

Reference: Mills, T. A., et al. (2022). Better maternity care pathways in pregnancies after stillbirth or neonatal death: A feasibility study. *BMC Pregnancy and Childbirth*, 22(634). https://doi.org/10.1186/s12884-022-04925-3

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This paper provides an analysis of global strategies aimed at reducing perinatal mortality, particularly in disadvantaged populations. It stresses the importance of robust data collection, international collaboration, and tailored interventions.

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This study investigates a quality improvement project designed to reduce late-gestation stillbirths in Australia, focusing on disadvantaged populations, such as Aboriginal and Torres Strait Islander communities.

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Cultural Safety

Culturally Sensitive Perinatal Bereavement Care for Indigenous Populations

This article focuses on the unique bereavement care needs of Indigenous populations, advocating for culturally sensitive care and integration of traditional practices into modern healthcare systems.

Reference: Pollock, D., et al. (2024). First Nations Peoples' perceptions, knowledge, and beliefs regarding stillbirth prevention and bereavement practices: A mixed methods systematic review. *Women and Birth*, 37, 101604. https://doi.org/10.1016/j.wombi.2024.101604

Memory-Making in Perinatal Bereavement

This research focuses on the therapeutic effects of memory-making practices for parents experiencing stillbirth. It highlights that creating tangible memories, such as photos or keepsakes, can significantly aid the grieving process, offering parents a way to affirm their child's life. The study suggests that healthcare systems must integrate these practices into standard bereavement care protocols.

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This paper examines the challenges parents faced during the COVID-19 pandemic in Aotearoa, where social distancing and movement restrictions exacerbated isolation, although compassionate adjustments helped mitigate some effects.

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Reference: Thornton, R., Nicholson, P., & Harms, L. (2020). Creating evidence: Findings from a

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Compassionate Support and What Families Think

Bereavement Support Following Perinatal Loss

This study focuses on the importance of compassionate and sensitive bereavement care, emphasising the role of healthcare professionals in providing support to grieving parents. It highlights how the quality of staff interactions, including empathy and sensitivity, can significantly impact parents' wellbeing. The study suggests that hospitals implement practices like bereavement stickers and provide extra time for parents to process their grief.

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This study explores grandmothers' experiences in supporting their children after pregnancy loss, revealing their need for more targeted bereavement resources and support to cope with their own grief.

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Impact of Health Professionals on Bereaved Parents' Recovery

This article addresses the significant role healthcare professionals play in the recovery of parents who have experienced a stillbirth. It examines how healthcare providers' behaviours, attitudes, and communication skills contribute to or hinder the grieving process. Positive and sensitive interactions were found to help parents through the grief process, and the study suggests that healthcare systems need to better prepare staff for such emotionally challenging situations.

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Impact of Stigma on Bereaved Parents' Grief

This article discusses the stigma surrounding stillbirth, focusing on how it exacerbates the grief process for parents. It highlights that social perceptions often lead to minimising the significance

of the loss, causing bereaved parents to feel isolated. The study calls for societal shifts to reduce stigma and for healthcare systems to provide more open, supportive environments for grieving parents.

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This study explores sibling grief after perinatal loss, highlighting how young siblings cope with the death of a sibling and the resulting changes in family dynamics.

Reference: Bornemisza, A. Y., et al. (2022). Sibling grief over perinatal loss—A retrospective qualitative study. *Journal of Loss and Trauma*, 27(6), 530–546. https://doi.org/10.1080/15325024.2021.2007650

Stillbirth: Sociocultural Considerations and Stigma

This study explores the stigma surrounding stillbirth and how it affects grieving parents. It calls for societal changes to reduce stigma and enhance supportive environments in healthcare settings.

Reference: Pollock, D., et al. (2020). Voices of the unheard: A qualitative survey exploring bereaved parents' experiences of stillbirth stigma. *Women and Birth*, 33(2), 165–174. https://doi.org/10.1016/j.wombi.2019.03.002

Women's Experiences of Transfer from Primary Maternity Unit to Tertiary Hospital in Aotearoa

This study explores the experiences of women who had to change their birthplace plans and transfer from a primary maternity unit to a tertiary hospital during pregnancy or labour. The findings reveal that most women felt unbothered by the transfer, especially when there was clear communication, a sense of control, and support from their midwives. Women who had a sense of agency and received effective communication from their caregivers had more positive

experiences. The study suggests that continuity of care, a hallmark of Aotearoa's maternity system, mitigates the negative aspects of such transfers and improves the overall birth experience. Reference: Grigg, C. P., Tracy, S. K., Schmied, V., Monk, A., & Tracy, M. B. (2015). Women's experiences of transfer from primary maternity unit to tertiary hospital in Aotearoa: Part of the prospective cohort Evaluating Maternity Units study. *BMC Pregnancy and Childbirth*, 15, 339. https://doi.org/10.1186/s12884-015-0770-2

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Reference: Qian, J., et al. (2021). Characteristics of perinatal bereavement care education programmes for nurses and midwives: A review of global practices. *Nurse Education Today*, 103, 104962. https://doi.org/10.1016/j.nedt.2021.104962

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International Best Practice

International Perinatal Mortality Review Tools

This article reviews various perinatal mortality review tools used worldwide, advocating for standardisation to improve the identification of preventable deaths and enhanced care systems.

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[i] expected loss due to congenital abnormalities/unexpected diagnoses

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