Sharing Data When You Are Malcolm in the Middle

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INTRODUCTION

In Australia, government agencies are working towards making administrative data available to the public and to researchers. In the past many researchers have obtained administrative data through personal contacts and relationships with government agency staff. However this type of informal arrangement is no longer acceptable in many cases because of: a) the type and volume of data now becoming available through collaborative arrangements between research groups and government agencies and other organisations (e.g. NGOs) and b) the desire of research groups to publish their findings or to make their research available to other groups (e.g. other government agencies).

MALCOLM IN THE MIDDLE

It is not uncommon for some researchers to obtain research data from one or more organisations and to make this data (or their research findings based on this data) available to staff in another organisation. In some cases the end-users could even be a selected group across several organisations or even the public at large. To make the situation more complex, some of the data provided from the source organisation may have been collected from other organisations.

This was the situation facing a research group at Griffith Health Institute’s Population and Social Health Research Program. The research group had developed a GIS decision support tool for health promotion officers, health service planners, decision makers and environmental health officers working with Queensland Health, the Greater Metro South Brisbane Medicare Local, Logan City Council and Griffith University researchers.

The system, named Epidoros (www.epidoros.org), is based on ArcGIS. It uses data from many sources to address the broad determinants of health such as the environment, financial resources, socio-economic measurements or community assets. While the majority of data used comes from the Australian Bureau of Statistics and other public sources, there is a substantial amount of data being sourced from local agencies and government authorities including local government.

It was determined that the semi-formal arrangement in place with the developing partners would no longer suffice. The research group involved obtained the services of a solicitor, Joe Siracusa, to develop both a standard data contributor’s agreement and an end-user's agreement. Joe had experience in this area working on the legal issues on data sharing in the Australian National Corpus (http://www.ausnc.org.au/).

The end-users agreement for using Epidoros needed to reflect any terms and conditions of data contributor’s agreement/s. It was decided that the end-user’s agreement for use of the system would be with the end-user’s employer who is the “subscriber” to the system. The subscribing organization is then responsible for the employee’s actions (i.e. the end-user).

At the same time many other research groups and Griffith, at the institutional level, are developing mechanisms and repositories to share data. In all of these cases the host research group or institution becomes “Malcolm in the Middle”. The work undertaken for the Health project described above provided a framework and a checklist used to help inform decision makers about what data to share and at what level.

This presentation will outline the framework used to develop the contributor’s agreements and discuss the essential elements of both contributor and end-user agreements.
ABOUT THE AUTHOR(S)

Malcolm Wolski

Malcolm Wolski is Associate Director (Scholarly Information and Research) in the Division of Information Services at Griffith University where he is responsible for Innovation and Business Development working closely with eResearch Services. Prior to taking up his current position, Malcolm worked in various management roles in eResearch and other information and communication technology service units.

Malcolm has an active ongoing role in assisting research groups to build information systems to manage the capture, collection and preservation of data, to develop collaboration and communication tools and to use advanced information technology tools and techniques during research.

Joseph Siracusa

Joe Siracusa is a solicitor who has held senior legal positions with national law firms in Canberra, Brisbane and Sydney, as well as with the Queensland Department of Justice and Attorney-General. He was awarded an Australia Day Achievement Medallion in 1998 for his work with that department. Before establishing Siracusa Legal (http://www.siracusalegal.com.au), Joe was a partner in a Brisbane-based commercial law firm.

In these roles he gained experience acting for a wide range of Commonwealth, Queensland and New South Wales government departments and agencies, and Australian and foreign companies, as well as universities and not for profit organisations. He has also worked as corporate counsel with a leading Australian telecommunications company.

Joe is a member of the Intellectual Property Society of Australia and New Zealand, a member of the Advisory Council of the Centre for Public, International and Comparative Law at The University of Queensland and has been a sessional academic in law at the Queensland University of Technology, The University of Queensland and Griffith University.

Natalie Kent

Natalie Kent is a Project Manager in the field of health informatics. She has worked on a number of projects for Queensland Health including pioneering its first electronic integrated clinical record in 2006. Natalie has led project teams in the development and implementation of various health information systems in both acute and community healthcare settings. In her current role as Program Manager for the Chronic Disease Place-Based Initiative, she works with universities, councils and non-government organisations to initiate innovative information management strategies that support better health outcomes for the local community. She is principal investigator for the Predictive Modelling for Chronic Disease Hospital Avoidance project as part of a joint venture with the Australian eHealth Research Centre and is managing the implementation of a geographical information system for health planning in conjunction with the Griffith Health Institute.