

Big data for small babies; the impact of gestational age on health and educational outcomes in New Zealand

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'Optimal' care pathways for pregnant women at risk of delivering their baby at extremes of gestational age are uncertain. While survival for babies born at 23 and 24 weeks gestation is possible, there remain many uncertainties about the implications of resuscitating and offering neonatal intensive care (NICU) to these vulnerable and high-risk infants. The complex decision about whether to initiate resuscitation and admission to NICU is shared between clinicians and parents with ultimately a choice made as to whether, in the event of birth at 23/4 weeks gestation, comfort cares or active intervention are most appropriate for that particular child. There is little robust long-term data on the health outcomes for these children; current decision-making is therefore based on limited international data, local practice and individual clinicians beliefs. As a result, current practice varies widely across NZ and there is a paucity of high-quality NZ data available to inform this decision-making. Similarly, at the other end of the gestational age spectrum, even small decrements in gestational age in the near-term range adversely impact later wellbeing.

To bring some clarity to these difficult and emotive areas of clinical practice, long-term follow up studies of large numbers of infants are needed. New Zealand's collection of governmental administrative and clinical datasets has recently become available for research purposes through the government's integrated data infrastructure (IDI). This newly created linked data source contains data on education, benefits, tax, families and households, health and safety, justice, migration, linked maternity records, well-child checks, hospitalisation datasets, prescription records, student loans and allowances, as well as a number of Statistics NZ survey datasets. This nationwide inter-sector prospectively recorded data set supports a unique opportunity to follow the entire life course of all individuals born in New Zealand as observed by government records, through a 'big data' approach to using the multiple large scale datasets. Such a large data source provides the ideal opportunity to determine gestational age specific health and educational outcomes. Understanding the impact of early life events is essential to provide evidence-based prognoses, and to safely and accurately counsel families about potential long-term outcomes for their child. These data also enable us to test the additional effect of environmental or non-medical influences on outcome; for instance, the amplification of housing-attributable respiratory morbidity in infants born preterm. However, these data are inherently associative; they complement the vast array of translational and biomedical research currently underway that aims to determine causal pathways and to develop novel therapeutic interventions.

This is the first study of its kind and represents a powerful mechanism through which equitable care pathways can be developed for those women at risk of extreme preterm birth. In addition, it provides a robust objective and unbiased portrait of the interaction between medical and environmental factors. These data are therefore essential for policy makers, clinicians and the communities they serve and will enable a transparent process of resource allocation supporting targeted initiatives to optimise life-course wellbeing.