

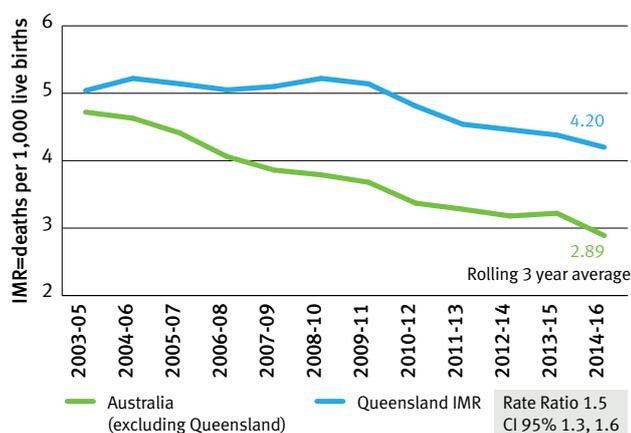
# Review of 2013 Queensland Post-Neonatal Infant Deaths

## Queensland State Summary Report

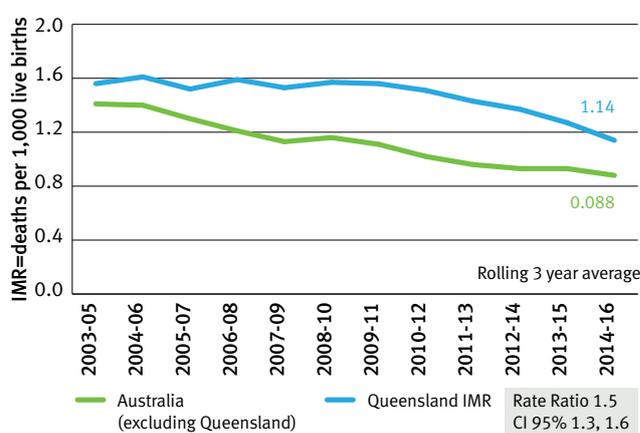
Prepared in July 2018

The Queensland Paediatric Quality Council (QPQC) convened its Infant Mortality Subcommittee in 2015 to examine Queensland's persistently high Infant Mortality Rate (IMR), which is 50% higher than the rest of Australia. QPQC's focus has been on the subgroup of post-neonatal infant deaths, for which Queensland has a 30% higher IMR rate (Figure 1, 2)<sup>1</sup>, and in particular, infants who died suddenly and unexpectedly.

**Figure 1. All Infants - Infant Mortality Rate IMR Queensland compared with the rest of Australia**



**Figure 2. Post Neonatal Infants - Infant Mortality Rate IMR Queensland compared with the rest of Australia**

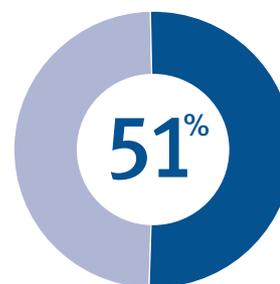


The QPQC Infant Mortality Subcommittee members have expertise in general paediatrics, community child health, midwifery and neonatal nursing, critical care, neonatology, forensic paediatrics, forensic and specialist pathology, university research on infant deaths, and non-government service provision. The subcommittee conducted expert panel reviews of all post-neonatal infant deaths (death at age 28-364 days) in Queensland (QLD) between January 1, 2013 to December 31, 2013. A summary of this detailed review is presented below.

### Post-neonatal Infant Death Review Findings

Ninety post-neonatal infant deaths occurred in 2013. A further nine neonatal infant deaths (0-27 days of age) were included in the QPQC review as these neonates died unexpectedly after leaving hospital maternity services.

Infant deaths were categorized as either Sudden Unexpected Deaths in Infancy (SUDI) or "non-SUDI" deaths. SUDI is a category of death for an infant (age under 1 year) who dies suddenly with no immediately obvious cause.<sup>2</sup> In Queensland, 51 infant deaths met the initial definition of SUDI (42 post-neonates and nine neonates). One non-SUDI and two SUDI cases were not reviewed as Coroner reports were not finalised. Two SUDI cases were due to inflicted injury, and considered separately from the remaining SUDI group. By comparison, in 2013 there were 55 SUDI reported in New South Wales (NSW)<sup>3</sup>. Using state birth rate<sup>1</sup> to calculate, Queensland's SUDI IMR was 1.5 times greater than NSW.

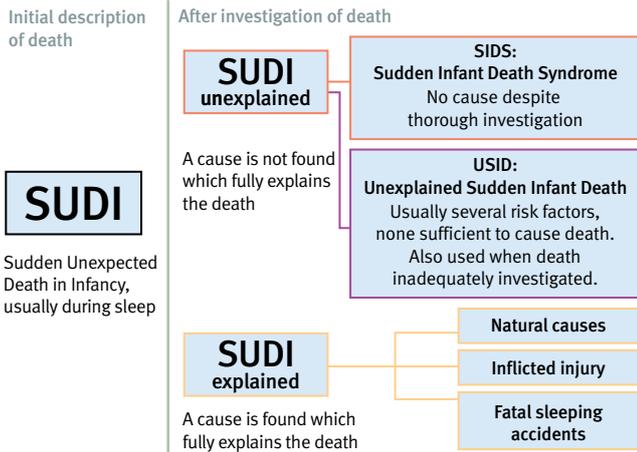


Died suddenly and unexpectedly

#### Queensland

- 96 deaths reviewed
- 49 SUDI reviewed
- 47 non-SUDI reviewed

Figure 3. Explanation of SUDI classification



There were 47 non-SUDI post-neonatal infant deaths reviewed. 25 infants died from congenital anomalies (including six cardiac, six chromosomal, five neurologic), 16 as a consequence of perinatal conditions, and four from acquired natural causes (including post-natally acquired infectious illnesses in three). Two non-SUDI infants died from inflicted injuries (bringing the total inflicted injury deaths to four).

Both SUDI and non-SUDI groups had an over-representation of infants born earlier than 37 weeks gestation and of birthweights less than 2500 grams. As expected, most of the non-SUDI infants whose deaths were attributed to perinatal conditions were born at extremely early gestation or low birth weight. However, many infants, particularly those who died suddenly and unexpectedly, were often within or close to, the expected term range for gestation and birth weight.

Infants of Aboriginal and/or Torres Strait Islander descent were over represented in both the SUDI (23%) and non-SUDI groups (22%). Males and females were evenly represented in both groups.

- Aboriginal and Torres Strait Island populations are over represented in all infant deaths
- Smoking in pregnancy is a major risk factor for SUDI and non-SUDI infant groups.

Cigarette smoking in pregnancy was very common for mothers experiencing SUDI, more than four times the general rate in pregnancies. 65% of mothers reported smoking up to 20 weeks of pregnancy and 53% were smoking after 20 weeks (self-reported in the Perinatal Data Collection (PDC)).

For the non-SUDI group, maternal smoking frequency was also high, more than twice the expected rate. Smoking up to 20 weeks was reported in 32% for non-SUDI mothers

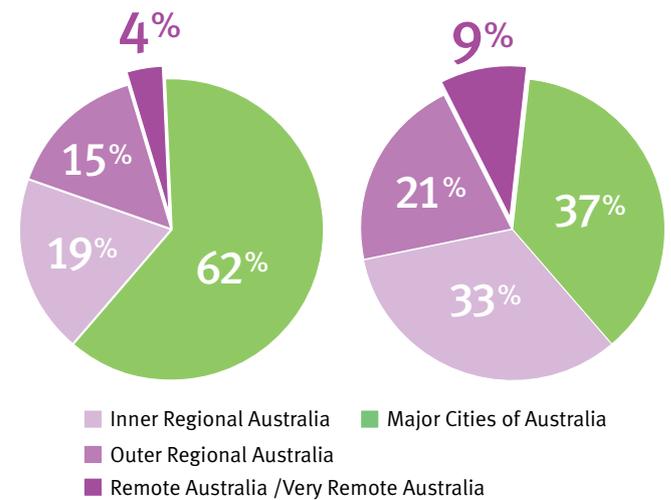
(compared with 15% of the overall Queensland population of mothers who gave birth in 2013), and smoking beyond 20 weeks pregnancy in 31% for the non-SUDI mothers (compared with 12% overall, as per PDC).

## Sudden and Unexpected Infant Deaths

Of the subset of 47 SUDI deaths (excluding inflicted injury), nine were found on investigation to have been due to natural causes including un-diagnosed heart conditions in four, infection / sepsis in three, and other natural cause in two. The remaining 38 SUDI deaths were examined in detail by the QPQC. In the majority of cases there was no one single cause of death, rather an interplay of multiple and different contributory conditions and risk factors. These findings reflect the complex nature of sudden infant deaths. It also compounds the difficulty in completing death reviews, when important details from the infant’s health history and/or death scene investigation are frequently not recorded. The QPQC panel determined that eight SUDIs were best described as due to asphyxiation or accidental suffocation. Only nine fitted the definition of Sudden Infant Death Syndrome (SIDS) and 21 did not fit the SIDS definition and were best described as cause “Undetermined”. See Figure 3 for explanation of SUDI classifications.

SUDI deaths were over-represented in the regional and remote areas of Queensland. Using the Australian Statistical Geography Standard Remoteness Structure (ASGS), SUDI occurred in Remote and Very Remote areas just under three times the expected frequency and in Outer and Inner Regional areas at 1.5-1.7 times expected (Figure 4).

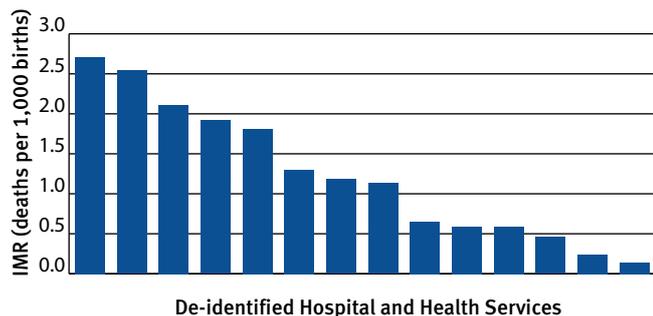
Figure 4. SUDI profile by ASGS Remoteness  
% Queensland 2013 live births      % of SUDI deaths



SUDI Infant Mortality Rate (deaths per 1,000 live births) can be calculated for geographic areas where birth numbers are known, such as Hospital and Health Service (HHS).

Variation in SUDI IMR by HHS is shown in Figure 5.

Figure 5. SUDI infant mortality rate by HHS



## SUDI infant care environment

One of the key themes to emerge from the reviews was the central importance of the infant/carer dyad. An infant is totally dependent on a responsive carer and cannot be reviewed without consideration of the primary carer and family circumstances. The mother was the main caregiver for 36 (95%) of the infants.

### Where SUDI occurs infant's family environment is complex.

In the period prior to the infant's death (day or evening of), 11% of primary carers had taken prescribed drugs and 8% disclosed they had consumed alcohol. Whilst only 3% of cases had documentation of illicit drug use in the police report, a more comprehensive health record review revealed that 14 families (38%) had a history of illicit drug use prior to the infant's death and in five of these families the mothers had Hepatitis C, a marker for intravenous illicit drug use.

A history of family violence was reported for 37% of SUDI families, and 35% of families had a history of police involvement with the parents. Just under half the infants' families (46%) were already known to the Department of Communities, Child Safety and Disability Services, almost always for a sibling of the infant. In three cases (8%) a previous infant of the mother had died in unexplained circumstances.

Thirty-five (90%) of the SUDI deaths reviewed occurred during a sleep time for the infant. The remaining three infants were either in a baby sling or the mother fell asleep whilst feeding on a sofa. These three infants were determined by the Coroner to have died from asphyxiation secondary to airway obstruction.

Unsafe sleep factors were examined for the 35 sleeping cases.

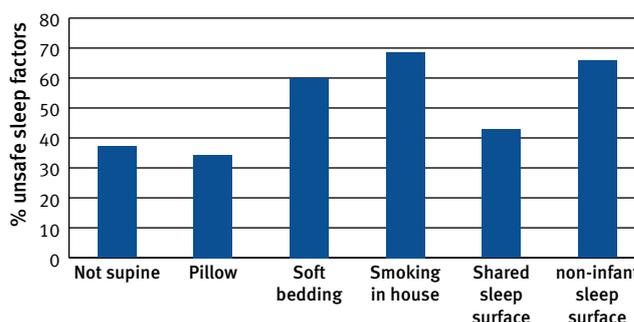
Unsafe sleep factors include<sup>4</sup>:

- sharing a sleep surface in presence of known risk factors,
- placing the infant prone to sleep (on the stomach),
- using pillows or thick, soft bedding,
- smoking in the house,
- using a sleep surface not designed for infants (e.g. adult bed or sofa).

### Unsafe sleep factors were common and multiple.

At least one unsafe sleep factor was present for every SUDI. Co-occurrence of multiple unsafe sleep factors was common (Figure 6). 86% of infants had two or more risk factors present. This is a likely under-estimate as important details of infant sleep factors at the time of death were limited or missing from some case reports. For example, "Placed-to-sleep" position details were missing from the reporting in 26% of cases.

Figure 6. Percentage of unsafe sleep factors (n=35)



## Key Messages

### 1. For SUDI deaths there is rarely a single cause of death in isolation

The Coronial process determines a forensic cause of death but does not always identify the complex set of risk and contributory factors which are active in the infant's death event. By condensing cause-of-death reporting down to one "cause", we reduce the ability to fully understand the importance and interplay of these factors. This review demonstrated the benefit of a multidisciplinary panel approach to SUDI death reviews, in which the diverse backgrounds and skills of panel members and the range of information sources used, identified many contributory risk factors. This extends understanding beyond a single underlying cause of death to identify opportunities for prevention.

## 2. Families in which SUDI occur do not necessarily act on safe sleeping messages

QPQC reviewed infant deaths with a focus on prevention, looking for modifiable risk factors which can be identified and influenced by interventions which may exist in Queensland or elsewhere. The ongoing contribution to SUDI of unsafe infant sleeping practices, particularly in the presence of other known risk factors such as smoking and drug use, is worrying, given the safe sleeping education initiatives, and the evidence that uptake of these recommendations by infant caregivers is associated with a reduction in many SUDI deaths.

Families may share a sleep surface with their young infant for any of several reasons, including not having an alternative infant sleep space, or because of not receiving / not understanding / or choosing not to accept the advice of “Safe Sleeping” recommendations. They may do so as a routine practice, sometimes with harm minimising strategies in place, or as an unplanned event in a maximally unsafe setting. Families do not necessarily disclose these arrangements to health providers. Red Nose, the national authority organisation on safe sleep practices, supports an evidence-based risk minimisation approach which does not dilute safe sleeping space recommendations but does provide families with extra guidance. Red Nose and Queensland Government guidelines which include risk minimisation statements are available.<sup>5,6</sup>

**Safe Sleeping Guidelines which include risk minimisation may provide families with more safe strategies.**

## 3. The family environment where SUDI occurs is complex and vulnerable

This QPQC review also highlighted that many of the infants were living in socially and physically challenging environments. In such settings, universal public health and community messages about safe sleeping are not leading to change where it is needed most. Frequently, the infants’ families have not engaged with primary health care services following their infants’ birth: in many cases health services had attempted contact with the families who had not responded or had declined services. Models of care to engage these at risk populations are needed.

## 4. There is an important role for Queensland Health and other sector services in the investigation of infant deaths and support for families following the death

This review indicates an important role for “health professional” assistance (paediatrician or child health nurse for example) in death scene investigation, family interviews and family support. Currently, HHS health professionals

are not notified of every infant death in the HHS, and some families miss out on ongoing support. Health professionals can take a protocolised infant health history and assist in the SUDI investigation. Improved history and investigation may provide more clarity on the causes and prevention of unexplained infant deaths. HHS health professionals can offer support to bereaved families.

**Police connecting with HHS staff after a SUDI can result in improved investigation and support for bereaved families.**

## Concluding remarks

The death of an infant is a tragic loss for family and community. Despite the concerted efforts made to reduce infant mortality in Queensland, the IMR gap between Queensland and elsewhere in Australia persists. This, and regional differences within Queensland which are not explained by remoteness or other demographics, indicate that more infant deaths can be prevented. Using lessons learnt from reviews in other jurisdictions, most recently NSW<sup>7</sup>, the QPQC is now developing a series of recommendations in consultation with stakeholders from within Queensland Health, Queensland Family and Child Commission, Office of the State Coroner, Queensland Police and other services.

Recommendations will be made in the areas of prevention, identification and support of at risk infants and families, immediate response following a sudden and unexpected infant death, improved death investigation, improved family support and follow up, and ongoing statewide review of deaths.

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