International Journal of Population Data Science

Journal Website: www.ijpds.org

If You Link It They Will Come, If They Like It They Will Stay: The Utah Population Database as a Model for Creating a Confidential Linked Population Health Research Registry

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Introduction

There is increasing demand for so-called big data for a range of uses. One of the challenges is the method by which these data are obtained, the identiers used for record linking, how they are linked, and the secure manner by which researchers may use these data ethically.

Objectives and Approach

The Utah Population Database (UPDB) has a long history of linking records derived from genealogies, death/birth certificates, medical diagnoses, and census records. This infrastructure offers a unique resource for genetic, public health, geographic and demographic investigations. The UPDB now holds information on 11 million individuals linked into multigenerational pedigrees. New data opportunities have arisen that provide value added to UPDB but that raise important infrastructure and privacy issues. This presentation will provide details and strategies for dealing with new challenges of adding new and complex sources of data.

Results

The record linking and data security measures developed for the construction of the UPDB, we suggest, is a model for other states and provinces. The ability for UPDB to obtain, store, link and dispense a diverse set of data at the individual and genealogical level for the research community for over forty years suggests that it has elements that are potentially replicable for other locations. The development of a unique and independent regulatory body, the Resource for Genetic and Epidemiologic Research (RGE), which oversees access to UPDB data, speaks to this as a model for protecting the confidentiality of the data while enhancing secure to researchers. We show the technical, statistical, legal and regulatory methods that have provided data for nearly 300 distinct health-related studies.

Conclusion/Implications

This study demonstrates how the careful and consistent application of secure data management and regulatory oversight allows for the development of the UPDB and its ability to link diverse data sources for the research community. The legal and administrative strategies used serve as a model for other states and provinces.

http://dx.doi.org/10.23889/ijpds.v3i4.1015