



COMMONWEALTH OF AUSTRALIA

# Official Committee Hansard

## SENATE

SENATE SELECT COMMITTEE ON HEALTH

**Health policy, administration and expenditure**

WEDNESDAY, 3 FEBRUARY 2016

CANBERRA

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## SENATE

### SENATE SELECT COMMITTEE ON HEALTH

Wednesday, 3 February 2016

**Members in attendance:** Senators McAllister, Moore, O'Neill, Williams.

**Terms of Reference for the Inquiry:**

To inquire into and report on:

- a. the impact of reduced Commonwealth funding for hospital and other health services provided by state and territory governments, in particular, the impact on elective surgery and emergency department waiting times, hospital bed numbers, other hospital related care and cost shifting;
- b. the impact of additional costs on access to affordable healthcare and the sustainability of Medicare;
- c. the impact of reduced Commonwealth funding for health promotion, prevention and early intervention;
- d. the interaction between elements of the health system, including between aged care and health care;
- e. improvements in the provision of health services, including Indigenous health and rural health;
- f. the better integration and coordination of Medicare services, including access to general practice, specialist medical practitioners, pharmaceuticals, optometry, diagnostic, dental and allied health services;
- g. health workforce planning; and
- h. any related matters.

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**McMAHON, Ms Bettina, Head of Risk and Assurance, National E-Health Transition Authority Ltd**

**Committee met at 16:36**

**CHAIR (Senator O'Neill):** I declare open this public hearing of the Senate Select Committee on Health. I welcome you all here today. On behalf of the committee I would like to acknowledge the traditional owners of the lands on which we meet and pay my respects to elders both past and present. I also extend that respect to Aboriginal and Torres Strait Islander people present today. This is a public hearing, and a *Hansard* transcript of the proceedings is being made. The hearing is also being broadcast via the Australian Parliament House website. I would like to take the opportunity to thank senators for joining us today.

Before the committee starts taking evidence I remind all witnesses that in giving evidence to the committee they are protected by parliamentary privilege. It is unlawful for anyone to threaten or disadvantage a witness on account of evidence given to a committee, and such action may be treated by the Senate as a contempt. It is also a contempt to give false or misleading evidence to a committee. The committee generally prefers evidence to be given in public, but under the Senate's resolutions witnesses have the right to request to be heard in private session. If a witness objects to answering a question, the witness should state the ground upon which the objection is taken, and the committee will determine whether it will insist on an answer, having regard to the ground which is claimed. If the committee determines to insist on an answer, a witness may request that the answer be given in camera. Such a request may of course also be made at any other time.

I welcome everyone to our first roundtable discussion and thank you all for making the time to come talk with us today. I remind committee members and officers that the Senate has resolved that an officer of a department of the Commonwealth or of a state shall not be asked to give opinions on matters of policy and shall be given reasonable opportunity to refer questions asked of the officer to superior officers or to a minister. This resolution prohibits only questions asking for opinions on matters of policy and does not preclude questions asking for explanations of policies or factual questions about when and how policies were adopted.

Is there anything you wish to add about the capacity in which you appear today?

**Dr Herkes:** I am also an intensive care doctor.

**CHAIR:** I invite each of you to think about what you would like to say in your opening remarks. We have allocated an hour for this session, so bear that in mind when you make your opening statements. Give the committee the flavour of key things that you would like to discuss. We will also have questions which may arise from previous contexts or reading of the material that we have received so far. We might start this time with Professor Glover.

**Prof. Glover:** Thank you. It has been interesting to read through the transcripts that have been sent to me by the earlier witnesses. The committee is very informed in questions and comments. While the discussions have been mainly around linked data and that is of interest, my particular concern relates to small area data that are not intended to be linked. They are aggregations of data at a geographic level. As such, there are privacy considerations but they are not the same or to the same extent as with the linked data.

The key aspects from the transcripts that I have seen that I want to focus on relate to the Primary Health Networks and the provision to them of data at the SA3 level—the 'S thing', as I recall it being said in the transcripts. But, yes, it is the Australian Bureau of Statistics statistical area level 3. I see that as a very large area that has implications for the PHNs and others in developing programs to improve the health and wellbeing of their populations.

Since 1990 I have been publishing small-area data that showed disparities across Australia, with the first national atlas in 1992 and subsequent other printed atlases more recently. Since 2008, there have been interactive online atlases. This work is has all been funded by the Commonwealth Department of Health for over 16 years. In fact, in the World Conference on Social Determinants of Health a few years back, in the closing ceremony the Australian government was noted as having funded this work through Liberal and Labor governments over many years.

Many of the data are now much more easily available than they were in the past. It has always been a bit of a battle; but, more recently, from the Department of Health we get data on bowel screening. Immunisation screening comes through in fine form. The Department of Social Services provides all the income-support data. States and territories have hospital inpatient data. But a major gap in the data we have relates to the Medicare Benefits Schedule data and the Pharmaceutical Benefits Scheme data. We cannot get it at what I believe is an appropriate geographic level—a level that will show the major variations that occur within our cities and within our regional and rural areas, particularly in variations in health outcomes, health service use and social determinants of health.

There has been a lot of talk, generally and in your meetings, about the new paradigm and the opening up of health data, and I think that is happening, but I still think there is this block. It perhaps may be at a lower level than the very tops of the departments, where people who are the delegates to sign off on these things are on the committees that decide whether I get access to these data. I think these people perhaps have not seen and moved on to the new way of thinking, or it may be that in fact the new way of thinking only relates to certain data sets to be shared with state governments. So, despite the fact that we get quite a lot of data sets from the Department of Health, these two particular ones are a problem.

I have been refused access to them for the particular area level we publish at. The area level we publish at includes about 1,100 areas across Australia. The SA3 level consists of about 350 areas across Australia. As you know, there are 31 Primary Health Networks. One example is the Gosford SA3, which the Department of Health is putting out for the Primary Health Networks to use and encouraging us to request data. I refuse to because it is inadequate. The SA3 for Gosford has 172,000 people. We have seven areas within that Gosford SA3, and those areas were designed and developed around Australia with each of the state and territory health departments. The Bureau of Statistics came up with a set of areas called SA2. There were 2,200—too many for many health data sets. We could not get things like low birth weight and breast screening outcomes. There were too few cases to make sense even by aggregating data, so we worked with the states and territories and came up with this set of areas for population health. These are the things that the Medical Locals were using, and now the Primary Health Networks go to our website. We get 11½ thousand page views a month on our website—lots of downloads, lots of queries from the Primary Health Networks, state health departments and others. It is the national small area database, which is on about the social determinants of health, health service use and health outcomes.

I have passed to Michael a page which seeks to show the extent to which, if we took one of these SA3s—

**CHAIR:** Is this sheet here the one to which you are referring?

**Prof. Glover:** Yes.

**CHAIR:** We have a couple of documents: an opening statement and this one.

**Prof. Glover:** That is the one.

**CHAIR:** Senator Muir, do you move that we receive these?

**Senator MUIR:** Yes, I do.

**CHAIR:** Thank you. Continue your remarks.

**Prof. Glover:** That page shows you an SA3 like in the Adelaide Hills. We have not got the pharmaceutical data, but there is this old set of data that the SA health department had and which we used in some work for them some time ago. I was able to have these because these were made publicly available. The numbers there are ratios for the variation within an SA3 but at our area level. It shows you that, for instance, in the Adelaide Hills there is a variation of 26 per cent between the rate of use of scripts for antipsychotics in the population health area with the lowest rate of scripts to the highest. You will see some figures like anxiolytics in Onkaparinga, one of our disadvantaged southern areas in Adelaide, is over three times. Hypnotics are 2½.

I have not got those same data for the rest of Australia, but I have put in a second thing under examples. I put down using the Bureau of Statistics index of relative socioeconomic disadvantage. You can see that for Sydney I have given the example of Fairfield. For the SA3 of Fairfield there are variations within the SA3 from an index score of 738, which is quite disadvantaged, to an index score of 1,022, which is quite advantaged. There are 25,000 people in the one with 738, and in our population health area with a 1,022 index score there are about 5,000 people. Auburn, again, has gaps. Brighton in Tasmania has the largest metropolitan gap, from 707 disadvantage to a much more advantaged score.

How would a Population Health Network address variations within their area if all they have got is the SA3 data? I have been working in this business since we did the first atlas for South Australia in 1990 and the first national atlas in 1992. It just does not work. While there is concern about the size of areas—that is why we are not

getting the MBS and PBS data—I met with Chief Information Officer Paul Madden in the Department of Health in May 2014. He was hoping to take a paper to the June 2014 meeting of the Australian Department of Health executive about improving the consistency of the release of data across the department. The paper never went.

He told me in that meeting that nothing that we wanted to release at our population health area level caused him any concern for PBS or MBS. But there were variations within the department and between the department's way they saw a dataset and another department that might have the same dataset. That has not been sorted out. Hopefully it will be with changes in secretary and high-level people. Paul Madden is still there in another role. The difficulty is in convincing people that this level of data is not going to release confidential information about people. We can cut off at any number of cases.

I was told that we could have medical benefits service data if we asked for the SA3 level with a cut-off at 50. Since then the department has published data with cut-offs as low as under six, so things are a bit inconsistent. But the point is that the SA3 level is very problematic. It will not help the population health networks address their concerns of the population's health and wellbeing in their areas. There is an alternative, which exists, which will not cause the release of confidential data. Thank you.

**CHAIR:** Thank you very much, Professor Glover, and that does reflect what you have given us in your submission. Can I just ask you to think, maybe further in the conversation and certainly for writing to us later on, if you have a recommendation around that that you might like to give us more formally.

**Prof. Glover:** Yes.

**CHAIR:** Can I go to Dr Herkes and Ms Katz. Do you both seek to make a statement or are you making a joint one?

**Dr Herkes:** I am going to make a statement on behalf the commission.

**CHAIR:** Dr Herkes, thank you.

**Dr Herkes:** The Australian Commission on Safety and Quality in Health Care uses both Commonwealth jurisdictional and local clinical data mainly to feed back to patients, clinicians and the hospital administrators on the performance of their services. The performance is measured by things like indicated development, monitoring and reviewing the delivery of services in local health districts or PHNs, and reviewing instant and severe adverse outcomes. As you may be aware the commission has recently published the *Atlas of Healthcare Variation* which took predominantly PBS and MBS data and mapped that against SA3 areas, and some of what Professor Glover has just mentioned is pertinent to that.

The commission understands and supports concerns about privacy especially around patients suffering from mental illness and cognitive impairment. I think the privacy principles are really important. However, understanding the whole of a patient's journey—as the patient moves from public and private hospitals, primary care, specialist rooms, consumes PBS, moves across jurisdictions within a state variations—is really important to understanding how our health system is performing.

As a clinician one of the things that always struck me as bizarre was that I could sit with a family and say, 'Look, I know that the Mayo Clinic has published data about people who have had a stroke like your loved one has had, and I can tell you what the outcome is in the Mayo Clinic in the US, but I can't actually tell you what your outcome is in Australia. We have the data but we do not have the tools yet to properly analyse it'. So it is our view that understanding the whole of a patient's journey, looking at their length of stay, looking at their readmissions, looking at their use of primary care services, specialist services in non-hospital settings, looking at the use of medicines and looking at their stays across different jurisdictions, will give us a much better understanding at a population level of how well the health service is actually serving our population. We do believe it is serving our population well, but there is so much more using data linkage that we could do to prove that for everyone's assurance.

**CHAIR:** Thank you, Dr Herkes, we will come back with some questions. We have an opening statement from Ms McMahon or Mr Fleming.

**Mr Fleming:** I will make the statement on behalf of NEHTA, if you do not mind. Thank you for the opportunity to be here. The main purpose of this statement is to make three points. Firstly, the quality of our future healthcare system will depend on how well we use our information assets whilst protecting the fundamental rights of Australians. Secondly, we have designed and built digital health foundations with consideration of the need to advance health data collection, linkage and use. Undoubtedly we will talk more about that. Thirdly, the more health information is shared on the national digital health record system, the better the returns will be for all Australians both in terms of informed health policy analysis, improved health outcomes and better health economics planning. Just to expand that a little bit, if we go back over a decade now, having high

quality health data which could be shared across the healthcare sector and consumers was not possible. We had areas of the health system that had wonderful computer systems but they did not share the information. We had a siloed environment.

NEHTA was established in 2005 and our objectives were to address the fragmentation of clinical information and reduce avoidable errors and hospitalisations. NEHTA has delivered the technologies of unique consumer and provider identification. We have a common structured encoded clinical language. We have authentication and encryption, and there is now a shared national health record system, leveraging and disabling infrastructure, and there are other infrastructures in place. There are now over 8,000 healthcare provider organisations who use NEHTA-compliant software which allows them to share data. In addition there are now 470 public hospitals connected to the health record and sharing data, and we are now seeing the start of private hospitals connecting up. There are 24. You will see those numbers increase quite rapidly over the next 12 months.

Driving the collection and sharing of high-quality clinical data is an absolute key to digital health. The value is the ability to connect with other systems and present data to consumers and their healthcare professionals. That does mean encouraging healthcare professionals to collect data in a standardised format so that it can be understood, used and reused in innovative ways to improve health outcomes. Consumers are deeply interested in ensuring sensitive information remains private and secure including from healthcare professionals who are not involved in providing their care and companies that provide health care insurance. Beyond the care of individuals the research community is a key motivator for the use of structured and coded content so that greater value can be extracted from our health data. As the volume and quality of clinical data content increases this data will provide a powerful resource for health and health service research and for public health analysis. Digital health record could be used to identify trends, predict outcomes and improve patient care.

In conclusion, we are now entering a new phase in the evolution of digital health. Much of the enabling infrastructure is actually in place. Our challenge is to encourage its use whilst protecting the rights of the citizen. I am very happy to answer any questions on those infrastructure aspects of where we are at.

**CHAIR:** Wonderful. Thank you very much. I am not sure if you got to see or hear any of the conversation that we had with Professor Stanley and Ms McKenzie yesterday afternoon. Although we had her on teleconference, Professor Stanley was nearly coming through the phone with excitement about the possibility of things that could be improved in health outcomes. Prior to that they we had a hearing from the Information Commissioner, and he had an incredibly deep knowledge and was very, very fulsome in his response to our questions. But there were concerns about the fact that privacy matters which are paramount, and you have all mentioned them today, and the capacity of law and adaptation legislative reform in the law are all tools that could be used. When I asked them if they had had any communications from the government prior to its announcement of public policy data statements or the *Public Sector Data Management Report* there had been absolutely no consultation. My question to each one of you is: have you or your organisation, prior to the government's new public data public policy statement being announced, been consulted? Did you feed into a process?

**Ms McMahan:** Not on that particular policy. We were consulted on NEHTA's work program, Myhealth record, and we work a lot with the Information Commissioner on that, but not on that particular policy you mentioned.

**CHAIR:** So that is the public data policy statement or they *Public Data Sector Management Report*, neither of those?

**Ms McMahan:** No, we were not specifically consulted on those.

**CHAIR:** Thank you. Dr Herkes?

**Dr Herkes:** I am afraid I am unaware so I will find out for the committee.

**CHAIR:** If you could take that on notice it would be wonderful. Professor Glover?

**Prof. Glover:** No.

**CHAIR:** Thank you. I might not go to other committee members who have questions to go straight to some of the evidence that you have had. Senator McAllister.

**Senator McALLISTER:** I thank you all of you so much for coming. Professor Glover, the chair has asked you for a recommendation about the way that we might approach small and spatially organised datasets. I wonder if we could talk through the issues associated with that from the perspective of all panellists to get a bit of an understanding about how, as policymakers, we should think about this proposition and the opportunities presented by spatially organised data?



**Prof. Glover:** It is partly what I said before. We rely of the geography that the Australian Bureau of Statistics develops. So from 1992 until the 2011 Census we used their statistical local area. We cut down the numbers a bit in a few city suburbs at the time, but most of them were local government areas or parts of local government areas. It was a geography that was well recognised for which we could get data. It showed good patterns in all the cities. It allowed you to see in Melbourne, between the eastern suburbs, the south-eastern and parts of the west, the quite strong variations in many aspects of the social determinants of health or in health outcomes, death rates and so on. When you go to a regional area there are also quite strong patterns particularly between the towns and the rural areas.

**Senator McALLISTER:** Just to clarify, the value in having that information is essentially in service planning, is that correct?

**Prof. Glover:** Yes. Because this data has been around since 1992, also monitoring changes, so we can look at a map. Even though the geography has changed, the areas are reasonably similar and you could put a map from Melbourne or a map from Sydney from smoking estimates that were made back in 2001 against those that were made in 2011. You can see the total drop and you can see also the areas where it is hanging on.

**Senator McALLISTER:** Right. So you can see temporal trends as well as spatial trends.

**Prof. Glover:** You can. You then have some information when you wanted to do targeting. The Department of Health for instance has used the estimates that we have made with the Australian Bureau of Statistics of obesity and overweight in funding local councils to run programs around obesity and so on. You can use it for monitoring, you can use it for program development, targeting and so on.

**Senator McALLISTER:** This may be a stretch, but do you think it is conceivable that it could also be used for evaluation should there be targeted investment in a particular kind of problem?

**Prof. Glover:** Some of the data can. Some of our data or estimates, particularly around chronic disease incidence, prevalence and so on, but when you then move to the linked datasets that people were talking about—yesterday I spoke with Andrew Stanley after his talk with you and others—that is when the evaluation becomes really powerful because you are dealing with data, as Robert and others have said, that links the patient journey.

**Senator McALLISTER:** The question we are talking about is not particularly important for evaluation and that is fine.

**Prof. Glover:** Yes, but it can be and you can actually see. For instance one example is that we have been trying to cut down premature mortality death before age 75. If we look at a series from 1989 to 2010 we can see that by 1994 the gap between the rich and the poor areas was down to its lowest and now in most states the gap between the rich and the poor in terms of having more premature mortality is worse than it was in 1989.

**Senator McALLISTER:** That are shocking.

**Prof. Glover:** In some states it took longer. In fact it was only in the last few years that the death rates in 20 per cent of the population in the most disadvantaged areas finally got down to the rate that most well off areas had 19 years before. That is one sort of evaluation you can do at a very broad level, but if you want to do real evaluation you go to the linked hospital data or the linked GP service data and so on.

Anyway, what I was finally going to say is that we have new areas where we have come up with a set that we believe—and I think I wrote a recommendation about—have been signed off by all the states and territories. We have had good feedback about the quality. I had a meeting with the Department of Health this morning and I feel a bit encouraged that the director of the area that has the contract with us is very keen that we go and have the discussions in the department—which we, perhaps, should have had many years ago—and we work with them and we talk about what data we do that they might use more wholesomely, because they are putting out other data that I think has some problems. The discussions might also help this whole business of rationalising what we get access to.

**Mr Fleming:** I would like to make some comments on the technology that we have and that you will see playing a far greater role in this in the future. I know Senator Moore would be well aware of some the numbers here, but one of the key pieces of infrastructure that has been built is the health identifier system. We have an identifier now for all Australians, all clinicians and all health organisations. We have a standard that is being rolled out around the country where, when a transaction is created for any health episode, those three key components are sent as part of a record so that we know who the patient is—which is a key component—which organisation they were treated at and their treating clinician. It is quite granular. Just to put it in context, as Senator Moore is aware, we are now getting over 13 million hits a month on that system—health providers accessing that system and picking up that record.

Over and above that, we have Australian Medicines Terminology, which is now fully integrated into the PBS system. It is very granular in terms of the medicines that are used and prescribed and we now capturing a lot of prescribed medicine information through our pharmacies and that will continue to grow. We also have a thing called SNOMED, Systematized Nomenclature for Medicine. It is an international exercise that we have been working through back probably 8 years, and in that context a company called IHTSDO was established. It involved ourselves, the Americans, the Canadians and the English et cetera, and we purchased this package. Since then, we have been developing it together and there are now well over 20 countries that subscribe to it. It contains over 300,000 medical terms. Over a period of time, the records that are being created in our computer systems—whether they be in hospitals, general practice, pathology or diagnostic imaging—are using those terms. So as we start to extract data—who the patient is, where they were treated—we have a lot of granularity in terms of the information.

We are moving into an environment where there is a lot more information going to become available and where the discussions around secondary use of data becomes far more important. I do know, because you mentioned Mr Madden in the department, that they have just recently issued a tender to the market to help them work on the consultation process around what processes need to be put in place to ensure that secondary use of data is being effectively used, whilst taking account of the privacy aspects. So there is a tender in the market for that at the moment. I also know through NHIPPC, the National Health Information and Performance Principal Committee, that the use of this data is also being effectively worked through between the states, the territories and the Commonwealth. There is quite a lot of information and work going on in that area which will help address the concerns that are being raised.

There is a lot of infrastructure in place. There is also a lot of work around supplies chains, where we now have over 400,000 medical products properly categorised and we know when those products are moving, and systems like Recallnet, where we are able to better understand recall processes. The key here is that through the governments of Australia—federal, state and territory, both current and past—a lot of investment has gone on to help ensure that we have a long-term position in those areas.

**Senator MOORE:** In relation to the tender, who is tendering that?

**Mr Fleming:** The Commonwealth Department of Health has recently released a tender in that area.

**Senator MOORE:** So for the record, the tender is from the Department of Health, and that is—

**Mr Fleming:** Through Mr Madden's area.

**Senator McALLISTER:** Does the tender seek support to undertake a consultation process?

**Mr Fleming:** Absolutely, and to make sure that the processes of so on are in place as we look at the secondary use of data.

**Senator McALLISTER:** Apologies because we are lay people in this world—well I am—when you speak of secondary use of data, does that include requests of the kind described by Professor Glover, in terms of spatially-organised data?

**Mr Fleming:** Yes, very much so.

**Senator McALLISTER:** Are there any other kinds of secondary uses that we ought to be thinking about in terms of this protocol, or indeed that the department is in contemplating the consultation process?

**Mr Fleming:** Absolutely. Professor Glover was talking about localised areas, which are very, very important. But if I use the My Health Record as an example, there are now over 2½ million consumers who have registered for that system and, obviously, we are now moving into a time where opt-out trials in Far North Queensland and the Nepean Blue Mountains area are about to start. In that context, what we do expect over a period of time, if those trials are successful, is that all 23 million Australians will have a health record which is consolidating that data, and so in that context we know who they are et cetera. There are clearly a lot of privacy laws, which you would be aware of, in place around that. And, yes, we can get granular in terms of understanding at an individual level or at a local area but we can also look at a national population health context—the Australian population, the Victorian population or whatever—to better understand trends that might be emerging.

**Senator McALLISTER:** So there is the potential value. The point that I believe Professor Glover is making is that there are existing datasets which also provide those insights, not to the degree that will be possible in the future, and that those datasets are presently not available to researchers who seek to use them. I am trying to understand, from all of you, whether you think that those restrictions are sensible at this point in time from a policy perspective or whether there is room to move. And, if so, what are the blockers in getting movement on this question?

**Mr Fleming:** Not being close to that particular issue I am not in a position to comment other than to say that I do know that the Department of Health, although I am not part of it, has issued that tender and is looking seriously at what data could and should be released. So I do know that there is action in that area.

**CHAIR:** Dr Herkes, did you want to add anything there?

**Dr Herkes:** I was just going to explain that the primary use of your health data is for looking after you. Anything past that is a secondary use. For instance, a jurisdiction might use data about emergency department presentations to model how it needs to put in emergency departments across its state, and so that is a secondary use of the presentation data.

**Senator McALLISTER:** Or fraud detection.

**Dr Herkes:** Fraud detection, and the atlas of clinical variation that the commission has published is a secondary use of primary data at a patient level and, because it is rolled up into populations, it means you cannot identify the individual population. I guess what Professor Glover was explaining to us was that you have to be careful about how you define the population and that you do not end up identifying an individual or, at a clinical side, an individual's practice. A simple example of that is my brother, who is a neurologist, used to provide services on the mid-North Coast of New South Wales, when he ran a clinic at Forster. That clinic at Forster had almost everyone—from Port Macquarie, Taree, Forster and Gloucester—who needed to see a neurologist being referred to him, because he was the only neurologist going to the area at the time. So, even though you have a huge geographical area with a huge population, if you just looked at neurological services, you would actually be identifying him and the good and bad things about his clinical practice. So there is a lot of science—and Professor Glover is an expert at this—in defining how big a population you need to avoid identifying an individual as a patient, an individual as a clinician or an individual as a health provider.

**Prof. Glover:** There is another slightly different angle on the primary and secondary thing that the Bureau of Statistics have on their website if you type in 'secondary data'. They talk about administrative data, which is what we get, and survey data and so on. They see primary data as something that they collect, hold and do something with; and secondary data is when there is a table out there that I go to, or someone goes to our website and gets that table. So there is primary and secondary use; and there is primary and secondary data.

The last thing is about the population and the size of the population in a number of services. The complication with getting the MBS and PBS data is the practitioner thing. It is like how the ABS has rules about the number of factories and the percentage of a factories in an area. If one factory has 90 per cent of the business and there are only three factories, you cannot release anything, because you could work out the other two. This is where things called algorithms can be run on computers, and the Department of Health wants to make sure that there are at least six practitioners in the area that is being looked at. That is fine; that is their rule. If they come out with that, that is fine. You run an algorithm. You do not just say, 'We can't do it.'

**Senator McALLISTER:** Why is practitioner privacy important? Arguably, many, if not all, of the procedures being undertaken are publicly subsidised.

**Prof. Glover:** The argument put to me is that we would find out the average income and the department could then work out what they earn. It is bit of a long bow, but that is the sort of argument that gets put to me.

**CHAIR:** So people are aware.

**Prof. Glover:** Yes.

**Senator McALLISTER:** As someone new to the question, I genuinely interested in the public policy rationale.

**Dr Herkes:** Putting my doctor's hat on, I do not personally think that individual practitioner privacy is particularly important, provided you are working within the constraints of a well-constructed health system. I know lots of my medical colleagues would find it really difficult for all of their practice to be individually identified.

**Senator MOORE:** The AMA has a policy on that.

**Prof. Glover:** I would like to give one example. We produced a report on the location of psychiatrists. We were given the data by the Department of Health—this was many years ago—we had it all printed and gave a final copy to the department. They had actually signed off on that, but we made a mistake and gave them another look at it. They worked out that, because an area had 0.3 full-time equivalents per thousand population of psychiatrists, someone would be able to take that, know that the population in that area was 10,000 and there was 0.3 per thousand psychiatrists in that area and they would somehow find out the income that was used by the Department of Health to create what was a full-time equivalent psychiatrists, then they would multiply it out and

get the person's income. That is the sort of thinking that has been going on for 10 or 12 years, and I still think it drives some of this. Those same people are still there.

**CHAIR:** What would your response be to them now, Professor Glover?

**Prof. Glover:** You can run an algorithm; you make sure you give data about the number of services. We had some very old GP data and we rolled it up; we produced our population set and we rolled it up even higher, especially in the country areas, because you know in country towns there is a doctor or two. The department should stick to its guns on making sure data is not released that will identify an individual GP or a practice or a surgeon or whatever. There are ways of doing this, and we should have that discussion.

**Senator MOORE:** Professor Glover, if I heard you correctly, and I have heard you speak a number of times, one of the issues is that there was a great deal of work invested in developing the model on which data could be collected—the right size for that work—over a long period of time. Is it now being used?

**Prof. Glover:** We have 30 or 40 topics and a few hundred datasets out there. It is being used by many people. There are a couple of datasets we cannot get, but it was disappointing to see the department put up a health.gov.au/phn website. SA 3 level is too big, and you cannot see the variations within it. They put up MBS data about where the GP works from, rather than whether people are, and that is not going to help the population health thing. Some of the other datasets do not have any denominators in them; they do not have the metadata that could be there. Perhaps, if they had spoken to us, we might have been able to work with them because a lot of the datasets could have been put up. I suppose National Health Performance Authority did their own data; they went the Bureau of Statistics to repeat some work that we had paid the Bureau of Statistics to do, but they did it in a different way—a way that I think is far less statistically valid. The bureau people will say the same thing—that it has error estimates on it that should not be published, but that is the data that is now on the department's website. Ninety per cent of it is okay, but it is the other 10 per cent that I am worried about.

**Senator MOORE:** I tend to think of this stuff as the bricks that build up to the information. The brick that you were using is the basic model but it is not the same size brick that the government is now using. The brick you were using is the same one that the Medicare Locals were using in building up their coverage areas. All that stuff is there somewhere.

**Prof. Glover:** Yes. The areas have slightly changed because the Bureau of Statistics changed the area base in 2011, but the ones we have now are quite similar and are built on the same sort of basis. Again they are based on the ABS areas and so they take the value and the strength of the new areas the ABS developed at the SA2 level—which are really good areas—but just make them a bit bigger so our health data can carry, because there often fewer deaths in an area or fewer women smoking in pregnancy.

**Senator MOORE:** My understanding is that most of the government process now is based on ABS data and ABS units. That is the basic model on which development is done. I have a frustration, which has built up over many years: if someone has done a lot of work, why does it need to be redone? Why not use what is already there? That is the theoretical whinge. Have any of you seen the submission from Prof Stanley, which shows the model they are working on in the Telethon Kids Centre in WA? It comes back to one of the core issues that this committee is looking at, and that is using the concept of the social determinants of health. In other words, we are not just talking about health; we are actually talking about all the elements in my life that can affect how well I am doing. Professor Stanley has produced a model at the Western Australian level, which draws upon housing data, local government data, geographical data, health data, corrective services data, education data, disability data and child protection data. We had an extended discussion yesterday about the value of such a model and about the problem that we do not seem to have such a model elsewhere. One of the issues is that a lot of this stuff is state based, and it comes down to the sharing of state and federal data. How do we move this forward, so that we are looking at the person in the context of all the elements that contribute to their health? How can we use data and the exchange of data to do the job that we hope we can do? I know it is a big question, but I would appreciate your views.

**Ms McMahon:** Most of our discussion so far has been about the secondary use of data; it has been about population health planning. The flip side of that is personalised medicine. It is about leveraging large datasets from disparate sources and targeting or focusing that on an individual, so that you, for example, have a way to see a range of risk factors that apply to you. Your GP or your heart specialist can look at those and identify problems that might arise in your health earlier—give an earlier diagnosis than you might otherwise have had, perhaps when you are presenting with symptoms. So that is the flip side of the secondary use, and it is part of the work that we have been doing with the Commonwealth to provide that portal. We are in the very early stages, but the power of this will be, as Mr Fleming earlier remarked, the greater sharing of data.

We have the infrastructure in place; we have built all of the foundations and so there is the potential to achieve these sorts of outcomes for individuals—not just population health improvements in a certain demographic but for I, Bettina McMahon, to find out that I have a high risk of cardiovascular disease five years earlier than I would otherwise have known and so I can take preventative health actions in my own life. That is really the focus, and that is where the medical community is really excited. A lot of the reforms they are looking at in their own practice has to do with leveraging data much better in their own clinical decision making, and that is what we are also trying to support. It needs to be backed up by the proper protections, and this committee is absolutely critical in looking at the sufficient privacy controls that are needed, so I am not concerned that my neighbour who is a nurse is able to search my records to see whether I smoked during pregnancy and those sorts of things. Consumers we have spoken to are very concerned about that, but they are also very supportive of sharing this information with the health-care providers. They do not want unnecessary blocks to this information because they see the value in having it used.

**CHAIR:** Anyone else?

**Dr Herkes:** I think there are similar processes in South Australia, certainly at SAHMRI, and in New South Wales with CheRel. One of the issues for all of these state based systems is: how do you track across jurisdictions? The New South Wales CheRel system happens to include ACT Health for instance, but it does not include data from patients in northern New South Wales who get transferred into southern Queensland for hospital care nor those in southern New South Wales who get transferred into Victoria. This ultimately needs a national approach.

**CHAIR:** So just information that has trouble moving across the boundaries.

**Dr Herkes:** Yes.

**CHAIR:** There are some dollars apparently too.

**Dr Herkes:** There are issues around which jurisdictions may be happy to share and which are not. Clearly, this needs senior leadership to untangle it.

**CHAIR:** Professor Glover.

**Prof. Glover:** We have done a fair bit with Professor Fiona Stanley, and Dr Di Hetzel, who works with me, has done a lot of work with ORACI in the early days. I think Fiona has put us on some committee that she is developing to do some new work. And we ran the first three national data linkage conferences in Australia, and Fiona was very heavily involved in the second. The FYDI database, and Fiona often says this, is one place where you can go and get, for the whole of Australia, the local government area level. For places that do not have local government areas—like Canberra, Brisbane and Darwin, which are one huge area—you can do other things. But for small areas we have a lot about education, disability, chronic disease and all those sorts of things—the social determinants. That is what drives our unit and our passion in our work.

The atlases that we put out over the years always start with that contextual stuff and have quite a lot of chapters that Dr Hetzel writes. The most recent one, which was a couple of years back, was called *Life Opportunities, Social Inclusion and Health Outcomes*. It should have gone out a few years before the words 'social inclusion' were first mentioned. The atlas lay around in government departments for a while and then, finally, we put some other words in front of 'social inclusion' and it was released, very quietly, on our website. That draws the whole pattern together. It talks about the whole thing, including Aboriginal culture and kinship. It also talks about the life course. It is really worth looking at for anyone who is looking into this area because it is another major document. It is for us very important.

I do not know exactly what has been said about the health record. That is a very important part, too—and this is another one. With these data, we can look back over time and come up to now and see. We were publishing Medical Benefits Schedule data up until 2009-10, since 1992, by these similar areas. But the department has decided now that it might have been wrong and should not have given it to us. We have been able to publish Pharmaceutical Benefits Schedule data in South Australia because the department was able to give them a file. But the world has not fallen apart in South Australia; no pharmacist has caused problems by saying we have identified their business, because we were very careful in the way we went about it.

**CHAIR:** I am sure you would be very interested in some of the information we received yesterday from the Office of the Australian Information Commissioner, which I think goes to some of the points you raised there. We asked particular questions about the historic separation of MBS and PBS, and we got some interesting answers on that too. So I would point you to that evidence because I am sure you would find it of considerable interest. I want to ask you some pretty basic questions, and, with your indulgence, we might send you some questions on notice.

Following our conversation and further review, I would invite you to send us any recommendations or key articles, such as the one Professor Glover just mentioned, that you think would inform and improve our reporting.

The RACGP and submissions to the committee from the Family Medicine Research Centre have described interoperability problems. Medical practitioners use different software programs that are being sold to them. These programs are about the efficiency of their businesses, for example. I do not know how they intersect with the language processes you are saying were embedded in that process that has been rolling out over 10 years. For software programs for data entry and data retrieval, are there problems in this space? How confident are you with the My Health record that this interoperability problem will disappear? Or will it be exacerbated? What is the situation?

**Mr Fleming:** I did not see the submissions, but I am presuming it was a comment from Dr Pinski in terms of the interoperability within general practice that you are referring to. Dr Pinski and I have discussed this on many occasions; I will assume it is the same issue. In the case of general practice, we have been working with the major vendors, which cover 99 per cent of the general practice market, to ensure that their systems use our standards—Medical Director, Zedmed, Genie, Best Practice: they are all involved. All of them are at slightly different stages but all of them are capable of pulling down data from the identifier system, sending up various summaries, creating a shared health summary et cetera. That part is tested and works very well.

Where Nathan has a concern, which he has raised with us, is that a number of practices have a front-end system and a back-end system. The front-end system is what you might see when you walk in, and the receptionist may enter some data. A number of practices choose to have a different system at the front than at the back. So they have an issue of interoperability between them. Part of that comes down to the systems that you choose within your own particular environment. Clearly, as you move into larger environments, it can explode out quite substantially. We are talking to the vendors about that. We work directly with over 70 individual vendor companies and their software in terms of how we can get exchange of data, but that component is still a way away. The data that is feeding through into the health systems themselves, the back-end systems, are absolutely compliant. Clearly, if you are a GP, though, it would be nice to know that if you keyed in something at the front-end, it is a different system that was talking. I think that is the issue Nathan has raised. We are well aware of it and we are talking to the various vendors about it, but I do think it will take a little while to fix.

As we move up into a slightly larger domain—for instance, a public hospital—they run multiple systems. Getting that working has been—

**CHAIR:** Within one jurisdiction, let alone going across jurisdictions.

**Mr Fleming:** Where we have ended up there is predominantly—it does depend by region—a piece of what I will call middleware that sits within the hospital environment that extracts data from all those systems and brings it together and sends that data through to My Health Record and other sources. That is working effectively. I mentioned 470 public hospitals, most of whom are linked to that system.

**CHAIR:** You are effectively describing patches to connect all these?

**Mr Fleming:** No, middleware—so a piece of software that sits within a local environment that is able to bring data from various different systems together. At a jurisdictional level—so, when you roll up—it depends. With a state like New South Wales, which has a fairly homogenous approach, it is relatively easy. In a state like Victoria, where each region can make its own decisions around systems, then you clearly have complexity in terms of how you bring that together. Therefore, where we tend to focus is talking about standards, where a system should contain certain pieces of information in that context. But it is a particularly challenging technical task.

**CHAIR:** We heard yesterday about the need for a federated system. There is some argument and tension, particularly with the acquisition of data in the Northern Territory, where people were very happy about the way that that has emerged and grown and its usefulness. We saw it in action while we were travelling in the north, particularly in remote Aboriginal and Torres Strait Islander communities. In relation to the nation as a set of federated states, what problems are there, and are they being considered and ameliorated in any way?

**Mr Fleming:** I will start with the Northern Territory. Over the best part of a decade, the Northern Territory has had their electronic health record, which has, as you mentioned, developed. In terms of our Indigenous population, it is very much focused on that area and covers literally over 95 per cent of the remote Indigenous population. It is a wonderful system. We have worked closely with the Northern Territory, and that system has now been effectively converted and is running on the Commonwealth My Health Record system. So any piece of functionality that exists in that system you saw there is now reflected in the Commonwealth system.

The problem we have in the Northern Territory at the moment is around the collection of pathology data, so we are getting data from every other aspect—shared health summaries, event summaries, diagnostic imaging. We are

unable to get data in terms of private pathology at the moment, and there is an ongoing dialogue with the pathology sector. So the first comment I would make on the Northern Territory is that any piece of functionality in that system you saw is now reflected in that Commonwealth system and is working effectively—fully in place, fully operational. The same rationale then applies, whether it be a large state like New South Wales, or the ACT, in that it is the same functionality in place and available to all jurisdictions.

**CHAIR:** So there are problems, but you are telling us that they are not insurmountable—

**Mr Fleming:** Absolutely.

**CHAIR:** And conversations are happening and we are a long way down the track from where we were even two or three years ago?

**Ms McMahon:** Yes, and we have assumed the federated model as the basis of the health system and we have aligned the design of the systems with that. If we look at the English system, for example, they have a big central IT system where there is a national spine, as they call it, and that is all part of the one system. In the US, they do not have any of that. They have started moving along a standards path, but generally they have IT systems that work within a health insurer network. So the health insurer you are with will have a number of hospitals, dentists, whatever, who can connect up, but they do not connect nationally.

Five or six years ago when we started designing the national system, we understood that states and territories provide health care here. The Commonwealth has a policy lead, and we want Australians to be able to move their health records wherever they go. So we looked at the reality of that—the reality that there is a vibrant software market where there are lots of different vendors out there who provide to states, to private practices and so on. With that, we have what has been described as a middle way, where we have defined standards for interoperability or exchange of information. It is not unlike the internet, where there is a set of standards that allow websites to share information. So, it does not matter what browser you have, it does not matter what email system you are using, you are able to get information and view it. But the standards are in place so that you are able to do that. So we have taken much more of a standards type approach, which Mr Fleming has described, to actually work within a federated model so that we do not have to have a national system that will be forced on everyone that can work within that healthcare structure.

**CHAIR:** Are the privacy dimensions within that similarly variant?

**Ms McMahon:** I am not best placed to answer that question; that would be the Office of the Information Commissioner, who we work closely with. But there is a national set of privacy controls in Commonwealth legislation that was set up around the establishment of the Healthcare Identifiers Service and My Health Record, and there are also state privacy controls, so they also still apply. So there are a number of layers of privacy controls at both state and federal levels.

**CHAIR:** We have heard about logjams in terms of trying to get information. We have also heard about significant delays and corruption of the capacity to really research in the areas that people want to research, because they just give up on trying to get responses. I understand some of that might go to particular historic conventions around PBS and MBS, but also to the role of custodians in keeping information. We have heard that custodians are critical in this particular area but that, for many of them, the custodianship of data is an add-on job that is secondary to their primary employment and is somewhat burdensome and not highly regarded in the context they are working in. Do you have any response to those issues?

My last question is based on Professor Stanley's evidence yesterday about the need to develop better analytical grunt, and the suggestion of an institute of population health data and wellbeing. If you would like to make comments on either of those matters, and then we will have to close this roundtable.

**Prof. Glover:** One of the difficulties with the datasets we cannot get is—you have been through this, I know—who owns which data, who the data custodians are. We go to the Department of Human Services and put a case to them for health data. They have a committee. Health sits on that committee and then basically decides whether or not you can have the data. The DHS people do not really know anything about the data and the policy issues; that comes from Health, and that decision is then made and passed back by email. You then complain and you make some comment, 'What about so and so, can we do this or that?', and then it goes back again. The same with PBS.

It is very hard to engage totally with whoever the custodian really is—in this case it is Health, even though you are dealing with the Department of Human Services, who would run the tables. That is the sum of the issue, and I think that can be addressed. It is an administrative thing and maybe will be addressed in this thing that Paul Madden is putting out about how data is released. The other one, about the analytical thing, yes, a lot of people have probably told you that there are quite a few people with skills but there could be more. This has always been

a bit of a thing in the health area—getting enough people with the background and the experience. I believe Professor Stanley is working towards something to address that issue.

**CHAIR:** Mr Fleming, you are nodding?

**Mr Fleming:** One of the biggest issues we have is the quality of data. If you go back through history, I am not a doctor but if I was running a small practice and was seeing a group of patients, the notes I take have historically been for me and I have built them up in whatever cryptic fashion may have been suitable to me. As we start to move into an environment where data is being used at different levels, the key issue we have is how over a period of time do we make sure that the quality of data that is flowing through is correct. That is one of the big challenges. When doctors talk about the difficulty of creating a shared health summary, from a technical perspective it is press a button and it is created within seconds; from a practical perspective it is very much dependent on the quality of data that is within their systems. One of the biggest challenges we have here, and it does not matter what level we are looking at data at, is the quality that we start with. That is an education process. That is started, that is underway, but it will take a lot more time and work to get right.

**Dr Herkes:** One of the important things that has not been emphasised enough is that they have done quite a lot of work around standardisation of terminology and standardisation of presentation. That is improving the system very significantly. There are five or six different brands of a drug called a beta-blocker but underneath that, in the PCHR, or the My Health Record, there is a standard way of describing the same drug even though it is produced by different manufacturers. Things are moving in the right direction, but standardisation of how doctors write in notes is something that has been a bugbear of hospital medicine forever, and I am sure it will be a 20- or 30-year project to get better—but it is improving.

**CHAIR:** As much as we would like to continue the conversation with you, the time for our roundtable has well and truly drawn to a close. Thank you so much for joining us this afternoon and for your work in the field. We look forward to any further information you feel would enhance the committee's report and any recommendations you have, based on the depth of knowledge you have, that would improve things.

**ANTONIUS, Dr Nicky, Acting Assistant Secretary, Information Knowledge Management, Department of Health**

**BOLAND, Ms Justine, Program Manager, Health and Disability Branch, Australian Bureau of Statistics**

**CRETENDEN, Mr Ian, Assistant Secretary, Health Analytics Branch, Department of Health**

**DENNIS, Mr David, Branch Manager, Policy Evidence Branch, Department of Social Services**

**FOSTER, Ms Alanna, First Assistant Secretary, Research, Data and Evaluation Division, Department of Health**

**NEAL, Mr Tim, Senior Adviser, Public Data, Department of the Prime Minister and Cabinet**

**NEIDECK, Mr Geoff, Group Head, Chief Information Officer Group, Australian Institute of Health and Welfare**

**OWENS, Ms Helen, Assistant Secretary, Public Data, Department of the Prime Minister and Cabinet**

**VAN HALDEREN, Ms Gemma, General Manager, Strategic Partnerships and Projects Division, Australian Bureau of Statistics**

**VON SANDEN, Dr Nick, Unit Head, Statistical and Analytical Support Unit, Australian Institute of Health and Welfare**

**WILSON, Ms Michelle, General Manager, Strategic Information Division, Department of Human Services**

[17:48]

**CHAIR:** I welcome representatives of the Department of the Prime Minister and Cabinet, the Department of Health, the Department of Social Services, the Department of Human Services, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. I remind committee members and officers that the Senate has resolved that an officer of a department of the Commonwealth or a state shall not be asked to give opinions on matters of policy and should be given reasonable opportunity to refer questions asked of the officer to superior officers or to a minister. This resolution prohibits only questions asking for opinions on matters of policy and does not preclude questions asking for explanations of policy or factual questions about when and how policies were adopted. Do you have any opening comments that you would like to share with us? No?



**Senator WILLIAMS:** Ms Owens, we get a lot of paper put in front of us, and reading it all is very difficult in my job. But this is the first thing that came to my office today, about the National E-Health Transition Authority:

The National E-Health Transition Authority (NEHTA) is the lead organisation supporting a national vision for eHealth for Australia.

They do the digital health uptake et cetera. Then there was the Australian Commission on Safety and Quality in Health Care, which is, 'A strong advocate for a linkage database to monitor and identify areas for improvement in the safety and quality of Australian health care'. There is the Public Health Information Development Unit, established in 1999, which does development of public health data, data systems et cetera—I am going on and on.

I have all these organisations collecting data and trying to get it together. The committee has heard clear evidence yesterday that if we can get the data together—easily accessible for doctors and hospitals around Australia—it would be a good thing and a good money saving. I think there is a scattergun approach here. Who is coordinating linking all this data together? We have seen Western Australia go ahead with the Department of Health some years back. Who is bringing this all together? I am fearful there is a scattergun approach, where this department is doing this, and the Bureau of Statistics is doing this; and PMC is doing this and the Department of Health is doing that; and this one is collating e-information and databases. Explain to the committee—who is doing the coordination of all of this? Please.

**Ms Owens:** Certainly. As part of the move of my area into the department of Prime Minister and Cabinet on 22 October, it was largely—

**CHAIR:** Last year?

**Ms Owens:** Last year. It was, in essence, the Prime Minister moving the data agenda into his portfolio so that it could be better coordinated than it is. Last year the APS commissioned a project on examining the use and reuse of public data—and there is a report that I believe you may have, which we published just in December. The recommendations in that report are now the responsibility of my branch to deliver. Our role now in the next year is to coordinate the activities and recommendations in that report, and to begin to work with the states and territories on a more national-scale coordinated approach.

Our previous secretary, Michael Thorley, indeed wrote to all of his counterparts in the states and territories late last year to raise this at the senior officials' meeting, and that has now kicked off a more national-scale conversation about how we share and coordinate data in all the various policy themes—health, if you like, just being one of them. In essence, we have now come into that role and we are just in the beginning stages of how that works.

**Senator WILLIAMS:** I know you cannot give an opinion, but I can. I hope you streamline it. I was just talking to Senator Moore about mental health problems. Mental health is a huge problem, especially amongst men—four in five suicides in Australia are men. Out in rural Australia, there has been a terrible time with drought et cetera, but we are throwing money at it. Rural councillors, Salvation Army, Centacare, Anglicare, this care, that care—I see the scattergun approach, where we just seem to be pouring money everywhere and probably not getting the best bang for the buck for the taxpayers. I am concerned that we are seeing this in the whole e-health situation. Your job is to coordinate and bring it all together as one; is that correct?

**Ms Owens:** Our role is really the coordination of the policy element. We would still rely upon our colleagues here at the table to do the actual coordination within their own thematic areas. We are not actually going to do the doing in this space; we are running a number of exemplar projects. Potentially, we could just let you know about one that we are doing in health, which is us coordinating it and then the agencies themselves actually delivering that project.

**Senator WILLIAMS:** Is this over a wide range of areas, not just health records et cetera?

**Ms Owens:** There is a particular one. I might refer to my colleague, Tim, to answer that one.

**Mr Neal:** There are seven projects, one of which is health. That particular one, 4.2, is 'Better targeting of mental health services.' It focuses around integrating data, primarily between the Bureau of Statistics and the Department of Health. That has been going on since August last year and it is expected to conclude in March this year.

**Senator WILLIAMS:** Ms Owens, I raised an issue yesterday about sharing interstate the history of parents who may not have been good parents. Did you see the coroner's report on the baby Ebony issue?

**Ms Owens:** Yes.

**Senator WILLIAMS:** Is there progress heading down that way to see that that information is shared throughout the states as well? I know there has been a call for it so that Families SA could have learnt a lot more

from New South Wales about the couple who were responsible for the care of that young baby, Ebony. It was a tragic end to her life. Do you also include that information in your coordination through the states?

**Mr Neal:** As part of the report, there was a general streamlining of governance within the public service down to three mechanisms: a secretaries data group, a deputy secretaries data group and then a data champions network in each of the departments. General coordination goes through those three mechanisms, and we coordinate with a particular leader in that area who is referred to as a data champion. Late last year, when the secretary of Prime Minister and Cabinet wrote to the states and territories to invite them to work with us on data sharing, it was through this mechanism that we were proposing that. A lot of the responses were focused on an interest in working together on health sharing. We will be coordinating how that works and then bringing in the leader from a particular subject matter area. In health, it would be them leading it and us assisting to make sure that the government is coordinated properly.

**Senator WILLIAMS:** My question is about whether that will also include data sharing on the behaviour as far as family care and families go—and DoCS et cetera.

**Mr Neal:** We would not be the particular experts on the type of data.

**Senator WILLIAMS:** I would like to see some coordination of that going through, given the coroner's report last week. Perhaps you might be able to raise it with the Prime Minister, Ms Owens, or look at it, as far as a coordinative sharing of data from states to states to territories. In this case, it is a health issue; it is protecting the lives of children.

**Senator MOORE:** You said in your comment, Mr Neal, that the way the coordination will operate is that each particular agency would have officers who had the key role in terms of being part of that. What level did you say they were at?

**Mr Neal:** It depends—there is a secretaries group, there is a deputy secretaries governance group and then there are the data champions, who are of varying levels.

**Senator MOORE:** There are three different groups?

**Mr Neal:** Yes.

**Senator MOORE:** The secretaries—you know they will not meet—are at that top level, so they have the nominal responsibility, because they will own it in their departments. What is the role of the deputy secretary group?

**Mr Neal:** The secretaries group sets the broad goals and then the deputies group is largely tasked with ensuring that is delivered.

**Senator MOORE:** So they are more operational. Then you have the people who actually work in the areas of data, and they have the work responsibilities that they feed up, okay.

**CHAIR:** Did you identify them as data champions?

**Mr Neal:** Yes.

**CHAIR:** Is this new language?

**Mr Neal:** Yes, following the public data management report.

**CHAIR:** Data champions: what would they have formerly had as their role description?

**Mr Neal:** It varies depending on the department, but largely they control the area or areas that have the most use of data. In their own policy areas they utilise it to make decisions. Generally it is not an ICT based person; it is generally someone in a policy area or a business area that uses data the most.

**Senator MOORE:** Is anyone around the table a data champion?

**Ms Van Halderen:** Yes, I could answer that for you, if you like.

**Senator MOORE:** You are now a data champion; what were you last month?

**Ms Van Halderen:** I am the nominated data champion for the Australia Bureau of Statistics. There are several streams to the role. The secretaries and the deputy secretaries group wanted the data champions to have a senior role within each organisation and have the responsibility and the level of influence that they could bring to senior forums within their own agency data opportunities as well as data barriers and issues. We do have a bit of a role around ensuring some of the action items that come from the deputy secretaries or the secretaries are actioned within our agencies, but our primary role is not a post office box or a sort of action governance role in that sense. Our primary role is to look at data cultures within our own organisations, to look at barriers within our own organisations to using data: using our data, sharing it with other agencies, addressing some of those barriers that

the research sector were talking about before—things like interoperability with our systems, potentially legislation and some of our internal policies, and then bringing those barriers and issues to the attention of our secretaries or deputy secretaries and saying, 'This would be an issue; if we were able to address this, then it would make some great strides in achieving the outcomes the public sector data report and the data policy statement that has been issued are trying to achieve.' So we have a real advocacy role, a communications role. We do have an actioning and a doing role, but in the main it is an advocacy role within our own institutions. We are meant to be at a sufficiently senior level that we have access to the senior people in our organisations.

**Senator MOORE:** I would imagine the Bureau of Statistics would be central to data. I mean, it is why you are there. And you are part of the multi-agency data integration project?

**Ms Van Halderen:** Yes.

**Senator MOORE:** You are the lead agency on that one?

**Ms Van Halderen:** The multi-agency data integration project—maybe I will give a very short, potted history of how this came about. A lot of the linking and maximising the use of data such as the health data has actually originated from the drive of individuals such as Fiona Stanley and the Western Australian model and the health research sector. Probably about 10 years ago or so, around 2009 or 2008, the Commonwealth Secretary of the Department of Health and Ageing, who was Jane Halton at the time, and the Australian Statistician, Brian Pink, got together and put forward a proposal to the Secretaries Board to introduce some safe and effective arrangements for data integration across the Commonwealth. Many of us in this room are involved in that process. That process, which kicked off around 2008 or 2009, has led to a variety of data linking projects around the Commonwealth—for instance, linking the census data to death data to get improved measures of Indigenous life expectancy; doing some linkage of income tax data to migrants' data that comes from the department of immigration to look at the outcomes of migrants in Australia—but it was developing all of these bilateral or individual projects. So several of the agencies—the deputies of the Bureau of Statistics, the Department of Health, Department of Human Services and the Department of Social Services—thought now was the time to bring together a multilateral type of approach to this and demonstrate the issues when you brought more than two datasets together. So over the last few years—

**CHAIR:** I would like to stop you there. When you said 'now was the time' what is the 'now'?

**Ms Van Halderen:** The now was—we are 2015; it was probably around 2013 or 2014. Conversations started happening at the deputies' level to say, 'Let's be champions for change, here, and identify the issues and barriers of working multilaterally, across the Commonwealth, to bring together a project.' This project has proceeded to what is called, now, the multi-agency data integration project. In addition to census data, health data and social security data we have brought in the Australian tax office with the income tax data, because that is a key bit of information for not only policy areas that are looking for using this data resource for program evaluation but also the research sector are particularly interested in those variables from the income-tax side. We have been working on that—

**Senator MOORE:** One of the things that is real is that this is historic. One of the issues I have with some of the stuff that has come to us in this committee is that there is some sense it all started last year. Even with an answer I got to a question on notice about these issues—when you read it, you would think that this multiagency data integration project and the work you described started in December. That is how it is written.

It is important for the knowledge base to know that these discussions had been going on for a long time and that people in your agencies had already identified there was a need to do a lot of this work. I am not saying that it is not a brave new world and there is not a lot of focus but, listening to your description, when you read the answer—you may have written the answer—

**Ms Van Halderen:** Is this an answer from the Bureau of Statistics?

**Senator MOORE:** I do not know where it has come from. It may be health—without pointing the finger at health. It was one of the things I was asking about, where it all came from. When you read it, it talks about the 'Commonwealth's big data strategy and the Public Sector Data Management Project report outlines the future work. One part of this work is the multi-agency data integration project.' It goes on to read as though this all started last month. It is important, for the record, to indicate that people have been working in this area for a long time and looking at where we could have best practice. I know that the work done last year—that you described, Ms Owens—in pulling it together and going into the future is wonderful. We should be looking into the future. It was not a trick question at all. I did not want to do it in that way. What you are describing to me now is exactly what I have in this answer, as though it is brand-new.

**Ms Van Halderen:** Hopefully we have set a bit of the record straight. I have been involved in this area of trying to access existing data and link it since about 2005. I have seen great progress over the last 11 years. A lot

of credit has to rest with the original work that was led by people like Fiona Stanley and D'Arcy Holman over in Western Australia and the health research sector. It has progressed beyond health now, because we are looking at welfare. We also have a burgeoning interest and research group, in the business sector, for reducing red tape and addressing the deregulation agenda, because data integration and reusing existing data is also a great opportunity to reduce some of the load on our business sector. The public sector data initiative takes it out of the particular sector of health, law, crime and justice or business and tries to put it in an authorising environment across all the different subject matters.

**CHAIR:** I remember, in the last parliament, looking at the charities bill. The phrase 'report once; use often' was, I think, one of the things attempted there. The gathering of data to be used in a range of ways does reduce the time in reporting—not to diminish accountability but to make it more efficient.

**Senator MOORE:** What is the reporting process for these various groups that are working in this area? There must be a centralised place where people have to go back and they have reporting mechanisms. I have seen the paper with the recommendations. What we have not seen yet is the government response to that, and with any kind of plan about when things are going to be done by. Do you have any idea when that will evolve?

**Ms Owens:** In this instance there will not be a government response to that report, because it was a self-commissioned study by the APS on the APS; it was not a government-commissioned study. So, there will not be a government response to it.

**Senator MOORE:** It does not go back to the Special Minister of State or anything like that?

**Ms Owens:** We are due to report back to government on progress against the public data policy statement later this year. We also have some mechanisms in place regarding the exemplar projects that we are doing, like the one Mr Neal mentioned. They are reporting into Prime Minister and Cabinet on progress, and then that progress is being monitored by the Deputy Secretary's data group and the Secretary's data group. But essentially the recommendations in this report form part of what my branch is there to achieve, and I guess we have the responsibility now to carry this forward. But yes, we are going back to government at some point during the year.

**Senator MOORE:** Can we get any detail about what the expectations of the reporting mechanisms are, and what the implementation plan is for the recommendations?

**Ms Owens:** Yes, I can provide that for you.

**Senator MOORE:** I very rudely cut you off earlier. Was there anything you were intending to go on with?

**Ms Van Halderen:** No, and I hope I answered your question.

**Senator MOORE:** You did. It was useful. So, basically what is happening is that we have a number of projects that have been identified, and this one that we know about is one of them. The people in this one you identified are Medicare, which is health; personal income tax; social security and related information; DSS; maybe Human Services, depending on how it interacts; and population and housing, which is—who?

**Ms Van Halderen:** That is the census—

**Senator MOORE:** That is just the census; that comes back to you—so, Stats. And when you are working together on the MADIP, is there an expectation that you have a regular meeting interaction? Or is it just that you can do it—

**Ms Van Halderen:** There is governance for the Public Sector Data Management initiative, but then each of the seven projects also has its own governance associated with it. The Multi-Agency Data Integration Project has several layers of governance. There are the deputy secretaries from each of our agencies, whom we report back to on how it is progressing. There is a technical group, which actually met yesterday, because we just finished off some linking in December, and they were doing some evaluation work.

**Senator MOORE:** So, these are systems people?

**Ms Van Halderen:** They are more the data people—

**Senator MOORE:** Statistics.

**Ms Van Halderen:** Yes, statistics and data people, dealing with all the metadata issues and the actual data issues. Then there are program managers and branch heads who regularly meet together to make sure that all the policy issues, the legislative issues, are being dealt with. Just so I am not misrepresenting any of my colleagues, I might just touch base, because it really is meant to be a multi-agency—

**Senator MOORE:** I think you are doing fine, judging by those nods around the table. Is there resourcing attached to each of these? This is time intensive and resource intensive. Are there resources attached to this work?

**Ms Owens:** From my perspective in Prime Minister and Cabinet, yes. My branch is 21 people including myself. While not all of those 21—

**Senator MOORE:** And this is your life? This is what—

**Ms Owens:** This is my life. There are some other things that I do as well, within those 21 people, but certainly my branch is very focused on delivering the recommendations in the report. And we play that coordination role. I could not answer for my colleagues in terms of their resources, but—

**Dr Antonius:** Each contributing agency makes a contributing effort as well, so resources are being in-posted to the ABS, essentially. So, we have resources from the Department of Health, who will be working within the ABS offices to work with the MADIP.

**Senator MOORE:** What is the term in the army when they do that? What do they do with people when they put them into the armed forces—embedded.

**Dr Antonius:** Embedded, yes.

**Senator MOORE:** So, you have people embedded in the Bureau of Stats?

**Dr Antonius:** That is right.

**Senator MOORE:** Do you also have people embedded in Stats?

**Mr Dennis:** Yes.

**Senator MOORE:** So, that is one of the methodologies of doing this combined project; you actually share each other. It is a very positive thing—learning, getting into the other systems. It is great.

**Dr Antonius:** And if I might just add one more fact, there is something that I think Ms Van Halderen wanted to add on, and that is the fact that the MADIP is looking at an enduring linked dataset. So, it is not the link-and-destroy that we talked about in December but is really for the ongoing future.

**Senator MOORE:** As you all know, we have had a lot of evidence on the frustration of the link-and-destroy model, which is how we have operated in the past. But this is an enduring process. Deb, I could go for hours on this kind of thing, but I will pass over to you, because I know you have lots of questions.

**CHAIR:** Perhaps I will just ask a few and then come back to you, because we have quite a bit of time remaining. You have probably seen the Public Data Policy Statement. I have been asking witnesses whether they were consulted prior to that statement, and it has been quite alarming to have so many experts come before us and none of them were consulted prior to the statement. Can anybody here give me an indication of the place from which the statement arose in the absence of that consultation?

**Ms Owens:** I can answer that, given that it was my area that actually published the statement and developed it. The statement was developed as a result of the recommendation in the report, as you will have seen. That was done through an interdepartmental committee process.

**CHAIR:** Could I ask you to sort of chunk that down—give me a bit of a time line on this, and give me some clarity around who was engaged at what points?

**Ms Owens:** For the Public Sector Data Management report we consulted during the period of around March through to June last year. And we consulted widely both within the public sector—25 agencies were consulted. The non-government sector was consulted. We spoke with organisations like Telstra, Google, the World Bank, the ABC, IBM, SAP. We also spoke with some research institutions—the Grattan Institute and the Crawford school at ANU. We then did some individual consultations with business leaders in the data space and open data space. That all occurred during that period around March through June.

**CHAIR:** Of 2015?

**Ms Owens:** Yes, 2015.

**Senator MOORE:** Was that March through June?

**Ms Owens:** Yes.

**Senator MOORE:** I had thought earlier that it was May through June, so I was a bit tetchy, but I am happier with March. It could just be the audio. Did you hear May?

**CHAIR:** I did, originally. So, we are clear that it was March through June?

**Ms Owens:** Yes.

**CHAIR:** You remember that 12 weeks well!

**Ms Owens:** Yes! At the time, I was part of the Department of Communications and I was seconded into Prime Minister and Cabinet to assist with the review. Our then Deputy Secretary, Dr Heather Smith, also travelled internationally, and she spoke with leaders in data and open data in both the UK and the US and then subsequently travelled to New Zealand. We also connected more digitally with Canada. Throughout that process there was regularly—I would say every two weeks—an interdepartmental committee that met at the deputy secretary level, and each of the stages of the development of the report were run through that committee. And then the report was handed down and—

**CHAIR:** Just before you go to that part, you mentioned 25 agencies before. Would you be able to identify which ones they were?

**Ms Owens:** Yes.

**CHAIR:** Perhaps you could just read that into the record—or do you want provide us with the document there?

**Ms Owens:** Yes, I have it here. It was Attorney-General's, Australian Bureau of Stats, the Public Service Commission, the Australian Taxation Office, the Department of Agriculture, the Department of Communications, the Department of Defence, the Department of Education and Training, the Department of Employment, the Department of Finance, the Department of Foreign Affairs and Trade, the Department of Health, the Department of Human Services, the Department of Immigration and Border Protection, the Department of Industry, the Department of Infrastructure and Regional Development, the Department of the Environment, the Department of Social Services, Veterans' Affairs, Treasury, National Archives of Australia, the Office of the Australian Information Commissioner, the Bureau of Meteorology, the Australian National Data Service, and the Australian Research Council.

**CHAIR:** Were there any agencies that missed out?

**Ms Owens:** There were some portfolio agencies potentially that missed out, because we targeted the high-level agency. So there might have been some smaller agencies that did miss out on that consultation. But we were very minimally resourced, and we thought we had consulted pretty widely.

**CHAIR:** So, the 25 agencies were represented in fortnightly meetings?

**Ms Owens:** Not all agencies were at the fortnightly meeting.

**CHAIR:** No, so who was there?

**Ms Owens:** They were a selected group of agencies—the lead agencies of the secretaries obviously who were overseeing the report: the Department of Finance, the Department of Communications, the Australian Bureau of Stats, DHS and the Australian Taxation Office. And obviously Prime Minister and Cabinet was there as well.

**CHAIR:** Was Health there?

**Ms Owens:** Gemma, can you remember whether Health was there?

**Ms Van Halderen:** I do not think so.

**Ms Owens:** But they were consulted through that process of the development of the report.

**CHAIR:** As an agency but not—

**Ms Owens:** As an agency, yes.

**CHAIR:** We had a similar response from specialists in the health field who have been saying that they had not yet been consulted. Professor Stanley saw the echo of much of her 2006 work in some of the statements. Was there any effort to locate key leaders in the community from the health sector in particular? I do not see many of them represented in the groups you mentioned.

**Ms Owens:** No.

**CHAIR:** Was there any rationale for excluding Health?

**Ms Owens:** No.

**CHAIR:** So, how was the list of participants—finance, communications, stats, DHS and tax—selected? What was the process involved there?

**Ms Owens:** Do you mean to be on the steering committee?

**CHAIR:** Yes.

**Ms Owens:** That was decided by Michael Thawley, who was the then Secretary of the Department of the Prime Minister and Cabinet, and it was based largely on, as I say, those agencies being the lead agencies on the project. And then it was a case that we needed then to more widely consult. I guess with a project like this it is

reasonably difficult if you have too many people on the high-level steering committee that is overlooking the development of a report. And that committee was responsible for telling us who we should talk to in terms of different agencies.

**CHAIR:** Maybe I am just a bit myopic about health, because I am on the health committee, but when I look at the profile of the people who were there and I think of health and education, which touch every family and are so significant in the way we live and how much data there is, and given that the electronic health record is so critical, I am a little surprised that Health was not incorporated at that level.

**Ms Owens:** Yes, and Paul Madden from Health, who is a data champion as well, was very closely involved in the development of the report. In fact, was Paul on the steering committee? I cannot remember.

**Ms Van Halderen:** Yes. I might just add to what Helen said there. There were sort of several tiers of governance, if you like. There were the three secretaries who were champions—Michael Thawley from PM&C, Jane Halton from the Department of Finance and at that time Drew Clarke from the Department of Communications. There was then a broader deputy secretaries group that included not only those agencies that Helen mentioned but the Department of Health as well as the education, employment and immigration departments. It had the department of industry, who do a lot of work in this area. Veterans' Affairs were involved in that. So there was a very big deputy secretaries group, but then there was a smaller group. Between all the deputies and the three secretaries was this smaller subgroup, if you like, which is what Helen mentioned to you. It is fairly standard. It is hard to craft reports and statements with a group of 20 or 30; that is like crafting something by committee. But you get the input of all the 30-odd agencies—I am just giving you a number; it is just an indicative number—and then you get a smaller group of five or six who then take all the feedback and work with it and then provide it to the secretaries. So I think the Department of Health, and Education, Employment, Immigration—all of those agencies—were part of the process in developing that statement.

**CHAIR:** At various points along the way, but not at the two-weekly meeting schedule? Okay. I just note that we have asked this question of a number of agencies, and we have not had a response yet, so I encourage you to be prompt in response to those questions on notice around that. We want to try to get a written and accurate verification of your engagement, if you can do that. For the ABS and the Institute of Health and Welfare: how many of your existing projects involve enduring linkage datasets?

**Mr Neideck:** I am happy to respond from the Australian Institute of Health and Welfare. At this stage we have not produced any enduring datasets from the linkage activity that we have undertaken, and we have undertaken over 100 data linkage exercises so far. We are currently in the process of working collaboratively with states and territories and through various health committees to establish an enduring data linkage key, which would enable us to store information about individuals that can be linked through projects. That would be an enduring asset in terms of making data linkage projects more efficient, ensuring that we can replicate linkage projects that occur and repeat them, if we are looking at updating exercises and so on. That would enable us to ensure that they are enduring information that can be repeated and retained for future reference.

**Dr von Sanden:** If I may, I will just add one extra thing to that. We did have an enduring linkage dataset project that started in November 2014, working with the Data Analytics Centre of Excellence. That was involving the ABS and the Taxation Office as well. But, when the MADIP and other projects kicked off, our project was through governments but had not received data. So, when the MADIP kicked off, that was seen as less a priority, and resources were diverted to the MADIP instead, so that project was ended.

**CHAIR:** So your big advance was halted mid—

**Dr von Sanden:** We were doing the same work, essentially at a smaller scale to what things like the MADIP were doing.

**CHAIR:** How is that project, which has seemingly fed in, going now?

**Dr von Sanden:** That project was ended when resources were diverted to the MADIP.

**CHAIR:** I misunderstood you then. I thought you said it had been picked up later on in the process with the new funds and the new structure.

**Dr von Sanden:** No, this started in November 2014, when we did not know about this process occurring. AIHW was not actually involved in much of those discussions. We heard about it later on through Health. Once we heard about the MADIP, we talked about the resources and the smaller scale of our project, and our project was determined to be ended because the MADIP was a much larger scale project with exactly the same aims.

**CHAIR:** Okay.

**Senator MOORE:** You do not have a jersey yourself in this team; you actually go on with Health because you are part of Health?

**Mr Neideck:** Yes, we work very, very closely with the Department of Health, and we are working very, very actively with state and territory health authorities.

**Senator MOORE:** If you are one of the key data areas—from my limited knowledge, in terms of health, anyway, AIHW are the health go-to people for that—I would have thought that somewhere along the line you would be caught up in this in your own right, as opposed to just as one element of Health.

**Mr Neideck:** Yes. We are progressing a number of projects and activities. We work closely with the Population Health Research Network. We have a number of data linkage projects already completed and now that we are in the process of acquiring MBS and PBS data from the Department of Health we have a number of projects in the waiting to undertake.

**CHAIR:** That is great. Just walk me through what is happening with those projects and what comes out at the other end. Where is that going to be available? Talk me through some of the privacy concerns that seem to be constantly considered.

**Mr Neideck:** Okay. The Australian Institute of Health and Welfare is one of three integrating authorities at the Commonwealth level, along with the ABS and the Institute of Family Studies, so we have the protocols, procedures and infrastructure in place to undertake data linkage activities on behalf of the Commonwealth. We have been undertaking quite a number of ad hoc data linkage activities using state data and some of our own data. Now that we are acquiring the MBS and PBS data that is opening up opportunities for a range of research activities. We work with the Population Health Research Network to provide access to researchers to be able to work with that data. We have application processes in place and ethics approval processes in place to support those arrangements and in each of those areas we are looking at ways of improving and streamlining those processes, ensuring that we are moving from the previous process of doing project-by-project approvals, which take a long time getting data custodian approvals and ethics committee approvals, to processes that will enable us to do a range of activities which might mean that activities are approved with data custodians and through the ethics committee to proceed and do not need to go back to those authorising bodies or may only need to go back for just approval given that infrastructure and other arrangements have been put in place to proceed with those projects.

In all of that we are very cognisant of privacy issues and we work very closely with data custodians in terms of how we set up the data governance around those projects and also ensure that we are compliant with various legislation that comes into play to ensure that we are meeting all the requirements in terms of protecting privacy of the individuals in those projects.

**CHAIR:** Mr Neideck, with regard to approval processes through ethics, you would have seen the evidence we heard in Sydney of five or six different gates that people had to get through to get an ethics approval. How does that fit in with what you were just describing there?

**Mr Neideck:** That is one of the things that we are working on with the various agencies that would previously have required those ethics approval arrangements or with the research institutes that have to go through their own ethics. We are working to establish that we can protect the privacy and provide the information that is needed back to data custodians. We can streamline those processes and reduce the number of activities that need to go via the ethics committee. I think that as these processes mature then the various players are becoming more aware, more confident and reassured that those processes are being protected, so we are seeing cases where previously ethics committees have been involved in processes they are now waiving that process and saying, 'We are satisfied if this goes through the AHWI ethics committee. That satisfies our requirements.'

**CHAIR:** So handing it up to a higher source?

**Mr Neideck:** To an alternative source, which covers off the exact same issues that they would have to deal with.

**CHAIR:** Okay. So this is about a guarantee of a particular standard in which the sector has confidence that will take away the responsibility or the risk management process for them at their level?

**Mr Neideck:** That is quite right and these processes are ongoing. We are still working with various departments and other stakeholders to ensure that we can streamline this process.

We are also working our way through to see how we actually can put in place those processes or streamline those processes. We have still got quite right way to go in a number of those arrangements but we are progressing



a number of demonstration processes to enable us to work more effectively and efficiently in getting data into the hands of researchers in a way that satisfies those requirements of privacy that various stakeholders have.

**CHAIR:** With regards to the PBS and the MBS data, as recently as yesterday we heard about people finding alternative research quite different from what they originally wanted to do because they were so fed up with getting knock-back after knock-back. You have mentioned MBS and PBS and getting access to that data. How has your access to that data more recently changed anything for researchers in the field at this point in time?

**Mr Neideck:** We are still in the process of acquiring that data and it has been quite a process for us to go through to get the requisite approvals, public interest certificates and so on that are needed. But that data is now coming into the institute, so we have plans and projects in place to proceed and have a number of demonstration projects to show that we can get that kind of data into the hands of researchers to work with. We are hopeful that we can set up processes that will make access to that information much more streamlined and make it much more widely available to researchers so that researchers do not have to go to alternative sources.

**CHAIR:** In terms of enduring linked datasets moving forward using that data, do you have any concerns around privacy? Have you discussed this with the Office of the Australian Information Commissioner?

**Mr Neideck:** Yes privacy is one of the foremost concerns for all of us. We are required from our legislation to ensure the privacy of individual information. We have had discussions with the privacy commissioner on a number of occasions around this and we are working with colleagues around the table to ensure that those privacy requirements are adhered to.

**CHAIR:** Do you think there are going to be many enduring datasets that will be able to be maintained or are we going to have this research-and-destroy model continue?

**Mr Neideck:** At the moment a number of us around this table are looking at alternative arrangements to enduring datasets. My colleague, Gemma Van Halderen, has mentioned the MADIP, which would be an enduring dataset. We are looking at working with states and territories in establishing an enduring data linkage key, which would mean that we would have the links to data as a sort of continuing ongoing spine of information that can be reliably used and not have to be recreated. Along with that, we would be looking at issues around how long datasets that are created using that mechanism would be retained for, and processes of updating that information. They are issues that we are continuing to work through at this stage.

**CHAIR:** Did you want to add anything, Ms Van Halderen?

**Ms Van Halderen:** I am happy to answer it in my broader ABS response. I will go back to your original question around how many enduring datasets are now available. In 2005, the Australian Bureau of Statistics announced a program of work called the Census Data Enhancement program. A key output from that program was an enduring linked dataset, a longitudinal census dataset. In consultation, including with the information privacy commissioner at the time, we undertook to produce an enduring longitudinal census dataset that links census over time. We released the first one of those products in late 2013. It took a bit of time to do that because we only run a census every five years. We took that 2006 data and linked it to the 2011 census data so we have got a two-wave dataset that is now publicly available on the ABS website. It is available there for anyone to access. There are no restrictions around having to be within Australia; it is internationally available. There is a small charge of about \$1,500 or something in that order for access to the public-use file. However, if you are a researcher within the university sector, there is an agreement with the university vice-chancellors that academics and researchers within their universities can access those files for free.

**CHAIR:** Is that for Australian universities?

**Ms Van Halderen:** Yes, for Australian universities. So there is quite widespread free access to this enduring linked dataset. We have got two time points in it available at the moment. We are about to run the population census this year and we are in the process of working to put the third wave of the population census into that dataset. That dataset is about five per cent of the Australian population so it is about one million people. It is extremely useful for research in quite difficult to get to groups such as Indigenous. Only about two per cent of the Australian population identifies as Indigenous so this is a very rich resource for Indigenous researchers, and we have quite a number of academics, particularly over at the Australian National University, who make quite extensive use of this for doing research around Indigenous life expectancy and informing things like the Closing the Gap targets that come through the Department of the Prime Minister and Cabinet. So that is one enduring dataset that we are funded to produce and we have committed to produce every five years.

The other enduring dataset that the ABS produces is the linking of the census data to the death data to get a better measure of Indigenous mortality. That dataset is used to produce statistics and those statistics are freely available on our website. Researchers can access them and there is quite a lot of research being done on that. We

are currently looking to see whether we can also make it into a public use file so that researchers can do more analytical research on it.

We also have an enduring research dataset around our labour collection so we have created a longitudinal file around labour force statistics that the labour economists and the labour market research sector can access and that is also freely available on our website. University academics can access that for free. Several of the datasets which are not as mature as those are around longitudinally linking business data to get better insights into firm-level productivity and the research development innovation agenda. I mentioned migrants before and the income tax data that comes from the tax office. We are seeing a real growth, not just in the area of health but also in the area of migration and income tax. This MADIP project that we are working on is one way of trying to build an enduring researchable asset that means that we are not redoing the same project or very similar projects over and over in these areas.

It is part of the ABS normal business practice that we would definitely put out statistics. Our legislation requires us, if we collect data, to disseminate it. But we also have a standard working business model, particularly in areas of social concern, of releasing public use files because of the huge analytical research interest. Tools such as the university vice-chancellor's agreement really break down some of those cost barriers for the research sector.

You asked some questions around privacy. The ABS has got a very strong relationship with the Office of the Information Commissioner. We have lots of different touch points with the privacy commissioner. We consult him on everything we do around our population census. We are very much guided by him and by the office around undertaking privacy impact assessments. We make sure that we comply with all the privacy principles about transparency, and around making sure the public know what we are doing. We inform our respondents when we are collecting information so that they are aware of what we are using the data for. We make sure that we are actively pursuing all of those. We also meet all of the standards that are set around the privacy information digest, ensuring there is a lot of transparency there.

We recently got a new Australian Statistician in 2014, Mr David Kalisch. He has been exploring the model that the New Zealand community has put in place, which is around developing what New Zealanders call an 'integrated data resource'. This integrated data resource not only brings together the social information but also the business information. It is sort of a multiagency data integration project but on a much larger scale. It will be updated on a regular basis to be longitudinal and bring in new datasets. There is great interest in bringing in the state and territory datasets. It actually also has the potential to bring in private sector datasets to the resource. An integrated data resource that has been developed and implemented in New Zealand has been championed by the Deputy Prime Minister, Bill English. He is a real champion for introducing this integrated data resource. He was a part of the consultation process that was undertaken with the Prime Minister and Cabinet work. He has also been recently out here to Australia, invited by the Institute for Social Science Research that is headed by the University of Queensland and strongly supported by the Department of Social Services and agencies like ourselves. There are some discussions going on around whether, instead of these single projects or even the single enduring projects, maybe we should be bringing a few of those together so that researchers could access the bits of the research that are of key interest to them. It would just release some of the costs on the data agencies in having to go through those processes.

**CHAIR:** This sounds like it is a quite lively process that is still malleable.

**Ms Van Halderen:** It is still malleable. Turning to your question about the research-and-destroy model, I mentioned earlier that the Commonwealth secretaries and some deputy secretaries across the Australian Bureau of Statistics, Department of Human Services, Department of Social Services and the Department of Health have been working in this area since about 2009 on some Commonwealth arrangements for data sharing and data use. The secretary commissioned a review of those arrangements in 2014. That review was undertaken by a consultant, Ms Susan Linacre, who used to be a deputy at the Australian Bureau of Statistics. She recommended to the deputy secretaries and the secretaries that the Commonwealth should move away from a link-and-destroy model to a create-and-reuse-and-keep model, so we are currently moving towards that. The MADIP is an example of that. There is a very strong appetite within the Commonwealth agencies and the members of that data integration initiative to put in place a research create-and-reuse-and-keep model, not a create-and-destroy model for data linking.

**CHAIR:** I will go to the Department of Health, the Department of Human Services, the Department of Social Services as well to give you an opportunity to contribute to the conversation at the roundtable here this afternoon with regards to the issues that have been raised so far and your concerns about integration into the process, about the linkages and about privacy, particularly with the breadth of social information, not just business information and dollars and taxation and those sorts of things. There is a degree of privacy concern around those. But the

privacy issues around health are ones that have been raised with us that go to identity, not just information that people do not want others in the local community to know.

Ms Foster, can I invite you to make some remarks about where you see the whole big data movement at this point—your integration with it, key issues that you are exploring and what you see on the horizon?

**Ms Foster:** I think we had the opportunity in December to go through a lot of those points. But to confirm a couple of things: in terms of the Australian Government Public Data Statement, I can confirm that health was represented on that group. Paul Madden is our data champion, as was mentioned. He has been instrumental over a number of years in contributing to the data debates across the public service and certainly in our department he is also helping to drive that sort of cultural change that we talked about at the December hearing—as, I would have to say, is the whole senior executive helping to drive that cultural change to make data available.

But having said that, while we are moving from that attempt to make data as available as possible to researchers and for policy development purposes there is that very key issue of privacy that we are concerned about. I think that for many years there was that culture, 'We must absolutely protect this data at all costs.' But, of course, as techniques—computing and statistical techniques and all sorts of things—get more sophisticated there are more ways to 'perturb' the data, as I think you referred to it, or to confidentialise the data so we can actually protect people's privacy and still be able to make information available for use by researchers.

In terms of enduring data sets, we also mentioned in December that we are developing a 10 per cent linked data set—

**Mr Crettenden:** Yes.

**Ms Foster:** Sorry, I think I might have got my words in the wrong order then!

**CHAIR:** Yes.

**Ms Foster:** For MBS and PBS. That will be an enduring set. There will be no linkage keys that will enable identification. But part of the reason that some of these things do take so long to develop is that concern around privacy, double-checking and challenging ourselves—can data be used to identify individuals? There are very strict guidelines under the National Health Act, the Health Insurance Act, the privacy guidelines and the Privacy Act. We also observe those provisions very strictly. Indeed, sometimes those rules can limit our own potential to use data internally. But we do have to be very conscious of those privacy rules to ensure that people's information cannot be identified.

We also mentioned that we have recently made information available to the Primary Health Networks around MBS and PBS. Those datasets are not linked, but PHNs can use some of that data now for their regional planning needs, for instance, to be able to look at their area's need assessments. Some of that data includes MBS, PBS, hospital data—

**Mr Crettenden:** Mental health data, aged-care data and there is HACC data.

**Ms Foster:** Yes, quite a list of different data sets to be able to inform their regional community needs.

**CHAIR:** We had some evidence earlier today—I am not quite sure if you were here or not—from Professor Glover about the SA 3 level as opposed to the level at which he considered more accurate data, that it might be of use to PHNs.

**Mr Crettenden:** I was not here for Professor Glover's evidence, but if he were suggesting a lower level of geography that would be difficult for a lot of the data that we have just mentioned because it would tend to allow identification.

**CHAIR:** I think I might have mischaracterised it. He was talking about the sensitivity at lower levels and higher levels, depending on the geography that you were trying to cover. It needed a subtlety, rather than a particular level to be declared as appropriate. I think that is probably a better characterisation of what I think I heard.

**Mr Crettenden:** Okay.

**CHAIR:** But could you have a look at his evidence and provide us with any response to that? I would find that very interesting, because the data that he was talking about really matches with my experience as a member of the lower house in particular with the very differentiated populations within an area necessary for good policy making. It is the tension between getting down to that granularity and at the same time using new technology and 'perturbation'—I think that was the word—to maintain adequate privacy for individuals.

**Mr Crettenden:** All right, yes. We will have a look at that.

**CHAIR:** That would be fantastic. I might just ask one more question of health before I ask for a general response to my question from the other two agencies. Yesterday Professor Stanley talked about it being time to get the Medicare number as our linkage key and having a unique identifier. Is that a live consideration in the department?

**Mr Crettenden:** Sorry, I did not quite catch that?

**CHAIR:** Using the Medicare number as a linkage key.

**Mr Crettenden:** We do not have the Medicare number ourselves; we have a perturbed version of the Medicare number, so it is not an issue for us. It might be something you could ask—

**Dr Antonius:** I might also just add that the Medicare number itself is not entirely unique. It may be unique to a household rather than to an individual. So whilst in layman's terms the Medicare number seemingly can be unique, there are known issues with that as well. So the impact of whatever systems we use to link individuals needs to be consistent and tested.

**Mr Crettenden:** Yes. We are able to link MBS and PBS data to each other using a perturbed, or a version of, the Medicare number, which means that there is no possibility of us being able to identify an individual while still being able to link the data for statistical or research purposes. I think that is probably the way we would want to proceed in future rather than using a number that can potentially identify an individual.

**CHAIR:** Okay. Ms Wilson, do you want to make some comments?

**Ms Wilson:** I think I explained this last time—that while the Department of Human Services hold a lot of data in our databases, we are not the custodians of the data. We rely on our policy department partners to work with us on release of data. For example, for health data we have a process that we go through when we release data through our data gateway or statistics gateway where we consult with the Department of Health. We actually have a collaborative process that we go through to make decisions about release of data. That process makes decisions on a number of factors.

For example: the recent Multi-Agency Data Integration Project, which has some data which comes from the Department of Human Services. We relied on a public interest certificate and a collaborative process to look at the privacy and secrecy issues with the Department of Health. Indeed, with the Department of Social Services data that relates to social security information we also have a collaborative process with the Department of Social Services. So it is generally not just up to the Department of Human Services about how the data is used. In fact we cannot really make decisions ourselves about how that data is used. We look after it, but we—

**CHAIR:** And how it is accessed? Do you have a say about that? I am just thinking as a researcher—I come to you and I am looking for access to a particular piece of information. I wonder how many times I have to wait for you to talk to the relevant agency—

**Ms Wilson:** Right, yes—

**CHAIR:** because we are hearing that people are not getting the information before the time of their funding agreement concludes.

**Ms Wilson:** Yes, sure. Under the Public Sector Data Management agenda, as you know, there are statements about making data more accessible and easier to access. Along those lines, we have been making efforts to work with our partners to get more data sets—obviously, in an aggregated way—up in the open data domain, on data.gov.au. We can provide you with a list of what is available there now.

**CHAIR:** Thank you.

**Ms Wilson:** We are progressively working, quite steadily, on releasing more and more data. For example, we have recently released some data from the Organ Donor Register. Obviously we have worked with our partners in the Department of Health on that. That is just an example of where we are going. If a researcher wants something which is a bit more specific and not available in the open data source, they can approach us and make an application through our statistics gateway on statistics@humanservices.gov.au. The decisions to release that data are staggered, depending on whether that data has been made available before. We often have coverage to release that data because it has already gone through those public interest processes. We also might work with a researcher on developing something that they can get on a quarterly basis, so the first time they get it from us they have to go through the process where we work with the Department of Health and apply, but once they have had that data once we can then provide it to them each quarter, because we make a decision that that is a safe thing to do, and at a lower cost than it might be for something very complex. Some very complex requests do take additional time, because there are a lot of considerations, and one of them is: can somebody be identified from the

data? Is the purpose of the use of the data sound? These are the considerations that we make with the Department of Health? Did I answer your question?

**CHAIR:** Yes, that is fine. Thank you very much. Mr Dennis?

**Mr Dennis:** The Department of Social Services recognises that it is a significant data custodian and manages, on behalf of Australians, important social datasets. We have endeavoured, especially in recent times, to be at the vanguard of testing technologies and new techniques and developing new techniques to allow more data to be released to intelligent sources. I would endorse everything that Ms Van Halderen has said this evening, and we work closely with the ABS—and AIHW, for that matter—in these endeavours. Internally, we have worked with DHS to streamline our approval processes and, in so doing, have devolved a lot of routine approvals to DHS directly so that they no longer need to seek recourse to DSS where routine approvals are involved, so it moves a lot more quickly.

Where we have been successful in this regard is by not treating every data application equally. In so doing, we have published to data.gov.au large amounts of information that is now open, albeit in a perturbed or confidentialised manner. That has allowed us to turn our minds to what we see as the current challenge, and perhaps the most complex challenge, of arranging for researchers to have access to individual unit record data in a safe and appropriate environment, because this is what they need to perform the statistical analyses that they want to perform. We have trialled a number of models to facilitate that—again, in company with ABS and soon, hopefully, with AIHW—using innovative products that I think you have heard about in previous sessions, such as the Secure Unified Research Environment, or SURE, which is provided by the Sax Institute, so that finally we can put an enduring dataset of DSS data in a safe place that credentialled individuals can access directly at the unit record level and where they can withdraw the products of those analyses, and we are assured that the data is safe and the researchers get the access that they need. We will be conducting trials in the short term with a set of researchers to determine the feasibility of this method. I look forward to informing you of increasing access not only at the low-involvement end, such as through data.gov.au, but also in the high-involvement end involving individual researchers with that fine-grained data.

**CHAIR:** I have a couple of quick questions arising out of some evidence we had about Western Australia and an MOU. We asked some questions yesterday of Fiona Stanley. Something happened in 2012 that led to a change in the MOU between the Commonwealth and the Western Australian government that allowed data to be linked. That was going on from 2007 to 2012. Are you aware of that?

**Ms Foster:** I would have to take that on notice.

**CHAIR:** Could you take that on notice, and we will send you a more fulsome question. I do not know if this might be a little quicker: NEHTA has informed the committee that the Department of Health have requested that the My Health Record system be excluded from the work currently being undertaken by the health data privacy framework, is that the case?

**Ms Foster:** Again, I do not know; I would have to take that on notice.

**CHAIR:** And, of course, we would be interested to find out how work is progressing on the health data privacy framework.

**Senator MOORE:** Also in that area, Ms Foster, we were told that recently a special project has been put out to tender on the secondary use of data and we would like to get some information on that tender.

**Ms Foster:** Okay. I understand the legislation allows that secondary use—

**Senator MOORE:** We just want to get some idea of the tender, the range of that tender, how much and all those things.

**Ms Foster:** Again, I would have to take that on notice.

**Senator MOORE:** Absolutely.

**CHAIR:** I thank you all for your attendance. I foreshadow that we may have some questions on notice after we have a look at everything we have got. We are hoping to go to reporting fairly soon. If there are details that we need and you can respond promptly, that will help us draw our work together. If we can have the 17th of February as the date prominently in your mind for the return of questions on notice. I think there are some still outstanding, so if they could be attended to promptly, as I indicated earlier. And any further ones we will try and get to you as quickly as we can so that that can be a cut-off date we can document to this period.

Once again, thank you for being here this evening and for giving us your evidence. Indeed, thank you to all of the witnesses who have appeared before the committee. Thank you to Hansard, to broadcasting and the secretariat

for their great endeavours in clarifying big data issues for Australia right now. That concludes today's public hearing and the committee stands adjourned.

**Committee adjourned at 19:07**