

GenV Special Care Nursery Registry Scoping Report

Executive Summary

(See [full paper](#))

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Abstract

Newborn babies who require specialist care account for substantial immediate and lasting burden of disease. The Australian and New Zealand Neonatal Network (ANZNN) has made major contributions towards improving the quality and consistency of neonatal intensive care data collection, but no comparable data set exists for the babies admitted to a special care nursery (SCN). Working with newborn experts across the state, this report aims to inform interim and final decisions as to whether to implement an ANZNN-harmonised extraction of data for all such babies born across Victoria, Australia, and entering GenV over two full years from mid-2021. This report considers requirements, likely data set, feasibility, stakeholder acceptability and consultation requirements, and funding and resourcing needs. We conclude that an SCN data extraction appears feasible, would generate translatable evidence, and could lay the groundwork for a stand-alone ongoing registry post-GenV.

Keywords

Special care nursery; Registry; Sick newborns; GenV

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Aboriginal acknowledgement

We acknowledge the Traditional Custodians of the land upon which we are situated. We pay our respect to their Elders—past, present and emerging.

Executive Summary

Objective

To inform interim and final decisions as to whether GenV will implement a 'within-GenV registry' for babies admitted to special care nurseries (SCN). This registry would contain additional standardised clinical data for all babies enrolled in GenV over two full years from mid-2021 who are admitted to an SCN or neonatal intensive care unit (NICU) but do not meet registration criteria for the Australian and New Zealand Neonatal Network (ANZNN) data set. The proposed SCN data set would potentially contain (a) a subset of the items in the ANZNN Data Dictionary and (b) additional items relevant to SCN admissions.

Nature of proposal

- To outline the value and rationale of routine extraction of an additional data set for all GenV babies admitted to NICU and/or special care nurseries across Victoria.
- To consider the feasibility and resourcing to achieve this goal.
- To develop the methods to implement the data extraction, including a ready-to-go data extraction tool complementing the ANZNN data set, in consultation with newborn experts across Victoria.
- To provide essential information for funding proposals.

Findings

Standardised SCN data extraction appears feasible within GenV. We present an extraction tool developed in consultation with newborn experts across Victoria that complements and harmonises with existing ANZNN data for the sicker babies entering NICUs. Its implementation would generate a 'depth' cohort (a substudy within GenV) that equates to a 2-year statewide registry within GenV. We also lay out the steps needed to engage all SCNs and to implement and tailor this data extraction.

Conclusion and impact

We conclude that SCN data extraction appears feasible within GenV, and could provide much-needed evidence to develop better models of care, and statewide and nationwide guidelines for sick newborns. It could also provide mechanisms to monitor and benchmark care and provide a translational platform to conduct trials during the GenV birth window. Depending on the feasibility demonstrated, perceived value and stakeholder appetite, it could also provide a 2-year window to plan a subsequent transition to a stand-alone ongoing SCN registry post-GenV.