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Evolving population data linkage services to transform large-scale biobanking services

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Introduction

Many population data linkage centres have been established to provide a mechanism for making linked administrative data available to approved third parties within robust governance frameworks. While current models support a wide variety of research, modifications are required for linked administrative data to better position biobanking research infrastructure.

Conclusion/Implications

Modest changes to population data infrastructure have significant potential to enhance biobank research infrastructure. By fast tracking biospecimen accrual for diseases of population subgroups of strategic importance, this new service is intended to promote biobank viability, accelerate the pace of clinical trials recruitment and improve patient access to trials.

Objectives and Approach

We have sought to reconfigure population data linkage services to enhance the value of a newly established state-of-the-art population and disease biobank embedded within a state based pathology network, equipped with robotic technology, with the capacity to store and process more than 3 million samples from participants consenting to data linkage and future unspecified research.

Results

Three data service streams have been developed: longitudinal data linkage, cohort management and targeted recruitment. Traditional infrastructure for population data linkage will support the longitudinal data linkage stream, making data and biospecimens available for research, without direct patient identifiers. Technical and governance changes are necessary to enable the rapid release of contemporaneous patient and health system data for cohort management and recruitment purposes. The cohort management stream seeks to significantly reduce the manual follow-up of administrative data. The newly developed targeted recruitment service will leverage on the jurisdictional data holdings and structure of the health system and pathology network, to identify optimal sites and service providers for patient recruitment at scale, in an expedited manner.