Pēpē-Infant sleep and sudden unexpected death in infancy in Māori

E Kō, kia ora, kua ao te rā!

He tikanga o te whakamoe pēpē me te mate ohorere i te wā e pēpē tonu ana

Melanie Estelle Christensen

A thesis submitted in complete fulfilment of the requirements for the degree of Doctor of Philosophy (PhD) in Paediatrics, The University of Auckland, 2022.

Dedication

This thesis is dedicated to the infants and families affected by the tragedy of sudden and unexpected death in infancy; and especially to the SUDI-bereaved families in Aotearoa-New Zealand and worldwide, whose stories of infant love and loss have contributed to this research.

This thesis is also future-facing and aspirational. Therefore, it is also dedicated to the infants whose lives will be saved as a result of existing and future research, and the tireless SUDI prevention efforts of many, many people.

E moe e kō me ō moemoeā
Kī pai i te mīharo me te aroha.
Kia oho ake kia ora ai ki tāu ake nā
Whakapuāwaitanga i aua wawata
Kia kitea ai to tupuranga
e tika ana ki tāu e pai ai.

Sleep precious baby, with dreams
Filled with love and wonder
Then wake so you may live your life
And realise your dreams
So we may watch you grow and fulfil your destiny

M Christensen; translated by Tom Roa, Associate Professor, University of Waikato

Abstract

Aotearoa-New Zealand has one of the highest rates of sudden unexpected death in infancy (SUDI) among developed countries. Indigenous New Zealand Māori are disproportionately affected by SUDI (1.36 deaths for every 1,000 births). In wealthier countries, and in New Zealand, SUDI mortality decreased dramatically following high-profile risk-reduction campaigns for modifiable risk factors, such as prone sleep position, and smoking in pregnancy. SUDI remains preventable if infant exposure to such known modifiable risks continues to reduce. Improvements in Māori SUDI have not kept pace with non-Māori.

This thesis investigated factors contributing to the inequitably high Māori SUDI rate by examining risks in the infant sleep environment, their relative effect on Māori and non-Māori infants, and the drivers influencing mothers' infant sleep decision-making.

This research drew on the New Zealand SUDI Nationwide case-control study (2012-2015), and a separate, locality-specific qualitative study. Kaupapa Māori methodologies were incorporated into each study. The SUDI Nationwide Study enrolled n=132 case infants and n=258 controls. Data collection was implemented using a project management approach. The initial results, particularly the dangerous combination of smoking in pregnancy and bed sharing, informed this PhD research. We confirmed the combined effect of these factors was the same for Māori and non- Māori. The difference was specifically in the prevalence of smoking in pregnancy. We also examined other hazards in the infant sleep environment. A qualitative study, based in the culturally and socioeconomically diverse region of Counties-Manukau, Auckland, New Zealand, was implemented from June to August 2019. Thirty mothers of infants aged 5-weeks to 5-months were interviewed at home about their infant sleep practices and the reasons for these. Two-thirds of mothers reported previous or current bed sharing. The need for adequate sleep motivated half the mothers, particularly Māori mothers, in the study to bed share.

This research has strengthened and informed our understanding of SUDI in New Zealand, especially for Māori. Smoking remains a modifiable behaviour. These findings highlight the need for the continued availability of effective, appropriate smoking cessation programmes, and the continued promotion of safe sleep, and supply of safe sleep beds for infants who need them.

He mihi

Ko Rangitoto te Maunga
Ko Waipa te Awa
Ko Matakore te Hapū
Ko Otewa Pa te Marae
Ko Ngāti Maniapoto me Raukawa ngā Iwi
Ara ko Tainui te Waka
Ko Tuhuatahi Adams rāua ko Neinei Warren ōku mātua tipuna i te taha o tōku mama
Ko Fred Christensen rāua ko Mabel McGinnity ōku mātua tipuna i te taha o tōku papa
Ko Max rāua ko Lorraine ōku mātua
Toko wha a māua tamariki
Ko Josh rāua ko Phoenix ōku tama
Ko Skyler rāua ko Helena ōku tamahine
Ko Melanie Estelle Christensen tōku ingoa, tēnā koutou katoa.

Tuatahi ka mihi ki te Matua nui i te Rangi, nana nei ngā mea katoa
Tuarua ka mihi ki ōku rangatira mo o tino kaha rawa nei ki te tautoko i ahau ki te whai ake nei i ngā taumata teitei o te Mātauranga
Te tini o koutou e manāki mai nei, kia ora mai koutou. Hei whakaoti aku korero me mihi koki ki ōku Mātua, Kuia, Koroua hoki e hautu mai nei i te hau Kāinga, mihi aroha mihi maioha kia koutou katoa….na Melanie
Nō reira, tēna koutou, tēna koutou, tēna tatou katoa.

Acknowledgements

I offer my deepest thanks and appreciation to:

My Academic Supervisors: Emeritus Professor Ed Mitchell and Associate Professor John Thompson, for their wise counsel and support; and Professor Beverley Lawton, my co-supervisor, for her strengths-based cultural guidance. Thanks also to Ms Tanisha Jowsey for her qualitative research expertise and positivity.

My Tikanga Advisory Group members: Ms Gwen Tepania-Palmer, Associate Professor Tom Roa, and my grand-uncle Mr Graham Warren - your aroha and manākitanga paved my way.

I also extend my gratitude to:

The Health Research Council for awarding me a Māori Career Development Award.

The Faculty of Medical and Health Sciences, Post Graduate Student Association and Auckland Medical Research Foundation for the opportunities to communicate my research widely.

The SUDI researchers and kaimahi who work tirelessly in SUDI prevention. I hope my research supports their efforts and contributes to saving infant lives.

David Aro - Communio, The Office of the Chief Coroner, and Coronial Services

Ms Matekitawhiti Chase, mō te reo atāhua, kia ora.

Past and present members of the national SUDI Liaison team, especially my good friends, Ms Shelley Jonas and Mrs Elaine McLardy, who also provided valuable assistance with the qualitative research.

Heartfelt thanks to:

The amazing and resilient families/whānau that participated in the SUDI Nationwide Study, and the Pēpē-Infant Sleep Practices Study, for generously sharing their stories. Without you, this research would not have been possible.

I acknowledge and extend my deepest sympathy to the families and infants affected by SUDI.

And finally:

My profound thanks to my mother, Lorraine, for her unwavering encouragement and support during the good times and the hard times. And to my children, you are my whole world, and I love you all to the moon and back.

Table of contents

List of figures

List of tables

Glossary

aOR	Adjusted odds ratio
CI	Confidence interval
CYMRC	Child and Youth Mortality Review Committee
DHB	District Health Board
Hapū	Community *(Māori)*
Harakeke	Native New Zealand flax plant whose leaves are prepared and woven into items such as baskets and Wahakura *(Māori)*
Hui	To meet or gather *(Māori)*
Karakia	Prayer *(Māori)*
Koha	Māori custom which can be interpreted as a gift, offering, present or contribution *(Māori)*
Manākitanga	Hospitality, being welcoming *(Māori)*
Mihi	A greeting, formal welcome speech, expression of thanks *(Māori)*
MOJ	Ministry of Justice
Mokopuna	Grandchild, great-nephew or great-niece *(Māori)*
NIIO	National Initial Investigation Office, Ministry of Justice
OR	Odds ratio
PAR	Population attributable risk
Pēpē	Baby, infant *(Māori)*
Pēpi-Pod®	Plastic bassinet to support safe infant sleep
PMMRC	Perinatal Maternity and Mortality Review Committee
Pono	To act with truth, honesty, and sincerity *(Māori)*
Pōwhiri	Māori welcome ceremony *(Māori)*
Reo Māori	Māori language *(Māori)*

SIDS	Sudden infant death syndrome
SUDI	Sudden Unexpected Death in Infancy (under one year). The term 'SUDI' is used increasingly in New Zealand and overseas and is broader than SIDS (sudden infant death syndrome) or Cot Death. SUDI includes both explained and unexplained causes of sudden unexpected death, including infants sleeping with adults where no direct evidence of overlying exists; and unascertained deaths
Tangihanga	A Māori funeral rite traditionally held on marae (Māori meeting house); involves a period of mourning and is often held at a relative's home *(Māori)*
TeleForm	An automated data extraction and collection software programme owned by Hewlett Packard
Tika	Correctness, acting in the right way *(Māori)*
Wahakura	Traditionally woven, Māori flax bassinet that provides an infant with his/her own portable sleep space *(Māori)*
Whānau	Family, including extended family *(Māori)*
Kaupapa	Māori approach, Māori customary practice *(Māori)*
Kaumatua	A respected male Māori elder *(Māori)*

Publications and awards relevant to PhD candidature

Publications during candidature

Lead Author (Published under MacFarlane):

MacFarlane, M., Thompson, J.M.D., Zuccollo, J., McDonald, G., Elder, D., Stewart, A.W., Lawton, B., Percival, T., Baker, N., Schlaud, M., Fleming, P., Taylor, B., Mitchell, E.A. *Smoking in pregnancy is a key factor for sudden infant death among Māori*. Acta Paediatrica. 2018. doi/10.1111/apa.14431

MacFarlane M. *A Case for the Use of Project Management Methodology to Implement Data Collection for a Nationwide Case-Control Study Investigating Sudden Unexpected Death in Infancy*. SAGE Research Methods Cases: Medicine and Health. 2020. doi.org/10.4135/9781529721072

MacFarlane M, Thompson JM, Wilson J, Lawton B, Taylor B, Elder D, Baker N, McDonald GK, Zuccollo J, Schlaud M, Fleming P, Mitchell EA. *Infant sleep hazards and the risk of sudden unexpected death in infancy*. Journal of Pediatrics (online ahead of print). 2022. doi.org/10.1016/j.jpeds.2022.01.044

MacFarlane M, Thompson JM, Mitchell EA, Lawton B, McLardy EM, Jonas SD, Tepania-Palmr G, Roa T, Warren G, Jowsey, T. *Pēpē - infant sleep practices and sudden unexpected death in infancy in Aotearoa New Zealand*. International Journal of Gynecology & Obstetrics. 2021. http://doi.org/10.1002/ijgo.13910

MacFarlane M, Jowsey T, Thompson JMD, Tepania-Palmer G, Roa T, Warren G, et al. *E Kō, kia ora! Kua ao te rā: Infant sleep practices and strategies to prevent sudden unexpected death in infancy in Aotearoa. Community Report*. School of Medicine, The University of Auckland, 2021.

Co-Author (Published):

Mitchell EA, Thompson JM, Zuccollo J, MacFarlane M, Taylor B, Elder D, et al. *The combination of bed sharing and maternal smoking leads to a greatly increased risk of sudden unexpected death in infancy: the New Zealand SUDI Nationwide Case Control Study*. NZ Medical Journal; 2017;130(1456):52-64.

Awards and grants during candidature

Māori PhD Career Development Award, Health Research Council, 2017.

First Runner Up - AMRF (Auckland Medical Research Foundation) Doctoral Oral Presentation Award, HealthEx, Faculty of Medical and Health Sciences Postgraduate Student Conference, University of Auckland, 2017.

First Place - Exposure Postgraduate Research Exposition, University of Auckland Postgraduate Student Conference, University of Auckland, 2017.

Chapter 1. Introduction

1.1 Chapter overview

This chapter provides the background for the thesis, and overall body of research. An explanation of sudden unexpected death in infancy (SUDI) is included, alongside an overview of the impact of SUDI in New Zealand, and for Māori, the indigenous people of New Zealand. The chapter ends with a high-level description of the Māori ethical framework that informed the research approach, and an outline of the thesis structure.

1.2 Background

The sudden and unexpected death of an infant is one of the most traumatic events parents and families can experience, and the impact on families can be devastating and long-lasting (1). The harm extends to the systems surrounding families, such as the wider whānau [family], Māori and non-Māori communities, iwi [Māori tribal affiliations], health and social services, and government agencies.

Sudden unexpected death in infancy (SUDI) is a broad term that describes the unexpected death of an infant less than one year of age and occurs most commonly during sleep. A thorough investigation may provide an explanation for the death, such as a previously unknown serious health condition, or a cause may not be found (2, 3). SUDI affects neonatal infants (first 28 days of life) and post-neonatal infants (28 days to <1 year). Investigations into SUDI deaths comprise a detailed clinical history, a review of the circumstances of death, and a full autopsy. Sudden Infant Death Syndrome (SIDS) is an exclusionary diagnosis applied to deaths that remain unexplained following an investigation. SIDS are included in SUDI deaths (4).

SUDI excludes deaths due to intentional or unintentional injury - including homicide or motor vehicle accidents – or medical conditions where death was a likely or expected outcome (4, 5).

SUDI mortality rates, which are based on the number of SUDI deaths that occur for every 1,000 live births in the population of interest, vary considerably worldwide. Between 2002 and 2010, New Zealand had the highest post-neonatal SUDI mortality rate (1.01, 95%

CI=0.92, 1.09) among eight developed and relatively high-income countries, and at 47%, the highest proportion of post-neonatal deaths attributable to SUDI. This compares with the United States of America (USA), which had the second highest SUDI rate (0.95, 95% CI=0.94, 0.96), followed by Germany (0.53, 95% CI=0.51, 0.55). The lowest rate was observed in the Netherlands (0.19, 95% CI=0.1, 0.21) (6).

The number of SUDI deaths in New Zealand has fluctuated in previous years (7) and SUDI rates are significantly lower than they once were (8). However, SUDI continues to be a leading cause of death for infants in New Zealand, and Māori infants are disproportionately represented in SUDI statistics, compared with other ethnic groups in New Zealand (7). Māori are the indigenous people of Aotearoa-New Zealand.

Some causes of post-neonatal death are potentially preventable and include a proportion of SUDI deaths (9). Factors known to increase or reduce the risk of SUDI have been identified and confirmed over time. Important risk factors to avoid include placing infants to sleep in the prone position or on their side, not breastfeeding, smoking in pregnancy, and bed sharing (5, 10).

Bed sharing bed sharing is defined as an infant asleep on the same surface as one or more other sleeping individuals (11).

Combinations of factors are known to interact in a way that may amplify their effect on infants, for example, the hazardous combination of smoking in pregnancy and bed sharing, which is thought to be a significant contributor to the high SUDI rates observed in New Zealand (5).

Protective factors, such as maintaining a smoke free pregnancy, breastfeeding - preferably exclusively for a minimum of six months, and placing infants to sleep in the supine position, and alone in their own bed, have provided the basis for SUDI prevention messaging in New Zealand and internationally (12). The implementation of these factors is determined largely by the behaviours and motivations of parents and caregivers; unlike unmodifiable factors that increase the risk of SUDI and are inherent in an infant, such as low birth weight, and prematurity. By adopting practices known to be protective against SUDI, the risk of exposure for infants can be greatly reduced (13).

Drastic improvements in SUDI rates over recent decades have resulted in thousands of infants, who would otherwise have died, celebrating their first birthdays (8). However, these gains have not been equitable, as evidenced in the higher mortality rates experienced by infants, children and young people living in areas of greatest social disadvantage, and who are more likely to be Māori, and Pasifika (7). Pasifika, or Pacific Peoples, is a collective term to describe the large and diverse New Zealand population that is comprised of many different Pacific Island nations. New Zealand's fourth largest major ethnic group (behind NZ European, Māori, and Asian), Pasifika people are a youthful population, with 13.4% aged 14 years or under (14). The Pasifika SUDI rate has increased and is the second highest in in New Zealand after Māori (7).

Deprivation has a direct effect on infant mortality outcomes, with higher SUDI rates observed for Māori, and Pasifika, who also reside in areas of greatest social disadvantage (7). In these circumstances, infants are more likely to be exposed to known SUDI risks, including smoking in pregnancy, bed sharing and overcrowded housing (14).

While there have been major improvements in SUDI rates in recent decades, and the use of preventive behaviours (15), SUDI remains a leading cause of infant death in New Zealand and internationally, and the pace of improvement has been markedly slower for pēpē Māori, and Pasifika infants (7).

A recent Waitangi Tribunal Report stated the need for Te Tiriti principles to be widened to incorporate the Principle of Equity (the right to expect equitable outcomes) and the Principle of Options (the right to expect good service at mainstream health outlets as well as access to Kaupapa Māori (by Māori, for Māori) services (16).

The systemic disparities and poorer health outcomes experienced by Māori, compared to the non-Māori population are well-known (17-20). The health inequities experienced by Māori are upheld by the number of New Zealand health policies and reports in which there is no mention of Māori health, and a lack of Crown (government) responsiveness to Te Tiriti (21). These policies are not aligned with global indigenous rights and declarations and increase health inequities for Māori (21). This was highlighted in a recent report, which stated that the current systems and processes for culturally safe healthcare decision-making have the potential to worsen the current levels of inequity for Māori (22).

To achieve its aim to reduce the incidence of SUDI in New Zealand to 0.1 in 1,000 infants by 2025, since 2017 the New Zealand government has established a new national SUDI prevention co-ordination service (23) and funded district health boards and other agencies to develop resources and provide SUDI prevention programmes. These include safe sleep campaigns, the supply of Wahakura (a Māori-designed, flax-woven bassinet) and Pēpi-pods as infant safe sleep beds, Wahakura wananga [teaching and weaving workshops] (24) and smoking cessation programmes (25). Community groups, Māori organisations and charity-based organisations across New Zealand also promote safe sleep and actively support safe sleep for infants in their local areas and communities (26).

1.3 Rationale for the research

A great deal of research has been carried out in New Zealand to understand the persistent drivers behind the high SUDI rates, and the potential solutions. An analysis of the SUDI disparities experienced by pēpē Māori, compared with non-Māori infants, was last undertaken following the New Zealand Cot Death study (NZCDS, 1987-1989) (27). The NZCDS found that the higher SUDI rate among Māori, in comparison with non-Māori, could be explained primarily by the increased exposure in Māori infants to maternal smoking and bed sharing (27).

Further research has contributed to our understanding of the risk factors for SUDI and informed the development of effective and appropriate SUDI prevention solutions. This thesis provided the opportunity to re-examine, from a nationwide and contemporary perspective, the reasons why SUDI continues to disproportionately affect infants in New Zealand, and especially pēpē Māori; and to strengthen and enhance new and existing SUDI prevention strategies to prevent the unnecessary loss of infant lives.

1.4 Aims of the research

The aim of this research is to understand and explain the reasons for the disparity in SUDI rates between pēpē Māori and non-Māori infants in New Zealand; to examine specific SUDI risks associated with the infant sleep environment; and explore the key influences that motivate mothers' infant sleep decisions and practices.

In doing so, this research will be able to strengthen and inform new and existing approaches for promoting and supporting infant safe sleep and SUDI prevention and help towards reducing SUDI in New Zealand.

1.5 The research approach

To achieve the aims of the research, data are drawn from two studies: 1.) the epidemiological New Zealand Case-Control SUDI Nationwide Study (2012-2015); and 2.) a qualitative research project to explore infant sleep decision-making and practices of mothers with young infants in Counties-Manukau, Auckland, New Zealand.

The New Zealand Case-Control SUDI Nationwide Study (2012-2015), hereafter referred to as the SUDI Nationwide Study, was implemented using a project management approach and included the national roll-out of the SUDI Liaison investigator role, which had previously been trialled in the Northland region of New Zealand. This study examined the SUDI risks experienced by pēpē Māori and non-Māori infants, particularly in the infant sleep environment, and identified the differences in risk exposure and SUDI outcomes between both groups.

A targeted, qualitative survey was developed and implemented to identify and understand the current knowledge about SUDI, and the practices linked to infant sleep, infant bed sharing, and the risk of SUDI. The qualitative survey also explored mothers' sources of safe sleep information, the factors that motivate Māori and non-Māori families to bed share with infants, the barriers and enablers of infant safe sleep, and opportunities to promote and facilitate safe and culturally acceptable safe sleep practices.

1.6 Kaupapa Māori research approach

Māori participation was a critical success factor in both studies in this thesis because pēpē Māori have long been over-represented in SUDI statistics, compared with non-Māori infants (7). Reducing the incidence of SUDI for pēpē Māori requires solutions that reflect Māori ideology and culturally appropriate approaches. Therefore, processes in this study reflect indigenous kaupapa Māori research methods and draw on key resources, such as Te Ara Tika, the Māori ethical framework published by the Health Research Council (28), and published researcher guidelines and cultural values (29).

The research was Māori-centred in that significant aspects were designed and led predominantly by Māori, and more than half of all participants in both studies identified as Māori.

Key concepts used in the research approach included: Tika, which is concerned with research design; Manākitanga, cultural and social responsibility; Whakapapa, relationships; and Mana, equity (28). These concepts were incorporated into all engagements with families in the SUDI Nationwide Study (2012-2015), including families in the case group, and the qualitative Pēpē-Infant Sleep Practices Study (2019).

Te Poutama o te Pōwhiri is a model that was initially developed as a system for growth, healing and learning in the addictions treatment space (30). The model provides a simple and effective framework for engaging with Māori (or anyone) in steps aligned to pōwhiri (Māori welcome) processes. This involves reciprocal greetings, prayer, respect for the host and the visitors, conversation and sharing of food. The principles of the framework were incorporated into the training updates and ongoing development with the SUDI liaison investigators in the SUDI Nationwide Study. This supported SUDI liaison team members to engage safely and appropriately with Māori whānau and other families from different ethnic backgrounds. SUDI liaison team members also engaged with kaumatua [a respected male Māori elder] from the local district health board for gu9idance in cultural safety for families, and for themselves.

These models, including the Māori ethical framework Te Ara Tika, and Te Poutama o te Pōwhiri, informed the design, implementation and concluding stages of the study, and guided the engagement and connection with iwi, Māori groups, service providers, and participants across all stages of the research. Further information about the Māori ethical framework is provided in Appendix B. Additional Information - Pēpē-Infant Sleep Practices Study.

1.7 Thesis structure

This thesis comprises four sections consisting of nine chapters, followed by an appendix.

Part One: Introduction

Part One provides the background and context for the research and an introduction to sudden unexpected death in infancy (SUDI). An overview of the literature related to SUDI is presented to establish the context in which the research was conceived and implemented. Chapter 1 introduces the research, including the background, aims and objectives. Chapter 2 contains a review of the existing SUDI literature that focuses on the context of SUDI in New Zealand overall, and for Māori, and includes definitions of terms, risk factors, and the role of quality information to support understanding of the mechanism/s of death and the role of the coroner in SUDI investigations.

Part Two: Epidemiological research

Part Two presents the methods and results of the epidemiological NZ SUDI Nationwide Study (2012-2015). Chapter 3 comprises a published case study outlining the project management method used to implement the NZ SUDI Nationwide Study. Chapter 4 provides additional methods information about the Communications workstream in the SUDI Nationwide Study, and the role of the SUDI Liaison team. Chapters 5 and 6 comprise two epidemiological papers, which focus on the SUDI disparity experienced by indigenous Māori in New Zealand, and the risk of SUDI from hazards in the infant sleep environment. Appendix A contains additional information and documents related to the SUDI Nationwide Study.

Part Three: Qualitative research

Part Three focuses on the qualitative research which explores the infant sleep practices and key influences for a group of mothers living in a geographic area with a high incidence of SUDI. This contains the qualitative research paper and the supplementary appendix. Further material about the Pēpē-Infant Sleep Practices Study is provided in Appendix B.

Part Four: Discussion and conclusion

Part Four contains an overall discussion of the research findings and provides a conclusion to the thesis. The implications for future research are discussed, and consideration is given to SUDI prevention strategies that are effective and appropriate for all families in New Zealand, especially Māori families.

1.8 Chapter summary

This chapter has provided background and contextual information relevant to the thesis and the two studies included in this research. Key terms have been defined, and SUDI data are provided to establish the importance of the research for New Zealand infants and families. The chapter introduced the Māori ethical framework and key concepts, which informed the research approach, and set out the structure of the thesis.

Part One: Introduction

Part One of the thesis introduces the research and sudden unexpected death in infancy (SUDI), and a description of the thesis structure. An overview of the relevant literature related to SUDI is also presented to establish the current situation, and the context in which the research was conceived and implemented.

> Ko te manu e kai ana i te miro nōnā te ngahere
> Ēngari, ko te manu e kai ana i te mātauranga nōnā te ao
>
> *The bird that consumes the miro owns the forest*
> *However, the bird that consumes knowledge owns the world*
> *Māori whakatauki (proverb)*

Chapter 2. Literature review

2.1. Chapter overview

In Chapter two, a critical review of the relevant literature is provided to establish the New Zealand context with regards to SUDI, and for Māori SUDI. The review also includes definitions of key terms, and information about the prevalence and impact of SUDI risk factors. The importance of collecting complete and accurate quality information about individual SUDI cases is emphasised, as it aids understanding of the mechanism/s of death and assists the role of the coroner in SUDI investigations.

2.2. Focus of the literature review

A review of the literature was conducted across three areas, including 1.) the definition of SIDS (sudden infant death syndrome) and SUDI, and the extent of the issue in New Zealand; 2.) the key risk factors associated with SUDI; and 3.) SUDI investigations, gathering information to determine cause of death. The literature search was effective from 1 April 2016 and was last updated on 15 March 2022.

2.3. Search strategy

A review of the literature commenced with basic searches of key words and their synonyms on Medline (Ovid). Medline is a United States (U.S.) National Library of Medicine bibliographic database and a key source of health-related journal articles. Medline uses Medical Subject Headings, or MeSH® terms, to match search terms with indexed words and terms that are linked, or often used to describe the search terms.

The key search terms were linked to key concepts in the research, namely Māori SUDI, and included Related Terms. Common acronyms were used as keywords where appropriate, such as SUDI, SIDS and SUID. Beginning the search in this way helped to refine the synonyms required for the concept searches. The results of basic searches provided a list of articles in order of relevance, thus permitting a visual scan of the titles.

Advanced searches of key words and synonyms identified relevant subject headings and MeSH® terms, such as ‘sudden infant death’. This enabled further inquiry of the Scope notes and Tree. Scope notes identify when a term was first used as an index heading, and any other terms that have been used previously, and terms linked to key words that are automatically included in the search. The Tree outlines the ‘family’ from which key terms originate, and where they branch out. This permits specific searches to be exploded (i.e. widened to include other related terms) or focused (i.e. narrowed to include fewer terms).

Combinations of synonyms for each key concept were searched using the Boolean operator "OR". Key concept searches were combined using “AND” to narrow the search for literature relevant to the research question. Truncation features the use of an asterisk symbol as a substitute for another letter in the search term. For example, truncation was useful for the terms infan* (to capture infant, infants or infancy) and M*ori (to capture Māori or Maori or Maaori). Medline searches were limited to English language and identified more than 243 articles, of which 30 appeared to be directly relevant to the literature review.

Searches of other databases required a less formalised approach than Medline and yielded a small number of new articles or texts. A search in Scopus combining “sudden infan* death”, “Zealand” and “M*ori” with “AND” provided 38 results, of which five were potentially relevant to the research and previously unidentified. Other databases searched included the University of Auckland Library’s ‘Articles and More’ and Index New Zealand, with the latter identifying relevant grey literature. Titles that appeared to be relevant were entered into Google Scholar to simplify locating the full text versions and exporting citations directly to an online reference management programme.

When relevant articles were identified, their cited references were searched to locate other possible literature. This information-seeking technique is referred to as Pearl Growing (31). Internet searches using the same terms were conducted to provide background information. Key author bibliographies were also searched for relevant articles.

Overall, 60 studies were identified through the search strategy, in addition to numerous other forms of literature, such as government reports, which were included in the review. It was conducive to begin the review with a structured search of Medline using basic searches, and progressing to advanced, followed by searches of the Scopus database, Articles and more, and Index New Zealand, using natural language with Boolean operators, and some truncation. Other grey literature identified was located in the author’s personal archives or accessed through connections within the author’s professional network.

Table 2.1: Key words used in the literature search

Key words related to the research question and associated synonyms (truncation shown in brackets)			
	Keyword 1	Keyword 2	Keyword 3
	SUDI	Māori	Ethnicity
Synonym 1	sudden unexplained death	Maaori	racial group (group*)
Synonym 2	sudden unexpected death	Zealand	ethnic group
Synonym 3	infant death (infan*)	Māori (M*ori)	
Synonym 4	SIDS		
Synonym 5	cot or crib death		
Synonym 6	Sudden infant death (MeSH® term)		

2.4. Defining SIDS and SUDI

Sudden infant death syndrome

Originally proposed by Beckwith in 1969, sudden infant death syndrome (SIDS) is an exclusionary diagnosis, and was said to include the:

> …sudden death of an infant or very young child which is unexpected by history, and in which a thorough post-mortem examination fails to demonstrate an adequate cause of death (32).

Known as the ‘Seattle definition (1969)’, this definition of SIDS was the basis for future refinements, as further information became available (2, 4).

In 1989, a group of experts from the U.S. and Canada gathered to consider the scientific evidence about the characteristics common to SIDS infants. The need for a revision of the 1969 definition was deemed appropriate at that time, as it would enable improved use of the term for diagnostic and research purposes (2).

The language in the original definition pertaining to infant age was vague, as were the requirements of an autopsy, and the meaning of ‘unexpected’. After examining available data, the group observed that most cases occurred in infants less than 6 months of age, at a median of 11 weeks, and rarely (2%) beyond one year of age. No strong predictive and/or diagnostic SIDS characteristics in mothers or infants were identified (2).

Concerns about the ability to make a reliable SIDS diagnosis in the absence of a full investigation, and the difficulties in performing death scene examinations, prompted the group to agree that the medical community should actively ensure that autopsy findings include a scene investigation (2). Other requirements were added to support a SIDS diagnosis and exclude a recognisable cause of death, including a medical and family history, and a review of the circumstances of death (2). Following discussions, the group agreed on a revised definition of SIDS known as the 'NICHD definition (1989)':

> The sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history (2).

Meanwhile, the improvement and standardisation of SIDS-related autopsy protocols (33) and death scene investigations (34) continued. By the turn of the century, the diagnostic profile of SIDS had changed as a result of more rigorous investigative techniques for reviewing clinical histories, death scene examinations and post-mortem testing (35).

In 2004, an international expert panel of paediatric pathologists, forensic pathologists, and paediatricians with extensive 'sudden infant death' experience, met in San Diego and agreed to redefine Sudden Infant Death Syndrome (SIDS) as:

> The sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history (4).

Referred to as the 'San Diego definition (2004)', this version was quickly endorsed at a workshop attended by forensic and paediatric pathologists working across Australia (3, 36), who recommended it be adopted nationally (4). The group also agreed to develop national standards and guidelines for infant autopsies (36).

Since then, the SIDS term has been both underused and overused. For example, instead of applying the term SIDS as a cause of death, some practitioners prefer less-specific terms, such as ‘unascertained’ and ‘undetermined’, to signal the lack of diagnostic features, when relevant (37). In 2004, Krous et al (4) stated that the term SIDS had been overused, in the sense that it was applied inappropriately; for example, where other, potential causes of death may have been identified (4).

A re-audit of the definitions used in peer-reviewed literature (n=50) in 2010-2011 found that the ‘NICHD 1991 definition’ was most frequently used (35.1%), followed by the ‘San Diego 2004 definition’ (26.3%) (38). Overall, in the five years since the previous audit in 2005, the authors noted the use of established definitions had increased (42% vs 68.4%), and idiosyncratic and missing citations had reduced (58% vs 31.6%) (38).

Byard (38) recommended the use of the San Diego definition, because it provides more detailed diagnostic criteria and is recognised as an international standard that has been endorsed by professional groups (38). In 2020, the application of the SIDS diagnostic criteria by pathologists, based on the ‘San Diego’ definition (4), was evaluated. Based on the results of the evaluation, the authors assert that with clear guidelines to aid interpretation, the ‘San Diego’ definition can be reliably and consistently applied. Furthermore, peer review processes can quickly and easily resolve any queries or concerns (39).

Sudden unexpected death in infancy

The panel members who met in San Diego also discussed the use of the broader term of Sudden Unexpected Death in Infancy (SUDI) (4), which is now commonly used in New Zealand and internationally. SUDI includes SIDS, as defined above; and deaths where an actual or possible cause is identified, such as asphyxiation.

SUDI also includes deaths where a cause is later identified based on clinical history and pathology results, for example, the illness pneumonia, which on its own may not have been sufficient to cause death (3). Byard (3) described three groups of sudden and unexpected death that may be seen at autopsy. They include 1.) apparently well infants who died within hours of an unexpected cardiac arrest or collapse, or who were found deceased in bed; 2.) mildly unwell infants who died in similar circumstances as the previous group; and 3.) infants who had a serious health condition that was known and thought to be stable (3).

SUDI excludes infant deaths where a fatal outcome was likely or expected, for example, from an intentional or unintentional injury – including homicide or a motor vehicle accident - or medical condition (4, 5).

The important point is that a SUDI death is sudden and unexpected in an infant under 1 year of age; and after a thorough investigation, a cause may or may not be found. If no cause is found, the death is regarded as SIDS, or ill-defined or unspecified (R99). Coroners may still attribute cause of death to SUDI; however, they may make note of specific risks that were present as additional information, for example, an unsafe infant sleep position, or the infant was bed sharing at the time. SUDI investigations include a detailed clinical history, review of the circumstances of death and a full autopsy.

2.5. Classification of SUDI

The World Health Organization (WHO) classification system for deaths is the International Classification of Diseases (ICD-10) which is currently in its tenth revision (40). Sudden infant death syndrome (SIDS) has been recognised by the WHO since 1979, when SIDS was allocated an ICD-9 code (41). The ICD system was adopted by New Zealand in 2000.

The following codes are considered to encompass most SUDI cases and allow for improved international comparison (6):

- R95-Sudden Infant Death Syndrome
- R96-Other sudden death, cause unknown
- R98-Unattended death
- R99-Other ill-defined and unspecified causes of mortality
- W75-Accidental suffocation and strangulation in bed
- W78-Inhalation of gastric contents
- W79-Inhalation and ingestion of food causing obstruction of respiratory tract.

The variation in SIDS classification and investigations (6, 33) has been compounded by the different approaches to autopsies, and the application of diagnostic criteria, and the use of definitions (33). Byard (6) points out that, in some cases, a diagnosis of suffocation is probably more accurate than SIDS, and by not identifying the cause of death as suffocation, these types of deaths are not being appropriately managed.

The SUDI-related codes used in eight high-income countries were reviewed. There was variation in the codes used to certify sudden infant death, and the methods and processes used to investigate the deaths, which has compounded the difficulty in comparing rates of sudden infant death between different countries (6).

In the review, SUDI was usually coded in New Zealand as R95 and W75. The U.S. also used codes R95 and W75, in addition to R99; whereas in England and Wales, Germany, The Netherlands, Australia, and Canada, the R95 and R99 codes were used most frequently. In contrast, Japan used code R96 thousands of times between 2002-2010, compared with six times collectively across the seven other countries included in the review (6).

In 2019, Byard et al (42) observed that the ‘San Diego definition’ of SIDS has not been applied consistently or rigorously. To assist in separating SIDS from 'unclassified sudden infant death', Byard and colleagues suggests using the statement ‘mechanical asphyxia not determined with certainty’ and including a classification algorithm with the definition (42). This is compatible with the view that improved standardisation and consistency in SUDI investigations, and the use of established protocols and definitions, will build greater capacity for epidemiological comparisons across a range of populations (6, 33).

Incidence of SUDI in New Zealand

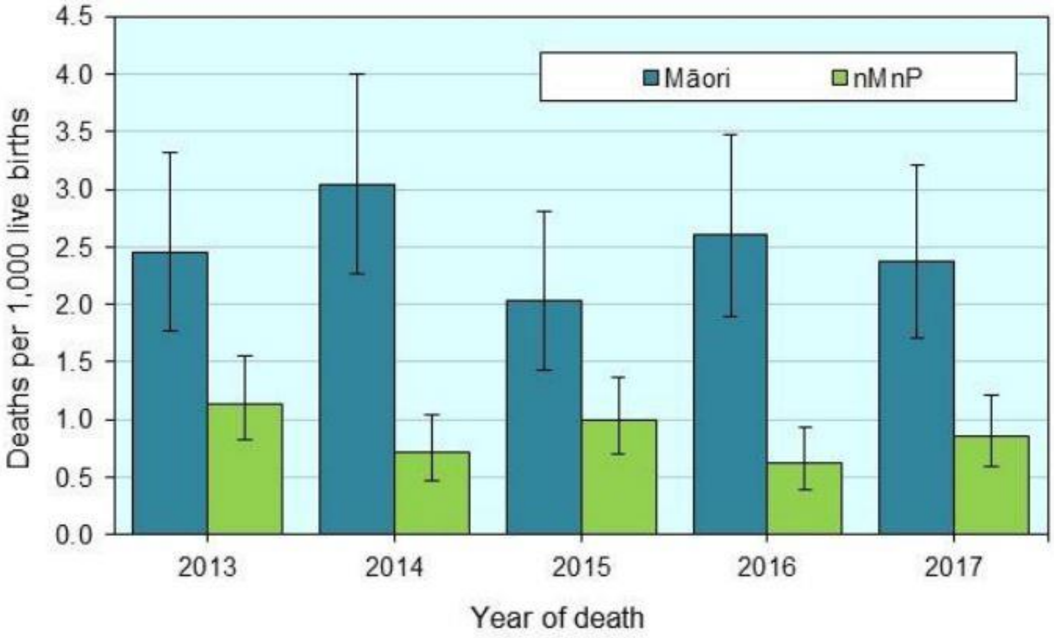
New Zealand SUDI rates have been among the highest in the world for developed countries (6). This is despite the steady reductions that have been observed since the high rates in the 1980s, including 1986, at which time the mortality rate was 4.0 per 1,000 live births (43). By 1991, the rate had reduced dramatically to 2.5/1000 (43).

During 2002 to 2017, 765 infants died from SUDI in New Zealand, giving an overall SUDI rate of 0.79/1000. However, annual SUDI rates varied during this period, and ranged from a low rate of 0.55/1000 in 2012, to a much higher rate of 1.05/1000 in 2003 (7).

The most recent data from 2013 to 2017 provides an overall post-neonatal SUDI mortality rate of 0.65/1000, with SUDI comprising 44% of post-neonatal mortality (n=195/444; 43.9%) in New Zealand, second only to post-neonatal deaths from medical causes (51.35%) (7).

SUDI comprises 7.6% (n=195/2556) of deaths from all causes for all infants, children, and young people in New Zealand, aged 28 days to 24 years, from 2013-2017. Currently, 40-50 post-neonatal infants die from SUDI annually in New Zealand (7).

After a period of fewer deaths from 2012 to 2016 (34 to 39 deaths per year), and an overall lower SUDI mortality rate compared with the previous 10 years (2002 to 2011), the data suggest that post-neonatal SUDI mortality increased slightly when 45 SUDI deaths were reported in 2017 (7) (Figure 2.1.).



2.1. Post-neonatal SUDI mortality (number of deaths and rates per 1,000 live births) by year of death, Aotearoa/New Zealand 2002-17 (n=765 deaths). nMnP=non-Māori, non-Pasifika. Reproduced from CYMRC 2019 (7), permission not required for use.

Neonatal SUDI

Among deaths of live born infants born after 35 weeks gestation and with no congenital anomalies, SUDI is the second highest cause of death in New Zealand. SUDI deaths of neonates are reported separately from post-neonatal mortality data in this country, and between 2007 and 2016, sixty-eight infants died from SUDI prior to four weeks of age (44). Of these neonatal infants, 66% (n=45) were Māori, and 18% (n=12) were Pasifika. Most of these very young infants were sleeping in higher-risk sleep situations at the time of death, for example, in a shared sleep space, on their front or side, and with pillows or bedding, such as bedclothes, sheets, bedcovers, blankets, duvets/doonas or eiderdowns. Only six (of 68) infants were found in sleep environments that were consistent with safe sleep guidance (44).

SUDI and Pēpē Māori

SUDI occurs more frequently in certain ethnic or racial groups, particularly among indigenous cultures and non-European populations, including African American, Alaskan Native, Native American, indigenous Canadians, Aboriginal and Torres Strait Islander, Pasifika and New Zealand Māori (5, 45-53).

Pēpē Māori have been affected by SUDI to a greater extent than infants of other ethnicities in New Zealand over many years (7, 54). The negative impact of SUDI on Māori is perpetuated by the existence of significant and sustained health inequities. These inequities exist because of the inequalities between pēpē Māori and other ethnicities with regards to SUDI (7), which are unnecessary and preventable (55).

Data for the period from 2013 to 2017 revealed that of the 214 post-neonatal pēpē Māori who died, more than half died from SUDI (n=116, 54.2%). The second highest cause of death for pēpē Māori during this period was medical conditions (n=88).

The SUDI mortality rate for all causes of death for pēpē Māori was significantly higher than for non-Māori/non-Pasifika infants (rate ratio 6.52, 95% CI=4.52, 9.40) (7) (Figure 2.2.*)*

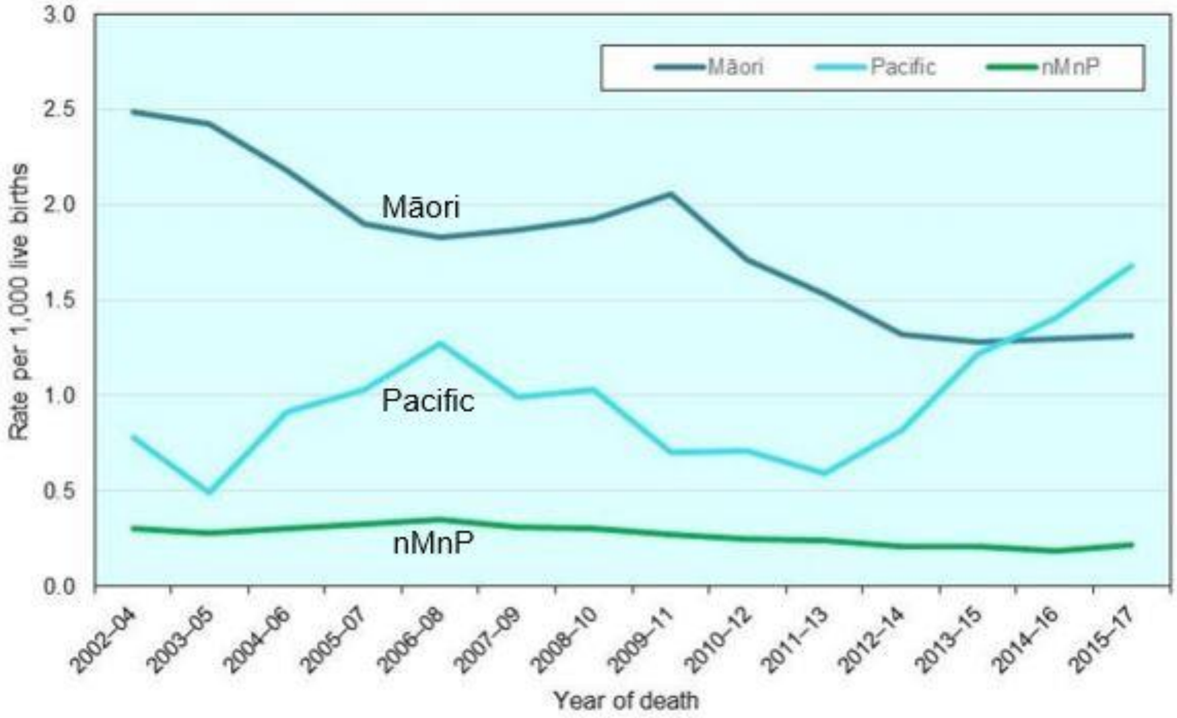


Figure. 2.2. Postnatal Mortality (rates pēpē, 1,000 live births and 95% confidence intervals) in post-neonatal Pēpē Māori by year of death, compared with non-Māori/non-Pasifika infants, Aotearoa/New Zealand. Reproduced from CYMRC 2019 (7), permission not required for use.

nMnP = Non-Māori non-Pasifika. Sources: Numerator: Mortality Review Database; Denominator; Ministry of Health Live Birth Registrations 2013-16, NZMRDG, 2017

The post-neonatal Māori SUDI rate plateaued during 2013 to 2017 (n=116; rate=1.36/1000 livebirths, 95% CI=1.11, 1.60), although the rate for Pasifika infants increased slightly in 2017 (n=41; rate=1.35/1000 livebirths, 95% CI=0.97, 1.83). SUDI rates for non-Māori/non-Pasifika (nMnP) infants remain low (n=38; 0.21/1000 livebirths, 95% CI=0.15, 0.29) (Figure 2.3. Post-neonatal SUDI mortality 3-year rolling rates).

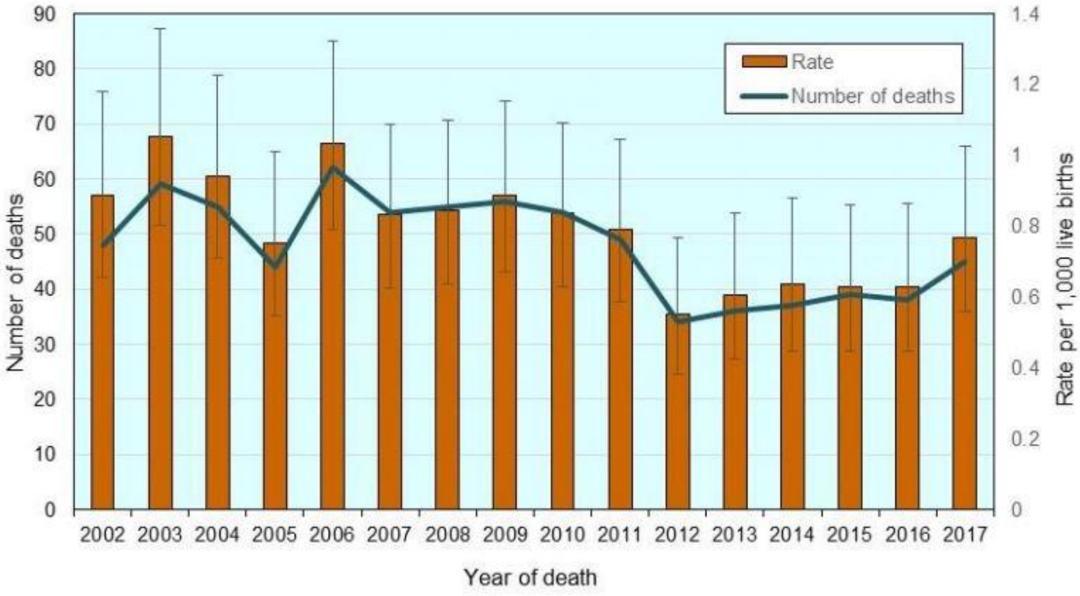


Figure. 2.3. Post-neonatal SUDI mortality (three-year rolling rates per 1,000 live births) by prioritised ethnic category and year of death (rolling three-year periods, Aotearoa/New Zealand 2002-17 (n=764 deaths)*. Reproduced from CYMRC 2019 (7), permission not required for use.

*Excludes one case with unknown ethnicity. nMnP = non-Māori non-Pasifika. Sources: Numerator: Mortality Review Database; Denominator; Ministry of Health Live Birth Registrations 2002-16, NZMRDG, 2017.

From 2013 to 2017, the overall SUDI rate in New Zealand was 0.65 per 1,000 live births (n=195; 95% CI=0.56, 0.74) (7). Overall, SUDI mortality rates for Māori remain the highest in the country compared with other ethnicities, and the total number of Māori infants affected by SUDI far exceeds that of all other infants in New Zealand (7).

Ethnic variation has replaced geographic variation

Geographic differences in SIDS rates in New Zealand were observed throughout the 1980s, with higher rates of SIDS reported in the South Island during this time. This peak in SIDS cases was thought to be due to the interaction between latitude and prone sleeping (56).

As the prevalence of prone sleeping began to decrease in conjunction with the roll-out of the National Cot Death Prevention Programme in 1991 (12), there was an overall decrease in SIDS/SUDI mortality in New Zealand (57, 58), particularly in the South Island, during the winter months (43, 59), and in the non-Māori population (10, 60).

It has been identified that infants living in circumstances characterised by deprivation and social disadvantage are at increased risk of infant mortality. Spencer and Logan (61) undertook a systematic review over the 42-year period to 1998, involving 52 studies from the United Kingdom (UK), USA, Canada, Brazil, Austria, Germany, Sweden, Norway, Denmark, Finland, Japan, Australia and New Zealand. They identified a dose-response relationship between SUDI and socioeconomic status, which can be extrapolated to mean that as the level of deprivation increases, so too does the risk of SUDI. After adjusting for maternal smoking, socioeconomic status maintained an independent effect on sudden infant death in nine out of 10 studies (61).

SUDI data from New Zealand’s twenty district health boards (DHBs) show that more deaths now occur in the North Island (7), but the drivers are no longer latitude and prone sleeping (56). The difference in SUDI rates between the North and South Islands now reflect the distribution of ethnic groups in New Zealand (11).

This is most notable in the DHB regions of Northland, Counties-Manukau (south and east Auckland), Waikato and Taranaki, which experience SUDI rates higher than the New Zealand average. Larger populations of Māori and Pasifika live in these areas compared with west and central Auckland (the catchment areas for Waitemata DHB and Auckland DHB), Wellington (Capital and Coast DHB), Nelson-Marlborough, and Canterbury (7), where SUDI rates are significantly lower (11). As a result, Māori and Pasifika families are more likely to experience higher levels of deprivation and social disadvantage compared with non-Māori/non-Pasifika families, and this has a disproportionate affect with regards to infant mortality, which is more evident among Māori families (7, 61) (Table 2.2).

Table 2.2: District health boards with the three highest rates of post-neonatal SUDI mortality (number of deaths and rates per 1,000 live births), by DHB of residence and prioritised ethnic category, Aotearoa-New Zealand 2013-17 combined (n=195 deaths)

DHB of residence	**Māori**			**Pasifika**			**Non-Māori/Non-Pasifika**			**Total**		
	Deaths	Rate	95% CI	Deaths	Rate	95% CI	Deaths	Rate	95% CI	Deaths	Rate	95% CI
Tairāwhiti	7	2.61	1.05-5.36	0	0	0	0	0	0	7	1.89	0.76-3.91
Whanganui	5	2.48	0.80-5.78	<3	s	-	<3	s	-	7	1.67	0.67-3.44
Counties-Manukau	26	2.40	1.57-3.52	21	1.77	1.09-2.701	<3	s	-	49	1.18	0.87-1.56

‘s’ indicates rate not calculated due to small numbers. nMnP = non-Māori non-Pasifika. Sources: Numerator: Mortality Review Database; Denominator; Ministry of Health Live Birth Registrations 2013-16, NZMRDG, 2017. Table created based on data in CYMRC 14th report (7)

2.6. Risk factors for SUDI

Risk factors can be described as attributes, characteristics, or the exposure of an individual, which increases their likelihood of experiencing injury or disease (40).

Protective infant care practices reduce SUDI risk by improving the overall safety of the infant. These include breast feeding, on-time and complete infant immunisation, and placing infants to sleep alone and supine in a cot (or similar) on a firm, well-fitting mattress, without pillows, bumpers or blankets, and in the parental bedroom.

Identifying the risk factors

The three-year, case-control New Zealand Cot Death Study (NZCDS) was implemented from 1st November 1987 to 31st October 1990 with the aim of identifying key risk factors for sudden infant death syndrome (SIDS). Results from the first year of the study confirmed many SIDS risk factors, including low socioeconomic status, unmarried mother, young mother, younger school leaving age of mother, younger age of mother at first pregnancy, late and/or lack of attendance at antenatal clinic, greater number of previous pregnancies, low birthweight, shorter gestation, male infant, and admission to neonatal intensive care unit. Additionally, a greater proportion of the infants that died were Māori (10, 62).

The NZCDS study (10, 63) was among the first to confirm the most important risk factors affecting the safety of infants, particularly during sleep, and especially the very high risk from the combination of bed sharing and maternal smoking during pregnancy. The study went on to provide compelling evidence about the need to develop interventions that addressed the importance of supine sleeping position and other major, modifiable risk factors, including maternal smoking during pregnancy, infant bed sharing and lack of breastfeeding (10).

More than twenty years later, the New Zealand Case-Control SUDI Nationwide Study (2012-2015) was implemented to re-examine the risks for SUDI and identify potentially modifiable risks, post-intervention campaigns. In doing so, the study aimed to inform and support the development of effective and appropriate SUDI prevention strategies to reduce the high incidence of SUDI in New Zealand compared to other countries in the OECD (5).

Some risk factors are modifiable, and therefore amenable to change, such as mothers' smoking status, whereas other factors are non-modifiable, such as the sex of an infant. The health sector seeks to eliminate risk factors, where possible, to maximise health and wellbeing and/or prolong life. If it is not possible to eliminate the risks, attempts are made to minimise the effects of the risks to reduce overall harm, and the likelihood of disease or injury (40). Modifiable and non-modifiable risk factors for SUDI are listed in Table 2.3.

Table 2.3: Modifiable and non-modifiable SUDI risk factors

Modifiable	Non-modifiable
Bed sharing Sleeping position Maternal smoking during pregnancy Soft bedding/mattress Temperature Drug and alcohol use by caregivers	Sex Age Prematurity/low birth weight/small for gestational age Young maternal age Multiple birth Parity Mild illness particularly respiratory Time of year/season Parental/family/caregiver socioeconomic status Previous SIDS/SUDI
Protective factors: Sleeping in the parental bedroom (and not bed sharing) Breastfeeding Complete and on-time immunisation Pacifier use	

Exposure to tobacco smoke

The evidence suggesting that maternal and antenatal smoking increases the risk of SUDI is overwhelming (5, 64-66). Smoking inhibits foetal growth and development during pregnancy and is a factor in many premature births. Furthermore, exposure to smoke reduces an infant's ability to rouse and elicit a gasp reflex which places the infant at increased risk if they are in a low-oxygen environment, such as prone sleeping (on tummy) or bed sharing (67).

The current smoking rate in New Zealand based on adults who smoke at least monthly, has fallen from 20% in 2006/07 to 17% in 2014/15 (68). The most substantial reduction in smoking rates was observed among young people aged 15–17 years, whose rate had more than halved from 16% in 2006/07 to 6% in 2014/15. Although there has been a reduction in the overall amount of tobacco used by Māori on a daily basis since 2006/07, the Ministry of

Health reports that Māori have the highest smoking rate (38%) across all ethnic groups in New Zealand (68).

Historically, the main reason for the Māori SUDI rate being higher than that of non-Māori was the increased prevalence of known SUDI risk behaviours across the Māori population (27) and this remains true today (5).

Previous studies have shown that 21% of Māori mothers smoked during pregnancy and bed shared with their infants. This is in contrast to 1% of the Other participants, who were predominantly NZ European mothers, that smoked during pregnancy and also bed shared (54, 69, 70). The interaction between smoking during and after pregnancy combined with bed sharing, and the increased risk to young infants, has become overwhelmingly clear in the last two decades (5, 71, 72).

Smoking is more common in areas of low socioeconomic status, and in the most deprived areas of New Zealand, more than a quarter (28%) of all adult's smoke. Being Smokefree by 2025 is a key performance target for the New Zealand government and especially DHBs, with some DHBs focusing strongly on smoking cessation during pregnancy (73). This is a critical opportunity for combining smoking cessation interventions with education about safe infant care practices.

Bed sharing

Bed sharing, in the context of SUDI and infant sleep practice, refers to an infant sharing any kind of sleeping space with another person who is asleep at the time (11), whether the sleeping surface is a bed, couch, mattress on the floor or in a car. The term 'co-sleeping' has been used interchangeably with bed sharing over the years. However, use of the term 'bed sharing' is preferred to co-sleeping, as the latter has been broadened to include room-sharing, which is protective against SUDI, and can lead to confusion between the two behaviours (11).

The earliest documented reference to sudden infant death appears in the bible (Kings 3:19 - King James version) when it was put to King Solomon that a "woman's son died in the night, because she lay on him." Until the end of the 19th century, the prevailing view was that sudden unexpected infant death was a result of overlaying by the infant's mother (10). Accidental mechanical suffocation had become the main documented cause of sudden infant death by the 1940s and was often noted in relation to bedding (10, 74). Half a century later, data from the New Zealand Cot Death Study (1987-1990) was the first to provide compelling evidence of the relationship between bed sharing and sudden infant death and to describe the risk as potentially modifiable (10).

The link between bed sharing and SUDI is now well-established (75, 76) and more than half of all SUDI in New Zealand is associated with unsafe sleeping, including bed sharing (77). The risk is greater for very young infants at a critical stage in their development (78) and when a bed sharer is a smoker (79). A meta-analysis of 11 studies found a combined SIDS odds ratio of 2.89 (95% CI, 1.99-4.18) in all bed sharing infants versus non-bed sharing infants (80).

Escott et al (81) reported that half of the SUDI deaths in a Wellington-based retrospective study occurred in a bed-sharing context. Likewise, an Auckland study using similar methodology found that over a 10-year timeframe, 64% of SUDI reported to the coroner were caused by, or associated with, sharing a bed (78). New Zealand’s Child Youth Mortality Review Committee (CYMRC) stated that many deaths (at least forty at the time) could have been avoided if safe sleep practices were applied (82). Findings from a systematic review of eight databases highlighted the importance of mothers being unimpaired during bed sharing to reduce the risk of SUDI, and for the infant to be healthy and responsive (83).

Bed sharing has been described as a dynamic, cultural practice among certain ethnic groups (45), including Māori (84) and is a relatively common practice. An estimated 8.5% of infants in New Zealand regularly sleep in the parental bed at 6 weeks of age (54, 85). This figure increases to 17% when including infants that sometimes sleep in the parental bed or share other sleep spaces (54). One study reported that Māori parents preferred their infant to sleep separately, but for a variety of reasons, separate sleep was not achieved (86).

New Zealand’s Perinatal Maternal Mortality Review Committee (PMMRC) recommended that the Ministry of Health, and District Health Boards (DHBs), improve maternal and infant safety during the perinatal period, which begins on completion of the 22nd week of pregnancy and ends one week after birth (44). As a result of several SUDI deaths occurring prior to discharge from hospital, specific recommendations were made to enable the active observation of mothers and infants in postnatal inpatient facilities who practice skin-to-skin contact; and ensure processes exist to assess and identify any additional needs of mothers whose infants may be at increased risk of SUDI (44). An evaluation in 2018 of a safe sleep and SUDI prevention programme based in Counties-Manukau, Auckland, found that 25% of infants in the sample needed a baby bed (87). Among SUDI deaths of infants up to four weeks of age from 2007 to 2016, up to one-third (n=22) of infants did not have regular access to a safe sleep space. This led the PMMRC to recommend that:

> Lead Maternity Carers and DHBs ensure that every baby will have access to a safe sleep place on discharge from the hospital or birth unit, or at home, that is their own place of sleep, on their back and with no pillow. If they do not have access to a safe sleep place, then a wahakura or Pēpi-pod must be made available for the baby's use prior to discharge from hospital. p11. (44).
>
> In New Zealand, the introduction of safe sleep beds has been a key aspect of SUDI prevention (88), including the need for infants to have their own sleep space. Safe sleep beds include the Māori-designed, woven flax baskets called wahakura, and specially designed lined plastic containers called Pēpi-pods®. Wahakura and Pēpi-pods were developed in New Zealand specifically to support safe infant sleep and infant bed sharing (88, 89).

Lack of breastfeeding

The protective factors of breastfeeding against SUDI are well-known (10, 90-92), especially breastfeeding upon discharge from the obstetric hospital (93). The positive effect of breastfeeding is stronger when infants are breastfed exclusively for the first 6 months (67, 90, 93). This is especially important as most SUDI deaths (90%) occur within the first 6 months and peak at 1-4 months of age (5, 94).

New Zealand has a relatively high uptake of breastfeeding with approximately 85% of infants breastfed up to 6 weeks of age. However, Māori mothers are more likely to stop breastfeeding earlier and supplement infant feeding with formula milk (54). This contributes to an overall lower uptake of exclusive breastfeeding for Māori infants at three months (63.2%) compared with non-Māori (72.2%) (95).

Advice and encouragement for mothers to breastfeed their infants would ideally be included with other SUDI prevention messages to reduce the risk of SUDI and promote breastfeeding for its range of infant and maternal health benefits (90).

There is debate about whether bed sharing and breastfeeding when there are no other hazards, are associated with SUDI (96).

Infant sleep position

Early research showing an association between sleep position and SIDS became more widely available from the 1980s onwards, due to studies in New Zealand (97) and Australia (98).

The NZ Cot Death Study (10, 63, 97) was among the first to provide persuasive evidence about the need to develop interventions that conveyed the importance of placing infants to sleep in the supine position, and other modifiable risk factors, such as maternal smoking in pregnancy, infant bed sharing and not breastfeeding (10).

By 1993, the amount of available data had greatly increased and at least 17 case-control studies had investigated the relationship between prone sleeping and SIDS, in New Zealand, Australia, the UK, Northern Ireland, Belgium and France, the Netherlands and Hong Kong. In 14 of the 17 studies, the association between SIDS and prone sleeping position was significant (76). The risk from infant side sleeping had been established, predominantly because infants were more likely to roll from their side onto their stomach and into the prone position (10), and advice around infant sleep positions was subsequently updated to reflect the new findings.

Infants asleep in the prone position are at risk of asphyxiation, a condition when there is insufficient oxygenation of the tissue (99) due, for example, to a build-up in carbon dioxide.

The risk of asphyxiation to infants is greater when they are asleep on soft under bedding or are covered by heavy or excess over bedding on their head or face, whether they are sleeping alone or bed sharing (100). These circumstances can lead to rebreathing - when an infant re-inhales their own breath, causing an increase in carbon dioxide in the blood, and a decrease in oxygen (100). Soft bedding that prevents the dissipation of carbon dioxide in a prone-sleeping infant exacerbates the danger of asphyxiation, such as sheepskin rugs (100) or beanbags (101).

Most infants in a high carbon dioxide/low oxygen sleep environment compensate by breathing more deeply, turning their head to the side, or waking up (100). However, prone-sleeping infants of smaller gestational age, whose mothers smoked in pregnancy (100), compared with infants of average or small gestational age whose mothers did not smoke during pregnancy (102), and newborn infants (103) were less able to mount an effective physical response.

Unintentional asphyxiation in infants has historically been misclassified or undetermined (104). Deaths from probable unintentional asphyxiation have been associated with bedsharing and excessive consumption of alcohol by parents (104, 105). An examination of 48 infant deaths from accidental suffocation in New Zealand between 2002 and 2009, were found to be more likely to occur in young infants less than one month of age during bedsharing and/or in an overlay or wedging situation (106).

The mechanism/s of SIDS in association with the prone sleep position is likely influenced by maternal smoking, which can affect an infant's arousal response, and exposure to cigarette smoke, which increases infant risk of developing respiratory illness (107-109).

By 2005, supine sleeping rates in NZ were at 72.3% (110). Choices by parents around infant sleep positions were commonly made in response to parental perception of the comfort of the infant. For example, parents thought their infants were more comfortable when they were sleeping in unsafe sleep positions. Furthermore, it is important for parents to understand the potential mechanism/s that make certain infant sleep positions unsafe, so that the advice is received and interpreted as plausible in order for safe sleep decisions to be made regarding infant sleep positions (111).

Sofas as an infant sleep space

Sleeping with an infant on a sofa places the infant at greater risk of sudden death compared with infants sleeping alone on a sofa (72, 105, 112). The danger is exacerbated by the narrow seating space, which can slope down towards the back of the sofa, and by the typically soft and yielding cushions (96, 113). Consequently, sofa sleeping with an infant creates a higher risk of suffocation from overlay or becoming wedged against the sofa or cushions (113). Rechtman (112) et al found that infant deaths on sofas were associated with side sleeping, changes in sleep location, exposure to smoking in pregnancy, and infants sleeping with others on the sofa. Parents should be advised to avoid placing an infant to sleep on the sofa alone, or with one or more other people who are also asleep. The risk of overlay is further elevated if the people sharing the sofa have recently used alcohol or drugs (96, 113). Other risk factors include the use of soft bedding, blankets, and pillows in the infant sleep space (114). Our understanding of the relationship between the sleep environment, particularly bed sharing, and other known risk factors for SUDI, such as smoking, alcohol and drug-use, remains limited (71, 115). Although duvets were not recommended in the UK and Australia, results from the NZCDS found that duvets were not associated with SIDS after adjusting for confounders (116).

Alcohol and drugs

Cannabis is the drug of choice among pregnant and non-pregnant women, and men and women at conception and postnatally (117-119). In New Zealand, the use of cannabis is relatively widespread, with up to 15% of adults from 2012/13 to 2017/18 reportedly using cannabis in the previous year, and higher usage reported among Māori (120). Amphetamine usage was less prevalent at 1% of adults (120). In 2012/13, a New Zealand-wide health survey found that 8% of women aged 15 years and over reported using cannabis in the past 12 months (121).

There is evidence of increased SUDI risk when infants bed share with a sleeping caregiver, and/or with a caregiver that has recently consumed alcohol or drugs (96, 105). As stated above with regards to using sofas as an infant sleep space, our understanding of the overall relationship between caregivers who have used alcohol or drugs and share a sleep space with an infant, is limited. However, there is evidence that suggests it creates a very dangerous situation for infants (71, 115).

Temperature and thermal stress

A review of the evidence by Mitchell (122) concluded that prone sleeping increased the risk of SIDS due to thermal stress in the infant and was more pronounced when combined with excess bedding and clothing. Other risk factors found to be involved were rebreathing expired gases, and the presence of infection and/or inflammation (122). A systematic review of 10 studies that examined the role of head covering in infants who had died from SIDS, found that head covering had occurred in 24.6% of SIDS deaths, compared with just 3.2% of controls (123). The effect of environmental (outdoor) temperatures on SIDS rates in New Zealand was examined in the NZCDS (1987-1990) and it was concluded to be minimal. Any effect was due to expected seasonal variations and minor changes in daily environmental temperatures (124).

Other maternal and infant factors

Other factors associated with SUDI include young maternal age (66, 125), single marital status, high parity, short intervals between pregnancies (125), low parental education, unskilled occupation or unemployment and poverty (126-128). Additional infant factors are male infants, low birth weight), preterm birth, intrauterine growth restriction (65, 66) and poor/late/delayed/no antenatal care (125). The characteristic age of SIDS cases is between 2-4 months, with fewer deaths in the first weeks and after 6 months (129). Also included as factors for infants are neonatal health problems at birth (130) and a preceding illness or infection, usually respiratory or gastric, and not sufficient to cause death (13).

2.7. Converging risks

In 1970, Bergman observed that SIDS occurred as a result of an interaction between risk factors, rather than because of a single infant characteristic (131). Two years later, the idea that SIDS occurred when a group of factors came together resonated with Wedgewood (1972) who then grouped several risk factors together to create the first triple risk hypothesis. Wedgewood then added three headings: 1.) general vulnerability, 2.) age-specific risks and 3.) precipitating factors. Other versions of the triple risk model emerged over the next few decades until 2004, when Filiano and Kinney presented their version of the model to explain how the convergence of three factors was necessary for a sudden infant death to occur (132). They also believed SIDS was preceded by a prenatal brain stem injury and so they created a subset of SIDS to capture this characteristic (131).

Interactions between risk factors

The risk factors in Table 2.3 are still applicable today, and the research community is constantly building on its collective understanding of the effects of these, and of the interactions between them. As depicted in the Triple Risk Model, when certain risk factors are combined, the harmful effects may be amplified to create a greater overall risk for infants, compared with the effects of the individual risks alone. The Triple Risk Model explains how the convergence of three factors is necessary for a sudden infant death to occur. These include: 1.) general factors that present underlying vulnerabilities for an infant that increase the probability of death from any cause, such as low birth weight, prematurity, poverty and prenatal exposure to tobacco smoke; 2) a critical developmental period for the infant during their first 12 months of life, and especially when aged between 1-4 months; and 3) precipitating external factors such as sleep position, bed sharing, illness or infection (131-133).

The central point at which these factors overlap creates an environment in which the infant is most at risk of SIDS and a sudden and unexpected death.

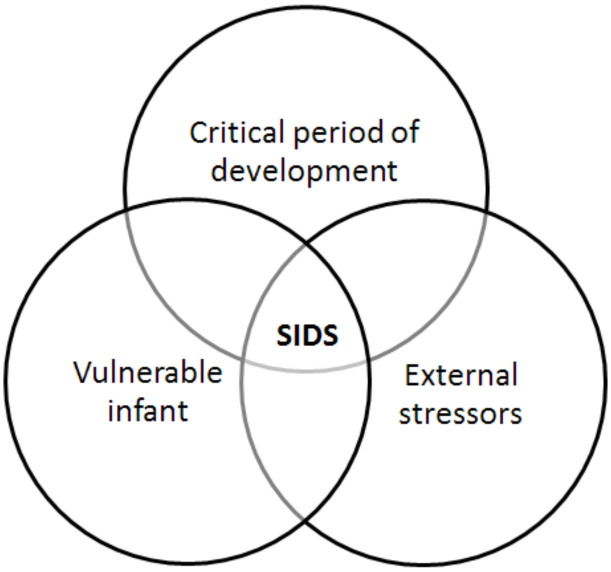


Figure 2.4. Triple Risk Model (modified from Filiano and Kinney, 2004)

There is debate about the extent to which the model has increased our understanding about the causes of SIDS (131). However, the model does provide a simple framework that can be applied to real-life situations to help understand an infant's risk of SUDI, and it has been adapted for use with other health-related issues, such as late stillbirth (134).

The model has been validated numerous times and illustrates the relationship between an infant's state of development, underlying physical or pathological vulnerability, and an unsafe sleep environment (13).

SUDI prevention in New Zealand

The results from the first year of the NZCDS (1987-1990) were so compelling, that Mitchell and colleagues published the results as soon as possible, and the findings about the risk factors of SIDS were confirmed on conclusion of the study (62). The characteristics of SIDS infants in the NZCDS were similar in other countries. Calculating the population attributable risk revealed that the main risk factors - infant prone sleep position, maternal smoking and not breastfeeding - accounted for 79% of all SIDS deaths in New Zealand (75).

The results demanded action. A collaboration led by the principal investigator of the NZCDS involved the Plunket Society, Department of Health, area health boards, Māori organisations, the New Zealand Cot Death Association, Commissioner for Children, and the study group.

This resulted in the launch of the New Zealand Cot Death Prevention Programme in 1991, which featured a wide range of strategies (12).

Resources were produced for different audiences, such as a detailed users' guide to the prevention campaign for healthcare workers. The document outlined the three streams of the campaign - encouraging a smokefree start to life, breastfeeding, and safe infant sleep – and strategies, key practices and information required to implement each stream (12). Materials were produced for new and pregnant mothers. The campaign was widely publicised (76) and the subsequent ‘‘Back to Sleep’’ campaign led to a dramatic reduction of SIDS mortality in New Zealand, and internationally (135).

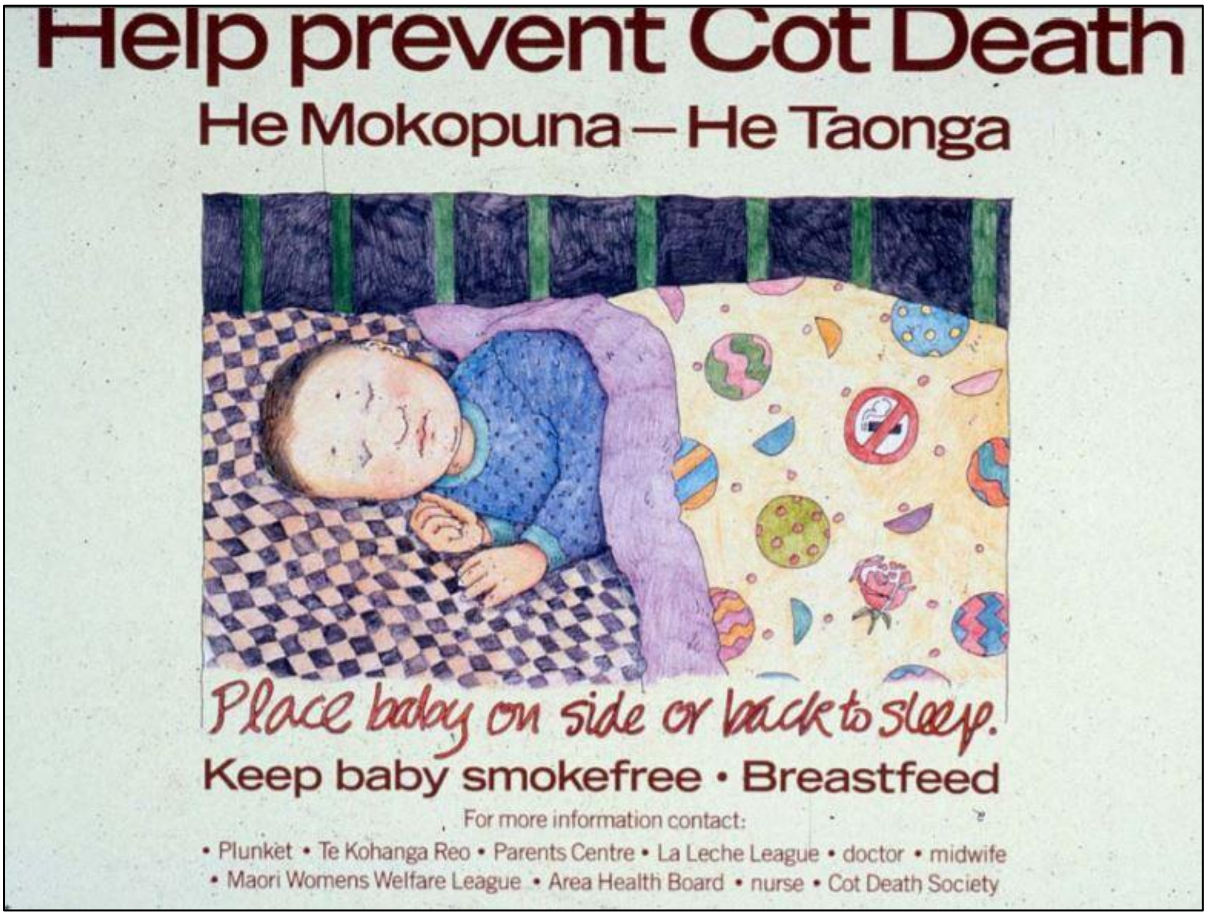


Figure 2.5. NZCDS Back to Sleep campaign (NZ Cot Death Prevention Campaign)

The SIDS prevention programmes aimed to educate parents about safe sleep and changes in practices occurred that reduced known SUDI risks and unsafe practices, such as bed sharing or maternal smoking (12, 77, 136).

The challenge today is to put in place effective strategies to further minimise the exposure to SIDS risks (13), particularly in geographic areas and populations where SUDI disparities exist. The New Zealand Health Quality Safety Commission (HQSC) oversees several statutory national committees that are mandated to review and report to the Minister of Health on particular types of deaths, such as perinatal, infant and child deaths (including SUDI).

Two of these committees receive region-specific data from the local committees that operate at the DHB level, including the national Perinatal Maternal Mortality Review Committee (PMMRC) and the Child and Youth Mortality Review Committee (CYMRC). These committees report on deaths of infants, children, and young people between 0-24 years of age and make recommendations to prevent similar deaths.

In June 2012, the Chairs of the HQSC and the national CYMRC sent a joint letter to all district health boards encouraging them to prioritise SUDI prevention and the development and implementation of safe sleep policies (137).

In late 2016, the Ministry of Health held a series of consultation hui (meetings) across the country to seek input from stakeholders and interested parties about what works well in preventing SUDI and suggestions for the way forward (136). Common themes included the need to invest in healthy pregnancies; smoking prevention and cessation; and promotion of breastfeeding and supporting mothers to breastfeed effectively (136). The need for a range of solutions that consider the changing social context for families and increasing levels of poverty was recognised. The use of a whānau ora approach was strongly supported as it could encompass the key influencers within a whānau to provide safe sleep messages and who may at times be the carer for the infant (136).

In February 2017, the Ministry of Health announced it had set an ambitious overall goal to reduce the incidence of SUDI to 0.1 in 1000 infants by 2025 (138).

To achieve this, the Ministry of Health issued a tender for the provision of a National SUDI Prevention Programme. The requirements of the programme were informed by a series of stakeholder meetings, a review of the literature and interviews with experts in the field. Hāpai te Hauora, a long-established Māori public health organisation, won the contract to deliver the programme. Hapai te Hauora set up the National SUDI Coordination Service to support district health boards to fund and deliver SUDI prevention services in their regions that are consistent with best practice (23). Prior to the establishment of the current Hapai te Hauora SUDI prevention coordination service, the incumbent organisation, Whakawhetū (previously Māori SIDS), had worked to progress the SUDI prevention agenda for a long time. Much of the work Whakawhetū undertook has been incorporated by Hapai te Hauora, for example, the use of the PĒPĒ safe sleep message, which been adopted by various organisations working in infant and child health (23).

There is continued widespread commitment to reducing SUDI rates in New Zealand, with the government funding district health boards to support a range of SUDI prevention programmes (24, 88). Some programmes available are not necessarily government-funded but are instead supported and delivered locally.

Programmes have included safe sleep education campaigns and dedicated national Safe Sleep days, the provision of safe sleep beds (e.g. Wahakura, Pēpi-pods®), Wahakura weaving wananga [workshops] and smoking cessation programmes nationally, regionally and locally. Of great importance is the need to ensure that expertise in the community is appropriately acknowledged. Experienced, expert wahakura weavers, especially those with knowledge of SUDI and safe sleep factors, must be remunerated in a way that fully acknowledges their time, and their cultural knowledge and expertise in the community.

Figure 2.6. Wahakura (Photo credit: S. Jonas)

Figure 2.7. Pēpi-pod (Photo credit: Change for Our Children)

2.8. SUDI investigations

Role of the coroner in determining cause of death in New Zealand

Coroners are independent judicial officers whose role is legislated in New Zealand through the Coroner's Act 2006 (139).

> Coroners have a duty to identify any lessons learned from the deaths referred to them that might help prevent such deaths occurring in the future. In order to publicise these lessons, the findings and recommendations of most cases are open to the public. Page pre3 (140).

In New Zealand, it is the role of the coroners, including the Chief Coroner, to consider the evidence and information collected from various agencies, and to exercise their independent authority in determining cause of death for particular types of deaths, including SUDI. If an infant death cannot be explained, the coroner will select the most appropriate finding(s) from the range of classification codes outlined below. They may note whether the death occurred in the presence of known risk factors. Coroners also make recommendations to prevent similar deaths from occurring, which may include a public statement. For example, one New Zealand coroner recommended (140):

> …that the Ministry of Health website be far more explicit in terms of the risks associated with unsafe sleeping practices and set out a guideline as to safe sleeping practices and unsafe sleeping practices with a graphic warning that if unsafe sleeping practices are followed there is a very real risk that the baby will die. Page 34

The role of quality information

To accurately determine cause of death and make informed recommendations, coroners require high quality, timely information. Prior to 2010, this information was predominantly supplied by police and pathologists, although coroners have the power to request other types of information deemed relevant to the case. In SUDI cases this may include the antenatal, birth and health records of mother and infant and/or testimony from expert witnesses, such as paediatricians. Information about events and circumstances leading up to an infant's death is collected by police from the people responsible for, and/or involved with, the infant's care at the time of their death.

This information is recorded in various police documents, statements, and photographs of the place of death obtained at the scene and/or during subsequent interviews. Items such as infant bedding, clothing and Well Child/Tamariki Ora child health record book may also be uplifted by police for further consideration.

An examination of the data included in SUDI case files in the Northland and Auckland regions between 2000 and 2009, revealed that large amounts of SUDI-specific data were missing. In 42% of cases the position the infant was placed to sleep was not recorded, and in more than a third (36.7%) of cases, the position in which the infant was found was not recorded. In 15% of cases, whether the infant died in a bed sharing situation or not, was not recorded. Where bed sharing was recorded, 19% of cases did not include the number of people in bed with the infant at the time (141).

Since 2010, the quality of information about SUDI cases available to coroners and pathologists has improved, particularly regarding information around the circumstances, and the scene of death. This is due to the introduction of the role of the national SUDI Liaison Team (preceded by the SUDI Referral Advisor, who engaged with SUDI families in Northland and Auckland only, as part of the feasibility study), whose SUDI investigation reports have improved the quality of data available about SUDI cases (44). In the early 2010s, there was a national reduction in the number of SIDS diagnoses allocated as an official cause of death. While this may have been due to the increased calibre of information available, the use of the terms 'undetermined' or 'unascertained' in SUDI cases had increased and may reflect a reluctance among some pathologists to use the term SIDS.

2.9. Chapter summary

Chapter 2 contained a review of the literature related to SUDI in New Zealand and internationally, including key definitions and classification information, and a description of the risk factors associated with SUDI. The chapter also provided an overview of the incidence of SUDI in New Zealand and the need for complete and accurate, quality information to be gathered to further build on our understanding of SUDI and support coronial investigations.

Part One: Summary

The first part of this thesis has provided background information and context for the research. This included key definitions and the impact of SUDI in New Zealand, particularly the inequities experienced by specific groups in the population, such as Māori and families living in circumstances of social disadvantaged. The risk factors for SUDI have been presented, as these are an essential component for SUDI prevention.

Part Two: Epidemiological research

Part Two includes the methods and results for the epidemiological New Zealand SUDI Nationwide Study (2012-2015). Chapter 3 comprises a case study (published), developed as a resource for post-graduate students. It contains a high-level description of the project management approach used to implement the data collection for the NZ Case-Control SUDI Nationwide Study (2012-2015). This approach can be applied to any sized research project. Chapter 4 provides additional detail about specific aspects of the project, including project governance, the SUDI Liaison role, and the national communications plan. These chapters provide contextual information relevant to the epidemiological research papers presented in Chapters 5 and 6. The first paper focuses on the SUDI disparity experienced by Māori in New Zealand (published), and the second paper examines the risk of SUDI from hazards in the infant sleep environment (published).

Mā te rongo ka mōhio; Mā te mōhio ka mārama;

Mā te mārama, ka mātau; Mā te mātau ka ora.

Through perception comes awareness; through awareness comes understanding; through understanding comes knowledge; through knowledge comes life and well-being.

Māori whakatauki (proverb)

Chapter 3: Manuscript - Use of Project Management Methodology to Implement Data Collection for a Nationwide Case-Control Study Investigating Sudden Unexpected Death in Infancy (SUDI) (Paper 1)

The following manuscript was published in SAGE Research Methods Cases: Medicine and Health by SAGE Publications Ltd, London, on 16th February 2020, and has been reproduced with permission.

MacFarlane, M (2020) A Case for the Use of Project Management Methodology to Implement Data Collection for a Nationwide Case-Control Study Investigating Sudden Unexpected Death in Infancy (SUDI). SAGE Research Methods Cases: Medicine and Health. DOI: doi.org/10.4135/9781529721072

3.1. Preamble

This paper provides an overview of the project management methodology used to implement the New Zealand SUDI Nationwide Study (2012-2015). Intended as a resource for postgraduate-level readership, this paper contributed to the first launch of the SAGE Research Methods ‘Cases’ collection, designed to support the research process. Note: the author was employed by consultancy company Communio whilst project managing the implementation of the SUDI Nationwide Study. The PhD commenced once implementation of the SUDI Nationwide Study had concluded.

3.2. Manuscript

Abstract

Background: This case study describes how project management was used to implement data collection for the SUDI Nationwide Case-Control Study (2012-2015), which investigated sudden unexpected death in infancy (SUDI) in New Zealand. SUDI is when an infant under one year of age dies suddenly, unexpectedly and usually during sleep; and New Zealand has one of the highest SUDI rates among developed countries.

Methods: The main conduit for data collection for the case and control groups was the SUDI Liaison team, whose role was implemented nationally for the study and continues to this day.

Findings: The SUDI Liaison team interviewed 96% (n=132) of families that experienced a SUDI during the study period for the case group, and 40% (n=258) of families selected for the control group. The participation rate was lower than expected among controls and was identified as an emerging issue through the project’s monitoring and control mechanisms. A change in approach was adopted. A project management approach provided a framework to implement and control this large-scale and complex study. Upon this framework, all project activity, governance, accountability, and decision-making were supported throughout the life of the project.

Conclusion: The project management approach successfully drew together the workstreams and related activities, necessary for the project’s success, into achievable and measurable steps.

Learning Outcomes

By the end of this case, students should be able to:

- Explain how a project management approach can be applied to any research project, beginning with the planning phase
- List the skills necessary to apply a project management approach to a research project
- Describe how workstreams are used in a project plan to group and organize related activities into achievable and measurable steps
- Discuss the high-level steps to undertake a project-related stakeholder analysis for a Communications Plan

3.3. Case Study

Project Overview and Context

This case study describes how project management was used to implement data collection for a national case-control study that investigated sudden unexpected death in infancy (SUDI) in New Zealand between March 2012 and February 2015. Project management can provide a framework to plan, implement and control any research project, and be scaled up or down to suit the size and complexity of the research. A project management approach involves people undertaking a set of coordinated activities to achieve specific objectives on budget and on time (142). It requires no special training or equipment, apart from basic organisational, communication and people skills.

Sudden unexpected death in infancy in New Zealand

SUDI is when an infant under one year of age dies suddenly, unexpectedly and usually during sleep. After a thorough investigation, a cause may or may not be found (4). New Zealand (NZ) has one of the highest SUDI rates among developed countries (6) at 0.76 per 1,000 live births, or approximately 50 deaths per year. SUDI is the leading cause of death in infants aged 28-364 days and, Māori, the indigenous people of NZ, are overrepresented in SUDI cases. SUDI deaths are investigated by a coroner. The coroners’ role is to determine cause of death, and if possible, make recommendations to prevent similar deaths from occurring (139).

SUDI Referral Advisor

I was a project manager for consultancy company Communio, which had previously partnered with Coronial Services (Ministry of Justice), Ministry of Health and the University of Auckland to develop the SUDI Referral Advisor (SRA) role. Over a two-and-a-half-year period, the SRA role was implemented through pilot and feasibility studies across Auckland and Northland, NZs northern region. The SRA was a health-trained professional who worked alongside families that had recently experienced a SUDI to support families through the coronial process. On behalf of the coroners, the SRA also gathered detailed health-focused information about the infant and the circumstances leading to the infant’s death, including a death scene investigation. An independent evaluation found that the SRA role had improved the support and information families received and provided coroners with accurate and concise information about SUDI cases. Based on the success of the SRA role, coupled with the alarmingly high SUDI rate, especially among Māori, the University of Auckland successfully applied for further funding from the NZ Health Research Council for the roll out of the SRA role in a three-year case-control NZ-wide SUDI study.

The New Zealand Cot Death Study

This was not the first three-year case-control study in NZ to investigate sudden, unexpected infant deaths. The New Zealand Cot Death Study (NZCDS, 1987-1990) examined the risk factors for sudden infant death syndrome (SIDS) (10, 62) and soon identified major risk factors, including infant prone (tummy) sleeping, maternal smoking, not breastfeeding and bed sharing. The significance of the prone sleeping finding was such that it was published before the study was completed (62). This, and other findings, led to the introduction in February 1991 of the official national SIDS Prevention Campaign. The prevalence of prone sleeping had begun to decrease from late-1989 and within a few years the number of SIDS deaths had more than halved, from 250 to 120 deaths per year (62).

The SUDI Nationwide Study

The principal investigator, who also led the original NZCDS, engaged Communio to implement data collection for the new study, in partnership with the University of Auckland and the Ministry of Justice. In doing so, he also became the project sponsor. The new study would reinvestigate the risk factors associated with SUDI, especially bed sharing. The

University of Auckland designed the study and obtained the necessary national and local ethics approvals. The (then) Chief Coroner of NZ was instrumental in setting up the project and facilitating access to SUDI families for inclusion in the case group. The project management approach was designed and executed by Communio.

I was appointed as project manager due to my experience in project management and background in Māori child and youth health. I was familiar with the SRA role, having shared an office with my SRA colleague. My involvement began six months prior to the study commencing and this time was spent preparing for the go-live date of 1st March 2012.

Section summary

- A project management approach can be applied to any research project and can be scaled up or down to suit the size of the project
- SUDI is when an infant under one year of age dies suddenly, unexpectedly and usually during sleep and a cause may or may not be found, even after a thorough investigation
- The SUDI Nationwide Study (2012-2015) reinvestigated SUDI risk factors identified 25 years before in the NZ Cot Death Study (1987-1990)

Research Design

Project phases generally include initiation, planning, execution (or implementation), control and closeout. The project team included a project lead to manage contract negotiations and high-level stakeholder relationships, a project manager to oversee the planning, documentation, communication, reporting and control of the project and to provide direction and support for the SUDI Liaison team, and other Communio staff to provide management support and coordination, as required. The project sponsor was also the principal investigator for the study and provided executive support and funding for the project. The other key person for the project was the (then) Chief Coroner of NZ.

In larger-scale projects such as this one, several workstreams may occur simultaneously and the project phases may overlap. This is reflective of the dynamic environments in which projects take place. Due to the scale of the project, a steering committee was established to provide strategic direction, support and decision-making for the Communio project team. The steering committee was integral to the governance of the project and comprised representatives of key stakeholders and organizations.

Following formal agreement between the University of Auckland, Ministry of Justice and Communio, project management of data collection for the study commenced. Fundamental decisions based on the contract were made during the development of the project plan.

Project plan

The project plan was a key output of the planning stage and the first step in operationalizing the contract. The project plan provided a tangible and measurable roadmap for achieving the aims and objectives within the constraints of resources and time. Deliverables and milestones were developed to measure success of the workstreams and the overall project.

An assessment was undertaken to identify the internal and external stakeholders of the project and the level at which they would be involved or affected, and how we would engage with and work alongside them. Stakeholders are individuals and organizations that are actively involved in the project, whose interests may be positively or negatively affected by the project or those that exert an influence over the project. Internal stakeholders included the project sponsor, Chief Coroner, project team and members of the steering committee. All others were external stakeholders. The environment within which the project was positioned was highly process-oriented and legislative, particularly with regards to Coronial Services, NZ police and district health boards (DHBs). DHBs provide health and disability services across NZ within defined geographic areas.

The SUDI Liaison Team

The SRA role was renamed SUDI Liaison (SUDIL) for the case-control study. The SUDIL team were the primary mechanism for data collection, they recruited and interviewed families in the control group and engaged with case families soon after the deaths of the infants.

Sensitivity and empathy were essential. Māori overrepresentation in SUDI meant it was vital for SUDIL staff to be culturally responsive and respectful, and this extended to Māori families and families of other cultural and religious backgrounds.

There was some concern among the project team about how we would find applicants with, or with the potential to develop, the unique skillset required to carry out the SUDIL role safely and well. Using the SRA position description as a basis, we finalised the necessary SUDIL attributes and competencies. These included familiarity with the health sector, the ability to communicate well and to provide support and empathy in difficult circumstances. I was responsible for the recruitment, training and ongoing management of the SUDIL team. The positions were advertised on an online recruitment site and extensively via word of mouth. Five people were appointed, three of whom were based in Auckland, one in Wellington and the fifth in Christchurch in the South Island. For logistical purposes we divided NZ into four regions. SUDIL staff would cover specific regions based on their location. FTE staffing levels were allocated to each region to match previous SUDI volumes.

Section summary

- The project plan was a key output of the project planning stage
- The project plan provides a roadmap for achieving the aims and objectives of the project within the constraints of available resources and time
- The SUDIL team was the primary mechanism for data collection in the study

Research Practicalities

Finalising the project plan

The finalised project plan was a key deliverable of the project. The project aimed to implement data collection for the study and ensure it was accurate and timely; ensure families that had experienced a SUDI had information about coronial processes; and, where there was an identified need at the time of engagement, case and/or control families were linked into appropriate health and support services.

The project workstreams and key tasks included:

1. Project management – project initiation, planning, implementation, control and closeout
2. SUDIL team - recruitment, development, management and supervision
3. Study protocol and policy framework development
4. Communications and stakeholder relations
5. Data – collection, management and quality review

Project governance

A steering committee was established to provide project governance and would meet monthly via teleconference. Members represented key stakeholder agencies or were clinical and academic experts. The committee was chaired by the project sponsor, and we would speak beforehand to run through the agenda, outstanding actions, apologies and issues arising. I provided secretariat support to the committee, including terms of reference, agenda, minutes, risks and issues register, status reports and other relevant documents. High-level or unresolved issues or risks were escalated to the committee for discussion, guidance and advice. The heterogeneous nature of the committee enabled a range of perspectives of the issues to be tabled and the allocation of subsequent actions to various members to be agreed. Actions were logged and followed up at each meeting.

SUDIL preparation

The SUDIL team received comprehensive training beginning with a four-day induction in Auckland, followed by a local/regional induction in their hometown. Team members received a research kit, laptop and mobile telephone and were trained in all aspects of the SUDIL role, including interview techniques and sleep scene doll reconstruction. The latter was provided by the lead SUDI investigator from the Miami-Dade Medical Examiner's Office in Florida, whom the principal investigator had arranged to come to NZ. Team members also met with families previously affected by SUDI.

Ethical and legal aspects

Approval was obtained from the NZ Northern Regional Ethics Committee and the ethics committees of the 16 DHBs involved in the control selection process. Informed written consent was obtained from all participants involved in the research. Written consent was not required to obtain information from case families for the separate coroners' dataset, but it was required if they participated in the research. Participants were identified by a study number to ensure confidentiality.

Recruitment of cases

All infant deaths referred to the coroner during the study were assessed by the National Initial Investigation Office (NIIO) against the inclusion criteria. Deaths due to suspected homicide or neglect (if known) were excluded. NIIO staff would notify me when a SUDI occurred. Processes were in place to ensure the criteria were correctly applied.

Inclusion criteria

- Age range from birth to 365 days
- Unexpected and unexplained (or initially unexplained)
- Not resulting from delivery complications
- Not resulting from accident or injury
- Not a result of a known congenital / genetic condition
- Cause of death that is not recognised by the family, including unrecognised infection or metabolic disease.

Prior to contacting families, the SUDIL team would confer with police for clearance to proceed to ensure the death was not considered to be suspicious, in which case the SUDIL team would not become involved. Once clearance was received, contact was made with the family and a time was arranged to meet with them, usually at home.

Recruitment of controls

Families for the control group were selected by DHBs from the obstetric hospital birth register using selection criteria supplied by the local SUDIL. The selection criteria matched the age, sex, ethnicity and obstetric hospital of infants who had previously died from SUDI over a seven-year period. An information sheet was mailed to the family and followed up with a telephone call at which time the SUDIL would invite them to participate in the study. If they consented, a time would be arranged to visit them at home. Families in the control group differed from the case group only in that their infant had not died.

Communications

An internal and external stakeholder analysis occurred during project planning and the results informed the development of the project Communications Plan. This involved identifying the full range of stakeholders, key messages, methods and frequency of the communications.

Data management and quality review

A system to collect and enter data directly into an electronic database in readiness for the University of Auckland was required. An automated data extraction and collection software program was selected and over the course of the study, the project manager and members of the SUDIL team managed this process.

Tracking the status of data collection

Throughout the project, we needed a mechanism to monitor progress and timeframes for engaging with case and control families and for managing the various administrative requirements. A detailed tracking system using Excel software was created for this purpose and to assist in control of the project.

Section summary

- Project management phases include project initiation, planning, implementation, control and closeout
- Stakeholder analysis during project planning contributes to the development of the Communication Plan
- Mechanisms are needed to track and monitor progress within the project

Method in Action

Project structure

The project structure provided a framework for project management, accountability and governance over the life of the project. Clear lines of communication and escalation were formalised. Risks and issues were quantified to determine appropriate action at the right level. The diverse representation by Steering Committee members enabled various perspectives to contribute to decision-making. See below Figure 3.1. Project Structure for SUDI the Nationwide Study

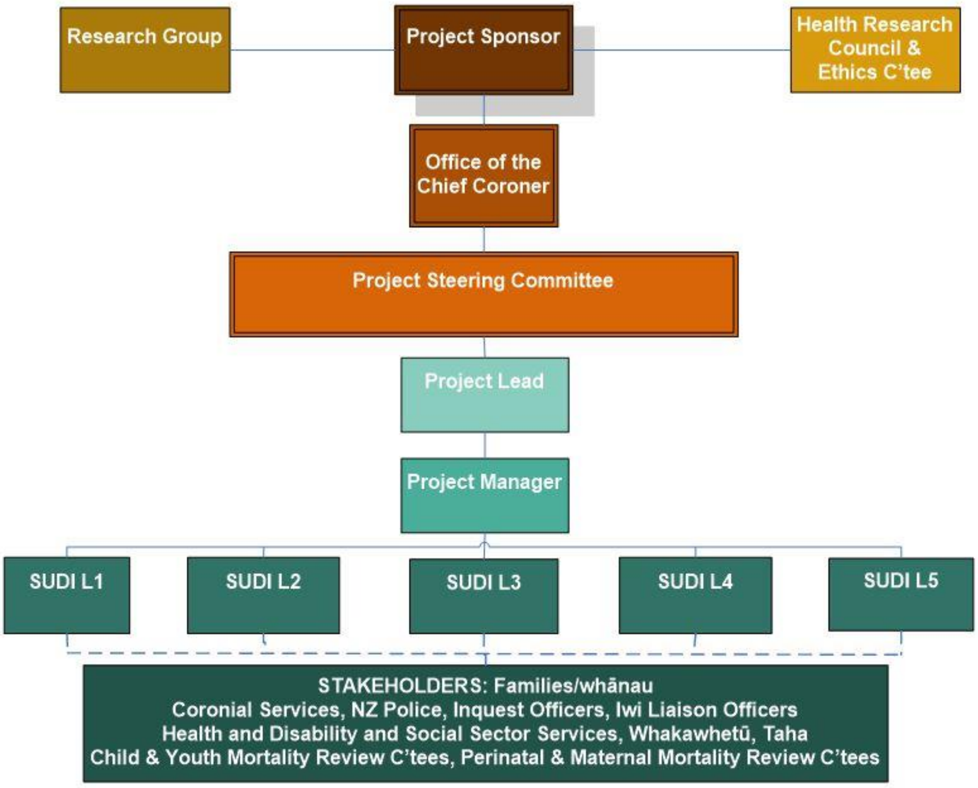


Figure 3.1. Project Structure for SUDI the Nationwide Study

Engaging with cases

Recruitment processes resulted in the referral of 303 infant deaths to be considered for the study. Of these, 137 deaths met criteria and 96% (n=132) of families were interviewed. Rapid engagement with case families sometimes created difficulties, for example, interrupting families' grieving practices. To avoid this, we decided that SUDILs should proceed after the burial or funeral service.

Uncontactable controls

A total of 649 infants were selected for the control group and 258 (40%) participated in the study. Of mothers who were selected but did not participate, many were uncontactable (n=182) or actively or passively refused (n=209). Of the passive refusals, many initially agreed but cancelled last-minute or did not show up or became uncontactable.

Excel tracking spreadsheets centralised case and control group information and at-a-glance allowed us to monitor data collection status. Tracking sheets were ‘live’ files accessed by the SUDIL team. Rules were in place to manage risks associated with multiple simultaneous users, such as ‘checking out’ tracking sheets to alert colleagues the file was in use.

It became apparent that participation among controls was lower than expected. Each selection had a four-week window for the interview. I could mitigate early project delays by shifting an interview to the second or third year. However, the issue was ongoing and a change in approach was adopted, including:

- Calling more frequently using different telephones at different times, in evenings and weekends, sending texts and leaving voicemail messages to mitigate ‘screening’ of unwanted calls
- Liaising with the maternity or well child providers and using the national immunization database to obtain accurate contact information
- Requesting contact information from DHBs sooner to identify incorrect contact numbers quickly
- Providing supermarket vouchers in areas with lowest participation rates

Each SUDIL developed a tailored approach and leveraged their networks to engage families in their regions. The Excel tracking sheets were important tools to monitor and control data collection.

SUDIL Team wellbeing and support

Lessons learned from the SRA were incorporated into the SUDIL role, for example, working normal hours Monday to Friday and limiting the period of engagement with case families to six weeks post-SUDI. Despite this, some aspects of the role lacked clarity and situations would arise outside the scope of the role. These presented opportunities to further clarify the boundaries of the SUDIL role with the team and was a continuous process. A comprehensive policy framework brought together the necessary documentation for SUDILs to perform their role. Team wellbeing was important, and we met fortnightly; the project sponsor, in his role as principal investigator, attended monthly. We would discuss recent activity and any risks or issues. SUDILs contributed different perspectives, and all brought something unique and valuable to the team collective.

Communications

The project used different methods to communicate with stakeholders and to share information about the study effectively with the target audience. SUDILs engaged in extensive networking across their networks, which led to positive outcomes for the study and for families, such as linking families into services.

To enhance the national recognizability of the study, a logo was created by a SUDIL skilled in graphic design. The name – SUDI Nationwide Study - was professionally combined with the by-line "increasing understanding of sudden unexpected death in infancy" and was used in all documents and presentations produced for the project. Project newsletters were published to provide information on the project and were email to 400-plus stakeholders.

Closing the project

The formal closeout meeting between the project sponsor, lead and manager was an opportunity to confirm that all project objectives and deliverables had been achieved. The quality-reviewed data had been delivered to the university and I had prepared the final report. This was sent to internal stakeholders, including the sponsor, members of the steering committee and the SUDIL team. The report was an important and final output of the study. It became a central record of everything that happened, including the unexpected, the lessons, and the remarkable. I organised a project closeout celebration and brought everyone together. It was attended by the project team, past and present SUDILs and the key people who were instrumental in making it all happen.

3.4. Section summary

- A project structure provides a framework for project management, accountability and governance over the life of the project
- A policy framework centralises the documentation people need to perform their role
- Regular meetings within a project are vital and offer opportunities for various roles to be shared, such as chairing, taking minutes or presenting a status report or risk register
- Team members contribute different perspectives, and all bring something unique and valuable to the team.

3.5. Results - Practical Lessons Learned

1. Supporting the SUDIL team

The SUDIL team was central to the SUDI Nationwide Study, and it was imperative they be supported to stay safe and well. Structures for communication enabled issues to be raised, documented and managed. We met regularly as a team, conversed individually and always debriefed after a challenging experience. Refresher training brought us together socially and for professional development. Group and individual supervision and access to the principal investigator were additional avenues for team support.

2. Project governance, a structure for accountability

The clear structure of the project enabled up and down communication, with the steering committee being the peak body. Some members represented major stakeholders and others brought considerable knowledge and expertise, meaning decisions made by the committee carried authority and weight. The effort expended on the secretariat role was worth it and the gains were critical to the success of the project.

3. Tracking progress and maintaining control

The using of tracking tools is essential for any project. In this study, the case and control Excel tracking tracks provided the visibility, which enabled the issue of low uptake among controls to be identified so that action could be taken. Although the response rate for controls was lower than anticipated, I could say with conviction that we did everything possible to successfully recruit families to the control group.

4. Communication leads to mutually beneficial relationships

Each SUDIL focused on developing working relationships with key agencies in their respective regions. Over time, processes became more streamlined and brought about unexpected gains leading to contact with families that would not otherwise have occurred, resulting in valuable data being collected and families' receiving support from various services and agencies. SUDILs and NZ police worked together numerous times to engage with case families with positive outcomes for those involved. For example, one mother with outstanding warrants had refused to meet with police and SUDIL. With support from a close relative, the mother agreed to attend court with the SUDIL and police regarding the outstanding warrants and met with the SUDIL later the same day.

5. Acknowledge the people and celebrate success

Project management provides the structure, but it is people that make the magic happen. Focus on nurturing the relationships, both internal and external, using communication as the basis. Acknowledge the smaller successes you have along the way, especially in longer projects. When the project comes to an end, bring the key people together and celebrate everything you have collectively achieved.

3.6. Conclusion

Data collection for the SUDI Nationwide Study (2012-2015) was implemented using a project management approach. This provided a framework to identify the workstreams and organise related activities into achievable and measurable steps, which brought order to the overall project. However, these benefits would apply to research projects of any size as the principles of project management would remain the same.

The project rolled out the SUDI Liaison role nationally and the team engaged with 96% (n=132) of families that experienced a SUDI over the three-year period. Previously unavailable detailed information was collected about SUDI cases. The study found that risk factors identified in the late 1980s in the New Zealand Cot Death Study, such as maternal smoking, prone sleeping, bed sharing and not breastfeeding, are still relevant today. Further analysis found that the SUDI disparity experienced by Māori is due to the higher Māori smoking rate.

The project itself was both challenging and complex, involving multiple partners, agencies and stakeholders, a significant geographic coverage area and, not least, hundreds of families, many of whom had experienced the tragedy and trauma of SUDI. The project successfully drew together the many strands required to achieve the project outcomes and for me, Communio and the SUDI Liaison team, it was a rewarding and remarkable experience.

I recommend applying the principles of project management to your next research project and an easy place to start is the planning phase. A final point is the importance of people, and specifically, investing time and energy to build good relationships with stakeholders and to communicate well, without which, even the best project plan will fail.

Communio continues to provide the national SUDI Liaison role for the Ministry of Justice and engage with families whose babies have died suddenly and unexpectedly. The team continues to gather information for the coroners and link families into health and other services, as needed at the time. Hopefully one day, there will not be any work for the SUDI Liaison team.

Section summary

- Identifying the workstreams and organizing related activities into achievable and measurable steps brings order to a project
- To apply project management principles to your next research project, start with the planning phase
- Building good relationships with stakeholders and communicating well can be the difference between a successful project and a failed one.

Classroom Discussion Questions

1. Think about a research (or other) project you would like to complete. What is it?
2. Thinking about your research (or other) project, what are the key components (or workstreams) needed to complete it?
3. Choose one component (or workstream). What are the steps needed to complete it?
4. List up to five individuals or groups that will be affected by your research (or other) project? Choose one person or group and write down two or three messages they will need and when. How best can these messages be delivered?

Multiple Choice Quiz Questions

1. What document is created based on the results of the stakeholder analysis?

   a. Issues and Risks Register
   b. Project Budget
   c. Communications Plan (CORRECT)

2. What is a key output of the project planning phase?

   a. Project Plan (CORRECT)
   b. Status Report
   c. Issues and Risks Register

3. What skills are needed to apply project management principles to a research project?

   a. Debating, computing and typing skills
   b. Organizational, communication and people skills (CORRECT)
   c. Audio-visual, coding and surveying skills

4. What provides the framework that supports project management, accountability and project governance?

   a. Project structure (CORRECT)
   b. Project sponsor
   c. Project budget

Further Reading

Atkinson, R. (1999). Project management: Cost, time and quality, two best guesses and a phenomenon, it’s time to accept other success criteria. International Journal of Project Management, 17(6), 337-342.

Bryson, J. M. (2004). What to do when stakeholders matter: Stakeholder identification and analysis techniques. Public Management Review, 6(1), 21-53.

Kerzner, H. (2017). Project management: A systems approach to planning, scheduling, and controlling. John Wiley & Sons.

Radujković, M., & Sjekavica, M. (2017). Project management success factors. Procedia Engineering, 196, 607-615.

Web Resources

https://www.mindtools.com/pages/main/newMN_PPM.htm

https://www.projectsmart.co.uk/introduction-to-project-management.php

3.7. Chapter summary

The published case study in Chapter 3 has provided an overview of the project management processes involved in collecting the data for the NZ Case-Control SUDI Nationwide Study (2012-2015), which leads into Chapter 4 and additional information about the communications strategy and SUDI Liaison role.

Chapter 4. Additional methodological information relevant to the New Zealand Case-Control SUDI Nationwide Study (2012-2015)

4.1. Preamble

Chapter 4 presents additional information about the Communications Workstream of the project, and the role of the SUDI Liaison team in data collection. This information builds on Chapter 3 and provides details that are not included in the manuscripts in Chapter 5 and Chapter 6, due to manuscript restrictions on length and scope. Vignettes from key stakeholders are included to provide context and unique insight into their experiences with the study.

4.2. Communications

Stakeholder analysis

During project planning, an internal and external stakeholder analysis was undertaken. Stakeholders are persons and organisations that are actively involved in the project, whose interests may be positively or negatively affected by the project, or they may exert an influence over the project. Freeman (143) defines stakeholders as groups and individuals who can affect or are “affected by the achievement of the organization’s objectives” p22. In this instance, the organisation was the SUDI Nationwide Study; and the objectives were linked to the implementation of data collection. The relationship of different stakeholders and their level of involvement with the project evolved throughout the life of the project.

Methods of communication

The project utilised a range of methods to communicate with stakeholders and ensure information about the study was delivered effectively and to the target audiences. This activity was captured in the project communications plan. During the establishment and implementation phases of the project, face to face meetings with individuals or groups enabled reciprocal flows of information to allow stakeholders to ask questions and seek clarification. Meetings were supplemented with other methods to reinforce the key messages and reach other stakeholders. Supplementary methods included telephone and email contact, PowerPoint presentations to relevant groups (for example, the team within Coronial Services that would notify the project when a SUDI death had occurred), and formal and informal written communications.

Building a network

The SUDI Liaison team members engaged in extensive communications throughout their network of contacts within their regions. This included planned, or opportunistic, visits with members of NZ Police, iwi liaison officers, or coronial services case managers, particularly if the SUDI Liaison was in a specific location to meet with a case or control family. Over time, the networks of each SUDI Liaison strengthened and led to mutually beneficial and respectful relationships which achieved positive outcomes for individuals and whole families. See Table 4.1. for a list of the key stakeholders

Table 4.1. Key stakeholders

Key stakeholders in the SUDI Nationwide Study

Key stakeholders for this project were:

- Research Team, University of Auckland, and associates
- Chief Coroner, local Coroners, Coronial Services Case Managers
- Child Youth Mortality Review Committee (CYMRC) members and coordinators
- Perinatal and Maternal Mortality Review Committee (PMMRC) members and coordinators
- Identified Liaison Paediatricians
- Forensic and/or Perinatal Pathologists
- NZ Police
- Iwi Liaison Officers
- District Health Boards
- Inquest Officers
- Funeral Directors
- Case Families/ whānau (bereaved)
- Control Families/ whānau
- Plunket, Family Start and other Well Child/Tamariki Ora Service Providers
- Whakawhetū (previously known as Māori SIDS)
- Taha (previously known as Pacific SIDS)
- Change for Our Children
- Sands New Zealand
- Cardiac Inherited Diseases Group (CIDG)
- Child Youth and Families (CYFs)

Project branding

A suite of communication materials was developed during the study. A logo and banner were created by Shelley Jonas, SUDI Liaison, to provide branding and enhance the national recognisability of the project and SUDI Liaison role. The name of the study was combined with the by-line “increasing understanding of sudden unexpected death in infancy” to create a stylish banner that was used in all project documents and communications. Communio had used a similar approach in other national projects and found this to be effective for enhancing nationwide communications.

The imagery draws on natural colours and uses motifs that are familiar to Māori and many New Zealanders. The ‘S’ in ‘SUDI’ was stylised to represent a traditional Māori fishhook, hei matau. Hei Matau is a symbol for strength, determination, authority, prosperity, abundance, good health, fertility, good luck, and safe travel across water (144). The weave securing the line tells the ‘story’ of the project, including the personnel and families involved, past, present, and future. The colours blend from earth brown to blue-green, representative of ‘change’.

Figure 4.1. Banner for the SUDI Nationwide Study

SUDI Nationwide Study Newsletters

Four project newsletters were published during the project. These were developed with input from the SUDI Liaison team and signed off by the Communio senior project lead and the University of Auckland project sponsor/principal investigator. The aim of the newsletters was to provide easily digestible information on a range of aspects about the project to a wide and varied audience. Newsletters were sent via email in pdf format to more 400 stakeholders and based on the feedback, were positively received (Appendix A.8. SUDI Study Newsletter Issue 3: April 2014).

SUDI Liaison team Flyer

A flyer with information about the SUDI Liaison role was produced to assist communications with services and agencies during initial engagement with Case families. The flyer was suitable for a broader audience but was most commonly provided to members of the police. The initial telephone call by the SUDI Liaison with police to ascertain the appropriateness of the SUDI Liaison contacting a family following a SUDI included an introduction of the role and explanation about whose authority the team worked under, namely the Chief Coroner of New Zealand. If the police officer was not familiar with the role, the SUDI Liaison would offer to email the flyer directly to the member of police, or others as the need arose. (Appendix 9. SUDI Nationwide SUDI Liaison team flyer, July 2013)

SUDI Liaison team Profile

A 1-page team profile to introduce each team member was produced and kept up to date. The team profile was sent to stakeholders in addition to the flyer. Both the flyer and team profile could be forwarded to colleagues via email and/or printed off and displayed within stakeholders' workplaces. (Appendix A.7. SUDI Liaison team profile, August 2013)

4.3. Role of the SUDI Liaison team in data collection

The SUDI Liaison team was an essential conduit for the collection of data for the study. It was imperative therefore that the team be ready prior to the study commencement date. This included recruiting appropriate people for the role, training them and providing them with all the tools necessary to perform their role safely and appropriately. The following information outlines the aspects involved in recruiting and developing the team.

SUDI Liaison recruitment

The initial recruitment drive resulted in the appointment of five SUDI Liaison. The key strengths of the successful applicants were their ability to communicate around sensitive matters, their problem management skills, experience in health and bereavement, managing ethical dilemmas, critical thinking and their knowledge and understanding of tikanga and cultural awareness. A second recruitment drive took place between March and May 2013 to replace SUDI Liaison team members in Auckland and Wellington.

SUDI role definition and development

Implementation of the SUDI Liaison role was set amid a context of competing priorities and strict adherence to coronial services processes. The original SUDI Referral Advisor role was the pre-cursor to the SUDI Nationwide study and the national roll-out of the SUDI Liaison team. Some aspects of the original role were retained, including co-ordinating a SUDI response for families, maintaining the integrity of coronial processes, gathering information about SUDI, and focusing on SUDI prevention.

A new SUDI Liaison role

The main differences with the new role included that it was implemented nationally and involved data collection for case-control research. The new role did not include providing families with grief counselling, advocacy, SUDI prevention education, or service coordination, as responsibility for these services resided with other agencies and organisations. The SUDI Liaison could provide tailored health education material and information about available services. They could facilitate links for families with local health or other services, where these were needed, and the family had agreed. If, at any time, the SUDI Liaison observed situations that put people, and especially children, at risk, they were obliged to escalate their concerns so that appropriate advice could be obtained, and any actions and outcomes were documented and followed up.

Dual roles perceived as a conflict of interest

At the time of their appointment to the team, two SUDI Liaison members had part-time roles as DHB Child and Youth Mortality Review Committee (CYMRC) local coordinators. Local coordinators provide information to their DHB CYMRC about deaths of children and young people aged 28 days to 24 years in their DHB area so these deaths can be reviewed, and similar deaths prevented in the future.

Initially, other members of the CYMRC network expressed concerns about perceived conflicts of interest for local coordinators in the SUDI Liaison role. Following discussion with the relevant team members, and with the Steering Committee, the concerns were deemed to be manageable with the correct processes in place. The concerns proved to be unfounded, and the relevant SUDI Liaison team members were considered to have the skills and professionalism to manage both roles separately. This proved to be the case and no further concerns were reported.

There were benefits for these SUDI Liaison of having worked within the confines of the mortality review committees, such as CYMRC. For example, information is disclosed and discussed under the strictest of terms. Therefore, a background in CYMRC local coordination seemed to provide the relevant team members with an ability to work comfortably and confidently within the procedural and legislative requirements of the SUDI role. Excellent training provided during induction, and close management and support moving forward, created an environment in which the SUDI Liaison team could develop their skills, expertise, and experience over time.

SUDI Liaison coverage areas

To manage the nationwide data collection, New Zealand was divided into four regions. The level of SUDI Liaison staffing for each area was aligned with SUDI volumes in the previous years. The South Island, although the largest land area and with a quarter of the New Zealand population, experienced lower numbers of SUDI than the North Island, and therefore had only one person based in Christchurch. The lower North Island had one SUDI Liaison (based in either Wellington or Palmerston North) and two people covered the central and upper North Island (Appendix A.6. Map of SUDI Liaison regions). The table below lists the DHBs in each region and the location of staff assigned to cover each region.

Table 4.2: Regions and District Health Boards

Region	DHB Areas	Location of staff
1. Upper North Island	Counties-Manukau; Auckland; Waitemata; Northland	Auckland
2. Central North Island	Waikato; Bay of Plenty; Lakes; Tairawhiti; Taranaki	Auckland
3. Lower North	Capital and Coast; Hutt; Wairarapa; Mid-Central; Whanganui; Hawkes Bay	Wellington/ Palmerston North
4. South Island	Nelson-Marlborough; West Coast; Canterbury; South Canterbury; Southern	Christchurch

The following table lists the members the SUDI Liaison team and personnel changes over the life of the project.

Table 4.3: SUDI Liaison team members

SUDI Liaison team Members		
Shelley Jonas	Regions 1 and 2	March 2012 – February 2015
Tracy Rewiri	Regions 1 and 2	March 2012 – October 2012
Elaine McLardy	Region 4	March 2012 – February 2015
Jazz Heer	Region 3	March 2012 – November 2012
Kola Fue	Region 1	March 2012 – July 2012
Rebecca Passi	Region 1	August 2012 – June 2013
Genevieve Ali	Regions 1 and 2	July 2013 – February 2015
Judy McIntyre	Region 3	August 2013 – October 2014
Melanie MacFarlane (project manager)	Regions 1,2,3,4	March 2012 – February 2015

Induction and ongoing development of the SUDI Liaison team

The SUDI Liaison team received special training to prepare them for the role, including a comprehensive induction programme prior to commencing the study. The purpose of the induction was to provide education and training to SUDI Liaison staff to adequately prepare them for their role.

The induction programme was divided into two distinct phases. The first phase was a central induction held in the Auckland Communio office over four days in February 2012, followed by a local/regional induction over the following two weeks.

Mid-way through the study. The project manager took three months maternity leave. During their absence, the Christchurch-based SUDI Liaison oversaw and coordinated the team and SUDI referrals into the study and supported the steering committee.

Clinical support for the SUDI Liaison team

Three liaison paediatricians were identified to provide locally based clinical support to the team, including the study principal investigator, Professor Mitchell in Auckland, Professor Dawn Elder in Wellington, and Professor Barry Taylor, in Dunedin. Clinical support included reviewing and verifying the inclusion or exclusion of a case to the study. Clinical support could also be arranged for families in the case group, for example, to explain the baby’s autopsy results, or to conduct a clinical examination on a surviving twin. These opportunities had not previously been as easily available to families that had experienced a SUDI.

Regarding control families, one challenge to manage was what to do when practices used by a family were creating unsafe, high-risk circumstances for their infant.

> Supervision and mentoring helped me here.
> – SUDI Liaison

Professional supervision

SUDI Liaison team members received professional group supervision from an external supervisor every six weeks (in person and via Skype) and one-to-one supervision, as required, on an individual basis. Supervision has been defined by Hawkins and Shohet (145) as a form of self-reflection that is undertaken jointly by a practitioner, with the help of a supervisor, to attend to their clients' and their own needs and in doing so, improve the quality of their work, promote personal development, and ensure their practices are ethical and safe. Providing access to supervision for the SUDI Liaison team was an important part of supporting their wellbeing, as the emotional burden of the role could be overwhelming at times, especially when caseloads were at their highest.

> I found skyping really good as it seemed more real for me being able to see colleagues.
> - SUDI Liaison

Koha – acknowledgement and thanks

There were no resources in the study budget to purchase small gifts for case families. SUDI Liaison team members instead sought sponsorship from organisations in their local regions as a way of providing a small gift in appreciation of their time and acknowledgment of their grief. The team were very grateful for the generosity of the sponsors that provided tinned and packet food items, fresh flowers, hand-painted memory boxes and care packages.

Food parcels containing different Heinz Wattie's products were given to families in the South Island and lower North Island. Hampers included a selection of pantry items such as tomato sauce, baked beans, spaghetti, peach slices, beetroot slices, pasta sauce, chicken with lite mayo, chopped tomatoes, mayonnaise, soup, stir-fry sauces, jam, tuna and peanut butter.

Bouquets of fresh roses were provided by Moffatt's Flowers Christchurch for families that experienced SUDI in the area. Care packages containing items for families specifically dealing with the sudden and unexpected death of an infant were provided by Sands Manukau and, in the later stages of the study, Forever Present (146). The packages were given to families in upper and central North Island during the first face to face contact with the SUDI Liaison, whether this was for the interview or merely initial contact, for example, at the mortuary or family home. The care packages were designed to help create memories, bring comfort to families, and provide useful and tailored information.

Figure 4.2: Care packages provided by Forever Present

It was important to ensure we complied with the operating standards of ethics committees, particularly around perceptions of coercion, inducement, and intimidation, which can "take many forms and occur directly or indirectly through financial or other rewards" (147). It was agreed that the provision of a small non-monetary gift for participants would be acceptable. Such gifts were always well-received and appreciated by families.

Doll re-enactment

The doll re-enactment was part of the wider set of objective measures collected at the time of interview. When an infant dies suddenly and unexpectedly, a thorough infant death scene investigation is necessary to accurately determine the cause and manner of death. Many people are not verbally adept enough to describe adequately how an infant was found; thus, the re-enactment becomes the visual representation of the infant death scene. Using a scene re-enactment doll, the placer (usually the caregiver) could show the exact position in which the infant was last placed down to sleep. The found position was then re-enacted in the same manner. These photographs became part of the report to the coroner. One of the forensic pathologists commented that:

> Internationally accepted best practice requires the collection of detailed information from the scene and associated persons, as well as scene reconstructions, by properly trained staff.
>
> - Forensic Pathologist

A selection of photographs is provided below to illustrate the types of images collected for the scene re-enactment, which formed part of the wider set of objective measures.

Figure 4.3. Sample doll re-enactment photographs

4.4. SUDI Liaison – Outcomes and lessons learned

The SUDI Liaison team successfully engaged with 96% of case families. Many families appreciated the opportunity to gain understanding about the circumstances of their infant’s death and to talk about their infant with someone outside of the family and social circle, and who was interested in them and, the life of their infant.

> It is so good to talk with someone outside of who we know.
>
> - Grandfather’s comment following case interview with SUDI Liaison

Every interview was different, however the approach always involved creating ‘space’ in the interview for families to tell their story. For example, if the infant had died early hours of Monday morning, one could open with “…tell me about that Sunday afternoon, was it a normal day?” Key points could then be clarified within the wider conversation. Other family members were often present at the interview to support the parents. This was often the first time these relatives had heard the story of what happened. At times, exploration of risk factors was difficult for families if these risk factors were present when their infant died, such as bed sharing in an overlay situation. One mother from the case group made the following comment:

> I’d rather talk with you than someone at the centre, they are all my whānau
>
> - A mother during a SUDI Liaison interview

Engaging early with case families

Establishing contact with a family or key contact within the first two days of a baby’s death indicated a higher likelihood of a successful engagement. Over the 6-week engagement period, families had someone other than coronial services to provide information about the processes and help demystify what it meant for them. A spokesperson for the parents often acted as the key contact person for SUDI Liaison, at least initially. This person was someone with mana [status, respect] within the family and was often a grandparent, aunt or grandaunt of the infant.

Early engagement was particularly relevant when the infant was away for an autopsy. Families often experienced confusion and helplessness compounded by a lack of information during this period; some did not know the whereabouts of their infant. One distressed mother asked during an interview -

> What’s happening with my baby?
>
> - Mother whose baby was away for the autopsy

SUDI Liaison facilitated linkages for bereaved families to services, such as DHB-based cultural advisory services, where these were available. SUDI Liaison personnel provided families access to cultural support services, which was a unique value-add of the SUDI Liaison role. The focus on rapid engagement with families raised two issues for the SUDI Liaison team. Mothers at the mortuary were mentally and emotionally unprepared to provide accurate, complete information. Furthermore, an interview within days of an infant's death could interrupt tangihanga or other mourning rituals. A more whānau-centric approach was incorporated whereby early contact was an opportunity to introduce the role and the idea of a meeting after tangihanga [mourning processes] were complete.

SUDI Liaison staff continued to meet families at the mortuary, particularly those from out of town, to establish contact, offer information and link families with other support, if possible, and if wanted by the family. Many families left town or did not return after tangihanga so re-engagement could be challenging; however, this brief engagement was preferable to interrupting families' last hours with their infant.

SUDI Liaison would sometimes contact the pathologist prior to visiting the family. This helped to identify specific areas for the SUDI Liaison to explore to enhance pathologists' understanding of the circumstances and inform their report to the coroner.

Working with NZ Police

The SUDI Liaison team and police (primarily the Iwi Liaison officers, detectives and inquest officers) worked together numerous times to engage with, and support case families, resulting in positive outcomes for families. At times, the SUDI Liaison team worked alongside Iwi Liaison to gain access to Māori families in the case group. An open-minded, inclusive, and respectful approach underpinned all communications and resulted in positive and effective engagement.

Working relationships with agencies and services

Each SUDI Liaison focused on developing effective working relationships with key agencies in their regions. In areas where SUDI was more common, processes became more streamlined and featured early/timely communication between SUDI Liaison and other agencies involved with the families, such as police and health and social service providers. This led to contact and engagement with families that would not otherwise have occurred and resulted in a large quantity of valuable data being collected and a range of needs of the families being identified and supported by various services and agencies.

Māori representation in the project and during engagement with families

A representative from Whakawhetū was a co-investigator and member of the research group involved in the development of the study. The governance group included Associate Professor Beverley Lawton, University of Otago, Wellington, who provided cultural oversight and advice for the project. An example of this was advice to maximise recruitment of controls. We reviewed our processes with Associate Professor Lawton and her team to identify opportunities for improvement. This helped to confirm that the mitigation strategies applied in the SUDI Nationwide Study were appropriate, and that the difficulties the team were experiencing were not unique.

Reasons for non-engagement with case families

In instances where the SUDI Liaison was not able to engage with families, the reasons included:

- Family refused to be seen, either directly or they were absent at the time of the arranged visit
- Caregivers, usually the infant's mother, became non-contactable (most common reason observed)

In general, case families that did not engage with the SUDI Liaison had a range of complexities affecting their family and social dynamics, which made successful engagement more challenging. Families with previous negative experiences with police either prior to, or at the time of the police response to the SUDI, was a key indicator of non-engagement; in addition to being known by police as having criminal connections, or previous offences for drugs or violence and outstanding warrants.

Recurring issues encountered by the SUDI Liaison team when engaging with families in the study are outlined below.

Table 4.4. Common issues affecting families in the study

Common issues affecting families in Case and Control groups
Common issues • Lack of housing or overcrowding, damp, mouldy, cold homes • Extreme poverty (in rural and urban settings) • Acute mental illness • Child protection for surviving siblings • Drug, alcohol, and other addictions • Involvement with the justice system • Marginalisation from mainstream agencies, systems, and services

Lower-level issues, although still important, related to safe environments and factors that contribute to (or reduce) wellbeing, such as smoking and safe sleeping. SUDI Liaison facilitated direct linkages for families with appropriate local services (usually health or social) based on families' needs and with their permission.

Collecting useful, accurate and timely data

A key outcome of the project was the provision of detailed, accurate, timely and consistent information about SUDI cases. The death scene investigation, doll reconstruction photographs and contextual, health-focused information increased the quality of data available about SUDI cases to coroners, pathologists, and mortality review committees. The feedback received about the project was that the information supplied assisted coroners and pathologists to understand more fully the circumstances surrounding each death. One coroner summed this up by stating that:

> Making accurate findings depends on quality and timely investigation. The information that the SUDI referral advisors gather – in particular, the reconstruction photos – and the timeliness of that information, has greatly enhanced the understanding of the circumstances of specific infant deaths. The advisors do an excellent job in this respect and engage effectively with families. Ultimately this benefits any prevention messages that Coroners make with a view to reducing similar deaths occurring in similar circumstances.

> – A New Zealand Coroner

Pathologists reported an increase in the ability to better understand the presence of certain risks, such as unsafe sleeping situations:

> Since we have been receiving this information from the SUDI coordinators our diagnostic ability to determine accidental asphyxia as the cause of death has increased, whereas previously these cases would have been labelled as Undetermined. As pathologists we received very little additional information apart from an extremely brief summary. Information regarding the scene, and in particular dangerous sleeping environments, was sorely lacking. Of no surprise then is that most cause of deaths were listed as Undetermined.
>
> – Forensic Pathologist

Maximising participation of Controls

The challenges with contacting control families were ongoing. The regions with the lowest recruitment uptake by the control group were Upper and Central North Island. In these areas, of all potential controls, one third participated, approximately one third refused and one third could not be contacted. The latter was largely considered to be a socioeconomic/demographic issue. For example, in the South Island the participation rate was satisfactory. In the North Island, regardless of whether the family were Māori, Pasifika or Pakeha, it was more difficult to recruit families into the research. A SUDI Liaison noted that:

> …it was usually the younger mums that gave an initial yes. My view is they said yes then changed their minds and it was easier to avoid my attempts at contacting them than saying no.
>
> - SUDI Liaison

A change in approach to recruiting controls in these areas was adopted, including:

- Calling using different telephones and at different times, including evenings and weekends, sending texts, and leaving a voicemail message as it was recognised that families ‘screen’ and avoid unwanted calls or unknown callers

- Liaising with Lead Maternity Carers to locate the mother/infant if they were still under care of the midwife who would introduce the study and provide the mother with SUDI Liaison contact details
- Requesting contact information from DHBs sooner to allow incorrect contact numbers to be identified as early as possible
- Providing a supermarket voucher in areas with lowest participation rates
- Liaising with well child providers, such as Plunket to engage with potential control mums and use of the national immunisation database to obtain accurate contact information
- Overall, each SUDI Liaison developed a tailored approach to engaging with families in the control and case groups in their respective regions; additionally, they used their comprehensive networks to increase the likelihood of successfully engaging with families. For example:

> For my region, I found sending the information letter was a useful way of introducing myself to the family and gaining their support for the study.
>
> - SUDI Liaison

4.5. Chapter summary

This chapter provided more information about the communications activities, including a stakeholder analysis, that identified the wide range of people, groups and organisations potentially affected by the study. The voices of stakeholders were represented through vignettes.

Chapter 5: Manuscript - Smoking in pregnancy is a key factor for sudden infant death among Māori (Paper 2)

The following manuscript was published in Acta Paediatrica by Wiley Online Library on 5th June 2018 and has been reproduced with permission.

MacFarlane, M., Thompson, J.M.D., Zuccollo, J., McDonald, G., Elder, D., Stewart, A.W., Lawton, B., Percival, T., Baker, N., Schlaud, M., Fleming, P., Taylor, B., Mitchell, E.A. (2018). Smoking in pregnancy is a key factor for sudden infant death among Māori. Acta Paediatrica., 2018, Vol 107(11), 1924-1931. doi/10.1111/apa.14431

5.1 Preamble

This chapter presents the results of an analysis on the drivers behind the difference in SUDI rates for Māori infants in New Zealand compared with non-Māori infants. As such, the paper seeks to explain the reasons for the persistent SUDI disparity experienced by Māori infants. Mitchell et al reported the very high risk to infants from the combination of maternal smoking and bed sharing (5). These factors interact in a way that amplifies the risks and combines to create a larger, more potent risk of SUDI for infants.

5.2 Manuscript

Abstract

Aim: To examine the sudden unexpected death in infancy (SUDI) disparity between Māori and non- Māori in New Zealand.

Methods: A nationwide prospective case–control study ran from March 2012 to February 2015. Exposure to established SUDI risk factors was analysed to investigate the disparity experienced by Māori. Infant ethnicity was based on mother's ethnicity. Māori ethnicity was prioritised. Non-Māori includes Pasifika, Asian, NZ European and Other.

Results: There were 137 cases and 649 controls. The Māori SUDI rate was 1.41/1000 live births compared to 0.53/1000 for non-Māori. Parents/caregivers of 132 cases (96%) and 258 controls (40%) were interviewed. Smoking in pregnancy was associated with an equally increased SUDI risk for Māori (adjusted OR = 8.11, 95% CI = 2.64, 24.93) and non-Māori (aOR = 5.09, 95% CI = 1.79, 14.47), as was bed-sharing (aOR = 3.66, 95% CI = 1.49, 9.00 vs aOR = 11.20, 95% CI = 3.46, 36.29). Bed-sharing prevalence was similar; however, more Māori controls smoked during pregnancy (46.7%) than non-Māori (22.8%). The main contributor relating to increased SUDI risk for Māori/non- Māori infants is the combination of smoking in pregnancy and bed-sharing.

Conclusion: The association between known SUDI risk factors, including bed sharing and/or smoking in pregnancy and SUDI risk, is the same regardless of ethnicity. Māori infants are exposed more frequently to both behaviours because of the higher Māori smoking rate.

Background

Sudden unexpected death in infancy (SUDI) is when an infant under one year of age dies suddenly, usually during sleep and initially without explanation. Sudden unexpected death in infancy is a broader term used to include sudden infant death syndrome (SIDS) deaths, which are deaths that remain unexplained even after a thorough investigation comprising full autopsy, clinical history and review of the circumstances of death. This includes a scene examination (4) and deaths where a possible cause may be identified, such as accidental asphyxia (148). Deaths where it may be an expected outcome, such as motor vehicle accidents, are excluded.

New Zealand has one of the highest post-neonatal (28–364 days) mortality rates among developed countries (148, 149). There has been a 29% reduction in overall post-perinatal (7–364 days) mortality from 2009 to 2015 (2.8 to 2.0/1000 live births) (77). SUDI rates for Māori have decreased but remain higher compared with non-Māori (148). Māori comprise less than a third of live births in New Zealand (150), yet half (49.6%) of the 137 SUDI cases between 2012 and 2015 were Māori (1.41 per 1000 live births), and overall, infants of Māori mothers were at an almost threefold risk of SUDI compared with infants of non-Māori/non-Pasifika mothers (5). The New Zealand Cot Death Study (1987–1990) identified key risk factors for SIDS and found that the higher SIDS rate among Māori, at that time, could be explained primarily by the higher exposure of Māori infants to smoking in pregnancy, bed sharing and their combination compared with non-Māori infants (27). The SUDI Nationwide Study (2012–2015) (5) reinvestigated the risk factors identified in the New Zealand Cot Death Study and specifically focussed on the sleep environment, which is crucial to the understanding of unexpected infant deaths.

The aim of this study was to examine the continuing disparity between Māori and non-Māori SUDI using data from the SUDI Nationwide Study. We hypothesised that the higher rates in Māori are due to the continuing higher prevalence of the combination of smoking and bed sharing.

Methods

The prospective case–control SUDI Nationwide Study was conducted across New Zealand from March 2012 to February 2015. Study methods and overall results have been reported in detail (5).

Cases

In New Zealand, sudden unexplained or unnatural deaths are referred to the Ministry of Justice for investigation by a coroner to identify causes and circumstances of death, to make recommendations to prevent similar deaths and to promote justice (139). During the study, infant deaths referred to the coroner were reviewed by the National Initial Investigation Office (NIIO). Deaths that appeared to meet the inclusion criteria were forwarded to the study project manager (MM). If NIIO staff were unsure whether a case was in scope, they notified the project manager who sought advice, if necessary, from the Principal Investigator (EAM).

Data on coronial infant deaths in the previous month and during the entire study were received from the Ministry of Justice, which enabled the project team to verify whether the criteria for cases were appropriately applied. Autopsies are performed in most SUDI cases by forensic or paediatric/perinatal pathologists. Autopsies followed a standard protocol modified from the International SUDI Protocol to align with cultural guidelines and the New Zealand Coroners Act (139).

Allocation of a cause of death

To classify cause of death for each case, an expert group met and reviewed the study data sets and pathology reports. The group comprised two pathologists, two paediatricians, a public health physician and the project manager. This process occurred independently from the certified cause of death, or the cause of death determined by the coroner.

Case definition

The following deaths were included:

- Clear asphyxia deaths occurring during sleep
- Unsafe sleeping, that is bed sharing with no direct evidence of facial occlusion wedging, sleeping on couch or in car seat
- Congenital anomalies, infection and other findings insufficient to explain the death
- Unascertained
- Unexplained causes of sudden unexpected death (in the presence of a normal history, autopsy and scene investigation, or SIDS)

The following deaths were excluded:

- Non-accidental injury, including suspected homicide and
- neglect, obvious accidental causes and concealed pregnancies
- No autopsy (due to parental objection)
- Perinatal asphyxia, antenatal problems and complications of prematurity
- Clearly identified cause at autopsy with prodromal symptoms and signs; and
- Congenital anomalies that clearly led to death.

Controls

Based on the distribution and characteristics of SUDI cases in New Zealand between 2003 and 2007, controls were randomly sampled and frequency-matched to cases by obstetric hospital of birth, sex, mother's ethnicity, and age at death. Infants were selected from hospital birth registers of each District Health Board (DHB) according to these criteria by a midwife or local coordinator of the DHB Perinatal Maternal Mortality Review Committee (PMMRC). Selecting infants in this way ensured the distribution and characteristics of cases and controls were similar regarding hospital of birth, ethnicity, sex and age.

Data collection

Data were collected through face-to-face interviews with parents/caregivers, usually the infants' mothers, who were responsible for the infant during the last sleep (cases) or nominated sleep (controls). Interviews were conducted by trained SUDI Liaison personnel and occurred at a time and place preferred by participants, usually at the family home. Each interview lasted 90–120 minutes. Occasionally, a second interview was necessary, for example, if one person placed the infant to sleep and another person found the infant unresponsive or awake, and this second person was unavailable at the first interview. Interviews were based on detailed, health-focused questionnaires that were virtually identical, except for the language around the last sleep (cases) or nominated sleep (controls).

During interviews, each mother self-identified her ethnicity/ethnicities (151). This report uses prioritised ethnicity to give a single ethnic group to each mother for analysis. Infants of Māori mothers are subsequently categorised as Māori infants. Māori is prioritised over all other ethnicities and is followed by Pasifika, Asian and NZ European/Other (151). Non-Māori includes Pasifika, Asian, NZ European and Other ethnicities.

Interview locations in the SUDI Nationwide Study

All interviews occurred at a time and place preferred by the participant in locations ranging from the Bay of Islands in the northern part of New Zealand, to Invercargill in the south. Interviews were most frequently conducted at the family's home by a member of the SUDI Liaison team. The next most common interview location was at a relative's home. Occasionally a public place such as a café was used, or the participant's workplace, social service provider facility, police station, mortuary, or occasionally, and for pragmatic and/or safety reasons, in the SUDI Liaison vehicle. Each interview took between 90-120 minutes. Interviews with participants in the case group would take place, wherever possible, where the infant had died to enable the collection of objective measures specific to the scene of death.

Recruitment of participants

All families received a letter with information about the study and an invitation to participate. Separate letters were developed for cases and controls. Follow-up telephone calls to control families were made within two weeks of the letter being sent. The calls provided opportunity to speak with parents/caregivers to clarify and/or provide information, repeat the invitation and arrange a time for an interview. In areas where families were highly transient, initial contact with control families was made by telephone, which enabled the accuracy of contact details to be confirmed quickly. The letter was delivered in person at the time of the control interview. Case families were initially contacted by telephone and received their letters at the interview.

Explanatory variables

The study investigated infant sleeping practices, antenatal and postnatal health and current living situation. Well Child/Tamariki Ora records, obstetric and medical records, where available, were reviewed, and a set of objective measures was obtained which included photographs of the sleep scene reconstruction (not part of this report).

Study size

All SUDI cases in New Zealand between 1 March 2012 and 28 February 2015 that met the SUDI criteria were eligible for the study. Based on previous SUDI mortality data (ref CYMRC 5th report), 210 SUDI cases were expected across the 36-month study period and a sample of 420 controls. If a risk factor had a prevalence of 20% in the control population, the study would be able to detect an odds ratio (OR) of 1.73 with a power of 80% at a level of significance of 5%. However, the participation rate of controls was lower than expected, so if a selected control could not be obtained, then a further control was selected. In total, 649 controls were selected.

Statistical methods

Univariable and multivariable analyses were undertaken to examine the relationships between variables for Māori and non-Māori. Unconditional multivariable logistic regression was used to adjust for potential confounders and determine the presence of interactions. The association of risk factors with SUDI was estimated using ORs with a 95% confidence interval.

Analyses were carried out in SAS (version 9.3, SAS Institute, Carry, NC, USA). This study applies the same statistical modelling used for the original publication based on these data (5). Sudden unexpected death in infancy mortality calculations were based on the number of live births in New Zealand between 2012 and 2014 (150). Population attributable risks (PAR) (152) were calculated for potentially modifiable risk factors.

Ethics approval

Ethics approval for the study was obtained from the Central Region Ethics Committee (CEN/11/09/045) and from selected DHBs to allow the study to receive information about infants selected as controls. All parents/caregivers provided informed written consent.

Results

During the study, 303 infant deaths referred to the coroner were considered for inclusion. One-hundred and thirty-seven deaths (45%) met the criteria for inclusion and of these, 96% (n=132) of parents/caregivers were interviewed. Figure 5.1 shows the flow of cases referred to the coroner and gives the reasons for exclusion. The 137 eligible cases were categorised in the following way:

- Clear asphyxia mechanism (n = 20)
- Unsafe sleeping (n = 50)
- Unsafe sleeping with minor findings not thought to have contributed to the death (n = 18)

- Presence of minor findings not thought to have contributed to the death, with no evidence of unsafe sleeping (n = 13)
- Unexplained (n = 36)

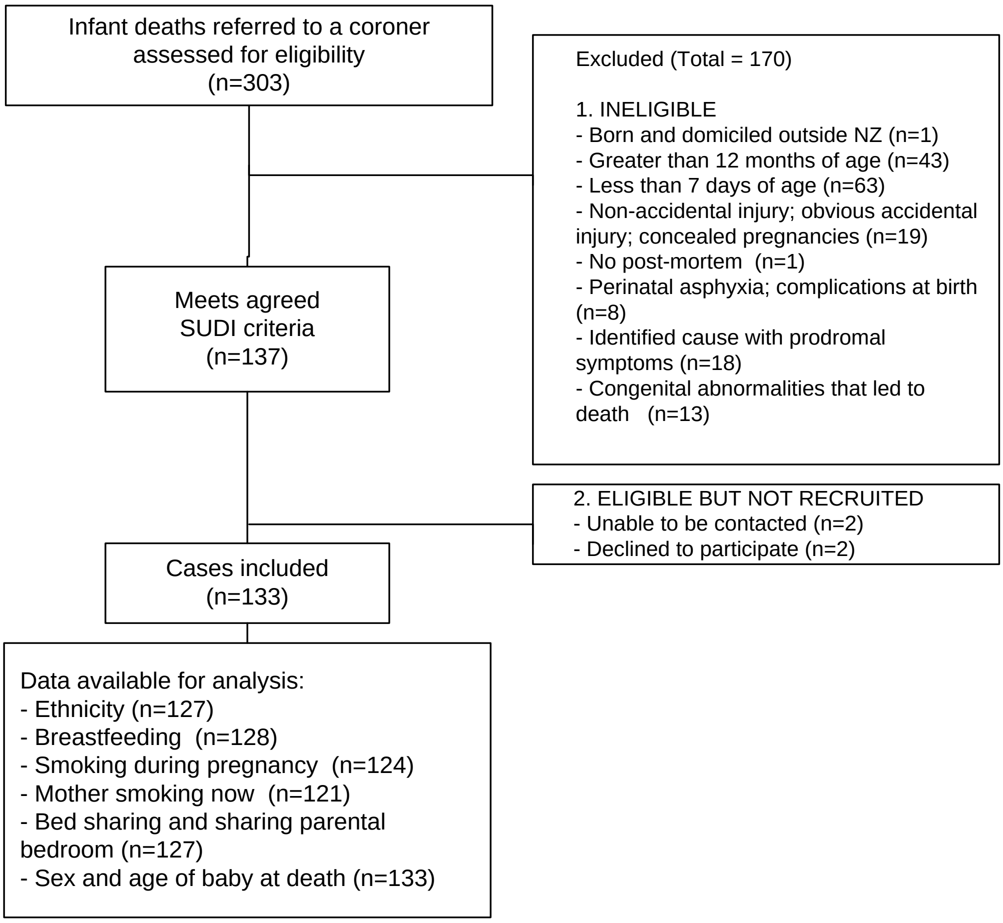


Figure 5.1. Participants in Case group – SUDI Nationwide Study

In total, 649 infants were selected for the control group and 258 (40%) participated in the study. Of the 391 mothers that were selected but did not participate in the study, 182 were uncontactable and 209 actively or passively refused to participate. Passive refusals included those that initially agreed to participate but then cancelled last-minute or were not at the agreed interview location and/or dropped out of contact. A breakdown of the number of participants selected, interviewed and excluded from the control group is shown in Figure 5.2.

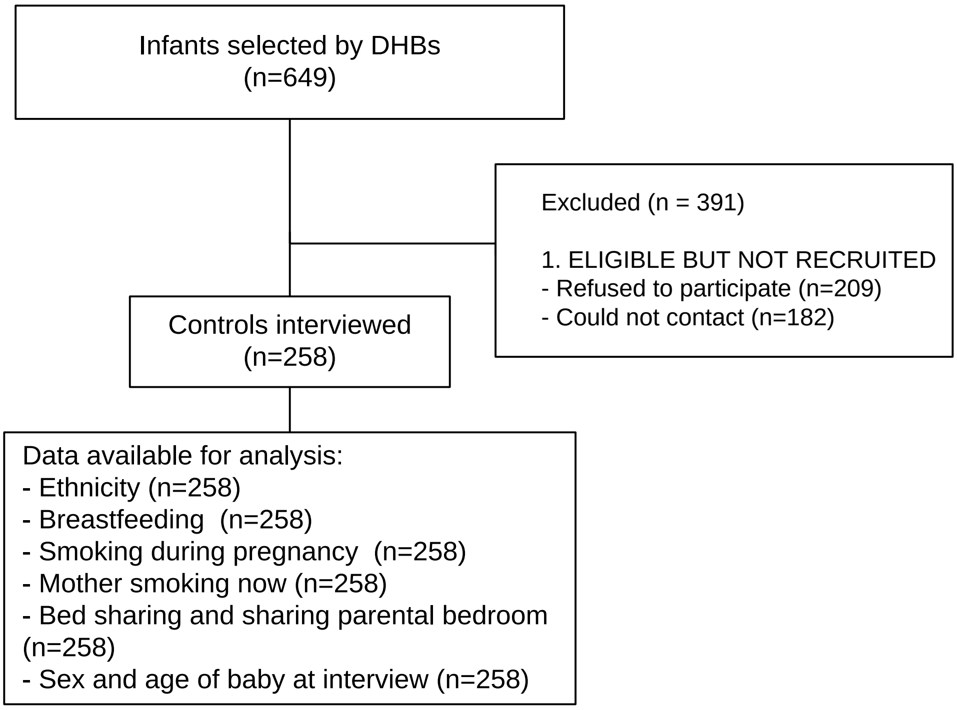


Figure 5.2. Participants in Control group – SUDI Nationwide Study

Māori infants comprised 49.2% of cases and 52.3% of controls. During the study, the SUDI mortality rate for Māori was 1.41 per 1000 live births compared to 0.53/1000 for non-Māori. The overall SUDI rate was 0.76/1000.

Magnitude of risk factors by ethnicity

Univariable and multivariable OR for sociodemographic, maternal, pregnancy, infant and infant care practice variables for Māori and non-Māori cases and controls are shown in Table 5.1. We adjusted for marital status.

Smoking during pregnancy was associated with a significantly increased risk of SUDI for Māori and non-Māori infants (Māori: adjusted OR = 8.11, 95% CI = 2.64, 24.93, and non-Māori: aOR = 5.09, 95% CI = 1.79, 14.47), as was bed sharing (Māori: aOR = 3.66, 95% CI = 1.49, 9.00; non-Māori aOR = 11.20, 95% CI = 3.46, 36.29). The magnitude of the risk did not differ by ethnicity (univariable interaction $x^2 = 0.35$, p = 0.55 and $x^2 = 0.00$, p = 0.96 respectively).

The effect of the combination of bed sharing and smoking in pregnancy for Māori and non-Māori was examined (Table 5.1). The risk for infants of mothers who smoked during pregnancy and bed shared was far greater than the risk for infants not exposed to smoking in pregnancy and bed sharing for both Māori and non-Māori (Māori: aOR = 22.71, 95% CI = 5.69, 90.68; non-Māori: aOR = 97.15, 95% CI = 15.50, 608.80). The ORs for prone sleep position (Table 5.1) for Māori (aOR = 5.45, 95% CI = 0.87, 34.22) and non-Māori (aOR = 3.45, 95% CI = 0.56, 21.16) were not statistically significantly different (interaction x^2= 5.28, p = 0.07); neither were the ORs for Māori and non-Māori infants not sharing the parental bedroom (aOR = 1.72, 95% CI = 0.71, 4.19 vs aOR = 6.31, 95% CI = 2.03, 19.56 respectively; interaction x^2= 0.70, p = 0.40).

Prevalence of risk factors in controls

Māori mothers in the control group were less likely to be married (p < 0.0001), and more likely to have smoked in pregnancy (p < 0.0001) than non-Māori mothers in the control group. The prevalence of all other risk factors did not differ significantly between Māori and non-Māori (Table 5.2).

The prevalence of bed sharing among Māori and non-Māori controls was similar at 18.5% and 17.1% respectively (p = 0.76); however, fewer non-Māori infants were exposed to the combination of smoking in pregnancy and bed sharing compared with Māori (3.3% vs 9.6%, p = 0.046). Overall, 63.4% of non-Māori infants in the control group were not exposed to either bed sharing or smoking in pregnancy compared with 44.4% of Māori infants.

Population attributable risk

The PAR results in Table 5.2 indicate the percentage by which SUDI could be reduced if Māori and non-Māori populations were unexposed to specific factors, compared with current levels of exposure, assuming that the factor was causally related to SUDI. As the magnitude of the ORs for smoking in pregnancy and bed sharing do not differ for Māori or non-Māori, PAR calculations using the all-ethnicities ORs reported by Mitchell et al. (5) provide a more accurate estimate of the magnitude of the risk; and indicates that the PAR is being driven entirely by the difference in the magnitude of exposure. The PAR for smoking in pregnancy for Māori and non-Māori was 67% and 49% respectively. For bed sharing, it was 49% for Māori and 47% for non-Māori. Māori infants not sharing the parental bedroom had a PAR of 19% compared to 29% for non-Māori. The PAR for the combination of smoking in pregnancy and bed sharing was 74% for Māori and 50% for non-Māori.

Discussion

Māori had the highest SUDI rate of 1.41/1000 (49.6% of all cases) compared to 0.53/1000 for non-Māori. Smoking in pregnancy was more prevalent among Māori cases and controls (86.9% and 46.7%) than non-Māori (61.9% and 22.8%). Bed sharing has been described as a dynamic, cultural practice among certain ethnic groups, including Māori (84). Unexpectedly, and in contrast to the New Zealand Cot Death Study, the prevalence of bed sharing was similar for Māori and non-Māori cases and controls (Māori: 58.1% and 18.5% respectively; non-Māori 56.3% and 17.1%). Bed sharing prevalence was consistent with a previous local study reporting that 17% of six-week-old infants sometimes bed shared (78).

The interaction between bed sharing and smoking in pregnancy showed no difference in the magnitude of the risk between Māori and non-Māori. Thus, the risk for infants from bed sharing and smoking combined is the same, regardless of ethnicity. We have previously reported that the risk of SUDI is 32-times higher than the risk for infants not exposed to bed sharing or smoking in pregnancy (5). The higher prevalence of smoking in Māori means that Māori infants are more likely to be exposed to the dangerous combination of bed sharing and smoking, as illustrated in the control group where 9.6% of Māori infants were exposed to both risk factors compared with 3.3% of non-Māori infants.

Overall, there was no statistical difference between Māori and non-Māori cases and controls regarding number of previous live births, maternal age, being a twin, sex of the infant, birthweight, front and side sleep position, ever having breastfed, sharing the parental bedroom and bed sharing.

Strengths and limitations

The high participation rate among cases (96%) was a key strength of the study, as was the fact that only one case was excluded due to no post-mortem examination.

Limitations included fewer cases (n = 137) than the 210 expected during the study, which reduced the power to detect the ORs planned; this was partially tempered by an increased control ratio.

The reduced number of cases represents a reduction in SUDI deaths across the study period (77). Contributing to this is the Safe Sleep Programme, which provides universal education and supplies safe sleep devices to families in specific areas and to infants with greater exposure to known SUDI risk factors (77). Safe sleep devices include traditionally woven Māori flax baskets called wahakura, and specially designed lined plastic containers called Pēpi-pods®. Wahakura and Pēpi-pods® were developed in New Zealand specifically to support safe infant sleep and infant bed sharing.

Having fewer SUDI cases in the study affected the ability to identify differences between the case and control groups. Due to our interest in the differences between both groups, families in the control group were selected using previous SUDI mortality data to maximise internal validity and enable the comparison of groups with similar characteristics. Because SUDI had occurred more frequently among families in lower socioeconomic areas, Māori populations and smokers, the control group reflects a higher proportion of SUDI risks than those in a nationally representative sample. As has been seen previously, controls selected from groups with greater risks and lower socioeconomic status, were less likely to participate (153). Transiency and turnover of mobile telephones were high among the control group. Overall, 60% of selected controls did not participate.

A potential limitation is that disparities in the clinical pathways experienced by Māori mothers in this study were not examined. Previous studies have shown that Māori mothers are less likely to attend antenatal services (10) or they attend late, after the first trimester (154). Māori mothers are also more likely to receive lesser quality of care from health services (155). Mothers who are unmarried, high parity, of low socioeconomic status and low educational attainment are also more likely to have reduced uptake of antenatal services and to experience inadequate antenatal care, which is associated with poor clinical outcomes (154, 156, 157).

In contrast, adequate and early uptake of antenatal services provides the opportunity for health screening, education, and interventions (158, 159), such as smoking cessation and infant safe sleep advice. In this study, those who refused or did not participate are more likely to be in this group. The low participation rate among the control group provides a proxy marker of reduced access and uptake to antenatal services and healthcare in general, and of the increased prevalence of higher risk behaviours. The very high risk of SUDI from the combination of smoking in pregnancy and bed sharing is highlighted by the PAR for Māori, which suggests that 74% of Māori SUDI could be prevented if the combination of these two behaviours was eliminated or the link was broken. For non-Māori, the potential reduction in

SUDI from not smoking in pregnancy or not bed sharing or from avoiding both behaviours is 50%, due to the lower prevalence of risk factors in this group.

This study compares Māori with non-Māori, rather than with non-Māori/non-Pasifika. Several reasons underpin this approach. Māori is the most adversely affected ethnic group in New Zealand in relation to SUDI. Māori experience systemic disparities and poorer health outcomes than the non-Māori population (17-20, 160) and improving health outcomes for Māori is a government priority. This extends to entities such as DHBs, which have a statutory responsibility for reducing Māori health inequalities (17, 19, 160-162).

Māori are indigenous to New Zealand and the Treaty of Waitangi (the Treaty) is one of New Zealand's founding documents. The principles of the Treaty are embedded into government policy and strategy in acknowledgement of the Crown's obligations as a Treaty partner. In recognition of this historical and contemporary context, this study has prioritised its focus on the SUDI disparities experienced by Māori. This does not detract from the burden of SUDI experienced by Pasifika families, whose rate is second to Māori. However, the small number of Pasifika infants in the study limits our ability to draw meaningful conclusions. To support the government's goal of reducing the SUDI rate to 0.1/1000 by 2025 (20) the Ministry of Health has funded a new national SUDI prevention programme to coordinate and report nationally on evidence- and outcomes-based SUDI prevention efforts. While SUDI has long been a significant health inequity for Māori, there is now increased potential to reduce the SUDI disparity experienced by Māori.

Conclusion

This analysis found that the magnitude of risk for the factors examined did not differ between Māori and non-Māori, although the prevalence of being unmarried and smoking in pregnancy was higher among Māori. This reinforces the view that ethnicity per se is not a risk factor for SUDI (27).

Acknowledgements

The authors thank and acknowledge Judge Neil MacLean (immediate past Chief Coroner of New Zealand) and the Ministry of Justice, including NIIO, the coroners and all members of the SUDI Study Steering Committee; Whakawhetū (Māori SUDI Prevention) and Taha (Pasifika SUDI Prevention); SUDI Liaison Team Trainer, Ms Yvonne Ledesma-Allard, Miami-Dade Medical Examiner's Office, Miami, Florida, USA; Communio and the SUDI

Liaison Team, past and present members; and most importantly, the infants and families who participated in the study and/or have been affected by SUDI.

Funding

We thank the Health Research Council of New Zealand for funding the feasibility study and SUDI Nationwide Study and Cure Kids for their support of EAM and JMDT during the SUDI Nationwide Study.

This research was conducted during tenure of a ‘Māori Health PhD Scholarship’ of the Health Research Council of New Zealand.

Conflict of interest

The authors report no conflict of interests.

Key notes (included with published paper)

The combination of smoking in pregnancy and bed sharing is the main contributor relating to increased sudden unexpected death in infancy (SUDI) risk for Māori and non-Māori infants.

The association between these, and other known SUDI risk factors, and SUDI risk is the same regardless of ethnicity.

Māori infants are exposed more frequently to both behaviours because of the higher Māori smoking rate.

Table 5.1: The number (percentage) or mean (SD) and univariable and multivariable odds ratios (95% CI) of sociodemographic, pregnancy, infant and infant care practice variables by Māori and non-Māori.

	Māori				**Non-Māori**			
Variable	**Cases n (%)**	**Controls n (%)**	**Univariable OR (95% CI)**	**Multivariable OR (95% CI)**	**Cases n (%)**	**Controls n (%)**	**Univariable OR (95% CI)**	**Multivariable OR (95% CI)**
Marital Status (missing=23)								
			p=0.09	p=0.94			**p=0.009**	p=0.51
Married	3 (5.4)	25 (18.5)	Reference	Reference	16 (28.6)	64 (52.9)	Reference	Reference
Cohabiting	31 (55.4)	64 (47.4)	4.03 (1.13, 14.40)	0.89 (0.16, 4.87)	22 (39.3)	36 (29.8)	2.44 (1.14, 5.24)	1.94 (0.63, 5.94)
Single	22 (39.3)	46 (34.1)	3.98 (1.09, 14.62)	1.04 (0.18, 5.98)	18 (32.1)	21 (17.4)	3.43 (1.49, 7.90)	1.36 (0.39, 4.72)
Number of previous live births (missing=13)								
			p=0.0001	p=0.06			**p=0.005**	p=0.25
0	31 (50.8)	25 (18.5)	Reference	Reference	32 (54.2)	34 (27.6)	Reference	Reference
1	8 (13.1)	31 (23.0)	0.21 (0.08, 0.53)	0.18 (0.05, 0.67)	6 (10.2)	31 (25.2)	0.21 (0.08, 0.56)	0.24 (0.06, 0.99)
2	7 (11.5)	19 (14.1)	0.30 (0.11, 0.82)	0.37 (0.09, 1.50)	9 (15.3)	22 (17.9)	0.44 (0.17, 1.08)	0.82 (0.22, 3.04)
3+	15 (24.6)	60 (44.4)	0.20 (0.09, 0.44)	0.34 (0.10, 1.14)	12 (20.3)	36 (29.3)	0.35 (0.16, 0.80)	0.63 (0.18, 2.16)
Maternal age at birth (mean years, SD) (missing=11)								

	Māori				Non-Māori			
			p=0.004	p=0.16			**p=0.0004**	p=0.224
Age in years	24.9 (6.6)	28.0 (7.0)	0.93 (0.89, 0.98)	0.95 (0.88, 1.02)	25.8 (6.4)	29.5 (6.1)	0.91 (0.86, 0.96)	0.95 (0.88, 1.03)
Smoking during pregnancy (missing=9)								Univariable interaction x^2 =0.35, p=0.55
			p<0.0001	**p=0.0003**			**p<0.0001**	**p=0.002**
No	8 (13.3)	72 (53.3)	Reference	Reference	24 (38.1)	95 (77.2)	Reference	Reference
Yes	52 (86.7)	63 (46.7)	7.57 (3.35, 17.13)	8.11 (2.64, 24.93)	39 (61.9)	28 (22.8)	5.51 (2.85, 10.67)	5.09 (1.79, 14.47)
Multiple birth (missing=5 cases)								
			p=0.28	p=0.49			p=0.98	p=0.98
No	60 (93.75)	131 (97.0)	Reference	Reference	60 (93.8)	123 (100)	Reference	Reference
Yes	4 (6.25)	4 (3.0)	2.18 (0.53, 9.03)	2.23 (0.23, 22.00)	4 (6.3)	0 (0)	Undefined	Undefined
Infant sex (missing=0)								
			p=0.25	p=0.78			p=0.78	p=0.08
Female	29 (43.9)	48 (36.6)	Reference	Reference	27 (40.3)	47 (38.2)	Reference	Reference
Male	37 (56.1)	87 (64.4)	0.70 (0.39, 1.28)	0.88 (0.37, 2.09)	40 (59.7)	76 (61.8)	0.92 (0.50, 1.68)	0.42 (0.16, 1.11)
Birthweight (mean gms, SD) (missing n=14)								

	Māori				Non-Māori			
			p=0.0004	p=0.33			**p=0.005**	p=0.21
Weight in grams	3049.6 (619.3)	3414.2 (614.0)	1.00 (1.00, 1.00)	1.00 (1.00, 1.00)	3265.2 (605.3)	3523.0 (538.4)	1.00 (1.00, 1.00)	1.00 (1.00, 1.00)
Position placed to sleep (missing=7)								Univariable interaction x^2 =5.72, p=0.06
			p<0.0001	**p=0.029**			p=0.63	p=0.41
Back	38 (59.4)	118 (87.4)	Reference	Reference	45 (72.6)	97 (78.9)	Reference	Reference
Side	18 (28.1)	11 (8.2)	5.08 (2.21, 11.71)	3.73 (1.07, 13.06)	13 (21.0)	20 (16.3)	1.40 (0.64, 3.07)	1.19 (0.32, 4.39)
Front	8 (12.5)	6 (4.4)	4.14 (1.35, 12.69)	5.45 (0.87, 34.22)	4 (6.5)	6 (4.9)	1.44 (0.39, 5.35)	3.45 (0.56, 21.16)
Ever breastfed (missing=5)								Univariable interaction x^2 =1.38, p=0.24
			p=0.22	p=0.58			**p=0.028**	p=0.10
Yes	57 (89.1)	127 (94.1)	Reference	Reference	58 (90.6)	121 (98.4)	Reference	Reference
No	7 (10.9)	8 (5.9)	1.95 (0.68, 5.64)	0.56 (0.07, 4.34)	6 (9.4)	2 (1.6)	6.26 (1.23, 31.96)	6.03 (0.72, 50.73)
Sharing the parental bedroom (missing=6)								Univariable interaction x^2 =0.60, p=0.44
			p=0.014	p=0.23			p=0.17	**p=0.001**
Yes	34 (54.0)	97 (71.9)	Reference	Reference	35 (54.7)	80 (65.0)	Reference	Reference
No	29 (46.0)	38 (28.2)	2.18 (1.17, 4.05)	1.72 (0.71, 4.19)	29 (45.3)	43 (35.0)	1.54 (0.83, 2.85)	6.31 (2.03, 19.56)

	Māori				**Non-Māori**			
Bed sharing (missing=6)							Univariable interaction x^2 =0.00, p=1.0	
			p<0.0001	**p=0.005**			**p<0.0001**	**p<0.0001**
No	26 (41.3)	110 (81.5)	Reference	Reference	28 (43.8)	102 (82.9)	Reference	Reference
Yes	37 (58.7)	25 (18.5)	6.26 (3.23, 12.16)	3.66 (1.49, 9.00)	36 (56.3)	21 (17.1)	6.25 (3.16, 12.35)	11.20 (3.46, 36.29)

Interactions shown in heading lines are univariable. Bold indicates significant at the 5% level. *Variables in model: ethnicity, marital status, number of previous live births, maternal age, antenatal smoking in pregnancy, multiple birth, sex, birthweight, age of infant, position placed to sleep, ever breastfed, sharing parental bedroom and bed sharing.

Table 5.2: Bed sharing and antenatal smoking in pregnancy combinations and the risk of SUDI for Māori and non-Māori

		Māori				**Non-Māori**			
		Cases	**Controls**	**Univariable**	**Multivariable***	**Cases**	**Controls**	**Univariable**	**Multivariable***
Smoking in pregnancy	**Bed-sharing**			**p<0.0001**	**p<0.0001**			**p<0.0001**	**p<0.0001**
No	No	6 (10.0)	60 (44.4)	Reference	Reference	15 (23.8)	78 (63.4)	Reference	Reference
No	Yes	2 (3.3)	12 (8.9)	1.67 (0.30, 9.27)	0.52 (0.05, 5.75)	9 (14.3)	17 (13.8)	2.75 (1.03, 7.33)	3.60 (10.87, 14.96)
Yes	No	20 (33.3)	50 (37.0)	4.00 (1.50, 10.73)	3.91 (1.12, 13.62)	12 (19.1)	24 (19.5)	2.6 (1.07, 6.31)	1.55 (0.40, 5.97)
Yes	Yes	32 (53.3)	13 (9.6)	24.62 (8.54, 70.92)	22.71 (5.69, 90.68)	27 (42.9)	4 (3.3)	35.10 (10.71, 114.97)	97.15 (15.50, 608.80)

*Bed sharing and antenatal smoking combinations were adjusted for ethnicity, marital status, number of previous live births, maternal age, antenatal smoking in pregnancy, multiple birth, sex, birthweight, age of infant, position placed to sleep, breastfeeding and sharing parental bedroom.

Table 5.3. – Comparison of the prevalence of risk factors for SUDI in controls by Māori and non-Māori

Variable	**Māori, n (%) n=135**	**Non-Māori, n (%) n=123**
Marital Status (missing=2)		x^2=33.59, **p<0.0001**
Married	25 (18.5)	64 (52.9)
Cohabiting	64 (47.4)	36 (29.8)
Single	46 (34.1)	21 (17.4)
Number of previous live births (missing=0)		x^2=7.05, p=0.07
0	25 (18.5)	34 (27.6)
1	31 (23.0)	31 (25.2)
2	19 (14.1)	22 (17.9)
3+	60 (44.4)	36 (29.3)
Maternal age at birth in mean years (SD) (missing=0) t=-1.84, p=0.07		
Age in years	28.0 (7.0)	29.5 (6.1)
Smoking during pregnancy (missing=0)		x^2=16.11, **p<0.0001**
No	72 (53.3)	95 (77.2)
Yes	63 (46.7)	28 (22.8)
Multiple birth (missing=0)	x^2=3.70, Fisher exact p=0.15	
No	131 (97.0)	123 (100)
Yes	4 (3.0)	0 (0)
Baby sex (missing=0)		x^2=0.20, p=0.66
Female	48 (36.6)	47 (38.2)
Male	87 (64.4)	76 (61.8)
Birthweight in mean gms (SD)		t=1.52, p=0.13
Weight in grams	3414.2 (614.0)	3523.0 (538.4)
Age of infant in mean weeks (SD)		t=0.39, p=0.70
Age in weeks	15.1 (11.0)	15.6 (9.6)
Position placed to sleep (missing=0)		x^2=4.12, p=0.13
Back	118 (87.4)	97 (78.9)
Side	11 (8.2)	20 (16.3)
Front	6 (4.4)	6 (4.9)

Variable		**Māori, n (%) n=135**	**Non-Māori, n (%) n=123**
Ever breastfed (missing=0)			x^2=3.19, p=0.07
Yes		127 (94.1)	121 (98.4)
No		8 (5.9)	2 (1.6)
Sharing the parental bedroom (missing=0)			x^2= 1.39 p=0.24
Yes		97 (71.9)	80 (65.0)
No		38 (28.2)	43 (35.0)
Bed sharing (missing=0)			x^2=0.09, p=0.76
No		110 (81.5)	102 (82.9)
Yes		25 (18.5)	21 (17.1)
Bed sharing and maternal smoking in pregnancy n (%)			x^2=3.48, p=0.32
Smoking in pregnancy	**Bed sharing**		
No	No	60 (44.4)	78 (63.4)
No	Yes	12 (8.9)	17 (13.8)
Yes	No	50 (37.0)	24 (19.5)
Yes	Yes	13 (9.6)	4 (3.3)

Table 5.4: Proportion of the population exposed to risk (p), relative risk (OR) and population attributable risk (PAR) for Māori and non-Māori seen in this study.

		Māori		**Non-Māori**	
	OR*	**p**	**PAR**	**p**	**PAR**
Smoking in pregnancy	5.28	0.467	0.67	0.228	0.49
Bed sharing	6.23	0.185	0.49	0.171	0.47
Not sharing parental bedroom	1.84	0.282	0.19	0.350	0.29
Smoking in pregnancy/bed sharing	31.1	0.096	0.74	0.033	0.50

*The odds ratios used in Table 5.4 relate to the all-ethnicity odds ratios reported by Mitchell et al (5)

Chapter 6: Manuscript - Infant sleep hazards and the risk of sudden unexpected death in infancy (Paper 3)

The following manuscript was published in the Journal of Pediatrics (online ahead of print) on 2nd February 2022 and has been reproduced with permission.

MacFarlane M, Thompson JM, Wilson J, Lawton B, Taylor B, Elder D, Baker N, McDonald GK, Zuccollo J, Schlaud M, Fleming P, Mitchell EA. (2022). Infant sleep hazards and the risk of sudden unexpected death in infancy. The Journal of Pediatrics., 2022 Feb 2. **https://doi.org/10.1016/j.jpeds.2022.01.044**

6.1 Preamble

This paper builds on the research in the previous chapter by examining several additional risks in the infant sleep environment and the relationship of these with sudden unexpected death in infancy (SUDI). The use of sofas as infant sleep spaces, especially alongside other people, increases an infant's risk of SUDI (112, 113). Alcohol and drug use by caregivers also raises the level of risk for infants (96, 112, 113). The findings of the study add to the current body of knowledge about infant risk of SUDI.

6.2 Manuscript

Abstract

Aim: To examine the effects of infant sofa-sleeping, recent use by caregivers of alcohol, cannabis, and/or other drugs, and bed type and pillows, on the risk of sudden unexpected death in infancy (SUDI) in New Zealand.

Methods: A nationwide prospective case–control study was implemented between March 2012 and February 2015. Data were collected during interviews with parents/caregivers. "Hazards" were defined as infant exposure to 1 or more of sofa-sleeping and recent use by caregivers of alcohol, cannabis, and other drugs. The interaction of hazards with tobacco smoking in pregnancy and bed sharing, including for very young infants, and the difference in risk for Māori and non-Māori infants, also were assessed.

Results: The study enrolled 132 cases and 258 controls. SUDI risk increased with infant sofa-sleeping (imputed aOR [IaOR] 24.22, 95% CI 1.65-356.40) and with hazards (IaOR 3.35, 95% CI 1.40-8.01). The SUDI risk from the combination of tobacco smoking in pregnancy and bed sharing (IaOR 29.0, 95% CI 10.10-83.33) increased with the addition of 1 or more hazards (IaOR 148.24, 95% CI 15.72-1398), and infants younger than 3 months appeared to be at greater risk (IaOR 450.61, 95% CI 26.84-7593.14).

Conclusions: Tobacco smoking in pregnancy and bed sharing remain the greatest SUDI risks for infants and risk increases further in the presence of sofa-sleeping or recent caregiver use of alcohol and/or cannabis and other drugs. Continued implementation of effective, appropriate programs for smoking cessation, safe sleep, and supplying safe sleep beds is required to reduce New Zealand SUDI rates and SUDI disparity among Māori.

Introduction

Sudden infant death syndrome (SIDS) is a diagnosis of exclusion for infant deaths that remain unexplained despite a thorough investigation comprising a detailed clinical history, review of circumstances, scene examination, and full autopsy (2).

However, deaths once certified as SIDS often are labelled as accidental suffocation and strangulation in bed (*International Classification of Diseases* code W75), or ill-defined and unspecified (R99) (6). The term SUDI (sudden unexpected death in infancy) is commonly used in one of two ways (3). The first describes the unexpected death of an infant younger than 1 year of age and usually during sleep. After investigation, some of these deaths are explained, for example, previously unrecognised cardiac anomalies and metabolic abnormalities. The second way combines three *International Classification of Diseases* diagnoses: R95 (SIDS), W75, and R99, which together, capture deaths previously labelled as SIDS. We use SUDI in this second way, consistent with its use by the Centers of Disease Control and Prevention, the American Academy of Pediatrics, and the Ministry of Health in New Zealand.

Bed sharing, when an infant is asleep on the same sleep surface as one or more other sleeping individuals (11), is known to increase the risk of SUDI, especially among very young infants (5), and features in more than one-half of all SUDI cases in New Zealand (5, 81). The combination of tobacco smoking in pregnancy and bed sharing creates a dangerous interaction that increases an infant’s risk of SUDI (5).

There is contention that bed sharing is only a risk if smoking or some other hazard is present (96). However, there is evidence that bed sharing continues to present some risk of SUDI in the absence of smoking and other hazards (5), including infant sleeping on a sofa, and recent use by caregivers of alcohol and/or cannabis and other drugs. Sofas have been shown to be unsafe for infant sleep (112, 113), particularly when shared with one or more sleeping individuals, and especially when the individuals have used alcohol or drugs recently (96, 112, 113). Infants asleep on a sofa, alone or with others, are potentially at risk of suffocation from overlay or becoming wedged against the sofa or the narrow, sloping seats (96, 113). Recent use of alcohol and drugs by caregivers is also associated with increased SUDI risk, especially when combined with bed sharing on any surface (96). Cannabis is used relatively commonly among pregnant and non-pregnant women, and men and women at conception and postnatally (117-119).

We investigated the risk of SUDI from hazards related to the infant sleep environment and the sleep environment itself, including for very young infants. The interaction of hazards with tobacco smoking in pregnancy and bed sharing were assessed, as was the difference in risk of hazards for indigenous New Zealand Māori and non-Māori infants.

Methods

The New Zealand case-control SUDI Nationwide Study was conducted between March 2012 and February 2015, inclusive. The study, which has previously been reported in detail (5), investigated infant sleep practices, antenatal and postnatal health, and infant living situations in relation to SUDI.

Cases

All cases were SUDI deaths in New Zealand during the study period. All such deaths are investigated by a coroner and include a police investigation, a SUDI Liaison (trained investigator) interview, and full autopsy. Cause of death (SIDS, ill-defined and unspecified, and accidental suffocation and strangulation in bed) was determined by an expert group after all investigations had concluded, independent of the coronial system. Deaths from other causes were excluded (5).

Controls

Controls were randomly sampled after frequency-matching to cases by obstetric hospital of birth, sex, maternal ethnicity (as recorded in hospital birth registers, which was confirmed during the interview), and age at interview aligned with the distribution of New Zealand SUDI cases between 2003 and 2007. Due to the control group being frequency matched in proportion to infants in the 2003-2007 SUDI cohort in respect of obstetric hospital of birth, sex, maternal ethnicity and infant age at death, the control group in this study was of greater risk of SUDI compared with a nationwide population-based representative sample.

The control group was selected to reflect the characteristics of the population most at risk from SUDI and allows the identification of more subtle differences between cases and controls. A District Health Board (DHB) midwife or mortality review committee coordinator identified the randomised infants from hospital birth registers according to these criteria.

Data collection

SUDI Liaison personnel collected data during face-to-face interviews with mothers, or other caregivers, responsible for the infant during the last sleep (cases) or nominated sleep (controls). Each control infant was allocated a nominated sleep time to reflect the distribution of the time of the last sleep of cases in previous years. If the infant was asleep at the nominated time, this sleep was explored during the interview. If the infant was awake at the time of the nominated sleep, the sleep explored during the interview was either the sleep period prior to, or after this nominated time. The direction was randomly attributed as part of the selection criteria.

Interviews lasting 90–120 minutes occurred at participants' homes and followed detailed, health-focused questionnaires that differed for cases and controls only in reference to the last or nominated sleep. Objective measures, general observations, and scene reconstruction photographs (not part of this report) were also obtained for the study, plus a separate dataset for each SUDI case's coroner. Mothers self-identified their ethnicity during the interviews (151). Where possible, relevant child health, obstetric and medical records were reviewed.

Recruitment

All families received an information letter inviting them to participate. Separate letters were developed for cases and controls. The SUDI Liaison telephoned control families within a fortnight of sending the letter to provide information and arrange an interview, if possible. In one DHB area (of relatively low socioeconomic status), controls were first contacted by telephone to enable timely confirmation of contact details. Case families were telephoned as soon as possible. Case families received their letters at the interview.

Explanatory variables

The three primary variables hypothesised to be associated with potentially hazardous situations within the sleep environment were infant sofa-sleeping for the last or nominated sleep; and recent use of alcohol and/or cannabis or other drugs, within 24 hours of the last (cases) or nominated (controls) sleep by the person who placed the infant to sleep and/or cared for them during sleep.

The number of standard alcoholic drinks consumed in the 24 hours preceding the nominated or last sleep (for controls and cases respectively) was collected. One standard drink in New

Zealand contains 10 grams of alcohol, for example, 100ml of table wine (12.5% alcohol), or 330ml of beer (4% alcohol) (163).

We examined these three hazards' variables to estimate the risk they pose individually and collectively ("combined hazards") to all cases and controls. We also stratified the sample by infant age to assess the effects of the hazards, tobacco smoking in pregnancy and/or bed sharing on the risk of SUDI among very young case and control infants (<3 months).

When determining the presence of hazards, an affirmative response ("yes") to any hazard variable was coded as "yes"; a hazard variable was coded as "no" if participants responded "no" to each of the hazards, or they were otherwise coded as missing. The presence of hazards was also assessed for any interaction with tobacco smoking in pregnancy, bed sharing or both. We define bed sharing as one or more individuals asleep with an infant on the same sleep surface, regardless of surface type.

Other sleep environment-related variables collected were type of bed, presence of pillows and their position in relation to the infant, how firmly bedding was tucked in, and whether other items were present when the infant was placed in a cot (crib) or cot-type bed e.g., cot bumpers or toys.

A cot-type bed is of similar shape to a cot and is specifically designed – or intended – for infant sleep. It includes cots, bassinets, Moses baskets, and safe infant sleep beds (*wahakura* and Pēpi-pods (89, 164). Mattress softness was measured by passing a 2kg weight through the aperture of a specially constructed board and measuring the depression in the mattress (165). Using the re-enactment dolls, mattress softness measurements in millimetres were taken in the location of the infant's chest when they were placed to sleep, and again where they were found unresponsive (cases) or awake (controls). All weights, boards, and dolls in each research kit were the same weight and size for consistency. Data on tobacco smoking in pregnancy and bed sharing were collected during interviews. Infant ethnicity was based on mothers' self-identified ethnicity at the time of interview.

Sample size

All infant deaths in New Zealand from March 2012 to February 2015 that met the criteria for SUDI were eligible for the study. Based on previous SUDI mortality data (82), 210 cases were expected across the 36-month study period and a sample of 420 controls. The number of SUDI cases was less than expected due to a decrease in unexpected infant deaths during the study period (77).

If a risk factor had a prevalence of 20% in the control population, the study could detect an odds ratio (OR) of 1.73 or higher with a power of 80% at a level of significance of 5%. However, fewer than expected controls participated in the study. To counter this, if a selected control could not be enrolled, a further control was selected.

Imputation and sensitivity modelling

Datasets of 90 participants (cases: n = 59, 44.7%; controls: n = 31, 12.0%) had missing data related to the hazards, tobacco smoking in pregnancy, and/or bed sharing. We used the multiple imputation procedure in SAS (version 9.4, SAS Institute) (166) to create 100 imputed datasets based on the distribution of characteristics and patterns of responses from the available data using infant sex, infant age, last bed sleep, bed sharing, breastfed, maternal smoking in pregnancy, maternal age, infant birth weight, parity, marital status, alcohol use, and drug use. Logistic regression models were run for each of the 100 imputed datasets and the MIANALYZE procedure was used to combine variable estimates and produce one set of odds ratios. The MI and MIANALYZE procedures assume that data are missing at random.

Data analyses

Univariable and multivariable analyses examined relationships between the relevant variables and the risk of SUDI. Unconditional multivariable logistic regression was used to adjust for potential confounders and determine the presence of interactions. The association of risk factors with SUDI was estimated using OR with a 95% CI. Analyses were carried out in SAS (version 9.4, SAS Institute). Logistic regression was applied using the SAS logistic procedure.

The covariates from the previous publication (5) were included in the multivariable models. These were maternal ethnicity, maternal age, parity, marital status, infant age, infant sex, birth weight, breastfeeding status, multiple birth status, sharing the parental bedroom, position placed to sleep, tobacco smoking in pregnancy, and bed sharing. We also examined interactions between the hazards, smoking in pregnancy, and bed sharing and the effects of the hazards on Māori and non-Māori. SUDI mortality rates were calculated using the number of live births between 2012 and 2014 inclusive (150). Although the controls were frequency matched based on the distribution of cases from 2003 to 2007, there is no guarantee that this will reflect the distribution of these variables within the cases during the study period. Thus, the variables that are used for frequency matching are controlled for in analyses. The ORs for these variables are not reported as they do not reflect the true level of risk associated with these variables, including them in the model simply helps to adjust for imbalances caused by the change in the distribution of these variables from that expected. These variables are not analysed in relation to hazards, except for purposes of stratification by ethnicity.

Ethics

The study received ethics approval from the Central Region Ethics Committee (CEN/11/09/045) and locality assessment was received from all DHBs. All parents/caregivers provided informed, written consent.

Results

During the three-year study, 303 infant deaths were referred to a coroner, of which 137 (45%) were classified as SUDI and eligible for the study. Of these, 96% (n=132) of families were interviewed, as were 40% (n=258/649) of selected control infants/mothers. Cases' interviews occurred between 24 hours and 7 days of death. Of the 391 controls who did not participate, 182 were uncontactable, and 209 refused, or accepted but were not available to interview. Approximately one-half of the infants in the case and control groups were Māori (49.2% and 52.3%, respectively). Overall, the national SUDI rate during the study period was 0.76 in 1000 live births (5). The national SUDI rates for Māori and non-Māori were 1.41 in 1000 and 0.53 in 1000 live births, respectively (167).

As reported previously, infant exposure to the combination of bed sharing and tobacco smoking in pregnancy statistically significantly increases the risk of SUDI (5). This dangerous combination was reconfirmed in the present study through analyses of imputed and unimputed data (imputed aOR [IaOR] 29.0, 95% CI 10.10-83.33; unimputed aOR 22.67, 95% CI 6.0-85.66). There was no statistically significant increase in risk associated with bed sharing on its own (IaOR 1.79, 95% CI 0.59-5.43; unimputed data aOR 1.96, 95% CI 0.46-8.41). Alone, tobacco smoking in pregnancy was associated with a significantly increased risk of SUDI (IaOR 2.53, 95% CI 1.04-6.11), which was not evident in the unimputed analysis (aOR 0.84, 95% CI 0.24-2.96).

Risks from exposure to the hazards

Sofa sleeping

Although uncommon (cases: n=11, 8.7%; controls: n=1, 0.4%), an infant sleeping on a sofa during the last or nominated sleep was associated with a significantly increased risk of SUDI (IaOR 24.22, 95% CI 1.65-356.40; unimputed aOR 38.43, 95% CI 2.13-692.50) (Table 6.1).

All 12 infants who slept on a sofa did so during the night or early morning. Of the 11 infants who died while asleep on a sofa, eight were sharing the sofa with their mother at the time.

Recent use of alcohol by caregivers

Recent use of alcohol by caregivers during the last sleep was reported in one-quarter of cases for whom data were available (n = 18, 25.4%) compared with 7.2% of controls (n = 17). Caregivers of cases who drank alcohol consumed a median of four standard drinks compared with caregivers of controls for whom one standard drink was the median. Alcohol consumption by caregivers did not result in a statistically significant increased risk of SUDI in the imputed analysis (aOR 2.40, 95% CI 0.90-6.39), but it did reach statistical significance in the unimputed analysis (aOR 3.04, CI 1.04-8.89) (Table 6.1).

Recent use of cannabis and other drugs by caregivers

Few caregivers reported recent use of cannabis and other drugs (cases: n = 6, 8.0%; controls: n = 1, 0.4%), and usage was not statistically significantly associated with SUDI (IaOR 6.92, 95% CI 0.59-81.02; unimputed aOR 6.41, 95% CI 0.44-94.26) (Table 6.1).

Risk from the combined hazards

The exposure of infants to one or more of the hazards (sofa-sleeping and recent use by caregivers of alcohol and of cannabis and other drugs) was reported in 43.2% of cases (n = 32) and 8.4% (n = 19) of controls (only three cases and no controls were exposed to two or more hazards). Exposure to one or more of these factors was associated with a significant increase in the risk of SUDI (IaOR 3.35, 95% CI 1.40-8.01; unimputed aOR 5.39, 95% CI 2.16-13.46) (Table 6.1).

Effects of the hazards on Māori and non-Māori

Māori infants exposed to 1 or more hazards, specifically sofa-sleeping, or recent use by caregivers of alcohol and/or cannabis and other drugs, were at a statistically significant increased risk of SUDI in the multivariable imputed analysis (aOR 6.51, 95% CI 1.67-25.46), whereas this did not reach statistical significance in non-Māori infants (aOR 1.92, 95% CI 0.54-6.86, respectively). However, a test for an interaction of hazards in Māori participants compared with non-Māori participants did not reach statistical significance (imputed p = 0.12, unimputed p = 0.14) (Table 6.2).

Risk from the hazards in combination with bed sharing and tobacco smoking in pregnancy

There was no statistically significant increased risk of SUDI associated with the presence of one or more of sofa-sleeping and/or recent use by caregivers of alcohol and/or cannabis and other drugs (IaOR 1.99, 95% CI 0.43-9.24; unimputed aOR 2.36, 95% CI 0.47-11.85). Similarly, the risk of bed sharing combined with one or more hazards did not reach statistical significance (IaOR 1.68, 95% CI 0.11-26.04; unimputed aOR undefined). However, these results are based on very low numbers (Table 6.3).

In the imputed and unimputed analyses for infants exposed to tobacco smoking in pregnancy plus one or more hazards (IaOR 13.02, 95% CI 2.85-59.37; unimputed aOR 12.31, 95% CI 2.62-57.83) (Table 6.3), a statistically significant increased SUDI risk was identified.

Although the combination of bed sharing, tobacco smoking in pregnancy, and the hazards increased the SUDI risk dramatically (IaOR 148.24, 95% CI 15.72-1398.31; unimputed aOR 159.89, 95% CI 15.28 to >999.999), this estimate is based on a single control (0.4%) reported to have been exposed to this combination, compared with approximately 20% of cases (Table 6.3).

Risk for very young infants

Infants younger than 3 months of age are at a statistically significant increased risk of SUDI when sleeping in a bed sharing situation even when not exposed to tobacco smoking in pregnancy and hazards (IaOR 10.65, 95% CI 1.55-73.11; unimputed aOR 15.95, 95% CI 1.33-191.14). The risk escalates further with the addition of tobacco smoking in pregnancy (IaOR 190.57, 95% CI 24.53-1480.30; unimputed aOR 180.77, 95% CI 11.10 to >999.999). Very young infants exposed to bed sharing, tobacco smoking in pregnancy, and one or more of sofa-sleeping and recent use by caregivers of alcohol, cannabis, or other drugs, are at extremely high risk of SUDI (IaOR 450.61, 95% CI 26.84-7593.14), although this is based on small numbers (Table 6.4).

Imputed versus unimputed analyses

The estimated ORs using imputed and unimputed data in multivariable analyses were all similar, except one. The OR associated with smoking in pregnancy showed no increased risk in the unimputed analysis but did show a two-fold increased risk in the imputed analysis.

Bed type

Infants who slept in an adult bed, or on a sofa or other surface, either alone or with another person, all showed a similar level of increased SUDI risk compared with infants who slept in a cot or cot-type bed (adult bed: unimputed unadjusted OR 7.14, 95% CI 4.33-11.75; and sofa/other OR 7.12, 95% CI 3.15-16.08). Pillows were more likely to be used by case infants compared with controls during the last or nominated sleeps (n = 72, 69.3%; n = 77, 30.4%, respectively). A univariable analysis based on unimputed data on the effect of pillows in the bed but not under the infant, identified an increased risk of SUDI (OR 3.83, 95% CI 2.06-7.11). The risk further increased (OR 6.55, 95% CI 3.69-11.62) when pillows were positioned underneath the infant (Table 6.5). The degree to which infants were tucked into their beds, whether in cots, adult beds, or sofas, was associated with SUDI risk. Being firmly or very firmly tucked compared with not tucked was protective (OR 0.24, 95% CI 0.13-0.44) (Table 6.5).

Mattress softness

Mattress softness measurements indicated very little difference in the softness of sleep surfaces of cases and controls between being placed to sleep and being found unresponsive (cases) or awake (controls). However, increased mattress softness was seen among cases and controls (23.3 mm vs 21.2 mm) when placed and showed a statistically significant relationship to SUDI risk (unimputed aOR 1.05 per mm, 95% CI 1.00, 1.10; p = 0.03) (Table 6.5). This equates to an increased risk of 1.63 per centimetre. Based on the difference between cases and controls of 2.1 mm, the increase in risk is approximately 1.11 for the average case, compared with the average control. The large SD indicates that some infants were at a marked increased risk due to mattress softness.

Cot bumpers and toys

Cot bumpers were used by a small proportion of infants (cases: n = 3, 11.1%; controls: n = 37, 19.8%) and did not present a significant increased risk of SUDI (OR 0.51, 95% CI 0.15-1.77). Likewise, soft toys in the cot were present in seven (30.4%) cases and 49 (26.3%) controls and did not show a significant risk (OR 1.22, 95% CI 0.48-3.15) (Table 6.5).

Discussion

We have shown that the prevalence of hazardous situations, in which infants are exposed to sleeping on a sofa, or to caregivers that have recently used alcohol and/or cannabis and other drugs (controls <0.5%, 7.2%, and <0.5%, respectively), is low in our high-risk control population. However, in situations where they do exist, the risk to infants appears to be very high, particularly in combination with maternal smoking and bed sharing.

The size of the infant population at risk from sofa-sleeping is unclear, as few studies have investigated this practice in detail. Infant deaths on sofas have been associated with side sleeping, changes in infant sleep location, and/or bed type by caregivers during the last sleep, exposure to tobacco smoking in pregnancy, and infants sleeping with others on a sofa (112). Of the hazardous situations reported in this study, very few infants slept on sofas (controls n = 1; cases n = 11). The eight infants who died while sharing the sofa were placed and found during the night and early morning, and they were at statistically significant increased risk of SUDI, which is consistent with previous research in this area (96, 112, 113).

The effects of habitual alcohol intake on the risk of SUDI are uncertain, as previous studies have found nil or weak evidence (71). In the present study, recent use of alcohol and/or cannabis and other drugs by caregivers was uncommon in the study population, and individually there was no statistically significant effect on SUDI risk when analysis was carried out using imputed data. Few caregivers in the control group reported using alcohol before or during the nominated sleep (7.2%). In comparison, the Ministry of Health's New Zealand Annual Survey reported that 20% of adults aged 15 years or older drank hazardously in the 12 months to mid-2019 (120). Although pregnant women and women of child-bearing age would likely comprise only a small portion of these figures, it may suggest that mothers in the control group were adhering to national guidance to avoid alcohol during infant care. Alternatively, the knowledge that they were drinking whilst caring for an infant could have led to under reporting.

New Zealand research in the 1990s reported that recent maternal alcohol use was not an independent risk factor for SUDI (71). An analysis of pooled data from five case–control studies—of which a large proportion of the alcohol data was imputed—concluded that infants of all ages of mothers who consumed two or more units of alcohol, room-shared, and had a non-smoking partner, but did not bed share or use drugs or have any other risk factors, were at an approximate five-fold increased risk of SUDI (79).

In our multivariable analyses, the imputed data showed no statistically significant increased risk for recent use by caregivers of alcohol (IaOR 2.40, 95% CI 0.90-6.39 vs aOR 3.04, 95% CI 1.04-8.89) or cannabis and other drugs (IaOR 6.92, 95% CI 0.59-81.02 vs aOR 6.41, 95% CI 0.44-94.26). In the 2012/2013 New Zealand-wide health survey, 8% of women aged 15 years and older reported using cannabis in the previous 12 months (121). As with alcohol use, this could indicate that mothers in the control group, who were generally the main caregivers, followed general health advice not to use cannabis while caring for their infant. Previous New Zealand–based and international research has reported regular cannabis use as a weak risk factor for SUDI (168), and that maternal cannabis use during pregnancy was not associated with an increased risk of SUDI after controlling for tobacco smoking in pregnancy (117).

The prevalence of the hazards (sofa-sleeping, caregiver use of alcohol, and/or cannabis and other drugs) was low in this study. However, the presence of multiple hazards increased the risk of SUDI, especially for very young infants (younger than three months of age). The key driver of risk in the interactions was tobacco smoking in pregnancy, whether in combination with bed sharing, or one or more hazards, or both. No other individual factor or combination was significant without smoking.

It should be noted that for young infants, bed sharing without exposure to tobacco smoking or hazards was associated with a statistically significant increased risk of SUDI. This contrasts with the contention of others that it is the presence of smoking or hazards that cause the increased risk associated with bed sharing.

The CIs for the interactions of the combined hazards, bed sharing, and tobacco smoking in pregnancy are wide, due to the very low prevalence of hazards in the control population. This suggests that the missing data were associated with smoking. This is feasible, as the missing data were predominantly from the case group, where Māori were over-represented, and Māori are known to have greater smoking rates than non-Māori (167).

The sleep environment is important as most SUDI deaths happen during sleep, and particularly overnight (14, 169). Detailed guidelines exist around the safety or otherwise of bed clothes, pillows, and other items in the sleep environment (169). Research has been carried out in relation to thermoregulation (114, 169) but few studies have investigated the physical nature of the sleep environment, including the surface, bedding, and items such as soft toys.

Cots or similar were the most common type of bed used among the controls and remain the safest place for infants to sleep. Pillows in the infant sleep environment have previously been reported as a danger to infants (115, 170), as has the use of soft bedding during bed sharing (171). This analysis further adds to this evidence and suggests an increased risk when pillows are in the sleep environment, and a greater risk when under the infant. No risk was observed in this study in relation to cot bumpers or toys in the cot.

The degree to which infants were tucked in, whether in a cot, adult bed, or sofa, was associated with SUDI risk. Being firmly or very firmly tucked in was protective (OR 0.24, 95% CI 0.13-0.44), compared with being untucked, loosely tucked, or uncovered (Table 6.5). These findings echo those of the New Zealand Cot Death Study (1989-1991), in which firm tucking contributed to reducing the risk of SUDI (170).

There was no discernible difference in SUDI risk among Māori and non-Māori controls in relation to use of a sofa as the nominated sleep space and/or recent use by caregivers of alcohol and/or cannabis and other drugs. This suggests that our previous findings, in which smoking in pregnancy is the key difference in the disparity in SUDI experienced by Māori compared with non-Māori, are still accurate (167). We note that maternal smoking of tobacco during pregnancy and after the birth of the child is highly correlated, but the effect of smoking in utero on the foetus is profound, resulting in reduced birthweight and reduced arousal response. (109, 172-174).

Key strengths of the study were the inclusion of nearly all eligible cases (96%), and the collection of complete datasets from controls. Limitations included a lower-than-expected response rate for controls and missing data across the variables for cases, compared with controls, although this has been mitigated by imputation. Imputation helped to minimise the issue of missing data, but it is also a limitation. However, a sensitivity analysis of the original individual participant data meta-analysis of SIDS and bed sharing showed that the results were consistent with the imputed results, suggesting we can have confidence in the imputed results (175).

The combination of tobacco smoking in pregnancy and bed sharing continues to present the greatest SUDI risk for infants, and very young infants are at even greater risk, which further increases with each additional hazard (sofa-sleeping and/or recent use by caregivers of alcohol and/or cannabis and other drugs). For infants younger than three months, bed sharing even without smoking and hazards is associated with an increased risk of SUDI. Further initiatives are required to address the environment in which a large proportion of SUDI deaths occur. Given that smoking remains a pivotal and modifiable risk factor, there is continued need for the implementation of effective, appropriate programmes for smoking cessation, safe sleep, and the supply of safe sleep beds, to reduce SUDI rates in New Zealand and address the significant and ongoing SUDI disparity among Māori and other vulnerable populations.

Acknowledgements

We extend our sincere thanks to the following people and organisations: the immediate past and present Chief Coroners of New Zealand, Judge Neil MacLean and Judge Deborah Marshall, and the Ministry of Justice, including the National Initial Investigation Office and the coroners; members of the SUDI Study Steering Committee; and to previous organisations, Whakawhetū (Māori SUDI Prevention) and Taha (Pasifika SUDI Prevention).

Special thanks to the SUDI Liaison Team Trainer, Ms Yvonne Ledesma, Lead SUID Investigator, Miami-Dade Medical Examiner’s Office, Florida, USA; and Mr David Aro, Communio Consultancy, for implementing the study; and the past and present members of the national SUDI Liaison Team, especially Ms Shelley Jonas and Ms Elaine McLardy. Above all, heartfelt thanks to the infants and families who participated in the study or have been affected by SUDI. This research was conducted during the Lead Author’s tenure of a ‘Māori Health PhD Scholarship’ of the Health Research Council of New Zealand.

Table 6.1. Effects of the hazards (sofa-sleeping and/or recent use by caregivers of alcohol and/or cannabis and other drugs) among cases and controls

	Cases (%) n=132	**Controls (%) n=258**	**Unimputed**		**Imputed**	
			Univariable OR (95% CI)	**Multivariable* aOR (95% CI)**	**Univariable OR (95% CI)**	**Multivariable* aOR (95% CI)**
Sofa-sleeping during the last sleep (cases) or nominated sleep (controls)	(Missing = 5)	(Missing = 0)				
Yes	11 (8.7)	1 (0.4)	24.37 (3.11, 190.99)	38.43 (2.13, 692.50)	23.50 (3.00, 184.09)	24.22 (1.65, 356.40)
No	116 (91.3)	257 (99.6)	Reference	Reference	Reference	Reference
Alcohol in last 24 hours	(Missing = 61)	(Missing = 22)				
Yes	18 (25.4)	17 (7.2)	4.38 (2.11, 9.06)	3.04 (1.04, 8.89)	3.26 (1.59, 6.68)	2.40 (0.90, 6.39)
No	53 (74.6)	219 (92.8)	Reference	Reference	Reference	Reference
Drugs (cannabis or other drugs †) in last 24 hours	(Missing = 57)	(Missing=197)				
Yes	6 (8.0)	1 (0.4)	21.57 (2.55, 182.15)	6.41 (0.44, 94.26)	12.48 (1.49, 104.76)	6.92 (0.59, 81.02)
No	69 (92.0)	248 (99.6)	Reference	Reference	Reference	Reference

	Cases (%) n=132	**Controls (%) n=258**	**Unimputed**		**Imputed**	
			Univariable OR (95% CI)	**Multivariable* aOR (95% CI)**	**Univariable OR (95% CI)**	**Multivariable* aOR (95% CI)**
Hazards combined (one or more hazards)	(Missing = 58)	(Missing = 31)				
Yes	32 (43.2)	19 (8.4)	8.34 (4.32, 16.09)	5.39 (2.16, 13.46)	4.88 (2.58, 9.20)	3.35 (1.40, 8.01)
No	42 (56.8)	208 (91.6)	Reference	Reference	Reference	Reference

*Covariates used in the multivariable analysis include maternal ethnicity, marital status, parity, infant sex, twin, breastfed, sharing parental bedroom, position placed to sleep, maternal age at birth of infant, baby birthweight, baby's age. † Cases: methadone n=2; and herbal highs n=1; controls: nil other drugs reported.

Table 6.2. Effects of the hazards (sofa-sleeping and/or recent use by caregivers of alcohol and/or cannabis and other drugs) on Māori and non-Māori controls

Māori						
	Māori Cases (%) n=62	**Māori Controls (%) n=135**	**Unimputed**		**Imputed**	
			Univariable OR (95% CI)	**Multivariable aOR (95% CI)**	**Univariable OR (95% CI)**	**Multivariable aOR (95% CI)**
Hazards	(Missing = 22)	(Missing = 20)		p=0.14		p=0.12
Yes	19 (47.5)	7 (6.1)	13.96 (5.22, 37.37)	10.02 (2.46, 40.88)	8.53 (3.31, 22.01)	6.51 (1.67, 25.46)
No	21 (52.5)	108 (93.9)	Reference	Reference	Reference	Reference
Non-Māori						
	Non-Māori Cases (%) n=70	**Non-Māori Controls (%) n=123**	**Unimputed**		**Imputed**	
			Univariable OR (95% CI)	**Multivariable aOR (95% CI)**	**Univariable OR (95% CI)**	**Multivariable aOR (95% CI)**
Hazards	(Missing = 28)	(Missing = 23)				
Yes	13 (38.2)	12 (10.7)	5.16 (2.07, 12.88)	2.76 (0.66, 11.54)	3.09 (1.28, 7.48)	1.92 (0.54, 6.86)
No	21 (61.8)	100 (89.3)	Reference	Reference	Reference	Reference

Table 6.3. The risk of SUDI in combination with bed sharing, tobacco smoking in pregnancy, and hazards (sofa-sleeping and/or recent caregiver use of alcohol and/or cannabis and other drugs)

	Unimputed data			Imputed data		
	Cases (%) n=73 (Missing = 59)	**Controls (%) n=227** (Missing = 31)	**Multivariable aOR (95% CI)**	**Cases (%) n=132** (Missing = 0)	**Controls (%) n=258** (Missing = 0)	**Multivariable aOR (95% CI)**
Bed sharing only	4 (5.5)	24 (10.6)	1.96 (0.46, 8.41)	11 (8.3)	27 (10.5)	1.79 (0.59, 5.43)
Smoking only	9 (12.3)	60 (26.4)	0.84 (0.24, 2.96)	25 (18.9)	68 (26.4)	2.53 (1.04, 6.11)
Smoking + bed sharing	18 (24.7)	13 (5.7)	22.67 (6.0, 85.66)	38 (28.8)	16 (6.2)	29.0 (10.10, 83.33)
Hazards (1 or more)	3 (4.1)	11 (4.8)	2.36 (0.47, 11.85)	4 (3.0)	12 (4.7)	1.99 (0.43, 9.24)
Hazards + bed sharing	1 (1.4)	2 (0.9)	<0.001 (<0.001, >999.999)	2 (1.5)	2 (0.8)	1.68 (0.11, 26.04)
Smoking + hazards	8 (11.0)	5 (2.2)	12.31 (2.62, 57.83)	10 (7.6)	6 (2.3)	13.02 (2.85, 59.37)
Smoking + hazards + bed sharing	20 (27.4)	1 (0.4)	159.89 (15.28, >999.999)	24 (18.2)	1 (0.4)	148.24 (15.72, 1398.31)
None	10 (13.7)	111 (48.9)	Reference	19 (14.4)	126 (48.8)	Reference

Table 6.4. Very young infants (<3 months) and the risk of SUDI in combination with bed sharing, tobacco smoking in pregnancy, and hazards (sofa-sleeping and/or recent caregiver use of alcohol and/or cannabis and other drugs)

	Unimputed data			**Imputed data**		
	Cases (%) n=37 (Missing=27)	**Controls (%) n=119** (Missing=20)	**Multivariable aOR (95% CI)**	**Cases (%) n=64** (Missing=0)	**Controls (%) n=139** (Missing=0)	**Multivariable aOR (95% CI)**
Bed sharing only	4 (10.8)	9 (7.6)	15.95 (1.33, 191.14)	7 (11.1)	10 (7.1)	10.65 (1.55, 73.11)
Smoking only	2 (5.4)	33 (27.7)	0.88 (0.06, 12.75)	6 (9.2)	38 (27.0)	1.59 (0.23, 10.72)
Smoking + bed sharing	10 (27.0)	6 (5.0)	180.77 (11.10 to >999.999)	24 (37.0)	6 (4.3)	190.57 (24.53, 1480.30)
Hazards (one or more)	0 (0.0)	3 (2.5)	<0.001 (<0.001 to >999.999)	0 (0.3)	4 (2.8)	NA
Hazards + bed sharing	0 (0.0)	1 (0.8)	<0.001 (<0.001 to >999.999)	0 (0.7)	1 (0.8)	NA
Smoking + hazards	2 (5.4)	3 (2.5)	8.33 (0.38, 182.89	3 (4.2)	5 (2.5)	9.05 (0.54, 152.17)
Smoking + hazards + bed sharing	15 (40.5)	1 (0.8)	514.26 (17.22 to >999.999)	18 (27.4)	1 (0.7)	450.61 (26.84, 7593.14)
None	4 (10.8)	63 (52.9)	Reference	6 (10.1)	76 (54.7)	Reference

Table 6.5. Bed used for last (cases) and nominated (controls) sleep

Place of last/nominated sleep	**Cases (%) n=132**	**Controls (%) n=258**	**Unimputed Univariable OR (95% CI)**
Bed sharing	(Missing = 6)	(Missing = 0)	p=<0.0001
No	53 (42.1)	212 (82.2)	Reference
Yes	73 (57.9)	46 (17.8)	6.35 (3.94, 10.22)
Last bed	(Missing = 5)	(Missing = 0)	p=<0.0001
*Cot/cot-type bed	39 (30.7)	196 (76.0)	Reference
Adult bed	71 (55.9)	50 (19.4)	7.14 (4.33, 11.75)
**Sofa/other	17 (13.4)	12 (4.7)	7.12 (3.15, 16.08)
Pillows used	(Missing = 28)	(Missing = 4)	p=<0.0001
No pillows	32 (30.8)	177 (69.7)	Reference
Yes, under baby	45 (43.3)	38 (15.0)	6.55 (3.69, 11.62)
Yes, but not under baby	27 (26.0)	39 (15.4)	3.83 (2.06, 7.11)
How firmly baby was tucked in when placed to sleep	(Missing = 29)	(Missing = 6)	p=<0.0001
Not tucked (including no bedding over baby) or loosely tucked	64 (62.1)	97 (38.5)	Reference
Neither loosely nor firmly tucked	23 (22.3)	52 (20.6)	0.67 (0.37, 1.20)
Firmly or very firmly tucked	16 (15.5)	103 (40.9)	0.24 (0.13, 0.44)
Sub-section Last Bed = Cot (or similar)	(Missing = 93)	(Missing = 62)	
Cot bumpers or similar in the cot	(Missing = 105)	(Missing = 71)	p=0.29
Yes	3 (11.1)	37 (19.8)	0.51 (0.15, 1.77)
No	24 (88.9)	150 (80.2)	Reference

Soft toys in the cot	(Missing = 109)	(Missing = 72)	p=0.68
Yes	7 (30.4)	49 (26.3)	1.22 (0.48, 3.15)
No	16 (69.6)	137 (73.7)	Reference
Objective measures of mattress softness	(Missing = 77)	(Missing = 59)	
Mattress softness where placed (mm)	23.3 mm (SD 5.9)	21.2 mm (SD 6.6)	p=0.03 1.05 (1.00, 1.10)
Mattress softness where found/woke (mm)	23.0 mm (SD 6.3)	21.3 mm (SD 6.7)	p=0.09 1.04 (0.99, 1.09)

*Cot-type beds - Controls: Pēpi-Pod® x6, Moses basket x8, hammock x2, Wahakura x1; Cases: Pēpi-Pod® x1, hand-made or household item x1. **Other - Controls: pushchair x2, held/cradled x2, car x1, sofa-bed x1 and bouncer x1; Cases: nil.

Part Two: Summary

This section focused on the epidemiological research contained in this thesis. A high-level description, with more detailed information was provided on the methods used to implement the New Zealand SUDI Nationwide Study (2012-2015). Chapters 5 and 6 comprise the epidemiological manuscripts, which focus on the SUDI experiences of Māori in New Zealand, and the hazards in the infant sleep environment that increase the risk of SUDI. Information specific to the SUDI Nationwide Study (2012-2015) is in Appendix A.

Part Three: Qualitative research

This section focuses on the qualitative research undertaken to explore the infant sleep practices and key factors that influence mothers with young infants who were living in a geographic area with a high incidence of SUDI. Part Three includes the paper based on the qualitative research (published) and the supplementary information.

Mehemea ka moemoeā ahau, ko ahau anake.
Mehemea ka moemoeā e tatou, ka taea e tatou

If I am to dream, I dream alone
If we all dream together, then we will achieve
Te Puea Herangi

Chapter 7: Manuscript - Pēpē-infant sleep practices and sudden unexpected death in infancy (SUDI) in Aotearoa New Zealand (Paper 4)

The following manuscript was accepted for publication in the International Journal of Gynecology & Obstetrics, Special Issue: A Call for Action in Indigenous and First Nations Women's Health and Wellbeing, by Wiley Online Library in November 2021 and has been reproduced with permission.

MacFarlane M, Thompson JM, Mitchell EA, Lawton B, McLardy EM, Jonas SD, et al. Pēpē‐infant sleep practices and sudden unexpected death in infancy (SUDI) in Aotearoa New Zealand. International Journal of Gynecology & Obstetrics., 2021, Vol.155(2), 305-17. DOI: doi.org/10.1002/ijgo.13910

7.1 Preamble

This paper arose from concern regarding the persistent over-representation of Māori infants in SUDI mortality in New Zealand, and the high number of deaths associated with bed sharing (5, 81). Previous studies have described bed sharing as a cultural practice that is natural and dynamic (84), but one that can be difficult for parents to achieve, regardless of a preference for their infant to sleep alone (86). The following paper builds on these concepts and explores the motivation that drives the decision-making by Māori and non-Māori mothers with regards to infant sleep.

7.2 Manuscript

Tuhinga Whakarāpopoto [Abstract]

Whainga [Aim]: To explore pēpē [infant] sleep practices and the key motivators among selected Māori and non-Māori māmā [mothers] in Auckland, New Zealand, in relation to the risk of sudden unexpected death in infancy (SUDI).

Tikanga [Method]: Qualitative research underpinned by a kaupapa Māori cultural framework was undertaken. In-depth face-to-face interviews occurred in the homes of māmā with young pēpē born in Counties Manukau, Auckland. Interview transcripts were analysed using general purpose thematic analysis.

Ngā putanga [Results]: Thirty māmā participated, including 17 Māori. Two-thirds of māmā reported previous or current bed sharing. The fundamental human need for adequate sleep motivated half the māmā in the present study, and especially Māori māmā, to bed share. The second most common reason given was closeness and convenience. This was followed by breastfeeding, which was cited as a reason by Māori māmā only. These findings were interpreted in terms of intrinsic fear, culture, and māmā deployment of knowledge.

Whakatau mutunga [Conclusion]: Service providers are encouraged to respond to the lived experiences and cultural realities, values, and beliefs of māmā when designing and delivering effective SUDI prevention interventions. Innovative approaches for providing structured and opportunistic, culturally appropriate education and support around safe sleep are likely to be well-received by māmā and their whānau [family/ies]. Māmā, partners, and the wider whānau have the capacity and capability to practice safe sleep at every sleep, for their treasured pēpē.

Kupu whakataki [Introduction]

Sleep is essential to human growth, development, and psychological wellbeing. Parents attempt to fulfil their own and their infants' sleep requirements against a backdrop of life's daily demands and other driving forces, including personal experience, knowledge, culture, and beliefs (46, 84, 86).

Pēpē [infant/s] bed sharing is defined as a pēpē asleep on the same surface as one or more other sleeping individuals (11), and is common in different cultures worldwide (176, 177), although there are differences in rates and methods (178). Reasons for bed sharing tend to include parental concerns about pēpē night waking, to comfort pēpē, bonding/closeness, enjoyment, having nowhere else for pēpē to sleep (83, 86), and most commonly, for breastfeeding (45, 179).

Māmā [mother/s] have described bed sharing as a natural, dynamic, and cultural practice (84, 177). Studies in the USA and England report bed sharing as being relatively common, occurring with almost half of participating pēpē (176, 180). Bed sharing occurs more frequently in communities with low socioeconomic status compared with those of higher socioeconomic status (176) and in pēpē of minority racial or ethnic groups (45). Studies in Aotearoa-New Zealand have reported prevalence of pēpē bed sharing in the range of 8.5% to 17.8% (5, 54, 85); however, the samples in these studies are not necessarily representative of the whole pēpē population. A recent nationwide case-control study found no difference in the prevalence of bed sharing between indigenous Aotearoa New Zealand Māori and non-Māori New Zealanders (167).

Despite potential benefits for māmā and pēpē, bed sharing is a risk factor for sudden and unexpected death in infancy (SUDI), and whānau [family/ies] are advised not to bed share (Table 7.1). SUDI occurs in pēpē under one year of age and usually during sleep (3). SUDI includes sudden infant death syndrome (SIDS). Deaths from SIDS remain unexplained despite a thorough investigation involving a complete autopsy, review of the circumstances of death, a scene examination, and comprehensive clinical history (4). SUDI is also classified as accidental suffocation, strangulation in bed, or as death from causes that are ill-defined and unspecified (6). SUDI is potentially preventable, and pēpē sleep practices can minimise the risk to which pēpē are exposed during sleep (Table 7.1). Rates of SUDI in Aotearoa New

Zealand are among the highest in the high-income world (6), and cases of SUDI are commonly (58%) associated with unsafe sleeping (5).

Table 7.1. PĒPĒ SUDI prevention messages

Place	Place baby in their own baby bed
Eliminate	Eliminate smoking in pregnancy
Position	Position baby on their back to sleep
Encourage	Encourage and support mum, so baby is breastfed

Note: Developed by Whakawhetū (https://www.whakawhetu.co.nz) and found at (https://www.healthed.govt.nz/system/files/resource-files/HE1228_Keep%20your%20baby%20safe%20during%20sleep_1.pdf). Abbreviation: SUDI, sudden unexpected death in infancy.

Māori experience SUDI more frequently than any other ethnic group in Aotearoa New Zealand (5) due mainly to the higher smoking rate among Māori (167). The SUDI rate for Pasifika pēpē in Aotearoa New Zealand is also disproportionately high (5). The trauma and grief from SUDI are wide-reaching and profound (1).

Motivation provides people with the impetus and inspiration to act, think and develop in specific ways (181). The amount of motivation experienced can vary in level (amount) and orientation (type). Orientation is the source of motivation, which may be extrinsic or intrinsic, and draws on the attitudes and goals that influence an individual's actions and thoughts (181). Extrinsic motivation is driven by external needs or forces, for example: working to earn money, studying to pass an exam, or abiding by the law to avoid punishment. In contrast, intrinsic motivation originates within oneself, based on personal values, interests, and enjoyment (181). Social context is also vital as this can support or hinder the processes of intrinsic motivation (182).

Previous studies and a recent systematic review have contributed to our understanding of the factors that motivate and influence pēpē sleep and bed sharing practices in Aotearoa New Zealand (54, 86) and internationally (111). In 2019, Māori and non-Māori māmā-pēpē sleep practices and knowledge, and the key influences informing their decision-making were explored.

Tikanga [Methods]

Ethics

This study and the study protocol received ethics approval from the Health and Disability Ethics Committees (18/CEN/273 Pēpē Sleep Practices Study) and localities approval from Counties-Manukau Health (Study #846). Participants provided informed written consent before being interviewed. Pseudonyms are used for all māmā.

Theoretical framework

Qualitative research investigates social phenomena and how people make sense of their ideas and experiences (183). This research incorporated an indigenous *kaupapa* Māori approach informed by a Māori ethical framework and published researcher guidelines and cultural values (184, 185). These include the principles of *Mana* (respect for māmā, their stories, and worldviews); *Tika* (appropriateness of the study design and approach); *Whakapapa* (engaging with māmā, so they feel safe and heard; allowing space for cultural or religious practices if desired); and *Manākitanga* (ensuring the research is culturally safe, strengths-based and conducted with integrity, and in partnership).

To acknowledge the relationship established with participants during the study, the researcher who conducted the interviews (Lead Author) contacted each mother when the study concluded to acknowledge their contribution and provide them with a copy of the study findings, and a koha (small gift) for the child.

Ethnicity

Prioritised ethnicity was used to give a single ethnic group to each mother. Māori is prioritised over all other ethnicities. Non-Māori includes Pasifika, Asian, and European (including New Zealand European and other) ethnicities. Hospital birth lists record pēpē ethnicity based on māmā ethnicity (151).

Sample

Participants were recruited from the large, culturally diverse region of Counties-Manukau in Tamaki Makaurau-Auckland, Aotearoa New Zealand. This region experiences a disproportionately greater number of SUDI deaths compared with other regions in Aotearoa

New Zealand (73, 186), and one-fifth of pēpē in Counties-Manukau reportedly bed share (54).

Purposeful criterion sampling was used, typical in qualitative research (183). Māmā were the primary participants. Other caregivers/support people could join the interview and contribute; however, only written consent from māmā was obtained, and only responses from māmā were analysed. All māmā had a pēpē under one year of age who was born in the main obstetric hospital in the Counties Manukau region.

The sample was designed to reflect the ethnic distribution of SUDI in Aotearoa New Zealand during the three-year SUDI Nationwide Study (March 2012-February 2015 inclusive), albeit on a smaller scale, in which more than half of māmā in the case group self-identified as Māori, and one third as Pasifika.

Selection

Criteria were provided to Counties-Manukau Health Maternity Services and the Health Intelligence and Informatics team to identify pēpē in the hospital birth register who met specific sex, date of birth, and ethnicity criteria. Selection numbers were provided if two or more pēpē were born on the specified date who also met the sex and ethnicity criteria. If/when these situations arose, the selection numbers guided pēpē selection based on order of birth.

Selection results were provided to the research team, including names and contact details. Pēpē were selected based on an expected age at interview of 1-6 months when pēpē are most vulnerable to SUDI, and ideally 2-3 months. In total, 120 selections were obtained. The selection process replicated that used in the SUDI Nationwide Study, previously described in detail (5).

Recruitment

Selection data were entered into a tracking sheet by the research team. Three weeks before the ideal interview date, an information letter and consent form were posted to the mother, followed by a telephone call. The letter provided information about the research, an invitation to participate, and the researcher’s contact details. When calling the mother, the researcher (Lead Author) introduced themselves and the research and reiterated the invitation to participate. Any questions were answered, and if possible, a day and time for the interview was arranged. If there was no answer, a text message was sent, briefly outlining the purpose of the call. Māmā were contacted again before the interview to confirm the appointment.

The interview "window" was two weeks on either side of the ideal interview date. For example, an interview with an ideal date of July 15, 2019 could occur anytime between July 1 and July 29, 2019. All interviews occurred within range of the intended dates.

Setting

Interviews were conducted at places chosen by māmā, usually their homes, where they likely felt most comfortable and where pēpē sleep practices occurred most frequently. Asking questions about sleep practices at the place where sleep occurred provided a natural memory prompt and potentially minimised the risk of recall bias (187). Three interviews occurred elsewhere, including emergency housing, a partner's house, and respite care home.

Data collection

Data were collected during face-to-face, semi-structured interviews, suitable for in-depth, qualitative data collection, and for exploring sensitive topics (188), such as sudden infant death. Interviews took place between June 10 and August 20, 2019. Data saturation was reached by the 30th interview as no other themes were emerging from the data (183) in terms of scope, relevance, and recurrence, as confirmed with the research team.

An interview guide provided a structure based on Māori *tikanga* [custom/protocol]. Interviews began with introductions to connect and build rapport. Important cultural practices, such as *karakia* [prayer] and sharing *kai* [food], were acknowledged before discussing the study or obtaining informed consent. The researcher provided *kai* during the interview and, on conclusion, a supermarket voucher as a token of appreciation.

Data collection commenced with demographic and contextual questions, followed by six open-ended questions linked to the research objectives. The questions were tested with two māmā known to the researcher, neither of whom participated in the study, resulting in minor changes to the wording and flow of questions. Each interview lasted 60-90 minutes.

Interviews were audio-recorded for verbatim transcription. Field notes from the interviews backed-up the audio recordings and transcripts and provided a means to check the accuracy of the transcribed data.

No relationship pre-existed between research team members and participants. Participants' knowledge of the interviewer included name, clinical background, study purpose, and position within doctoral research, and that it built on the NZ SUDI Nationwide Study (2012-2015).

Transcript verification by participants

Participants received their transcripts via email within two weeks of the interview, or if preferred, they received duplicate paper copies via post. Participants were asked to provide feedback within 14 days of the transcript being emailed/delivered. Extra time and a stamped, addressed envelope for the return of annotated transcripts were provided to māmā who preferred paper copies.

Comparing Māori with non-Māori

This study explores māmā views and practices related to pēpē sleep and bed sharing. At times, Māori and non-Māori are compared because SUDI affects Māori more frequently than any other ethnic group in Aotearoa New Zealand, and bed sharing is a major risk factor for SUDI.

Māori experience systemic disparities and poorer health outcomes compared with non-Māori (17), and improving Māori health outcomes is a government priority (161). Aotearoa New Zealand’s 20 district health boards have a statutory responsibility for reducing Māori health inequalities (17, 161).

Te Tiriti o Waitangi [the Treaty of Waitangi] is a founding document of Aotearoa New Zealand, whose principles are embedded into Government policy and strategy to acknowledge the Crown's obligations as a *Tiriti* partner (17). In recognition of this historical and contemporary context, where relevant, our analysis differentiates between the responses from Māori and non-Māori māmā.

Analysis

A general-purpose thematic data analysis approach was used to explore the values, meanings, and practices informing māmā with young pēpē (183, 189). Two authors (Lead Author and Last Author) were directly involved in the analysis. Transcripts were reviewed for accuracy using field notes from the interviews and audio recordings before deidentifying and uploading the transcripts to the software programme, QSR (QSR International, Melbourne, Australia) Nvivo (183). Observational data were thematically coded, and a draft coding scheme was created, which was independently reviewed against the transcripts. The Lead Author and Last Author grouped similar codes to create higher-order concepts (189). These concepts were checked against the data frequently to ensure the interpretation was consistent. To ensure data emersion, the entire dataset was read and re-read. This in-depth process of data emersion and coding allowed the wider team to agree on emergent themes.

Reflexivity and bias

Conscious bias, also known as reflexivity, is used by qualitative researchers to enhance their work's rigor by reflecting on their known biases and how these influence their research (183). For example, the Lead Author is a member of Aotearoa New Zealand’s SUDI Liaison team. This role involves interviewing whānau that have recently experienced a SUDI as part of the coronial investigation process. Bed sharing is a common factor in these cases, and the Lead Author views bed sharing as a potentially severe risk to pēpē safety. The research team ensured this bias did not unduly influence the findings by identifying the potential for bias and maintaining objectivity towards the data. Work was undertaken independently and jointly during data analysis and to verify findings (190).

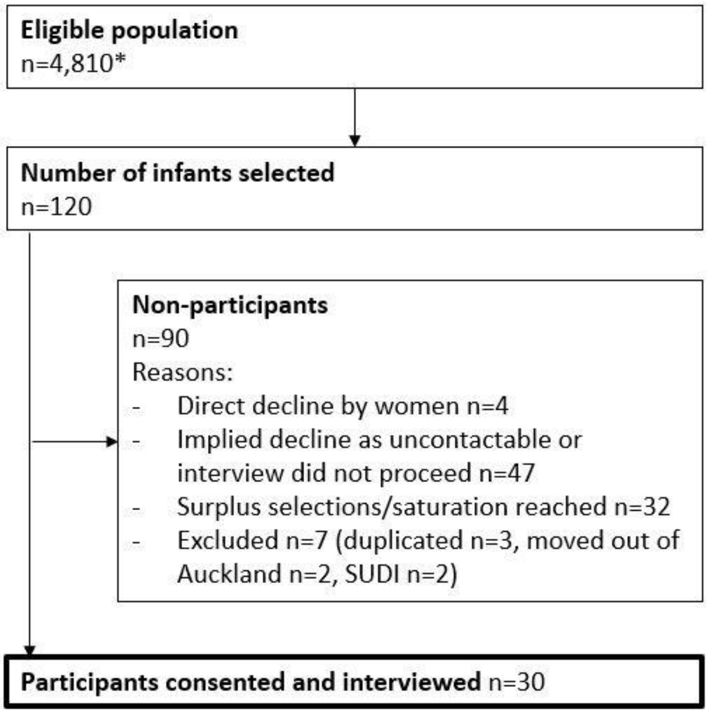
Ngā putanga [Findings]

Participant characteristics

Thirty māmā participated in the study (Figure 7.1), of whom 17 (57%) were Māori. Non-Māori māmā identified as Pasifika (n=9, 30%), and European, including New Zealand/Other, and Asian (n=4, 13%). The mean age of māmā was 26.7 years, and over one-third (n=11, 37%) were first-time parents. Three-quarters of māmā currently breastfed (Māori: n=13, 76%; non-Māori n=10, 77%). Six māmā smoked during pregnancy (Māori: n=5, 29%; non-Māori n=1, 8%). *Iwi* (tribal) affiliations of Māori māmā and other information are provided in Table 7.2.

Māmā of 18 male pēpē and 12 female pēpē participated in the study. The age range of pēpē was 5-24 weeks, with a mean age of 12.2 weeks (Table 7.3).

Number of participants



*Average number of births over a 9-month period, equivalent to the selection period, based on total births in Counties Manukau DHB in 2018 *(Ref. Counties Manukau Health – Womens Health and Newborn Annual Report 2019)*

Figure 7.1. Flowchart of Pēpē Sleep Practices Study population

Thematic findings

The themes and sub-themes are presented in Table 7.4. Other findings are collated separately in Chapter 8. The themes in this paper are discussed in turn. Where Māori and non-Māori percentages are provided, these relate to the specific group, not the total sample.

Table 7.4. Pēpē [infant] sleep thematic findings

(1) Pēpē sleep environment:
    1.1. Pēpē sleeping alone
    1.2. Bed sharing
(2) Reasoning behind the pēpē sleep environment:
    2.1. Culture and experience versus intrinsic fear
(3) Māmā knowledge
    3.1. SUDI prevention knowledge
    3.2. Factors that support and prevent pēpē safe sleep

Supplementary themes reported in Chapter 8.

    A. Pēpē bedding and sleep positions
    B. How whānau bed share
    C. Whānau influence and previous pēpē sleep experience
    D. Advice to others from māmā about pēpē safe sleep
    E. Consistency versus variation in the pēpē sleep routine
    F. Self-soothing versus parent-assisted soothing

Theme 1: Pēpē sleep environment

1.1.Pēpē sleeping alone

Of pēpē who routinely slept alone at the time of the interview (Māori n=7, 41%; non-Māori n=8, 62%), 10 had always slept alone, and five had previously bed shared. Māmā of lone sleeping pēpē were motivated to avoid bed sharing for pēpē safety concerns, although one non-Māori mother slept her pēpē alone to encourage independent sleep.

> I’ll never [bed share]. I’m too scared. I’m one of those scared mums. Shay (Participant 15, Māori)

> I have a little fear about [SUDI], to be honest. … But when he does sleep, he sleeps safely. That’s my thing. Denise (Participant 04, European)

> I find it…safer for him to sleep in the cot. And I just want to get him used to sleeping by himself, so he’s not stuck to [someone] all the time. So, he can have a good sleep too. Taylor (Participant 19, Pasifika)

Most pēpē slept at night in a cot, or cot-type bed (Māori: n=14, 82%; non-Māori: n=12, 92%), including five pēpē (Māori: n=2, 12%; non-Māori: n=3, 23%) who slept in safe-sleep beds (*wahakura* and Pēpi-pods®). Safe-sleep beds are a type of portable bassinet with their own mattress and bedding and provide pēpē with discrete bed space and firm sides to separate and protect them from others in the bed (35). *Wahakura* are Māori-designed and hand-woven with flax (35), while Pēpi-pods® are made from specially designed plastic containers (36). In the present study, safe sleep beds were placed on the parental bed alongside one or both parents, as per their intention and purpose for “safer bed sharing.”

> I just put the Pēpi-pod® on my bed and sleep next to her… She used to sleep in the bassinet when she was newborn. But I used to be so paranoid - is she breathing, is she ok? - so I started using the Pēpi-pod® and it was way better. That way if I wake up or she was crying I would just get up and look over. Belle (Participant 21, Māori)

Māmā were intrinsically motivated to use Pēpi-pods® or *wahakura* for convenience and portability, often placing them in the adult bed for closeness, pēpē safety, and improved pēpē sleep.

> A Pēpi-pod® is just awesome. You can carry it everywhere; you can bring it in here. [Baby’s older siblings] know where baby is sleeping, and once they see the Pēpi-pod®, they’re like, “oh, baby’s in there” … So, it’s like an alert to them that baby is in the Pēpi-pod® on the bed. Tina (Participant 02, Pasifika)

Pēpi-pods® and *wahakura* were offered to some, but not all, māmā during pregnancy. Others had tried but could not access one or were still waiting.

> You can’t get Pēpi-pods®. You have to request them upon birth or something, so I was calling around and was trying to find a way to get hold of one. That’s how much I was looking for [a Pēpi-pod®]. Ruth (Participant 29, Māori)

One mother received a Pēpi-pod® from nursing staff while supporting a seriously ill relative in hospital but had to return it when the relative was discharged. The mother was so exhausted that upon returning home, she bed shared with her pēpē on the sofa every night for a month.

During the day, most pēpē slept in a cot or cot-type bed (Māori: n=9, 53%; non-Māori: n=12, 92%), including the five pēpē who slept in Pēpi-pods® and *wahakura* at night. Six pēpē regularly slept on an adult bed or mattress during the day, two of whom slept alone. Five pēpē (Māori: n=4; non-Māori: n=1) regularly slept on the sofa during the day, with or without supervision.

Car-seats, pushchairs, prams, bouncers, rockers, a baby nest, sheepskin, baby carriers, and being cradled by a parent or relative were among the other bed-types and sleep spaces used during the day by pēpē (n=8, 27%). Using these sleep spaces helped māmā maintain proximity with their pēpē for supervision and continue their daily routines, such as running errands, tending to older children, grocery shopping, or exercise.

1.2.Bed sharing

Two-thirds of pēpē (n=20, 67%) currently or previously bed shared, including most pēpē Māori (n=13 of 17). The most common motivator for bed sharing was to support quality sleep for māmā and pēpē due to lack of sleep and/or maternal exhaustion (Māori: n=11 of 13; non-Māori: n=5 of 7).

> I had not slept for maybe three days straight, so I was going a bit sad/crazy sleep-deprived, having all these thoughts and … we both decided, just put her in bed with me. And I did, I fed her, tummy to tummy the same, and I got sleep. And I wasn’t a crazy, sleep-deprived, grumpy human anymore. Gemma (Participant 10, Māori)

> I know that she shouldn’t have been on the couch [with me], but it was like that was the only place she would sleep. And I was super tired. So, I gave into it and left her there when I shouldn’t have. Because they told me so many times just don’t do it

> because of the cot death thing, the sudden infant, that sudden death thing. Chloe (Participant 24, Māori)

Closeness and convenience were the second most common motivators for bed sharing (Māori: n=3 of 13; non-Māori: n=5 of 7), followed by breastfeeding (Māori: n=6 of 13; non-Māori: n=0 of 7).

> Because I get to have a sleep and then when she cries, I can just reach her instead of having to get out of the bed. When she cries, I tap her bum and just go "shhhhh” so she falls back asleep. Valerie (Participant 26, Pasifika)

> I like him close to me, he's warm, and I can hear him, and it's easier to breastfeed. Tara (Participant 11, Māori)

Some māmā were intrinsically motivated to bed share for enjoyment and cultural reasons, or because they mistrusted advice from mainstream service providers to avoid bed sharing. Others were extrinsically motivated to bed share because of encouragement from relatives.

> [My family] give really bad recommendations. My sister-in-law … encouraged me to [bed share.] Even my mother-in-law said “just let him sleep with you,” [and so] we did. [Although] when my partner puts him to sleep, it’s [in] the bassinet. Tara (Participant 11, Māori)

> I used to sleep with him because my mum wanted me to. Because she thinks it’s a “*wairua*” [spiritual] thing. But when my midwife said all the risks, I was like, “nah I’m not sleeping with him by me.” Jade (Participant 17, Māori)

> Because there’s a lot of Islanders [Pasifika] that sleep with their babies and their babies end up dying because they don’t listen. They don’t believe the Palangis. Valerie (Participant 26, Pasifika)

Theme 2: Reasoning behind the pēpē sleep environment

This theme explores the influence of culture, beliefs, and practices associated with pēpē sleep, in addition to the previous experiences of māmā.

2.1. Culture and experience versus intrinsic fear

Māmā reported that culture and prior experience significantly informed their motivations and decisions concerning pēpē sleep practices. The primary motivation for practicing safe sleep reported by māmā was their fear that their pēpē would be accidentally suffocated or squashed to death if they bed shared with others. This fear was so strong in some māmā that they described it overriding the influence of their culture or their partner/whānau. This pattern was observed in findings regardless of whether the participant was Māori, Pasifika, or European.

Fear as an intrinsic motivator:

> Well, he can’t sleep with us, or me. Because my son sleeps with me sometimes. And I just find it more safe. Safety reasons definitely … Squashing him. Rolling over on him. We’ve had an incident and it’s happened, and it killed our cousin’s baby. So, we’ve been through that. My cousin’s partner did it. And she was just breastfeeding and forgot to put her baby in his own bed. Karla (Participant 07, Māori).

> He was maybe a week old. Because I didn’t get any sleep, I was a walking zombie. When I was feeding him in the middle of the night, I just could not keep my eyes open. It was terrible. That’s what happened. […] I’m not trying to find excuses for myself. I’m just, I don’t know how to say it. I learnt my lesson, and nothing happened, but it did give me a fright. And I was just very careful since then. Even more careful. Lisa (Participant 08, European)

Some participants, who may or may not have reported experiencing a strong level of fear concerning the potential death of their pēpē, chose to practice safe sleep because, they said, they had been advised to do so by their healthcare practitioner, including the midwife, well-childcare provider, or other health professional.

> [Midwives are] qualified, they’re the ones who you look to, to trust them with the information that they’re giving. Chloe (Participant 24, Māori)

> I’m just following her advice. Lisa (Participant 08, European)

Participants who did not report practising safe sleep and/or who bed shared typically did not have an intrinsic fear of their pēpē dying. Some māmā reported that they were "*light sleepers"* (Melissa, Participant 01, Māori) and could therefore sleep safely with their pēpē. Melissa (Participant 01, Māori) reported propping her pēpē up on a pillow near her head to ensure his safety during sleep. Tina (Participant 02, Pasifika) kept her pēpē in his Pēpi-pod® during night sleeps but bed shared during the day, with pēpē having "*his own space"* separated from her by a pillow. This māma did not describe other safety concerns such as the pēpē falling off the bed, becoming wedged/stuck between the bed and the wall, or suffocating under the blankets. Libby (Participant 03, Pasifika) initially reported that her reason for bed sharing was *"cos I'm too lazy to walk over to his crib"* but later explained that she usually did use his crib because she was *"scared of rolling onto him or squashing him."*

Karla (Participant 07, Māori) clearly demonstrates the tension between culture/whānau and fear:

> Interviewer: So, they wake him up?
> Karla: Yeah [family wake him up] and it ruins my whole routine, and I don't like it.
> Interviewer: Does that stop you from doing the safe sleep?
> Karla: Yup, [that stops me from doing the safe sleep] because when he's asleep, they don't put him down. They hold him while he's asleep.
> Interviewer: But they're awake?
> Karla: Sometimes they'll [paternal nana] be sitting on the couch and they'll fall asleep with the baby. So, I just swoop and take the baby.
> Interviewer: That has happened?
> Karla: It has, and I don't like it. I get really angry.
> Interviewer: How many times has that happened?
> Karla: Twice [paternal nana has fallen asleep while holding baby]. Too many times.
> Interviewer: But you've always been here?
> Karla: Yup, and I always take the baby.

Theme 3: Māmā knowledge

This theme presents māmā knowledge about SUDI prevention using the PĒPĒ acronym (Table 7.1.), including pēpē safe sleep and the supports and barriers that help or hinder safe sleep.

3.1. SUDI prevention messaging

The Māori word ‘pēpe’, also meaning infant or baby, is used in Aotearoa New Zealand as an acronym to teach new and expectant māmā about SUDI prevention (Table 7.1). Māmā in the study were asked about SUDI prevention messages. Most māmā knew that pēpē should have their own bed or sleep space (n=26, 87%) and that supine sleep (on back) is the safest pēpē sleep position for pēpē (n=23, 77%). Fewer māmā raised the importance of being smokefree during pregnancy (Māori: n=7, 41%; non-Māori: n=2, 15%), and although most māmā currently breastfed their pēpē (n=23, 77%), only four identified breastfeeding as protective against SUDI.

Additional messages known by māmā included keeping bedding clear of pēpē faces (n=26, 87%) and providing a smokefree environment after birth (Māori n=6, 35%; non-Māori n=2, 15%). Māmā responses about the prevention of SUDI have been mapped to published “PĒPĒ” SUDI prevention messages in Table 7.5.

Six māmā (20%) were unaware of SUDI, SIDS, or cot death after prompting, and one believed that safe sleep advice was irrelevant after six weeks of age.

Most māmā received information from midwives (n=22, 73%), mainstream and Māori well-childcare providers (n=14, 47%) and hospital or birth unit nurses (n=13, 43%). Key information sources included friends and whānau, particularly grandmothers and other female relatives (n=6, 20%). Māmā attended antenatal or parenting classes (Māori: n=2, 12%, non-Māori: n=2, 15%). Some māmā first received safe sleep information after birth from hospital nurses or in the birthing unit before going home.

> Back for sleep, front for play. Belle (Participant 21, Māori)

> The sleep lady […] helped me because we had just got into a bad routine and he wouldn’t sleep unless he was being held. Lucille (Participant 22, European)

3.2. Factors that support safe pēpē sleep

When asked what helps pēpē safe sleep, māmā replied that safe sleep is supported when they receive practical, hands-on help with pēpē sleep (n=6, 20%), especially from partners and female relatives (n=6, 20%). Ani (Participant 13, Māori) recalled her partner demonstrating how to place their new-born pēpē safely in the cot. Ani said, *"I knew absolutely nothing about children,"* and later explained that her partner had earlier experienced a near-miss SUDI in his own whānau.

Māmā identified the need for quality sleep for themselves and their pēpē and to feel well-rested (n=4, 13%). Māori māmā cited the need for safe sleep equipment (n=6, 20%), such as a cot. As reported above, intrinsic fear in māmā of pēpē harm, especially among māmā with knowledge of SUDI/SIDS, motivated them to practice safe sleep consistently (n=10, 33%).

> I don't want to wake up and be like, is my baby underneath me or is my baby dead. Mere (Participant 05, Māori)

A shared commitment between māmā, partners, and whānau members to practice safe sleep as prescribed by māmā was important for Māori and non-Māori māmā. Based on personal experience of being home alone, exhausted, and breastfeeding in bed while her partner worked shifts, Tara (Participant 11, Māori) recommended whānau develop a plan outlining how, collectively, whānau and friends will apply safe sleep theory in real-world situations.

> Talking about how to make [safe sleep] happen, [my midwife] never discussed that beyond, "do you have a bassinet, do you have a cot." I knew the "what," I just didn't know the "how." Tara (Participant 11, Māori)

Similar responses were provided by non-Māori māmā in terms of needing support, access to resources ("*a baby bed*") and help from female relatives. Non-Māori māmā (n=5, 39%) commented on the need for accurate and consistent safe sleep information (n=4, 31%).

> It's so helpful to have [my grandma] to watch one while I put down the other one to sleep, and then come and get the other one. I like to put them down to sleep at the same time. Rachel (Participant 12, Pasifika)

> What helps is [my family are] all on the same page. We've all got the same values. [My family say] "ok, well, that's what you want so that is what we will do." And then

> you have a sense of security … because then you can trust them. Denise (Participant 04, European)

3.3. Barriers to safe pēpē sleep

Māori and non-Māori māmā reported maternal exhaustion and/or the need for improved sleep for māmā-pēpē as the main barrier to safe sleep (Māori: n=11, 65%; non-Māori: n=5, 38%), followed by pēpē exposure to the unsafe practices or advice of others (Māori: n=4, 24%; non-Māori: n=7, 54%).

Other barriers cited included unsettled pēpē, pēpē that sleep best in unsafe positions or bed sharing, and a lack of resources and equipment, such as an appropriate bed (Māori: n=4, 24%; non-Māori: n=4, 31%). Māori māmā identified disturbances by older siblings or whānau members as a barrier (Māori: n=4, 24%; non-Māori: n=0, 0%), particularly as they were more likely to have older children compared with non-Māori māmā (n=12, 71% vs. n=7, 54% respectively).

> When I was fully drained, like battery dead. That's probably the most difficult time, trying to physically get her into [her] bed. Belle (Participant 21, Māori)

> I've experienced one point where I was really exhausted that I just didn't know what I was doing. Sadie (Participant 25, Pasifika)

> He just cries and cries when I put him in his cot. Like early hours of the morning. So, I put him in my bed and give him cuddles, and he goes to sleep. Stella (Participant 16, Māori)

> I decided to listen to the midwives, and [my partner's] family was sort of looking at me like, "oh, she doesn't listen [to our advice]." Chloe (Participant 24, Māori)

> For me to use unsafe sleep practices, it's easier for him to sleep (on his tummy). Riley (Participant 23, Māori)

Kōrerorero [Discussion]

The aim of the present study was to explore how māmā manage the sleep needs of their pēpē and themselves, and the factors that influence their pēpē sleep decisions. Five key strategies were identified that did or could have motivated and supported māmā to practice pēpē safe sleep (Table 7.6).

Table 7.6. Key strategies that support pēpē safe sleep

1. Quality sleep for māmā and pēpē, supported by partners and female relatives (for example) providing practical help, especially for exhausted māmā.
2. Appropriate safe sleep equipment, such as a cot, *wahakura* or Pēpi-pod® prior to birth.
3. A shared understanding and commitment to safe sleep among all the people involved in pēpē sleep and care, and a shared plan that enables safe sleep to be practiced, including when māmā is not present and when māmā is alone or at risk of using unsafe practices.
4. Intrinsic fear by māmā of pēpē harm, especially among māmā with knowledge of SUDI/SIDS.
5. Accurate and consistent safe sleep information.

The key findings build on existing literature, and concern: 1) the environment in which pēpē sleep, 2) the reasoning behind these sleep environments, and 3) māmā knowledge about SUDI prevention and safe pēpē sleep. These elements are interconnected and informed by culture, whānau, knowledge, and prior experience.

Lone sleep vs. bed sharing

Infant bed selection is a critical element of the sleep environment. Māmā translated their knowledge about pēpē needing to sleep in their own space, on their backs, and with faces clear of bedding into action, as evidenced by 50% of pēpē in this study who routinely slept alone. The use of *wahakura* and Pēpi-pods® was encouraging and indicative of a SUDI prevention programme provided by the local district health board (Counties Manukau), in which safe sleep beds are supplied to pēpē identified at high risk of SUDI (191).

Safe sleep beds support “safer bed sharing,” which promotes safe sleep, breastfeeding, and bonding (164), and contributed to a recent dip in cases of SUDI (77). A recent study reported that Māori parents prefer their pēpē to sleep separately; however, parental and whānau discomfort with pēpē crying, culture (i.e. “being Māori”), whānau influences, and safety and convenience meant that few parents achieved this (86).

The critical motivators for bed sharing in the present study align with existing research, and include breastfeeding, comfort, and improved sleep for māmā and pēpē (45, 83, 86, 111). These are reflected in the present study, with the top reason being better sleep for māmā and pēpē. Breastfeeding, which was identified only by Māori māmā, ranked third. Bed sharing for closeness, convenience, comfort, and a sense of parental security are closely aligned and rank second in the systematic reviews and in the present study (45, 83). As a reason for bed sharing, “better or improved sleep” for māmā and pēpē is almost a euphemism for the debilitating exhaustion that some māmā described in this study, which inadvertently led to bed sharing.

Fear was identified as a powerful and intrinsic motivator among some māmā who practiced safe sleep, which was not as evident among māmā who bed shared. Bed sharing māmā tended to minimise the safety risk by rationalising that they slept lightly, or by separating pēpē from others in the bed using pillows and bedding, or they thought the risks would not affect them. These are unreliable mitigation strategies as the heads of pēpē are often covered by bedding or clothing during bed sharing, without their parents' knowledge (83), and bed sharing is clearly associated with SUDI (5).

Māmā knowledge

Supports in place for safe sleeping are numerous. The important elements māmā identified as supporting safe pēpē sleep are listed below.

The prevailing advice in the early 1990s discouraged bed sharing in favour of pēpē sleeping alone. Since then, a shift has occurred away from the perception of safe sleep messaging as “anti-bed sharing.” The safe sleep message has a strengths-based approach in which whānau are educated about safe sleep and the need for their pēpē to be in their own bed. Māmā demonstrated high levels of knowledge about some SUDI prevention messages (pēpē in own space/bed, face clear, on back) but not others (smokefree pregnancy, smokefree environment, breastfeeding, room sharing) (Table 7.5).

A high proportion of māmā in this study smoked during pregnancy, compared with the national figure of 13.1%, although this is based on first registration with a midwife (192). Rates of smoking in Counties Manukau are among the highest in the country, with an estimated 40% of Māori women currently smoking at time of birth in 2018 (191), and the region has invested significantly in supporting pregnant women to become smokefree (191).

The sources and methods of receiving information about the prevention of SUDI influenced māmā willingness to adopt safe sleep practices. Specific circumstances for māmā varied, as did their relationships with the people in their lives, including whānau and health professionals. Where relationships were positive and caring, māmā were more amenable to the advice. This form of extrinsic motivation was sufficient for māmā to adopt safe sleep advice, which over time, can become internalised and intrinsic (182). Where māmā disagreed with advice or felt they knew it to be incorrect or unsafe, they were intrinsically motivated to reject it.

Decisions by māmā around bed sharing and pēpē sleep are highly subjective and influenced by their cultural backgrounds, personal knowledge, experience, and the people in their lives (46, 83).

Simple pēpē care practices, such as supine sleep, are easier to change compared with actions associated with parental behaviours and deep cultural beliefs, including bed sharing, as illustrated in Figure 7.2. As bed sharing is not a simple pēpē care practice, advice to avoid bed sharing is ineffective, and may be dismissed by parents as being culturally irrelevant (46). Advice must come from a trusted source to be credible to parents, and when parents understand the mechanism/s by which safe sleep is protective, they are more likely to adopt new practices (111).

Māori parents with strong connections to their Māori whānau and culture were more likely to bed share and follow pēpē care advice from whānau (84). Pēpē sleep advice from grandmothers and older female relatives in ethnic minority communities is influential because they are often well-respected; however, the advice is sometimes incorrect (193). In the present study, close female relatives featured prominently in the care of pēpē, regardless of ethnicity. Some māmā received unsafe advice from whānau that they knew, or did not know, was unsafe yet they deemed the advice credible because it came from a trusted and/or experienced source. Māmā in the present study were open to innovative approaches in education regarding prevention of SUDI that involve the key people involved in caring for the pēpē, especially partners and close female relatives (i.e., “whole whānau education”).

Bed sharing experiences and motivation

Figure 7.2 illustrates the interconnected nature of the present findings, and the way these influence the practices and decision-making of māmā around pēpē sleep, using bed sharing as an example. The uppermost section of the model represents the overarching cultural background and context for māmā, which frames and informs their beliefs, knowledge, and practices related to pēpē sleep. Three vertical columns indicate the types of influences that impact decision-making and actions of māmā, including: prior experience (learned behaviours), core beliefs and values (intrinsic motivators), and external influences (extrinsic motivators) - all of which are interconnected. Examples are provided in each column to further illustrate how learned behaviours, intrinsic motivators, and extrinsic motivators vary and can exert powerful influence on the views and practices of māmā around pēpē sleep. This model offers a cultural and holistic lens with which to consider and understand the factors that motivate pēpē sleep practices by māmā, and others involved in pēpē sleep.

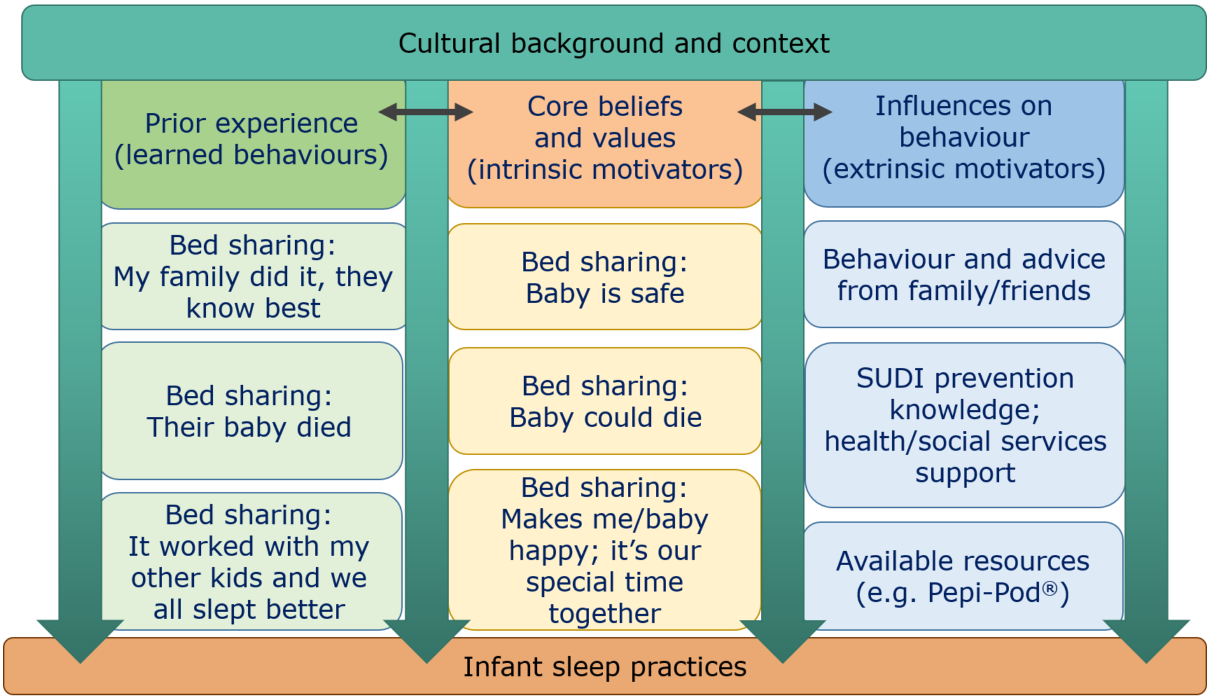


Figure 7.2. Bed sharing experiences and motivation model

Whirikoka me Kōpiri [Strengths and Limitations]

Strengths of the study include the richness of the data and the similar ethnic distribution of this sample to the case group in the recent Aotearoa New Zealand case-control SUDI Nationwide Study. The *kaupapa* Māori approach ensured that the research was safe, appropriate, and respectful to Māori and provided a space for Māori māmā voices to be heard and distinguished, where appropriate, from those of non-Māori.

The limitations of the present study include the relatively small sample size and the high rate of SUDI in that region compared with other regions in Aotearoa New Zealand, which potentially affect the generalisability of the findings to other populations and geographic areas.

Whakatau mutunga [Conclusion]

The present study made strengths-based observations of parenting practices to identify and understand the influences and motivations governing whānau pēpē sleep practices. The findings strengthen and inform future approaches to the prevention of SUDI, including the messages, communicating these messages, and facilitating change so that fewer whānau, Māori and non-Māori, experience the lasting trauma of the sudden and unexpected death of their pēpē. Service providers are encouraged to respond to the lived experiences and cultural realities, values, and beliefs of māmā when designing and delivering effective interventions for the prevention of SUDI. By helping to further refine the approach and messaging for whānau, which may be different from what works for, or is preferred by non-Māori, or other Māori, this research will contribute to the development and wellbeing of Māori parents, pēpē, and whanau, and further reduce the burden of SUDI in Aotearoa New Zealand. Māmā, partners, and their wider whānau have the capacity and capability to routinely practice safe sleep with their treasured pēpē, and some māmā may benefit from receiving individualised, strengths-based support.

Table 7.2. Māmā [mothers] characteristics and demographics

	Māori n (% Māori) **n=17**	**Non-Māori** n (% non-Māori) **n=13**	**Total** n (% total sample) **n=30**
Māmā ethnicity			
Pasifika	-	9 (69.2)	9 (30)
(NZ) European	-	3 (23.1)	3 (10)
Asian	-	1 (7.7)	1 (3.3)
Total	17 (56.7)	13 (43.3)	30 (100)
Iwi tribal affiliations of Māori māmā			
Ngāpuhi	5 (29.4)	-	5 (16.6)
Ngāti Porou	4 (23.5)	-	4 (13.3)
Te Arawa	2 (11.7)	-	2 (6.7)
Tainui, Waikato, Whakatōhia, Te Rarawa, Ngāti Pāoa, Tūhoe, Ngāti Whātua, Ngāti Amaru, Ngāi Te Rangi and Ngāti Ranginui. (Six māmā identified with multiple iwi)	11 (64.7)	-	11 (36.6)
Māmā age in years n (%)			
16 - 19 years	1 (5.9)	1 (7.7)	2 (6.7)
20 - 24 years	5 (29.4)	4 (30.8)	9 (30)
25- 29 years	7 (41.2)	3 (23.1)	10 (33.3)
30+ years	4 (23.5)	5 (38.5)	9 (30)
Marital status			
Single	6 (35.3)	0 (0.0)	6 (20.0)
Married	3 (17.6)	9 (69.2)	12 (40.0)
Co-habiting	8 (47.1)	4 (30.8)	12 (40.0)
Type of birth			
Normal	9 (52.69)	3 (23.1)	12 (40.0)
Intervention required (i.e., planned or emergency c-section, forceps, induction, including one due to pre-eclampsia)	8 (47.1)	10 (76.9)	18 (60.0)

	Māori n (% Māori) **n=17**	**Non-Māori** n (% non-Māori) **n=13**	**Total** n (% total sample) **n=30**
Gestation at birth			
36 - 37	0 (0.0)	3 (23.1)	3 (10.0)
38 - 40	16 (94.1)	10 (76.9)	26 (86.7)
41 - 42	1 (5.9)	0 (0.0)	1 (3.3)
Maternal smoking			
Smoking in pregnancy	5 (29.4)	1 (7.7)	6 (20.0)
Smoking now	5 (29.4)	1 (7.7)	6 (20.0)
Number previous children			
0	5 (29.4)	6 (46.2)	11 (36.6)
1	5 (29.4)	4 (30.8)	9 (30.0)
2	3 (17.6)	1 (7.7)	4 (13.3)
3+	4 (23.5)	2 (15.4)	6 (20.0)
Number of children living at home (incl. infant)			
1 - 2	-	-	18 (60.0)
3 - 4	-	-	8 (26.7)
5 - 6	-	-	3 (10.0)
7+	-	-	1 (3.3)
Number adults living at home			
1 - 2	12 (70.6)	5 (38.5)	17 (56.7)
3 - 4	2 (11.7)	3 (23.1)	5 (16.7)
5 - 6	3 (17.6)	5 (38.5)	8 (26.7)
Number adults living at home that smoke			
0	4 (23.5)	9 (69.2)	13 (43.3)
1	9 (52.9)	2 (15.9)	11 (x1 vaping) (36.7)
2 - 3	4 (23.5)	2 (15.9)	6 (20.0)

Table 7.3. Pēpē [infant] characteristics and demographics

	Māori **n (%)** **n=17**	**Non-Māori** **n (%)** **n=13**	**Total** **n (%)** **n=30**
Pēpē sex (missing=0)			
Male	10 (58.9)	8 (61.5)	18 (60.0)
Female	7 (41.2)	5 (38.5)	12 (40.0)
Age in weeks (missing=0)			
0 - 8 weeks	2 (11.8)	3 (23.1)	5 (16.7)
9 - 12 weeks	8 (47.1)	7 (53.8)	15 (50.0)
13 - 16 weeks	6 (35.3)	2 (15.4)	8 (26.7)
17+ weeks	1 (5.9)	1 (7.7)	2 (6.6)
Breastfeeding (missing=0)			
Breastfeeding NOW	13 (76.5)	10 (76.9)	23 (76.6)
Bed-type – NIGHT SLEEP (multiple bed types selected) (missing=0)			
Cot or similar	14 (82.4)	12 (92.3)	26 (86.6)
Subset: Pepi-pod® or wahakura on parental bed	2 (11.8)	3 (23.1)	*5 (16.7)*
Adult bed/mattress	6 (25.3)	1 (7.7)	7 (23.3)
Sofa	1 (5.9)	0 (0.0)	1 (3.3)
Other: held/cradled	1 (5.9)	0 (0.0)	1 (3.3)
Bed-type – DAY SLEEP (multiple bed types selected) (missing=0)			
Cot or similar	9 (52.90)	12 (92.3)	21 (70.0)
Subset: Pepi-pod® or wahakura on parental bed	2 (11.8)	3 (23.1)	5 (16.7)
Adult bed/mattress	4 (23.5)	2 (15.4)	6 (20.0)
Sofa	4 (23.5)	1 (7.7)	5 (16.7)
Other: held/cradled, baby rocker/swing, pram, car seat, carrier, sheepskin, baby nest	7 (41.2)	4 (30.8)	11 (36.6)

	Māori **n (%)** **n=17**	**Non-Māori** **n (%)** **n=13**	**Total** **n (%)** **n=30**
Usual sleep position(s) (missing=0)			
Back only	11 (64.7)	8 (61.5)	19 (63.3)
Back and side	5 (29.4)	1 (7.7)	6 (20.0)
Back and stomach	0 (0.0)	0 (0.0)	0 (0.0)
Back, side and stomach	0 (0.0)	2 (15.4)	2 (6.7)
Side only	0 (0.0)	2 (15.4)	2 (6.7)
Side and stomach	1 (5.9)	0 (0.0)	1 (3.3)
Bed sharing (missing=0)			
Yes (NOW or EVER, DAY or NIGHT)	13 (76.5)	7 (53.8)	20 (66.7)
If yes, bed sharing with 2 or more people	*4 (23.5)*	*3 (23.1)*	*7 of 20 (35.0)*
No (NEVER)	4 (23.5)	6 (46.1)	10 (33.3)
Top reasons for bed sharing	n (%) n=13	n (%) n=7	
1. Better sleep for māmā-pēpē	11 (84.6)	5 (71.4)	16 (53.3)
2. Closeness/convenience	3 (23.1)	5 (71.4)	8 (26.7)
3. Breastfeeding	6 (46.2)	0 (0.0)	6 (20.0)

Table 7.5. SUDI prevention messages known by māmā

	Māori n=17 (%)	Non-Māori n=13 (%)	Total n=30 (%)
Core messages			
Own space/bed	14 (82.4)	12 (92.3)	26 (86.7)
Supine (on back) position for sleep	13 (76.5)	10 (76.9)	23 (76.7)
Smokefree pregnancy	7 (41.2)	2 (15.4)	9 (30.0)
Breastfeeding	2 (11.8)	2 (15.4)	4 (13.3)
Additional messages			
Face clear of bedding	15 (88.2)	11 (84.6)	26 (86.7)
Smokefree environment for pēpē	6 (35.3)	2 (15.4)	8 (26.7)
Room sharing with parents	1 (5.9)	3 (23.1)	4 (13.3)
Gentle handling	0 (0.0)	0 (0.0)	0 (0.0)
Heard of SIDS/SUDI/Cot Death	13 (76.5)	11 (84.6)	24 (80.0)

Chapter 8: Supplementary Paper –E Kō, kia ora, kua ao te rā! [Baby, a new day has dawned!]: Pēpē-Infant sleep practices and sudden unexpected death in infancy in Aotearoa New Zealand

Introduction

This document contains additional thematic findings not included in the manuscript in Chapter 7: Pēpē-infant sleep practices and sudden unexpected death in infancy in Aotearoa New Zealand. The authors provide this additional information to make it available for any person, group or organisation interested in SUDI prevention in New Zealand. The themes and sub-themes presented in the main paper (Chapter 7) and in this supplementary report are outlined in Table 8.1.

Thematic findings reported in Chapter 7	**Additional themes in the Supplementary Report**
(1) Pēpē [infant] sleep environment: 1.1. Pēpē sleeping alone 1.2. Bed sharing	A. Pēpē bedding and sleep positions B. How whānau [families] bed share
(2) Reasoning behind the pēpē [infant] sleep environment: 2.1. Culture and experience versus intrinsic fear	C. Whānau [family] influence and previous pēpē sleep experience
(3) Māmā [mothers'] knowledge: 3.1. SUDI prevention knowledge 3.2. Factors that support and prevent pēpē safe sleep	D. Advice to others from māmā about pēpē safe sleep
	(4) Pēpē sleep routine: E. Consistency versus variation in the pēpē sleep routine F. Self-soothing versus parent-assisted soothing

Table 8.1. Overview of thematic findings and additional themes

A. Pēpē [infant] bedding and sleep positions

Eleven māmā [mothers] kept their pēpē close by during the day, whether pēpē were asleep or awake, by using a pram, car seat, carrier, baby rocker/swing, sheepskin, or baby nest, or by cradling them. Māmā used these spaces to keep pēpē close, or to supervise pēpē while doing other tasks. One (Māori) māmā slept her pēpē in a smaller, portable bed until they were ready to move into a cot. Similarly, one māmā, whose pēpē slept in a Pēpi-pod® also had a cot in anticipation of their increasing size.

> We put him in [the bassinet] so he gets used to sleeping in his own bed. Kylie (Participant 18, Pasifika)
>
> He has his own cot when he outgrows the pod. – Libby (Participant 03, Pasifika)

One māmā first placed the Pēpi-pod® on the bed after advice from her partner.

> I couldn't get [a *wahakura*, so my midwife] gave me a Pēpi-pod® and [baby] absolutely loved that. She slept well right next to me and if I'd hear her talk in the middle of the night then I'd just roll over and she's here, right here. So, I could touch her, and she knows I'm nearby. [The Pēpi-pod® is] the safest place for her. – Ruth (Participant 29, Māori)
>
> I know it's safe to put her into her own cot. – Leilani (Participant 30, Pasifika)
>
> When [baby] first came home, he slept in the pod inside the cot… but then 'cause he was unsettled, and I just kept getting up … my partner said 'why don't you bring the baby pod into the bed?' And I didn't know I was allowed that, so then I read up [and learned] that we can have the baby pod on the bed. - Libby (Participant 03, Pasifika)

One māmā received a Pēpi-pod® but had been expecting a wahakura. Several māmā proactively sought safe sleep beds for their pēpē, including one māmā who contacted her local marae and participated in a wahakura weaving workshop. Another was determined to have a Pēpi-pod® for her pēpē and found a service provider to assist her.

> I had Māori midwives and I asked [for] a Pēpi-pod®. I thought that was the flax one. And they gave me that and I thought, woah! - Olivia (Participant 14, Māori)

Not all māmā and pēpē liked safe sleep beds. Māmā who disliked using Pēpi-pods® or wahakura said it was because their pēpē did not sleep well in them, or thought the beds posed a safety risk.

> We tried the wahakura next to me, but no. I could have been in the wahakura with her, and she still wouldn't [sleep]. - Gemma (Participant 10, Māori)
>
> He just whacks the sides [of the Pēpi-pod®] and he doesn't like it. I would never put that in my bed next to me because it might just fall off the bed. – Olivia (Participant 14, Māori)

Bedding

Māmā used blankets to keep their pēpē warm and secure, and to improve the quality of pēpē sleep. Pillows were frequently used to position pēpē and provide a barrier, or create space, between the pēpē and the wall or other people, often during bed sharing.

Some māmā expressed concern about the potential risk posed to their pēpē from blankets and other bedding, including Valerie (Participant 26, Pasifika), who said: "*When she's wrapped,* *she's on her back with her shoulders on the pillow. It's really dangerous if her shoulders are in sync with the pillows, she has to be above."*

Tina (Participant 02, Pasifika) spoke of being shown how to safely use the blankets supplied with a Pēpi-pod®, explaining that *"the baby goes in the blanket, and it goes under his arms. [Then] the baby goes in his blanket, and the arms. So, I do it like this. It's how it's presented in the Pēpi-pod®."*

Māori and non-Māori māmā reported using blankets, pillows and other bedding in ways that contradict safe sleep advice, for example, to maintain the position of their pēpē during sleep, or to prop them up while awake. Dominique (Participant 06, Māori) illustrated this when saying: "*I prop her up with pillows so she can watch TV. Then she'll either cry to eat or she'll just fall asleep …, so I'll just pull the pillows away and let her lie flat … I think the electric blanket helps, too. [It] makes it really hot. Like toasty warm. But yeah, it just makes her sleep even heavier. She won't turn at all if the [electric] blanket's on."*

Others received warnings from whānau [family] members about the risk of bedding to pēpē. At times māmā also received unsafe advice, such as Ani (Participant 13, Māori), who recalled that *"Mum's advice was [to] give her a pillow [and] tri-pillows are best for babies. I thought, well, she's got eight kids, she knows what she's doing."*

Pēpē [infant] sleep positions

Most māmā (Māori=11; non-Māori=8) described placing their pēpē to sleep in the supine position (on their backs), in line with safe sleep advice. Several māmā said they re-position their pēpē on their back if pēpē rolls onto their side or stomach (prone), including Tara (Participant 11, Māori), who said "*He's always on his back. He does somehow get himself on his side, but I always put him back on his back."*

Of the remaining 11 pēpē, eight slept on their side or prone, and supine. Three pēpē slept only on their side or prone. Reasons for placing pēpē to sleep on their sides or prone included to avoid their head becoming misshapen (i.e., "flat"), for pēpē comfort, and because the pēpē falls asleep and sleeps better that way.

> Usually she's on her back, but sometimes she's on her side. But then I put her on her side, so she doesn't get a flat head. – Dominque (Participant 06, Māori)
>
> He sleeps all sorts. He sleeps up, with the pillows behind him. Up on the side mostly. Sometimes on his back. - Olivia (Participant 14, Māori)
>
> When we have the little naps, I would put him on his tummy, and he'll fall asleep. And I'll just leave him there because it looks like he's comfy. - Taylor (Participant 19, Pasifika)

B. How whānau [families] bed share

Some pēpē regularly bed shared with two or more people (Māori n=4; non-Māori n=3). Several māmā believed the risk was low when bed sharing for short periods of time, or with one person. Several pēpē routinely bed shared for five hours or more. Māmā described creating a space or barrier around their pēpē during bed sharing to keep them safe, often with pillows or bedding.

> It's only her and I in the bed. … I have a pillow on the side of her … I know there's no way she could .... suffocate or fall off, of course, or anything like that. – Gemma (Participant 10, Māori)
>
> We'll sleep for like five hours, early in the morning… just during the morning. So, five hours [sharing the bed] and two hours [in the cot], kind of like that. – Taylor (Participant 19, Pasifika)

Māmā described being '*mindful*' of their pēpē while bed sharing and believed they would wake if their pēpē moved or was in danger. They perceived others as posing a greater risk, especially their partners, whom they described as physically large, or deep sleepers.

> And a woman knows, a mother has a thing, but men don't. He might accidentally squash her something. – Valerie (Participant 26, Pasifika)
>
> My bed is tiny and my partner's fat. Daddy takes up a lot of room. – Rachel (Participant 20, Māori)

Dominique (Participant 06, Māori) provided insight into why she thought whānau would continue to bed share, regardless of the risks and the advice against bed sharing. She considered bed sharing to be more common among Māori whānau, and in poorer areas where whānau have more children, less focus on safety, fewer resources to access help and a lack of safe sleep role models:

> Everyone here sleeps with their babies. … I do know two [mothers who don't bed share] but they're white. They usually live somewhere better. A better area. [The people that bed share are] all Māori. Or they're half-castes. Maybe it might be what they copied from their mothers. And it's also the area they live in. I'm sure people pay more attention to safety around there [wealthier areas]. Maybe they [have] more money to hire someone to help. … I think maybe because they've got their mothers to show them more. Plus, I find people have more kids around here [south Auckland]. So, it's more about just trying to get some sleep. … Whereas on [Auckland's North] Shore people have like one or two. … I don't think that you will ever be able to fully get rid of [bed sharing]. Because even then, even the Islanders [Pasifika] and that, everyone sleeps together as babies. I know Māoris, most of them do. – Dominique (Participant 06, Māori)

C. Influence of whānau and previous pēpē sleep experience

Māmā (n=15) with older children drew on their previous experiences when managing sleep time with their new pēpē. Most māmā practices had changed, whereas others had not. Māori māmā were more likely to employ the same practices as they had with their previous children.

Where practices had changed, this was due to māmā having new knowledge, more experience and increased confidence. These māmā were willing to try different approaches to parenting their new pēpē. Others described being in a different environment or circumstances with their new pēpē, and/or having different people around them. Other times it was simply because their new pēpē preferences were not the same as their older siblings' and several māmā expressed a desire to avoid the difficulties they had experienced when their previous children were pēpē.

> The tactics that I use, used to work on his older sister. I just feel more comfortable doing it that way. – Riley (Participant 23, Māori)
>
> With the new baby I didn't want her to turn out like he did. We babied him so much, we'd always pick him up. And now he hardly sleeps so I don't want that to happen. – Mere (Participant 05, Māori)
>
> Night-time [baby's older siblings] would wake up. All of them, except this one. I was like, you know what, I want to do the routine on you, see if it works. So, I tried one last time and it actually does. It took me like three times. – Tina (Participant 02, Pasifika)

Whānau was a significant source of information and advice for māmā. Some māmā with previous children reported receiving advice from their whānau, or from their partners' whānau. In some instances, advice from whānau members had changed with the new pēpē. For some māmā, their personal circumstances, living environment and the people around them had changed since their previous children were pēpē. Māmā and other female relatives were important and influential role models. Some māmā heeded advice from whānau, while others ignored it.

> I reckon the influence from my mum and that side is the whole self-soothe. They all did it. But that's kind of, I don't think [self-soothing is] a Tongan or Māori kind of thing. I think it comes from my European side. – Mere (Participant 05, Māori)

Despite advice from whānau members, some māmā chose to parent in their own way, whether they were first-time māmā or had older children. However, even experienced māmā were open to ideas from their partner or other whānau members and were willing to adopt new and effective practices.

> He did fall asleep during tummy time once. And I went to pick him up and my mother-in-law said, 'oh just let him sleep.' And I didn't because I couldn't actually see his face. – Tara (Participant 11, Māori)
>
> I've always just done it my own sort of way. I will listen to my partner. But if his family tells me to do something, I'm like, I've had enough children that I don't care. It doesn't matter what they say to me. But I do listen to my partner. I guess he's more of an influence than the family. But if I see them do something that works then I copy them. – Dominique (Participant 06, Māori)

D. Māmā [mothers'] advice to others about pēpē safe sleep

Māori (n=7) and non-Māori (n=5) māmā said they would advise new māmā to practice safe sleep, especially sleeping babies in their own space, on their backs and with their faces clear. Another said they would advise māmā to sleep baby at the foot of the bed. Although Māori and non-Māori māmā had previously mentioned the danger of pillows in baby's sleep space, only one māmā (Māori) said they would advise other māmā about this risk. Others said if māmā choose to bed share, do so safely placing a safe sleep bed, i.e., a Pēpi-pod® or wahakura, on the adult bed. One non-Māori māmā advised parents to get a bigger bed to enable safer bed sharing, and one Māori māmā said if they must bed share, "*do it on their own terms*" – Riley (Participant 23, Māori). Another recommended a well-known online auction site to obtain the necessary equipment to support safe sleep.

Māmā said they would advise new māmā to speak with health professionals and access information about safe sleep, but ultimately, many would advise māmā to do what's best for them and for baby, and to give themselves time. Advice from one Māori māmā would be to create a safe sleep plan together with whānau/household members. Another (non-Māori) said it was important to challenge unsafe advice and practices by whānau members.

> I'd just tell them to do what feels right. And don't listen to everyone's advice because it will mix you up. – Dominique (Participant 06, Māori)
>
> Making sure there's no space between the mattress, … no gaps. – Taylor (Participant 19, Pasifika)
>
> I'll tell them to get the Pēpi-pod®. And use it, don't use it for your laundry or for storage. – Tina (Participant 02, Pasifika)
>
> Spend more on the right sleeping equipment, rather than on toys. The first thing I do is go on Trade Me and see if I can get it three times cheaper. – Lisa (Participant 08, European)

When should women receive safe sleep information?

Māmā said the best time to share safe sleep information with women was before, during and after their pregnancies. More than half of māmā (Māori n=8; non-Māori n=8) recommend women seek information while pregnant to help prepare for baby's arrival and ensure the information is fresh in their minds when baby is born. One (non-Māori) māmā described the amount of information women receive after birth as 'overwhelming'. Others said māmā should prepare for baby's arrival during pregnancy by obtaining the correct equipment and learning how to sleep baby safely. A few suggested speaking with whānau members in advance of baby's birth and creating a safe sleep plan with the people who will help with baby's sleep time.

Others (Māori n=8; non-Māori n=8) said safe sleep information should be given after birth to provide a timely reminder for māmā about safe sleep and enable them to put the information into practice immediately. However, one (Māori) māmā said providing information in the first week may be too late. A non-Māori māmā thought safe sleep information should be given after birth and only during the first six weeks because she (incorrectly) believed SUDI is a danger to pēpē less than six weeks of age.

> Definitely during pregnancy so you can prepare for it. – Chloe (Participant 24, Māori)

> I learnt so much from the beginning [of my pregnancy] and then got to the end and I just didn't remember most of it. – Valerie (Participant 26, Māori).
>
> During that first week in the hospital [or] birthing unit, it's overwhelming to get so much information. – Denise (Participant 04, European)
>
> Not when they're pregnant, because [that is] too early. [Nurses and midwives should] keep providing us with information [during] the first 6 weeks … because it's involving baby's life and death. [After six weeks, safe sleep information is] not relevant anymore … the critical time is when the baby first comes out [and] the first 6 weeks when the midwife is still visiting the mum. – Delwyn (Participant 28, Asian)

Māmā recommended safe sleep information be provided in different ways to suit the learning styles and needs of pregnant women and māmā. This included verbal information sharing and storytelling (Māori n=11; non-Māori n=9), written information (Māori n=8; non-Māori n=5) and through demonstrations (Māori n=3; non-Māori n=4). Māmā felt that information should be shared in person and delivered more than once, in a non-threatening, non-judgemental way. Such approaches provide opportunity for māmā to ask questions and engage in a conversation. Being able to identify with the professional providing the information was also important, particularly with respect to ethnicity and culture. Written information can support face to face conversations and include graphics that illustrate how, and how not, to sleep pēpē safely. The limitations of written information were raised, such as language and literacy barriers. Information should be available in languages that māmā understand, or in "*simple English*" (Rachel - Participant 12, Pasifika). Others said some māmā prefer not to read.

Demonstrations that combine conversation and hands-on practise of new skills were favoured. Such approaches could help translate theory into learning through action. One māmā said Māori māmā are more likely to learn new skills in this way. Learning can be reinforced verbally and with printed or electronic material at māmā' convenience. Some said this is how they would support new māmā in their own whānau/social circle. One māmā felt strongly that sharing experiences and true stories with pregnant women and māmā was useful.

Other māmā suggested the use of videos or short films (Māori n=5; non-Māori n=3), the internet and popular video-based social media sites (Māori n=4; non-Māori n=4). Videos need to be clear, well-structured, well-presented and accessible online - or as one māmā suggested, viewed on the television screens in doctors' waiting rooms that play health promotion and education segments on a loop. One Māori māmā suggested utilising mainstream and Māori television and radio, and locations Māori parents and whānau gather, such as marae and Māori-based early education facilities (to target parents of young pēpē). One māmā suggested an online safe sleep application ('App') that could push out alerts and key messages to māmā based on pēpē age, like the commercially run pēpē-product websites.

> When it's from a Māori person, it's a lot easier to receive. Māori to Māori. – Shay (Participant 15, Māori)
>
> I would go to them and talk to them about it and help them out. I wouldn't write it down [or] email it [or] message it [or] text it. I would go there. Because you never know if that person needs more help than what they are asking for. – Tina (Participant 02, Pasifika)

> Experiences. Like true stories. It’s good that [expectant mothers/mothers] are afraid. Because me, I never believed in cot death or anything until [someone I knew experienced it]. Then I realised I would never want to experience that. I would rather die. – Valerie (Participant 26, Pasifika)
>
> There’s so much information, that if it is just a one-off, people feel just like ‘ah yeah, let’s forget it.’ I’m not a person who likes to read books. So, it might [need to] be brief or [have] pictures. Easy to understand. [Otherwise it is] just words, [they] go in one ear and out the other. – Delwyn (Participant 28, Asian)
>
> Videos can be confusing. At the marae [the video] was all over the place. They jumped from one subject to another. If it was structured a bit better, then I’d understand it properly. – Kylie (Participant 18, Pasifika)
>
> The magnet was helpful. It was only a couple of steps [for safe sleep]. It was a reminder and you kind of need reminding. Once the information’s gone and it’s not in front of you it becomes kind of irrelevant. - Sadie (Participant 25, Pasifika)

Most Māori and non-Māori māmā said the best people to share safe sleep information with pregnant women and māmā with pēpē are midwives (Māori n=10; non-Māori n=12). The next most popular response was whānau, especially female relatives, and friends (Māori n=7; non-Māori n=7). Non-Māori māmā (n=6) were more likely to cite hospital staff (nurses and doctors) as key sources of safe sleep information, compared with Māori māmā (n=2). However, more Māori māmā (n=5) stated ‘professionals and experts’ were an important source of information, compared with non-Māori māmā (n=1). A small number of Māori māmā (n=3) and non-Māori māmā (n=2) said Well Child Care providers were well-placed to provide safe sleep information, although one non-Māori māmā disagreed, based on her personal, negative experience. Other suggestions from Māori and non-Māori māmā included receiving information from non-professionals, provided they have accurate information.

> [Midwives are] qualified, they’re the ones who you look to, to trust them with the information that they’re giving. – Chloe (Participant 24, Māori)
>
> Your family. Your own mother, your grandmother or whoever raised you. The other women who have had babies in your family. – Gemma (Participant 10, Māori)
>
> If I go on an appointment with a midwife, whatever she says to me, I listen to it. – Lisa (Participant 08, European)
>
> When the midwife is educating the mum, it should [include] mum, the husband and the family. Because they can influence young mums [and] first time mums. In Pacific Island families, you’re expected to listen. But [family] don’t understand times have changed. It’s good for them [family] to know as well, so they don’t force their bad advice [onto the mum]. – Rachel (Participant 12, Pasifika)
>
> [The WCC providers] come in and start to interrogate you, kind of thing. I know they’re doing it for a good reason but sometimes you can feel like you don’t want to listen to them. They’re so full on. Sometimes they just hammer you with questions and just do this, do this. It can be off-putting. – Rachel (Participant 12, Pasifika)

E. Consistency versus variation in pēpē sleep routines

According to māmā, most pēpē slept when they were ready, whether as part of a consistent routine, with sleep occurring at the same times each day and night, or as part of an ad hoc pattern of sleep with different sleep times. Some māmā described taking steps to establish and maintain a routine for baby's sleep, with varying success.

Consistent routine

> I just go with him. […] the routine has only just come into place. – Rachel (Participant 20, Māori)
>
> He naturally has always put himself to sleep around that time – Tara (Participant 11, Māori)
>
> She's pretty easy, an easy baby. She sleeps when she wants to sleep – Ani (Participant 13, Māori)
>
> She kind of puts herself to sleep. Because she knows what time she goes to bed. It's like she knows – Dominique (Participant 06, Māori)
>
> He naturally has always put himself to sleep around that time – Tara (Participant 11, Māori)
>
> I generally try and keep him to his routine because I think it helps him – Denise (Participant 04, European)

Varied sleep routine

> I've tried to keep it a pattern. But within the past week and a half, she's been cluster feeding. So the pattern is way out the window. – Belle (Participant 21, Māori)
>
> She is, I would call a night-time baby. She sleeps during the day. She's wide awake during the night. – Belle (Participant 21, Māori)
>
> We've noticed that when we try to give him our own routine, it doesn't work with him. – Sadie (Participant 25, Pasifika)
>
> He doesn't sleep during the time I want him to sleep. He'll want to stay awake. – Taylor (Participant 19, Pasifika)
>
> He doesn't really have a sleep pattern as of yet – Lucille (Participant 22, European)

Recognising and interpreting baby's cues

Māmā described anticipating baby's needs and/or recognising and responding to their cues, such as grizzling, rubbing their eyes or yawning, to soothe and settle them to help baby fall asleep. Some parents felt they had learned how to read their baby's sleep cues but said they sometimes did not interpret the signs correctly.

> So he normally gives me cues which I know that he's tired and then I'll go and wrap him up and put him in his bed and let him fall asleep by himself. – Shay (Participant 15, Māori)

> He'll start rubbing at his eyes. Or he just starts grizzling. Because I know he's fed, he's changed, I've eliminated all the things he needs. So obviously it's sleep he wants – Shay (Participant 15, Māori)
>
> Sometimes I know he's tired because he starts to cry and then he starts rubbing his eyes. Or he'll start going like this to your shirt. – Taylor (Participant 19, Pasifika)
>
> They're smart. Babies can tell us; we just really have to listen. – Sadie (Participant, 25Pasifika)
>
> Sometimes I would need to put him in the bassinet, put dummy in his mouth again and again and again, a number of times, because he spits it. I'm just rocking the bassinet. If he's not very tired, if I didn't read his signs right, it might take me ages to rock him to sleep – Lisa (Participant 08, European)

Pēpē sleep routines do not always align with parental preferences.

> He doesn't sleep during the time I want him to sleep. He'll want to stay awake. – Taylor (Participant 19, Pasifika)
>
> We've noticed that when we try to give him our own routine, it doesn't work with him. – Sadie (Participant 25, Pasifika)

F. Self-soothing versus parent-assisted soothing

Most māmā said their pēpē slept when they were ready. Māori and non-Māori māmā were equally likely to attempt to establish a regular pēpē sleep routine.

> She's pretty easy, an easy baby. She sleeps when she wants to sleep. – Annette (Participant 13, Māori)
>
> I generally try and keep him to his routine because I think it helps him – Denise (Participant 04, European)
>
> I've tried to keep it a pattern. But within the past week and a half, she's been cluster feeding. So, the pattern is way out the window. - Belle (Participant 21, Māori)

Māori and non-Māori māmā (n=7 and n=5, respectively) described anticipating and/or recognising the needs of their pēpē and responding to cues, but not always correctly – such as grizzling, eye-rubbing, yawning – to soothe and settle the pēpē to sleep.

> He normally gives me cues, [so] I know that he's tired. Then I'll go and wrap him up and put him in his bed and let him fall asleep by himself. – Shay (Participant 15, Māori)
>
> Sometimes I would need to put him in the bassinet, put dummy in his mouth again and again and again, a number of times, because he spits it. I'm just rocking the bassinet. If he's not very tired, if I didn't read his signs right, it might take me ages to rock him to sleep. – Lisa (Participant 08, European)

Māmā (Māori n=4; non-Māori n=4) said their pēpē soothe themselves to sleep, and remain asleep without continued intervention, provided their basic needs were met. This typically involved pēpē being fed, burped, changed and cuddled before being placed to sleep.

Others (Māori n=5; non-Māori n=3) reported it was difficult to coax their pēpē to sleep without providing "*something more*" and would respond with extra cuddles, rocking, backpatting, swaddling, singing, walking, background noise/sounds, driving the pēpē in the car or offering an additional feed, usually from the breast.

> He's pretty easy. You just give him a kai. Make sure he's got a clean bum and he's all dry and his wind's brought up. And yeah, he just goes back to sleep. – Karla (Participant 07, Māori)
>
> She generally puts herself to sleep. She's quite the nap-nap baby. I guess the tit just knocks her right out, when she has a feed, she's just tired. – Belle (Participant 21, Māori)
>
> I want him to be able to sleep on his own. To make my life easier. - Libby (Participant 03, Pasifika)

Other māmā found it effective to place their pēpē in their preferred bed or location (including bed sharing, usually with māmā). Māmā (Māori n=5; non-Māori n=6) described their pēpē as needing to be asleep or nearly asleep before being placed into bed.

> He's able to soothe himself, like I can just let him lie down, he'll play around and then just go to sleep. – Libby (Participant 03, Pasifika)
>
> We listen to our baby and he's been telling us how he feels, what he wants. We listen carefully to the different types of crying. It tells us if he's hungry or sleepy. And it really helped us. Our days have been much better with him. – Sadie (Participant 25, Pasifika)
>
> We've tried multiple ways of trying to settle him. We've tried music, which he did used to like, but it doesn't seem to work as much as it used to. – Kylie (Participant 18, Māori)

Part Three: Summary

The third section of this thesis presented the qualitative research undertaken as part of this PhD, including the main manuscript and the supplementary appendix on the pēpē-infant sleep practices used by whānau in the sample group. Additional information related to the Pēpē-Infant Sleep Practices Study, including key sections of the study protocol are contained in Appendix B.

Part Four: Discussion and conclusions

Chapter Nine contains an overall discussion of the research findings and the potential implications for future research. Approaches for enhancing the effectiveness and appropriateness of SUDI prevention strategies for Māori and non-Māori families in New Zealand will be considered, and the strengths and limitations of the research.

Me huri kaukoe i ngā whārangio neheraa
ka whakatuwhera i tētahi whārangi hōu
mō ngā mea o te rā nei, mō āpōpō hoki

You must turn over the pages of the past
you must open a new page
for the things of today and tomorrow
Sir James Carroll (Timi Kara)

Chapter 9: Discussion and conclusions

9.1 Discussion

Paper 1: Use of Project Management Methodology to Implement Data Collection for a Nationwide Case-Control Study Investigating Sudden Unexpected Death in Infancy (SUDI)

Summary of key findings

The project management method outlined in Chapter 3 and Chapter 4 provided a structure for implementing the multifaceted data collection requirements for the three-year SUDI Nationwide Study.

Project management involves a coordinated effort to achieve specific objectives on budget and on time (142). In 2002, project management was viewed more as an operational asset rather than a method for carrying out health research (194). Very little published information exists about the use of formal project management in health and medical research (195). Few health researchers have published data about their use of project management methodology, yet those who have, reported delivering their health research projects according to protocol, within budget and on time (195).

A project management approach has the flexibility to incorporate other methodologies and ways of thinking to guide and influence the research conception, design, and activities. New Zealand's indigenous Māori population are most affected by SUDI in this country. Therefore, SUDI research in New Zealand should always give careful and thoughtful consideration to including kaupapa Māori principles to ensure the research is appropriate for Māori and does not cause harm for Māori participants (196).

The NZ Health Research Council published a Māori ethical framework for all research involving or affecting Māori (184). The framework is based on the principles in Te Tiriti o Waitangi: partnership, participation, and protection (161). These provide the foundation for the relationship between the partners to Te Tiriti – the Crown (and government entities) and Māori (161). Other published researcher guidelines and cultural values (29) are also readily available, which provide guidance about how these aspects can be easily incorporated into the research design if they are incorporated at the very early stages of conception. The silence around Māori health in much of New Zealand’s health policy documents (21), and the processes in healthcare provision with regards to Māori health decision-making, perpetuates these inequities (22).

The project workstreams and processes involved in the data collection for the SUDI Nationwide Study comprised many elements, some of which were varied and complex, and involved stakeholders with competing priorities. However, the formal project management structure, combined with the range of experience and expertise of the people involved, enabled the project to be successfully delivered. Any issues were managed satisfactorily and quickly, at the appropriate level for the severity of risk.

Project management in health research allows for continuous improvement of the processes involved (195). This agility was important when managing and responding to the various aspects of the research. For example, the low uptake of participants in the control group was recognised as an issue, which enabled the project team to respond with strategies that were developed with, and ratified by, the project’s Steering Committee.

Strengths and weaknesses

A key strength was the diversity, expertise, and high level of authority of the Steering Committee members. This enabled high-risk issues to be worked through, sometimes requiring committee members to work within their organisation to work through the issues and find a resolution. This allowed the SUDI Liaison team to focus on engaging with and recruiting participants to the study. The skills and experience of the SUDI Liaison team were a further strength. This includes their knowledge, skills, and clinical backgrounds, their cultural diversity and ability to engage appropriately and effectively with families of both cases and controls. Team members engaged with 96% of families that experienced a SUDI during the study period. SUDI Liaison engagement with participants helped some families to achieve outcomes that meant having one less worry in the aftermath of their infant’s death. For example, linking families into services they may have needed, such as primary care or whānau ora (holistic Māori-focused services), or by assisting families in the control group to provide a safer environment for their family by advocating on their behalf with government housing and accommodation providers. A third strength was the use of a national communications strategy. This was designed for a diverse audience and included multiple methods of communication. Specially designed, highly recognisable imagery was created featuring Māori imagery that represented, among other things, strength.

A weakness in applying a project management approach is potentially the cost of engaging an external provider to manage the project, or researchers with little experience in project management having to learn what is involved. However, project management need not be onerous, and experienced researchers are already skilled in planning and undertaking small- and large-scale research projects, and for being accountable to funders.

Implications for practice

The key implication for researchers is to infuse formal elements of project management into their research activities, that they are not already doing. The protocol for a research project is the basis for the project management plan. Aspects relating to stakeholder analysis and communications are simple to incorporate into the research activities. Establishing a steering committee to suit the size of the project, and including regular meetings, reporting, and risks and issues management, is achievable. This is likely to be second nature to experienced researchers. Their role could be to mentor inexperienced and emerging researchers to consider the research in terms of a wider framework, with multiple workstreams running simultaneously or at different times, depending on the status of the project.

Future research directions

Formal research into the use of project management in health and medical research would be useful to fill the gap that currently exists and would ideally commence at the beginning of the research process, or as early as possible to maximise the benefits that the structure would provide. Including kaupapa Māori methodologies and world views at the conception and design phase of a research project will likely lead to better and improved outcomes for Māori.

Paper 2: Smoking in pregnancy is a key factor for sudden infant death among Māori

Summary of key findings

Chapter 5 contains a description of the approach we used to examine the continued disparity in SUDI rates in New Zealand between Māori infants and non-Māori infants. Mitchell et al had previously reported that, based on the first paper from the SUDI Nationwide Study dataset that was also used for the analysis in this paper, infants exposed to the combination of maternal smoking and bed sharing were at far greater risk of SUDI than infants who were not exposed to both factors (5). While the findings were valuable and important, they did not examine the reason for the higher rate of SUDI for Māori.

In this paper, we examined the prevalence of risk factors, and the effect of these on the risk of SUDI for Māori and non-Māori. We sought to identify differences that might explain the higher SUDI rate observed for Māori infants.

Our analysis found that the magnitude of the individual effects of smoking in pregnancy and of bed sharing, and the combination of both factors, were of similar risk for Māori and non-Māori infants with regards to SUDI.

When we compared the prevalence of risk factors between Māori and non-Māori, the prevalence of bed sharing among Māori and non-Māori infants was virtually the same in both cases and controls. When the prevalence of smoking in pregnancy was assessed, we identified significant differences in the prevalence between Māori and non-Māori infants. Māori infants were more likely to be exposed to smoking in pregnancy.

This was highlighted by population attributable risk (PAR) for smoking, which for Māori was 67%, compared to 49% for non-Māori. There was little difference in PAR calculations for both groups for bed sharing, although eliminating exposure of infants to the combination of bed sharing and smoking in pregnancy could reduce SUDI in Māori by as much as 74%, and 50% in non-Māori.

As alluded to above, infants of mothers who smoke and bed share have a 32-times increased risk of SUDI than infants not exposed to bed sharing or smoking in pregnancy (5). The prevalence of bed sharing in both groups in this study is strikingly similar (Māori 17.1% and 18.5% non-Māori). This is indicative of the universality of bed sharing behaviours among families with infants and is consistent with the prevalence of bed sharing reported in previous studies (148).

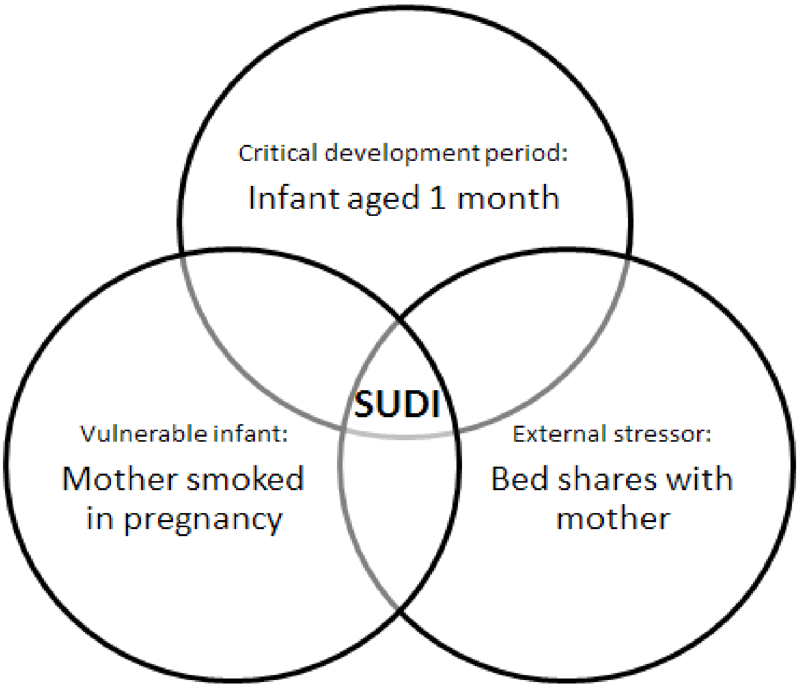


Figure 9.1 Modified Triple Risk Model

The Triple Risk Model discussed in Chapter 2 (132) provides a framework for us to consider these results in the context of the research in this thesis and the implications for Māori infants. The model focuses on the combined effect when three types of risk factors converge to create an environment in which infants are more likely to die from SUDI.

Carpenter (79) found that the combination of smoking and bed sharing was higher in young infants. This is a three-way interaction, which did not differ between Māori and non-Māori. We can apply this thinking to the Triple Risk Model as smoking in pregnancy creates an intrinsic vulnerability for an infant. Once this particular risk is present, it resides as a latent vulnerability until another factor is introduced. Adding the external stressor of bed sharing with mother to an infant one month of age, would create a high-risk environment in which SUDI is a more likely outcome compared to infants not exposed to such a combination.

Strengths and weaknesses

There are several key strengths associated with this paper, some of which apply to all the papers produced from SUDI Nationwide Study. At present, this study is the only known case-control SUDI study to have occurred in the previous decade. The authorship of this paper, and the other papers that are based on the same dataset, include expert world-renowned SUDI academics and clinicians from New Zealand, Germany, and the United Kingdom. The project management approach used to implement the study provided a robust structure for all implementation-related activities prior to, during, and after the data collection period, and is an additional strength of the study. A further strength was the high participation among cases (96%). The inclusion of cases in the study was dependent on infants undergoing a post-mortem examination. Just one case did not have a post-mortem and was excluded from the study.

There were fewer deaths (n=137) than the expected 210 SUDI cases over the 3-year study due to a decrease in unexpected infant deaths during that period. This impacted the statistical power in analyses and thus our ability to detect odds ratios of the magnitude determined in the initial study design. Although there was very little missing data among controls (n=258), which was a strength, one of the weaknesses of the study was that 60% of selected controls did not participate. We hypothesise that because controls were selected to reflect previous SUDI mortality data, the study was attempting to recruit mothers with multiple SUDI risk factors. These included mothers who were likely to be Māori, smokers, and living in areas of socioeconomic disadvantage, as opposed to a nationally representative sample. Attempting to recruit participants with this increased level of risk and lower socioeconomic status often results in a high refusal rate (197), which was experienced in this study. Furthermore, in some geographic areas, the high turnover rate of mobile telephone numbers and transience among selected controls compounded attempts to engage with them. We did not examine the known disparities associated with Māori mothers’ access to maternal health care, and this is a possible limitation. Māori mothers are less likely to present to antenatal services (10) or they attend late (153, 154), and are more likely to receive poorer quality health care (155).

Implications for practice

Based on the evidence of the risk of SUDI from the combination of bed sharing and smoking in pregnancy, the implication for practice is for people who work with, or support, pregnant women, and mothers of infants to continue to actively discuss and facilitate –during pregnancy and throughout infancy - infant safe sleep, and to normalise safe sleep as a part of the usual infant care routine. Similarly, continued emphasis of the importance of mothers being smoke free during pregnancy is another important implication for practice.

Future research directions

Further research into strategies that reduce the inequities experienced by Māori mothers with regards to earlier access and improved engagement with maternal health, and smoking cessation programmes would be beneficial. Continued research and evaluation into the use, appropriateness, effectiveness, acceptability, and availability of safe sleep beds is also important as these are an important component of SUDI prevention.

Paper 3: Infant sleep hazards and the risk of sudden unexpected death in infancy (SUDI)

Summary of key findings

Chapter 6 is a paper that describes our analysis of data from the SUDI Nationwide Study to determine the level of risk to infants from various hazards in the infant sleep environment.

The prevalence of hazardous situations, which include infants exposed to sleeping on a sofa, or to caregivers that have recently used alcohol and cannabis or drugs, was low in our high-risk control population. However, when infants were exposed to these situations, these factors appeared to be highly dangerous, especially for very young infants (younger than three months of age).

The risk to an infant from sofa sleeping increases when the infant shares the sofa with another person who is also asleep; and the risk increases further when that person has recently used alcohol or drugs (96, 112, 113). While the use of sofas for infant sleep was uncommon in our sample, when this did occur during the last or nominated sleep, there was a significantly increased risk of SUDI for the infant. Of the eleven infants who died on a sofa, eight infants were sharing the space with their mother at the time. These infants had been placed and found during the night and early morning, which is consistent with previous findings (96, 112, 113).

We have previously confirmed that the combination of smoking during pregnancy and bed sharing increased the risk of SUDI (5). Furthermore, we identified that the risk from this combination increased with the addition of each of the hazards – sofa sleeping, and the recent use by caregivers of alcohol, and of cannabis and other drugs.

We also examined the use of bedding, pillows, cot bumpers and toys. We identified that infants sleeping in an adult bed, or sofa/other, or with pillows underneath them, were at increased risk of SUDI compared with infants that were not exposed to these risks. The presence of cot bumpers and soft toys in the cot were uncommon and did not present a significant increased risk of SUDI.

The use of firmly tucked bedding was associated with a reduced risk of SUDI for infants. We found no discernible difference in the effect of the risks between Māori and non-Māori infants. The greatest risk for infants was the combination of smoking in pregnancy, bed sharing and with the addition of one or more hazards (sofa sleeping, and recent caregiver use of alcohol, or drugs).

Strengths and weaknesses,

This analysis builds on the findings in the previous paper (167). Thus, the strengths and weaknesses of this analysis mirror those of the previous study. This paper provides information on the effects of the risks of hazards in the infant sleep environment based on a nationwide case-control study and is the most recent study in the world to do so.

The additional strengths associated with this paper, was the use of imputed data, which helped to overcome the issue of missing data. This paper also included an analysis of the effects of the hazards on Māori and non-Māori infants.

The limitations specific to this paper included the amount of missing data across the variables for cases, compared to controls, although this was mitigated to an extent by imputation.

Implications for practice

The results of this paper can be used to inform health education and promotion messaging about safe sleep, and specifically the risks associated with hazards in the infant sleep environment. These include advising the avoidance of sleeping infants on a sofa, the use by caregivers of alcohol, and cannabis or drugs, and the use of bedding and pillows. Informing mothers of the lower risk of firmly tucked bedding compared to loose bedding may also be useful.

Future research

The inevitable lag time between the conception of a SUDI research project and publishing the results is problematic. Also, the lower number of SUDI deaths today compared with four decades ago, while extremely positive from a prevention perspective, also leads to fewer cases to compare with controls, which limits the statistical power to identify differences between the groups. This suggests a need for ongoing monitoring of SUDI deaths to enable the expedient identification of changes that may be occurring, and which might indicate potentially new risk factors. For example, the use of vaping is increasing and the full effects of this practice on an unborn infant, or after birth, are not yet fully understood. Recently the Ministry of Health included vaping into its 'Smokefree 2025' harm-reduction tobacco control programme (198). This follows the passage of the Smokefree Environments and Regulated Products (Vaping) Amendment Bill (199) being passed in parliament. Bed sharing does not seem to be reducing at the pace required to adequately reduce the rates of SUDI with more than 50% of deaths occurring in a bed sharing context (5) and very little difference in bed sharing between Māori and non-Māori controls (167).

Paper 4: E Kō, kia ora, kua ao te rā! [Baby, a new day has dawned!]: Pēpē-infant sleep practices and sudden unexpected death in infancy (SUDI) in Aotearoa-New Zealand

Summary of key findings

Chapter 7 contains a paper that draws on data from a qualitative study that explored the infant sleep practices of mothers with infants born in the district health board region of Counties-Manukau, Auckland, and the motivators influencing infant sleep decisions.

Thirty mothers participated in the study (Māori n=17; non-Māori n=13). Three-quarters of mothers had breastfed or were still breastfeeding at the time of interview, which is reassuring as the benefits associated with breastfeeding are well-known. The number of mothers who reported smoking in pregnancy was smaller than expected compared with the high smoking rate in Counties-Manukau among pregnant women (73). Six mothers reported smoking in pregnancy, five of whom were Māori. This lower rate of smoking among participants in the study suggests these mothers are most likely to be at lower risk of SUDI.

Two-thirds of mothers' bed shared currently or had done so previously. Mothers' main reasons for bed sharing included the need for improved sleep for both mother and infant, closeness and convenience, and breastfeeding. However, breastfeeding was only given as a reason for bed sharing by Māori mothers. Mothers had good knowledge of key SUDI prevention messages, especially the need for their infant to have their own bed, to keep their face clear of bedding, and to place their infant in the supine sleep position. Six mothers were unaware of SUDI, SIDS, or cot death, even after prompting. Mothers described their close female relatives and partners as being highly influential regarding their infants' sleep routine, and involving these key people in safe sleep education, would support mothers to routinely practice safe sleep.

Strengths and weaknesses

A major strength of the study was that it used an indigenous kaupapa Māori research approach. This provided a culturally appropriate framework with which to engage with mothers in a way that was respectful and accommodating to their individual preferences. For example, the offer was made at the beginning of each interview to start with a karakia [prayer], and almost all mothers agreed. A koha was provided to each participant to acknowledge their contribution to the research. In line with the approach, periodic contact was maintained, where possible, with the mothers, for example to request images for the community report that was produced based on the findings of the study (Appendix B.9.), and to provide updates on progress with the research. A further strength was the large amount of rich data that was provided by the mothers who participated and who provided a rich source of data about their SUDI-related knowledge and infant sleep practices. These data have not yet been fully analysed.

While the ethnic distribution among participants was representative of the distribution of SUDI in the SUDI Nationwide Study, the sample was small due to the qualitative nature of the research, and the smoking rate among the sample was much lower than expected. This is despite deliberately selecting participants from a geographic area with a high incidence of SUDI and high smoking rates among pregnant women (191).

A further weakness was the number of mothers who declined to participate (n=51), either by direct decline, or for the majority (n=47), by implied decline due to being uncontactable, or the interview did not proceed. In the SUDI Nationwide Study, Māori were less likely to participate in the research compared with non-Māori. It is possible, if not likely, the mothers who did not participate have a higher risk profile than the mothers in the study. This means the results are less able to be extrapolated to higher risk populations.

Implications for practice

The implications for practice from this paper are the importance of continued provision of safe sleep education and promotion, and smoking cessation support. Mothers indicated they would be open to safe sleep education that involved their close female relatives and partners, due to the important role these people have in relation to infant sleep routines.

Future research

An exploration of innovative approaches of providing safe sleep education involving mothers and the other key people involved in caring for infants and infant sleep, especially partners and close female relatives.

9.2 Conclusion

The research described in this thesis has strengthened and informed our understanding of sudden unexpected death infancy in New Zealand, especially for Māori infants who continue to be over-represented in SUDI mortality rates. The effects of the combination of smoking and bed sharing for Māori and non-Māori infants has been confirmed and the magnitude of risk the same for both groups. The notable difference however is in the prevalence of smoking in pregnancy which is significantly higher among Māori women. We have also confirmed the danger of this combination of smoking in pregnancy and bed sharing, with the addition of hazards in the infant sleep environment, including sofa sleeping, and recent use of alcohol and cannabis and other drugs – again, the magnitude of risk is no different for Māori and non-Māori infants. The safest place for infants to sleep is in a cot, or cot-type bed on their own bed, with blankets firmly tucked in the parents' room. The qualitative research on the infant sleep practices of mothers of young infants living in Counties-Manukau identified that mothers who shared a bed with their infant, did so mainly due to exhaustion, especially among Māori mothers. The research also found that intrinsic fear was a powerful motivator for mothers to practice safe sleep. The kaupapa Māori approach used in the qualitative study, and during the engagement with participants in the SUDI Nationwide Study, led to a range of positive interactions, despite some of those occurring in the context of the death of an infant. Smoking is a modifiable behaviour, and these findings highlight the need to continue to promote the availability of effective, appropriate smoking cessation programmes, alongside the continued promotion of safe sleep, and the supply of safe sleep beds for infants at high risk of SUDI.

List of appendices

Appendix A: Appendices related to the SUDI Nationwide Study

Appendix B: Appendices related to the Pēpē-Infant Sleep Practices Study

Appendix A: Appendices related to the SUDI Nationwide Study

Appendix A.1. Project management and governance roles in the SUDI Nationwide Study

The project management approach

Implementing the SUDI Nationwide Study involved considering the needs of a range of stakeholders, processes, and legal requirements. Consulting company Communio was selected to implement and manage the complexities of the project requirements, through a robust project management approach. Communio was selected to manage the project because of its experience managing the SUDI Referral Advisor pilot and the feasibility study, its knowledge of, and existing relationship with New Zealand Coronial Services, and specialist expertise in project management and implementation. A Communio project manager/consultant (author of this thesis) was appointed project manager for the SUDI Nationwide Study. The role officially commenced on 1st October 2011, although the involvement of Communio in the implementation planning phase began in August 2011.

The following information describes the objectives of the project and the approach used to achieve these, including arrangements for governance.

Project governance – the Steering Committee

Project governance of the study was provided by a steering committee comprising representatives from key stakeholder agencies, such as Coronial Services, New Zealand Police and SUDI-related clinical research and academic experts, and cultural advisors.

Members included the Chief Coroner of New Zealand at the time, judicial support and operations managers from Coronial Services, an Auckland coroner, several paediatricians, the Chair of the Child and Youth Mortality Review Committee, forensic and perinatal pathologists, an academic Māori advisor and, during project establishment, NZ Police. The committee was chaired by Professor Mitchell (the Principal Investigator).

An illustration of the project structure for SUDI Nationwide Case-Control Study and the Steering Committee members is provided in Chapter3.

Role of the Steering Committee

The purpose of the group was to direct and provide governance for the implementation of the project (to collect data for the SUDI Nationwide Study) by providing oversight of all project components during all project phases.

The SUDI Liaison team and project manager provided secretariat support for the committee, including the production and distribution of agenda, minutes, the risks and issues register, status reports and other relevant documents pertaining to each meeting. Two hours prior to the meeting, the chair of the steering committee, who was also the principal investigator for the study, and the project manager would conduct a pre-meeting. This provided an opportunity to run through the agenda, discuss any issues that had arisen, and the actions taken, and any apologies received from members unable to attend the meeting and, if applicable, the details of the person attending on their behalf.

Any issues arising within the project were managed in the first instance at an operational level by the project manager and the Communio project lead (the Communio executive manager). Significant or ongoing issues or risks were discussed by the committee, which would provide guidance and advice to the team. The range of backgrounds and expertise within the committee supported the opportunity for robust discussion about the issues. Actions to resolve specific issues were agreed and allocated to various members of the committee. These were recorded in an action log and followed up at each meeting. Changes in committee membership occurred over the life of the project, mainly due to people changing roles. Prior to leaving the committee, members would identify a replacement, thus ensuring key representation was maintained throughout the project.

Role of the project manager

The project manager's role was to ensure the project objectives were met, including that: 1.) accurate, comprehensive, and timely data collection for the study occurred; 2.) families that had experienced SUDI had information about coronial processes; and 3.) families were linked into health and support services they may have needed at the time. As previously described, the SUDI Liaison team was the main conduit by which these outcomes were achieved.

Project objectives

The key objectives for the project are listed below and are discussed in greater detail throughout this chapter. The objectives included:

- Governance – Use project management approach and establish structures for project governance
- Communications - Deploy a comprehensive communications plan
- Stakeholder management - Manage key stakeholder relationships
- Data collection - Provide the data collection tools and mechanisms for data management
- SUDI Liaison team - Recruit, develop, manage and supervise appropriately qualified and competent SUDI Liaison staff
- Policy framework - Document all processes and timeframes for the SUDI Liaison role, including development of a study protocol and a policy framework that prioritises maximum responsiveness to Māori

Project human resources

Human resources allocated to the project included a half-time project manager (0.5 FTE-full time equivalent), SUDI Liaison staff based in Auckland, Wellington or Palmerston North, and Christchurch (2.5 FTE), the project lead (0.1FTE), and for the first year, a project co-ordinator (0.1 FTE).

Appendix A.2. Participant information and invitation letters

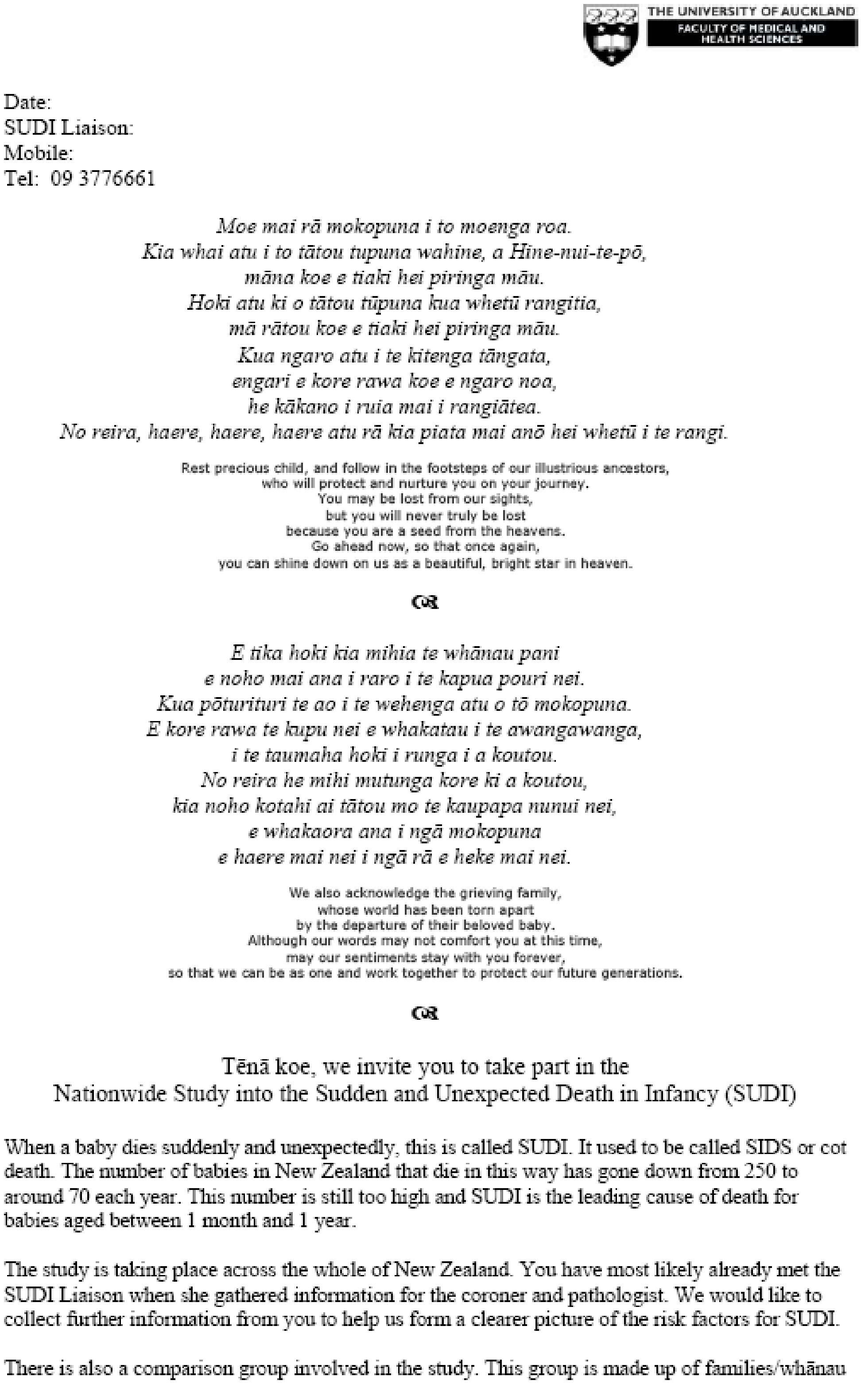
Each family was provided with a letter containing information about the study and an invitation to participate. Specific letters were developed for cases and for controls. Each letter began with a mihi (greeting) composed by Whakawhetū (previously Māori SIDS).

The mihi for families in the control group acknowledged their support for the research and the benefits from their involvement for future infants and their families. For families in the case group, the mihi speaks first to the infant that has passed to reassure them they are cared for in heaven and loved here on earth. This is followed by an acknowledgement of the pain the family is experiencing and blessings of comfort and hope. English translations for each mihi were included in the invitation letters.

Mihi [Māori greetings] were incorporated by some SUDI Liaison into the opening stages, or settling period, before the interview actually started, when whakapapa (‘connections’ in this context) are shared to find a common bond and a base from which to proceed: where people feel safe, heard and not judged. As described in chapter one, karakia (prayer) was offered as a way to open the interview and clear the path for a conversation that was invariably confronting and painful for families.

The invitation letters for cases and controls are provided below.

Appendix A.3. Invitation Letter for Cases



THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND HEALTH SCIENCES

Date:
SUDI Liaison:
Mobile:
Tel: 09 3776661

Moe mai rā mokopuna i to moenga roa.
Kia whai atu i to tātou tupuna wahine, a Hine-nui-te-pō,
māna koe e tiaki hei piringa māu.
Hoki atu ki o tātou tūpuna kua whetū rangitia,
mā rātou koe e tiaki hei piringa māu.
Kua ngaro atu i te kitenga tāngata,
engari e kore rawa koe e ngaro noa,
he kākano i ruia mai i rangiātea.
No reira, haere, haere, haere atu rā kia piata mai anō hei whetū i te rangi.

Rest precious child, and follow in the footsteps of our illustrious ancestors,
who will protect and nurture you on your journey.
You may be lost from our sights,
but you will never truly be lost
because you are a seed from the heavens.
Go ahead now, so that once again,
you can shine down on us as a beautiful, bright star in heaven.

* * *

E tika hoki kia mihia te whānau pani
e noho mai ana i raro i te kapua pouri nei.
Kua pōturituri te ao i te wehenga atu o tō mokopuna.
E kore rawa te kupu nei e whakatau i te awangawanga,
i te taumaha hoki i runga i a koutou.
No reira he mihi mutunga kore ki a koutou,
kia noho kotahi ai tātou mo te kaupapa nunui nei,
e whakaora ana i ngā mokopuna
e haere mai nei i ngā rā e heke mai nei.

We also acknowledge the grieving family,
whose world has been torn apart
by the departure of their beloved baby.
Although our words may not comfort you at this time,
may our sentiments stay with you forever,
so that we can be as one and work together to protect our future generations.

* * *

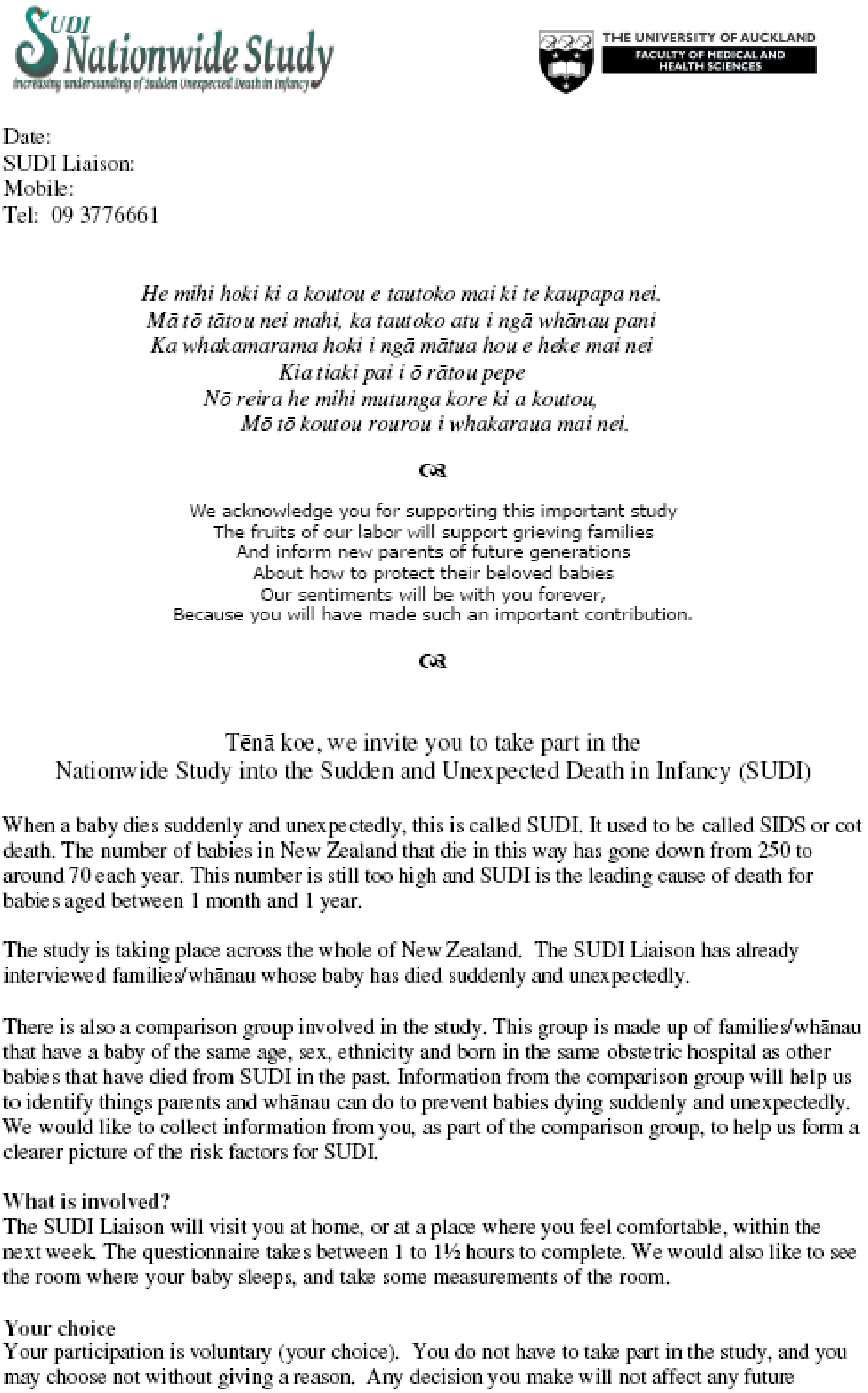
Tēnā koe, we invite you to take part in the
Nationwide Study into the Sudden and Unexpected Death in Infancy (SUDI)

When a baby dies suddenly and unexpectedly, this is called SUDI. It used to be called SIDS or cot death. The number of babies in New Zealand that die in this way has gone down from 250 to around 70 each year. This number is still too high and SUDI is the leading cause of death for babies aged between 1 month and 1 year.

The study is taking place across the whole of New Zealand. You have most likely already met the SUDI Liaison when she gathered information for the coroner and pathologist. We would like to collect further information from you to help us form a clearer picture of the risk factors for SUDI.

There is also a comparison group involved in the study. This group is made up of families/whānau

Appendix A.4. Invitation Letter for Controls



SUDI Nationwide Study
Increasing understanding of Sudden Unexpected Death in Infancy

THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND HEALTH SCIENCES

Date:
SUDI Liaison:
Mobile:
Tel: 09 3776661

He mihi hoki ki a koutou e tautoko mai ki te kaupapa nei.
Mā tō tātou nei mahi, ka tautoko atu i ngā whānau pani
Ka whakamarama hoki i ngā mātua hou e heke mai nei
Kia tiaki pai i ō rātou pepe
Nō reira he mihi mutunga kore ki a koutou,
Mō tō koutou rourou i whakaraua mai nei.

◆

We acknowledge you for supporting this important study
The fruits of our labor will support grieving families
And inform new parents of future generations
About how to protect their beloved babies
Our sentiments will be with you forever,
Because you will have made such an important contribution.

◆

Tēnā koe, we invite you to take part in the
Nationwide Study into the Sudden and Unexpected Death in Infancy (SUDI)

When a baby dies suddenly and unexpectedly, this is called SUDI. It used to be called SIDS or cot death. The number of babies in New Zealand that die in this way has gone down from 250 to around 70 each year. This number is still too high and SUDI is the leading cause of death for babies aged between 1 month and 1 year.

The study is taking place across the whole of New Zealand. The SUDI Liaison has already interviewed families/whānau whose baby has died suddenly and unexpectedly.

There is also a comparison group involved in the study. This group is made up of families/whānau that have a baby of the same age, sex, ethnicity and born in the same obstetric hospital as other babies that have died from SUDI in the past. Information from the comparison group will help us to identify things parents and whānau can do to prevent babies dying suddenly and unexpectedly. We would like to collect information from you, as part of the comparison group, to help us form a clearer picture of the risk factors for SUDI.

What is involved?
The SUDI Liaison will visit you at home, or at a place where you feel comfortable, within the next week. The questionnaire takes between 1 to 1½ hours to complete. We would also like to see the room where your baby sleeps, and take some measurements of the room.

Your choice
Your participation is voluntary (your choice). You do not have to take part in the study, and you may choose not without giving a reason. Any decision you make will not affect any future

medical care you may need. If you do agree to take part, you can withdraw your information from the study at any time without having to give a reason.

Confidentiality
Nothing that could personally identify you or your baby will be used in any reports on this study.

ACC (Accident Compensation Corporation)
It is extremely unlikely that you will be physically harmed as a result of participating in this study. However, if you are, you may be entitled to compensation by ACC under the Accident Compensation Act 2001. If you have any questions about ACC, contact your nearest ACC office or ask the SUDI Liaison.

Benefits of taking part
By participating in this survey, you are helping to build New Zealand's knowledge and understanding about what we can change to make it safer for babies and lower the number of babies that die from SUDI.

Ethical approval
This study has received ethical approval from Central Regional Ethics Committee. If you have any questions or concerns about your rights as a participant in this study you can contact an independent health and disability advocate: Freephone 0800 555 050; Free fax 0800 2787 7678; Email advocacy@hdc.org.nz.

What happens now?
The SUDI Liaison will contact you in the next week or so. You will have the opportunity to ask questions and to say whether you would like to take part. In the meantime, if you have any questions, please let us know.

Ngā mihi mahana ki a koe,

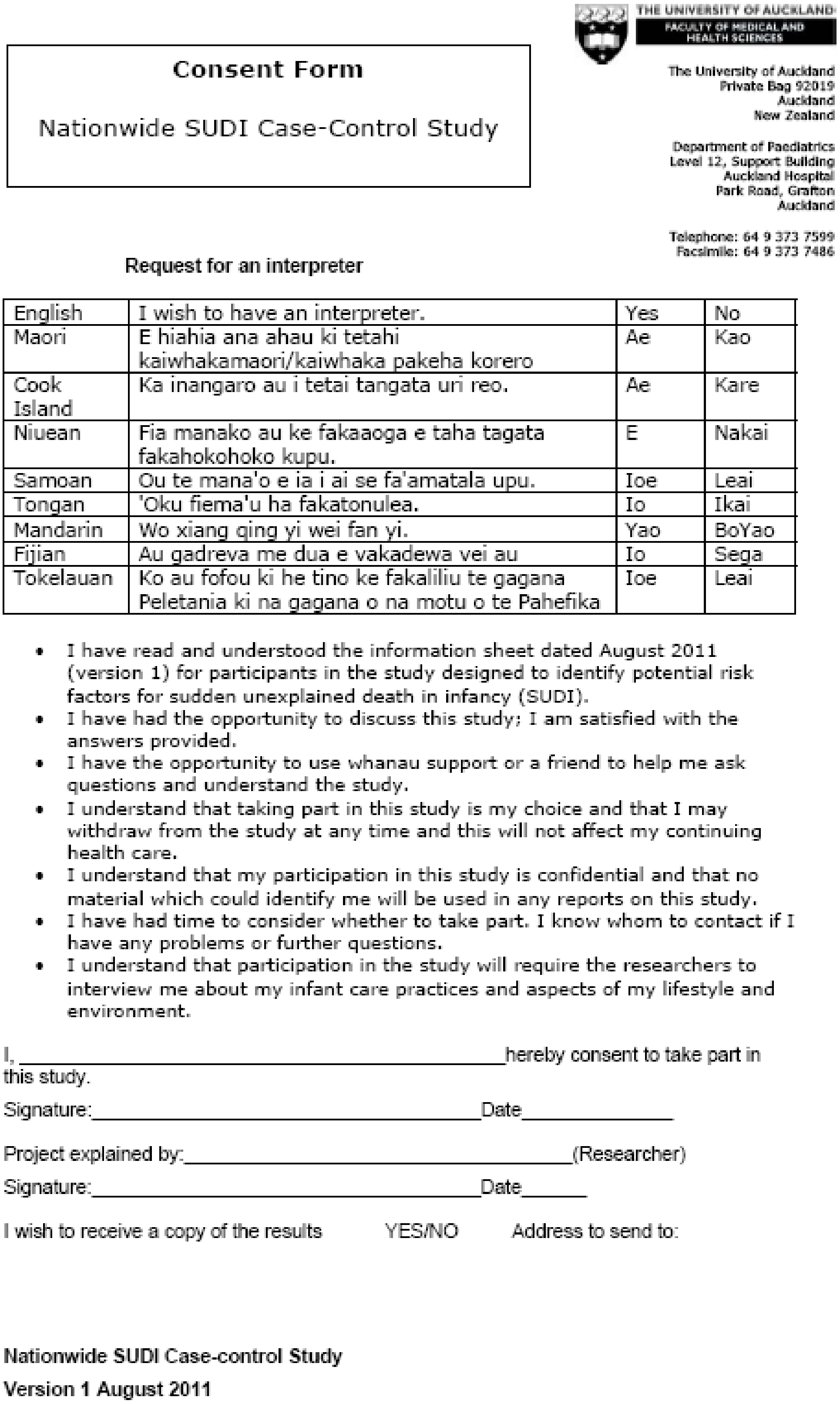
Ed Mitchell

Professor Ed Mitchell
Principal Investigator
Department of Paediatrics
The University of Auckland
Private Bag 92 019, Auckland.
Tel: 09 373 7599 ext 86431

For more information, please contact:
Melanie MacFarlane, Project Manager
Communio
M: 021 330370
Tel: 09 3776661
melanie.macfarlane@communio.co.nz

* * *

Appendix A.5. SUDI Study Consent Form



THE UNIVERSITY OF AUCKLAND
FACULTY OF MEDICAL AND HEALTH SCIENCES

The University of Auckland
Private Bag 92019
Auckland
New Zealand

Department of Paediatrics
Level 12, Support Building
Auckland Hospital
Park Road, Grafton
Auckland

Telephone: 64 9 373 7599
Facsimile: 64 9 373 7486

Consent Form

Nationwide SUDI Case-Control Study

Request for an interpreter

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero	Ae	Kao
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai
Samoan	Ou te mana'o e ia i ai se fa'amatala upu.	Ioe	Leai
Tongan	'Oku fiema'u ha fakatonulea.	Io	Ikai
Mandarin	Wo xiang qing yi wei fan yi.	Yao	BoYao
Fijian	Au gadreva me dua e vakadewa vei au	Io	Sega
Tokelauan	Ko au fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	Ioe	Leai

- I have read and understood the information sheet dated August 2011 (version 1) for participants in the study designed to identify potential risk factors for sudden unexplained death in infancy (SUDI).
- I have had the opportunity to discuss this study; I am satisfied with the answers provided.
- I have the opportunity to use whanau support or a friend to help me ask questions and understand the study.
- I understand that taking part in this study is my choice and that I may withdraw from the study at any time and this will not affect my continuing health care.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.
- I have had time to consider whether to take part. I know whom to contact if I have any problems or further questions.
- I understand that participation in the study will require the researchers to interview me about my infant care practices and aspects of my lifestyle and environment.

I, ____hereby consent to take part in this study.

Signature:___________________________________Date______________

Project explained by:__________________________________(Researcher)

Signature:___________________________________Date______

I wish to receive a copy of the results YES/NO Address to send to:

Nationwide SUDI Case-control Study
Version 1 August 2011

Appendix A.6. Map of SUDI Liaison Regions

Appendix A.7. SUDI Liaison team Profile, August 2013

SUDI Nationwide Study

increasing understanding of Sudden Unexpected Death in Infancy

The SUDI Liaison Team

Melanie MacFarlane, Dip.RCN, BSc, MSc, (Ngāti Maniapoto, Raukawa)

Consultant, Communio; Melanie is based in Auckland and project manages the data collection for the **SUDI Nationwide Study,** on behalf of the University of Auckland.

Mobile: 021 330370; Tel: 09 377 6661; melanie.macfarlane@communio.co.nz

Genevieve Ali, BA/BHSc, BAHONS (First Class)

SUDI Liaison and Project Coordinator, Communio; Genevieve is based in Auckland and, with Shelley Jonas, covers **Upper and Central North Island**, including Northland, Auckland, Waitemata, Counties Manukau, Waikato, Bay of Plenty, Taranaki, Lakes and Tairawhiti DHBs.

Mobile 021 825 518; Tel: 09 377 6661; genevieve.ali@communio.co.nz

Shelley Jonas, NZRN, B. Visual Arts

SUDI Liaison, Communio; Shelley is based in Auckland and, with Genevieve Ali, covers **Upper and Central North Island**, including Northland, Auckland, Waitemata, Counties Manukau, Waikato, Bay of Plenty, Taranaki, Lakes and Tairawhiti DHBs.

Mobile 021 825 010; Tel: 09 377 6661; shelley.jonas@communio.co.nz

Judy McIntyre, NZRGON, B. Fine Arts (Distinction)

SUDI Liaison, Communio; Judy is based in Palmerston North and covers the **Lower North Island** region incorporating Capital and Coast, Hutt Valley, Wairarapa, Hawkes Bay, MidCentral and Whanganui DHBs. Judy also assists in Taranaki and Tairawhiti.

Mobile 021 825 856; Tel: 09 377 6661; judy.mcintyre@communio.co.nz

Elaine McLardy, RM, RGON. MZ applied Midwifery

SUDI Liaison, Communio; Elaine is based in Christchurch and covers the **South Island** region incorporating Southern, South Canterbury, West Coast, Canterbury and Nelson Marlborough DHBs.

Mobile 021 825 546; Tel: 09 377 6661; elaine.mclardy@communio.co.nz

Nationwide SUDI Liaison team profile, August 2013

Appendix A.8. SUDI Study Newsletter Issue 3: April 2014

Issue 3: April 2014

SUDI Nationwide Study

increasing understanding of Sudden Unexpected Death in Infancy

IN THIS ISSUE

- Welcome
- Introduction
- Overview
- Incidence of SUDI
- SUDI Cases Communication
- Police Iwi Liaison
- First Contact with Families
- Linking Services to Whanau
- Coroner's Case Manager
- Key Challenges
- Health Care Providers
- SUDI Liaison Team Update
- Final Words
- Further Information

CONTACT US

For more information about any aspect of the SUDI Nationwide Study, please contact:

Melanie MacFarlane
Project Manager
Mob: 021.330370
Tel: 09-3776661

melanie.macfarlane@communio.co.nz
PO Box 7485, Wellesley Street, Auckland

Welcome

Tēnā koutou katoa, nau mai, haere mai

Kia ora and welcome to the SUDI Nationwide Study newsletter, designed to provide you with updates on the progress on the study.

Introduction

We are now two-thirds through the 3 year Sudden Unexpected Death in Infancy (SUDI) Nationwide Study research project which aims to develop an understanding of New Zealand parenting practices, especially related to baby sleep. This project, funded by the Health Research Council and led by Prof. Ed Mitchell, University of Auckland, aims to interview more than 400 families/whānau. This has active support of and the authorisation of Judge A N MacLean, Chief Coroner.

Overview

Previous newsletters have outlined the processes used for both Case and Control families when they participate in the SUDI Nationwide Study. This edition outlines the communication processes used in the study and some of the key challenges. There are two distinct parts to the study. The first part relates to SUDI Cases and the team's duty to collect information for the Coroner. If whānau give their consent, a research interview is completed. The second part relates to whānau in the comparison group (Controls).

Incidence of SUDI

Although devastating for whānau that are affected, SUDI is a relatively rare event. In 2013, Statistics New Zealand reported that the number of infant deaths and the infant mortality rate were at record lows in 2012. The National Child and Youth Mortality Review Committee released a special report in March 2013 highlighting the reduction over the past 20 years of the SUDI death rate in New Zealand from 200 per year to 60.

SUDI Cases Communication

The first organisation to learn of a SUDI is usually the Police. Police forward a brief to the National Initial Investigation Office (NIIO). NIIO provides 24-hour Coronial oversight for any death under a Coroner's jurisdiction. When the case is a SUDI, this triggers a notification to the manager of the SUDI Nationwide Study. A member of the SUDI Liaison team is then assigned to begin the chain of communication with the family, as well as with official organisations that are involved. The SUDI Liaison calls the local Police by way of introduction and obtains clearance to make the first call to the family.

Police Iwi Liaison

For some families, a Police Iwi Liaison Officer may already be involved and this can smooth the path of introduction and subsequent interaction with the family about an infant SUDI.

Iwi Liaison help to create a safe, open and mutually respectful environment where potentially high risk situations may otherwise have existed. This facilitates increased understanding of whānau and cultural values so families feel more at ease opening up and sharing the details of the death and its impact upon the whānau.

Involvement by Iwi Liaison has often provided opportunity for individual discussions with family members about their concerns, personal experiences and grievances following the death, allowing all parties to feel heard and understood. Opportunities are also created to facilitate further support for whānau through Iwi-lead community services.

The SUDI Nationwide Study newsletter is proudly produced by Communio
www.communiogroup.com

SUDI Nationwide Study

increasing understanding of Sudden Unexpected Death in Infancy

First Contact with Families

Each SUDI Case family is approached with their unique needs as the prime concern.

The first phone contact by the SUDI Liaison is made as close as possible to the time death. At this time, an arrangement is made to visit the family at their home or place where the death occurred. The timing of this visit can vary due to personal and cultural practices. The information asked of families during the visit is specific and follows a standard format. This is to assist the Coroner in making their finding about the cause of death. The Coroner shares this information with the pathologist who is responsible for the post-mortem.

Linking Services to Whanau

If appropriate, and with whānau consent, the SUDI Liaison can link them with other services to provide additional support or assistance. For example, with the local paediatrician, well child or tamariki ora providers and/or whānau ora services.

Coroner's Case Manager

The Coroner's Case Manager assists the Coroner in managing the work file and is the key person for whānau for information about coronial processes. The SUDI Liaison keeps the Case Manager informed of any follow-up during the engagement period and again at six weeks, when the SUDI Liaison role with the family is finalised.

Key Challenges

The project is now in its final year and is due to end on 28 February 2015. One of the biggest challenges faced by the study has been the recruitment of Control families. Effectively engaging with potential Control families takes time, due largely to people's busy and sometimes transient lifestyles. Control families all have babies under 1 year and there is often other siblings and extended whānau. It comes as no surprise to people and organisations that work with whānau that despite best efforts, a high number either cannot be contacted or choose not to participate in the study.

In acknowledgement of people's valuable time, we like to offer families a small gift for their participation and there are different programmes in place across the country depending on contributions we have received. We are grateful to Heinz Watties, Moffats Flower Company Ltd, SANDS Manukau, Whakawhetu for their support.

Any suggestions you have or offers to provide gifts are welcome.

Health Care Providers

If you are a primary care worker, lead maternity carer, well child/tamariki ora or Whānau Ora provider, you may have whānau who have received an invitation to participate in the study as a Control. Please encourage them to take part.

If the family has turned down the opportunity and then change their mind after speaking with you, it may still be possible for them to be involved if the interview can take place within the month-long window.

SUDI Liaison Team Update

Based in Auckland and covering Upper and Central North Island are Shelley Jonas and the most recent addition to the team, Genevieve Ali. They are supported by Rebecca Passi and Melanie MacFarlane, who have both recently returned to work following the births of their baby boys. Based in Palmerston North and covering Lower and parts of Central North Island is Judy McIntyre. Elaine McLardy is based in Christchurch and covers the South Island. Elaine also provided coordination and valuable support to the team over summer while Melanie was on parental leave.

Genevieve Ali, Upper North Island SUDI Liaison

Final words

Professor Mitchell and the research team will commence analysis and reporting later in 2015, on the completion of the data collection period. The knowledge generated will aid those who work with families of new-borns and babies by providing evidence-based information to assist parents/caregivers in modifying specific parenting practices to reduce the SUDI rate even further. This advice will be appropriate to individual and cultural circumstances as no two families are the same.

Further Information

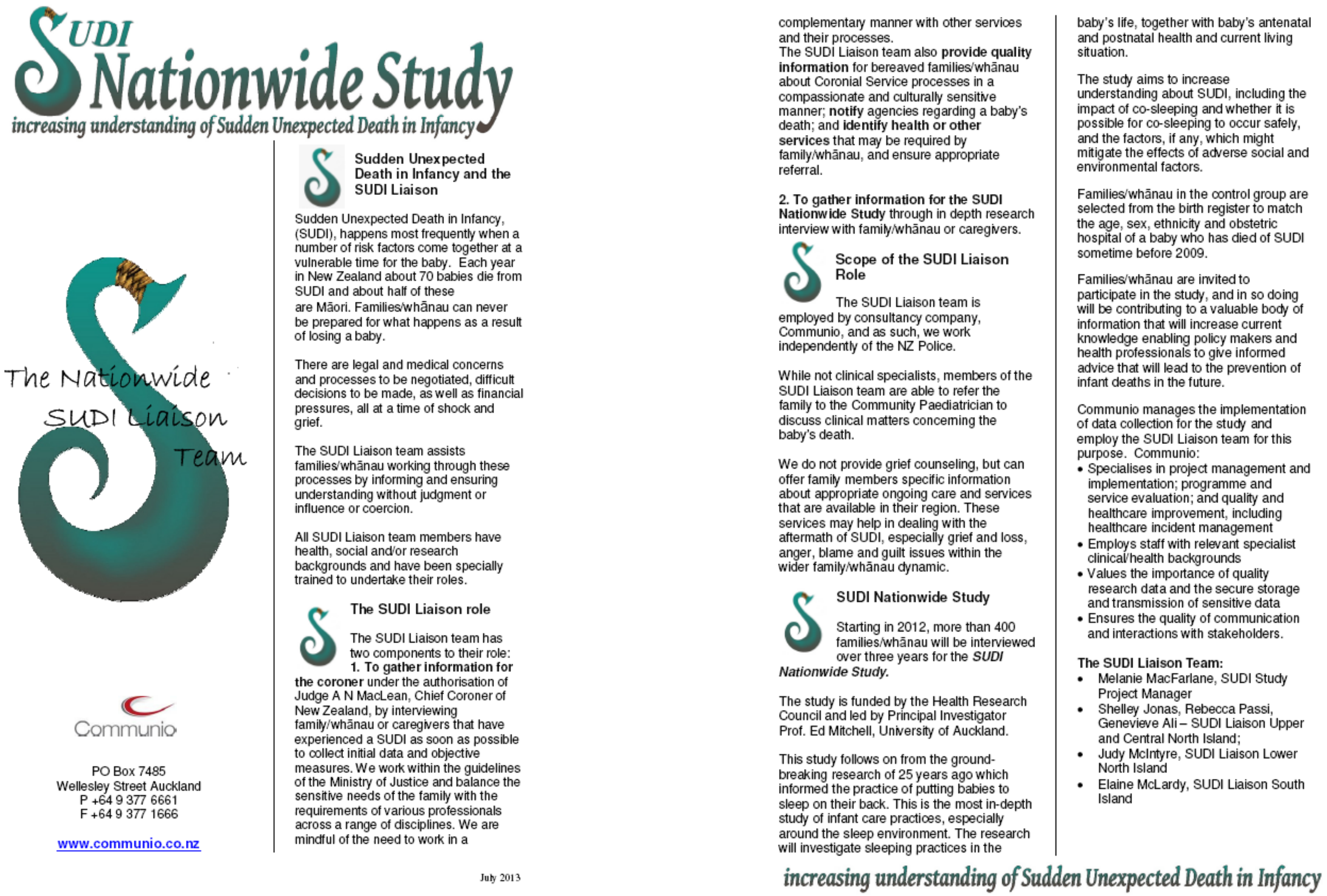
http://www.stats.govt.nz/browse_for_stats/population/births/BirthsAndDeaths_MRYeDec12.aspx

http://www.hqsc.govt.nz/assets/CYMRC/Publications/CMYRC-special-report-March-2013.pdf

The SUDI Nationwide Study newsletter is proudly produced by Communio
www.communiogroup.com

SUDI Study Newsletter Issue 3: April 2014

Appendix A.9. Nationwide SUDI Liaison team Flyer, July 2013



SUDI Nationwide Study

increasing understanding of Sudden Unexpected Death in Infancy

The Nationwide
SUDI Liaison
Team

Communio

PO Box 7485
Wellesley Street Auckland
P +64 9 377 6661
F +64 9 377 1666

www.communio.co.nz

Sudden Unexpected Death in Infancy and the SUDI Liaison

Sudden Unexpected Death in Infancy, (SUDI), happens most frequently when a number of risk factors come together at a vulnerable time for the baby. Each year in New Zealand about 70 babies die from SUDI and about half of these are Māori. Families/whānau can never be prepared for what happens as a result of losing a baby.

There are legal and medical concerns and processes to be negotiated, difficult decisions to be made, as well as financial pressures, all at a time of shock and grief.

The SUDI Liaison team assists families/whānau working through these processes by informing and ensuring understanding without judgment or influence or coercion.

All SUDI Liaison team members have health, social and/or research backgrounds and have been specially trained to undertake their roles.

The SUDI Liaison role

The SUDI Liaison team has two components to their role:
1. To gather information for the coroner under the authorisation of Judge A N MacLean, Chief Coroner of New Zealand, by interviewing family/whānau or caregivers that have experienced a SUDI as soon as possible to collect initial data and objective measures. We work within the guidelines of the Ministry of Justice and balance the sensitive needs of the family with the requirements of various professionals across a range of disciplines. We are mindful of the need to work in a complementary manner with other services and their processes.
The SUDI Liaison team also **provide quality information** for bereaved families/whānau about Coronial Service processes in a compassionate and culturally sensitive manner; **notify** agencies regarding a baby's death; and **identify health or other services** that may be required by family/whānau, and ensure appropriate referral.

July 2013

2. To gather information for the SUDI Nationwide Study through in depth research interview with family/whānau or caregivers.

Scope of the SUDI Liaison Role

The SUDI Liaison team is employed by consultancy company, Communio, and as such, we work independently of the NZ Police.

While not clinical specialists, members of the SUDI Liaison team are able to refer the family to the Community Paediatrician to discuss clinical matters concerning the baby's death.

We do not provide grief counseling, but can offer family members specific information about appropriate ongoing care and services that are available in their region. These services may help in dealing with the aftermath of SUDI, especially grief and loss, anger, blame and guilt issues within the wider family/whānau dynamic.

SUDI Nationwide Study

Starting in 2012, more than 400 families/whānau will be interviewed over three years for the ***SUDI Nationwide Study.***

The study is funded by the Health Research Council and led by Principal Investigator Prof. Ed Mitchell, University of Auckland.

This study follows on from the ground-breaking research of 25 years ago which informed the practice of putting babies to sleep on their back. This is the most in-depth study of infant care practices, especially around the sleep environment. The research will investigate sleeping practices in the baby's life, together with baby's antenatal and postnatal health and current living situation.

The study aims to increase understanding about SUDI, including the impact of co-sleeping and whether it is possible for co-sleeping to occur safely, and the factors, if any, which might mitigate the effects of adverse social and environmental factors.

Families/whānau in the control group are selected from the birth register to match the age, sex, ethnicity and obstetric hospital of a baby who has died of SUDI sometime before 2009.

Families/whānau are invited to participate in the study, and in so doing will be contributing to a valuable body of information that will increase current knowledge enabling policy makers and health professionals to give informed advice that will lead to the prevention of infant deaths in the future.

Communio manages the implementation of data collection for the study and employ the SUDI Liaison team for this purpose. Communio:

- Specialises in project management and implementation; programme and service evaluation; and quality and healthcare improvement, including healthcare incident management
- Employs staff with relevant specialist clinical/health backgrounds
- Values the importance of quality research data and the secure storage and transmission of sensitive data
- Ensures the quality of communication and interactions with stakeholders.

The SUDI Liaison Team:

- Melanie MacFarlane, SUDI Study Project Manager
- Shelley Jonas, Rebecca Passi, Genevieve Ali – SUDI Liaison Upper and Central North Island;
- Judy McIntyre, SUDI Liaison Lower North Island
- Elaine McLardy, SUDI Liaison South Island

increasing understanding of Sudden Unexpected Death in Infancy

SUDI Liaison team flyer, July 2013

Appendix A.10. Data management in the SUDI Nationwide Study

Survey form development

The set of variables examined in the study was developed by the study research team, which was led by the principal investigator, and included the project manager. Variables were based on previous New Zealand and international research on SIDS and SUDI, and advice from the principal investigator's international research colleagues. The variables and the questions for the surveys were developed over a series of meetings between August and October 2011. Several members of the research team tested the draft surveys with six mothers, all of whom had infants less than 1 year of age. The volunteers were identified by members of the research team and invited to participate in testing the surveys for flow/order of questions, wording and time taken to complete.

TeleForm

A member of the research team recommended the use of the TeleForm system as a way of collecting and entering data directly into an electronic database. TeleForm is an automated data extraction and collection software programme now owned by Hewlett Packard (200).

Creating the survey forms

Once the variables and questions had been finalised, Otago University created the machine-readable TeleForm forms and the system functions to enable the completed forms to be scanned and verified before committing the data to CSV files. Otago University also provided technical support and troubleshooting of issues experienced by the SUDI Liaison team members responsible for the TeleForm component of the project.

Five TeleForm survey documents were developed for the study. For cases, these included 1.) the research questionnaire, 2.) objective measures form and 3.) a general observations form. A separate document entitled the 'SUDI Initial Information Collection Form' was used to collect information about SUDI cases for the coroner, as part of the study's service requirement to the Ministry of Justice.

In the SUDI Nationwide Study, this component was referred to as the coroner's initial dataset This form was first developed for the SUDI Referral Advisor pilot and feasibility study. The form was not amended for the study and a TeleForm-compatible version was not created. The control group required two survey forms, including: 1.) the research questionnaire, which also contained the objective measures, and 2.) the general observations form. The research questionnaires were 35 pages long. Objective measures were recorded over two pages and general observations were recorded on a single page. General observations were completed by the SUDI Liaison separately from the interview.

Differences between the research questionnaires

Questions in the detailed case and control questionnaires were virtually identical apart from language around the ‘last sleep’ for cases and the ‘nominated sleep’ for controls. The questionnaire for controls also recorded the ‘direction’, which was applied if the control infant was awake at the time of the ‘nominated’ sleep. The direction was part of the controls sampling data and would indicate to the SUDI Liaison whether to focus the interview on the sleep that occurred before or after the ‘nominated sleep’ time if the infant had not been asleep at the nominated sleep time.

Survey form unique identifiers

Each set of TeleForm survey forms had a unique identifier listed at the top of every page. This enabled de-identified information to be collected and analysed while retaining the ability to track responses back to participant(s). This was vital during data cleaning when details, such as dates of birth, needed to be cross-checked between the tracking sheets and the CSV files.

Data entry and data cleaning

The specially designed survey forms were scanned and validated in TeleForm, and then converted into CSV files in readiness for data cleaning and quality control. Data were checked for accuracy in the CSV files. This involved, for example, ensuring the data were in the correct columns and that the values were the correct type (i.e., alpha or numeric) and within the appropriate range (i.e. within pre-defined values for each question).

Managing data in the TeleForm system, including scanning and verification, was shared by the project manager and another member of the SUDI Liaison team. Access was permitted to the University of Auckland’s Evaluations and Scanning Centre and the computer containing the TeleForm programme one day per month. Eventually, remote access to the TeleForm computer was arranged and this enabled data the Teleform process functions to be managed remotely, and more efficiently.

Data storage

All data were stored securely in electronic format in the Communio SharePoint IT system, and in hard copy. An integrated electronic filing system was created as a repository for the vast amount of documentation associated with the project. The electronic filing system was designed to provide easy access for the SUDI Liaison team, some of whom were based remotely and therefore had reduced access to the peer support available to team members based in the Auckland Communio head office.

Hard copies for each case and control file were kept in locked metal cupboards in a secure office. These were provided to the University of Auckland upon completion of data collection. Electronic data were stored on a secure server and uploaded via TeleForm to a safe electronic location by the University of Auckland.

Tracking the status of data collection

Throughout the project, detailed data tracking systems were used to monitor the status of data collection in the case and control groups and assist with reporting to the steering committee and other stakeholders.

A Communio administrator set up the internal management and tracking systems. Two Excel workbooks were created and used as “Tracking Sheets” to centralise information for cases and for controls on the Communio server. The workbooks were located in an electronic space dedicated solely to the SUDI Nationwide Study and were kept separate from other Communio project documentation. Each spreadsheet contained demographic details and family contact information, communication log, tasks checklist and formulae-adjusted target dates for each participant referred to, or selected for, the study. Each row in the spreadsheets was colour-coded to indicate the participant’s position in the process.

For example, controls were colour-coded in the following way:

- Pink - to signal that selection information had been requested from a DHB but not yet received
- Yellow - to indicate an interview date had been agreed with a family
- Green - to show that an interview had been completed

- Red - to flag that the family had declined to participate
- Grey – to show the family were uncontactable.

Each SUDI Liaison was responsible for maintaining accurate and up to date records in the cases tracking sheet for all SUDI cases they were managing; and for the controls tracking sheet linked to their coverage area (i.e., Region 3 Lower North Island).

Version control of the tracking sheets

The tracking sheet spreadsheets were ‘live’ files accessed and updated by all SUDI Liaison team members. To manage the risks associated with multiple people adding data, potentially simultaneously due to the geographic spread of team members, there were rules to guide usage. For example, the SUDI Liaison would ‘check out’ the document to alert a colleague the file was in use. Team members would use ‘save as’ to rename the file and add the current date to indicate it was the most current version. Previous versions were archived but still available to reference if any issues arose with the active spreadsheets.

The project manager received monthly data from the Ministry of Justice on all infant deaths reported to the coroner that had occurred in the previous month, and over the life of the study. Information on non-SUDI infant deaths was merged into the cases spreadsheet. This provided an opportunity to verify whether all cases that appeared to be SUDI-related had been referred to the study, thereby confirming whether the entry criteria for cases were being applied appropriately by Coronial Services.

In the cases spreadsheet, rows of information about non-SUDI deaths were generally hidden from view to prevent the spreadsheet from becoming unwieldly and to maintain its usability for the SUDI Liaison team.

Benefits of the tracking sheets

The tracking sheets provided the project manager with nationwide visibility of all SUDI and non-SUDI cases referred to the coroner, as well as the SUDI Liaison team’s progress with the various elements of engaging with families and collecting the data. The controls tracking sheet helped the SUDI Liaison team and project manager to manage the timelines associated with identifying, contacting and recruiting controls from across the country into the study. Whereas the cases tracking sheet comprised of a single worksheet, the controls file contained multiple worksheets, which helped the project manager to maintain oversight of the hundreds of sets of selection criteria used throughout the study.

The tracking sheets were among the most important tools used to manage the data collection for the project.

Reselections of controls

Recruiting participants to the control group proved challenging and uptake was lower than expected. During the first year of the study, a high number of selected mothers could not be contacted, nor could the accuracy of available contact information be verified. The inability to contact mothers was an issue in areas such as South Auckland and parts of central and lower North Island, and no issue at all in others, such as the South Island.

The SUDI Liaison study recruitment strategy needed to evolve; therefore, in year two of the study, if a mother could not be contacted, the relevant district health board was asked to select another infant and mother using the same criteria. If a new selection could not be obtained in time to meet the timeframe for interview, and if it was possible, re-selection occurred in the following year.

A further reason for re-selections was the delay experienced in obtaining ethics approval from the relevant district health boards to allow the study to receive data retrieved from hospital birth registers. This delay occurred in the first six to seven months of the study and led to timeframes for some of the earlier interviews being missed. To mitigate this issue, affected selections were moved in the tracking sheet to the following year, for example, an ideal interview date of 15 May 2012 could be moved to 15 May 2013. A separate worksheet in the controls tracking sheet contained the full and original set of criteria for controls in the study. This enabled cross-checking and quality review in the event of an issue with the tracking sheet.

If the re-selected control could not be contacted, the selection would again be added to the following year (e.g., 15 May 2014). Eventually, this was not possible as the study was concluding in February 2015. During the first and second years, the issue of being unable to contact mothers, or to verify the accuracy of the contact information, led to further sets of criteria being reselected in 2014. If the re-selected mother was contactable but refused to participate, this was recorded as a refusal and no re-selection was made. Overall, an additional 124 selections were made.

Passive refusals

Passive refusals occurred when correct contact details were available but attempts to make contact were unsuccessful. Passive refusals also occurred when there was agreement from the person to participate but a lack of subsequent engagement, or they were absent at the agreed time and place. This led to timeframes for these interviews to be exceeded slightly. Passive refusals, which were not distinguishable from outright refusals in the tracking sheets, occurred most frequently in lower socioeconomic areas and among Māori and younger mothers (< 20 years).

Number of refusals

Across the four SUDI Liaison regions, refusal rates ranged from 29% in the South Island to 37.6% in the lower North Island. Overall, Māori were more likely to refuse to participate, particularly in Counties-Manukau DHB (44 of the 58 refusals, 75.8%) and Waikato DHB (20 of the 25 refusals, 80%). Counties-Manukau DHB had the greatest number of refusals and reselections; however, this must be considered in the context of Counties-Manukau DHB also having greatest number of controls at the beginning of the study. This was due to selected controls mirroring the demographics of SUDI cases between 2003 and 2007, in which Māori families and those living in areas of higher deprivation, such as South Auckland, were over-represented.

Appendix B: Appendices related to the Pēpē-Infant Sleep Practices Study

Appendix B.1. Māori ethical framework

Māori participation is a critical success factor for this research. Therefore, the processes in this study are based on Kaupapa Māori research methodology. Guidelines to assist those intending to undertake health-related research involving Māori participants include Te Ara Tika, which is a framework designed to consider and address Māori ethical issues associated with research (184). This ensures that the development and completion of the research is culturally appropriate and responsive to Māori.

In practice, if the research reflects the values of tika, pono and aroha (to be correct, to uphold truth and love (201), it will contribute to improved outcomes for Māori health and wellbeing whilst using processes that maintain and enhance mana Māori (184).

These primary values (kawa) are implemented through locally specific practices and customs of Māori tikanga. Collectively these values and practices provide an ethical framework within which health related research can occur (184).

Key points of this research related to Kaupapa Māori research methodology include:

- Māori are major participants
- the lead investigator is Māori
- processes for engagement reflect Māori cultural practices
- the analysis undertaken will produce Māori knowledge (184).

The four tikanga-based principles in Te Ara Tika, which underpin this framework are: Tika, which is concerned with research design; Manākitanga, cultural and social responsibility; Whakapapa, relationships; and Mana, equity. The framework spans the design, implementation and concluding stages of the study, and includes engaging and connecting with iwi, Māori groups, service providers and participants across all stages.

Māori research should set out to make a positive difference for those being researched (185) and improve the circumstances amongst Māori communities (202). Essentially, the framework ensures whānau are at the centre of the research; that engagement is respectful and non-judgemental and the views of whānau are ‘right’.

Smith’s (203, 204) set of cultural values to underpin Kaupapa Māori research were elaborated by Cram (203) to define the conduct expected from researchers in this space. A table combining Smiths values, Crams researcher guidelines (204) and elements of Te Ara Tika (184) has been adapted for this research (Appendix B.2.).

The University of Auckland defines koha as *“an unconditional gift where the recipient has neither stipulated that it be given, nor has an expectation of receiving it.”* Furthermore, the “*giving of koha is an integral part of Māori culture.”* page 2 (205).

The researcher will provide kai (i.e., store-bought baked goods, fresh fruit and juice), which is a common aspect of Māori culture, to share during the ‘settling in’ period. This period includes the introductory kōrero (conversation), whanaungatanga (establishing relationships and connections) and karakia (prayer).

In addition, mothers participating in the study will be given a koha in the form of a gift card or voucher, such as for Westfield, a supermarket, or petrol station, at the completion of the interview. The interviewer will not discuss koha prior to the interview to ensure there is no real or perceived coercion to participate. The Pro Vice Chancellor (Māori) of the University of Auckland advised that providing kai and a $40 gift card or voucher is appropriate for this study and relative to the contribution by participants (206).

Tikanga Advisory Group

A key consideration for the research is the need to engage with iwi and other Māori groups. The lead researcher is fortunate to be supported by a Tikanga Advisory group comprising several experienced senior Māori leaders/elders who are experts in the fields of health and disability and social services, education, research and tikanga Māori. This group regularly provides invaluable tikanga-related advice and guidance to the lead researcher.

Appendix B.2. Kaupapa Māori research cultural values and researcher guidelines: how these apply to this research

Cultural Values (Smith, 1999)	**Researcher Guidelines (Cram, 2001)**	**How these values apply to this research**
Aroha ki te tangata	A respect for people – allow people to define their own space and meet on their own terms.	Offer to meet with iwi and other Māori groups or service providers during initial communication, and after the research, as required. Enable participants to choose when to meet and, if not at home, at their preferred place. NB: Links with Te Ara Tika – Mana with regards to communication with mana whenua.
He kanohi kitea	It is important to meet people face to face, especially when introducing the idea of the research, "fronting up" to the community before sending out long, complicated letters and materials.	Offer to meet with iwi and other Māori groups or service providers during initial communication to discuss shared aspirations of improved infant and whānau wellbeing. An information letter followed by a telephone call to potential participants will be the first points of contact by the researcher. NB: Links with Te Ara Tika – Whakapapa with regards to engagement; and with tūmanako (sharing aspirations).
Titiro, whakarongo… kōrero	Looking and listening (and then maybe speaking). This value emphasises the importance of looking/observing and listening, in order to develop understandings and find a place from which to speak.	The researcher will be guided during initial communication meetings by the hosts, and will respond in kind, as appropriate for the people present and the setting.

Manaaki ki te tangata	Sharing, hosting, being generous. This is a value that underpins a collaborative approach to research, one that enables knowledge to flow both ways and that acknowledges the researcher as a learner and not just a data gatherer or observer. It also facilitates the process of "giving back", of sharing results, and of bringing closure if that is required for a project but not to a relationship.	This extends across the life of the study, from initial communication with iwi and other Māori groups or service providers, early engagement with potential participants, during interviews and after the research has been completed. This includes being generous with knowledge, time, kai and koha, and following-up after the study to share the results.
Kia tūpato	Be cautious. This suggests that researchers need to be politically astute, culturally safe, and reflective about their insider /outsider status.	Again, this applies to the initial consultation – being mindful of processes around tikanga; avoiding raising unrealistic expectations about the research or research processes; maintaining safety on a personal and cultural level and safety of participants. NB: Links with Te Ara Tika – Manaakitanga with regards to cultural safety.
Kaua e takahia te mana o te tangata	Do not trample on the "mana" or dignity of a person. This is about informing people and guarding against being paternalistic or impatient because people do not know what the researcher may know.	This is about being respectful at all times, both culturally and generally; appreciating and acknowledging people's generosity with their time, knowledge and hospitality, and reciprocating in kind. Honest, straightforward and genuine communication is key.
Kaua e māhaki	Do not flaunt your knowledge. This is about finding ways to share knowledge, to be generous with knowledge without being a "show-off" or being arrogant. Sharing knowledge is about empowering a	During initial communication the type of information and the method of delivery may vary among different audiences. For example, some groups may prefer a short presentation, while others, including

	process, but the community has to empower itself.	participants may prefer an informal, conversational approach. Again, honest, straightforward and genuine communication is key.

*Adapted from Table 4.3.p130. “Community-Up Approach to Defining Researcher Conduct” 2008: Denzin and Lincoln (with Smith) Chapter 4: The Landscape of Qualitative Research

Appendix B.3. Consolidated criteria for reporting qualitative research (COREQ): planning of the qualitative study Pēpē-Infant Sleep Practices Study

DOMAIN 1: RESEARCH TEAM AND REFLEXIVITY	
Personal characteristics	
1. Interviewer/facilitator	**Which author/s will conduct the interview or focus group?** Melanie MacFarlane
2. Cultural affiliations and credentials	**What are the researcher's cultural affiliations?** Māori and NZ European/Pākehā. Tribal affiliations include Ngāti Maniapoto and Raukawa **What are the researcher's credentials, e.g., PhD, MD?** DipRCompN, BHSc (Nursing), MSc (Advancing Healthcare Practice)
3. Occupation	**What is their occupation at the time of the study?** PhD student (FT); SUDI Liaison (PT)
4. Gender	**Is the researcher male or female?** Female
5. Experience and training	**What experience or training does the researcher have?** • Participated in the SUDI Liaison investigator induction training (February 2012) and ongoing refresher training throughout the SUDI Nationwide Study (2012-2015) • During the SUDI Nationwide Study, Melanie managed and backfilled for the SUDI Liaison team during holiday periods by interviewing families in the SUDI case group. • Melanie continues to be a part-time member of the SUDI Liaison team during her PhD studies
Relationship with participants	
6. Relationship established	**Will a relationship be established prior to study commencement?** No
7. Participant knowledge of the interviewer	**What will the participants know about the researcher, e.g., personal goals, reasons for doing the research?** Name, clinical background, purpose for doing the study, which is part of a PhD and follows/builds on from the SUDI Nationwide Study
8. Interviewer characteristics	**What characteristics will be reported about the interviewer/facilitator, e.g., Bias, assumptions?** *This will be reported in the Methods section*
DOMAIN 2: STUDY DESIGN	
Theoretical framework	
9. Methodological orientation and theory	**What methodological orientation was stated to underpin the study, e.g., grounded theory, discourse analysis, ethnography, phenomenology, content analysis?** General thematic analysis In relation to understanding the culture of groups with shared characteristics (i.e., mothers of infants under one year of age, living in a specific geographic area) and conducting interviews in a natural setting (i.e. in mothers'

	home where infant care beliefs and behaviours are most widely practiced). It is anticipated that infants will be aged between 1-6 months at the time of the interview with most clustered around 2-3 months, which is the age SUDI is most likely to occur. Te Ara Tika framework, which helps consider and address Māori ethical issues associated with the research will also be applied, as will published Māori cultural values and researcher guidelines.
Participant selection	
10. Sampling	**How will participants be selected? e.g., purposive, convenience, consecutive, snowball** A purposive sample will be used based on the distribution of previous SUDI cases in a given period, 90 participants were randomly sampled to ensure participants have similar characteristics to families that have experienced SUDI (with regards to hospital of birth, ethnicity, gender and age). Selection criteria were provided to the DHB(s) to identify potential mothers for the study. A further 30 participants were selected to reach saturation.
11. Method of approach	**How will participants be approached, e.g., face-to-face, telephone, mail, email?** Potential participants received the information letter in the mail followed by a telephone call. The purpose of the call was to: - Introduce self and the research, answer any questions - Reiterate invitation to participate in the research - Agree a day/time for the interview, which will be face to face (kanohi kitea)
12. Sample size	**How many participants are expected to be in the study?** 30 mothers are expected to participate
13. Non-participation	**How many people refused to participate or dropped out? Reasons?** The study had 90 non-participants. Reasons for non-participation included direct decline by women (n=4), implied decline as uncontactable or interview did not proceed (n=47), surplus selections after saturation was reached n=32, excluded n=7 (duplicated n=3, moved out of catchment area n=2, SUDI n=2)
Setting	
14. Setting of data collection	**Where will the data be collected, e.g., home, clinic, workplace?** Participants' homes
15. Presence of non-participants	**Will anyone else be present besides the participants and researchers?** Occasionally, family member(s) or friend(s) were present or near during the interview. These people were welcome to contribute to the conversation but only mothers' informed, written consent was obtained and only mothers' responses were analysed.
16. Description of sample	**What are the important characteristics of the sample, e.g., demographic data, date?** Mothers of infants born in Middlemore Hospital meeting specified criteria for age, ethnicity (minimum 50% Māori)
Data collection	
17. Interview guide	**Will questions, prompts, guides be provided by the authors? Will it be pilot tested?**

	Yes, an interview guide with questions and prompts was developed and tested.
18. Repeat interviews	**Will repeat interviews be carried out? If yes, how many?** Repeat interviews were not required.
19. Audio/visual recording	**Will the research use audio or visual recording to collect the data?** The interviews were audio recorded following consent
20. Field notes	**Will field notes be made during and/or after the interview or focus group?** Field notes will be made during and possibly after the interviews to provide a back-up to the audio recordings
21. Duration	**What is the expected the duration of the interviews or focus group?** 60-90 minutes per interview, plus settling in time (up to 30 mins)
22. Data saturation	**Will data saturation be discussed?** *This will be reported in the Methods section*
23. Transcripts returned	**Will transcripts be returned to participants for comment and/or correction?** Transcripts were returned to participants for their feedback and to provide an opportunity for clarification and corrections.
DOMAIN 3: ANALYSIS AND FINDINGS	
Data analysis	
24. Number of data coders	**How many data coders (will) code the data?** Melanie MacFarlane, and one or more others. This will be discussed and verified with the researcher's supervisors
25. Description of the coding tree	**Did authors provide a description of the coding tree?** *This will be reported in the Results section*
26. Derivation of themes	**Will themes be identified in advance or derived from the data?** Both. In developing the research questions and hypotheses and reviewing data in the SUDI Nationwide Study (2012-2015), a number of potential themes have emerged. It is anticipated that further themes will be identified during analysis.
27. Software	**What software, if applicable, will be used to manage the data?** NVivo will be used. This is a qualitative data analysis (QDA) computer software package designed for qualitative researchers working with very rich text-based information or where deep levels of analysis on small volumes of data are required.
28. Participant checking	**Will participants provide feedback on the findings?** Yes
Reporting	
29. Quotations presented	**Will participant quotations be presented to illustrate the themes / findings? Was each quotation identified, e.g., participant number?**

	Yes, it is expected that quotations will be used and will be labelled with a pseudonym, ethnicity and participant number.
30. Data and findings consistent	**Was there consistency between the data presented and the findings?** The author will take care to ensure consistency between the data presented and the findings; the author will work alongside the PhD supervisors to ensure this occurs
31. Clarity of major themes	**Will major themes be clearly presented in the findings?** Major themes were identified and clearly presented in the findings
32. Clarity of minor themes	**Will there be a description of diverse cases or discussion of minor themes?** It is expected that minor themes will be identified and discussed
33. Sharing of results	The results will be submitted to/published in a peer-reviewed journal and will form part of the researcher's PhD by publication. Results will be communicated to all stakeholders, including Counties-Manukau Health (DHB) and all Maaori and mainstream stakeholders involved in the study.

*Adapted from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care; Volume 19, Number 6: pp. 349–357 10.1093/intqhc/mzm042. Advance Access Publication: 14 September 2007

Appendix B.4. Information letter and consent form - Pēpē-Infant Sleep Practices Study

E moe e kō me ō moemoeā
Kī pai i te mīharo me te aroha.
Kia oho ake kia ora ai ki tāu ake nā
Whakapuāwaitanga i aua wawata
Kia kitea ai to tupuranga
e tika ana ki tāu e pai ai

Sleep precious baby, with dreams
Filled with love and wonder
Then wake so you may live your life
And realise your dreams
So we may watch you grow and fulfil your destiny

M MacFarlane; translation by Associate Professor Tom Roa, University of Waikato

Study Title:	Infant Sleep Practices Among Māori and Non-Māori
Locality:	Counties-Manukau, Auckland
Lead investigator:	Melanie Macfarlane
Ethics committee reference:	18/CEN/273
Contact phone number:	021xxxxxxx

Tēnā koe, my name is Melanie MacFarlane and I'd like to invite you to take part in a study on infant sleep practices.

What is the purpose of this study?

Every family/whānau has its own way of managing their baby's bedtime. In this study, we'd like to know what it's like for you to get your baby off to sleep: What works for you and your baby? Is baby's bedtime planned or does it vary? Where does baby usually sleep, and do they sometimes sleep alone or with someone else?

My interest in infant sleep is linked to my research on sudden and unexpected death in infancy, or SUDI (previously known as SIDS or cot death). Nowadays, fewer babies in New Zealand die from SUDI, however, 40-50 babies still die each year and some of these deaths are preventable. This study is part of my PhD degree with the University of Auckland and is funded by the Health Research Council of New Zealand. It is based in Counties-Manukau, Auckland. The study has received Health and Disability Ethics Committee approval (18/CEN/273) and Counties-Manukau Ethics approval (CMH Study #846).

Your information will be used to inform and strengthen messages about safer infant sleep for all families/whānau. We can work together to ensure more babies wake up and go on to live their lives and realise their dreams.

What is involved?

You have been chosen to participate because your baby matches the selection information based on age, hospital of birth, ethnicity and sex. I will visit you at home, or at a place where you feel comfortable and ask about your knowledge and practices around infant sleep.

The interview will take between 1 to 1½ hours to complete and will be voice-recorded. I will record the interview, so I can focus on our conversation, rather than on writing. I aim to interview approximately 30 families/whānau for this study.

I will also collect some health information during the interview, including the health of you and your baby during pregnancy and after birth. The study does not involve questions which may be sensitive or cause embarrassment; however, you may decide not to answer certain questions if you choose. There is no cost to you for participating in the study.

Your choice

Whether or not you take part is **your choice**. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. I will go through this information with you and answer any questions you may have. You do not have to decide today whether you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is four pages long, including the Consent Form. Please make sure you have read and understood all the pages.

If English is not your first language, an interpreter may be available to help you understand this form and with the interview. If you would like an interpreter, we can talk about this when I call you on the telephone in the next few days.

Benefits of taking part

By participating in this study, you are helping to build New Zealand's knowledge and understanding about infant sleep and how we can make it safer for babies and lower the number of babies that die from SUDI.

Possible risks of taking part

Part of the interview will be spent talking about bed sharing and other infant sleep practices in the context of sudden infant death. It is possible that this may cause you to have an emotional response, especially, for example, if you have had previous experience of infant death, or from some other cause. If this occurs, you can choose to take a break, move on to another topic or stop the interview, without affecting your rights.

What if something goes wrong?

It is extremely unlikely that you will be physically harmed as a result of participating in this study, especially as there are no medical tests involved and we will just be talking. However, if you are harmed, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery. If you have private health or life insurance, you are welcome to check with your insurer that taking part in this study won't affect your cover.

Your rights

- Your participation is voluntary, and you are free to decline to participate, or to withdraw from the research at any practicable time, without experiencing any disadvantage.
- You have the right to access information collected about you or your baby as part of the study.
- Your participation in the study is confidential. Nothing that could personally identify you or your baby will be used in any reports on this study.

If you have any questions or concerns about your rights as a participant in this study, or you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate: Freephone 0800 555 050; Free fax 0800 2787 7678; Email advocacy@hdc.org.nz.

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone:	0800 4 ETHICS
Email:	hdecs@moh.govt.nz

What happens after the study or if you change your mind?

Data collected during the study will be stored on a secure server at the University of Auckland and will be de-identified. Signed consent forms will be held for 5 years after the results of the study have been submitted for publication. Personal information collected in this study will be protected from loss and unauthorised access. The information will only be held on protected systems supplied by the University of Auckland. On completion of the study, the findings will be shared with local health services and community groups. They will also be published in a peer-reviewed journal and in my PhD thesis. If you would like to receive a copy of the results in early 2020, please let me know.

Who to contact for more information about the study

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Melanie Macfarlane
PhD Candidate, Lead Researcher
09 923 1422 or 021 xxx xxx
m.macfarlane@auckland.ac.nz

What happens now?
I will call you and if you would like to take part, we can set up a time to meet within the next week or two. In the meantime, if you have any questions, please call or email me.

Ngā mihi mahana ki a koe,

Melanie Macfarlane

Department of Paediatrics
The University of Auckland
Private Bag 92019, Auckland

Appendix B.5. Consent Form: Pēpē-Infant Sleep Practices Study

---

I have read or have had read to me in my first language, and I understand the information sheet. *(Researcher only: was an Interpreter used? YES NO)*

I have been given sufficient time to consider whether to participate in this study.

I have had the opportunity to use a legal representative, family/whānau support or a friend to help me ask questions and understand the study.

I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.

I consent to the research staff collecting and processing my information, including information about my health.

I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.

I understand the compensation provisions in case of injury during the study.

I know who to contact if I have any questions about the study in general.

I understand a transcript of the interview will be sent to me within two weeks and that I will provide any feedback within 14 days of the transcript being sent. Email address (or by post, if preferred):

I understand my responsibilities as a study participant.

If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.

YES ☐ NO ☐

I wish to receive a copy of the results: (If yes, confirm address)

YES ☐ NO ☐

Declaration by participant:

I hereby consent to take part in this study.

Participant’s name: ______________________Signature: _________________Date_____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant and have answered the participant’s questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher’s name: ______________________Signature: _________________Date_____

Appendix B.6. Survey Form / Interview Schedule - Pēpē-Infant Sleep Practices Study

Planning information	
Date and time of interview:	
Address:	
Mothers name:	
Contact number(s):	
Email address: (for transcript and study results)	
Infant's name:	

Part 1: Introduction/greeting (20 mins)

Greetings and invitation into home/interview venue

Give/share the kai, undertake whanaungatanga/make connections, share a bit about myself
Offer karakia mō te kai (grace the food)

E te Atua	Lord God
Whakapainga ēnei kai	Bless this food
Hei oranga mō ō mātou tinana	For the goodness of our bodies
Whāngaia hoki ō mātou wairua ki te taro o te ora	Feeding our spiritual needs also with the bread of life
Ko Ihu Karaiti tō mātou Ariki	Jesus Christ, our Lord
Ake, ake, ake	Forever and ever
Amine	Amen

Introduce the research aim and objectives

Aim: To increase understanding of whānau infant sleep practices, including infant bed sharing, to strengthen and inform new and existing approaches for promoting safe infant sleep and SUDI prevention; and reduce the number of SUDI, especially for Māori.

Objectives:

- To understand what parents/whānau like yourself know about infant safe sleep and what you do at baby's sleep time and why
- To identify what works and what doesn't work in relation to infant safe sleep
- To identify the infant safe sleep messages and information whānau think would be helpful and what the best opportunities are to share these

Geographic area covered: Counties-Manukau, Auckland
How participants were selected: From the hospital birth list based on your baby's date of birth, sex and ethnicity (based on the ethnicity/ies recorded for mother in the birth list). The information was provided by an authorised staff member from Counties Manukau DHB (Middlemore Hospital)
Do you have any questions so far? It's OK to use family/whānau or a friend to help you ask any questions about the study.

Explain:
Your participation is totally your choice, and you can withdraw from the study at any time without affecting your health care.
Your privacy will be protected in the study and your information will be anonymised

I will email you the interview transcript within two weeks of the interview and ask that you provide any feedback within 14 days. We'll talk about this more at the end of the interview.
My contact details are in this information sheet, which you should have received in the post (provide them with a copy if they haven't received one in the mail or do not have it with them).
If you have any problems or have further questions you can contact me. We'll go through the consent form shortly, and there are other contact details if you have other kinds of questions.

The interview will take about an hour.

Permission:
Gain consent to audio record interview and/or take notes if participant doesn't want to be recorded.
Go over consent form and have participant sign it (one copy for participant, one for the study).
Confirm contact details at top of this form, make any corrections (email, telephone, home address).

Part 2: Interview (60 mins)

Read mihi aloud in Māori and/or English (refer to Participant Information Sheet).
Offer karakia timatanga (opening prayer)

He hōnore, he korōria ki te Atua	Honour and glory to God
He maungārongo ki te whenua	Peace on Earth
He whakāro pai ki ngā tāngata katoa	Goodwill to all people
Hangā e te Atua he ngākau hou	Lord, develop a new heart
Ki roto, ki tēnā, ki tēnā o mātou	Inside all of us
Whakatōngia to wairua tapu	Instil in us your sacred spirit
Hei awhina, hei tohutohu i a mātou	Help us, guide us
Hei ako hoki i ngā mahi mō tēnei rā	In all the things we need to learn today
Amine	Amen

DEMOGRAPHICS AND LIVING SITUATION

Names of those present at interview

Thank you so much for being part of the interview today. I'd like to record the names of everyone present for the interview (is that OK?). Can I have your names, please?

Mother and baby

Mothers full name (confirm above):
Mothers age:
Mother's ethnicity/ies (tick all that apply): Māori (Iwi:) NZ European Samoan Cook Island Māori Chinese Indian Tongan Niuean Other (specify)
Mother's country of birth:
Mother's marital status: Married…………………… Co-habiting……………..Single
Confirm baby's name (as above):
Baby's age in weeks:
Number of previous babies:
Baby's ethnicity/ies (tick all that apply): Māori (Iwi:) NZ European Samoan Cook Island Māori Chinese Indian Tongan Niuean Other (specify)
How was this pregnancy? How was the birth?

How is baby’s health?	
Is baby’s breastfed or does he/she have formula, or both?	Breastfed………Formula……………Both
If baby is not being breastfed, was he/she ever breastfed? If yes, how old was he/she when breastfeeding stopped?	Yes……………………No
Did you smoke during this pregnancy?	Yes……………………No
Do you smoke now?	Yes……………………No

Father/Partner

Father’s name:		
Father’s age:		
Father’s ethnicity/ies (tick all that apply):		
Māori (Iwi:)	NZ European	Samoan
Cook Island Māori	Chinese	Indian
Tongan	Niuean	Other (specify)
Father’s country of birth:		

Baby’s living situation

How many adults (18yrs+) and children live at baby’s main home?	
Number of adults:	Number of children:
Do any of these adults smoke? If so, how many?	
How many bedrooms are there?	

Appendix B.7. Open-Ended Questions

Now we're going to move on to some open-ended questions about baby's sleep time. I'm going to start the recording now. Is that OK?

1. Baby's sleep time

Let's start with baby's usual sleep time.

- a. How does baby's sleep time usually work?
- b. How do you get baby to sleep?
- c. Who puts baby to sleep?
- d. Where are the places or beds that baby usually sleeps?
- e. Why does he/she usually sleep there?
- f. What beds are available for baby's sleep time?
- g. Were you offered a safe sleep device, such as a Pēpi-pod or Wahakura?

BED OPTIONS: Cot, Portable cot, Bassinet/moses basket, Pēpi-pod, Wahakura, Bed, Mattress(es) on floor, Waterbed, Airbed, Sofa/couch/armchair, Swing/jolly jumper, Floor, Stroller sitting or lying position, Car seat, Change table, Bouncinette, Bean bag, Other (specify)
BED SIZE: Single/Double/Queen-King

2. Bed sharing

- a. Has baby ever shared a bed or other sleep space with someone else (e.g., bed, couch, mattress on the floor)?
- b. If yes, how often would you say this happens?
- c. How does this come about?
- d. How long does baby spend in each location/sleep space (in hours)?
- e. If baby hasn't ever shared a bed (or other sleep space) with anyone else, why is this?

3. Sleep time decision-making

- a. How did you decide to settle baby to sleep the way you do?
- b. If this is not your first baby, have your practices around baby's sleep changed?
- c. How does your family/whānau influence you, if at all, when it comes to baby's sleep time?
- d. How much does your (Māori or other) culture influence baby's sleep time?

4. Safe infant sleep information

- a. Let's talk a little bit now about safe infant sleep information. <u>Do you recall receiving any messages or information about safe sleep for baby?</u>
- b. When was this and who shared this information with you?
- c. What can you remember?
- d. Have you heard about SUDI (when a baby dies suddenly and unexpectedly; it used to be called SIDS or Cot Death)?
- e. Can you remember any messages or information about SUDI prevention?

[Recap key SUDI prevention and safe sleep messages]

5. **5.** Enablers/barriers of safe infant sleep

    a. Thinking about infant safe sleep, what helps, or would help to put these into practice for your baby?
    b. What makes, or would make it difficult?
    c. What would you tell other mums just starting out to help them to practice safe sleep for their new baby?

6. **6.** Sharing safe infant sleep information

    a. When would be the best time to share safe sleep information with new mums or hapū/pregnant women?
    b. Who would you like to receive this information from?
    c. How would you like the information to be delivered?

7. **7.** Further information / questions

    a. Is there anything else you'd like to add?
    b. Do you have any questions?

Part 3: Closing (10 mins)

Turn off recorder

- I will send a full transcript of the interview by <X date> and once sent, if you could please send me any feedback you have within 14 days. After this, I will take it as you've consented for to use it for the analysis and the final report.
- Would you like to receive a summary of the final report? **YES** **NO**
- If yes, how would you prefer to receive it? **EMAIL** **POST** **IN PERSON**
- I will have the summary ready by early 2020.
- Thank you for your participation. Please accept this koha as a token of my appreciation of your time and your valuable contribution. (Give koha)
- Offer to say closing karakia (if opening karakia used):

Kia tau ki a tātou katoa Te atawhai o tō tātou Ariki, a Ihu Karaiti Me te aroha o te Atua Me te whiwhingatahitanga Ki te wairua tapu Ake, ake, ake Amine	May the grace of the Lord Jesus Christ, and the love of God, and the fellowship of the Holy Spirit be with you all Forever and ever Amen

Goodbyes and exit

Appendix B.8. Interview checklist – Pēpē-Infant Sleep Practices Study

Pre-Interview Checklist[1]

This checklist can be used to confirm arrangements 2 to 3 days prior to visiting a family/whānau for the Infant Bed Sharing Study.

Name of contact:

Contact number:

Pre-agreed date/time (daylight hours):

1) Is it still OK for me to visit you on this (the pre-agreed) day? Do you have any appointments to go out for e.g., pick children up from kindy/school etc?

2) Can you please re-confirm your home address?

3) Do you have another contact number I can use if needed (e.g., landline or mobile)?

4) Do you have any dogs at the house? Yes No If "Yes" can you restrain them before I arrive?

5) If the place is hard to find, are there any distinguishing landmarks to watch out for? How far is it from……..?

7) Are there any cultural traditions/customs I need to know about if I visit you at your home?

8) NOTE for researcher - Notify local person (colleague, supervisor, family etc) for safety prior to visit and once visit is complete.

[1] Adapted from document supplied by Dr Barry Taylor, Otago University

References

1. Clarke E, McCreanor T. He wahine tangi tikapa…: Statutory investigative processes and the grieving of Maori families who have lost a baby to SIDS. Kōtuitui: New Zealand Journal of Social Sciences Online. 2006;1(1):25-43.

2. Willinger M, James LS, Catz C. Defining the sudden infant death syndrome (SIDS): deliberations of an expert panel convened by the National Institute of Child Health and Human Development. Pediatric pathology. 1991;11(5):677-84.

3. Byard RW. Sudden unexpected death in infancy (SUDI)—the role of the pathologist. Current Pediatric Reviews. 2010;6(1):21-6.

4. Krous HF, Beckwith JB, Byard RW, Rognum TO, Bajanowski T, Corey T, et al. Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach. Pediatrics. 2004;114(1):234-8.

5. Mitchell EA, Thompson JM, Zuccollo J, MacFarlane M, Taylor B, Elder D, et al. The combination of bed sharing and maternal smoking leads to a greatly increased risk of sudden unexpected death in infancy: the New Zealand SUDI Nationwide Case Control Study. N Z Med J. 2017;130(1456):52-64.

6. Taylor BJ, Garstang J, Engelberts A, Obonai T, Cote A, Freemantle J, et al. International comparison of sudden unexpected death in infancy rates using a newly proposed set of cause-of-death codes. Arch Dis Child. 2015 Nov;100(11):1018-23.

7. Child and Youth Mortality Review Committee. 14th data report: 2013-17. Wellington: Health Quality & Safety Commission; 2019.

8. Mitchell EA BP. SIDS prevention: 3000 lives saved but we can do better. NZ Med J. 2012;125(1359):50-7.

9. Freemantle J, Ellis L. An Australian Perspective. 2018.

10. Mitchell EA, Taylor BJ, Ford RPK, Stewart AW, Becroft DMO, Thompson JM, Scragg R, Hassall IB, Barry DMJ, Allen EM. Four modifiable and other major risk factors for cot death: the New Zealand study. J Paediatr Child Health. 1992;28(s1):S3-8.

11. Mitchell E. Co-sleeping and suffocation. Forensic Sci Med Pathol. 2015;11:227-78.

12. Department of Health. Cot death prevention programme: Information for health workers. The Department of Health, Child and Adolescent Policy Unit and Health Education Services; 1991.

13. Mitchell EA, Krous HF. Sudden unexpected death in infancy: A historical perspective. J Paediatr Child Health. 2015;51(1):108-12.

14. Leach CE, Blair PS, Fleming PJ, Smith IJ, Platt MW, Berry PJ, et al. Epidemiology of SIDS and explained sudden infant deaths. Pediatrics. 1999;104(4):e43.

15. Goldstein RD, Kinney HC, Willinger M. Sudden unexpected death in fetal life through early childhood. Pediatrics. 2016;137(6).

16. Tribunal W. HAUORA: report on stage one of the health services and outcomes kaupapa inquiry-WAI 2575. New Zealand: Lower Hutt. 2019.

17. Minister of Health. New Zealand Health: Strategy Future Direction. Wellington: Ministry of Health; 2016 April.

18. Russell L, Smiler K, Stace H. Improving Māori health and reducing inequalities between Māori and non-Māori: has the primary health care strategy worked for Māori. New Zealand: Health Research Council of New Zealand and the Ministry of Health Wellington. 2013.

19. King A, Turia T. He Korowai Oranga. Ministry of Health; 2002.

20. Reducing sudden infant death by 86% in 8 yrs [Internet].; 2017 [updated June 13,; cited June 16, 2017]. Available from: https://www.national.org.nz/reducing_sudden_infant_death_by_86_in_8_yrs.

21. Came HA, Herbert S, McCreanor T. Representations of Māori in colonial health policy in Aotearoa from 2006-2016: a barrier to the pursuit of health equity. Critical Public Health. 2019:1-11.

22. Adcock A, Tipene-Leach D. Choosing Wisely Means Choosing Equity, 2020. Choosing Wisely Aotearoa New Zealand; 2020.

23. National SUDI Prevention Coordination Service [Internet]; Undated [updated Undated; cited Nov 10, 2020]. Available from: https://hapai.co.nz/content/national-sudi-prevention-coordination-service.

24. Pēpi-pods keeping pēpi safe [Internet].; 2019 [updated Dec 7; cited Jun 1, 2020]. Available from: http://www.huttvalleydhb.org.nz/media-and-latest-news/latest-news/2019-12-07-pepi-pods-keeping-pepi-safe/.

25. Counties Manukau District Health Board. Smokefree pregnancy incentive programme newsletter, February 2015. Auckland: Counties-Manukau DHB; 2015.

26. Pepi pods making homes safer [Internet]; Undated [updated Undated; cited April 5, 2021]. Available from: https://www.redcross.org.nz/stories/new-zealand/pepi-pods-making-homes-safer/.

27. Mitchell EA, Stewart AW, Scragg R, Ford RP, Taylor BJ, Becroft DM, et al. Ethnic differences in mortality from sudden infant death syndrome in New Zealand. BMJ. 1993 Jan 2;306(6869):13-6.

28. Health Research Council of New Zealand. Guidelines for researchers on health research involving Māori: Version 2. 2010.

29. Smith LT. Decolonizing methodologies: Research and indigenous peoples. London: Zed Books; 2013.

30. Huata P. Unpacking the Pōwhiri Poutama. Workshop sponsored by Waikato Institute of Technology. Hamilton, NZ; 2011.

31. Schlosser RW, Wendt O, Bhavnani S, Nail-Chiwetalu B. Use of information-seeking strategies for developing systematic reviews and engaging in evidence-based practice: the application of traditional and comprehensive Pearl Growing. A review. International Journal of Language & Communication Disorders. 2006;41(5):567-82.

32. Beckwith JB. Discussion of terminology and definition of the sudden infant death syndrome. Sudden Infant Death Syndrome Proceedings of the Second International Conference on the Causes of Sudden Death in Infants, 1970; University of Washington Press; 1970.

33. Bajanowski T, Vege Å, Byard RW, Krous HF, Arnestad M, Bachs L, et al. Sudden infant death syndrome (SIDS)—standardised investigations and classification: recommendations. Forensic Sci Int. 2007;165(2-3):129-43.

34. Hanzlick RL, Iyasu S, Rowley DL. Guidelines for death scene investigation of sudden, unexplained infant deaths; recommendations of the Interagency Panel on Sudden Infant Death Syndrome. 1996.

35. Mitchell E, Krous HF, Donald T, Byard RW. Changing trends in the diagnosis of sudden infant death. The American journal of forensic medicine and pathology. 2000;21(4):311-4.

36. Byard RW, Ranson D, Krous HF. National Australian workshop consensus on the definition of SIDS and initiation of a uniform autopsy approach to unexpected infant and early childhood death. National Australian workshop consensus on the definition of SIDS and initiation of a uniform autopsy approach to unexpected infant and early childhood death. 2005.

37. Blair PS, Byard RW, Fleming PJ. Sudden unexpected death in infancy (SUDI): suggested classification and applications to facilitate research activity. Forensic science, medicine, and pathology. 2012;8(3):312-5.

38. Byard RW, Lee V. A re-audit of the use of definitions of sudden infant death syndrome (SIDS) in peer-reviewed literature. Journal of forensic and legal medicine. 2012;19(8):455-6.

39. Shipstone RA, Young J, Thompson JM, Byard RW. An evaluation of pathologists' application of the diagnostic criteria from the San Diego definition of SIDS and unclassified sudden infant death. Int J Legal Med. 2019:1-7.

40. Health Topics: Risk Factors [Internet].; 2016 [cited October/19 2016]. Available from: http://www.who.int/topics/risk_factors/en/.

41. Shapiro-Mendoza CK, Parks S, Lambert AE, Camperlengo L, Cottengim C, Olson C. The Epidemiology of Sudden Infant Death Syndrome and Sudden Unexpected Infant Deaths: Diagnostic Shift and other Temporal Changes. In: SIDS Sudden Infant and Early Childhood Death: The Past, the Present and the Future. Adelaide: University of Adelaide Press; 2018. p. 257-82.

42. Byard RW, Shipstone RA, Young J. Continuing major inconsistencies in the classification of unexpected infant deaths. Journal of forensic and legal medicine. 2019;64:20-2.

43. Mitchell EA, Brunt JM, Everard C. Reduction in mortality from sudden infant death syndrome in New Zealand: 1986-92. Arch Dis Child. 1994 Apr;70(4):291-4.

44. Clark T. Equity for Maori: Reflecting on the data from the 12th PMMRC Annual Report. Coming together to be better. 2018.

45. Salm Ward TC. Reasons for mother–infant bed-sharing: A systematic narrative synthesis of the literature and implications for future research. Maternal Child Health J. 2015;19(3):675-90.

46. Ball HL, Volpe LE. Sudden Infant Death Syndrome (SIDS) risk reduction and infant sleep location–Moving the discussion forward. Soc Sci Med. 2013;79:84-91.

47. Moon RY, Horne RS, Hauck FR. Sudden infant death syndrome. The Lancet. 2007;370(9598):1578-87.

48. Freemantle CJ, Read AW, De Klerk NH, McAullay D, Anderson IP, Stanley FJ. Sudden infant death syndrome and unascertainable deaths: trends and disparities among Aboriginal and non-Aboriginal infants born in Western Australia from 1980 to 2001 inclusive. J Paediatr Child Health. 2006;42(7-8):445-51.

49. Bartick M, Tomori C. Sudden infant death and social justice: A syndemics approach. Maternal & child nutrition. 2019;15(1):e12652.

50. Gould GS, Munn J, Watters T, McEwen A, Clough AR. Knowledge and views about maternal tobacco smoking and barriers for cessation in Aboriginal and Torres Strait Islanders: a systematic review and meta-ethnography. Nicotine Tobacco Res. 2013;15(5):863-74.

51. Zealand SN. Ministry of Pacific Island Affairs.(2010). Health and Pacific peoples in New Zealand. 2010;31.

52. Shipstone RA, Young J, Kearney L, Thompson JM. Prevalence of risk factors for sudden infant death among Indigenous and non-Indigenous people in Australia. Acta Paediatrica. 2020;109(12):2614-26.

53. Ministry of Pacific Island Affairs and Statistics New Zealand. Health and Pacific Peoples in New Zealand. Health and Pacific peoples in New Zealand. 2010;31.

54. Tipene-Leach D, Hutchison L, Tangiora A, Rea C, White R, Stewart A, et al. SIDS-related knowledge and infant care practices among Maori mothers. NZ Medical Journal. 2010;123(1326):88-96.

55. Mills C, Reid P, Vaithianathan R. The cost of child health inequalities in Aotearoa New Zealand: a preliminary scoping study. BMC Public Health. 2012;12(1):1.

56. Mitchell EA. The changing epidemiology of SIDS following the national risk reduction campaigns. Pediatric pulmonology Supplement. 1997;16:117-9.

57. Mitchell EA, Tuohy PG, Brunt JM, Thompson JM, Clements MS, Stewart AW, et al. Risk factors for sudden infant death syndrome following the prevention campaign in New Zealand: a prospective study. Pediatrics. 1997 Nov;100(5):835-40.

58. Mitchell EA, Ford R, Taylor BJ, Stewart AW, Becroft D, Scragg R, et al. Further evidence supporting a causal relationship between prone sleeping position and SIDS. J Paediatr Child Health. 1992;28(s1):S9-S12.

59. Scragg RK, Mitchell EA. Side sleeping position and bed sharing in the sudden infant death syndrome. Ann Med. 1998;30(4):345-9.

60. Mitchell EA, Brunt JM, Everard C. Reduction in mortality from sudden infant death syndrome in New Zealand: 1986-92. Arch Dis Child. 1994;70(4):291-4.

61. Spencer N, Logan S. Sudden unexpected death in infancy and socioeconomic status: a systematic review. Journal of Epidemiology & Community Health. 2004;58(5):366-73.

62. Mitchell EA, Scragg R, Stewart AW, Becroft DM, Taylor BJ, Ford RP, et al. Results from the first year of the New Zealand cot death study. N Z Med J. 1991;104(906):71-6.

63. Mitchell EA, Scragg R, Stewart AW, Becroft DMO, Hassall IB, Ford RPK. Cot death: the New Zealand study. Contemporary Health. 1989(1989):1.

64. Zhang K, Wang X. Maternal smoking and increased risk of sudden infant death syndrome: a meta-analysis. Leg Med. 2013;15(3):115-21.

65. Friedmann I, Dahdouh EM, Kugler P, Mimran G, Balayla J. Maternal and obstetrical predictors of sudden infant death syndrome (SIDS). The Journal of Maternal-Fetal & Neonatal Medicine. 2017;30(19):2315-23.

66. Stewart AW, Mitchell EA. Are nappy sterilisers associated with SIDS? New Zealand Cot Death Study Group. Arch Dis Child. 1995;73(2):164-5.

67. Mitchell E. Sudden unexpected death in infancy: where are we now? Best practice. 2013;Issue 56:pp.3-7.

68. Ministry of Health. Annual Update of Key Results 2014/15: New Zealand Health Survey. Wellington: Ministry of Health; 2015.

69. New Zealand Child and Youth Epidemiology Service, (NZCYES). Te Ohonga Ake: The Health Status of Māori Children and Young People in New Zealand. Ministry of Health; 2012.

70. Hutchison L, Stewart A, Mitchell E. SIDS-protective infant care practices among Auckland, New Zealand mothers. The New Zealand Medical Journal (Online). 2006;119(1247).

71. Scragg R, Mitchell EA, Taylor BJ, Stewart AW, Ford RP, Thompson JM, et al. Bed sharing, smoking, and alcohol in the sudden infant death syndrome. New Zealand Cot Death Study Group. BMJ. 1993 Nov 20;307(6915):1312-8.

72. Blair PS, Fleming PJ, Smith IJ, Platt MW, Young J, Nadin P, et al. Babies sleeping with parents: case-control study of factors influencing the risk of the sudden infant death syndrome. CESDI SUDI research group. BMJ. 1999 Dec 4;319(7223):1457-61.

73. Counties Manukau Health. Annual Report 2019. Auckland: Counties-Manukau Health; 2019.

74. Abramson H. Accidental mechanical suffocation in infants. J Pediatr. 1944;25(5):404-13.

75. Mitchell EA. SIDS: past, present and future. Acta Paediatrica. 2009;98(11):1712-9.

76. Mitchell EA, Tonkin S. Publicity and infants' sleeping position. BMJ: British Medical Journal. 1993;306(6881):858.

77. Mitchell EA, Cowan S, Tipene-Leach D. The recent fall in post-perinatal mortality in New Zealand and the Safe Sleep Programme. Acta paediatrica. 2016.

78. Hutchison BL, Rea C, Stewart AW, Koelmeyer TD, Tipene-Leach DC, Mitchell EA. Sudden unexpected infant death in Auckland: a retrospective case review. Acta Paediatrica. 2011;100(8):1108-12.

79. Carpenter R, McGarvey C, Mitchell EA, Tappin DM, Vennemann MM, Smuk M, et al. Bed sharing when parents do not smoke: is there a risk of SIDS? An individual level analysis of five major case–control studies. BMJ open. 2013;3(5):e002299.

80. Vennemann MM, Hense H, Bajanowski T, Blair PS, Complojer C, Moon RY, et al. Bed sharing and the risk of sudden infant death syndrome: can we resolve the debate? J Pediatr. 2012;160(1):44,48. e2.

81. Escott A, Elder DE, Zuccollo JM. Sudden unexpected infant death and bedsharing: referrals to the Wellington Coroner 1997-2006. The New Zealand Medical Journal (Online). 2009;122(1298).

82. Child and Youth Mortality Review Committee, Te Roopu Arotake Auau Mate o te Hunga Tamariki, Taiohi. Fifth Report to the Minister of Health: Reporting mortality 2002–2008. Wellington: Child and Youth Mortality Review Committee; 2009. Report No. 5.

83. Baddock SA, Purnell MT, Blair PS, Pease AS, Elder DE, Galland BC. The influence of bed-sharing on infant physiology, breastfeeding and behaviour: A systematic review. Sleep Medicine Reviews. 2019;43:106-17.

84. Abel S, Park J, Tipene-Leach D, Finau S, Lennan M. Infant care practices in New Zealand: a cross-cultural qualitative study. Soc Sci Med. 2001;53(9):1135-48.

85. Morton S, Atatoa Carr PE, Grant CC, Lee AC, Bandara DK, Mohal J, et al. Growing Up in New Zealand: A longitudinal study of New Zealand children and their families. Report 2: Now we are born. Auckland: Growing up in New Zealand; 2012.

86. Jones H, Barber CC, Nikora LW, Middlemiss W. Māori child rearing and infant sleep practices. New Zealand Journal of Psychology (Online). 2017;46(3):30-7.

87. McIntosh C, Trenholme A, Stewart J, Vogel A. Evaluation of a sudden unexpected death in infancy intervention programme aimed at improving parental awareness of risk factors and protective infant care practices. J Paediatr Child Health. 2018;54(4):377-82.

88. Tipene-Leach D, Abel S. Innovation to prevent sudden infant death: the wahakura as an Indigenous vision for a safe sleep environment. Australian journal of primary health. 2019;25(5):406-9.

89. Cowan S. The Pēpi-Pod Programme 2013 Report. Christchurch: Change for our Children Limited; 2014.

90. Hauck FR, Thompson JM, Tanabe KO, Moon RY, Vennemann MM. Breastfeeding and reduced risk of sudden infant death syndrome: a meta-analysis. Pediatrics. 2011 Jul;128(1):103-10.

91. Vennemann MM, Bajanowski T, Brinkmann B, Jorch G, Yücesan K, Sauerland C, et al. Does breastfeeding reduce the risk of sudden infant death syndrome? Pediatrics. 2009;123(3):e406-10.

92. Young J, Watson K, Ellis L, Raven L. Responding to evidence: breastfeed baby if you can-the sixth public health recommendation to reduce the risk of sudden and unexpected death in infancy. Breastfeeding Review. 2012;20(1):7.

93. Ford RP, Taylor BJ, Mitchell EA, Enright SA, Stewart AW, Becroft DM, et al. Breastfeeding and the risk of sudden infant death syndrome. Int J Epidemiol. 1993 Oct;22(5):885-90.

94. Task Force on Sudden Infant Death Syndrome. SIDS and other sleep-related infant deaths: Updated 2016 recommendations for a safe infant sleeping environment. Pediatrics. 2016:e20162938.

95. Ministry of Health. 2013/14 New Zealand Health Survey: Breastfeeding indicators, by gender, Maori and non-Maori. 2015.

96. Blair PS, Sidebotham P, Pease A, Fleming PJ. Bed-sharing in the absence of hazardous circumstances: is there a risk of sudden infant death syndrome? An analysis from two case-control studies conducted in the UK. PLoS One. 2014;9(9):e107799.

97. Tonkin SL. Infant mortality. Epidemiology of cot deaths in Auckland NZ Med J. 1986;99:324-6.

98. Beal SM. Sudden infant death syndrome: epidemiological comparisons between South Australia and communities with a different incidence. Aust Paediatr J. 1986;22:13-6.

99. Richards CE, Wallis DN. Asphyxiation: a review. Trauma. 2005;7(1):37-45.

100. Galland B, Taylor B, Bolton D. Sudden Infant Death Syndrome (SIDS): Research and Prevention. Childrenz Issues: Journal of the Children's Issues Centre. 1999;3(2):23-8.

101. Cole R, Young J, Kearney L, Thompson JM. Infant care practices and parent uptake of safe sleep messages: a cross-sectional survey in Queensland, Australia. BMC pediatrics. 2020;20(1):27.

102. Galland BC, Taylor BJ, Bolton D, Sayers RM. Respiratory responses to hypoxia/hypercapnia in small for gestational age infants influenced by maternal smoking. Archives of Disease in Childhood-Fetal and Neonatal Edition. 2003;88(3):F217-22.

103. Galland BC, Bolton D, Taylor BJ, Sayers RM, Williams SM. Ventilatory sensitivity to mild asphyxia: prone versus supine sleep position. Arch Dis Child. 2000;83(5):423-8.

104. Garstang J, Ellis C, Griffiths F, Sidebotham P. Unintentional asphyxia, SIDS, and medically explained deaths: a descriptive study of outcomes of child death review (CDR) investigations following sudden unexpected death in infancy. Forensic science, medicine, and pathology. 2016;12(4):407-15.

105. MacFarlane ME, Thompson JM, Wilson J, Lawton B, Taylor B, Elder DE, et al. Infant Sleep Hazards and the Risk of Sudden Unexpected Death in Infancy. J Pediatr. 2022.

106. Hayman RM, McDonald G, de C Baker, Nick J, Mitchell EA, Dalziel SR. Infant suffocation in place of sleep: New Zealand national data 2002–2009. Arch Dis Child. 2015;100(7):610-4.

107. Chang AB, Wilson SJ, Masters IB, Yuill M, Williams J, Williams G, et al. Altered arousal response in infants exposed to cigarette smoke. Arch Dis Child. 2003;88(1):30-3.

108. Horne RS, Franco P, Adamson TM, Groswasser J, Kahn A. Influences of maternal cigarette smoking on infant arousability. Early Hum Dev. 2004;79(1):49-58.

109. Tirosh E, Libon D, Bader D. The effect of maternal smoking during pregnancy on sleep respiratory and arousal patterns in neonates. Journal of perinatology: official journal of the California Perinatal Association. 1996;16(6):435-8.

110. Hutchison BL, Stewart AW, Mitchell EA. SIDS-protective infant care practices among Auckland, New Zealand mothers. The New Zealand Medical Journal (Online). 2006;119(1247).

111. Pease A, Garstang JJ, Ellis C, Watson D, Ingram J, Cabral C, et al. Decision-making for the infant sleep environment among families with children considered to be at risk of sudden unexpected death in infancy: a systematic review and qualitative metasynthesis. BMJ Paediatrics Open. 2021;5(1):e000983.

112. Rechtman LR, Colvin JD, Blair PS, Moon RY. Sofas and infant mortality. Pediatrics. 2014;134(5):e1293-300.

113. Byard RW, Beal S, Blackbourne B, Nadeau JM, Krous HF. Specific dangers associated with infants sleeping on sofas. J Paediatr Child Health. 2001;37(5):476-8.

114. Galland BC, Elder DE. Sudden unexpected death in infancy: biological mechanisms. Paediatric respiratory reviews. 2014;15(4):287-92.

115. Blair PS, Sidebotham P, Evason-Coombe C, Edmonds M, Heckstall-Smith EM, Fleming P. Hazardous cosleeping environments and risk factors amenable to change: case-control study of SIDS in south west England. BMJ. 2009;339:b3666.

116. Mitchell EA, Williams SM, Taylor BJ. Use of duvets and the risk of sudden infant death syndrome. Arch Dis Child. 1999;81(2):117-9.

117. Klonoff-Cohen H, Lam-Kruglick P. Maternal and paternal recreational drug use and sudden infant death syndrome. Arch Pediatr Adolesc Med. 2001;155(7):765-70.

118. El Marroun H, Brown QL, Lund IO, Coleman-Cowger VH, Loree AM, Chawla D, et al. An epidemiological, developmental and clinical overview of cannabis use during pregnancy. Prev Med. 2018;116:1-5.

119. Jaques SC, Kingsbury A, Henshcke P, Chomchai C, Clews S, Falconer J, et al. Cannabis, the pregnant woman and her child: weeding out the myths. Journal of Perinatology. 2014;34(6):417-24.

120. New Zealand Health Survey: Annual Data Explorer, November 2019 [Internet].; 2019 [updated November; cited 7 August 2020]. Available from: https://minhealthnz.shinyapps.io/nz-health-survey-2018-19-annual-data-explorer/_w_337a677b/#!/explore-topics.

121. Ministry of Health. Cannabis Use 2012/13: New Zealand Health Survey. Wellington: Ministry of Health; 2015.

122. Mitchell EA. What is the mechanism of SIDS? Clues from epidemiology. Developmental Psychobiology: The Journal of the International Society for Developmental Psychobiology. 2009;51(3):215-22.

123. Blair PS, Mitchell EA, Heckstall-Smith EM, Fleming PJ. Head covering–a major modifiable risk factor for sudden infant death syndrome: a systematic review. Arch Dis Child. 2008;93(9):778-83.

124. Williams SM, Mitchell EA, Stewart AW, Taylor BJ. Temperature and the sudden infant death syndrome. Paediatr Perinat Epidemiol. 1996;10(2):136-49.

125. Getahun D, Amre D, Rhoads GG, Demissie K. Maternal and obstetric risk factors for sudden infant death syndrome in the United States. Obstetrics & Gynecology. 2004;103(4):646-52.

126. Blair P, Fleming P, Platt MW. Babies sleeping with parents and sudden infant death syndrome. BMJ. 2000;321(7267):1020.

127. Malloy MH, Eschbach K. Association of poverty with sudden infant death syndrome in metropolitan counties of the United States in the years 1990 and 2000. South Med J. 2007;100(11):1107-13.

128. Pickett KE, Luo Y, Lauderdale DS. Widening social inequalities in risk for sudden infant death syndrome. Am J Public Health. 2005;95(11):1976-81.

129. Horne RS, Hauck FR, Moon RY. Sudden infant death syndrome and advice for safe sleeping. BMJ. 2015;350.

130. Fleming PJ, Blair PS, Ward Platt M, Tripp J, Smith IJ, CESDI SUDI Research Group. Sudden infant death syndrome and social deprivation: assessing epidemiological factors after post-matching for deprivation. Paediatr Perinat Epidemiol. 2003;17(3):272-80.

131. Guntheroth WG, Spiers PS. The triple risk hypotheses in sudden infant death syndrome. Pediatrics. 2002 Nov;110(5):e64.

132. Filiano JJ KH. A perspective on neuropathologic findings in victims of the sudden infant death syndrome: the triple-risk model. Neonatology. 1994;65(3-4):194-7.

133. Trachtenberg FL, Haas EA, Kinney HC, Stanley C, Krous HF. Risk factor changes for sudden infant death syndrome after initiation of Back-to-Sleep campaign. Pediatrics. 2012 Apr;129(4):630-8.

134. Warland J, Mitchell EA. A triple risk model for unexplained late stillbirth. BMC pregnancy and childbirth. 2014;14(1):1.

135. Mitchell EA, Hutchison L, Stewart AW. The continuing decline in SIDS mortality. Arch Dis Child. 2007;92(7):625-6.

136. Ministry of Health. National SUDI Prevention Programme: Needs assessment and care planning guide. Wellington, New Zealand: Ministry of Health; 2019.

137. Chair Health Quality and Safety Commission, Chair Child and Youth Mortality Review Committee. Letter from the Health Quality and Safety Commission to district health boards. (Viewed at: https://www.hqsc.govt.nz/our-programmes/mrc/news-and-events/news/523/ on 18 October 2016.) 2012.

138. Ministry of Health. National SUDI Prevention Programme: Research and Consultation phase - summary of findings of the Literature and Hui series. 2017.

139. Coroners Act of New Zealand 2006 (Amended October 2016), 2006.

140. Ministry of Justice. Recommendations Recap: A summary of coronial recommendations and comments made between 1 October - 31 December 2011, Issue 1. 2012.

141. Mitchell E. Sudden unexpected death in infancy (SUDI) case-control feasibility study. 2010; HRC 10/260.

142. Lester A. Project management, planning and control: managing engineering, construction and manufacturing projects to PMI, APM and BSI standards. Elsevier; 2006.

143. Bryson JM. What to do when stakeholders matter: stakeholder identification and analysis techniques. Public management review. 2004;6(1):21-53.

144. Some Basic Design Elements and Their Meanings [Internet].; 2016 [cited March 8, 2019]. Available from: https://boneart.co.nz/pages/meanings.

145. Hawkins P, Shohet R, Ryde J, Wilmot J. Supervision in the helping professions. McGraw-Hill Education (UK); 2012.

146. Forever Present [Internet].; 2016 [updated December; cited December/18 2016]. Available from: http://islaandpema.webs.com.

147. Ministry of Health. Operational Standard for Ethics Committees: Updated edition. Wellington: 2006.

148. NZ Mortality Review Data Group. Child and Youth Mortality Review Committee 9th Data Report 2008-2012. Otago: University of Otago; 2013. Report No.: 9.

149. Garstang J, Ellis C, Sidebotham P. An evidence-based guide to the investigation of sudden unexpected death in infancy. Forensic science, medicine, and pathology. 2015;11(3):345-57.

150. Live Births, Stillbirths by District Health Board (Maori and Live Births) [Internet].; 2016 [cited 2017]. Available from: http://www.stats.govt.nz/browse_for_stats/population/births/births-tables.aspx.

151. Poutasi K. Ethnicity Data Protocols for the Health and Disability Sector. Wellington, New Zealand: Ministry of Health. 2004.

152. Whittemore A. Estimating attributable risk from case-control studies. Amer J Epidemiol. 1983(117):76.

153. Low P, Paterson J, Wouldes T, Carter S, Williams M, Percival T. Factors affecting antenatal care attendance by mothers of Pacific infants living in New Zealand. . 2005.

154. Essex C, Counsell AM, Geddis DC. The demographic characteristics of early and late attenders for antenatal care. Australian and New Zealand journal of obstetrics and gynaecology. 1992;32(4):306-8.

155. Ratima M, Crengle S. Antenatal, labour, and delivery care for Maori: Experiences, location within a lifecourse approach, and knowledge gaps. Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health. 2013;10(3):353-66.

156. Beeckman K, Louckx F, Putman K. Predisposing, enabling and pregnancy-related determinants of late initiation of prenatal care. Matern Child Health J. 2011;15(7):1067-75.

157. Stacey T, Thompson J, Mitchell EA, Zuccollo JM, Ekeroma AJ, McCowan LM. Antenatal care, identification of suboptimal fetal growth and risk of late stillbirth: findings from the Auckland Stillbirth Study. Australian and New Zealand Journal of Obstetrics and Gynaecology. 2012;52(3):242-7.

158. Corbett S, Chelimo C, Okesene-Gafa K. Barriers to early initiation of antenatal care in a multi-ethnic sample in South Auckland, New Zealand. The New Zealand Medical Journal (Online). 2014;127(1404):53.

159. Antenatal care: NICE clinical guideline 62 [Internet].; 2018 [updated 2008 [updated June 2010; cited February]; cited 5 February 2018]. Available from: https://www.nice.org.uk/guidance/cg62.

160. King A. The New Zealand Health Strategy. Wellington: Ministry of Health. 2000.

161. He Korowai Oranga [Internet].; 2014 [cited 15 March 2018]. Available from: https://www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga.

162. Ministry of Health. Reducing inequalities in health. Wellington: Ministry of Health; 2002 September.

163. Alcohol [Internet].; 2019 [cited 2 August 2020]. Available from: https://www.health.govt.nz/your-health/healthy-living/addictions/alcohol-and-drug-abuse/alcohol.

164. Tipene-Leach D, Abel S. The wahakura and the safe sleeping environment. J Prim Health Care. 2010 Mar;2(1):81.

165. Schlaud M, Dreier M, Debertin AS, Jachau K, Heide S, Giebe B, et al. The German case-control scene investigation study on SIDS: epidemiological approach and main results. Int J Legal Med. 2010;124(1):19.

166. SAS Institute Inc. SAS/STAT 15.1 User's Guide. In: Cary, NC, USA: SAS Institute Inc.; 2018. p. 6376.

167. MacFarlane M, Thompson J, Zuccollo J, McDonald G, Elder D, Stewart AW, et al. Smoking in pregnancy is a key factor for sudden infant death among Māori. Acta Paediatrica. 2018;107(11):1924-31.

168. Scragg R, Mitchell EA, Ford R, Thompson J, Taylor BJ, Stewart AW. Maternal cannabis use in the sudden death syndrome. Acta Paediatrica. 2001;90(1):57-60.

169. Moon RY, Task Force on Sudden Infant Death Syndrome. SIDS and other sleep-related infant deaths: evidence base for 2016 updated recommendations for a safe infant sleeping environment. Pediatrics. 2016;138(5).

170. Wilson CA, Taylor BJ, Laing RM, Williams SM, Mitchell EA, New Zealand Cot Death Study Group. Clothing and bedding and its relevance to sudden infant death syndrome: further results from the New Zealand Cot Death Study. J Paediatr Child Health. 1994;30(6):506-12.

171. Blair PS, Ball HL, McKenna JJ, Feldman-Winter L, Marinelli KA, Bartick MC, et al. Bedsharing and Breastfeeding: The Academy of Breastfeeding Medicine Protocol# 6, Revision 2019. Breastfeeding Medicine. 2020;15(1):5-16.

172. Abraham M, Alramadhan S, Iniguez C, Duijts L, Jaddoe VW, Den Dekker HT, et al. A systematic review of maternal smoking during pregnancy and fetal measurements with meta-analysis. PloS one. 2017;12(2):e0170946.

173. Juárez SP, Merlo J. Revisiting the effect of maternal smoking during pregnancy on offspring birthweight: a quasi-experimental sibling analysis in Sweden. PloS one. 2013;8(4):e61734.

174. Richardson HL, Walker AM, Horne RS. Maternal smoking impairs arousal patterns in sleeping infants. Sleep. 2009;32(4):515-21.

175. Carpenter JR, Smuk M. Missing data: A statistical framework for practice. Biometrical Journal. 2021.

176. Willinger M, Ko C, Hoffman HJ, Kessler RC, Corwin MJ. Trends in infant bed sharing in the United States, 1993-2000: the National Infant Sleep Position study. Arch Pediatr Adolesc Med. 2003;157(1):43-9.

177. Ateah CA, Hamelin KJ. Maternal bedsharing practices, experiences, and awareness of risks. Journal of Obstetric, Gynecologic, & Neonatal Nursing. 2008;37(3):274-81.

178. Nelson EAS, Taylor BJ, Jenik A, Vance J, Walmsley K, Pollard K, et al. International child care practices study: infant sleeping environment. Early Hum Dev. 2001;62(1):43-55.

179. Ball HL, Moya E, Fairley L, Westman J, Oddie S, Wright J. Bed- and sofa-sharing practices in a UK biethnic population. Pediatrics. 2012;129(3):e673-81.

180. Blair PS, Ball HL. The prevalence and characteristics associated with parent–infant bed-sharing in England. Arch Dis Child. 2004;89(12):1106-10.

181. Ryan RM, Deci EL. Intrinsic and extrinsic motivations: Classic definitions and new directions. Contemp Educ Psychol. 2000;25(1):54-67.

182. Jungert T, Landry R, Joussemet M, Mageau G, Gingras I, Koestner R. Autonomous and controlled motivation for parenting: Associations with parent and child outcomes. J Child Fam Stud. 2015;24(7):1932-42.

183. Savin-Baden Maggi, Howell-Major Claire. Qualititaive Research: The Essential Guide to Theory and Practice. London: Routledge; 2012.

184. Putaiora Writing Group, Hudson M, Milne M, Reynolds P, Russell K, Smith B. Te Ara Tika, Guidelines for Maori Research Ethics: A framework for researchers and ethics committee members. Auckland: Health Research Council of New Zealand; 2010.

185. Smith LT. Decolonising methodologies. Research and Indigenous peoples. 1999.

186. NZ Mortality Review Data Group. SUDI data request for the Ministry of Health. 2016: University of Otago; 2016 14 November.

187. Hassan E. Recall bias can be a threat to retrospective and prospective research designs. The Internet Journal of Epidemiology. 2006;3(2):339-412.

188. Drever E. Using Semi-Structured Interviews in Small-Scale Research. A Teacher's Guide. Edinburgh: Scottish Council for Research in Education; 1995.

189. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. American journal of evaluation. 2006;27(2):237-46.

190. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. International journal of qualitative methods. 2002;1(2):13-22.

191. Sudden Unexpected Death Infancy (SUDI) Prevention Programme [Internet]; 2019 [updated Updated 18 November; cited 26 October 2020]. Available from: https://countiesmanukau.health.nz/our-services/maternity-services/sudden-unexpected-death-infancy-sudi-prevention-programme/.

192. Ministry of Health. Report on Maternity 2017. Wellington: Ministry of Health; 2019.

193. Zoucha R, Walters CA, Colbert AM, Carlins E, Smith E. Exploring Safe Sleep and SIDS Risk Perception in an African-American Community: Focused Ethnography. Public health nursing. 2016;33(3):206-13.

194. Killen CP, Jugdev K, Drouin N, Petit Y. Advancing project and portfolio management research: Applying strategic management theories. Int J Project Manage. 2012;30(5):525-38.

195. Payne JM, France KE, Henley N, D'Antoine HA, Bartu AE, Elliott EJ, et al. Researchers' experience with project management in health and medical research: Results from a post-project review. BMC Public Health. 2011;11(1):1-11.

196. Hudson M. No title. He matatika Maori: Maori and ethical review in health research. 2004.

197. Shavers VL, Lynch CF, Burmeister LF. Racial differences in factors that influence the willingness to participate in medical research studies. Ann Epidemiol. 2002;12(4):248-56.

198. Ministry of Health. Proposals for a Smokefree Aotearoa 2025 Action Plan: Discussion document. Wellington: Ministry of Health; 2021 April 15.

199. Parliament NZ. Smokefree Environments and Regulated Products (Vaping) Amendment Bill. New Zealand Parliament. 2020.

200. Brochure Hewlett Packard - Teleform [Internet].; 2015 [updated Mar 1,; cited 15 February 2016]. Available from: http://www.hpengage.com/products/teleform.

201. Mane J. Kaupapa Māori: A community approach. Mai Review. 2009;3(1):1-9.

202. Cram F, Mertens DM. Negotiating solidarity between indigenous and transformative paradigms in evaluation. Evaluation Matters—He Take Tõ Te Aromatawai. 2016;2:161-89.

203. Pipi K, Cram F, Hawke R, Hawke S, Huriwai T, Mataki T, et al. A research ethic for studying Maori and iwi provider success. Social Policy Journal of New Zealand. 2004;23(3).

204. Denzin NK, Lincoln YS, Smith LT. Handbook of critical and indigenous methodologies. Sage; 2008.

205. Donations and Koha Policy [Internet].; 2015 [updated 10 September; cited 10 September 2018].

206. Peters J. Koha Personal communication with Jim Peters. 2018 Aug, 22.

The End