Unlocking the potential of health systems using privacy preserving record linkage: A pilot project exploring the research potential of developing a linkable general practice dataset

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Background

General practice is a rich source of health data for research. It is an important resource which can be used to improve patient management, reduce costs and improve patient outcomes. Traditionally, the challenge has been around access to general practice data which remains hard to ‘join up’.

This abstract describes technology developed to support aspirations of the MedicineInsight program to provide linked de-identified general practice data that can be used to derive insights to enable better patient outcomes.

Main Aim

The aim of this project was to use real-world data to identify technical, logistical and analytical requirements throughout the linkage process. Logistical aims covered the negotiation, approval and data acquisition processes, as well as data linkage and data delivery aspects performed by technical and data service stakeholders.

Methods/Approach

Given the sensitivity of the information involved, the project employed a privacy preserving record linkage methodology. This method uses encrypted personal identifying information (Bloom filters) in a probability-based linkage framework to help mitigate risk while maximising linkage quality.

Existing MedicineInsight systems were extended to automatically generate encoded linkage data at each general practice. Pilot linkages were then used to validate the capability/capacity of CDL infrastructure to create secure extensible linked general practice datasets.

Results

The project has successfully developed interoperable technology to create a transparent data catalogue which is linkable to other datasets. This technology has been embedded with MedicineInsight systems and results of the pilot linkages are being evaluated. The project will make recommendations to enable consistent delivery of linkage services across care settings.

Conclusion

Outcomes from the project will improve delivery of record linkage services to the health and broader research community. Using linked data from across the care continuum, researchers will be able to evaluate the effectiveness of service delivery and provide evidence for policy and programme development.

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