



HEALTH QUALITY & SAFETY  
COMMISSION NEW ZEALAND

*Kupu Taurangi Hauora o Aotearoa*



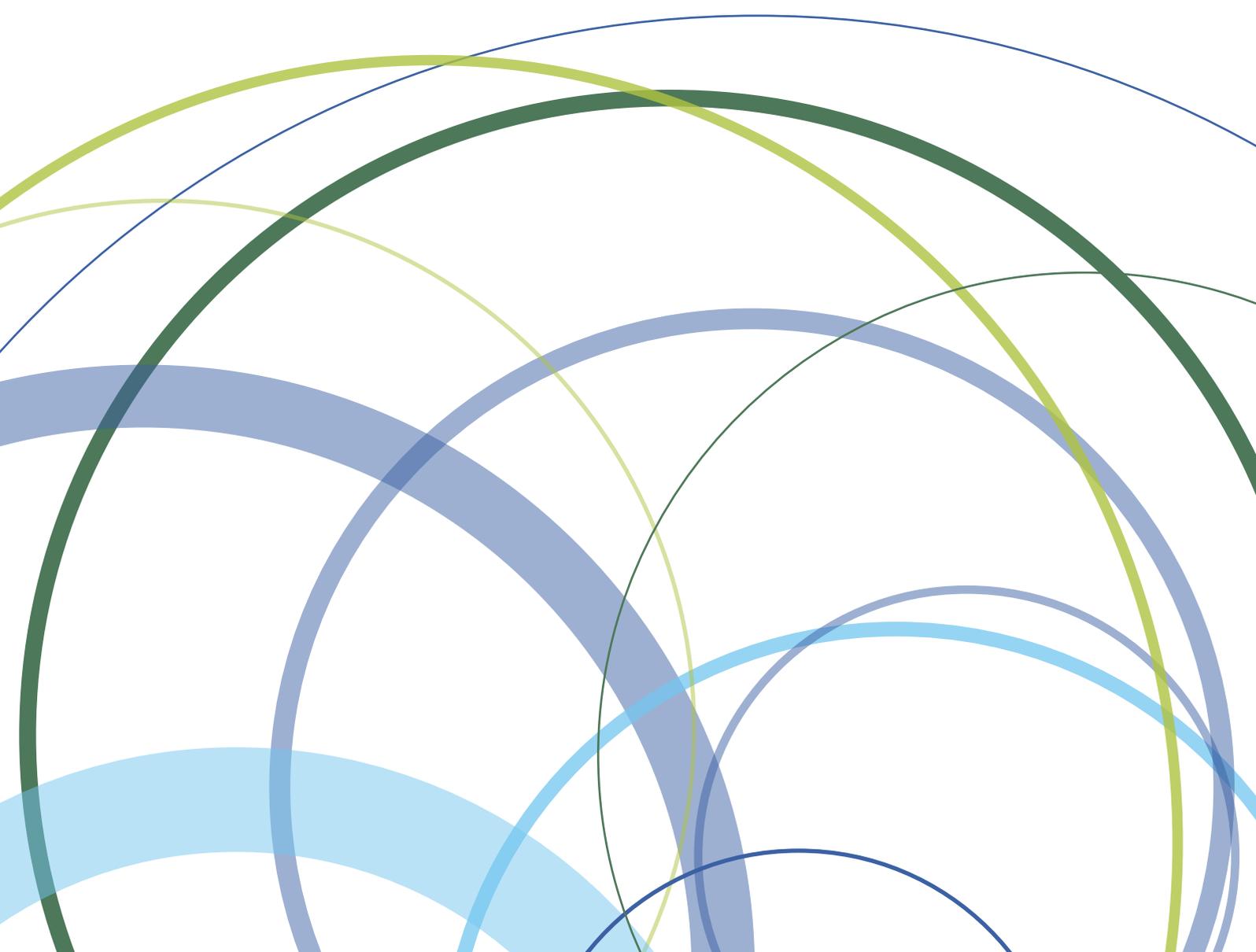
**Child and Youth  
Mortality Review  
Committee**

Sudden unexpected death in infancy (SUDI)

Special report

June 2017

---



This report was written for the Child and Youth Mortality Review Committee by Dr Gabrielle McDonald, Dr Paula King, Dr Felicity Dumble, the Mortality Review Committee Secretariat with the input of the CYMRC members.

Citation: Child and Youth Mortality Review Committee, Te Rōpū Arotake Auau Mate o te Hunga Tamariki, Taiohi. 2017. *Sudden unexpected death in infancy (SUDI): Special report. June 2017.* Wellington: Child and Youth Mortality Review Committee.

Published in June 2017 by the Health Quality & Safety Commission,  
PO Box 25496, Wellington 6146, New Zealand.

ISBN 978-0-908345-59-5 (Online)

This document is available on the Health Quality & Safety Commission website: [www.hqsc.govt.nz](http://www.hqsc.govt.nz).

For information on this report please contact [info@hqsc.govt.nz](mailto:info@hqsc.govt.nz)



# Acknowledgements

The Child and Youth Mortality Review Committee (the CYMRC) would like to thank the following individuals and groups for their involvement in the development of this report.

- The New Zealand Mortality Review Data Group at the University of Otago for extracting, collating and analysing the data; in particular, Dr Gabrielle McDonald for leading the analyses.
- Prof Edwin Mitchell from the University of Auckland for his input from the beginning of the process when he was a member of the CYMRC through to his peer review of the draft report after his membership had finished.
- The local child and youth mortality review groups (LCYMRGs) that reviewed the details of many of the SUDI deaths included in this report, and those who reviewed the draft report.
- The Mortality Review Committees' Māori Caucus for reviewing the report: Prof Denise Wilson (Chair), Dr Fiona Cram, Dr Paula King, Dr Terryann Clark, Keri Parata, Ngaroma Grant and Dr Sue Crengle.
- The Perinatal and Maternal Mortality Review Committee for providing the neonatal data that is used in this report, and assisting with the selection of neonatal cases.
- The organisations, academics, policy makers and medical professionals who provided feedback on the draft report and/or recommendations, including:
  - Professor David Tipene-Leach – Eastern Institute of Technology
  - Stephanie Cowan – Change for our Children
  - Kathleen Logan – Office of the Children's Commissioner
  - Karen Magrath, Helen Connors, Marianne Grant, Sandra Innes, Zoe Tipa and Sue Campbell – Plunket
  - Raewyn Bourne – Tipu Ora, Rotorua
  - Eric Tibbott, Jimmy Patea and Fleur de Bos – New Zealand Police
  - Judge Deborah Marshall – Office of the Chief Coroner
  - Harry Johnson – Ministry of Justice
  - Kathrine Clark – Whakawhetu
  - Dr Teuila Percival – TAHA
  - Dr Nick Baker – Nelson Marlborough Health DHB, Chair of the Nelson Marlborough LCYMRG and former Chair of the CYMRC
  - Carol Bartle – College of Midwives
  - Kylie McCosh, Jane Chambers, Dr Bryn Jones, Gabrielle Baker and Stephnie Roberts – Ministry of Health
  - Paul Arts – Ministry for Vulnerable Children, Oranga Tamariki.
- The Mortality Review Committees' Secretariat at the Health Quality & Safety Commission.

# About the Child and Youth Mortality Review Committee

The New Zealand Child and Youth Mortality Review Committee (the CYMRC) is a mortality review committee appointed by the Health Quality & Safety Commission (the Commission) under section 59E of the New Zealand Public Health and Disability Act 2000.

The CYMRC is one of four permanent mortality review committees. It focuses on reducing preventable deaths of children and young people aged 28 days to 24 years through an interdisciplinary and interagency approach.

Using analyses and reviews that local child and youth mortality review groups have conducted, the CYMRC provides annual national reports to the Commission. These reports include recommendations about local and national actions to reduce preventable deaths. Over the past 15 years the CYMRC has produced 12 annual data reports and seven special reports investigating particular types of deaths. Across these reports, sudden unexpected death in infancy (SUDI) has been a common theme. The *Fifth Report to the Minister of Health: Reporting mortality 2002–2008* (CYMRC 2009) includes a chapter about SUDI, and the CYMRC has published a special report about suffocation and strangulation in all ages. However, this is the first time the CYMRC has dedicated a report to SUDI.

## Current CYMRC members:

- Dr Felicity Dumble (Chair)
- Dr Stuart Dalziel (Deputy Chair)
- Dr Paula King
- Dr Terryann Clark
- Prof Shanthi Ameratunga
- Dr Arran Culver
- Dr Rebecca Hayman
- Dr Janine Ryland (ex-officio member, Ministry of Health)
- Fale Lesa (consumer representative)

## Previous members who were involved in the report:

- Prof Ed Mitchell
- Gillian Buchanan (ex-officio member, Ministry of Social Development)
- Kathy Mansell (advisor, Children's Action Plan)
- Jacqui Moynihan (advisor, Children's Action Plan)

## About local child and youth mortality review groups (LCYMRGs)

An LCYMRG works within each of the 20 district health boards (DHBs) to review the deaths of children and young people in its region. Each LCYMRG has a diverse range of members (eg, police, DHB staff, social workers, youth health workers) but the exact mix varies between different regions and categories of review. For each death, the LCYMRG coordinator compiles as much of the relevant information as they can (eg, police report, post-mortem, clinical notes, case notes from service providers) and presents it to the LCYMRG, which then reviews the case.

The LCYMRG examines how systemic factors contributed to the death and makes recommendations on how various systems may be changed to prevent similar deaths in the future. The recommendations are not limited to the health system and cover a broad range of organisations and groups, such as: the Ministry for Vulnerable Children, Oranga Tamariki; New Zealand Police; social service providers; emergency services; DHB staff; social workers; and education and youth health workers.

# Contents

Acknowledgements	i
About the Child and Youth Mortality Review Committee	ii
Foreword	1
Chair's introduction	2
Executive summary	3
Introduction	6
Section 1: What the data tells us	7
Overview of SUDI mortality trends and prevalence	7
Inequitable reduction for Māori	8
Key risk factors for SUDI	8
Demographic factors	9
Insights from the local child and youth mortality review groups	15
Section 2: Next steps for SUDI prevention in New Zealand	17
A national SUDI Prevention Programme	17
Universal and tailored approaches	18
Universal and tailored smoking prevention and cessation products and services	18
The SUDI Prevention Programme must be prioritised, monitored and evaluated by DHBs	19
Supportive physical environments	21
Improved care and investigation after the death of a baby	23
References	25
Appendix 1: Data and methods	28

## Glossary

**Bed sharing** is when two or more individuals share a surface, for example, a bed or couch, when they are asleep (either intentionally or unintentionally). In this report, these individuals are an infant and one or more other people, who could be one or more children or adults.

**Sudden infant death syndrome (SIDS)** is the sudden death of an infant (under one year of age) that cannot be explained after a thorough examination is conducted, including an autopsy, examination of the death scene and review of the clinical history (CDC 2017a). **Sudden unexpected death in infancy (SUDI)** is an umbrella term that describes the death of an infant that was not anticipated as a significant possibility 24 hours before the death, or where a similarly unexpected collapse caused the death or triggered the events that led to the death. The group of deaths categorised as SUDI contains a spectrum of cases from those that are unexplained following full investigation (SIDS, as above) to fully explained cases (explained SUDI). Between them are cases where a pathologist or coroner cannot be certain as to whether the death is explained or not; these are often labelled 'unascertained' (CYMRC 2013).

At first these deaths were known as 'cot deaths' and then people began to use the term SIDS. Now the preferred term is SUDI, although this umbrella term includes the group of unexplained SIDS deaths, as noted above. This report uses both 'SIDS' and 'SUDI' according to the term that people were using at the time, particularly in research papers that this report references.



## Foreword

I am pleased to introduce the Child and Youth Mortality Review Committee's (the CYMRC's) special topic report on sudden unexpected death in infancy (SUDI).

SUDI is a leading cause of preventable death. It is estimated that, of the 44 babies that died from SUDI in 2015, up to 37 deaths could have been prevented. This report shows that while our rates have dropped significantly since the 1980s, there are still too many of our babies dying from SUDI.

This is the seventh special topic report that the CYMRC has produced and it builds on previous investigations related to SUDI – in 2009 the CYMRC included a chapter about SUDI in its *Fifth Report to the Minister of Health: Reporting mortality 2002–2008*, and in 2013 the CYMRC published a special topic report on unintentional suffocation, foreign body inhalation and strangulation. However, this is the first time the CYMRC has dedicated a report to the investigation of SUDI.

The CYMRC has engaged widely to develop the recommendations in this report, which are supported by the Commission. Reporting on special topics, and developing recommendations, involves extensive consultation with national experts and leaders that can influence system change. Preventing death reduces trauma for families, whānau and communities affected by the death of a loved one. In its recent report, *Open4Results*,<sup>1</sup> the Commission shows the number of children and young people who died each year fell from 638 in 2002 to 488 in 2014. Although the value of a life saved is, in reality, beyond something that can be measured in financial terms, *Open4Results* estimates the financial saving to the New Zealand economy to be \$175 million (Health Quality & Safety Commission 2016).

Congratulations to Dr Felicity Dumble, CYMRC Chair, and the other members of the CYMRC for their work on this report and their commitment to reducing SUDI.

I would like to join Dr Dumble in recognising the sadness and loss that parents, families and whānau experience with the death of a baby to SUDI. I hope this report will contribute to ongoing work to further reduce SUDI rates in New Zealand.

**Prof Alan Merry** ONZM FRSNZ

*Chair, Health Quality & Safety Commission*

---

<sup>1</sup> Available at: [www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/2956](http://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/2956).



## Chair's introduction

Forty-four babies died from sudden unexpected death in infancy (SUDI) in 2015. While this is much fewer deaths than previous years, there is no doubt that our SUDI rates are still too high. Thanks to the combined efforts of many committed experts in this field, a lot has been learnt about how to prevent SUDI. Knowledge about the key risk factors for SUDI and a change in safe sleep practices (lying babies on their back to sleep, not smoking during pregnancy and breastfeeding) have seen our very high rates of SUDI in the 1980s reduce significantly. Unfortunately, though this reduction has not been shared equitably. SUDI rates continue to be higher for Māori, Pacific peoples, young mothers and those living in deprived neighbourhoods.

This report provides recommendations to: contribute to SUDI prevention strategies that protect and support whānau, families and households most at risk of experiencing the death of an infant; support the prevention work in this area that is already under way; and provide information for programmes that are about to be established. Most of all, this report highlights the need to better serve our Māori whānau and communities, who bear the heaviest burden of this tragic loss.

While much has been learnt about SUDI prevention, we still need to know more about how to prevent SUDI for Māori and Pacific babies as well as babies to young mums and those living in deprived neighbourhoods. We need to acknowledge the complexity of people's lives and the impact that deprivation can have on reducing access to adequate housing, heating and smoking cessation. These factors limit or remove people's choices and expose them to increased risk. We need to work together to address these determinants of health in addition to specific actions of the SUDI Prevention Programme, which is the focus of this report.

I would like to acknowledge the fantastic work of the CYMRC members, and the Mortality Review Committee Secretariat at the Commission, for their expertise and commitment. I would also like to acknowledge the local coordinators and chairs throughout the country, and all of those involved in the local child and youth mortality review groups. Much of the data in this report comes from the local child and youth mortality review groups. Reviewing cases is not an easy task and the CYMRC values their expertise and passion for this work.

It is my hope that over the coming years we continue to see a decline in SUDI rates particularly for Māori and Pacific babies, and spare more families from losing their babies to SUDI.

### Dr Felicity Dumble

*Chair, Child and Youth Mortality Review Committee*

## Executive summary

Sudden unexpected death in infancy (SUDI) is a leading cause of preventable death in New Zealand babies. Since the 1980s, the number of SUDI deaths reduced from 250 per year (over 4.4 per 1000 live births) to 44 deaths in 2015 (0.92 per 1000 live births). New Zealand has made substantial headway in reducing the rate of SUDI but too many of our babies are still dying. It is estimated that up to 37 of the 44 deaths in 2015 could have been prevented (Mitchell et al 2017).

SUDI rates dropped significantly due to the identification and reduction of four factors that make SUDI more likely: prone (front) sleep position; maternal smoking; lack of breastfeeding (Mitchell et al 1991); and bed sharing (Mitchell et al 1992), particularly for babies of mothers who smoke (Scragg et al 1993). This information formed the basis of sudden infant death syndrome (SIDS)<sup>2</sup> prevention advice to parents from the 1990s (Mitchell 2014). Between 1988 and 1992, the rate of SIDS dropped substantially from 4.4 per 1000 live births to 2.3 per 1000 (Mitchell et al 1994).

In the late 1990s the SIDS prevention advice was updated on the basis of further research findings, to recommend that babies sleep on their backs only and not on their sides or fronts. Researchers considered that uptake of the new advice contributed to the gradual decline in SIDS rates up until 2000 (Mitchell et al 2007). These SUDI prevention public health messages, first promoted in the 1990s, remain applicable today (Mitchell et al 2017). A safe sleep and smokefree environment is vital for every baby and this message should be reinforced and supported through a mix of universal and tailored SUDI prevention services.

More recently, the combination of bed sharing and maternal smoking in pregnancy has been established as extremely hazardous to babies, leading to a 32-fold increased risk of SUDI, compared with babies not exposed to either risk factor (Mitchell et al 2017). It can be very difficult for pregnant women and mothers to quit smoking, especially if their friends and other members of their household are smokers. As such, tailored, supportive and appropriate smoking cessation services are required. Similarly, widespread availability of safe sleep devices will help support a safe sleep environment for baby, wherever they may be.

Although the SUDI rates have reduced significantly since the 1980s, they did not fall equitably across the whole population. The SUDI risk for Māori and Pacific babies has remained consistently higher than for non-Māori non Pacific babies. In fact, Māori babies are nearly seven times more likely, and Pacific babies are nearly four times more likely, to die from SUDI. In addition, mothers under 25 years of age and those living in deprived neighbourhoods are also much more likely to experience the loss of a baby due to SUDI.

This report shows that babies living in the most deprived areas (decile 10 on the deprivation index) had a 7.05 times higher SUDI rate (95% CI 4.37, 11.36) than babies living in the least deprived areas (decile 1). Of all the SUDI cases during our study period (2002–15), 75 percent were babies living in decile 7–10 areas (585 deaths) and 53 percent were living in the two most deprived areas (deciles 9 and 10) (408 deaths).

Whānau and families living in higher-deprivation areas are likely to face significant challenges in providing warm and safe sleeping spaces for babies. The local child and youth mortality review groups examine how systemic factors contribute to SUDI deaths, and have collected information providing insight into some of the common underlying factors. Typically, these include inadequate housing, insufficient financial resources, lack of access to transport, and difficulty accessing support from health providers. These challenges create stressful living situations and can make it difficult for whānau and families to engage, or stay engaged, with health care and support services. SUDI prevention programmes need to take account of the impact of deprivation on the lives of whānau and families, and work with other agencies, including housing, social service and income support providers, to provide effective services.

District health boards (DHBs), and in particular lead maternity carers and Well Child/Tamariki Ora providers, have a significant role in modelling, delivering and supporting SUDI prevention advice and services. Identifying and promoting effective and culturally appropriate ways of engaging, and staying engaged, with women most at risk of SUDI early in their pregnancies is critical to achieving equitable health outcomes. It has been established that Māori and Pacific

<sup>2</sup> In the 1980s and earlier, 'SIDS' or 'cot death' were the terms used to refer to the unexplained and sudden death of an infant. More recently the umbrella term 'SUDI' is used to refer to both unexplained sudden infant deaths (SIDS) and explained deaths.

peoples are among those who receive lesser quality of care from health services, including antenatal, postnatal and Well Child/Tamariki Ora services (Ratima et al 2013; Makowharemahihi et al 2014; Houkamau and Clarke 2016).

This report recognises that the death of a baby has a devastating impact on whānau and families. It supports the development of a multi-agency protocol for the care of whānau and families after the sudden and unexpected death of a baby. All first response services, such as the police, pathologists and funeral directors, need to undertake their work in ways that are sensitive, supportive and culturally appropriate to grief-stricken whānau. Further, many whānau and families do not have access to the after-death support services they need, including grief counselling and medical explanations for post-mortem findings.

This report calls for those who bear the heaviest burden of this tragic loss, particularly Māori and Pacific communities, and those in living in the most challenging and deprived living situations, to be better served. The Child and Youth Mortality Review Committee acknowledges all the SUDI prevention work that has been undertaken by other organisations, including the Ministry of Health. It is our hope that this report supports, strengthens and builds on that work.

### Report aims:

- To support the development of tailored SUDI prevention strategies that protect and support whānau, families and households most at risk of experiencing the death of a baby.
- To support the prevention work in this area that is already underway.
- To inform the Ministry of Health's SUDI Prevention Programme, which is being established.
- To support improved whānau and family care following the death of their baby.

### Data used in this report

This report draws on quantitative and qualitative data from the Mortality Review Database. The multidisciplinary review of a large number of SUDI deaths over a long period of time has provided a depth of information and valuable insights for understanding both the context in which these deaths are occurring and viable avenues for prevention. The report also draws on national and international literature, as well as the input of SUDI experts and other key stakeholders.

### CYMRC recommendations

#### Development of a national SUDI Prevention Programme

1. The Ministry of Health leads and enables the development of a comprehensive SUDI Prevention Programme that includes effective SUDI prevention information and support products and services that are evidence-based, and delivers equitable health outcomes for Māori and Pacific communities.
2. The Ministry of Health's SUDI Prevention Programme incorporates:
  - universal approaches that are accessible, culturally appropriate and effective for all pregnant women and their babies
  - tailored approaches for priority populations most at risk of experiencing a SUDI death, specifically Māori and Pacific mothers, mothers under 25 years of age, and mothers who smoke.
3. The Ministry of Health and DHBs fund and provide universal and targeted smokefree prevention information and support products and services that are culturally appropriate and known to be effective for Māori and Pacific women and their whānau and families. This includes interventions that:
  - discourage people from taking up smoking at all, especially during pregnancy
  - support people to stop smoking, especially during pregnancy
  - support everyone living with, or caring for, pregnant women and babies to be smokefree.
4. The Ministry of Health, in its contracts with DHBs, requires DHBs to prioritise, monitor and evaluate a SUDI Prevention Programme to ensure equitable benefits for priority population groups identified. This should include smokefree support packages and initiatives that support whānau and families to live in warmer, drier homes that are free from crowding.

## Creating supportive environments

5. The Ministry of Health works with the Ministry for Vulnerable Children, Oranga Tamariki and other relevant government agencies to promote the SUDI Prevention Programme across government. The aim is for all health, social and housing agencies and providers in contact with pregnant women, and whānau and families with babies, to provide access to effective SUDI prevention interventions that deliver equitable health outcomes. These agencies and providers should ensure whānau and families have the income and housing support they need to live in warm, dry homes that are free from crowding. Critical contact points include, but are not limited to, visits with:
  - lead maternity carers
  - Well Child/Tamariki Ora providers
  - primary care providers, especially for immunisation
  - Family Start
  - Work and Income services
  - social housing services
  - Whānau Ora providers.

## Provision of universal after-death care

6. The Ministries of Health and Justice, and the Ministry for Vulnerable Children, Oranga Tamariki, the Chief Coroner and New Zealand Police work with whānau and families to develop a multi-agency protocol for the care of whānau and families after the sudden and unexpected death of a baby. The protocol could build on existing services and should:
  - commence immediately during the first response of a SUDI investigation
  - ensure professional case management and culturally appropriate counselling and support services to support bereaved whānau and families is provided during the investigation, and for one year following the death
  - provide whānau and families with access to a paediatrician to interpret and discuss post-mortem results
  - ensure immediate notification to the lead maternity carer, Well Child/Tamariki Ora provider and general practitioner, or named primary health provider, so ongoing care and support can be provided, including any additional health care and safeguards for subsequent babies
  - prioritise timely information sharing between agencies during the investigation, including notification of death to all agencies involved with the infant to ensure whānau and families, as well as providers, are not further distressed by appointment notifications or home visits after the death of the baby.

# Introduction

In 2015, 44 babies died as a result of sudden unexpected death in infancy (SUDI). This devastating and potentially avoidable loss of life is alarming. Based on recent national data, up to 37 of these deaths could have been prevented (Mitchell et al 2017).

This report aims to:

- contribute to SUDI prevention strategies that protect and support whānau, families and households most at risk of experiencing the death of a baby
- support the prevention work in this area that is already under way
- provide information for programmes that are about to be established.

Most of all, this report highlights the need to better serve our Māori whānau and communities who bear the heaviest burden of this tragic loss, as well as those living in the most deprived areas. This report recognises that social environments play an important part in health and wellbeing. A person's social environment can limit their choices and their ability to make changes to their environment which often lie outside their control. Therefore, changes at a systems level are needed. As Marmot et al (2008) note, 'much of the high burden of illness leading to appalling premature loss of life arises because of the immediate and structural conditions in which people are born, grow, live, work, and age'.

The report is set out in two main sections. The first section provides an overview of SUDI mortality trends and prevalence, key risk factors for SUDI, demographic factors and insights from local child and youth mortality review groups. The second section looks at next steps for SUDI prevention in New Zealand and provides the rationale for the six recommendations the Child and Youth Mortality Review Committee (the CYMRC) makes in this report.

The report draws on quantitative and rich qualitative data from the Mortality Review Database, which is housed by the New Zealand Mortality Review Data Group. The qualitative data provides insightful information to inform our understanding about the context for these deaths.

The data contained in the Mortality Review Database includes:

1. **quantitative data** collected from a number of sources, including the Ministry of Health; Births, Deaths and Marriages; Coronial Services Unit and individual coroners; Child, Youth and Family; Ministry of Transport; Water Safety New Zealand; and data entered by the local child and youth mortality review group (LCYMRG) coordinator after an LCYMRG completes a death review. For this report, the Perinatal and Maternal Mortality Review Committee gave permission for SUDI cases in its age range to be included also. Therefore, all quantitative data analyses are for SUDI cases aged from birth until the first birthday, who died between 1 January 2002 and 31 December 2015
2. **qualitative data** collected from case reviews by local child and youth mortality review groups. This includes the narratives of each case which were compiled by the local coordinator, and the key issues identified and the recommendations made by the local groups.

The methods for analysing the data are described in Appendix 1.

# Section 1: What the data tells us

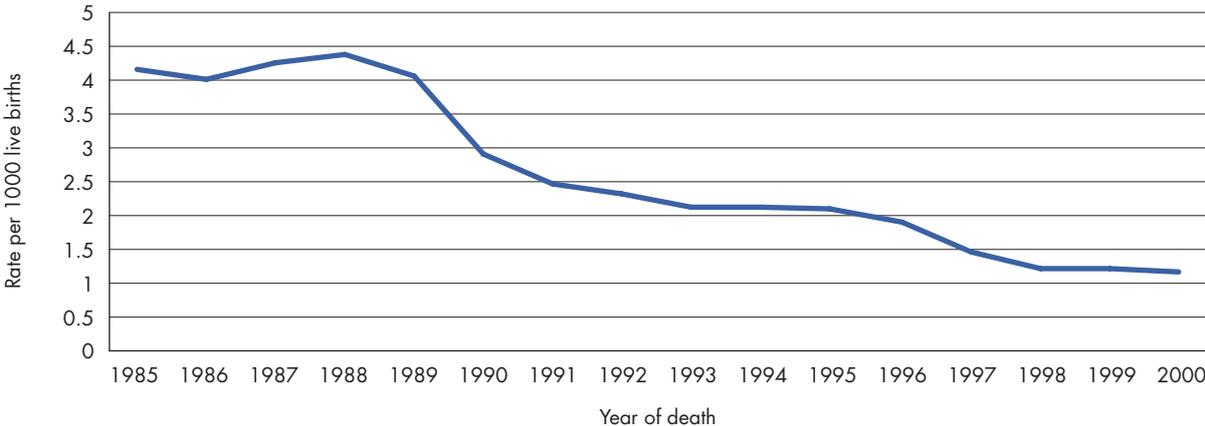
This section sets out the quantitative and qualitative data from the Mortality Review Database and from published literature.

## Overview of SUDI mortality trends and prevalence

In the 1980s, New Zealand had one of the highest rates of sudden infant death syndrome (SIDS) compared with similar countries such as the United Kingdom, United States of America, Canada and Australia. The rate (over 4 per 1000 live births) was equivalent to over 250 SIDS deaths per year (Mitchell 2014).

In response to the high SIDS rate, the New Zealand Cot Death Study (1987–90) was designed and undertaken. Preliminary results from the study identified three key factors that increased the risk of SIDS: the baby lying in a prone (front) sleep position, having a mother who smoked, and the baby not being breastfed (Mitchell et al 1991). Researchers calculated that by avoiding these three risk factors, New Zealand could reduce its SIDS rate by 79 percent (Mitchell et al 1992a). On the basis of these findings, the Ministry of Health launched a national SIDS prevention programme in 1991 that urged parents to: sleep their babies on their back or side; not to smoke; and to breastfeed (Mitchell et al 1992a). The SIDS mortality rate fell dramatically in the 1990s following this ‘Back to sleep’ campaign: from 4.4 per 1000 live births in 1988 to 2.3 per 1000 in 1992 (Mitchell et al 1994) (Figure 1).

Figure 1: SIDS mortality rate by year of death, New Zealand 1985–2000



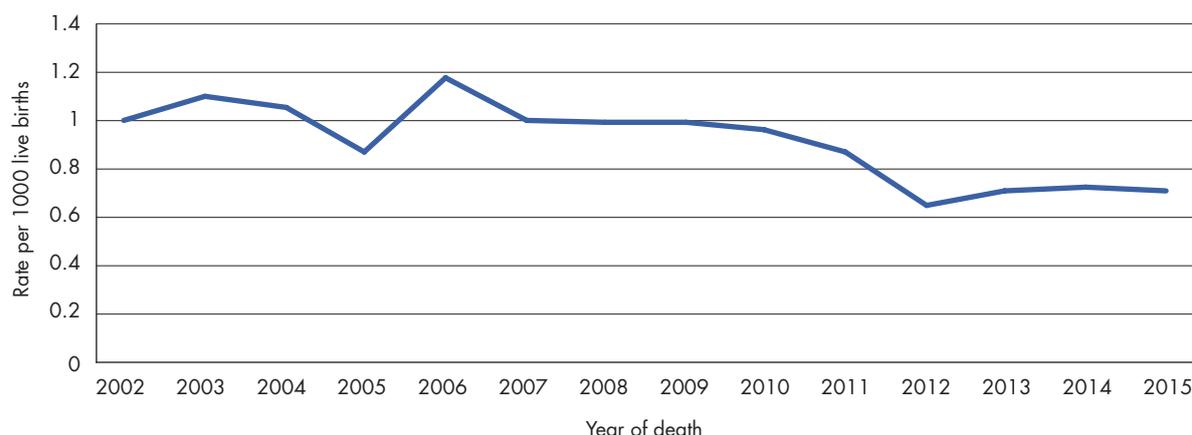
Source: Mitchell and Blair 2012.

In 1992, new data showed bed sharing increased the risk of SIDS (Mitchell et al 1992b), particularly for infants of mothers who smoked (Scragg et al 1993). This new finding was then also included in SIDS prevention advice to parents (Mitchell 2014).

Later in the 1990s the SIDS prevention advice was again updated to recommend that babies sleep on their backs only (and not their sides or fronts). Researchers considered that the change from side to back sleeping position contributed to the gradual decline in SIDS rates up until 2000 (Mitchell et al 2007).

Data from the Mortality Review Database shows that the SUDI rate for the total population for 2002 to 2015 was 0.92 per 1000 live births. The SUDI mortality rate fell between 2002 and 2015, which was statistically significant according to a test for trend (incident rate ratio (IRR) 0.97, 95% confidence interval (CI) 0.95, 0.98). Most of the decline occurred in the last five years (Figure 2).

Figure 2: SUDI mortality rate by year of death, New Zealand 2002–15



Sources:  
 Numerator: Mortality Review Database.  
 Denominator: Ministry of Health live birth registrations 2002–15.

## Inequitable reduction for Māori

Following the SIDS prevention initiatives in the 1990s, SIDS mortality did not decrease at an equitable rate for all population groups in New Zealand. Specifically, the rate of SIDS mortality in Māori babies did not fall as fast as it did for New Zealand European babies. In 1992 the SIDS rate in non-Māori was 1.6 per 1000 live births, down from 3.6 per 1000 in 1986, which is a 56 percent decrease. However, the SIDS rate in Māori in 1992 was 6.9 per 1000, compared with 7.4 per 1000 in 1986 (Mitchell et al 1994), which is a 7 percent decrease. Marked inequities for Māori and Pacific babies compared with non-Māori, non-Pacific babies persist today.

Earlier studies have looked at the higher SIDS rate in Māori (Mitchell et al 1993b). Researchers suggest that much of the increased incidence is because risk factors for SIDS are more common among Māori. In particular, Tipene-Leach et al found that for a cohort of 299 Māori women with babies, 21 percent smoked and shared the bed with the baby (Tipene-Leach et al 2010).

## Key risk factors for SUDI

While not a new finding, a recent nationwide New Zealand study has shown there are three major risk factors for SUDI that can be avoided:

1. infants sleeping on their side or front rather than on their back (supine)
2. bed sharing
3. the mother smoking in pregnancy (Mitchell et al 2017).

**Of the risk factors listed above, the combination of maternal smoking in pregnancy and bed sharing is extremely hazardous to babies. This leads to a 32-fold increased risk of SUDI compared with babies not exposed to either risk factor (Mitchell et al 2017).**

In New Zealand the main risk factors for SUDI deaths are prone (front) sleeping; and bed sharing where the mother smoked in pregnancy. Other studies have also shown breastfeeding helps to protect the baby against SIDS (Mitchell et al 1991; Ruys et al 2007; Vennemann et al 2009; Hauck et al 2011).

## Sleeping position

Sleeping position has long been identified as a key risk factor for SIDS (Beal 1988; Fleming et al 1990; Dwyer et al 1991; Mitchell et al 1991). A major reason why SIDS rates fell in the 1990s was the promotion of messages telling

parents and caregivers to place infants to sleep on their backs (Mitchell 2014). In the recent New Zealand SUDI case control study, babies who slept prone were at increased risk of SUDI (adjusted odds ratio 3.85, 95% confidence interval (CI) 1.07, 13.89) (Mitchell et al 2017).

### Smoking

Numerous studies have examined the relationship between smoking and SUDI (Mitchell et al 1993a; Mitchell and Milerad 2006; Ruys et al 2007). Mitchell et al (2017) found that, where the mother smoked during pregnancy, the risk of SUDI for the babies was six times higher (odds ratio 6.01, 95% CI 2.97, 12.15). Evidence indicates that the main risk is from antenatal smoking, rather than environmental smoke exposure after birth, although environmental smoke exposure is still a risk factor for SUDI (Mitchell and Milerad 2006). While smoking is related to other independent risk factors for SUDI, such as low birthweight, when this is controlled for, smoking remains a significant risk factor (Mitchell 1992b).

### Smoking and bed sharing

Having parents who smoke, and in particular having a mother who smoked in pregnancy, places infants at a much greater risk of SUDI when the parents also bed share. In a recent nationwide case-control study, Mitchell et al (2017) showed that babies of a mother who smoked during pregnancy and bed shared were at a 32 times greater risk of SUDI than those who neither had a mother who smoked nor bed shared (odds ratio 32.8, 95% CI 11.2, 95.8).

### Bed sharing

It is well established that bed sharing combined with smoking and alcohol and/or drug use is a risk for SUDI (Mitchell et al 1991; Blair et al 2009). However, it is less clear as to whether bed sharing remains a risk in the absence of other risk factors for SUDI, most notably, smoking. Carpenter et al (2013) and Ruys et al (2007) both found that bed sharing was a risk factor for SUDI, even when other factors had been controlled. The highest risk was for babies of younger ages (under five months), while the risk decreased with increasing age. For young babies, the risk of bed sharing was up to eight times higher.

While the increase in risk for bed sharing on its own may be much smaller than the increase in risk when it is combined with the mother’s smoking in pregnancy, no one should see bed sharing as safe or as a way of protecting babies against SUDI (Scragg et al 1995).

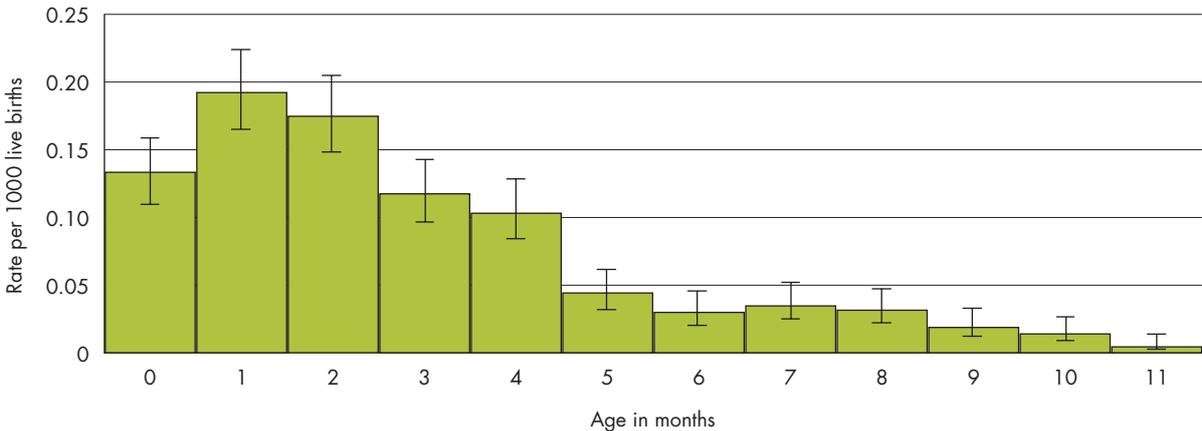
## Demographic factors

The following demographic factors are associated with an increased risk of SUDI. The data describing these demographic factors is from the Mortality Review Database.

### Infant age

Younger infants are at the highest risk of SUDI, with the peak in deaths at one month of age. Fifty-five percent of deaths occur in infants under three months of age; 80 percent occur before five months (Figure 3).

Figure 3: Age of infant at time of death, New Zealand 2002–15

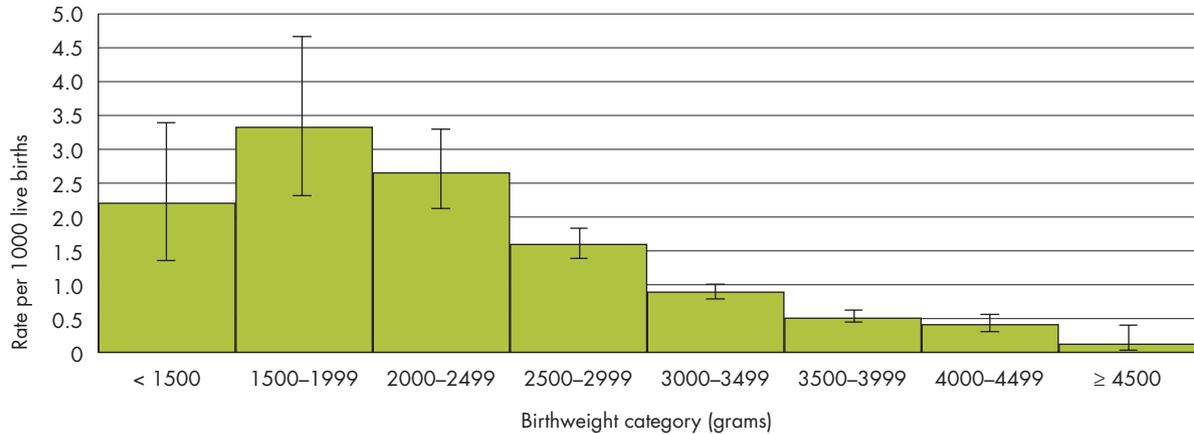


Sources:  
 Numerator: Mortality Review Database.  
 Denominator: Ministry of Health live birth registrations 2002–15.

## Infant birthweight

Infants who have a low birthweight are at a higher risk of SUDI. Infants weighing 1500–2499 g at birth have a SUDI rate that is statistically significantly higher than the rate for infants weighing 2500 g or more at birth (Figure 4).

Figure 4: Birthweight in infants dying from SUDI, New Zealand 2002–15

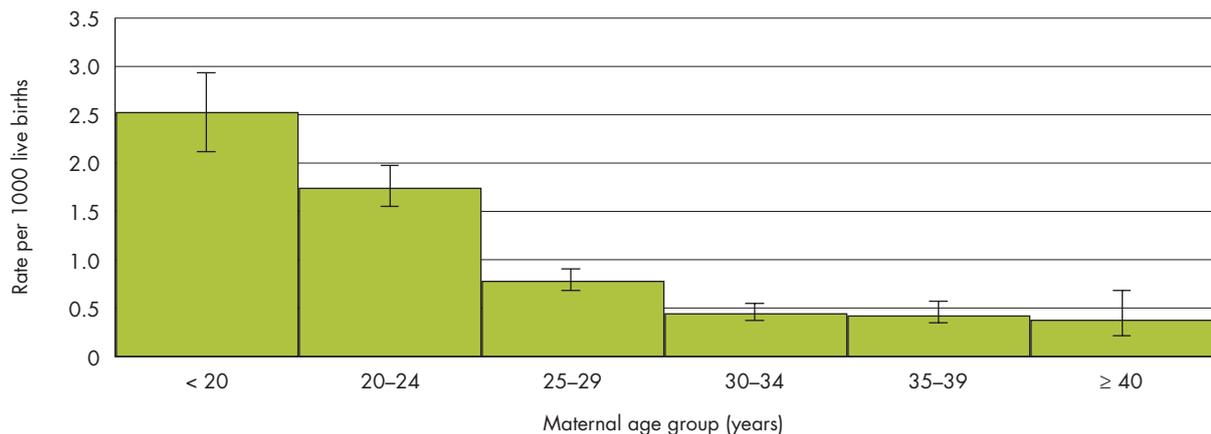


Sources:  
Numerator: Mortality Review Database.  
Denominator: Ministry of Health live birth registrations 2002–15.

## Mother's age

The infants of the youngest mothers (mothers under 20 years of age) have the highest rate of SUDI followed by those with mothers aged 20–24 years. The rate of SUDI is more than five times higher for infants of mothers who are younger than 20 years compared with infants of mothers who are aged 30–34 years (IRR 5.68, 95% CI 4.28, 7.55). Infants of mothers in the oldest age groups have the lowest risk of SUDI (Figure 5).

Figure 5: Maternal age at time of birth of infant, New Zealand 2002–15

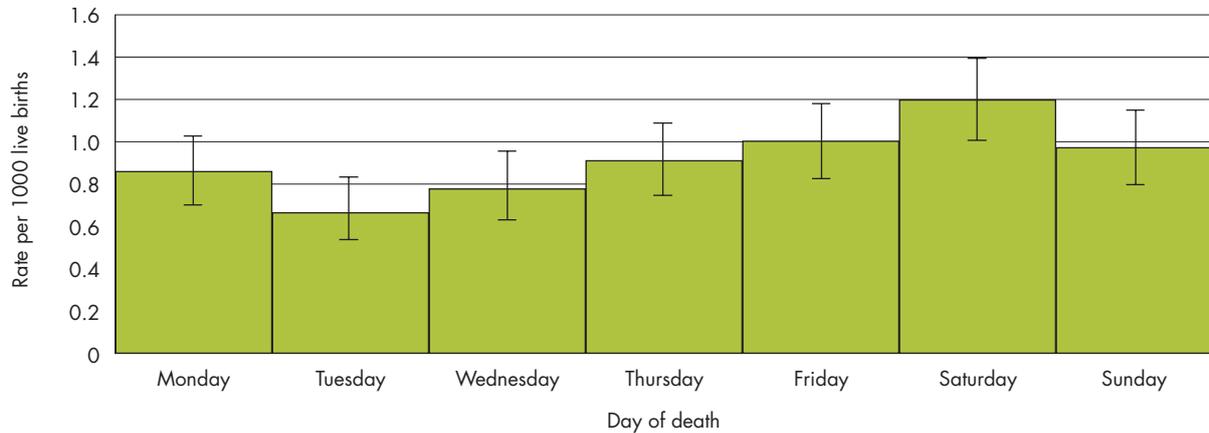


Sources:  
Numerator: Mortality Review Database.  
Denominator: Ministry of Health live birth registrations 2002–15.

## Day of the week

SUDI occurs more on weekends, particularly Saturdays. The rates are lowest on Tuesdays and Wednesdays. A 'day' is defined as from midnight to midnight, so for example, 'Saturday' deaths occurred between midnight on Friday and midnight on Saturday (Figure 6).

Figure 6: SUDI rates by day of the week, New Zealand 2002–15

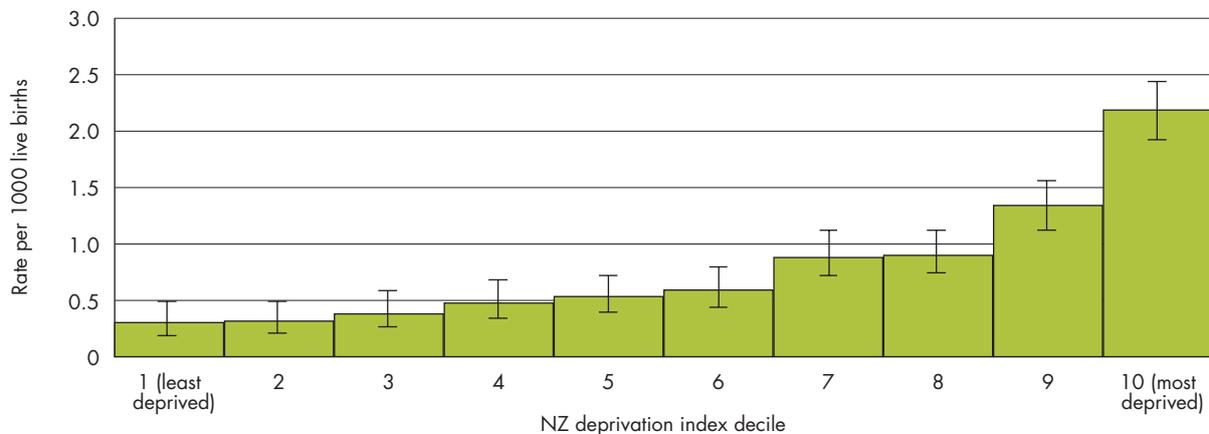


Sources:  
 Numerator: Mortality Review Database.  
 Denominator: Ministry of Health live birth registrations 2002–15.

## Socioeconomic deprivation

Infants living in more socioeconomically deprived areas have substantially higher rates of SUDI compared with those living in the least deprived areas. The SUDI rate for infants living in the most deprived areas (decile 10 on the deprivation index) was 7.05 times higher (95% CI 4.37, 11.36) than the rate for infants living in the least deprived areas (decile 1). Of all the SUDI cases, 75 percent were infants living in decile 7–10 areas (585 deaths) and 53 percent were living in the two most deprived areas (deciles 9 and 10) (408 deaths) (Figure 7). Seventy-five percent of infants who died from SUDI and who lived in the most deprived areas (deciles 9 and 10) were Māori and 17 percent were Pacific peoples.

Figure 7: SUDI mortality rate by deprivation, New Zealand 2002–15

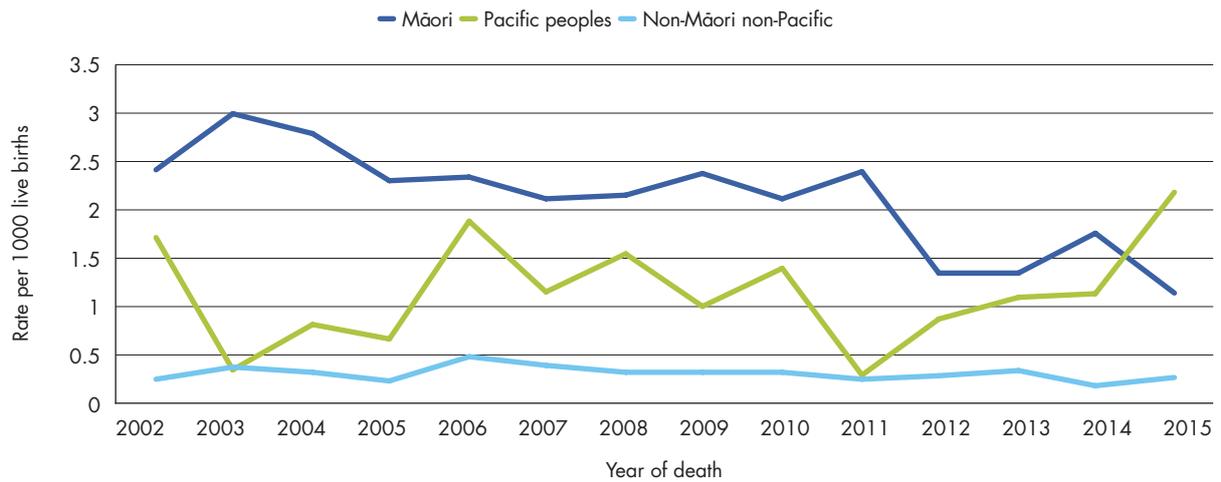


Source:  
 Numerator: Mortality Review Database.  
 Denominator: Ministry of Health live birth registrations 2002–15.

## Ethnic group

Since the 1980s, SUDI rates have decreased for all ethnic groups. However, SUDI rates continue to be much higher for Māori and Pacific babies (Figure 8). Between 2002 and 2015, the risk of dying from SUDI was nearly seven times higher for Māori infants (IRR 6.92, 95% CI 5.79, 8.29) and nearly four times higher for Pacific infants (IRR 3.77, 95% CI 2.94, 4.82) compared with non-Māori, non-Pacific infants. While the rate for Māori infants has declined from 2002, it has remained at the same level overall for Pacific infants despite some fluctuations over the study period (Figure 8). Of the 44 SUDI deaths in 2015, 20 were Māori and 14 were Pacific infants.

Figure 8: SUDI mortality rate by prioritised ethnic group, New Zealand 2002–15



Sources:  
Numerator: Mortality Review Database.  
Denominator: Ministry of Health live birth registrations 2002–15.

## Season

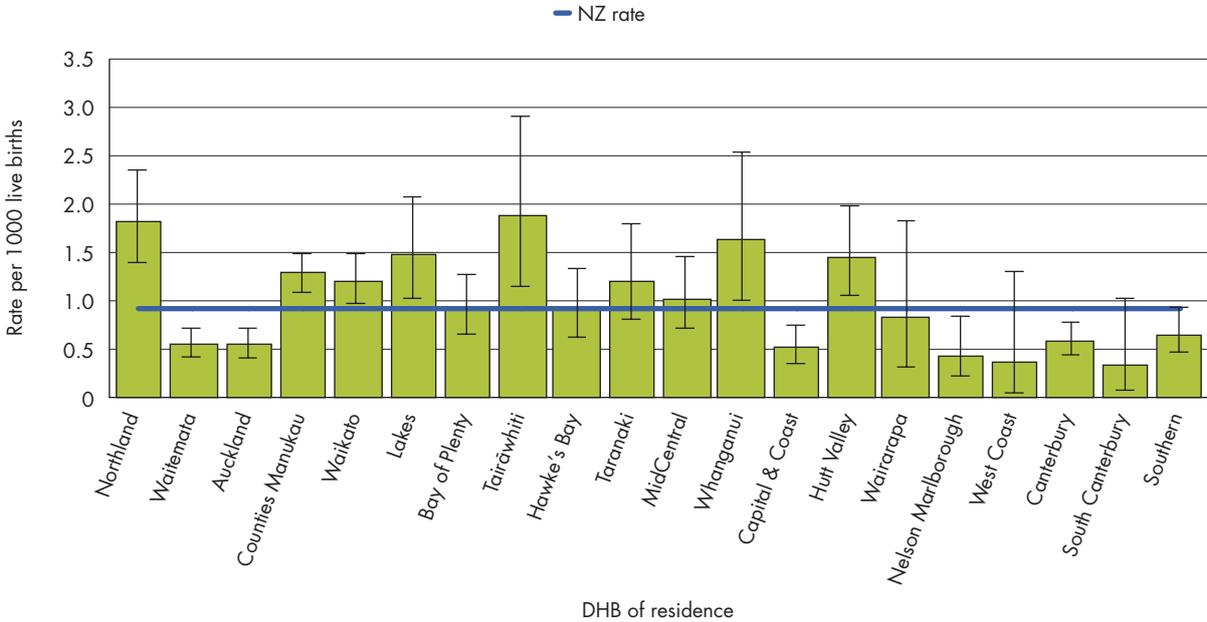
In the late 1980s, SUDI rates differed substantially by season, with the most deaths occurring in winter (Mitchell et al 1994, 1999). However, the variation between seasons has reduced. While SUDI rates from 2002–15 were slightly higher in winter and lower in summer, the differences are not statistically significant (data not shown).

### District health board of residence

SUDI mortality rates varied substantially by the district health board (DHB) area in which the infants lived. The SUDI rates in Waitemata, Auckland, Capital & Coast, Nelson Marlborough and Canterbury DHBs were all statistically significantly lower than the overall New Zealand rate. Rates were high in Northland, Counties Manukau, Waikato, Lakes, Tairāwhiti, Whanganui and Hutt Valley DHBs. Although Wairarapa, West Coast, South Canterbury and Southern DHBs had a lower SUDI rate overall, this was not statistically significant. Rates were intermediate in the other DHBs (Figure 9).

Many factors influence SUDI rates in DHBs, including service delivery and the characteristics of the population the DHB serves. An adjusted analysis of the data was undertaken to take account of some of the differences between DHB populations, such as differences in ethnic groups, levels of socioeconomic deprivation, mother’s age and birthweight. The adjusted analysis showed the rate ratios of almost all DHBs were not statistically significantly different from each other (Table 1). The exception was Hutt Valley DHB, where the rate remained higher than the other DHBs (adjusted IRR 1.80, 95% CI 1.19, 2.73,  $p = 0.006$ ).

Figure 9: SUDI mortality by DHB of residence, New Zealand 2002–15



Source:  
 Numerator: Mortality Review Database.  
 Denominator: Ministry of Health live birth registrations 2002–15.

Table 1: SUDI mortality by DHB of residence, New Zealand 2002–15, unadjusted and adjusted rates and rate ratios

DHB	Incident rate per 1000 live births (number of deaths)	IRR (95% CI)	p-value	Adjusted* IRR (95% CI)	p-value
Auckland	0.5 (49)	1		1	
Bay of Plenty	0.9 (37)	1.68 (1.10, 2.58)	0.017	0.86 (0.55, 1.33)	0.487
Canterbury	0.6 (51)	1.07 (0.72, 1.59)	0.730	1.14 (0.76, 1.70)	0.521
Capital & Coast	0.5 (28)	0.95 (0.60, 1.52)	0.842	0.86 (0.53, 1.38)	0.524
Counties Manukau	1.3 (151)	2.35 (1.70, 3.24)	< 0.001	1.24 (0.90, 1.72)	0.195
Hawke's Bay	0.9 (29)	1.68 (1.06, 2.66)	0.027	0.81 (0.51, 1.30)	0.385
Hutt Valley	1.5 (42)	2.65 (1.76, 4.01)	< 0.001	1.80 (1.19, 2.73)	0.006
Lakes	1.5 (33)	2.71 (1.74, 4.21)	< 0.001	1.13 (0.72, 1.78)	0.601
MidCentral	1.0 (32)	1.88 (1.20, 2.93)	0.006	1.14 (0.72, 1.79)	0.587
Nelson Marlborough	0.5 (10)	0.82 (0.41, 1.62)	0.564	0.86 (0.43, 1.71)	0.670
Northland	1.8 (57)	3.32 (2.27, 4.87)	< 0.001	1.38 (0.93, 2.06)	0.108
South Canterbury	0.3 (3)	0.63 (0.20, 2.02)	0.439	0.70 (0.22, 2.25)	0.546
Southern	0.7 (33)	1.21 (0.78, 1.88)	0.398	1.23 (0.79, 1.93)	0.362
Tairāwhiti	1.9 (20)	3.42 (2.03, 5.75)	< 0.001	1.14 (0.67, 1.95)	0.619
Taranaki	1.2 (26)	2.23 (1.38, 3.58)	0.001	1.52 (0.93, 2.49)	0.092
Waikato	1.2 (90)	2.20 (1.55, 3.12)	< 0.001	1.25 (0.88, 1.80)	0.216
Wairarapa	0.8 (6)	1.53 (0.66, 3.58)	0.324	1.09 (0.46, 2.56)	0.841
Waitemata	0.5 (58)	1.00 (0.68, 1.46)	0.995	1.03 (0.69, 1.51)	0.899
West Coast	0.4 (2)	0.66 (0.16, 2.70)	0.559	0.56 (0.14, 2.33)	0.429
Whanganui	1.6 (20)	2.99 (1.78, 5.03)	< 0.001	1.42 (0.84, 2.41)	0.191

IRR = incident rate ratio.

\* Adjusted for the following variables: sex, prioritised ethnic group, deprivation, maternal age, birthweight and year of death.

## Insights from the local child and youth mortality review groups

As part of their case reviews, the local child and youth mortality review groups examine how systemic factors contributed to the death and make recommendations about how to prevent similar deaths in the future. The following section provides insight into some of the living situations and challenges experienced by some whānau and families who lost a baby to SUDI, based on the rich narrative information contained in the Mortality Review Database.

### Inadequate housing

Many of the whānau and families whose baby died from SUDI were living in poor quality housing, and/or in houses with not enough space, which resulted in crowded conditions. Some whānau and families were not in settled accommodation and moved around between various living situations. This happened for a range of reasons, including unaffordable housing, intimate partner violence and fall-out with families or friends. Some whānau and families were staying with others in crowded situations, some were living in temporary or emergency accommodation, and a few were living in cars or converted garages. Many of these living situations were damp and cold, with many babies having ongoing physical health problems prior to death.

### Unsafe sleeping environments

Some whānau and families experienced SUDI when their baby was not sleeping in their usual place of sleep, and/or was staying away from their usual home. Some of these babies were also in the care of people other than their parents or usual caregiver. In many of these situations, the baby was bed sharing, sleeping in an improvised sleeping environment (for instance on couches and/or on a shared sleep surface with pillows), or sleeping in a porta cot with a poorly fitted mattress.

Unintentional bed sharing also occurred when baby was unsettled, and when the temperature in the house was cold and it was warmer in the bed with others. In other instances, baby was brought into the bed for feeding or resettling, and tired parents/caregivers fell asleep with baby still with them. Bed sharing also occurred with one or more adults, or other siblings, due to space limitations and crowding.

### Insufficient financial resources

Many whānau and family had very low incomes and lacked financial resources. This restricted not only their housing options, but also affected their ability to pay for heating, to access transport, and to purchase credit for their phones. All of these challenges were likely barriers to being able to provide a safe sleep environment for baby, and/or access services that might be able to help and provide SUDI prevention support.

Among many other things, lack of money also affected the ability of whānau and families to purchase quality bedding for their babies. Use of cheap synthetic blankets was common.

### Limited smoking cessation support

Many whānau and families smoke and it can be very hard to quit. Smoking cessation support for women who smoke in pregnancy may not take account of how the smoking behaviour of others in the household impacts on a woman's ability to quit smoking. Some women could not take up smoking cessation support in the antenatal period and postnatal period as it was not delivered or provided in a way that could be acted on.

### SUDI prevention services do not reach everyone

Some whānau and families are not reached by SUDI prevention messages and services, and may not have received safe sleep advice in a way they understood, or could implement. Some did not receive the follow-up health care they needed or had lost touch with lead maternity carers and Well Child providers.

For some, the challenge to engage with services and supports was very significant, especially for those in accommodation situations that changed often, and for those with limited or no access to transport or phones. For others, early and difficult life experiences may have negatively impacted on their knowledge about where, and how, to reach out for help for themselves and their babies (for instance, those suffering poor health, 'baby blues' or whose own caregivers had been chronically unwell or absent for any reason). Also, for those with limited health literacy where English was not their first language and/or their experience of health care services was minimal, the SUDI prevention messages were not always heard.

The following vignette is a composite story that encapsulates the experiences of many. While it is not the story of any one particular whānau or family, it provides some context to the situation many are in.

Baby (10 weeks old) usually slept in his own cot in our bedroom. That night the house was cold, the heater was not working properly and I decided to bring baby into bed with us. Baby was wrapped in his own blanket and placed to sleep on his back next to Mum. Baby was breastfed and re settled at 2.00am. I woke at 7.00am to get ready for work and noticed baby was on his side and his face was partially covered. I turned baby over and noticed he was blue... I blame myself for suggesting we bring baby into bed with us. It was so cold. I thought I was doing the right thing... We split up six months later, I couldn't stay in that house, I couldn't talk about it.

### Inconsistent after-death care

Some whānau and families have their grief exacerbated by lack of care after the sudden and unexpected death of an infant. For instance, it can be very distressing when a Well Child/Tamariki Ora provider or lead maternity carer comes to visit without any prior knowledge that the baby has died. It is similarly upsetting, for whānau and families to receive health appointment reminders for baby after their baby has died.

Whānau and families usually receive a copy of the post-mortem in the mail. Sometimes they were advised ahead of time that it had been posted, but often they had not been expecting it. Especially in the case of the latter, opening such sensitive mail can be very distressing.

Many whānau and families are not offered an opportunity to meet with a health professional who can offer support and explain the medical terminology and results. Although whānau and families may be advised to contact their GP to discuss the post-mortem, for many, cost could be seen as a barrier.

## Section 2: Next steps for SUDI prevention in New Zealand

This section discusses how SUDI can be further reduced. This is informed by the quantitative and qualitative findings from the Mortality Review Database and from published literature.

### A national SUDI Prevention Programme

The CYMRC supports the work currently under way by the Ministry of Health to lead and develop a national SUDI Prevention Programme. This programme needs to be comprehensive and include clear and consistent information about safe sleep.

A safe sleep environment is vital for every baby. Our data showed that deaths are more common during the weekend, particularly on Saturdays, and that some whānau and families have experienced SUDI when their baby was not in the care of their parents or usual caregiver and/or not staying in their usual home. This suggests the sleeping routine and environment may have been different, and one reason could be that baby was out of their normal routine. This highlights that babies need a safe sleep space for every sleep, whether they are at home or away.

The increased risk of SUDI for Māori babies, especially when the mother smokes and bed shares with her baby, underlines the need for culturally appropriate solutions to address bed sharing. This was the driver for promoting the use of wahakura, a woven flax bassinet, in 2006. Another portable safe sleep device, the Pepi-Pod<sup>®</sup>,<sup>3</sup> became available shortly after, following regional trials in 2010. Pepi-Pods<sup>®</sup> were more widely distributed immediately after the Canterbury earthquakes in 2011 to provide a safe sleep space for vulnerable babies at a time when many families were displaced from their usual environment (Cowan et al 2013). While at first there was little evidence-based research to prove the safety of devices such as these, a recent randomised controlled trial with the wahakura found that they were at least as safe as bassinets, and in addition encouraged breastfeeding (Baddock et al 2017). These sleep devices allow the baby to have their own sleeping space, while supporting cultural values of bed sharing for Māori and Pacific communities.

Now that evidence-based safe sleep devices, such as the wahakura, are available, it is possible for babies to be in their usual and safe bed for every sleep, even when away from home. However, other people who are looking after babies also need to be familiar with safe sleep practices. Babies are especially at risk in unfamiliar positions and it can be easy for an inexperienced caregiver to place a baby to sleep in an unsafe position, such as prone (on their front). Local review groups felt it is imperative that safe sleep messages reach every new generation of mothers, their fathers, whānau and families and friends, and especially those living in very challenging or deprived situations who may find it more difficult to provide a safe sleep space for their baby.

The Ministry of Health has been very active in promoting safe sleep messages and environments and this work now needs to be extended to reach more mothers, families and whānau. A national SUDI Prevention Programme is currently being developed by the Ministry of Health and the CYMRC supports this work.

#### Recommendation 1:

The Ministry of Health leads and enables the development of a comprehensive SUDI Prevention Programme that includes effective SUDI prevention information and support products and services that are evidence-based, and delivers equitable health outcomes for Māori and Pacific communities.

<sup>3</sup> A Pepi-Pod<sup>®</sup> is a plastic box with a well-fitting mattress in the bottom. As well as the sleep space, these devices are always provided with safe sleep messaging.

## Universal and tailored approaches

There has been good progress in reducing these preventable deaths since the early 1990s when the SUDI rates were high. However, the New Zealand rate remains high compared with similar countries, and interventions to date have generally only been effective for some groups within the population. The data clearly shows that Māori, Pacific peoples, mothers under 25 years of age and people living in deprived neighbourhoods are much more likely to experience the loss of a baby to SUDI (CYMRC 2009). The CYMRC considers these population groups must be prioritised so that they experience equitable outcomes from SUDI prevention services.

Current service delivery models in SUDI prevention are not effective for all whānau and families in New Zealand. Agencies and services need to change the way they provide safe sleep messaging so that all whānau and families benefit equitably from safe sleep recommendations. In addition, for health services that have contact with pregnant and/or young mothers, it should become required practice to:

- carry out a socioecological health needs assessment of each baby and mother that takes account of the person's wider environment (individual, interpersonal, organisational, community and policy levels [CDC 2017b])
- refer babies and mothers to the relevant services when the assessments identify needs, including referring young mothers to education providers approved by the Ministry of Education.

Overall, the number of Māori babies dying from SUDI is decreasing, which suggests that current prevention efforts are having an impact. However, as most babies dying from SUDI are Māori (66 percent of all deaths between 2002 and 2015), prevention efforts must do more for Māori whānau and communities. If we are to achieve equitable outcomes for Māori, we must develop prevention efforts that meet the needs of Māori.

Of concern is the SUDI rate for Pacific babies, which is four times higher than the rate for non-Māori non-Pacific infants. In addition, the Pacific rate has not changed over the study period, despite declining rates in other groups. Culturally appropriate interventions are needed for Pacific communities.

### Recommendation 2:

The Ministry of Health's SUDI Prevention Programme incorporates:

- universal approaches that are accessible, culturally appropriate and effective for all pregnant women and their babies
- tailored approaches for priority populations most at risk of experiencing a SUDI death, specifically Māori and Pacific mothers, mothers under 25 years of age, and mothers who smoke.

## Universal and tailored smoking prevention and cessation products and services

Pregnancy is a time when women's motivation to quit smoking can be high (DiClemente et al 2000) and when they can be more receptive to messages to stop smoking (McBride et al 2003). Studies have shown a number of interventions have helped women to stop smoking in pregnancy (Chamberlain et al 2017). Some women manage to quit spontaneously but they are likely to have smoked less than other smokers, be less seriously addicted, have a non-smoking partner and have more support at home to quit (Chamberlain et al 2017). However, relapse rates after giving birth can be high (DiClemente et al 2000).

Glover and Kira (2011) examined barriers for New Zealand women to quit smoking while they are pregnant. They found that while many pregnant women were highly motivated to quit smoking, it was difficult for them to actually quit, in part because all of the pregnant women in the study lived with another smoker. In addition, a high proportion of the women's friends and work colleagues smoked. Where smoking is the norm for everyone in the household, changing this behaviour is really difficult. Other studies have also found the partner's smoking status is influential (DiClemente et al 2000). While the focus may be on quitting smoking in pregnancy, the decision makers (eg, government, DHBs) need to take account of the environment in which people live and work, and support a

community focus on quitting smoking. In keeping with New Zealand's aim of becoming Smokefree Aotearoa 2025, the ultimate aim is to prevent people, particularly young females, from taking up smoking at all.

The evidence that Māori and Pacific peoples under-use services indicates that current service delivery models are not sufficiently effective. Services need to offer sensitive, culturally competent, health-literate and appropriate smoking cessation resources and supports that are consistent with cultural beliefs, values and practices of whānau and families.

To be an effective channel for preventing SUDI, antenatal care and smoking cessation services must change their service delivery model to give equitable access to smoking cessation resources and supports to Māori women, Pacific women and young women, and their whānau and families. Simply providing information is a poor tool for making sustained changes to behaviour (WHO Europe 2008). Abel and Tipene-Leach (2013) noted the limited success of smoking cessation programmes among Māori pregnant women, who still have high rates of smoking. They argue that 'pervasive marketing of tobacco alongside the difficulties of dealing with smoking addiction in poorly resourced communities have made progress in this area very challenging'.

The Māori SIDS Prevention Programme recognised that it was very difficult for those living in stressful and deprived environments to quit smoking. To support people to quit smoking and reduce bed sharing, the providers delivered a message about creating smokefree environments for babies. They also saw bed sharing and cigarette smoking as sensitive issues, which were 'dealt with at a personal and whānau level by the workers, within a relationship of respect and trust' (Tipene-Leach et al 2010).

### Recommendation 3:

The Ministry of Health and DHBs fund and provide universal and targeted smokefree prevention information and support products and services that are culturally appropriate and known to be effective for Māori and Pacific women and their whānau and families. This includes interventions that:

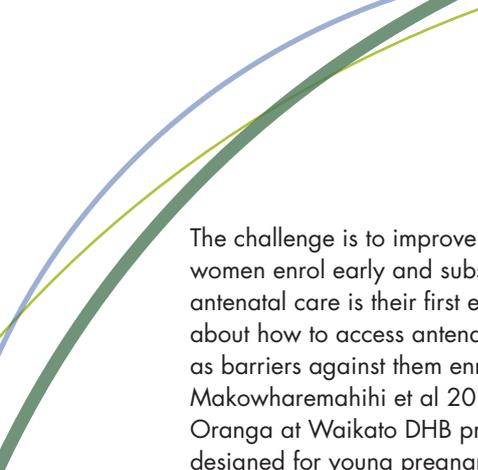
- discourage people from taking up smoking at all, especially during pregnancy
- support people to stop smoking, especially during pregnancy
- support everyone living with, or caring for, pregnant women and babies to be smokefree.

## The SUDI Prevention Programme must be prioritised, monitored and evaluated by DHBs

According to the New Zealand Public Health and Disability Act 2000, DHBs are responsible for, among other things, improving, promoting and protecting the health of people and communities. They are also responsible for reducing health disparities by improving health outcomes for Māori and other population groups, and reducing – with a view toward eliminating – health outcome disparities between various population groups.

Given the peak age for SUDI is one to two months and 80 percent of cases occur before the baby is five months of age, it is important to deliver safe sleep messages before birth and as early as possible after birth to mothers of all ages. While whānau and families can have contact with many different professionals for care both during pregnancy and immediately after birth, and during the first 12 months of the baby's life, such contact is most intense around the time the baby is born. It is therefore critical to have safe sleep policies and processes and adequate training for all involved in DHB maternity services.

Access to antenatal care is also very important. When a pregnant woman enrolls early with a lead maternity carer, health providers gain useful opportunities to help reduce the risk of SUDI in the unborn child by supporting her to quit smoking, if required, and promote healthy behaviours. Lead maternity carers can also raise the mother's awareness of safe sleep practices and connect her with other agencies and programmes.



The challenge is to improve the way that providers engage with women and provide their services so that pregnant women enrol early and subsequently experience better health outcomes. For many young pregnant women, antenatal care is their first experience of primary health care without their parents. Young women can feel confused about how to access antenatal care and may feel care providers are judging them. These experiences can act as barriers against them enrolling early with midwives and attending appointments (Pacific Perspectives 2013; Makowharemahihi et al 2014). Services need to trial and evaluate other service models. For example, Te Puna Oranga at Waikato DHB provides Hapu Wānanga, a kaupapa Māori labour, birth and parenting programme designed for young pregnant women and their whānau and families (Waikato DHB 2017).

The New Zealand Health Strategy (Minister of Health 2016) notes that the health system struggles to 'give all New Zealanders equitable access to health services: some population groups continue to benefit less from the health system than the population as a whole'. Too often, the responsibility for accessing health care services is placed on individuals – and particularly on Māori and Pacific peoples, who experience lower levels of service access than the population as a whole. Māori and Pacific peoples are also among those who receive lesser quality of care from health services, including antenatal, postnatal and Well Child/Tamariki Ora services (Pacific Perspectives 2013; Ratima and Crengle 2013; Makowharemahihi et al 2014; Houkamau and Clarke 2016). Currently, because the main time for providing safe sleep messages is when people are interacting with health care services, Māori and Pacific whānau and families may be less likely to receive safe sleep messages. By improving and tailoring SUDI prevention initiatives, we can better meet the health needs and aspirations of Māori and Pacific peoples.

Safe sleep initiatives need to be run by and for the communities who are at risk. It is also important that they:

- use Te Ao Māori and Whānau Ora approaches and engage with diverse Pacific families (within this group of 'Pacific peoples' in New Zealand are many ethnicities, each with their own culture, language, history and practices)
- collaborate with organisations that can effectively communicate with Māori, Pacific peoples and young mothers, and their whānau and families (which includes considering content, language, style, mode and timing of communication)
- broaden the range of modes of delivery for safe sleep messages (for example, using mobile phones; kanohi ki te kanohi (face-to-face) interaction with trusted providers) and distribution of safe sleep devices
- monitor the effectiveness of communication with Māori, Pacific peoples and young mothers and adjust approaches accordingly
- identify a range of avenues, other than health care services, for delivering safe sleep messages and devices to achieve equitable outcomes for Māori, Pacific peoples and young mothers, and their whānau and families.

#### **Recommendation 4:**

The Ministry of Health, in its contracts with DHBs, requires DHBs to prioritise, monitor and evaluate a SUDI Prevention Programme to ensure equitable benefits for priority population groups identified. This should include smokefree support packages and initiatives that support whānau and families to live in warmer, drier homes that are free from crowding.

The following case study is an example of a DHB initiative that uses the process of weaving a wahakura (bassinet), which the pēpē (baby) will sleep in, to teach Māori hapū māmā (pregnant mothers) key safe sleep messages.

## An approach to sharing safe sleep messages with hapū māmā and whānau

Te Aka Oranga Waikawa Wahakura Wānanga is a one-day programme that uses the process of weaving a wahakura (bassinet), which the pēpē (baby) will sleep in, to teach Māori hapū māmā (pregnant mothers) key safe sleep messages.

Our aim is to reduce the rates for SUDI for Māori to align with non-Māori rates, and to develop a programme that would help spread Safe Sleep messages throughout Māori and wider communities (Waitemata DHB 2017).

This programme involves a partnership between the master weavers and Māori hapū māmā. Harakeke (flax) is harvested and prepared the day before the workshop as hapū māmā are tapu (sacred) and not allowed to harvest. During the weaving, master weavers from the community (in partnership with He Kamaka Waiora, Māori Health Services) share safe sleep messages with Māori hapū māmā around smoking, breastfeeding and safe sleep practices. They also give them supporting resources to promote safety messages. The hapū māmā then take the wahakura home as a safe sleeping space for pēpē and as a reminder of the safe sleep practices discussed during the programme.

[T]he mamas who attend the programme have a responsibility to pass on the Safe Sleep strategies to their wider whānau and friends so that the fingers of knowledge can spread wider into the community (Waitemata DHB 2017).

Comments from a Māori hapū māmā reflect the holistic nature of the programme.

The whole process of making the waikawa wahakura, it was an awesome bonding and healing time. Like just how we were weaving the flax together, we were able to mend the broken harakeke spiritually within ourselves ... For myself and my mum to complete the wahakura was just awesome and to be able to take it home as well (Waitemata DHB 2017).

Waitemata DHB has reported participants are highly engaged in Te Aka Oranga Waikawa Wahakura Wānanga and give positive feedback about it.

The wahakura are being well used by the participants, and the appealing traditional design is a talking point for families. This enables the Safe Sleep messages to be shared more openly in the community (Waitemata DHB 2017).

Waitemata DHB is now looking at how community partners could provide the programme to local communities.

## Supportive physical environments

The environment people live in and the social and economic circumstances that shape their lives all have an impact on people's capacity to experience health and wellbeing. The Māori concept of wai ora recognises that the environments in which we live have a significant impact on the health and wellbeing of individuals, whānau and communities (Ministry of Health nd).

This report clearly shows that babies living in the most deprived areas have a much higher SUDI rate than those living in the least deprived areas. The local review groups noted that many of the whānau and families whose baby died from SUDI were living in poverty and in substandard houses that were damp and cold, and many babies had ongoing physical health problems before death. For whānau and families living in unsettled, crowded and substandard conditions, it is challenging to provide a safe sleep space for their babies.

McManus et al (2010) highlight that SUDI prevention efforts have turned attention away from the sociocultural, economic, historical and political causes of hardship, and that public health programmes to prevent SUDI have

been very successful where social and economic hardship is not an issue. They advocate for an approach to prevent SUDI by targeting whānau and families who are experiencing socioeconomic deprivation and building on a social determinants of health framework to achieve health equity.

We need to acknowledge the complexity of people's lives and the impact that deprivation can have on reducing access to adequate housing, heating and smoking cessation. These factors limit or remove people's choices and expose them to increased risk. The challenge is to adjust our prevention approach and tackle the social and environmental factors that make it difficult for some whānau and families to achieve health and wellbeing, including protecting their babies from SUDI. Many of the cases examined by the LCYMRGs had been living in neighbourhoods with the greatest socioeconomic deprivation (deciles 7–10), where crowding, housing insecurity and poor-quality, cold, damp homes are more common.

More interagency collaboration, as happens between DHBs and Housing New Zealand in some areas, is needed to address the wider influences on health. Programmes that provide a 'wrap-around' service, such as Family Start, have the potential to improve outcomes, and should be supported and evaluated. Additionally, the new Ministry for Vulnerable Children: Oranga Tamariki has a significant role to play in supporting SUDI prevention initiatives to deliver equitable outcomes for all babies and their whānau and families in New Zealand.

Some healthy housing projects are operating, such as the Healthy Housing Project, the Snug Homes Project (both in Counties Manukau), and the Manawa Ora Healthy Homes initiative which supports tamariki and whānau to live in warmer, drier, healthier homes by providing insulation, heating, bedding, curtains, carpets, ventilation and/or education (Manaia Health PHO nd). The following case study shows that some providers offer an integrated and holistic approach.

### Recommendation 5:

The Ministry of Health works with the Ministry for Vulnerable Children, Oranga Tamariki and other relevant government agencies to promote the SUDI Prevention Programme across government. The aim is for all health, social and housing agencies and providers in contact with pregnant women, and whānau and families with babies, to provide access to effective SUDI prevention interventions that deliver equitable health outcomes. These agencies and providers should ensure whānau and families have the income and housing support they need to live in warm, dry homes that are free from crowding. Critical contact points include, but are not limited to, visits with:

- lead maternity carers
- Well Child/Tamariki Ora providers
- primary care providers, especially for immunisation
- Family Start
- Work and Income services
- social housing services
- Whānau Ora providers.

## Kia Puawai – Western Heights Child Health Programme (Tipu Ora)

Tipu Ora focuses on the health and wellbeing needs of children, their whānau and their extended whānau and provides a wide range of primary health, social and education services accessible to all people living in the Rotorua area. It has an integrated approach to its service delivery to its clients. This means that clients receive a continuum of care, according to their needs, over time and across a range of Tipu Ora's services. Some of its services are: Family Start; Parents as First Teachers; Aukati KaiPaipa Smoking Cessation; Well Child/Tamariki Ora; Startwell Service; and Kia Puawai.

The free Kia Puawai – Western Heights Child Health Programme delivers primary maternity care, early parenting and well child health services targeting families living in the western suburbs of Rotorua. Its aim is to develop healthy attachment and bonding between the child and their parents/caregivers, recognising that the first relationship for a baby is the cornerstone to future long-term wellbeing.

The focus of this programme is on early identification and intervention, and investing in children and their whānau during the most formative times (antenatal and in the first year of life). A team – consisting of midwife, registered nurse, Kaitiaki (community support worker) and Āhuru Mōwai born to learn educators – helps people throughout the programme.

The approach is an all-encompassing, holistic, Māori approach to early identification, prevention and intervention to benefit (mostly) Māori babies – before birth and as newborns – and their whānau.

For more information, go to: [www.tipuora.org.nz/western-heights-child-health-program](http://www.tipuora.org.nz/western-heights-child-health-program)

## Improved care and investigation after the death of a baby

Effective care for families after a baby dies from SUDI relies largely on the capability and capacity of the responding service to deliver compassionate, culturally appropriate services to whānau and families during and after the SUDI investigation. Edwards et al (2009) argue that the death of a baby is one of the most tragic events that can affect a family, particularly when the death is sudden and unexplained and there is no obvious cause at the time it happens.

For Māori, 'the trauma is amplified by an insensitive and intrusive statutory investigative process that ignores Māori grieving rituals and cultural restrictions around the body delays the expected grieving process' (Edwards et al 2009, p 130). In their study, Edwards et al (2009) conducted in-depth interviews with nine Māori men who offer poignant narratives about their experiences following the death of their baby from SUDI. We include the following narratives from their study from two different whānau to help people understand the trauma, chaos and burden of doubt about cause of death that can confront whānau and families.

We were getting questioned a lot by the police. They came and were interviewing me and my wife. We weren't really in the right frame of mind when they were questioning us, we were answering them. When he was having his autopsy, we got interviewed by the police for hours. Straight after he had died the ambulance turned up. Not long after the police were questioning us straight after he'd died, they wouldn't let us go with him. They kept us back at the house; they thought we had done it intentionally. We didn't even know how he had died. It felt like they were pointing the finger at us. Like we had done it on purpose.

Before we knew it we had 20 or so people. I didn't even know who they were. We had a guy from a funeral home parked in our driveway waiting outside, there were about four or five cops outside, detective wanting to do interviews, it just all happened at once. There is family, of course. The whole place was bombarded with people.

After a baby dies from SUDI, families need support from a range of service providers working across different sectors. Professionals need education and training to respond appropriately so they can deliver services that are sensitive, culturally appropriate, coordinated and timely. It is important that support is provided to mothers, whānau and families after the death of their baby. Mothers who have previously had an infant death, should also receive additional support with subsequent pregnancies and babies.

To deliver coordinated, timely and culturally appropriate services after the death of a baby from SUDI, we also need a multi-agency protocol for caring for whānau and families and investigating SUDI. This protocol should cover the first response following a SUDI. It should include the investigation, coroner, pathologist, medical practitioner, spiritual advisors and funeral directors to ensure bereaved families receive professional case management, culturally appropriate counselling and support services.

Local review groups report that in many cases a lack of after-death care makes the grief of suddenly losing a baby even worse but note there are a number of ways to improve this situation. For instance, it is helpful if service providers send appropriate information to the pathologist in a timely manner, and whānau and families have the opportunity to meet with an appropriate medical expert to explain the post-mortem results and connect them with support services. Such support services include culturally appropriate grief counselling and maternal mental health services if the mother becomes pregnant in the future. Local review groups also considered it important to notify all health and social service providers involved with the whānau or family of the baby's death. These providers could then avoid sending recall letters or making home visits that add to the grief and intrusion. The review groups also noted that providers should have systems to identify people who have previously suffered an infant death. For example, a mother's file should have an alert if she has experienced an infant death to indicate that providers should offer her additional support.

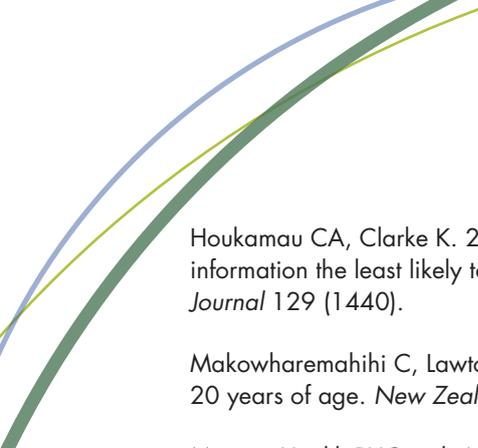
### Recommendation 6:

The Ministries of Health and Justice, and the Ministry for Vulnerable Children, Oranga Tamariki, the Chief Coroner and New Zealand Police work with whānau and families to develop a multi-agency protocol for the care of whānau and families after the sudden and unexpected death of a baby. The protocol could build on existing services and should:

- commence immediately during the first response of a SUDI investigation
- ensure professional case management and culturally appropriate counselling and support services to support bereaved whānau and families is provided during the investigation, and for one year following the death
- provide whānau and families with access to a paediatrician to interpret and discuss post-mortem results
- ensure immediate notification to the lead maternity carer, Well Child/Tamariki Ora provider and general practitioner, or named primary health provider, so ongoing care and support can be provided, including any additional health care and safeguards for subsequent babies
- prioritise timely information sharing between agencies during the investigation, including notification of death to all agencies involved with the infant to ensure whānau and families, as well as providers, are not further distressed by appointment notifications or home visits after the death of the baby.

## References

- Abel S, Tipene-Leach D. 2013. SUDI prevention: a review of Māori Safe Sleep innovations for infants. *New Zealand Medical Journal* 126(1379): 86–94.
- Baddock SA, Tipene-Leach D, Williams S, et al. 2017. Wahakura versus bassinet for safe infant sleep: a randomised trial. *Pediatrics* 139(2): e20160162.
- Beal S. 1988. Sleeping position and SIDS. *Lancet* 2: 512.
- Blair PS, Sidebotham P, Evason-Coombe C, et al 2009. Hazardous cosleeping environments and risk factors amenable to change: case-control study of SIDS in South west England. *British Medical Journal* 339:b3666. DOI: 10.1136/bmj.b3666.
- Carpenter R, McGarvey C, Mitchell EA, et al. 2013. Bed sharing when parents do not smoke: is there a risk of SIDS? An individual level analysis of five major case-control studies. *British Medical Journal Open* 3: e002299. DOI: 10.1136/bmjopen-2012-002299 (accessed 17 May 2012).
- CDC. 2017a. About SUID and SIDS. Centers for Disease Control and Prevention. URL: [www.cdc.gov/sids/aboutsuidandsids.htm](http://www.cdc.gov/sids/aboutsuidandsids.htm) (accessed 8 March 2017).
- CDC. 2017b. Social ecological model. Centers for Disease Control and Prevention. URL: [www.cdc.gov/cancer/crccp/sem.htm](http://www.cdc.gov/cancer/crccp/sem.htm) (accessed 2 June 2017).
- Chamberlain C, O'Mara-Eves A, Porter J, et al. 2017. Psychosocial interventions for supporting women to stop smoking in pregnancy. *Cochrane Database of Systematic Reviews* 2. Art no.: CD001055. DOI: 10.1002/14651858.CD001055 (accessed 13 May 2017).
- Cowan S, Bennett S, Clarke J, et al. 2013. An evaluation of portable sleeping spaces for babies following the Christchurch earthquake of February 2011. *Journal of Paediatrics and Child Health* 49(5): 364–8.
- CYMRC. 2009. *Fifth Report to the Minister of Health: Reporting mortality 2002–2008*. Wellington: Child and Youth Mortality Review Committee, Te Rōpū Arotake Auau Mate o te Hunga Tamariki, Taiohi.
- CYMRC. 2013. *Special Report: Unintentional suffocation, foreign body inhalation and strangulation*. Wellington: Child and Youth Mortality Review Committee, Te Rōpū Arotake Auau Mate o te Hunga Tamariki, Taiohi.
- DiClemente CC, Dolan-Mullen P, Windsor RA. 2000. The process of pregnancy smoking cessation: implications for interventions. *Tobacco Control* 9(Suppl III): iii16-iii21.
- Dwyer T, Ponsonby A-LB, Newman NM, et al. 1991. Prospective cohort study of prone sleeping position and sudden infant death syndrome. *Lancet* 337: 1244–7.
- Edwards S, McCreanor T, Ormsby M, et al. 2009. Māori men and the grief of SIDS. *Death Studies* 33(2): 130–52. DOI: 10.1080/07481180802602774 (accessed 13 May 2017).
- Fleming PJ, Gilbert R, Azaz Y, et al. 1990. Interaction between bedding and sleeping position in the sudden infant death syndrome: a population based case-control study. *British Medical Journal* 301: 85–9.
- Glover M, Kira A. 2011. Why Māori women continue to smoke while pregnant. *New Zealand Medical Journal* 124(1339): 22–31.
- Hauck FR, Thompson JMD, Tanabe KO, et al. 2011. Breastfeeding and reduced risk of sudden infant death syndrome: a meta-analysis. *Pediatrics* 128(1): 101–10.
- Health Quality & Safety Commission. 2016. *Open4Results*. Wellington: Health Quality & Safety Commission. URL: [www.hqsc.govt.nz/assets/Health-Quality-Evaluation/PR/Open4Results-Oct-2016.pdf](http://www.hqsc.govt.nz/assets/Health-Quality-Evaluation/PR/Open4Results-Oct-2016.pdf) (accessed 3 November 2016).



Houkamau CA, Clarke K. 2016. Why are those most in need of sudden unexplained infant death (SUDI) prevention information the least likely to receive it? A comment on unconscious bias and Māori health. *New Zealand Medical Journal* 129 (1440).

Makowharemahihi C, Lawton BA, Cram F, et al. 2014. Initiation of maternity care for young Māori women under 20 years of age. *New Zealand Medical Journal* 127(1393).

Manaia Health PHO. nd. *Manawa Ora: Healthy home initiative*. URL: [www.manaiaapho.co.nz/ManawaOra](http://www.manaiaapho.co.nz/ManawaOra) (accessed 10 April 2017).

Marmot M, Friel S, Bell R, et al. 2008. Closing the gap in a generation: health equity through action on the social determinants of health. *Lancet* 372: 1661–9.

McBride CM, Emmons KM, Lipkus IM. 2003. Understanding the potential of teachable moments: the case of smoking cessation. *Health Education Research* 18(2): 156–70.

McManus V, Abel S, McCreanor T, et al. 2010. Narratives of deprivation: women's life stories around Māori sudden infant death syndrome. *Social Science & Medicine* 71: 643–9.

Minister of Health. 2016. *New Zealand Health Strategy: Future direction*. Wellington: Ministry of Health.

Ministry of Health. nd. *He Korowai Oranga, the Māori Health Strategy*. Wellington: Ministry of Health. URL: [www.health.govt.nz/our-work/populations/ma-ori-health/he-korowai-oranga](http://www.health.govt.nz/our-work/populations/ma-ori-health/he-korowai-oranga) (accessed 15 May 2017).

Mitchell EA. 2014. Howard Williams oration: Preventing the unpreventable: the 'cot death' story. *Journal of Paediatrics and Child Health* 50: 855–60.

Mitchell EA, Blair PS. 2012. SIDS prevention: 3000 lives saved but we can do better. *New Zealand Medical Journal* 125(1359): 50–7.

Mitchell EA, Milerad J. 2006. Smoking and the sudden infant death syndrome. *Reviews on Environmental Health* 21(2): 81–103.

Mitchell EA, Scragg R, Stewart AW, et al. 1991. Results from the first year of the New Zealand cot death study. *New Zealand Medical Journal* 104(906): 71–6.

Mitchell EA, Aley P, Eastwood J. 1992a. The national cot death prevention program in New Zealand. *Australian Journal of Public Health* 16(2): 158–61.

Mitchell EA, Taylor BJ, Ford RPK, et al. 1992b. Four modifiable and other major risk factors for cot death: the New Zealand Study. *Journal of Pediatrics and Child Health* 28(Suppl 1): S3–8.

Mitchell EA, Ford RPK, Stewart AW, et al. 1993a. Smoking and the sudden infant death syndrome. *Pediatrics* 91: 893.

Mitchell EA, Stewart AW, Scragg R, et al. 1993b. Ethnic differences in mortality from sudden infant death syndrome in New Zealand. *British Medical Journal* 306: 13–6.

Mitchell EA, Brunt JM, Everard C. 1994. Reduction in mortality from sudden infant death syndrome in New Zealand: 1986–92. *Archives of Disease in Childhood* 70: 291–4.

Mitchell EA, Clements M, Williams SM, et al. 1999. Seasonal differences in risk factors for the sudden infant death syndrome. *Acta Paediatrica* 88: 253–8.

Mitchell EA, Hutchison L, Stewart AW. 2007. The continuing decline in SIDS mortality. *Archives of Disease in Childhood* 92: 225–6.

Mitchell EA, Cowan S, Tipene-Leach D. 2016. The recent fall in post-perinatal mortality in New Zealand and the Safe Sleep Programme. *Acta Paediatrica* (online).

- Mitchell EA, Thompson JM, Zucullo J, et al. 2017. 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. *New Zealand Medical Journal* 130(1456): 52–64.
- Pacific Perspectives Ltd. 2013. *Maternity Care Experiences of Teen, Young, Māori Pacific and Vulnerable Mothers at Counties Manukau Health*. Wellington: Pacific Perspectives. URL: [www.countiesmanukau.health.nz/assets/About-CMH/Reports-and-planning/Maternity/2013-CMH-maternity-care-experiences-of-teens.pdf](http://www.countiesmanukau.health.nz/assets/About-CMH/Reports-and-planning/Maternity/2013-CMH-maternity-care-experiences-of-teens.pdf) (accessed 13 May 2017).
- Ratima M, Crengle S. 2013. Antenatal, labour, and delivery care for Māori: experiences, location within a lifecourse approach, and knowledge gaps. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health* 10(3): 353–66.
- Ruys JH, de Jonge GA, Brand R, et al. 2007. Bed-sharing in the first four months of life: a risk factor for sudden infant death. *Acta Paediatrica* 96(10): 1399–403.
- Salmond C, Crampton P, Atkinson J. 2007. *NZDep2006 Index of Deprivation*. Wellington: Department of Public Health, University of Otago.
- Scragg R, Mitchell EA, Taylor BJ, et al. 1993. Bed sharing, smoking, and alcohol in the sudden infant death syndrome. *British Medical Journal* 307: 1312–8.
- Scragg R, Stewart AW, Mitchell EA, et al. 1995. Public health policy on bed sharing and smoking in the sudden infant death syndrome. *New Zealand Medical Journal* 108(1001): 218–22.
- Tipene-Leach D, Hutchison L, Tangiora A, et al. 2010. SIDS-related knowledge and infant care practices among Māori mothers. *New Zealand Medical Journal* 123(1326): 88–96.
- Vennemann MM, Bajonowski T, Brinkmann B, et al. 2009. Does breastfeeding reduce the risk of sudden infant death syndrome? *Pediatrics* 123(3). URL: [www.pediatrics.org/cgi/content/full/123/3/e406](http://www.pediatrics.org/cgi/content/full/123/3/e406) (accessed 13 May 2017).
- Waikato DHB. 2017. *Hapu Wānanga*. URL: [www.waikatodhb.health.nz/directory-of-our-services/te-puna-oranga/hapu-wananga](http://www.waikatodhb.health.nz/directory-of-our-services/te-puna-oranga/hapu-wananga) (accessed 12 April 2017).
- Waitemata DHB. 2017. Te aka oranga waikawa wahakura wananga. URL: <http://2014.qualityaccounts.health.nz/quality-initiatives/patient-family-centred-care/stories/type/view/storyid/152> (accessed 17 May 2017).
- WHO Europe. 2008. *Behaviour Change Strategies and Health: The role of health systems*. Regional Committee for Europe fifty-eighth session, Tbilisi, Georgia.

# Appendix 1: Data and methods

## Mortality analysis and coding

### Mortality data

The data for this report comes from the Mortality Review Database. It was extracted on 12 October 2016. Data came from the Perinatal Maternal Mortality Review Committee (for those aged 0–27 days at death) and the Child and Youth Mortality Review Committee (for those from 28 days up to one year of age). The data in this report refers to those who died from birth up to but not including one year of age. Stillbirths and terminations are not included. In all tables and figures, the year of death means the calendar year in which the individual died, rather than the year the death was registered. This approach is different to some official collections, which use the year the death is registered. Overseas residents were excluded from the analysis.

### Case selection

For deaths in infants under one year of age, sudden unexpected death in infancy (SUDI) was given as the cause of death where any one of the following ICD-10-AM codes was listed as the underlying cause of death in the Mortality Collection: 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 – consistent with current coding practice in the Ministry of Health and with research practice in New Zealand (Mitchell et al 2016).

In addition, from mid-2006 onwards, Perinatal Society of Australia & New Zealand (PSANZ) coding, as assigned by the Perinatal Maternal Mortality Review Committee and recorded in the Mortality Review Database, was available on all neonatal cases (0–27 days). For deaths in neonates where PSANZ coding was available, the following Neonatal Death Classification codes (and their sub-codes) were used to select cases:

- 7.1 Sudden Infant Death Syndrome
- 7.31 Accidental trauma
- 7.91 Unclassified sudden infant death.

Cases were further individually reviewed to ensure only SUDI deaths were included. If cases had a PSANZ code and history consistent with SUDI, they were included, no matter what ICD-10 code they had been given.

### Ethnicity

Ethnicity data in the Mortality Review Database comes from multiple sources: Births, Deaths and Marriages, the Ministry of Health, coronial records and the information that local child and youth mortality review group coordinators enter when reviewing a death. These data sources are prioritised based on evidence of their quality and completeness in New Zealand.

This report uses prioritised ethnicity to give a single ethnic group to each individual. In prioritised output, each respondent is allocated to a single ethnic group using the following priority system: Māori, Pacific peoples, Asian, MELAA,<sup>4</sup> other groups except NZ European, and NZ European. Our ethnicity analyses only used three ethnic groups: Māori, Pacific, and non-Māori non-Pacific. The latter group contained all ethnicities except Māori and Pacific peoples. Those people for whom the ethnic group was unknown were excluded from ethnicity analyses.

### DHB of residence

The person's address as supplied by the coroner, police or Births, Deaths and Marriages is used to categorise their DHB of residence. The address is the individual's self-identified 'usual' place of residence, and does not necessarily reflect their legal residential status.

<sup>4</sup> MELAA refers to Middle Eastern/Latin American/African.

## Deprivation

NZDep2006 Index of Deprivation (NZDep2006) is a census-based small area measure of neighbourhood deprivation that combines nine socioeconomic variables from census information. NZDep2006 provides an ordinal score and a continuous scale dividing New Zealand into tenths of the distribution of the score. An NZDep2006 score of 1 indicates that the area is in the least deprived 10 percent of NZDep2006 small areas of New Zealand, while a score of 10 indicates that the area is in the most deprived 10 percent (Salmond et al 2007). Given that our study period covered 2002–15, we chose NZDep2006, and forward- or back-mapped deaths that occurred outside the period when NZDep2006 was in use (2002–08 and 2015) to calculate the NZDep2006 score.

## Statistics

The New Zealand Mortality Review Data Group analysed the data presented in this report from the Mortality Review Database. The denominator used in this report was the number of live births in New Zealand, as supplied by the Ministry of Health. Year was determined from the year of registration of birth, rather than the year of birth itself. Rates for infant deaths are expressed as per 1000 live births. Some of the figures required a day of the week or month of death denominator. To estimate this, we gave all babies in the live birth set a random 'date of "death"' by randomly adding a number between 1 and 364 to each birth date. From this, day of the week and month of death were calculated for the denominator. Trends across time were calculated using Poisson regression.

## Multivariate analysis

Multivariate analysis was conducted to estimate adjusted rate ratios for DHB of residence, independent of demographic variables. In the model were sex of the baby, prioritised ethnic group, NZDep2006 quintile, mother's age, birthweight and year of death. Poisson regression was used to estimate adjusted incident rate ratios for each DHB. There were a number of missing variables, which reduced the total numbers of cases that could be included in the model ( $n = 763$  included;  $n = 14$  with missing variables).

## Limitations

This report used data collected from administrative databases as well as data from the local review of cases. While the administrative data is largely complete, not all cases were reviewed locally, in part because local child and youth mortality review groups were established over a number of years between 2003 and 2010.



## Child and Youth Mortality Review Committee

---

*“...Unuhia i te rito o te harakeke...”*  
*“...taken away too early...”*

[newzealand.govt.nz](http://newzealand.govt.nz)