

THE ETHICAL, LEGAL, AND SOCIAL
ACCEPTABILITY OF HEALTH DATA
LINKAGE IN THE AUSTRALIAN
CONTEXT: AN INVESTIGATION OF
CURRENT PRACTICES, PERCEPTIONS,
AND PUBLIC ATTITUDES

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ABSTRACT

Vast collections of electronic data are held by a variety of health organisations, including government and non-government agencies, hospitals and universities. Data linkage involves combining such data sets for secondary purposes such as population health research. Data linkage currently occurs in Australia and is rapidly developing into a key tool both for Government and researchers. There are considerable benefits to data linkage, including the ability to conduct high quality research which may lead to advances in clinical practice, the development of public health policy, the prevention of disease, the conduct of public health surveillance. However, the associated ethical and legal issues require analysis and consideration to determine the moral and legal ramifications of such uses of data and so that indeterminate ethical and legal issues do not restrict agencies' and researchers' ability to fully support a co-ordinated national approach to data linkage. Lagging substantially behind recent developments in Australia and internationally is knowledge and clarity about the public's acceptance of data linkage practices.

This thesis presents findings of a multi-phase project comprising a theoretical component and two empirical studies. The theoretical component examines the ethical, legal and social acceptability of data linkage (Phase 1), and two empirical components (Phases 2 and 3) present the views of community members about data linkage.

In Phase 1 I argue that the non-consensual use of data is morally acceptable under certain conditions. It is currently legally acceptable in Australia despite certain impediments arising from the strict interpretation and complexity of Australian privacy legislation, an issue which is currently being addressed through amendments to the Australian Commonwealth privacy legislation.

Phase 2 comprised in-depth face-to-face interviews to determine participant views in relation to privacy and their preferred consent options in four hypothetical data linkage scenarios. Phase 3 involved the administration of a questionnaire before and after a citizens' jury to gauge, amongst other issues, these citizens' attitudes to health data linkage and to determine whether the provision of detailed information about the data linkage process, as well as the ethical and legal issues it raises, had an impact on previously held views and perceptions.

Participants quickly acquired an understanding of data linkage. They generally supported the non-consensual use of data provided that there were protection mechanisms in place such as the removal of identifiable data. Most participants believed that consent should be sought for data linkage projects if the linkage were being conducted by researchers with fully identifiable data. Participants weighed up opposing values such as the need for privacy against the potential benefits arising from data linkage research using an informal moral reasoning framework. The wealth of justifications for their decisions highlighted the participants' values.

This research aims to contribute to the Australian and international literature at a time when this method of combining data is being considered by researchers world-wide. In addition, the findings will assist in discussions and activities in relation to the development of the national data linkage framework, a key Australian Government research target within the next five to ten years.

THESIS STATEMENT

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution to Vicki Xafis and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

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* Xafis, V., C Thomson, AJ Braunack-Mayer, KM Duszynski, and MS Gold (2011). "Legal impediments to data linkage." Journal of Law and Medicine **19**(2): 300-315.

Vicki Xafis, PhD Candidate, The University of Adelaide

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PRESENTATIONS ARISING FROM THIS THESIS

Contributors, Date, Location	Conference	Title
V Xafis, AJ Braunack-Mayer, C Thomson, MS Gold 2012, 26-29th June (NETHERLANDS, Rotterdam)	11 th World Congress of Bioethics	<i>The lay person's view of privacy in data linkage - do theory and people's perceptions intersect? (Poster)</i>
Ms Vicki Xafis, Ms Katherine Duszynski, Professor Annette Braunack-Mayer, Dr Michael Gold 2011, 29th October (AUSTRALIA, Adelaide)	Public Health Association of Australia (SA) Conference 'Population Health: Working across sectors, settings and ages'	<i>Public understanding of data linkage - indications from a South Australian citizens' jury.</i>
V. Xafis, A. J Braunack-Mayer, C. Thomson, M.S. Gold, K. Duszynski 2010, 20-22nd September (UNITED KINGDOM, University of Oxford)	International Data Sharing Conference	<i>Ethical, legal and social considerations in administrative health data linkage in Australia.</i>
Ms V Xafis, Prof C Thomson, Prof A Braunack-Mayer, Dr M Gold, Ms K Duszynski 2010, 17-19th August (AUSTRALIA, Adelaide)	Public Health Association Australia 12 th National Immunisation Conference	<i>Legal impediments to data linkage: Remoto impedimento, emergit actio</i>
Ms Vicki Xafis 2010, 1-4th July (AUSTRALIA, Adelaide)	Australasian Bioethics and Health Law Conference	<i>Privacy considerations in data linkage.</i>
Ms V Xafis, A/Prof A Braunack-Mayer, Dr M Gold, Prof C Thomson 2009, 31st October (AUSTRALIA, Adelaide)	2009 State Population Health Conference: Challenges and Successes in Population Health	<i>Health data linkage in Australia: analysing the ethical, legal and social issues and exploring public perceptions and values.</i>

AWARDS ARISING FROM THIS THESIS

I was awarded the Faculty of Health Sciences Postgraduate Travelling Fellowship to support my attendance at the International Data Sharing Conference, 20-22nd September 2010, University of Oxford, United Kingdom.

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Coming to the end of my thesis I look back and think about all the people who helped along the way and enabled me to reach the point of writing this section. While this is one of the most important pieces of research I will ever tackle on my own, it could not have been completed without the support and guidance of a number of people.

First and foremost, I am indebted to my supervisors, Professor Annette Braunack-Mayer, Associate Professor Michael Gold, Professor Colin Thomson, and Professor Garrett Cullity. I consider myself very privileged to have worked with this exceptional group of academics over the past few years, to have been guided by them, to have learnt from them, to have been offered opportunities to develop as an academic, and to have been supported by them in very difficult personal times. Not only are they exceptional in their fields but they have proven to be remarkable human beings with compassion and understanding. I particularly thank Annette and Mike for their unwavering support and understanding.

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Ms Katherine Duszynski, Project Manager of the VALiD Study, contributed the diagram depicting the data linkage process used in Phase 2 of the thesis and assisted with the mail-out of the explanatory materials and the feedback to participants. Katherine also contributed to the materials which were designed for the Citizens' Jury (Phase 3). Katherine is one of those individuals you consider to be privileged to have met and with whom you wish to maintain a lasting friendship.

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A thesis is by no means a piece of work completed with technical assistance alone. There is a very human dimension to it all.

On a number of occasions during my candidature, I was asked to present the student's perspective to new PhD candidates so that they would be prepared, encouraged, and informed as they entered this new phase of their lives. What I always stressed during these talks is the fact that this large body of research needs to be completed within a limited number of years, and try as we may, it is impossible to put the rest of our lives on hold. Amidst the inevitable dramas of the research itself, there would be great life events some of which included weddings, births, deaths, divorces, and health issues, to name but a few.

What had previously been a simple observation later became a constant reminder in my own life. The events that unfolded from the second year until the final year of my studies were the most significant I have ever experienced and came like an avalanche, one after the other, as if to test my ability to cope. I am truly blessed to be surrounded by extraordinary people. I would like to thank them all for their support and for the laughter and joy they have always brought into my life.

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This thesis, entitled: “The Ethical, Legal and Social Acceptability of Data Linkage in the Australian Context: An Investigation of Current Practices, Perceptions, and Public Attitudes”, is one component of a four-part study entitled *Vaccine Assessment Using Linked Data (VALiD) Safety Study*.

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As this thesis was one component of VALiD Study, I feel that it appropriate to acknowledge the various **VALiD Advisory Committees** comprising the following members:

Overall Advisory Committee: A/Prof Michael S Gold, Chair (University of Adelaide, SA); Prof Annette J Braunack-Mayer (University of Adelaide, SA); Prof Philip Ryan (University of Adelaide, SA); Prof John McNeil (Monash University, Vic); Dr Lee Taylor (New South Wales Department of Health, NSW); Dr Jim Buttery (Royal Children’s Hospital, Vic); Prof Elizabeth Elliot (The University of Sydney, NSW); Prof Colin Thomson (University of Wollongong, NSW); A/Prof Glenda Lawrence (University of New South Wales, NSW); A/Prof Jane Freemantle (University of Melbourne, Vic); A/Prof Elizabeth Roughead (University of South Australia, SA); Dr Gary Lacey (Therapeutic Goods Administration, ACT); A/Prof Peter Richmond (University of Western Australia, WA); Sean Tarrant (Medicare Australia, ACT); Tony Woollacott (SA Health, SA).

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PREFACE

A journey of a thousand miles must begin with a single step.

Lao Tzu [The Way of Lao-Tzu, 64]

In retrospect, I did travel a thousand miles to reach the point of commencing my doctoral studies, and then another thousand to reach the point of writing this section. Not by design, my education and professional career have followed a somewhat unusual path. Each turn, however, has offered a new dimension thus helping to integrate my current views within a multidisciplinary base.

Having obtained my teaching qualification, I spent many years teaching English as a second language and then studied linguistics, this already appearing to be a backward process. I felt that I discovered myself when, coincidentally, I fell into research ethics as a researcher, and then obtained a Master of Bioethics while at the same time having moved on and working as a professional in the area of research ethics.

Initially, my views on research ethics and the application of the law to research activities were rigorous and unyielding, shaped in the culture of the institution where I first encountered the discipline of ethics. Over time, however, as I developed more experience in the area, and aided by both my studies in bioethics and later by teaching medical ethics, I developed a more flexible and balanced approach to the tensions that often exist between moral values and other important interests when trying to determine the most ethically acceptable course of action. In addition, I began to better recognise that the conduct of research within a legal framework is also often fraught with tensions.

Coincidentally, once again, doctoral research became available in the already defined research area of data linkage and vaccine safety surveillance. As much as I would like to say that I had pondered the ethical, legal and social acceptability of data linkage long

before realising my dream of conducting research in the area, I obviously cannot. What I have pondered for many years, however, are issues of privacy, consent, research and policy transparency, which includes uses of personal and health data, and the application of the law in research and policy development.

My teaching background offers me the confidence that people with no prior knowledge of an area can, and do, acquire an adequate understanding of the most complex areas of human activity provided that the presentation of information is digestible, and that they have some interest in understanding it. I dare speculate that we all have an interest in data linkage, even if we are members of the general public, given that it potentially involves the use of our very own personal and health data.

Before articulating the research problem, research questions, aims and objectives of this research and the theoretical framework within which it was conducted, I present in the introductory chapter a non-technical description¹ of what data linkage entails and does not entail, aided by a diagrammatic representation of the process considered best-practice due to its attention to privacy protections.

¹ Greater detail on the technical aspects and some benefits of data linkage are available in (1) presented in Chapter 4. Chapter 4 comprises a legal paper published as part of the thesis and necessarily contains a brief description of some key technical features of data linkage as well as benefits arising from such activities. Hence, I felt that a non-technical description of the process was appropriate in the Introduction.