The investigation of sudden unexpected deaths in infancy in Australia

Heather E Jeffery AO[1], Angela E Carberry[1], Adrienne Gordon[2,3], Susan Arbuckle AM[4]

The term "sudden unexpected death in infancy" (SUDI) encompasses all deaths and collapses leading to deaths of infants (to twelve months of age) that would not have been reasonably expected 24 hours prior to the event and for which there was no apparent pre-existing medical cause of death, regardless of whether the death was subsequently explained or not. Sudden infant death syndrome (SIDS) refers to cases that remain unexplained after a complete investigation, including history taking, death scene investigation, and autopsy.[1]

SUDI requires thorough investigation according to international standards and guidelines.[2-4] Determining whether a death can be explained is important for parents and their future children, as well as for prevention, public health policy, and research into the risk factors for SUDI. How well these standards are implemented in Australia is unknown. Doctors in all states and territories are legally required to report SUDI to the coroner, who has the statutory duty to investigate. During 2005–2015, 113 to 143 deaths classified as SUDI were reported each year; most were deemed preventable because known risk factors were involved, such as prone or unsafe sleeping practices or parental smoking.[5]

In 2018, we surveyed Australian chief state coroners and their equivalents about the SUDI investigation process. The survey was developed with advice from the National Scientific Advisory Group of Red Nose Australia (https://rednose.org.au), and the questionnaire was piloted with two coroners. The final survey was forwarded via REDCap, a secure web application, to the chief coroners or their equivalents in each of the eight states and territories. The questionnaire included items on the definition of SUDI, first responders, death scene investigation, medical and social history collection, post mortem examination, communication with parents, and the proportions of cases in which the cause of death could be determined (Supporting Information). The University of Sydney Human Research Ethics Committee approved the study (project number: 2017/506).

We received responses from all eight jurisdictions during May 2018 – October 2019, either from the chief state coroners or their equivalents or from their principal registrar or designated paediatric/forensic pathologist. We assumed that responses reflected actual practice. The responses indicated considerable variation in how SUDI is investigated, but the process is predominantly led by police, including the recording of the medical history, the death scene investigation, and (in some cases) the early communication of post mortem findings to parents (Box 1).

Four models of SUDI investigation were identified by a 2015 systematic review: coroner/medical examiner-led, health care-led, police-led, and a joint agency approach. The authors found that the police-led model does not meet the minimum standards required for a SUDI investigation.[4]

In the United Kingdom, the Kennedy report (second edition, 2016) defined the requirements for appropriate investigation of

1 Summary of responses by Australian state and territory coroners to our survey about the investigation of sudden unexpected death in infancy (SUDI)

Theme	Number of jurisdictions (of eight)
Coroners apply one of two Australian definitions of SUDI[1,6]	7
First responders (if death at home)	
Police	8
Police and ambulance	7
Death scene investigations: responsibility	
Police	8
Police and forensic pathologist	2
Police and paediatrician	1
Death scene investigation: procedure	
Always within 24 hours of SUDI*	5
Standardised procedure	6
Doll re-enactment	2
Medical history recorded: responsibility	
Police	7
Police and paediatrician	4
Police and nurse	1
Police and somebody else (eg, social worker)	1
Medical history recorded: location	
Home	6
Emergency department	2
Medical history shared with pathologist prior to autopsy	
Always	5
Usually	2
Sometimes	1
Standardised autopsy	1
Autopsy: timing*	
Within 24 hours	1
24–48 hours	5
More than 48, within 72 hours	1
Autopsy: pathologist	
Any forensic pathologist	4
Forensic pathologist specialised in SUDI	3
Paediatric/forensic pathologist	1

Continues

[1]School of Public Health, the University of Sydney, Sydney, NSW. [2]Charles Perkins Centre, the University of Sydney, Sydney, NSW. [3]Royal Prince Alfred Hospital, Sydney, NSW. [4]The Children's Hospital at Westmead, Sydney, NSW. angela.carberry@sydney.edu.au • doi: 10.5694/mja2.51833

1 Summary of responses by Australian state and territory coroners to our survey (continued)

Theme	Number of jurisdictions (of eight)
Molecular (genetic) autopsy if SUDI unexplained*	
Sometimes	5
Rarely	2
Electrocardiography of first degree relatives if SUDI unexplained	
Never	4
Rarely	3
Sometimes	1
Support for family after autopsy (72 hours to one week)	8
Usual time to completion of inquest (if applicable)	
1–2 months	1
5–6 months	3
More than six, within twelve months	4
Final cause of death communicated to parents (in person, phone, writing)	8
Follow-up appointment with parents (after final cause of death provided)*	4
Proportion of cases with identified cause of death†	
10–20%	1
20–30%	4
40–50%	1

* No response for one jurisdiction. † No response for two jurisdictions. ◆

2 The core components of evidence-based investigation of sudden unexpected death in infancy (SUDI), based on the findings of the second edition of the Kennedy report (United Kingdom, 2016),[1] adapted for Australia

- First responders: police and ambulance should resuscitate the infant if appropriate and transport them to the nearest hospital.
- Initial multi-agency planning of overall response once the body of the infant has been transferred to the morgue.
- Expert paediatric assistance with death scene investigation; for example, trained SUDI paediatrician rather than police only (investigation of any suspicious death is responsibility of police). Includes:
  - Family interviews in nearest hospital emergency department;
  - Death scene investigation (for Australia: should include doll re-enactment by paediatric specialist).
- Experienced paediatric specialist and police to record medical history (for Australia: paediatric specialist to review the early and subsequent post mortem findings to facilitate further specific history taking if required).
- Standardised protocols for SUDI pathology investigation, with specific requirements for standard investigations.
- SUDI autopsy by specialist paediatric pathologists or, if this is not possible, consultation with paediatric specialist.
- Final multi-professional case discussion meeting, chaired by a paediatrician to define cause of death, family support and ongoing needs, and referrals (eg, geneticists).

SUDI[1] (Box 2). Each part of the process requires a standardised protocol, but also the flexibility to add new items; for example, the medical history should be recorded by a health care professional, preferably a paediatrician, using a standardised questionnaire. Most Australian jurisdictions rely on the limited histories collected by the police. Further, the paediatrician who collects the history should be knowledgeable about SUDI, sensitive to the parents' situation, sufficiently competent and confident to deal with unexpected infant deaths, and with sufficient regular SUDI experience to maintain these skills. The essential components of the required history and post mortem examination have been outlined.[7] A genetic history is increasingly important as new channelopathies (most with dominant inheritance, with implications for first-degree relatives) and other genetic causes of SUDI are discovered.[8]

The SUDI investigation process in Australia should be upgraded to international standards, as every family has the right to have their child's death properly investigated. Parents are largely unaware that this often does not happen. Led by our coroners and supported by multi-agency collaboration, it is time to correct this situation.

Acknowledgements: We thank the chief state coroners or equivalents and their representatives for completing the questionnaire. We thank Red Nose Australia and their National Scientific Advisory Group for their help in refining the questionnaire, and the coroners who tested the survey and provided feedback.

Open access: Open access publishing facilitated by The University of Sydney, as part of the Wiley – The University of Sydney agreement via the Council of Australian University Librarians.

Competing interests: No relevant disclosures. ■

Received 9 September 2022, accepted 6 December 2022

1 Royal College of Pathologists (United Kingdom). Sudden unexpected death in infancy and childhood: multi-agency guidelines for care and investigation. 2nd edition. Nov 2016. https://www.rcpath.org/uploads/assets/874ae50e-c754-4933-995a804e0ef728a4/Sudden-unexpected-death-in-infancy-and-childhood-2e.pdf (viewed Dec 2022).

2 Krous HF, Beckwith JB, Byard RW, et al. Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach. *Pediatrics* 2004; 114: 234-238.

3 Bajanowski T, Vege A, Byard RW, et al. Sudden infant death syndrome (SIDS). Standardised investigations and classification: recommendations. *Forensic Sci Int* 2007; 165: 129-143.

4 Garstang J, Ellis C, Sidebotham P. An evidence-based guide to the investigation of sudden unexpected death in infancy. *Forensic Sci Med Pathol* 2015; 11: 345-357.

5 Freemantle J, Ellis LE. An Australian perspective. In: Duncan JR, Byard RW, editors. SIDS. Sudden infant and early childhood death: the past, the present and the future. Adelaide: University of Adelaide Press, 2018; pp. 349-374. https://www.adelaide.edu.au/press/titles/sids (viewed Dec 2022).

6 Ombudsman NSW. NSW Child Death Review Team: annual report of child deaths registered in 2013. 1 Aug 2022. https://www.ombo.nsw.gov.au/Find-a-publication/publications/child-death-review-team-reviewable-deaths/cdrt-annual-reports/nsw-child-death-review-team-annual-report-2013 (viewed Dec 2022).

7 Sidebotham P, Marshall D, Garstang J. Responding to unexpected child deaths. In: Duncan JR, Byard RW, editors. SIDS. Sudden infant and early childhood death: the past, the present and the future. Adelaide: University of Adelaide Press, 2018; pp. 85-115. https://www.adelaide.edu.au/press/titles/sids (viewed Dec 2022).

8 Keywan C, Poduri AH, Goldstein RD, Holm IA. Genetic factors underlying sudden infant death syndrome. *Appl Clin Genet* 2021; 14: 61-76. ■

Supporting Information

Additional Supporting Information is included with the online version of this article.