Australian Paediatric Surveillance Unit

STUDY PROTOCOL

COMMENCED SEPTEMBER 2019

Paediatrician experience with management of Sudden Unexpected Death in Infancy (SUDI)

(One-off survey)

BACKGROUND

In developed countries SUDI remains a leading cause of mortality in infancy outside the neonatal period despite a reduction from the early 1990s following greater understanding of some risk factors, particularly related to sleep.[1] Recent research has identified a number of potential mechanisms for SUDI including abnormalities of serotonin and other neurotransmitters such as substance P and orexin.[2] It is proposed that cardiac arrhythmia and/or cardiac abnormalities may account for up to 15% of SUDI. [3] Many of these cases are dominantly inherited so genetic screening for first degree relatives may be important. Although frequency data are unknown, other infants may experience epileptic phenomena, particularly related to changes in the hippocampus leading to sudden unexplained death in sleep (SUDEP).[4]

In 2008 NSW Health released a Policy Directive titled *Procedures for Management of Sudden Unexpected Death in Infancy* [5] in response to the 2005 report of the NSW Child Death Review Team (CDRT). The Policy Directive aims to ensure that appropriate support is provided to the family as well as facilitating the collection of comprehensive medical history to assist in determining the cause of death. The Directive identifies a senior paediatrician as the clinician to conduct the medical history and includes a *History Protocol* in Appendix B.

In NSW there are approximately 40 unexplained deaths of infants each year.[6] All post mortems are conducted either in Sydney at the Department of Forensic Medicine, Lidcombe, or the Department of Forensic Medicine, at Royal Newcastle Hospital. An accurate medical history is essential to help determine cause of death however data from the CDRT suggests that this is not available in many cases. In fact an adequate paediatric medical history was provided in only 28% of cases referred to the coroner for 2016-2018.[6] In many cases, details of history are only available from police reports with the concern that important aspects of medical and family history are missing, limiting the ability to fully investigate and identify genetic or other medical causes of death. This in turn may have implications for the individual family and their grieving process, for genetic counselling related to future pregnancies and for prevention of SUDI at a community level.

In response to recommendations from the NSW Child Death Review Team, the NSW Department of Premier and Cabinet led a cross-agency working group to improve the interagency response to SUDI. As part of this process, NSW Health has revised the Policy Directive published on July 30 2019. Information from this one-off study will give NSW paediatricians the opportunity for their perspective to be considered.

STUDY OBJECTIVES

1. To identify paediatrician knowledge and use of the current NSW Policy Directive for the Management of SUDI
2. To identify barriers to use of the current Policy Directive
3. To determine paediatrician recommendations for best management of SUDI

CASE DEFINITION

The NSW Health Policy Directive applies:

- When there is an unexpected infant death during an admission to hospital
- Following an unexpected death of an infant outside of hospital, where the infant is brought into an Emergency Department

Sudden Unexpected Death in Infancy is defined as:

The death of an infant less than 12 months of age that was sudden in nature and unexplained.

Exclusions: unexpected death as the result of misadventure leading to external injury (e.g. motor vehicle and accidental drowning).

INVESTIGATOR CONTACT DETAILS

1. Professor Heather Jeffery, Paediatrician and Neonatologist, Professor International Maternal and Child Health, Sydney School of Public Health, The University of Sydney
   Heather.Jeffery@sydney.edu.au
2. Dr Anne Morris, Senior Research Fellow (APSU Representative), Australian Paediatric Surveillance Unit, Kids Research SCHN, The Children's Hospital Westmead, Sydney
   Anne.Morris@health.nsw.gov.au
3. Professor Elizabeth Elliott, Director APSU (APSU Representative), Australian Paediatric Surveillance Unit, Kids Research SCHN, The Children's Hospital Westmead, Sydney
   Elizabeth.Elliott@health.nsw.gov.au

SELECTED REFERENCES

1. Fleming PJ, Blair PS, Pease A. Sudden unexpected death in infancy: aetiology, pathophysiology, epidemiology and prevention in 2015 *Archives of Disease in Childhood* 2015; 100 984-988
2. Bright MF, Vink R and Byard RW. Neuropathological developments in Sudden infant death Syndrome 2018 VOl 21(6)515-521 Pediatric and Developmental Pathology
3. Wong LCH, Behr ER. Sudden unexplained death in infants and children: the role of undiagnosed inherited cardiac conditions Europace (2014) 16, 1706–1713 doi:10.1093/europace/euu037
4. Morse AM, Kothare SV. Pediatric Sudden Unexpected Death in Epilepsy Pediatr Neurol 2016; 57: 7-16
5. NSW Policy Directive : Management of Sudden Unexpected Death in Infancy
   https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2019_035
6. NSW Child Death Review Team 2019, *Biennial Report of the Deaths of Children in NSW: 2016 and 2017; incorporating reviewable deaths of children*. NSW Ombudsman June 2019. Page 63. NSW Ombudsman, Sydney

   SIDS Sudden infant and early childhood death: The past, the present and the future edited by Jhodie R. Duncan and Roger W. Byard https://www.adelaide.edu.au/press/titles/sids

   Lutz TL, Elliott EJ, Jeffery HE. Sudden unexplained early neonatal death or collapse: a national surveillance study. Pediatr Res. 2016. https://www.ncbi.nlm.nih.gov/m/pubmed/27384403/

AUSTRALIAN PAEDIATRIC SURVEILLANCE UNIT
Kids Research, Sydney Children's Hospital Network
Locked Bag 4001, Westmead NSW 2145
Phone: 02 9845 3005 • Email: SCHN-APSU@health.nsw.gov.au • Fax: 02 9845 3082

The APSU is affiliated with the Faculty of Medicine and Health, The University of Sydney
and the Royal Australasian College of Physicians (Paediatrics and Child Health Division)
The APSU is funded by the Australian Government Department of Health.
This study has been approved by a Human Research Ethics Committee properly constituted under NHMRC guidelines.