

# Notes for Productivity Commission

## Data Access and Linkage Issues<sup>1</sup>

<b>TABLE OF CONTENTS</b>	<b>Page</b>
<b>1. Background</b>	<b>2</b>
<b>2. Privacy matters</b>	<b>3</b>
<b>3. Issues</b>	
<b>3.1. Current situation</b>	<b>4</b>
<b>3.2. Use of public sector data</b>	<b>4</b>
<b>3.3. Managing conflicts of interest</b>	<b>5</b>
<b>4. The current opportunity</b>	<b>7</b>
<b>5. Looking ahead</b>	<b>7</b>
<b>6. A Public Information Commissioner?</b>	<b>8</b>
<b>7. Infrastructure and resource issues</b>	<b>9</b>
<b>REFERENCES</b>	<b>10</b>
<b>Annex 1. Case studies in the health sector</b>	<b>11</b>
<i>Deep venous thrombosis and air travel</i>	
<i>Cancer risks following CT scans</i>	
<b>Annex 2. A social compact for the use of de-identified data for public benefit</b>	<b>15</b>

---

<sup>1</sup> John Mathews – School of Population and Global Health, University of Melbourne

## 1. Background

Australia has been well-served by the checks and balances between different levels and agencies of government, by the creative tension between the public and private sectors, and by analysis and commentary from the media and from academia.

However, there are unintended negative consequences when sectional interests predominate over the wider interests of society. This happens when the competition of ideas is replaced by an almost fixed belief that a sectional interest or reputation must be protected at all costs. Most working cultures, whether in government, the private sector, the professions, unions or academia, tend to develop strong beliefs which discriminate between “us and them”. However, such beliefs become counterproductive when they discourage the sharing of information between interest groups, jurisdictions, agencies and sectors that would otherwise bring new social benefits for Australians, and improve the efficiency and effectiveness of the economy.

Fortunately, there is now an emerging consensus, from the highest levels of government, about the added value that could come from greater cooperation and transparency, and from sharing of digital information and the aggregation and linkage of data between different agencies and sectors.

### *a. Discharging our duty of care in the modern world*

The rise of modern science and technology has been of enormous benefit to mankind, but it has also delivered complex new problems for society to solve. For example, it is no longer possible for any medical practitioner to understand how to deal with all possible health problems at the level of detail; society has responded through systems that depend upon specialisation and referral, and by requiring that medical procedures be evidence-based whenever possible.

Pharmaceutical and technological advances, driven by new science and by commerce, offer great health benefits, but it has often been the case that the risks (such as cancers caused by CT scans in childhood) have taken longer to be recognised than the benefits. Indeed, when risks are significant but rare, individual practitioners will almost never notice them, and when they do, they will be unable to conclude that the adverse outcome was caused by the prior exposure. The only way to prove the case is by pooling observations across large numbers of exposures. In Australia, the risks of CT scans could be studied because the Medicare billing system records all Commonwealth-funded scans, and because of the national cancer register held at AIHW (see Annex 1 “Case Studies of Data Aggregation Linkage in the Health Sector”). Similarly, by linking records of the Pharmaceutical Benefits Scheme to other records, it is possible to detect adverse outcomes of prescription medicines that would otherwise go undetected. Further, by linking PBS records of pregnant women to birth and family records in Medicare or to birth defects registers, effects on the unborn child can also be detected.

In the longer-term, as digital health records for individuals become more complete and more reliable, it is inevitable that they will be linked (in de-identified form) to help identify new health risks and benefits, and to improve the efficiency, effectiveness and safety of health services. Indeed, once privacy can be guaranteed, there would be an implicit obligation on all

Australians, and all service providers , to allow their electronic records to be used in this way for public benefit purposes.

The 2013 report from a Menzies Foundation workshop summarised some of the issues affecting data access and linkage, and the benefits that could flow to the health sector from improved data access, an improved evidence-base, and improved service provision.

Although the social benefits flowing from improved data usage are perhaps most evident in the health sector, there are comparable social benefits to be won by integrating data and improving evidence within and between sectors such as education, welfare, criminal justice systems.

## **2. Privacy matters**

The right to privacy is very important, but it cannot be absolute, as when the privacy right for an individual comes into conflict with the community obligation to protect itself against crime or terrorism.

Health information is of particular sensitivity. Protecting the privacy of personal health information is important, but absolute protection will inevitably be in conflict with obligation for society to use aggregated health information for public benefit research purposes. Accordingly, exemptions in privacy legislation do allow for personal data to be used for public benefit research, provided that other measures are in place to protect privacy.

Other personal information is also sensitive, but in the modern commercial world, Google, Apple, Facebook, and other digital giants have collected a wealth of personal information about most of us. Bank information on purchases through card transactions can be used to generate personal profiles that can be sold-on to other commercial interests. Thus over the last two decades, the private sector has been responsible for a substantial erosion of personal privacy.

This private sector information has been collected and managed in ways that are technically not in breach of the privacy principles, but the de facto situation has been that consumers have had to accept the conditions of use laid down by the banks and digital providers. Most people, if they think about it, are resigned to the end-use of our personal and financial data for commercial purposes, and accept it as part of living in the modern world.

However, as a society we need to remind ourselves that we should not allow a double standard in the use of personal information, whereby we tolerate the aggregation of personal information in the private sector for commercial purposes, but unduly restrict the aggregation of public sector data for public benefit research purposes.

Consideration should be given to the reframing of privacy legislation governing public sector data, so that agencies and data custodians are obliged to release aggregated data for public benefit research purposes, subject only to the adequacy of measures to protect personal privacy.

### 3. *Issues*

#### *a. Current situation*

*Stakeholders* include all private sector, government, and academic agencies that collect, store or use data, as well as the consumer and legal communities with an interest in regulation of data-use, data protection and privacy.

*Private sector data* is subject to regulation through the national privacy principles, but it is widely understood that personal and financial information about most Australians is collected, used for business purposes, and often sold-on to other business interests for purposes other than those originally intended. This is how the private sector must work in the modern world. Most Australians see the private sector as essential, they have a general understanding of what is happening, they are resigned to it, and only occasionally challenge the accuracy of data relating to them<sup>2</sup>.

*Public sector data* has hitherto been more robustly protected by government agencies and data custodians, who have often resisted calls for data to be used for public benefit purposes that were not always foreseen in the legislation governing the original data collection. Government has now signalled that attitudes should change, and that public sector data should be used for public benefit purposes provided that privacy is protected.

#### *b. Use of public sector data*

To fully discharge their duty of care in the modern world, governments must promote data access and data linkage, and cooperate with research and professional groups, consumer representatives and with the private sector to ensure that data-based evidence is developed and used to improve the effectiveness, efficiency and safety of services.

- When personal details are accessed for aggregation or linkage purposes, such access must be limited to persons who already have the statutory or professional responsibility to care for the identified data.
- Personal identifiers must be removed from linked and aggregated data-sets, and the linkage keys must be held in high security by those with statutory or professional responsibility.
- Researchers with ethical approval from a Human Research Ethics Committee (HREC) working to NHMRC guidelines<sup>3</sup> should be eligible to receive de-identified data sets for the approved research.
- Before receiving data, researchers and their host institutions must sign agreements that impose legal penalties for any attempt at re-identification of individuals or communities, or for any other use of the data that is not been approved in advance by the HREC.

---

<sup>2</sup> The private sector experience shows that Australians are accepting of what they see as understandable and reasonable. This provides a rationale for explaining, to all Australians, the social benefits that will flow from the use of aggregated and de-identified data from the public sector. The other lesson to learn from the private sector is that it would be dangerous for the public sector to sell health data or other sensitive data to the private sector without firm guarantees for the protection of privacy.

<sup>3</sup> Or another appropriate ethics committee for research in sectors other than health.

*c. Managing conflicts of interest*

*The right to privacy* is in potential conflict with the social benefits to be derived from the use of aggregated data for research and evaluation purposes.

- This potential can be minimised by explaining the social benefits and by promoting the idea of a new social compact, in which citizens approve the aggregation of their individual data for public benefit purposes, provided that their privacy is protected.
- Privacy can be protected by statutory requirements for prior ethical approval of research and evaluation projects, by requirements for aggregated research data to be de-identified and for legal penalties to be imposed for any re-identification or misuse of data by researchers.
- For some research projects involving individual patients or clients, ethics committees will approve temporary access to identified data by a researcher on a need to know basis, subject to informed consent from each subject, provided that identification details are dropped subsequently from aggregated data. If consent is not feasible, an exemption may be granted by an ethics committee, provided all other measures to protect privacy are met.

*Recognising and managing stakeholder risks:* Increased transparency and data-sharing have the potential to reveal information that is financially sensitive, to uncover risks that were previously unknown, to reveal a higher incidence of adverse outcomes than would be reasonably expected, or to otherwise reflect upon the professional competence or integrity of those whose responsibilities are reflected in the data under consideration.

- The potential for data-based research and evaluation to reflect adversely on the agencies or professionals with custody of the data may help to explain a past reluctance of some government and service agencies to approve the release of records for research and evaluation purposes.
  - For example, state and territory agencies have often been reluctant to share jurisdictional data with the Commonwealth, perhaps because it relates to areas for which the Commonwealth is not responsible, or because of a state fear that an uninformed analysis would reflect adversely on their performance, or because the state is seeking to exchange the data for additional funding from the Commonwealth<sup>4</sup>.
  - Until recently, health and some other Commonwealth agencies have also refused to release de-identified public sector data for external research and evaluation projects, even though the motivation and in-house expertise to do the work themselves is lacking. Such refusals were purportedly justified

---

<sup>4</sup> For example, state-based agencies can claim that they need additional funding to provide data to a national agency such as AIHW, and they demonstrate their need by failing to provide data on-time. This may help to explain why most states have currently reported cancer data to AIHW only up to 2012. Communicable disease data has been another bone-of-contention between jurisdictions; the states have reluctantly shared data on notifiable communicable diseases with the Commonwealth, but have withheld information on personal identifiers to protect privacy. This leaves the states and territories in charge of dealing with disease outbreaks. However the delays and deficiencies in national reporting will continue to delay national responses in which Commonwealth powers such as quarantine may need to be exercised.

on the grounds of privacy protection and the legal ambiguities around data release to third parties. They also attest to the short-term focus of past decision-makers in the health culture, to some scepticism about the relevance of research, and to a wide gap between the bureaucratic culture and the medical and research culture in Australia<sup>5</sup>.

- Recently, the Commonwealth has provided leadership towards a national electronic health record which would eventually improve the efficiency of day-to-day service delivery and make it a better experience for both practitioner and patient. In the short-term this initiative has encountered predictable problems including concerns about privacy, data ownership<sup>6</sup> and liability, as well as the more concrete problems of creating a digital system that will be good enough to encourage all the stakeholders (patients, practitioners, hospitals and governments) to use it, and improve it. In the longer term, a successful electronic record system should lead to many new gains to be made through research and evaluation.
- In the short term, the potential conflict seems likely to be resolved by a whole-of-government commitment to support data access in the public interest, even if it proves to be at the expense of temporary reputational damage to some service agencies or professional groups.
- In the longer-term, data-based research and evaluation will benefit all interest groups, who will see the value for them as well as the social benefits from the enhanced national commitment to evidence-based policies and practices.

#### *Financial considerations*

Steps that would have enhanced a national data system have often not been taken because of financial constraints; even if the jurisdictions and agencies could agree on the need, there has usually been difficulty in deciding who should pay. For example, for many years, there has been discussion about the need for a national suicide register. However, because of competing priorities, and because the Commonwealth could see this as a way for the states to ask for more funding, the idea has not been supported. Consequently, some states have developed their own registers, but without uniform criteria, so that the aggregated data are much less useful than they could have been.

---

<sup>5</sup> Since the early 1980s, following concerns about the undue influence of doctors, Commonwealth Health has employed few staff with medical qualifications; those that have been employed have been advisers rather than decision-makers, so that even the Chief Medical Officer has had a limited role in determining policy and practice. The lack of staff with medical and health expertise in the responsible Commonwealth department contrasts with the situation in the states and territories, where professional expertise is more valued, and with the situation in the Department of Agriculture, Forestry and Fisheries, where a lack of professional expertise would not be tolerated by stakeholders involved in primary production.

<sup>6</sup> Medical organisations used to argue that a doctor's records were owned by the doctor concerned. However in a complex (public) hospital system, with many contributors to each patient record, ownership by individual doctors could not continue to apply, so that legal ownership, and most liability, became vested in the hospital employer. Under Freedom of Information legislation, patients now have a right to access information about them that is held by a public (ie government-funded) hospital; rights of access also apply under Privacy Principle 6, which also applies to records held by private practitioners or private hospitals. However access to privately-held records is more likely to be disputed using certain exemptions to PP6. Additional complexities arise if a doctor claims copyright of records, or when the rules of evidence apply in legal proceedings.

#### **4. The Current Opportunity**

The highest levels of government have recently made a commitment to promote the availability and use of “big data” in Australia, following on from earlier initiatives through NCRIS and RDSI. The reference to the Productivity Commission to investigate the “benefits and costs of options for improving the availability and use of data”, and to report to government by March 2017, provides a great opportunity for all stakeholders to shape the way that Australia is going to reap the benefits of the digital revolution. A Senate Committee has recently produced an interim report on the issues affecting access to health data, and is likely to complete its task in the next parliament.

#### **5. Looking Ahead**

- There should be a continuing public discussion of the value of enhanced national data systems. The use of aggregated and de-identified data for public benefit research will improve knowledge and improve the efficiency, effectiveness, safety and transparency of services. The public commitment to such research should be seen as enhancing the social compact that Australians have already made with each other for their mutual benefit.
- In planning for enhanced data systems, consideration must be given to conflicts of interest between jurisdictions and agencies, between research and privacy interests, between governments and researchers, between research and service providers, and between public sector and commercial interests.
- The Council of Australian Governments should commit to a cooperative model for managing this national data initiative, and in doing so, it should learn from the successes that followed the creation of ABS in the early years after federation, the successes of AIHW from the 1980s, and the later work done under NCRIS; it should also learn from the more recent failures in cooperative federalism that have from time-to-time inhibited the sharing and use of Australian public sector data in the public interest.
- Governance arrangements for this national data initiative should be developed and approved through COAG. This could involve enabling legislation to strengthen the leadership roles for ABS and AIHW in their respective domains, and/or the creation of a new body<sup>7</sup>; in either circumstance, the governing body or bodies should report to Australian governments through COAG.

---

<sup>7</sup> The governing body should have senior representation from all Australian governments, and it should receive expert advice from specialist committees on research and data priorities, data security and privacy issues, legal obligations, and the economic costs and benefits of data aggregation and research in Australia.

- Strategic planning and priority setting for the enhanced national system would involve experts, consumers and jurisdictional representatives, whose recommendations would go to the governing body.
- Privacy legislation, and legislation authorising data collections by governments, should be reviewed and amended to ensure that there are no impediments to the release of de-identified data for public benefit research and evaluation.
- Complementary legislation should be considered to address legal indemnities that could arise as a result of proposed developments in national data systems.
- Researchers, and their host institutions, should be required to sign legal agreements, with penalties for any re-identification or any other breach of confidentiality or for any data-use not approved in advance by the appropriate ethics committee.
- For research proposing to use national data for ethically approved research, legal authority to govern approvals and agreements should be vested in the national agency (eg AIHW for health projects) with state and territory representation; this would avoid the need for multiple applications and separate agreements with all state and territory jurisdictions. States and territories could maintain a power of veto over use of their data, but only by objecting to a release decision, and by showing cause that their objection was reasonable.
- Data custodians within government should be required to promptly consider all data requests for ethically approved research, and to show cause if any request is unreasonable refused or deferred.

## **6. A Public Information Commissioner?**

- Consideration should be given to overarching legislation that would:
  - Establish a Public Information Commissioner with the responsibility of promoting public benefit research using public sector data;
  - Oblige government agencies and data custodians to release data for research purposes approved by the Public Information Commissioner.



## 7. Infrastructure and resource issues

There should be new investment in infrastructure and expertise to support the administration of the new systems for project approval, data aggregation and linkage; in the first instance this would provide enhanced support for state and territory centres of excellence<sup>8</sup> and for AIHW and ABS, which have been designated as national agencies for the confidential linkage of data.

### *Managing demand and supply*

Inevitably, the demand for data and data linkage has already far outstripped the capacity of the current system to respond. Even in an enhanced system of the future, demand will still outstrip supply. There are several options to be followed:

- Strategic decisions would identify high priority data-sets and generic research questions to be addressed, so that researchers and evaluators would obtain faster access to such data; this would minimise the churn from repetitive but slightly different project demands in popular areas.
- The aggregation and linkage agencies would charge the research team to recover their marginal costs of providing data for each project; this would work well for public sector projects, as it would queue projects according to a capacity to pay, which would usually be related to project quality. For example, if a project were funded by NHMRC it could be assumed to be of high scientific quality as well as socially important. Likewise a government agency, university or charitable foundation would need to be convinced of the social value of a project before making funds available.
- Data requests for commercially-funded projects would need to be assessed and approved by a committee with the necessary specialist and commercial expertise.

---

<sup>8</sup> Already established and monitored with funding provided through the Public Health Linkage Network.

## References

Productivity Commission Issues Paper <http://www.pc.gov.au/inquiries/current/data-access>

### **NHMRC Guidelines on data sharing**

<https://www.nhmrc.gov.au/grants-funding/policy/nhmrc-statement-data-sharing>

### **NHMRC Health and Research Ethics Guidelines**

<https://www.nhmrc.gov.au/health-ethics>

Department of Prime Minister and Cabinet Report of Data Management Project (Dec 2015) [https://www.dpmc.gov.au/sites/default/files/publications/public\\_sector\\_data\\_mgt\\_project.pdf](https://www.dpmc.gov.au/sites/default/files/publications/public_sector_data_mgt_project.pdf)

Senate Health Committee

[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Health/Health/Sixth\\_Interim\\_Report](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Health/Health/Sixth_Interim_Report)

Wellcome Trust: Summary report of qualitative research into public attitudes to personal data and linking personal data. July 2013

UK Academy of Medical Sciences. Personal data for public good: using health information in medical research. January 2006

Holman CD et al . A decade of data linkage in Western Australia. *Aust Health Rev* 2008; 32(4): 766–777

<http://blogs.crikey.com.au/croakey/2013/07/28/are-governments-locking-up-information-that-could-be-used-to-improve-our-health/>

Menzies Foundation Workshop - Position papers and Discussion Paper (2013)

<http://menziesfoundation.org.au/partnerships/workshops/187-data-based-research-to-improve-health>

Department of Prime Minister and Cabinet Report of Data Management Project (Dec 2015)

<https://www.dpmc.gov.au/public-data/public-sector-data-management-project>  
and [https://www.dpmc.gov.au/sites/default/files/publications/public\\_sector\\_data\\_mgt\\_project.pdf](https://www.dpmc.gov.au/sites/default/files/publications/public_sector_data_mgt_project.pdf)

National Innovation and Science Agenda Data Sharing statement and policy (Dec 2015)

<http://www.innovation.gov.au/page/data-sharing-innovation> and  
[https://www.dpmc.gov.au/sites/default/files/publications/aust\\_govt\\_public\\_data\\_policy\\_statement\\_1.pdf](https://www.dpmc.gov.au/sites/default/files/publications/aust_govt_public_data_policy_statement_1.pdf)

Glyn Davis article in *The Conversation* (April 2016)

<https://theconversation.com/investing-in-big-data-could-improve-research-quality-in-australia-57492>

Kelman CW, Kortt MA, Becker NG, Zhengfeng Li, **Mathews JD**, Guest CS, Holman CDJ. Deep vein thrombosis and air travel: record linkage study. *BMJ*, Nov 2003; 327: 1072 – 1076

**Mathews JD**, Anna V Forsythe, Zoe Brady, Martin W Butler<sup>3</sup>, Stacy K Goergen, Graham B Byrnes, Graham G Giles, Anthony B Wallace, Philip R Anderson, Tenniel A Guiver, Paul McGale, Timothy M Cain, James G Dowty, Adrian C Bickerstaffe, Sarah C Darby *Cancer risk in 680 000 people exposed to computed tomography scans in childhood or adolescence: data linkage study of 11 million Australians.* *BMJ* 2013;346:f2360 doi: 10.1136/bmj.f2360

## **Annex 1.**

### **Case Studies of Data Aggregation and Linkage in the Health Sector**

#### *Deep venous thrombosis following long-haul air travel*

For many years Western Australia has been a national and international leader in linking health data collected on behalf of the state government, although it had little success in persuading the Commonwealth to allow linkage of state data to Medicare, PBS or other Commonwealth data.

In 2000, the international community was faced with growing concern about reports of deep venous thrombosis (blood clots in the legs) and pulmonary embolism (clots blocking blood flow to the heart) in those who had just experienced a long-haul air-trip.

This provided a new incentive and opportunity to link WA data with Commonwealth data. Specifically, it was possible to link details of passengers arriving from incoming international flights into Perth airport (using Department of Transport data), with WA hospital admissions for deep venous thrombosis and pulmonary embolism. This linked but de-identified data-set allowed us to show that the estimated absolute risk from a long haul flight was small, and to show that the increased risk following a flight was over within 14-21 days of arrival.

This study became possible because of our awareness of the WA linkage system, and because at the time I was a senior public health adviser within the Commonwealth Department of Health, which also gave us access to relevant decision-makers in Transport. Although the study provided an important precedent for what data-linkage could achieve, it also created anxiety at senior levels within the health department, apparently because of concerns about “what might be found”. Subsequently, a decision was made to close-down the small linkage unit within the Department of Health.

#### *Cancer risks following CT scans in childhood*

From about 2000 onwards, there were increasing theoretical concerns about the possibility of increased cancer risks following childhood exposures to computer tomography (CT) scans, which create three dimensional images using multiple exposures to X-rays. These concerns were not based on data from children actually exposed to CT scans, but were largely based on dose extrapolations from other exposures, such as those in survivors of the Japanese atomic bombs. It seemed sensible to try and actually look at the question in those who had actually been exposed to ionising radiation from CT scans.

It was clear that this question could be addressed by linking Medicare records of CT scan exposures to the national register of cancer notifications (administered by the Australian Institute of Health and Welfare on behalf of the states and territories who contribute the data). By 2005, I was back at the University of Melbourne after having left the Department of Health in 2004. The Department of Health declared that it would not allow Medicare records to be linked for research purposes. Nevertheless, I continued to lobby with the Department, and worked towards a research protocol that could be assessed by the NHMRC Human Research Ethics Committees and data custodians in all states and territories who would need to approve the release of national cancer data. Our first application to NHMRC for funding to support the research was rejected in 2007, but our second application in 2008 was successful.

Even though we had funding, and approval from all states and territories to access cancer data through AIHW, we still did not have Commonwealth approval for access to de-identified Medicare data. There was no response from senior Commonwealth officers, and no clear guidance emerged about who would have responsibility for giving approval. We managed to roll some of the NHMRC grant forward in time to protect our precious research funding, and we continued to lobby with the Commonwealth. Eventually, in mid-2010, a meeting of responsible Commonwealth officers (from Health, Medicare and AIHW) was convened in Canberra to discuss with us how the data could be provided, and formal approval was given shortly thereafter. We received the relevant Medicare service data, in de-identified form, for over 10 million young Australians by early 2011, and the cancer notifications for the same cohort came from AIHW by September 2011. We linked the service records with the cancer records, using a unique but anonymised patient number provided by the Department of Health. Linkage was thus achieved without any of the agencies having had access to any personal data beyond what was required to fulfil their usual statutory responsibilities. (ie Health and Medicare officers did not have access to cancer data, and AIHW officers did not have access to Medicare service data.) The final research file combined both sets of information, but only in de-identified form.

Our BMJ paper, published in April 2013, reported that cancer risk was increased by an average of 24% for persons exposed to CT scans before the age of 20 years. However the increase was as large as 200% for brain cancers in the small number of children with CT exposures at very young ages. The publication attracted a great deal of interest, and some criticism, and it became the most highly cited of any BMJ article in calendar year 2014.

In 2013-14 we advised the Commonwealth CMO, ARPANSA, RANZCOR and the Commission on Safety and Quality in Health Care who were working to inform medical professionals and the public about the evidence on cancer risks and to develop educational materials. This initiative helped to ensure that CT scan doses would be reduced, and that CT scans, especially in children, would be limited to those that could be fully justified on clinical grounds.

#### *Learning from the CT scan study*

- (1) The CT scan study would have been almost impossible without some special circumstances:
  - i) Insights in radiation epidemiology from time in Oxford, and as an adviser to the Commonwealth on radiation through AIRAC;
  - ii) Knowledge of what could be achieved by linking Medicare records to cancer registry records.
  - iii) Being in the twilight of my career, I had little to lose and was not (unduly) deterred by the long delays in obtaining approvals; younger researchers, to be competitive in the research game, would have had to cut their losses and move on to more immediately productive projects.
- (2) Thus a lesson from this experience is that we should try and create a national data system that can be both more strategic and more rapidly responsive, so that projects of potential national importance do not have to depend upon happenstance.

- (3) It is still the case that the Australian CT scan cohort provides the largest and the most-convincing body of evidence in the world about cancer risks following CT scans. Our publication was not the first, as the smaller UK study, with more limited conclusions, reported in 2012.
- (4) Our study showed that some 500 additional cases of cancer occurred in the CT cohort beyond what would have been expected from cancer risks in the age-matched cohort of unexposed Australians. (Cancers attributable to reverse causation or confounding bias have been excluded from this estimate.)
- (5) Had our study been approved sooner, and been able to proceed at an earlier date (say in 2008), we would have had results sooner, with potential benefits in terms of improved guidelines for CT usage, lesser exposures and fewer cancers.
- (6) Criticism of our results has come from some radiologists who question the need to obtain informed (parental) consent for CT scanning at young ages. They argue that the evidence is insufficient to justify causing alarm and anxiety in parents, who are likely to refuse consent for a scan even if it is strongly indicated for their child. A more measured response would see that in seeking parental consent, the radiologist would also have the incentive to critically examine his own position about the indications for a scan in this particular child. He or she would have to balance the risks of a scan (a small increase in cancer risk) against the risks of not doing it (missing a treatable condition, loss of reputation and loss of business.)
- (7) Some radiologists may see CT research as a threat to their CT-based business model; this could explain why the WA government was previously asked by radiological interests to withhold CT usage data from researchers.
- (8) In the best of all possible worlds, there would be a long-term study of all CT exposures with prospective measurements of exact radiation doses. Unfortunately, although most companies manufacturing CT scanners provide automatic software to prospectively record radiation doses, this software comes at such an additional cost that the option is almost never taken up by radiologists, whether in the public or private sector. Consequently, there is no systematic and prospective recording of diagnostic radiation doses in Australia, and we have to make do with retrospective estimates, which are inexact and time-consuming.
- (9) Our study also showed that the average increase in risk of solid cancer, per unit of radiation dose from CT scans, was greater than estimates based on cancer risks per unit of dose in Japanese atomic bomb survivors, suggesting that the risk of cancer, per unit of dose, is greater at low doses; this questions the conventional wisdom about the linearity of the dose response curve for cancers due to low-dose radiation.

*Continued follow-up of the CT scan cohort*

- (10) Our BMJ paper was based on a mean follow-up period of 10 years from CT exposure, with a final cut-off date of 31 December 2007. We were refunded by NHMRC from 2015 to continue the follow-up for another 5 years (ie to 31 Dec 2012) in order to confirm and extend our earlier finding. It was anticipated that national cancer notifications would be available to that date by end 2015. Unfortunately, registrations

are lagging; data finalised by the end of 2016 will only be to a cut-off date of 31 December 2012, so that our new follow-up has been deferred, leading to further inefficiencies<sup>9</sup> (albeit minimised by rolling NHMRC funds forward in time).

*Detecting effects of parental exposures*

- (11) Today there is a case to be made to extend the use of de-identified Medicare and health care records to allow for the linkage of outcomes in a child (eg birth defects or cancers) to prior exposures of the mother or father. Medicare records can be used to track most family relationships and complement data from birth defect and other registers.

---

<sup>9</sup> Government has recently moved to outsource the registration of cancer *screening* (eg to detect cervical and colon cancers) to Telstra, although this will have no direct effects on the registration of *incident* cancers in the short term.

## ANNEX 2.

### The social compact for use of de-identified data for public benefit purposes

*Most Australians would expect that personal information, collected at public expense, would be routinely aggregated, de-identified to protect privacy, and used to the fullest extent possible for public benefit purposes.*

Unfortunately, Peter Martin's report (22 July 2016) in the Fairfax media implies that the retention and use of census records by the Australian Bureau of Statistics (ABS) constitutes a breach of privacy and a breach of trust in "tracking" individuals. On the contrary, privacy has not been breached, as the Australian Statistician has a legal obligation to collect information for public benefit purposes, and he has been scrupulous in protecting the names and identifying details of all individuals. ABS has simply linked census records to other records collected at public expense to create an aggregated but de-identified data-set that will be even more valuable for the planning of services and other public benefit purposes.

Other ground-breaking work in Australia has already used aggregated but de-identified data to document important risks that would otherwise have gone un-noticed or been imperfectly understood. These include risks from folic acid deficiency in pregnancy, risks of blood clots from long-haul air travel, and increased cancer risks after CT scans (X-rays) in childhood.

In our increasingly complex world, members of the public should be reassured that, without any risk to privacy, the personal information collected from them can be aggregated and used in such ways to inform and protect them, and to increase the efficiency and effectiveness of public services. Indeed by understanding, approving and monitoring the use of de-identified information in this way, citizens are extending the social compact that they have made with each other and with government for their mutual benefit.

The Productivity Commission is currently exploring issues around the availability and use of data in Australia. The Commission will realise that the use of Australian data for public benefit purposes is lagging behind what is possible in UK, Canada, New Zealand and other democracies. Australian developments have been inhibited by concerns about whether it is possible to guarantee privacy protection. However, the experiences in Australia and overseas show that data aggregation projects have not led to breaches of privacy, and that any theoretical risks are more than justified by the countervailing public benefits.

Thus with support from the public, and with stringent legal penalties for any attempt to breach privacy, Australia will be poised to make major advances in its use of data for public benefit purposes. We congratulate the Australian Statistician for his leadership in this important area of public policy and practice.

#### **Professor Fiona Stanley AC, FAA, FASSA**

Telethon Kids Institute

Distinguished Research Professor, University of Western Australia

Vice-Chancellor's Fellow, University of Melbourne.

#### **Professor Terry Nolan AO FAHMS**

Redmond Barry Distinguished Professor

Head | Melbourne School of Population and Global Health

#### **Prof John Mathews AM**

Professorial Fellow | Melbourne School of Population and Global Health