International Journal of Population Data Science

Journal Website: www.ijpds.org

Multiple operating models for data linkage: A privacy positive

Irvine, Katrina^{1*} and Hollis, Stephanie¹

¹Centre for Health Record Linkage, New South Wales Health

Objectives

The data linkage landscape is rapidly evolving and a variety of operating models are used across dedicated data linkage centres. We have reviewed various operating models and redesigned the technical operating models for our multi-jurisdictional data linkage system to better manage new privacy risks, support data custodian participation and improve access timeframes for end users.

Approach

A steering committee with key data custodians was formed to oversee the review and assessment of different operating models, development of local system requirements and conceptual design of new operating models. The development process included consultation with researchers, data custodians and our data linkage community reference group, independent privacy and security impact assessment and review and approval by relevant data custodians and ethics committees.

Results

Critical design issues for data custodians included the separation principle, management of re-identification risk, data integrity, communication with researchers, researcher access and ongoing sustainability. In particular, data custodians desired the flexibility of multiple operating models to enable their participation in data linkage studies and to accommodate specific features of their data collections. A solution that offers cascading levels of data storage and handling on behalf of data custodians has been developed and supported as “privacy positive” in formal Privacy Impact Assessment.

Different operating models can have significant implications for end user timeframes, operational efficiency and linkage quality. Published evidence on comparative outcomes from different models is scant, but the available literature has substantially as-

sisted with our analyses and stakeholder communication around the risk-benefit of new models and the expected realisation of public benefit.

Conclusion

Our data linkage centre will implement new operating models with cascading levels of data handling on behalf of custodians. Sharing or publication of empirical evidence on timeframes, efficiency and quality can provide useful inputs in the design of new operating models and assist with the development of stakeholder and public confidence.

*Corresponding Author:

Email Address: katie.irvine@moh.health.nsw.gov.au (K. Irvine)