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Data stories and stories as data: Indigenous-led research projects

Nicola Dsouza¹, Rhonda Marriott¹, Paola Vásquez¹, Akilew Adane¹, and Dezerae Miller¹

¹Ngangk Yira Institute for Change, Perth, Australia

Background

Ngangk Yira Institute for Change is an Indigenous-led research organization working closely with Aboriginal communities both locally and nationally. One of its centres is the Yorga, Maaman and Koolanga Research Centre which focuses on supporting Aboriginal mothers, families, and communities from pregnancy through parenthood, aiming to promote empowered, healthy children and families. Core research projects include: ICARE, Baby Coming, You Ready? and Replanting the Birthing Tree project explore various aspects of the first 2,000 days of life, capturing the experiences, needs of parents and babies to inform culturally safe interventions and policy change.

Methods and Results

In Western Australia, the Developmental Pathways custodians manage the data linkage program, PeopleWA, which connects researchers with government agencies and facilitates the translation of research into policy and practice. The projects use different datasets such as the Hospital Morbidity Data System, Mental Health Information System, Midwives Notification System, Emergency Department Data Collection and WA Registry of Births, Deaths and Marriages. Data are securely transferred with identifying fields removed, and access is governed by protocols. A data sovereignty approach ensures that Aboriginal and Torres Strait Islander peoples lead and guide the aspects of this work and maintaining cultural oversight.

Conclusion and Implications

All research aligns with Indigenous data sovereignty principles outlined in Maiam nayri Wingara and applies Indigenous CARE and FAIR principles. The linked data is to be used to better reflect community priorities and are relevant to lived experiences, supporting policy and service development that is responsive to Aboriginal families' needs.

