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Renal disease in Aboriginal children and young adults (ARDAC): evolution to a data linkage study

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Focus of Presentation: The 'Antecedents of Renal Disease in Aboriginal Children and Young Adults' (ARDAC) Study was the first large population-based longitudinal cohort study seeking to identify the early emergence and trajectory of kidney disease among Aboriginal and non-Aboriginal children. Since 2002, 3758 young people (2155 Aboriginal and 1603 non-Aboriginal) from across New South Wales, Australia, were enrolled, with clinical data collected every two years. However, the confluence of a maturing cohort, local issues (bushfires), and the COVID19 pandemic made follow-up screenings a challenge. As such, in 2021, ARDAC evolved into a data linkage to evaluate the cohort's healthcare utilization and kidney health trajectory.

Findings: The ARDAC dataset contains 340 variables, which have been linked to a further 878 variables from state and federal government agency administrative datasets. Data incorporated in the linkage includes perinatal, pharmaceutical, hospital admissions, literacy, kidney health, kidney transplant, and death data. Preliminary findings from this unique and important linkage will be the focus of this presentation.

Conclusions/Implications: The breadth and scope of this data linkage makes it the largest on the kidney health of First Nations Peoples internationally. Analysis will provide a detailed understanding of the healthcare usage of this population and identify critical gender-specific timepoints and risk factors to inform the development of co-designed, community-driven strategies for future

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Key messages: With governance provided by a strong Investigator-Advisory Group nexus, with extensive representation from Aboriginal and Torres Strait Islander researchers, patients, and community leaders, ARDAC is an exemplar of Aboriginal community-led research.