

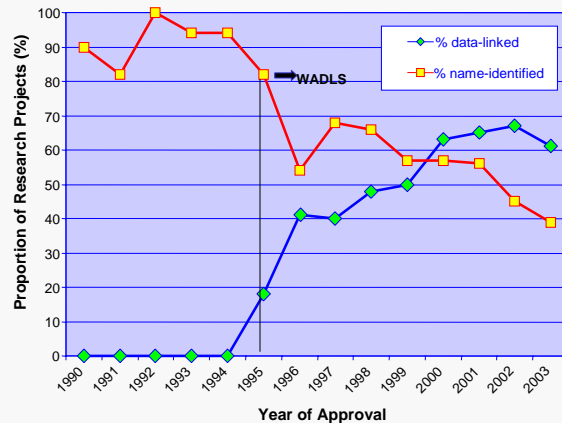
Impact of WA Data Linkage on Protection of Privacy in Health Research

Brooke Trutwein
C. D'Arcy J. Holman
Diana L. Rosman

Introduction

- Concern exists surrounding the use of linked data and its impact on privacy of health data
- Concerns are partly fuelled by the recent growth in computer technology (1) that now enables electronic information to be obtained and distributed rapidly and effortlessly
- Differences exist in the way privacy legislation is interpreted (2,3) and how the processes and outcomes of health data linkage are conveyed to the general population
- Systematic population-based data linkage allows researchers to access information they need to answer a wide range of epidemiological research objectives without accessing named data
- It is plausible that more research is now being done in WA, but with far less invasion of privacy.

Figure 1. Proportions of name-identified and linked data extracts for research in WA



Aim

To determine if WA health researchers are now using less name-identified data, to conduct population-based research, since the inception of the Western Australian Data Linkage System (WADLS) in 1995.

Method

- Review of WA Department of Health administration records from 1990-2003.

Route A: Project does not require linked data

Route B: Project requires HREC & CHIC approval for linked data - involves identifying data

Route C: Project requires HREC approval for linked data - does not involve identifying data

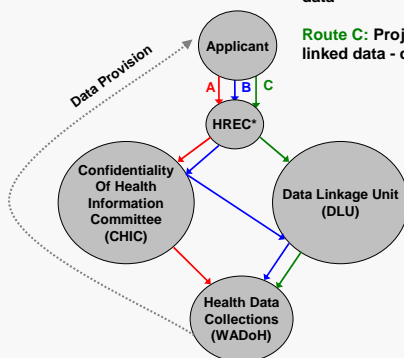


Figure 2. Flow process of research application to access WADoH data

*Health Research Ethics Committee

Main Results

- Rise in the usage of linked data
- Fall in the usage of name-identified data

Figure 1 summarises the results and shows that research projects requesting linked health data increased from 0% in 1994, the year prior to commencement of the WADLS, to 61% in 2003. Research projects using name-identified data fell from 94% in 1994 to 36% in 2003. Pearson's correlation coefficient between the two trend lines is -0.94 ($p < 0.001$) (4).

Conclusion

- The first study of its kind in WA
- Data linkage conducted in accordance with best practice protocol is an effective intervention now available to conserve patient privacy in a research rich environment (4)

Data linkage in WA provides a means for health researchers to access health information about the WA population. However, a central repository of data about WA citizens does not exist; rather the WADLS provides a facility where information from two or more sources can be brought together (4). This linking of health information is not performed by health researchers, instead linking is performed by the Data Linkage Unit staff. However the bringing together of de-named data is only carried out when database custodians and ethics committees are convinced the research project is justified (4) based on the research application process as shown in Figure 2.

References

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For more information visit <http://dla.org.au> or contact brooke.trutwein@health.wa.gov.au ph:(08) 9222 2370