

CHAPTER TWELVE

RATIONALE FOR ACCESS TO PUBLIC SECTOR INFORMATION

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INTRODUCTION

New technological methods and computer capacity now permit the acquisition, storage, linkage and analysis of large data sets from public sector agencies. The most challenging and ‘wicked’ problems (social or environmental) facing our society demand the best data to ascertain longitudinal trends accurately and across all groups in the population to enable the most cost effective decision making. If we have the capacity to improve situations for people, deliver more effective services, prevent diseases or other problems, avoid or ameliorate damaging environmental problems and so on, and if we do not do so, we are negligent. Public sector agencies collect a significant amount of information, much of which is not used or used simplistically or ineffectively to address major problems or to make public agencies more effective and accountable to the communities they serve. In Australia, such data exist in both Federal and state agencies, non-government organisations and within academic institutions. This paper makes the case for increased access to, and better use of, such data, with examples that are vital to Australia’s future success and prosperity.

THE CHALLENGES OF ‘WICKED’ PROBLEMS IN TODAY’S SOCIETY

Australia, along with other developed countries, is facing increases in major problems such as environmental degradation, climate change, child abuse and neglect, mental health problems and disengaged youth. We have data to show that these problems exist and are increasing; that they share certain characteristics of so called ‘wicked’ problems¹: they are difficult to clearly define, have many interdependencies and multiple causes, are often not stable, have no clear solution and are socially complex. Some wicked problems are characterised by chronic policy failure and hardly ever sit within the responsibility of only one organisation or one set of professionals. Figure 1 lists some of these ‘wicked’ societal challenges which appear to be increasing in Australia and in other developed countries.

¹ Australian Public Service Commission (APS) (2007). *Tackling Wicked Problems. A Public Policy Perspective. Contemporary Government Challenges*. Canberra.

Poor Health and Wellbeing

- Low birth weight
- Complex diseases (asthma, diabetes, obesity)
- Mental ill health
- Substance abuse
- Teenage pregnancy
- Disabilities

Social Dis-ease

- Child abuse/domestic violence
- Behavioural problems/unrest
- Educational problems
- Juvenile crime
- Workplace stress
- Reduced social human capital
- Terrorism

Environment

- Climate change
- Degradation
- Water
- New and emerging infections

Figure 1: Societal changes

Our research is suggesting that these problems are not only increasing in incidence but also in severity and complexity (e.g. children are more likely to have more than one problem), are occurring at younger ages than they used to, they share complex antecedents, are costly to treat or manage and are causing crises in the various services (health, mental health, education, justice, child protection).² We have also some data on the risk and protective factors for these problems – interestingly we may be able to explain most of their increases by the changes we have observed in families, communities and the global environments which now impact (either negatively or positively) on the trajectories for the development of children.³ Figure 2 suggests those larger ‘drivers’ of risk or protective factors which either enable or disable the capabilities of our families and communities to provide environments which positively influence child health, development and wellbeing. The list on the left describes the enhancing cultural attributes which make for a civil society and those on the right are more likely to result in damaging inequalities and poor outcomes for children – an uncivil society.⁴ Such complex problems demand complex information to monitor, study and prevent them.

We need to use all the data at our disposal to guide the best services, give parents and the community the best information on what to do to turn around these enormously worrying trends.

A similar case could be made for our response to the environmental challenges facing Australia. Whilst not my area of expertise, we used this as an example in our presentation to the Prime Minister’s Science, Engineering and Innovation Council (PMSEIC) in our 2006 presentation Data for Science.⁵ It was clear that this complex problem (or set of problems) facing our environments needed timely, joined up, longitudinal and complex data to enable us to monitor, investigate, evaluate and mitigate in scientifically rigorous ways. The State of the Environment

² Stanley F., Richardson S. & Prior M (2005). *Children of the Lucky Country?* Sydney: Pan Macmillan Australia.

³ OECD (2008). www.oecd.org/document/51/0,3343,en_21571361_31938349_37115187_1_1_1_1,00.html [accessed 31 October 2008].

⁴ Stanley (2005).

⁵ DEST (2006). www.dest.gov.au/sectors/science_innovation/publications_resources/profiles/Presentation_Data_for_Science.htm [accessed 31 October 2008]. Also www.innovation.gov.au/Section/pmseic/Pages/DataForScience.aspx

report was a frightening example of data not being accessed or accessible (in some cases not even available) to enable our scientists, public servants and the general public to be guided as to the best solutions.

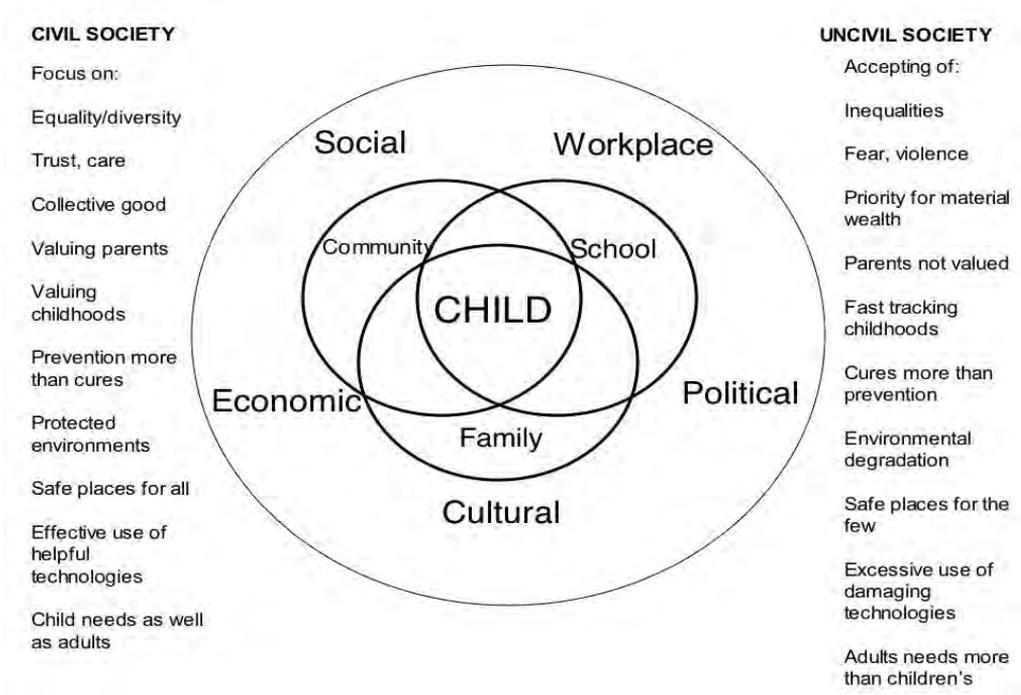


Figure 2: Factors influencing the development of children.

TURNING DATA INTO WISDOM NOW ACHIEVABLE VIA TECHNOLOGY AND CULTURAL CHANGES

In Western Australia we have a unique system of population data bases from health and other government agencies, with disease and problem registers, surveys and special data collections which we can link together to enable complex and intelligent ‘mining’ and analysis. This system has been established for over 30 years with considerable improvement and increasing capacity and sophistication as technology, analytical capacity and storage rapidly improved.

Figure 3 shows the WA Data Linkage capacity. This has enabled a large number of outputs which have been fed back into the public system to improve health and other services.

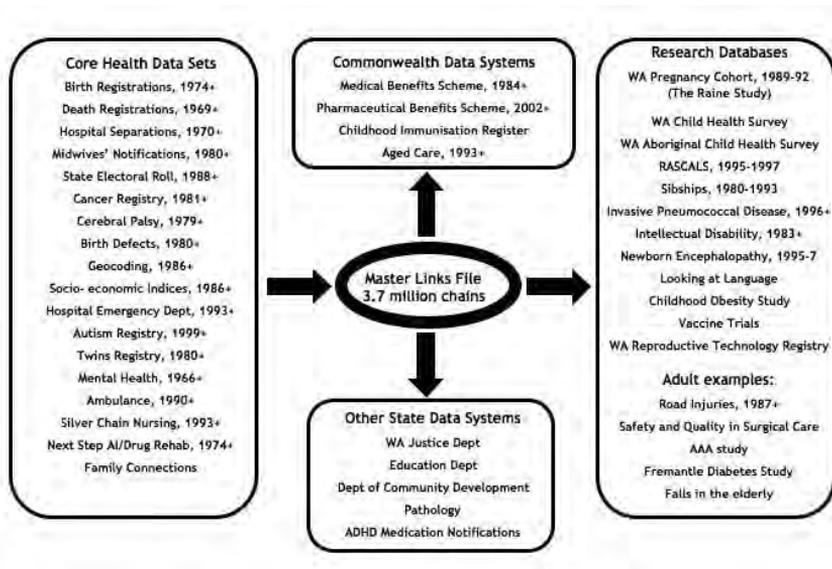


Figure 3: WA Data Linkage capacity.

The National Collaborative Infrastructure Strategy has funded this model to be rolled out nationally to enable similar analyses and uses for the whole nation.

'DATA FOR SCIENCE' – INTERNATIONAL TRENDS AND RECOMMENDATIONS FROM THE PMSEIC PRESENTATION

The recommendations put forward by the PMSEIC working group on Data for Science⁶ relate, broadly, to three areas: 1) the whole of the research system – a national strategic framework, a national network of digital repositories, data access and sharing protocols and the need to ensure that privacy and intellectual property regulations do not impede data sharing; 2) cultural and institutional change – which covers how to encourage better data management practices; and 3) how to develop the skills required for researchers and others to be able to work within the emerging information infrastructure and the new data environments.

The first set of recommendations from this report covered the need for a National Strategic Framework for Scientific Data which includes all data in government agencies and data in all areas of science such as social sciences, humanities and Indigenous knowledge. We recommended that this would need leadership, improved capacity for data management within agencies, best practices, infrastructure and considerable public funding to enable a national network of repositories of data with appropriate access.

In order to get to better data management, access, sharing of data across jurisdictions to tackle these major problems, we need to change the culture within public sector agencies and within academia, and encourage partnerships between them to encourage better use and re-use of publicly funded data.

⁶ *ibid.*

One recommendation was: ‘That standards and standards-based technologies be adopted and that their use be widely promoted to insure interoperability between data, metadata, and the data management systems, providing authentic users of the data with appropriate processes and safeguards’. These are essential prerequisites to better use and sharing of data.

A most important recommendation related to making data more freely available – the topic of this paper ‘That the principle of open equitable access to publicly-funded scientific data be adopted wherever possible and that this principle be taken into consideration in the development of data for science and programmes’.

As part of this strategy, and to enable current and future data and information resources to be shared, mechanisms to enable the discovery of, and access to, data and information resources must be encouraged.

In relation to academic researchers and those that might obtain research grants to use agency data the following recommendation is relevant ‘That funding agencies offer incentives to encourage researchers and institutions to:

- Develop data management plans for each research grant application involving data collection and generation, and that standards be made freely available and widely disseminated as to encourage best practice in data management
- Introduce policies and practices to encourage collaboration and sharing of data across Australia’s research institutions and across agencies
- Analyse and re-use existing data’.

There is another point here, which is that research funding agencies must fund more analysis of existing data, rather than their seemingly preferred option of funding new research grants in order to collect new data. The use of precious collected existing data sets may actually be best practice, and many of them are under-utilised resources.

There were a set of recommendations around the need to remove any regulatory impediments to the use of data: ‘That funding agencies such as the NHMRC and ARC ensure that best practices and policies are developed and followed that allow bona fide researchers to access individual population data, including the linking of data from multiple sources, whilst protecting privacy, and ensuring that ethics committees fully understand these policies and their rationale’; and ‘That in the context of developing the strategic framework for scientific data management, Australia’s intellectual property approaches be checked to ensure they do not impede the sharing of data’.

We felt that it was important that, in particular Australia, should follow the OECD Committee for Scientific and Technological Policy guidelines on access to research data and the International Council for Science statements about the benefits of sharing data. Sharing data is now international best practice and the intellectual property issues relate to discoveries that result from the data rather than the data itself.

These ideas and recommendations are re-iterated and stressed in the recently released National Innovation Review⁷ which suggests that collaborations and sharing of data and resources are essential prerequisites to enable Australian innovation – for both research and development and innovation for challenging societal problems.

⁷ www.innovation.gov.au/innovationreview/Pages/home.aspx [accessed 31 October 2008].

PRIVACY ISSUES

Concerns about privacy are often raised; fear of unauthorised disclosure and of individual data being used for malicious, political, or commercial interests is perceived as directly conflicting with the use of these data for monitoring, evaluation and research. Discussions in the media about the collection, linkage, and use of data on the various aspects of individuals usually focus on the threats to privacy and rarely understand or discuss the huge opportunities for public good that are increasingly possible from such information and could be lost if such access is not allowed. If not adequately addressed these fears have the potential to hinder improvements in the health and well being of both individuals and populations and to effectively tackle the ‘wicked’ problems referred to earlier.

It has been accepted for over half a century that ‘*the highest attainable standard of health*’ is a fundamental human right for which governments have a responsibility to help their peoples achieve,⁸ – individual health is a matter of social justice and fundamental to the common good of nations. The same may be said of education and employment. If we acknowledge that collective action is required for the promotion of the health and well-being of populations then we need to recognise the importance of partnership, citizenship, and community in the development of a healthier nation.⁹ That this may require some relinquishing of self-interest for the greater good comes right up against the increasing demand for individual rights in today’s developed societies.

If we recognise that both privacy and health are fundamental human rights, can we avoid them conflicting and as proposed by Gostin (2001),¹⁰ balance both of these goals so that both are enhanced?

McCallum et al. (1993) conducted focus groups to identify what concerns Australians had about data linkage.¹¹ The people interviewed reported that they valued high profile health research that potentially has public benefit, trusted medical research undertaken by Universities, and recognised that there was a low risk to them from academic uses of their data. In this study, even people who initially refused consent to have their data linked agreed to participate following open discussion of the issues and an opportunity to weigh up and balance the potential risks and public health benefits. This clearly indicates the need to educate the public about this issue, particularly to give them examples of the public good (or the harm of not improving health services, for example).

A recent Australian survey indicated that 66% of the general public and 64% of health consumers support data linkage by researchers while the proportion increases to 82% and 86% (respectively) for data linkage where a unique number rather than a name is used.¹² Overall,

⁸ WHO (1948). *Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, 19–22 June 1946*, World Health Organization, New York.

⁹ Gostin, L. O. (2004). ‘Law and ethics in population health’, *Australian and New Zealand Journal of Public Health*, 28: 1, pp. 7–12.

¹⁰ Gostin, L. O. (2001). ‘Health information: reconciling personal privacy with the public good of human health’, *Health Care Analysis*, 9: 3, pp. 321–35.

¹¹ McCallum J., Lonergan J. & Raymond C. (1993). *The NCEPH Record Linkage Pilot Study: A preliminary examination of individual Health Insurance Commission records with linked data sets*, Working Paper Number 1, National Centre for Epidemiology and Population Health, The Australian National University, Canberra.

¹² NHMRC (2005). *Getting in on the Act: The review of the private sector provisions of the Privacy Act 1988*, Australian Government, Office of the Privacy Commissioner, Sydney, NSW.

survey participants recognised the importance of data linkage for improving health care and public health

The Australian Law Reform Commission Report¹³ has reviewed the situation of access to public sector information and responded to the considerable sway of opinion that public good must be made of these public sector databases. They say:

‘Greater facilitation of research’

The *Privacy Act* allows researchers to obtain and use personal information for health or medical research, without the consent of the individuals concerned, where approved by a Human Research Ethics Committee.

The ALRC heard many concerns, however, from researchers in the health and medical field – as well as social scientists, criminologists and others – that an overly cautious approach to the application of the *Privacy Act* was inhibiting the conduct of research, even where the threat to individual privacy was limited or non-existent and the potential value of the research was very high. For example, epidemiological research can play a very valuable role in planning and promoting public health campaigns and in allocating scarce resources. In such cases, researchers are not concerned with the identity or information of individuals within the sample, but rather are seeking to identify broad trends and patterns in the population.

The ALRC also recognises that there are other forms of research that provide benefits to the community that require access to personal information in situations where it is difficult to obtain consent – such as research on child protection or factors associated with criminal behaviour.

The ALRC recommends that the research exception to the ‘Collection’ and ‘Use and Disclosure’ principles in the model UPPs allow information to be collected, used and disclosed for research purposes – including in areas other than health and medical research – where a number of conditions are met, including approval by a Human Research Ethics Committee.

Figure 4 is from the Australian Productivity Commission report on Overcoming Indigenous Disadvantage.¹⁴ It shows the pathways to improving outcomes and the data required to monitor whether we are implementing those things which will improve the situation for Aboriginal people. It illustrates the power of data to both inform public policy and monitor whether or not services and government activities are achieving their required outcomes. It is the best way to ensure government accountability to the communities and people they serve. These could even be used as Key Performance Indicators for those responsible for service delivery.

OECD WORLD FORUM ON FOSTERING AND MEASURING THE PROGRESS OF SOCIETIES

In June 2007, the OECD held a major forum in Istanbul on How to Foster and Measure the Progress of Societies.¹⁵ Major international agencies such as UNESCO, UNICEF, WHO and

¹³ www.austlii.edu.au/au/other/alrc/publications/reports/108/ [accessed 31 October 2008].

¹⁴ www.pc.gov.au/gsp/indigenous [accessed 31 October 2008].

¹⁵ OECD (2008).

UNDP met with senior politicians, bureaucrats, economists, researchers and government statisticians to decide on how best their countries could introduce and measure those things which enhanced our societies. It was a most important meeting with the following themes:

- Data to build modern democracies and civil societies (human rights)
- Data (power) to the people: accountability, governance, culture
- Sustainable development, inequalities
- Demographic change, work, migration
- Climate change, biodiversity, technology, energy, water
- The world's children, families, poverty, gender differences, Millennium Development Goals
- Health, education, data to knowledge to policy
- Globalisation, economic, financial, corporate and NGO roles
- Data leads to knowledge leads to policy.

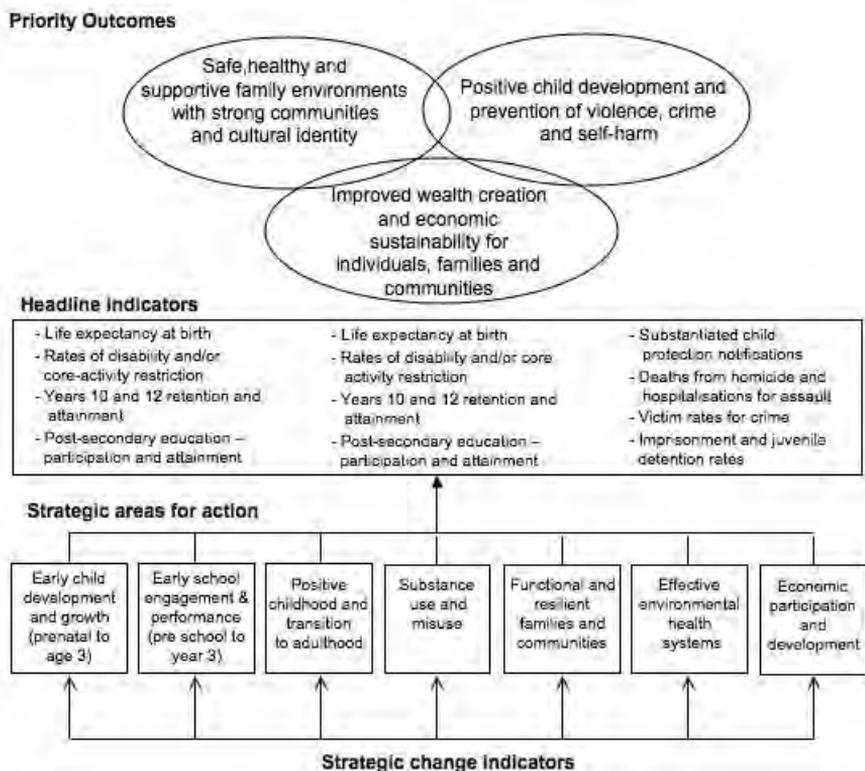


Figure 4: Overcoming Indigenous Disadvantage: Indicator Framework

The Istanbul Declaration fits beautifully with the points I am trying to make in this paper. The declaration suggested:

- Measurements of progress go beyond GDP per capita (e.g. MDGs)
- Societal welfare (wellbeing) is dependent on evidence based and accountable policy making
- Statistical indicators (social, environmental and economic) disseminated to citizens enables democracy
- Official statistics are a key ‘public good’ to foster progress of societies.

This declaration and the debates had in Istanbul are exactly the messages I want to convey in this paper.

SUMMARY AND CONCLUSIONS

We have never had such an era where the need for data is so urgent, nor the capacity to produce and use it is so great. The only things holding us back from using public sector data are ignorance, fear, lack of funding and a poor understanding of the power of data by data custodians and public sector workers, most of who stand to benefit most from its wider accessibility and use.

I would like to end with a quote from Professor Lawrence O Gostin from the University of Georgetown.¹⁶

In the late 20th century, scholars and politicians posed a key question. ‘What desires and needs do you have as an autonomous rights bearing person to privacy, liberty and free enterprise?’ Now it is important to ask another kind of question. ‘What kind of community do you want and deserve to live in, and what personal interests are you willing to forgo to achieve a good and healthy society?’

¹⁶ Gostin, L. O. (2004).