

Health, Political Arithmetic and Public Accountability: Bringing Down the Great Cth-State Data Divide

Winthrop Professor C. D'Arcy J. Holman
Valedictory Lecture of the Chair in Public Health
29 July 2014



Good evening, everyone.

Thank you, Professor Geelhoed, for your generous introduction; and Professor Kickett, may I please acknowledge your traditional welcome to the Noongar people's country, express my respect for your elders and my admiration of you personally for everything you've achieved.

Let me start by explaining the header of my topic. The World Health Organisation defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.¹ This definition is sometimes criticised for being too utopian, unrealistic or confusing health with happiness.² My use of the word 'health', is in one sense even broader, but in another contains a merciful element of prioritisation.

I refer to 'health', as an object of community conversation and concern; the aspects of health status and health services that pre-occupy the hearts and minds of ordinary people; that attract the focus of media attention; that drive our needs for a large health workforce and a complex and expensive 'health system'; and that create portfolios for policy decisions within governments and the many institutions with health interests within our society. In short, what I mean by 'health', is the 'health agenda'.

The words 'political arithmetic' have a lineage dating back more than 300 years,³ when Sir William Petty the elder coined the term as a method of 'reasoning by numbers', that pertain to a 'political unit', such as a nation, state or municipality. For our purposes it means health statistics, related research results and their interpretation.

¹ World Health Organization. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June 1946, and entered into force on 7 April 1948.

² Saracci R. The World Health Organization needs to reconsider its definition of Health. *BMJ* 1997; 314: 1409-10.

³ Petty W. Political arithmetick. London: R. Clavel & H. Mortlock, 1690 (published posthumously). <http://www.marxists.org/reference/subject/economics/petty/index.htm> 21 March 2014.

And finally, 'public accountability', which according to *Black's Law Dictionary* refers to the obligations of those entrusted with public resources to be answerable to their social and fiscal responsibilities.⁴ Given that the total cost of the Australian health system is in the vicinity of \$140 billion per annum, of which 70% is serviced by public resources,⁵ and a further 13% by quasi-public resources in the form of insurance premiums, I suggest that the ethical administration of health services, does indeed involve, a high degree of public accountability.

Sadly, in our nation, this public accountability for health system expenditure and performance is severely compromised by the evolution of our constitutional system of governments and, in particular, the failure of our Cth to cooperate with the states in joining their respective information resources to plan and evaluate the Australian health system in its entirety.

But what if this great data divide could be torn down and we could see the full picture? How many tens of thousands of lives would be saved and how many billions of dollars of waste would be averted? This evening, I can offer little more than a glimpse of the truth to these questions. I can only trust it's a glimpse you'll not forget, especially those who are young professionals and our hope for the future.

So now the real work of this lecture begins.

There are two principal eras in the use of health statistics in WA to plan and evaluate our health system: before comprehensive data linkage in 1995, and afterwards. I've undertaken two decades of professional life in each era, and the difference has been mind-numbing.

Let me give you a sense, briefly, of what it was like in pre-data linkage times. Even by the 70s, the only systematic collection of health stats involved notifications of infectious diseases and deaths. Registrations of cancers and birth defects didn't arise until the early 80s and although statewide coverage of hospital stats started in 71, their use was limited to sets of tables, from which one could discern some trends from year to year. My first employment, as a Public Health Medical Student Resident during the Christmas of 1972, was to tabulate figures like this, being numbers of intestinal parasite infections found in the patients of Swanbourne Hospital.⁶



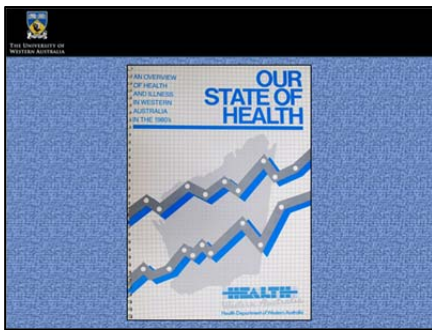
⁴ Garner BA, ed. *Black's Law Dictionary*, 9th edition. Eagan, Minnesota: West Group, 2009.

⁵ Australian Institute of Health and Welfare. *Health expenditure Australia 2011–12*. Health and welfare expenditure series no. 50. Cat. no. HWE 59. Canberra: AIHW, 2013.

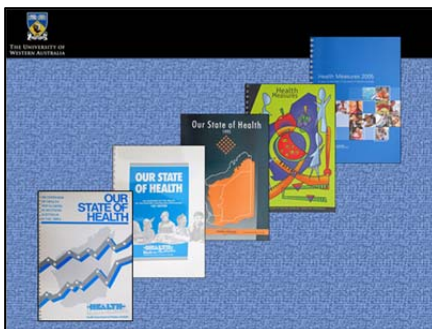
⁶ Health Statistics Branch Report. In: *Report for the Year 1972*. Commissioner of Public Health, Western Australia. Perth: Public Health Department, 1973.

The information technology available to me wasn't of the digital electronic form, but consisted of a mechanical dinosaur known as the Hollerith card sorter. The point is that what we could do with health statistics, even as recent as the 1970s, was severely constrained by the technical infrastructure available to us.

A decade later, as the inaugural director of the Health Department's Epidemiology Branch in 1984, I was tasked with analysing the growing collections of government data to create a more useful overview of health and illness in WA.



This led to a comprehensive system of reporting a wider range of health statistics, including 'Our State of Health',⁷ the first of what became a series ...



... of compilations of health measurements. It was through this process we learnt for the first time, barely 30 years ago, that our leading causes of premature death, expressed as years of life lost before age 70, were in large part preventable, being road trauma, heart disease, lung cancer, stroke, large bowel cancer, chronic liver disease and breast cancer; whereas mental disorders were at that time the largest cause of hospital bed occupancy.

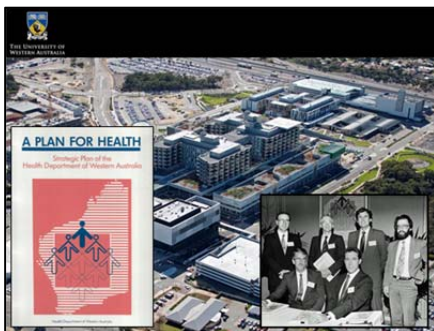


⁷ Holman CDJ (Ed.) and 41 others. *Our State of Health. An Overview of Health and Illness in Western Australia in the 1980's.* Steering Committee for the Review of Health Promotion and Health Education in Western Australia. Health Department of Western Australia, Perth, 1986.

We also discovered how to use our health data in innovative ways to support prevention and treatment services. It was works in WA like the *Quantification of Drug-Cased Morbidity and Mortality* that became Australia's first official statistics on diseases and deaths caused by tobacco, alcohol and illicit drugs.⁸



Some may recall the tobacco death clock by the Horseshoe Bridge and how this and other creative applications of our health stats were used, and are still used, by our most influential advocates such as Professor Mike Daube, to argue for anti-tobacco legislation and many other health improvements.



We also learnt how to better use our health data to plan hospital services. *A Plan for Health*, published 25 years ago as the WA Health Department's first comprehensive strategic plan,⁹ was the peak document straddling the planning foundations of the evolving public and private hospital campuses as we know them today. I recall, as the Assistant Commissioner for Planning, chairing the panel that awarded bed licences for St John of God Health Care to proceed at Murdoch, knowing from our data that one day we'd need a large private and public hospital precinct in the Murdoch area.

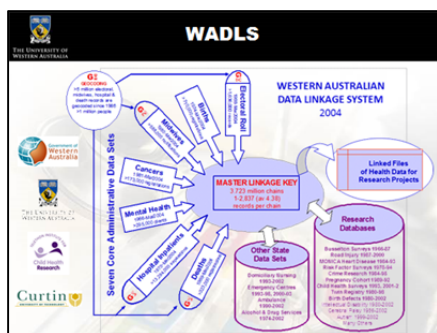
The point I make is that our health information systems are an incredibly precious community resource to achieve better health and better health services.

⁸ Holman CDJ, Armstrong BK, Arias LN, Martin CA, Hatton WM, Hayward LD, Salmon MA, Shean RE, Waddell VP. The Quantification of Drug Caused Morbidity and Mortality in Australia. Part 1 and Part 2. Commonwealth Department of Community Services and Health, Canberra, 1988 (republished in 1990).

⁹ A Plan for Health. Strategic Plan of the Health Department of Western Australia 1989-1993 (CDJ Holman, Principal Author). Health Department of Western Australia, Perth, 1989.

However, despite the new found utility of our political arithmetic, its use prior to 1995 remained mostly descriptive, and it was left to university academics using labour-intensive field methods to investigate what actually happened to people exposed to health hazards or receiving treatments for their diseases. In short, we could describe health problems, even plan for future needs, but we lacked the tools to evaluate outcomes or to settle questions of fact to inform policy debates within the health agenda.

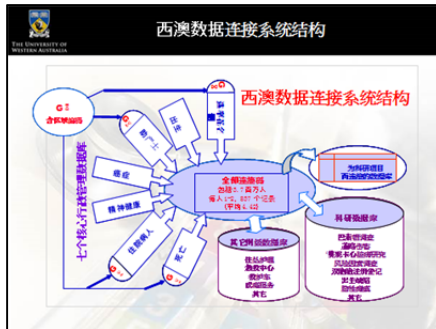
It was against this backdrop that the WA Data Linkage System came to revolutionise how we could use health statistics.¹⁰ I won't go into the fascinating history of how 'waddles', as we called it, came to fruition. Suffice to say it wasn't merely a technical accomplishment, seizing the opportunities afforded by advances in IT, but above all, a dazzling community achievement in social capital and solidarity, for which a number of individuals in this room, including Professors Fiona Stanley, James Semmens, David Preen and Nick de Klerk; and Dr Merran Smith, Diana Rosman and Carol Garfield, should share in considerable credit.



For those unfamiliar with WADLS, it's a combination of computers and protocols that create anonymous links between health and welfare data collections. It uses computerised probabilistic matching to create a master linkage key, an integrating map if you like, between over 30 pre-existing health databases on the people of WA. The links mean that the journeys of individuals through the health system can be followed anonymously over many years and thus their risk factors for major diseases, and the use and outcomes of health services can be evaluated using anonymous information. It was once said that putting WADLS in the hands of an epidemiologist is like putting a particle accelerator in the hands of a physicist; both of them cause a paradigm shift and open up a new era of knowledge.

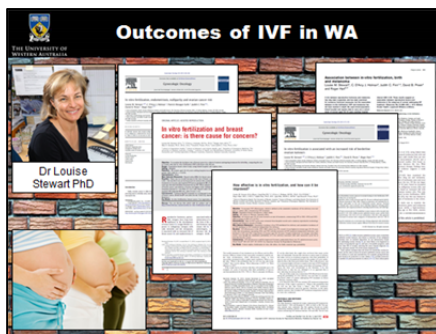
WADLS also opened up a new era of collaboration between the WA Health Department, the three academic partners in the enterprise and, I'm both grateful and proud to say, our health consumer movement.

¹⁰ Holman CDJ, Bass AJ, Rouse IR, Hobbs MST. Population-based linkage of health records in Western Australia: development of a health services research linked database. *ANZ J Public Health* 1999; 23(5): 453-459; Holman CD, Bass AJ, Rosman DL, Smith MB, Semmens JB, Glasson EJ, Brook EL, Trutwein B, Rouse IL, Watson CR, de Klerk N, Stanley FJ. A decade of data linkage in Western Australia: Strategic design, applications and benefits of the WA Data Linkage System. *Aust Health Rev* 2008; 32(4): 766-777.



Twenty years later, not only has WALDS been copied across every state in Australia, but it has also been the object of intense interest and site visits from around the world.

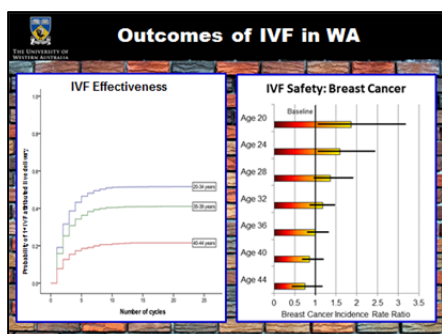
To illustrate this further, let me to show you results from two projects based on WA linked data without the involvement of the Cth. These, as with all results covered this evening, represent the efforts of my research students. Of all the joys of my career, there's none that exceeds the satisfaction from working with the 98 new researchers, who entrusted me with their training. The word 'student' poorly describes these superb colleagues, given that 13 of them are now professors, and many others occupy senior positions. I'm immensely proud of what these good people are achieving, not least Dr Julie Owen, who's seated in the audience with my family. I find it difficult, however, that I've barely time enough to show you only a little of the work of just ten of my VIP superstars.



Dr Louise Stewart published a series of remarkable doctoral research papers concerned with the effectiveness and safety of IVF.¹¹ I was delighted to work with Dr Stewart due to my involvement back in the 80s in our reproductive technology legislation,¹² and its provisions for a register of mothers and babies exposed to this greatly valued but also intrusive intervention, so that its effects could be responsibly measured over time. Dr Stewart's research made anonymous use of this register, linked to perinatal, cancer and death records.

¹¹ Stewart LM, Holman CDJ, Hart R, Finn J, Qun Mai, Preen DB. How effective is in vitro fertilization, and how can it be improved? *Fertility Sterility* 2011; 95(5): 1677-1683; Stewart LM, Holman CD, Hart R, Bulsara MK, Preen DB, Finn JC. In vitro fertilization and breast cancer: is there cause for concern? *Fertility Sterility* 2012; 98(2): 334-340; Stewart LM, Holman CDJ, Aboagye-Sarfo P, Finn JC, Preen DB, Hart R. In vitro fertilisation, endometriosis, nulliparity and ovarian cancer risk. *Gynaecol Oncol* 2013; 128(2): 260-264; Stewart LM, Holman CD, Finn JC, Preen DB, Hart R. In vitro fertilization is associated with an increased risk of borderline ovarian tumors. *Gynaecol Oncol* 2013; 129(2): 372-376; Stewart LM, Holman, CD, Finn JC, Preen DB, Hart R. Association between in vitro fertilization, birth and melanoma. *Melanoma Res* 2013; 23(6): 489-95.

¹² *Human Reproductive Technology Act 1991 (WA)*.



Among her results are two compelling examples of the use of data linkage to evaluate outcomes from the viewpoints of effectiveness on one hand, and safety on the other. The graph on the left shows how the chance of taking home a liveborn child is higher in younger women, but most importantly, regardless of age, there's good value to be derived from each of the first five cycles of IVF, some modest further value from the next five cycles, but beyond 10 cycles the prospect of a liveborn child becomes remote.

The second graph, comparing 8,000 women starting IVF with 13,000 receiving other infertility treatments, an exposure contrast carefully designed by Dr Stewart to reduce confounding from constitutional and lifestyle factors, shows how the possibility of developing breast cancer from IVF is a consideration mostly for women who start IVF in their 20s.

So here we have IVF effectiveness and safety results that are important to the 1,000's of women, and their partners, who seek assistance from the health system for a reproductive disability, both in terms of informed consent, and the justified use of health dollars.

Dr Stewart's research was concerned with aggregate outcomes.



My second example, the doctoral work of Professor Sonj Hall, illustrates the use of data linkage to evaluate distributive outcomes; in other words, the fairness of the health system.¹³ Professor Hall used WADLS to evaluate how outcomes of cancer treatments varied between regional WA and metropolitan Perth. She found that patients living in the bush with colorectal, prostate, breast and lung cancers fared up to 20% worse in terms of survival, and

¹³ Hall SE, Holman CDJ, Hendrie DV, Spilsbury K. Unequal access to breast-conserving surgery in Western Australia 1982-2000. *ANZ J Surgery* 2004; 74(6): 413-41; Hall SE, Holman CDJ, Sheiner H. The influence of socio-economic and locational disadvantage on patterns of surgical care for lung cancer in Western Australia 1982-2001. *Aust Health Rev* 2004; 27(2): 69-80; Hall S, Holman CD, Sheiner H, Hendrie D. The influence of socio-economic and locational disadvantage on survival after a diagnosis of lung or breast cancer in Western Australia. *J Health Ser Res Pol* 2004; 9(Suppl.2): 10-16; Hall SE, Bulsara CE, Bulsara MK, Leahy TG, Culbong MR, Hendrie D, Holman CDJ. Treatment patterns for cancer in Western Australia: does being indigenous make a difference? *Med J Aust* 2004; 181(4): 191-194; Hall SE, Holman CDJ, Wisniewski ZS, Semmens J. Prostate cancer: socio-economic, geographical and private-health insurance effects on care and survival. *BJU Int* 2005; 95(1): 51-58; Hall SE, Holman CDJ, Finn J, Semmens JB. Improving the evidence base for promoting quality and equity of surgical care using population-based linkage of administrative health records. *Int J Quality Health Care* 2005; 17(5): 415-420; Hall SE, Holman CDJ, Platell C, Sheiner H, Threlfall T, Semmens J. Colorectal cancer surgical care and survival: do private health insurance, socioeconomic and locational status make a difference? *ANZ J Surgery* 2005; 75(11): 929-935.

were up to 70% less likely to get potentially curative treatment than their Perth counterparts, all other things being equal. Not only was this work cited at length by an Australian Senate inquiry, ...



... it also led to the IRCO Trial, standing for Improving Rural Cancer Outcomes,¹⁴ led by an university team in partnership with the Cancer Council and Health Department, and managed by UWA Health Science graduate, Victoria Gray. It's evaluating two interventions to cut delays in rural cancer presentation and treatment, one the *Find Cancer Early* campaign targeting symptom awareness and seeking medical help; and the other aiming to speed up diagnosis and specialist referral using novel inservicing techniques for rural GPs.

Thus not only has WADLS' research already led to a new early detection service in regional WA, but it'll also evaluate the results of this important trial. Even it's only one half effective, the interventions will save around 40 cancer deaths a year in our regional areas.

Given that I've shown you just two of more than 750 research projects supported by WADLS during the last two decades, one might query if this represents a significant invasion of privacy. To the contrary, the effects of data linkage on privacy have been exactly the opposite, with a profound privacy benefit compared with the way we did research before.



Here's what real medical records look like, courtesy of a patient who's given permission for them to be displayed. Lots of documents, and now computer screens, liberally plastered with the patient's name and address. During the first 20 years of my career, I waded through countless thousands of records like this. It was tedious and inefficient work, especially because often one had to pour through reams of paper to find just the one or two important facts to answer the research question. Data linkage has turned this approach on its head, ...

¹⁴ Emery JD, Walter FM, Gray V, Sinclair C, Howting D, Bulsara M, Bulsara C, Webster A, Auret K, Saunders C, Nowak A, Holman CDJ. Diagnosing cancer in the bush: a mixed methods study of symptom appraisal and help-seeking behaviour in people with cancer from rural Western Australia. *Fam Pract* 2013; 30(3): 294-301; Emery JD, Walter FM, Gray V, Sinclair C, Howting D, Bulsara M, Bulsara C, Webster A, Auret K, Saunders C, Nowak A, Holman D. Diagnosing cancer in the bush: a mixed methods study of GP and specialist diagnostic intervals in rural Western Australia. *Fam Pract* 2013 doi:10.1093/fampra/cmt016.

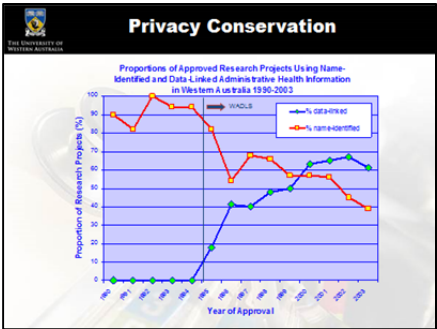
The screenshot shows a spreadsheet with a header row containing various data fields. The 'Name' column contains names of individuals, such as 'John Smith', 'Jane Doe', etc. The spreadsheet is titled 'Privacy Conservation' and is part of a presentation from The University of Western Australia.

so that during the last 20 years, what I've worked with has looked like this: No names and addresses, age rather than date of birth, contains only the information needed to answer the research question, and just a number is used to represent each person, although for any two research projects that system is different, so the patients don't even have a unique number. Nevertheless, use of the same number for the same anonymous person in each project, illuminates the crucial connections within and between different data collections, so that the outcomes can be measured.

In this case, which consists of fake training data, a single person was admitted to hospital 14 times ...

This screenshot is similar to the first one, but it highlights a specific row with a red circle and a red arrow pointing to the right, indicating a specific data point or connection.

... and then died from their disease. Whilst there's still some important epidemiologic research that cannot be conducted without access to identified medical records, the majority of our studies now simply don't require this.



Thus after WADLS came on stream, over the next decade, as shown by the red line, there was a dramatic fall in research projects needing patient names.¹⁵ I've not personally seen a name on a record since the day that WADLS started 20 years ago. This is a triumph for privacy conservation, and I submit that WADLS has done more for the protection of privacy

¹⁵ Trutwein B, Holman CDJ, Rosman DL. Health data linkage conserves privacy in a research-rich environment. *Ann Epidemiol* 2006; 16(4): 279-280.

in research than any regulatory initiative has ever done, because there's a world of difference between this ...



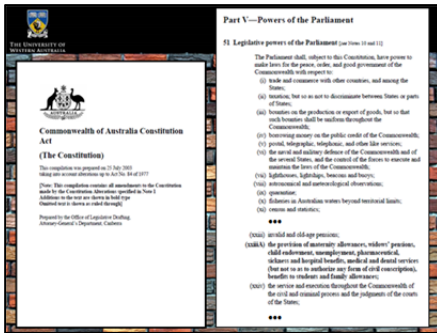
... some of my medical records, and this ...

... what we give to a linked data analyst.



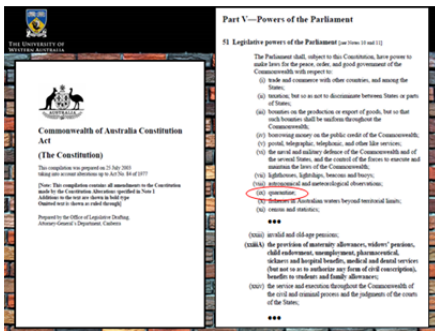
But there's more to the ethics side of the data linkage story. Anne McKenzie and Hayley Haines, and earlier on, Rebecca Coghlan, worked with us as the first consumer advocates ever appointed to a health research organisation in Australia, and over the years brokered a remarkable program that has engaged consumers as empowered partners in research, and altered the perceptions of researchers about the value of community engagement. We now simply don't do big data linkage research without a significant consumer voice brought into our governance structures.

Colleagues, by now you must be thinking that he's so effusive about data linkage, it all seems too good to be true. Unfortunately, you're right to be sceptical. There's one glaring deficiency in what this paradigm shift in political arithmetic can do for us; and the source of this blight upon the landscape of public accountability is this:

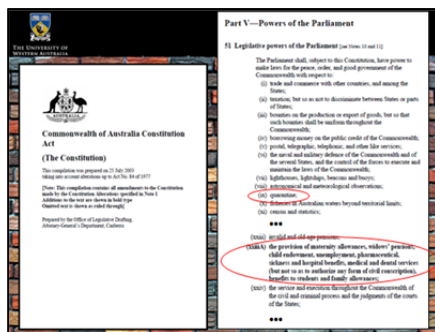


the *Commonwealth of Australia Constitution Act*, which entered into force in 1901.¹⁶

Section 51 defines the legislative powers of the Cth Parliament, and in regard to health, these were originally limited to a responsibility under subsection (ix) ...



... for the quarantine of incoming vessels. In the fervour of national solidarity after World War II, the Australian Social Services Referendum of 1946 was successful in amending the Constitution to add subsection (xiiiA), ...



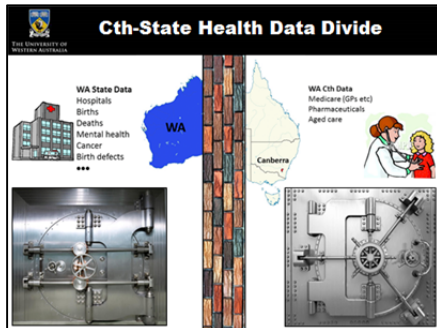
... which is the basis for the Cth's domination of Medicare, pharmaceutical and aged care subsidies. Australia differs from other federations, Canada for example, in that our Cth Government has not directed its financial support for these integral components of health care through the states, but has established itself as a separate vertical player.

Much has been written about the mess this creates with cost-shifting and many other problems. To quote the National Health and Hospital Reform Commission of 2009, "our fragmented health system, with a complex division of funding responsibility and performance accountabilities between different levels of government ... is ill-equipped to respond to the

¹⁶ *Commonwealth of Australia Constitution Act 1900* (Imp).¹

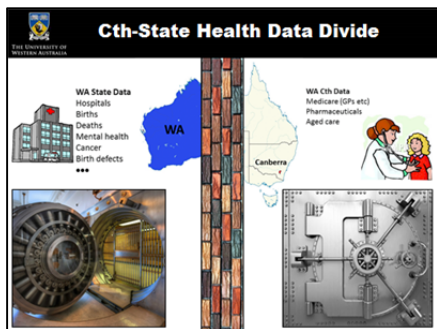
challenges” of large increases in demand, unacceptable inequalities in outcomes and growing concerns about safety and quality.¹⁷

This separation in funding, policy and accountability is manifest also as a great Cth-State divide in the collection and intelligent use of health data.



There are essentially two impenetrable fortresses of health data, one managed by the State and concerned with hospitals, births, deaths, mental health, cancer, birth defects, and so on, and the other managed by the Cth in Canberra and concerned with use of GPs, specialists, diagnostic tests, medicines and aged care.

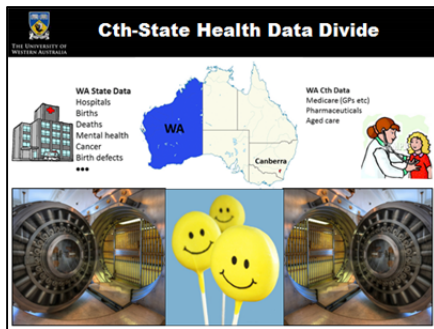
To its great credit, the WA Health Department’s co-leadership of WADLS has meant that one of these data fortresses has already been opened, ...



... for the public’s benefit, in accordance with modern privacy standards, contemporary thinking about freedom of information; open and transparent government; and the astonishing notion that governments should facilitate the research use of their data to achieve public good.

But when WADLS was established, unlike our counterparts in other countries, we were unable to include crucial Cth political arithmetic on the use of GPs, pharmaceutical and aged care services. Sadly, that glaring deficiency remains in place today, but, for just a limited window of time, between 2007 and 2012, things were different: ...

¹⁷ NHHRC. A healthier future for all Australians – Final report of the National Health and Hospital Reform Commission – June 2009. Canberra: NHHRC, 2009.



The two separate information systems were permitted to talk one with the other.

A short reprieve of different senior administration in the Cth led to a collaboration with the State to include the Medicare, pharmaceutical and aged care data within the WADLS system. This was the first and only instance since federation that the Cth and an Australian State agreed to integrate their data in a functional way to create a total picture of health system performance. For a brief period in history the health agenda was served by political arithmetic that had the potential to achieve public accountability of the likes we'd never seen before.



In a job far better suited to a younger epidemiologist, given I've barely made it to the eve of my retirement to tell my story, it took me over 15 years to broker and derive some public good from this arrangement. So dense was the purported legal minefield that during this period I even completed a law degree, won Murdoch University's law medal, and wrote Australia's only text on data linkage law, because I became so disenchanted with public officers citing legal barriers, which on closer scrutiny, I discovered not to exist.

The adventure began in 1998, when I circulated a proposal to the relevant officials for a pilot linkage for patients with diabetes. My proposal was supported in writing by Diabetes Australia. After more than three years of negotiations, during which there was a further change in Cth administration, an inter-agency agreement was executed, albeit a further two years passed before any pilot data were available. Nevertheless, we learnt a great deal about how to solve many technical teething problems during this prolonged pilot phase.

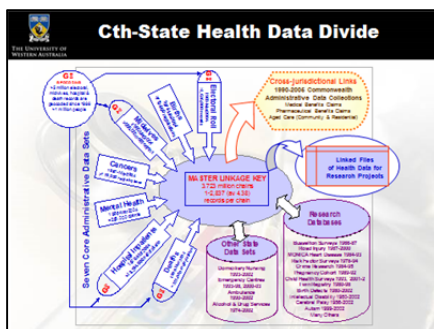
Meanwhile, in a rush of uncharacteristic enthusiasm from the Cth in 2002, there came into existence a remarkable agreement, for a master linkage key, for the entire WA population. The way it happened was like this. I'd been seconded to WA Health and had prepared a draft of this non-trivial agreement for our Director General to send to the Cth Secretary. I sheepishly sent it off, expecting long years of bureaucratic positioning and legal wrangling to ensue, but to my astonishment the draft document, which fortunately didn't have the word 'draft' stamped on it, was returned within the week, duly executed with the Cth Secretary's moniker. Naturally, I lost no time securing the WA DG's signature on the same historic

parchment and the deal was done. To this day I wonder if the first signature was in fact a mistake, because getting the agreement signed was the only easy thing about this arrangement, as I found in the gruelling role of chairing the Steering Committee set up under the agreement.

It was more than six years later that data were eventually released to support major NHMRC-funded projects, like those I'll show you shortly. In fact, I resigned from the steering group so I could more readily play an advocacy role, joined by Professor Fiona Stanley and our consumer partners, who by this stage were upset that over 100 medical researchers waiting for Cth data, had \$11 million in precious public research funds, mostly from NHMRC, simply going to waste.

It's worth mentioning that the problems were entirely bureaucratic and didn't involve politicians and ministers, except in the sense that when we complained they ignored us. Our political leaders appear to have little real executive interest in a proper data system to evaluate our huge public investment in health services. Something I've learnt from WA's creation and leadership of the International Health Data Linkage Network is that, in this regard, Australian politicians seem quite unlike those in the UK and Canada, where it's commonplace for ministers to assume personal responsibility for chairing high-level, inter-agency groups, like the one I chaired, because the political arithmetic they gain from health data integration is simply too important to the health agenda to leave it to anyone else.

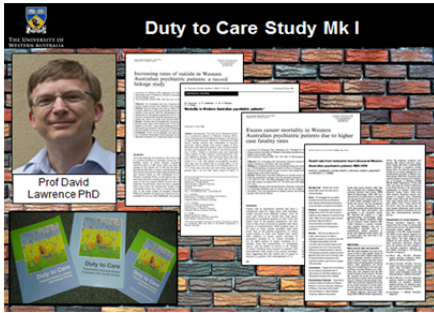
With the Herculean efforts of Dr John Bass, the computer system architect of WADLS, ...



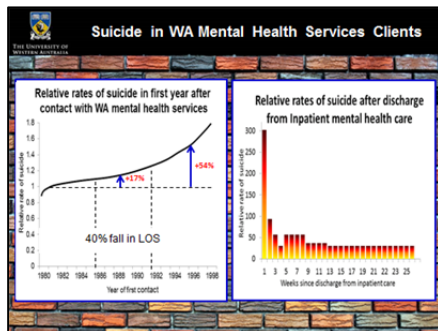
... we linked 16 years of retrospective Cth data covering 1990 to 2005. As with all our work, this didn't mean that the Cth data were all sent to WA – the WALDS isn't a centralised data repository. Rather, it became possible to make requests to the Cth to release specific data sets that were linkable through an encrypted key for the same anonymous patients.

This created unprecedented opportunities for the health agenda, for political arithmetic and for public accountability. In the time remaining, I'd like to show you two examples of these benefits in action. Both case studies show how without the Cth data, we were headed in the wrong direction; and how the true state of affairs became clear only when we were briefly permitted to see the full picture.

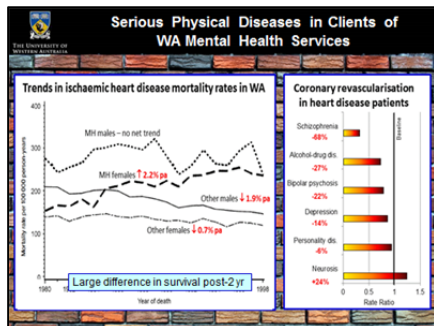
Before we proceed, I do wish to emphasise that all of the research results shared with you this evening have been subjected to rigorous peer review and have been published in reputable scientific journals. In fact, the majority of my students have even won best paper awards or other competitive acknowledgments of research excellence.



The first illustration began in 1997, when Professor David Lawrence completed a PhD based on a ground-breaking study of the physical health problems of 165,000 West Australians who'd used mental health services during the 80s and 90s.¹⁸ This represented 8% of the WA population.



At first we concentrated on suicide, given that suicide rates were elevated seven-fold and accounted for almost one half of all WA suicides. We showed, on the left, that suicide rates after discharge from a mental hospital had worsened during the 80s and early 90s, when there was a 40% drop in length of stay due to de-institutionalisation of that sector. The figure on the right shows that the risk was concentrated within the first few weeks after discharge, a finding taken up by the mental health service to improve discharge planning and follow up.



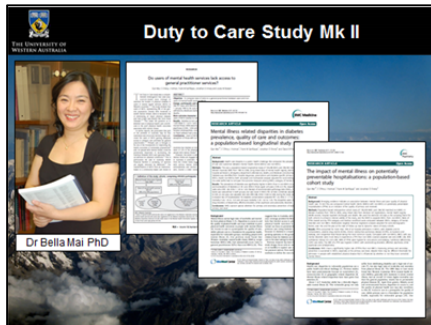
But the most striking results were these. We uncovered a hidden burden, characterised by poor survival from chronic physical diseases, leading to a life expectancy some 10-15 years less than the remainder of the population. The biggest killer wasn't suicide, but excess

¹⁸ Lawrence DM, Holman CDJ, Jablensky AV, Fuller SA. Suicide rates in psychiatric inpatients: an application of record linkage to mental health research. *ANZ J Public Health* 1999; 23(5): 468-470; Lawrence D, Holman CDJ, Jablensky AV, Threllfall TJ, Fuller SA. Excess cancer mortality in Western Australian psychiatric patients due to higher case fatality rates. *Acta Psych Scand* 2000; 101(5): 382-388; Lawrence D, Jablensky AV, Holman CDJ, Pinder TJ. Mortality in Western Australian psychiatric patients. *Soc Psych Psych Epidemiol* 2000; 35(8): 341-347; Lawrence DM, Holman CDJ, Jablensky AV, Fuller SA, Stoney AJ. Increasing rates of suicide in psychiatric patients in Western Australia: a record linkage study. *Acta Psych Scand* 2001; 104(6): 443-451; Lawrence DM, Holman CDJ, Jablensky AV, Hobbs MST. Death rate from ischaemic heart disease in Western Australian psychiatric patients 1980-1998. *Brit J Psych* 2003; 182: 31-36.

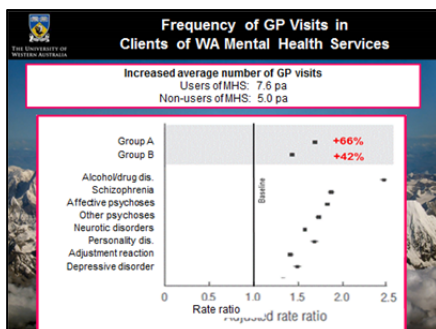
deaths from heart disease. On the left you see how unlike everyone else, heart disease trends in the mentally ill were, if anything, getting worse, and on the right, how those with established heart disease were much less likely, 68% less likely for schizophrenics, to get access to coronary revascularisation procedures such as angioplasty and bypass grafts.

Something was amiss with the coordination of physical health care for this vulnerable population, and our working hypothesis became that people with mental illness mightn't participate in holistic care and case management provided by general practice.

In fact, it was only after the Cth data came on stream that this appealing theory was proven to be incorrect.



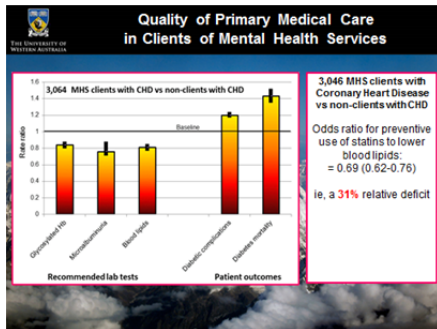
Dr Bella Mai's PhD was one of the first to be completed using Cth Medicare and pharmaceutical data combined with WA mental health, hospital, cancer and death data.¹⁹



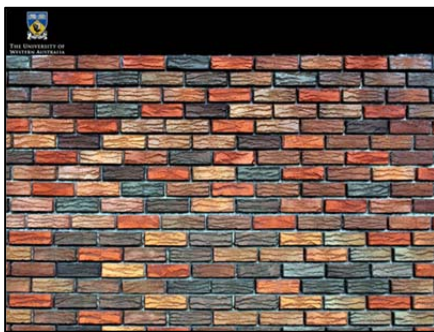
Dr Mai found, to our surprise, that most people with mental illness attended GPs at rates that were over 50% higher than average; for example, 7.6 visits per annum compared with just 5 for other people. The high rate of visits applied across both groups of mental health clients studied by Dr Mai, denoted here by groups A and B, and across all categories of mental illness. The one notable exception, not shown on the slide, was the 4% of mental health clients with no fixed address – almost all of this homeless group never saw a GP at all. But the main findings for the vast majority of 96% turned our working hypothesis on its head. We were barking up the wrong tree based on the WA data alone, and it was only when we were permitted to see the whole picture that the truth became clear.

¹⁹ Qun Mai, Holman CDJ, Sanfilippo FM, Emery JD, Stewart LM. Do Users of mental health services lack access to general practitioner services? *Med J Aust* 2010; 192(9): 501-506; Qun Mai, Holman CDJ, Sanfilippo FM, Emery JD. The impact of mental illness on potentially preventable hospitalisations: a population-based cohort study. *BMC Psychiatry* 2011; 11(1): 163, doi:10.1186/1471-244X-11-163; Qun Mai, Holman CDJ, Sanfilippo FM, Emery JD, Preen DB. Mental illness related disparities in diabetes prevalence, quality of care and outcomes: a population-based longitudinal study. *BMC Medicine* 2011; 9(1): 118, doi:10.1186/1741-7015-9-118.

That led Dr Mai to look elsewhere for explanations and, again, the linked Cth data provided the essential clues. Looking at causes of hospitalisation, she'd noted that conditions preventable by a higher quality of primary medical care, such as diabetic complications, were elevated in mental health clients.



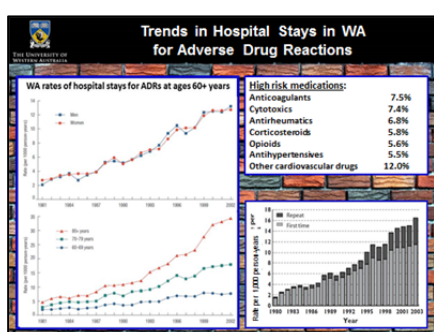
So linking in the Cth data, she saw that diabetics who also had a mental illness, were getting a substandard quality of care, as shown in the first three bars on the left, with inadequate use of recommended laboratory monitoring tests, such as glycosated haemoglobin, microalbuminuria detection and blood lipids. This was despite having more diabetic complications and deaths, as shown by the middle two bars. Moreover, as noted on the right, mental health clients with heart disease were 31% less likely than similar patients without mental illness to be prescribed statins, to reduce their blood fats and improve their survival. Without the Cth data, it was simply impossible to know these facts, which go to the nub of what the National Health and Hospital Reform Commission described as unacceptable inequalities in a health system that has prided itself on universality. These results have only recently appeared and are now being championed by our consumer advocates.



Unfortunately, I see no prospect that my successors will be able to use linked Cth data in the foreseeable future to evaluate if things have improved.



I now turn the second illustration, which relates to medication safety in older Australians. One of our earliest Master of Public Health graduates, Dr Vivienne Dawes, had shown that the rate of hospital stays in seniors attributed by doctors to adverse drug reactions doubled during the 80s.²⁰



This work was updated by Health Science graduate, Christel Burgess, who found, as shown on the upper left, that by 2002 the rate of hospital stays for drug reactions had reached epidemic proportions, increasing five-fold since 1980.²¹ Look down on the left and you'll see how the increase was especially marked in the oldest age groups. Six categories of medicines were the ones apparently most responsible: oral anticoagulants (or blood-thinning drugs); cytotoxics used to treat cancers; antirheumatics for arthritis; corticosteroids to reduce inflammation and immune responses; opioids, which are strong pain killers; antihypertensives for blood pressure; and a range of other drugs for heart disease. One can calculate that for people like me, approaching age 60, one in four of us will be hospitalised by age 85 for a side effect from one of these medications.

Using WADLS, our research group then focussed on how much of the problem involved readmissions for a recurrent medication safety issue. Post-doc fellow, Professor Min Zhang, found that repeat pharmaceutical poisonings, shown as the darker bar segments at the lower right, had grown faster than new ones and had risen to become 30% of the overall burden.²² This is what we call a revolving door class of problem.

These reports were highly cited and alerted quality use of medicine proponents to a growing epidemic of avoidable hospitalisations from pharmaceutical poisoning in older Australians. However, there were significant limitations on how far we could go with just the WA State data. Our research had relied on the ability of hospital doctors to identify an adverse drug

²⁰ Dawes VP. Poisoning in Western Australia: overview, investigation of therapeutic poisoning in the elderly (MPH dissertation). Perth: The University of Western Australia, 1994.

²¹ Burgess CL, Holman CDJ, Satti AG. Adverse drug reactions in older Australians, 1981-2002. *Med J Aust* 2005; 182(6): 267-270.

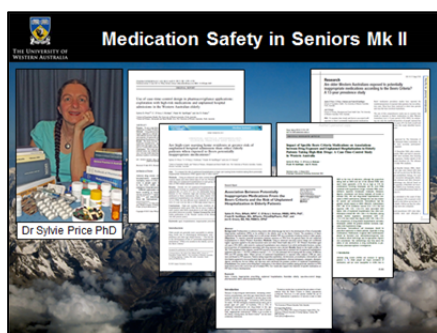
²² Zhang M, Holman CDJ, Preen DB. Epidemiology of repeat adverse drug reactions in older Australians: a Population-based longitudinal study 1980-2003. *Aust Epidemiol* 2006; 13(3): 85

reaction as the underlying cause of an admission. We felt that through no fault of the medical profession, inevitably some would be missed.

The cost-benefit calculus was also challenging, because the identified high risk drugs were extremely valuable, life-enhancing medicines that prevent strokes; stop fatal blood clots; control severe pain and inflammation; and fight cancer. They are, in fact, among the most powerful weapons available to doctors in the modern medical war chest; and some of them, like cytotoxics and anticoagulants demand an inherently delicate balance between receiving enough to be of therapeutic value; but not so much as to cause dangerous side effects.

It was then I became aware of another group of drugs now placed on a list of medications to be avoided in seniors, because over time, evidence of problems has emerged that isn't sufficiently justified by the benefits; and, besides, safer alternatives are generally available. These are known as potentially inappropriate medications, or PIMs for short.

After the Cth data were released, at last we were in a position to investigate these issues properly.

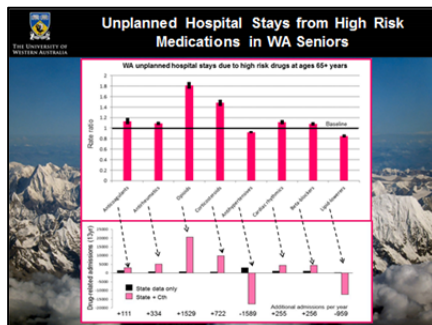


It was Dr Sylvie Price, awarded her PhD barely a few weeks ago, whose work has, in the words of one of her Eastern States examiners, “taken the rigour of medication safety research in Australia to an entirely new level”.²³

For the epidemiologists in the audience, Dr Price used an enhanced case-time-control design where index subjects acted both as cases and their own historic controls, while background time trends in exposure due to aging, disease progression and treatment patterns were adjusted using similarly constituted case and control windows in a reference patient group, drawn from the same drug domain as that being studied in each index subject. This provided very strong technical control for all known and unknown fixed confounders, and a good level of control for time-varying confounders. It also enabled Dr Price to assess, far more accurately than ever before, the true burden of emergency hospital stays in seniors from both the known high-risk drugs, and also the less well appreciated potentially inappropriate ones.

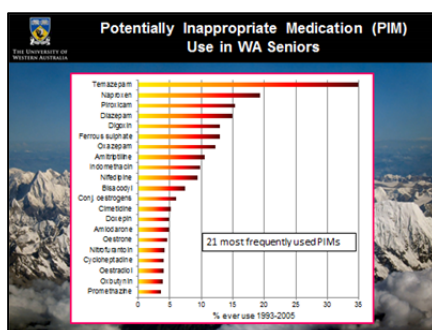
²³ Price SD, Holman CDJ, Sanfilippo FM, Emery JD. Use of case-time-control design in pharmacovigilance applications: exploration with high-risk medications and unplanned hospital admissions in the Western Australian elderly. *Pharmacoepidemiol Drug Safety* 2013; 22(11): 1159-1170; Price SD, Holman CDJ, Sanfilippo FM, Emery JD. Association between potentially inappropriate medications from the Beers Criteria and the risk of unplanned hospitalization in elderly patients. *Ann Pharmacother* 2014; 48(1): 6-16; doi: 10.1177/1060028013504904; Price SD, Holman CDJ, Sanfilippo FM, Emery JD. Are older Western Australians exposed to potentially inappropriate medications according to the Beers Criteria? A 13-year prevalence study. *Australas J Ageing*, in press (accepted 3 December 2013); Price SD, Holman CDJ, Sanfilippo FM, Emery JD. Are high-care nursing home residents at greater risk of unplanned hospital admission than other elderly patients when exposed to Beers potentially inappropriate medications? *Geriatr Gerontol Int*, in press (accepted 21 October 2013); Price SD, Holman CDJ, Sanfilippo FM, Emery JD. Are elderly patients taking high-risk drugs at increased risk of unplanned hospitalisation when exposed to specific Beers Criteria medications? *Drugs Aging*, in press (accepted 16 February 2014); Price SD, Holman CDJ, Sanfilippo FM, Emery JD. Does ongoing GP care in elderly patients help reduce the risk of unplanned hospitalization related to Beers potentially inappropriate medications? *Geriatr Gerontol Int*.

The scope of Dr Price’s project was somewhat jaw-dropping. It involved a study of 1.9 million unplanned hospital admissions in just over a quarter of a million WA seniors. But to do this she had to analyse 153 million digital records from six different data collections, three State and three Cth, which required the creation of some 1,000 intermediate computing files occupying 1 Tb of disk space. She wrote more than 600 programs with over 150,000 lines of computing syntax. Some of her macros were so intensive, they required up to three days of powerful computer processing time to finish their work.



What she found was that the true level of pharmaceutical poisoning from the high risk drugs was around double that recorded using routine medical coding, 1,340 versus 681 emergency admissions per year. Based on the rate ratios in the top part of this figure, meaning the change in risk caused by each drug, we see in the bottom half how the corresponding accurate number of hospital stays shown in pink were much higher than what the official hospital records, shown in black, had led us to believe.

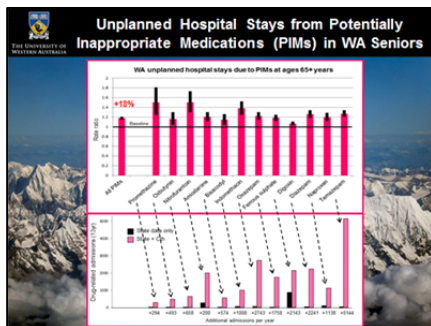
However, this didn’t apply across the board. Our results showed that for drugs that lowered blood pressure or blood fats, the net effect was to prevent rather than cause unplanned hospital admissions. Of course, it’s impossible for a hospital to record the day when someone’s not admitted to their care. However, even taking this trade-off benefit into account, the study exposed a large net under-ascertainment of the risks of most of these life-saving medications, which does become relevant when doctors are considering their use for marginal clinical indications.



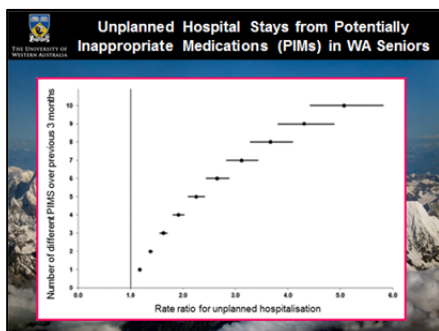
Even more remarkable was the very substantial hidden burden of emergency hospital stays caused by the exposure of a staggering proportion of older West Australians to PIMs. Using the linked Cth data, Dr Price found that 3 out of every 4 WA seniors had taken at least one PIM during the study and 45% in any one year. PIMs were more likely prescribed to patients who were female, older, in residential care and taking multiple medicines.

Many of these drugs will be familiar to members of this audience. For example, at the top of the list is temazepam – a sleeping tablet, used by 1 in 3 older people, and in fourth position is a related drug, diazepam, or Valium, used to treat anxiety in 1 in 6. There are now three safer alternatives to diazepam in oldies and five safer alternatives to temazepam; ... and so the list goes on.

Some of these inappropriate medications may cause unplanned hospital episodes through subtle and indirect causal pathways. For example, drowsiness from temazepam might cause an elderly patient to fall and fracture their hip, but the identification of temazepam as the underlying cause only becomes possible to measure using the Cth data and advanced epidemiologic methods. And indeed, our results showed that these potentially inappropriate medications, not recommended in seniors, are certainly not without serious problems.

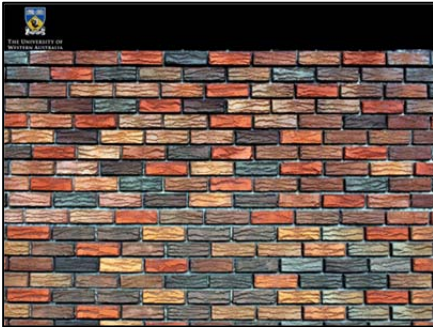


A senior taking a PIM was 18% more likely, on average, to be carted off to hospital for an unplanned admission, with elevations in risk seen across many items on the PIMs list as shown in the upper part of this figure. We attributed 1,752 preventable admissions of WA seniors every year to the use of PIMS. As seen by again contrasting the pink columns with the black ones, very few of these preventable admissions were identified in the hospital records; in some cases the real number based on the combined Cth and State data was over 100-fold higher than what was apparent from the WA data alone. The number of pharmaceutical poisonings from these deceptively unsafe medications is actually larger than that attributed to the known high risk drugs, which still accounted for a sizeable 6.9% of emergency admissions. It was just that the PIMs accounted for an even larger 9.1% and, unlike the known high risk drugs, PIMs are classified as inappropriate.



In other aspects of her research, Dr Price found that the risk of an unplanned hospital admission increased progressively with the number of PIMs being taken by patients during the previous three months – there were, in fact, patients taking up to 10 different PIMs at the same time.

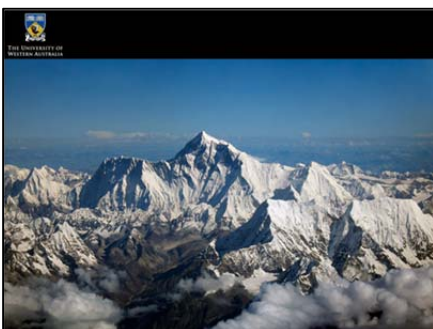
The combined burden of adverse drug reactions from these medications amounts to over 3,000 unplanned hospital admissions per year in WA alone; it would be 30,000 per annum nation-wide. We now know about some political arithmetic that was previously hidden behind the great data divide between Cth and State. It's now on the health agenda. And given the significant human and financial costs involved, there should now be public accountability for a response with appropriate policy reforms, including professional and patient education.



Sadly, as is the case with advancing the health of the mentally ill, the success of these interventions to prevent thousands of older Australians becoming sick and admitted to hospital from adverse drug reactions won't be possible, because in 2012, the Cth Health Department withdrew its participation from the linkage agreement. The short-lived window of cooperation was closed and to date hasn't been replaced by any functional alternative, which would be capable of supporting work of the technical calibre performed by Dr Price or Dr Mai.

This detrimental Cth policy decision has again blinded us to the truth of the health system and denies us what would have been a powerful paradigm-shifting tool for public accountability for our 140 billion dollar spend per year.

You might ask: how on Earth could such an inept decision occur? Did something go wrong? Well nothing went wrong; rather things were never right from the start. There's a fundamental perversity in two governments with vertical programs competing for the leadership of a singular health system; and it's this arrangement that can never be right from the start. The more salient question, is how on Earth did we manage to keep the dream barely alive for as long as we did.



Colleagues and friends, may I please thank you sincerely, for your generosity in blessing me with your presence this evening.

This is Mount Everest as seen last November from a flight half-way between Dehli in India to Paro in Bhutan. As I peered through the aircraft window at this magnificent “mother of the world”, as the Tibetans call it, I reflected that I’d never stand upon its summit during my lifetime. But it wasn’t an unhappy thought, because unlike most people, together with my lovely wife, Belinda, at least we’d enjoyed the privilege to fly past on a beautiful day, to gaze in wonder; and that alone was a most satisfying experience.

So it is with what I’ve said this evening. The cross-jurisdictional linkage project provided merely a glimpse through a window in history, when a short-lived, uneasy truce in bureaucratic hostilities enabled myself and a few comrades to scramble over the great data divide and take an unprecedented look at our health system in its entirety. In one sense, our mission was a failure, because our efforts to bring down the divide were time-limited and our achievements were not sustained.

Nevertheless, I’m proud of what was accomplished, given that we in WA have gone further towards the ideal in this area than anyone else in the country has ever gone before. We have at least some research results, which will drive better health outcomes and avoid waste. Also, I’ve barely touched on the array of new and exciting technical methods we created to analyse such complex linked data sets. This technical know-how was incorporated into UWA’s international training program, delivered in six different countries around the world and described in 2011 by the UK’s Medical Research Council as the pre-eminent source of training for linked data analysts in that country.

Most significant of all, my co-investigators and I feel privileged to have demonstrated, with tangible results, where health, political arithmetic and public accountability will best be served. Tonight I’ve shared our adventure with you; and for the future I have faith that an inspired and publically spirited generation of younger health leaders, and political leaders, will one day complete the demolition of this non-sensical and damaging knowledge divide, once and for all.

To my younger colleagues, in particular, let me say:

perhaps you’ll remember this address; you’ll remember that someone has seen the summit of a proper health information system for our country; and you will know, regardless of what others might tell you; whilst the climb is indeed fraught with difficulties; the prize is not an impossibility.



Thank you, and a very good evening to you all.