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Linking Pathology Datasets – Trials and Triumphs

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Background with rationale

The burden of chronic kidney disease (CKD) has increased rapidly in Australia over recent years. The financial cost of treating people with end-stage kidney failure by conventional models of dialysis or transplantation represents a substantial healthcare cost and is likely to continue to increase in coming years. Tasmania, the smallest state of Australia and its only island state, has the highest burden of chronic disease nationally, including kidney disease. The aim of this study was to use data-linkage to develop a state-wide dataset to quantify the burden and distribution of CKD, including identifying barriers to dialysis treatment services.

Methods/Approach

The Tasmanian Data Linkage Unit (TDLU) used a complex data linkage design comprising seven disparate datasets representing public and private pathology, public hospital admitted patient and emergency department data, cancer records, dialysis and transplant records and death notifications. A cohort was selected from public and private providers of pathology services in the state to support the establishment of a comprehensive researchable dataset. The datasets spanned the period 2004-2017 and included linkage of both state and national data.

Results

The study cohort comprised just under 490,000 individuals in the Tasmanian population from the two pathology datasets, with a combined total of 1,347,00 total links made across all datasets. Individual unit records were geocoded according to the Australian Statistical Geographic Standard (2011) with over 92% of the 374,000 unique addresses identified in the public pathology dataset geocoded to address level.

Conclusion

The final researchable dataset compiled by the research team following linkage is providing an enormously powerful asset to help answer questions specific to CKD in Tasmania, and that in turn is anticipated to result in greater access to services, improved care and better patient outcomes.

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