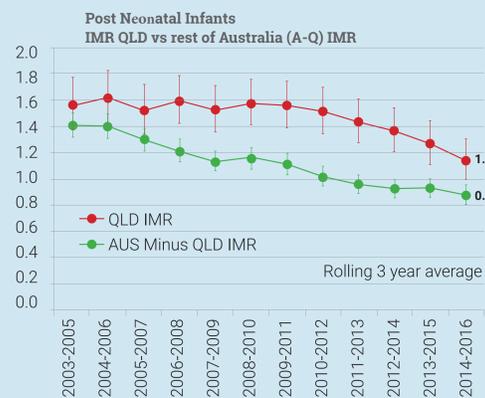# The Voice of the Infant.

Cause of death coding does not always reflect what really mattered in the life of the infant who died suddenly and unexpectedly.

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Background

- The Infant Mortality Rate (IMR) in Queensland (QLD) is higher than the rest of Australia and the reasons for this are unclear. This also is true for QLD's post-neonatal IMR (see graph).[1]

- IMR differences between states and within QLD are not explained by QLD's geography or demography, and QLD non-indigenous as well as indigenous IMRs are raised.[1] This does not support unmodifiable reasons (specific-to-QLD) for the higher IMR. It is more likely that the excess QLD infant deaths are preventable.

**Post Neonatal Infants
IMR QLD vs rest of Australia (A-Q) IMR**

QLD IMR
AUS Minus QLD IMR
Rolling 3 year average
1.14
0.88

- Following safe sleeping campaigns in the 1990s in most developed countries, IMRs including Sudden Infant Death Syndrome (SIDS) rates have decreased, while remaining Sudden Unexpected Deaths in Infancy (SUDI) are more frequently classified as Undetermined Sudden Infant Death (USID) or "accidental suffocation".[2]

- International and interstate comparisons are hampered by definitional differences, lack of consistent investigation practices, and lack of an autopsy marker to distinguish SIDS or accidental suffocation.[2,3,4,5,6]

- Cause-of-death coding to an international standard (eg ICD-10) enables comparisons over time and between jurisdictions, however condensing a complex set of risk factors into one coded cause of death does not identify the interplay of factors nor possible interventions. Classification systems have been proposed to emphasize this uncertainty and highlight the importance of the sleep environment.[3,4,5,6]

- Use of a classification system which identifies modifiable factors may identify avoidable infant deaths in QLD.

Aims

- To classify SUDI deaths by expert panel review considering social, intrinsic and extrinsic risk factors.

- To understand the interplay of multiple factors and identify opportunities for preventive intervention.

Methods

- QPQC conducted a retrospective multi-record review of all post-neonatal infant deaths in Queensland in 2013. Included in this review was a subgroup of neonates identified by ICD-10 code as having died suddenly and unexpectedly after discharge from birth hospital.

- The San Diego definition was used to categorize death as "explained", SIDS or USID (Unclassified Sudden Infant Death).[3]

Relevant health records for the infant, mother's birth record, autopsy reports, police death scene investigations and coroner reports were obtained.

A Data Collection Tool was developed to systematically analyse record content.

Case reviews were undertaken by an expert panel with experience in paediatrics and paediatric sub-specialties, child health, nursing, midwifery and neonatal nursing, child protection, and forensic and anatomical pathology. Two reviewers per case with group discussion and consensus.
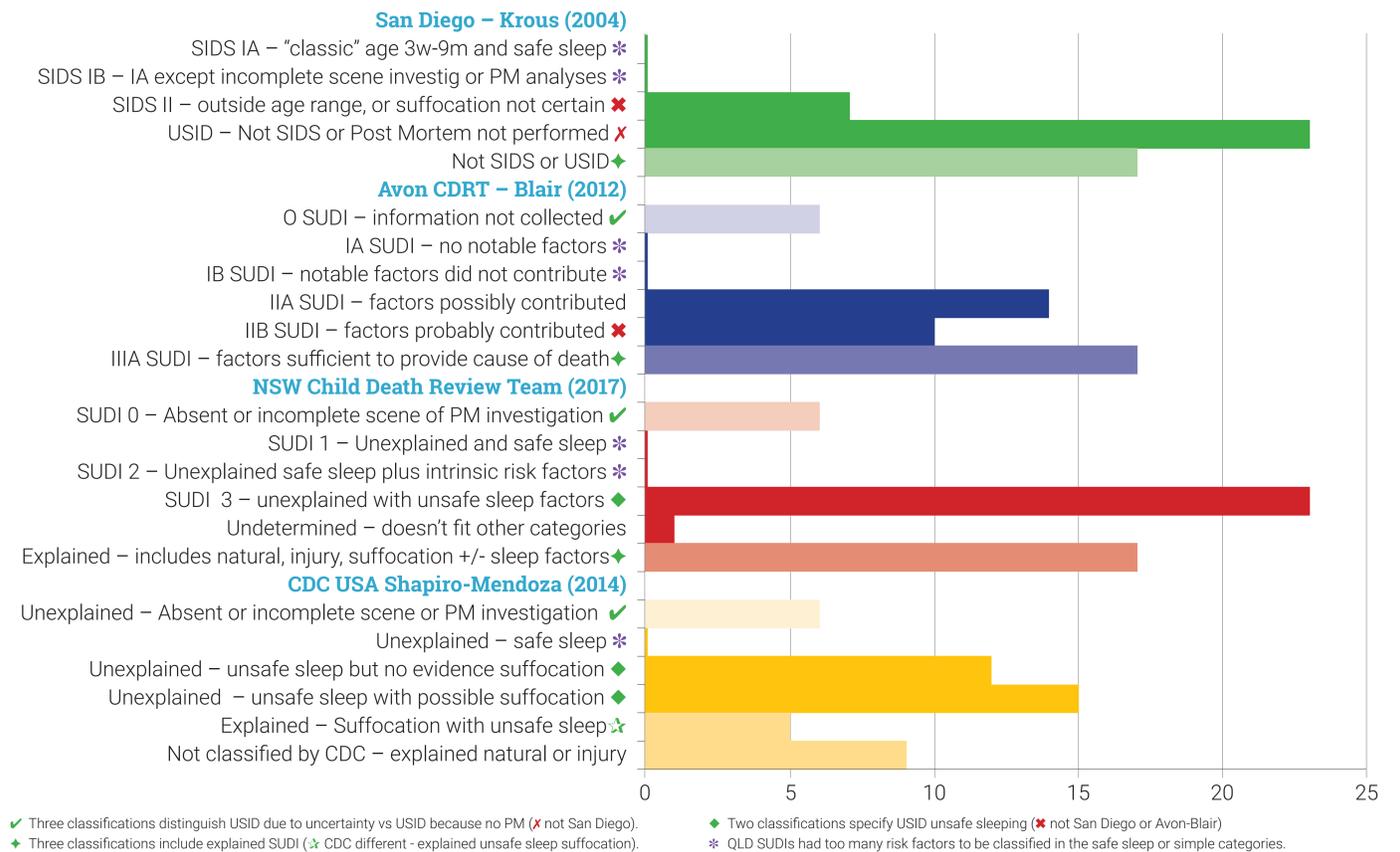
Quantitative data analysis was undertaken using REDCap™ and qualitative data were thematically analysed.

- SUDI were also classified according to various published systems: Avon UK (Blair)[4], New South Wales (Child Death Review Team)[5], Centres for Disease Control SUDI Registry USA (Shapiro-Mendoza)[6].

- This work was supported by a funding grant from the Clinical Excellence Division. The documents were obtained in accordance with legislation supporting QPQC as a Quality Assurance Committee. An Ethics Waiver was approved by the Children's Health Queensland Health Research Ethics Committee.

Results

- 51 deaths met the definition of SUDI. The SUDI IMR in QLD was higher than NSW. Rate Ratio QLD vs NSW = 1.5 (95% CI 1.002-2.155)[7,1]. 4 were excluded from further review (2 incomplete from Coroner, 2 fatal abusive injury). 47 remaining SUDI were re-classified as follows.

SUDI Re-Classification using San Diego-Krous, Avon-Blair, NSW CDRT, CDC-Shapiro Mendoza Classifications

San Diego – Krous (2004)
SIDS IA – "classic" age 3w-9m and safe sleep ✳
SIDS IB – IA except incomplete scene investig or PM analyses ✳
SIDS II – outside age range, or suffocation not certain ✖
USID – Not SIDS or Post Mortem not performed ✗
Not SIDS or USID ✦

Avon CDRT – Blair (2012)
O SUDI – information not collected ✔
IA SUDI – no notable factors ✳
IB SUDI – notable factors did not contribute ✳
IIA SUDI – factors possibly contributed
IIB SUDI – factors probably contributed ✖
IIIA SUDI – factors sufficient to provide cause of death ✦

NSW Child Death Review Team (2017)
SUDI 0 – Absent or incomplete scene of PM investigation ✔
SUDI 1 – Unexplained and safe sleep ✳
SUDI 2 – Unexplained safe sleep plus intrinsic risk factors ✳
SUDI 3 – unexplained with unsafe sleep factors ◆
Undetermined – doesn't fit other categories
Explained – includes natural, injury, suffocation +/- sleep factors ✦

CDC USA Shapiro-Mendoza (2014)
Unexplained – Absent or incomplete scene or PM investigation ✔
Unexplained – safe sleep ✳
Unexplained – unsafe sleep but no evidence suffocation ◆
Unexplained – unsafe sleep with possible suffocation ◆
Explained – Suffocation with unsafe sleep ✫
Not classified by CDC – explained natural or injury

✔ Three classifications distinguish USID due to uncertainty vs USID because no PM (✗ not San Diego).
◆ Two classifications specify USID unsafe sleeping (✖ not San Diego or Avon-Blair)
✦ Three classifications include explained SUDI (✫ CDC different - explained unsafe sleep suffocation).
✳ QLD SUDIs had too many risk factors to be classified in the safe sleep or simple categories.

24 SUDI were recoded regarding cause of death code

Reasons included:

7 in the "explained" subgroup, because autopsy did not fully explain death, recoded to USID

2 recoded from USID to suffocation because details available about infant position were sufficient to state airway obstruction occurred from unsafe sleep setting

Pre reviw coding totals
Changes in coding after review
IMSC review process coding totals

SUDI Explained **18** → SUDI Explained 11 / SIDS 1 / USID 6 → SUDI Explained **17**

SIDS **21** → SUDI Explained 4 / SIDS 5 / USID 12 → SIDS **7**

USID **8** → SUDI Explained 2 / SIDS 1 / USID 5 → USID **23**

The subgroup of SIDS was the group most commonly recoded (76%) – mostly to USID

Reasons included:

16 with multiple unsafe sleep factors, some with suspicion of suffocation; 4 had sufficient details about airway position to recode as suffocation; others missing details about airway obstruction

14 with multiple social, environmental and intrinsic risk factors including 12 child safety involvement with family, 10 significant parental mental health issues, 9 domestic violence, 9 illicit drugs / alcohol

6 where autopsy did not fully explain death and 6 where autopsy incomplete or not done

Why USID instead of SIDS?
- Unsafe sleep factors (n=16)
- Infant being carried or feeding (n=3)
- Infant-carer risks: drugs, child safety, family violence, neglect (n=14)
- Autopsy not done or incomplete (n=6)
- Autopsy findings did not fully explain death (n=6)

Conclusions

- The word "infant" comes from the Latin "unable to speak". An infant who dies suddenly and unexpectedly relies on others for a voice to speak to the circumstance of the death.

- What really mattered in the life and death of the infant who died suddenly and unexpectedly, was the complex interplay of multiple social, intrinsic and extrinsic factors that combine with unsafe sleep factors, to compromise survival.

- When SUDI are re-classified heeding this interplay of factors, very few SUDI can be correctly coded as SIDS. In our series, half the death codes were inappropriate. A misapplied diagnosis of SIDS may be more comforting to parents than

"undetermined" as a cause of death but this does no justice to the infant.

- ICD-10 coding to a 'beyond reasonable doubt' forensic standard serves legal requirements, but results in a unidimensional descriptor which fails to describe preventable factors in infant death.

- Whilst research progress is being made to better understand SIDS, complacency that "SIDS is just something that unfortunately happens" persists. SUDI classification which accounts for multiple factors offers opportunities to prevent further infant deaths.

Key Message
SUDI are multifactorial

Key Message
Unsafe sleep remains a factor in most SUDI

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