

Background

“Data rich, information poor” is a common cliché in these days of massive data processing systems and databases, and it has been especially true in the health field. The information being extracted from these databases and the questions being addressed are often limited to the operational needs of the owners (hospitals, state and national health departments). Because the information is not linked between jurisdictions, there is little chance of producing real knowledge, findings that will actually change clinical practice and improve patient outcomes.

To address this situation, the University of Melbourne held a health informatics roundtable on May 15 2008, bringing together participants including clinicians, researchers, educators and representatives from all levels of government. The roundtable produced a set of concrete and achievable research proposals, as well as proposals to overcome a number of “roadblocks” that are common to most population level health studies.

The roundtable discussed a number of themes for research based on sharing of data that is currently kept separate within organisations across various government levels and jurisdictions. It also identified specific research projects within each theme. These projects are only suggestions, and many other projects would be possible under each theme, limited only by the relatively small amount of funding that would be needed for most, and the creation of linkages between the datasets.

Summary

The roundtable attempted to identify some concrete research proposals which are achievable today with moderate funding. It also looked at some of the main obstacles facing such proposals, and possible mechanisms to overcome them. Australia has some unique databases which, if utilised fully, could provide major insights into population health issues both nationally and internationally. The results of the roundtable are presented below.

Further details of the proposals and a list of participants can be obtained by contacting health-informatics@unimelb.edu.au

Acronyms:

ABS Australian Bureau of Statistics
AIHW Australian Institute of Health and Welfare
DOHA Department of Health and Ageing
GP General Practice / Practitioner
MBS Medicare Benefits Schedule
NCRIS National Collaborative Research Infrastructure Strategy
PBS Pharmaceutical Benefits Scheme
VAED Victorian Admitted Episodes Dataset
VEMD Victorian Emergency Minimum Dataset

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Theme	Major Research Proposals	Data Sources	Other possible proposals
Use of untapped health-related data	<ul style="list-style-type: none"> • Create a “Register of Data Registries” • Effect of early childhood health on later childhood outcomes 	Datasets from all players in the health field, including: <ul style="list-style-type: none"> - Hospitals / state health depts. (VAED, VEMD and disease data, Births Deaths and Marriages) - Federal agencies (MBS and PBS data, AIHW) - GP-held data and private diagnostic data - Others data sources (ambulance, psychiatric, etc) - VAED and VEMD data - Peri-natal, Birth outcomes and Infant Welfare 	<ul style="list-style-type: none"> - Investigation of linkage of GP data with public health datasets - Linkage of school health records with other childhood health data - Investigation of Sudden Epileptic death in the community (Death Registry and hospital diagnosis records) - Encouragement of individuals to become “health data donors”, and establishment of a mechanism to enable this at all levels of the health system
Linkage to non-health datasets	<ul style="list-style-type: none"> • Investigation of Socio-economic factors in the incidence of diseases • Investigation of the effect of climate on the spread of Ross River Fever 	<ul style="list-style-type: none"> - State level admission and disease data - Community- level ABS data, including social and economic disadvantage, housing, education, employment - Possible links to community level police data - State level admission and disease patterns over the past 30 years, by locale - Climate records for the same period and locales 	<ul style="list-style-type: none"> - Investigation of other environmental factors in the incidence of diseases, e.g. land use and the incidence of cancers
Evaluation of Interventions	<ul style="list-style-type: none"> • Evaluation of public health campaigns targeting adult obesity • Post-marketing surveillance of the effect of a new drug on the health of the target population 	<ul style="list-style-type: none"> - State health departments – VAED and Outpatient records of attendance - Departmental research databases or GP databases which include height and weight or Body Mass Index - Market research surveys into awareness of advertising campaigns - State health departments – VAED and Outpatient records of attendance - Medicare / DOHA – PBS records of prescriptions for the drug, and drug costs / subsidies 	<ul style="list-style-type: none"> - Evaluation of the effectiveness of marketing campaign aimed at childhood obesity, possibly including access to school health records of height and weight before and after the campaign
Indigenous Health	<ul style="list-style-type: none"> • Analysis of factors other than traditional health interventions on the incidence of diseases in local indigenous communities • Analysis of the effectiveness of future intervention policies 	<ul style="list-style-type: none"> - State health dept records - ABS census and economic data - Other data. E.g. police records, school records - State health dept records - Other databases that are available, e.g. alcohol sales, early childhood data, police records, school literacy records 	

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Area	Current Obstacles	Possible “Enablers” for success
Ethics, Privacy and Limiting Legislation	<ul style="list-style-type: none"> - Lack of “mutual recognition” or a mechanism to make “global” ethics submissions, even at the state level - Lack of a standard template for applications for data access - Current legislation which severely limits possible uses of data from some datasets 	<ul style="list-style-type: none"> - Web Portal with a list of “data custodians” for all health and related datasets, at all levels of jurisdiction, and including requirements for access to their data and application forms and guidelines - Support for NCRIS and other initiatives to develop a national (or at least state-wide) framework for cooperation in data linkage of health information - Encourage studies detailing the cost of not linking data from all possible sources
Researcher Experience, and available toolsets	<ul style="list-style-type: none"> - Limited number of researchers who have had training and experience in population health research - Lack of information about available tools for this type of research, e.g.: <ul style="list-style-type: none"> o Extraction of data from various source databases o Transmission of data, including security considerations o Data linkage, including information about cost and effectiveness / complexity of different tools o Data quality and cleansing tools o Data analysis tools and techniques – what tools are available, at what cost, and when to apply each type of tool 	<ul style="list-style-type: none"> - Web Portal to also include resources and lessons learned in previous studies, e.g.: <ul style="list-style-type: none"> o Researchers who have completed research projects in the past, and the type of project o Comparison of tools in each category, including cost, ease of use, areas of applicability, potential problems, and researchers/projects which have used the tool successfully