It is a pleasure to have been invited to speak at this COAG Reform Council Workshop.

The Workshop organisers have courageously proposed that someone from outside of your usual circles provide some insights into information collection and dissemination. While I certainly come from a different perspective, I hope there are a number of aspects from our experience at the Australian Institute of Health and Welfare that are directly applicable to your information needs, and some of our information may even be of direct relevance to your interests.

Establishment of the Australian Institute of Health and Welfare

I want to start with some background on the Australian Institute of Health and Welfare, so you can understand the context of what I will say about information collection and dissemination.

The second reading speech introducing the legislation to establish the Australian Institute of Health, noted that the need for an agency such as the Institute was highlighted in a number of Parliamentary Committee reports in 1978 and 1980. These Parliamentary reports noted the desirability of evaluation of health and welfare services, information that would assist with the proper planning of the health and welfare system and that would support effective and efficient operation of agencies, and a body to provide independent, objective and publicly available facts related to the Australian health industry.

There was then a reasonably long gestation period between those Committee reports and the subsequent government decisions (finally taken by the incoming Hawke government) to first establish the Institute within the Commonwealth Department of Health, and then three years later as a separate agency.

While the welfare functions were not part of the original legislation and statutory agency in 1987, they were added five years later. The more comprehensive remit of the Institute, across the health and welfare spheres, provides the major benefit that a number of the key inter-relationships between health and welfare can be investigated in much more detail than would otherwise be possible.
The AIHW was established under Commonwealth legislation as an independent statutory body. For those with an interest in governance structures, it was established as and remains a Commonwealth Authorities and Companies Act agency, with a management board, and reports to the Australian Parliament through the Minister for Health and Ageing.

The management board has an independent chair, currently Dr Andrew Refshauge, and a range of government and non-government representatives from across the health and welfare sectors. Most importantly, the Board has senior level representation that provides insights and expertise to the strategic directions and management of the Institute.

The AIHW’s position within government enables it to attract staff with prior government experience while its independent statutory position and focus on publication of results is attractive to those who have come through an academic or research pathway. The Institute has also traditionally had a number of formal collaborations with research units at selected universities to undertake specific programs of work in key areas (e.g., dental, injury surveillance, perinatal, asthma monitoring).

The major functions of the Institute are well expressed within our legislation, to:

- collect and produce health and welfare related information and statistics
- conduct and promote research, including enabling researchers to have access to information and statistics
- develop, in consultation with the ABS, specialised statistical standards and classifications
- publish methodological and substantive reports

Contemporary perspectives on the AIHW

To give you a contemporary sense of the Institute, it:

- is the custodian of major national health and welfare data collections, especially those derived from administrative data;
- conducts research, but also promotes research through providing access for others to its information resource;
- develops statistical and information standards, working with the ABS and others involved in the health and welfare sectors, and I will come back to the importance of this later in the presentation; and
- publishes both methodological and substantive reports, including a biennial review of Australia’s health and Australia’s welfare respectively, that is tabled in the Commonwealth Parliament.

Our primary focus on administrative data collections, primarily sourced from the states and territories, complements the household surveys and the census material produced by the ABS. The AIHW also manages household surveys, such as the national drug and alcohol survey, that is undertaken in conjunction with Roy Morgan
We then use our own information, and information drawn from other sources including the ABS and other research, to produce around 140-150 reports a year. These reports range from our flagship Australia’s Health or Australia’s Welfare publications, that can be 500 pages in length, through to shorter bulletins that may only be available on our website. The key issue for us is working out what is required by the users of our information and seeking to deliver that.

Since COAG agreed to reformed federal financial arrangements in 2008, the AIHW has expanded its role in providing information linked to performance monitoring. AIHW-sourced information is a major input for reporting by the COAG Reform Council reporting on national agreements and national partnerships across health, housing and community services. This builds upon the information provided by the AIHW using the national health performance framework and the information released every January in the Report on Government Services.

The AIHW expertise in information for performance reporting has been put to good use in our design and management of the MyHospitals website, started in December 2010, and further developed since that time.

The AIHW undertakes all this with an annual budget of around $50 million, with around 340 staff. What is a little tricky to manage is that our guaranteed annual government appropriation is around $17 million, so the remaining $35 million in revenues is generated through fee for service activity, placing the acid on the Institute to keep delivering quality outputs but also to seek future revenues from potential sources.

The AIHW cannot operate as an island. We rely on the cooperation of governments, statistical agencies such as the ABS, other independent bodies such as the CRC and the PC, and close engagement with the non-government sector that delivers a lot of health and welfare services.

The AIHW has just refreshed its strategic plan, which serves two main purposes of helping guide internal decision making as well as promoting greater understanding among our external stakeholders of what we are seeking to achieve.

This new plan has put greater focus on the authoritative nature of our work, our policy linkages, the availability of information, focus on information quality, utilising the contemporary information and IT environment, and valuing our staff.

I will touch on each of these aspects in a bit more detail next, when I intend to draw out some of the key learnings from the AIHW experience.

Key learnings from the AIHW experience

From my perspective, I would suggest that there are ten main reasons why the AIHW has been successful. There may be more.

The ten general aspects I have chosen to focus on are independence, publication policy, staff expertise, engagement with policy, seeking to maximise the benefits, trust, standard-setting, improving the quality of information, presentation of information, and being alert to future opportunities. A number of these features are also reinforcing and, in combination, deliver even better outcomes.
Independence

As I mentioned earlier, the AIHW’s status as an independent statutory authority is enshrined in our legislation.

While we are a Commonwealth statutory authority, our CAC Act status, with the Management Board provides further checks and balances in the oft-contested Commonwealth-state environment. Independent Board members and representatives from both Commonwealth and State/Territory governments provides a good balance of ensuring there is engagement with the policy agenda while broader sector interests are also heard and considered around the Board table.

I should recognise that legislation and governance structures, while important in setting the basis for operating, also needs to be backed up by the operating principles and culture of the organisation. Actual behaviours and decisions of an organisation can just as important, as they are the aspects experienced by our stakeholders, who rarely are aware of our legislative structures.

With this independence also comes responsibility, supported by effective governance structures and consultation processes.

Independence does not give organisations carte blanche to do whatever they wish and report in whatever way they wish. Statutory organisations, such as the AIHW, still need to be able to justify what we do to Parliamentary Committees and to our multiple stakeholders.

We have a responsibility to robustly undertake our work. We want our work to inform the policy decisions. However, we are not an active player in the political contest.

Publication

The second virtue of the AIHW is its general policy to publish everything we do. We produce on average three reports every week.

This reinforces our independence and gives the broader community the opportunity to get maximum benefit from our work.

We do, in limited circumstances, make exceptions and will agree to non-publication of some work. For example, the general policy of publication may be over-ruled in specific circumstances, such as where the work or the findings relate to a very sensitive policy arena, where the AIHW is well placed to undertake the work, where the work would increase our corporate analytical capability and where the AIHW would not be given the task if we were to insist upon our general publication approach.

The AIHW has for some time had a policy of pre-releasing information to particular stakeholders, on an embargo basis, prior to its formal release to the general community.

We provide information to relevant Ministers and their officials seven days prior to the formal release, so they can be properly briefed when reports are released. This facility is available, equally, to Commonwealth and State/Territory governments. It is premised on a ‘no surprises’ approach.
We also provide our publications to the media 48 hours prior to their release. We will answer their queries prior to release and we hope that this leads to better informed reporting across the electronic and print media. With one recent exception, we have found the media to be very responsible in their use of the material that is supplied to them on a pre-embargo basis.

Governments have got used to this approach. We do not always put out information that is welcomed by the government of the day, or the opposition for that matter.

Again, with publication comes responsibility – responsibility to be factually accurate and to present material in an objective manner. This is not always value free, and judgements do sometimes come into play.

*Staffing and external expertise*

The governance and structural arrangements that have been put in place for the AIHW enable prospective employees to view the AIHW as a highly sought after place to work.

The independence provided to the AIHW and the publication approach can help attract and retain people with the necessary technical expertise, who might otherwise be attracted to an academic or research career.

From the very start of the AIHW, it was able to draw together a significant pool of talent from universities and government. This has continued over the nearly 25 years of the AIHW’s existence. More recently, there has been a significant refreshing of the workforce such that there is now approximately half of the workforce that has been here for less than two years. We have a good balance of experience and innovation.

For some of the technical work that the AIHW does in terms of checking the veracity of the information supplied to us and working with data suppliers, there are major advantages in having a group of people who do this work and understand the data sources in some detail. These skills are not easy to find or develop.

We have people that have expertise in data management, statistical methodology, analysis of information, performance monitoring, data integration, robust governance and privacy arrangements and innovative reporting options, to name a few of our major activities. The largely project-based nature of our work allows most tasks to be managed in a structured way, although we also need to be able to deal flexibly with developing government priorities and changing policy interests.

The internal expertise of the AIHW is supported and complemented by our engagement with experts from across the health and welfare sector.

We have a number of Advisory Groups that bring together people with research and service delivery expertise. This provides us with quality advice so we can make better informed judgements. We also engage extensively with those who have detailed knowledge of the information environment, and their insights help us to have richer understandings of data and information options. They can then also support effective implementation of information strategies across the sector.
**Engagement with policy**

The AIHW makes considerable effort to engage with policy makers across government as well as policy analysts and advocates in the non-government sector.

To provide information that is most useful for policy development and decision making, we need to know and understand the nature of the current policy issues. We want our information to inform current policy debates, and lead to better policy design.

This engagement with current policy debates does not constrain the AIHW to only deal with current issues, as given the length of time involved in the development of information, where possible we need to anticipate the issues that will be pertinent to policy in the future and ensure there is good information capture and reporting of these aspects.

I would characterise our role as contributing to the policy debates rather than seeking to be an active policy player. Our role is to contribute quality information, and we seek to position the latest data and information within the considered research evidence.

Others in the health and welfare sectors, media, community and political domains have the opportunity to advocate for particular policy outcomes, using information we can provide, while a smaller sub-set actually make the policy choices.

This protects the true and perceived independence of the AIHW, as our brand does not get tarnished by the political process. Those who use our information can be guaranteed that we have sought to fairly and objectively report the information as we see it.

**Maximising the benefits from the information**

Over the past few years, I have noticed a distinct shift in the public debate towards ensuring that we make greater use of the national information resource that is collected and reported at considerable cost. While these costs are largely met from government budgets, ultimately the community pays these costs through their taxes, and the community should therefore get the benefits of this information.

This is currently being given effect through new information agreements (being signed for the community services and housing sectors and being negotiated in the health sector) between the Commonwealth and the states/territories. The most recent COAG Health Reform Agreement also has an increased emphasis on expanded but efficient development and use of the national information resource.

One of the major challenges is to recognise and seek to respond to the multiple users (and demanders) of information. All possible users of information do not have the same needs for information, and also do not access information in the same manner.

The AIHW has taken some time and effort to seek to understand how our information is accessed and the respective uses to which our information is used. This has shaped our work and publication plan, as well as the respective formats we use to
present information. I will comment upon our approach to information reporting slightly later in this presentation.

A major challenge with extensive use of data sourced primarily from administrative activity is to ensure the veracity of the information. One approach is to deliver some benefits to the provider of the information, so they not only incur the cost and inconvenience of the data supply, but also get some meaningful information back that helps them or their organisation to better carry out their required activities. Hopefully, the beginnings of a virtuous information cycle, linking providers to users.

**Trust and governance**

For an organisation like the AIHW to succeed and prosper, we largely rely on funding from governments and the delivery of information from service providers (including governments). This is particularly apt in the sensitive health and welfare sphere.

The AIHW has effective governance structures, a long history of sound adherence to robust privacy and statistical processes and an impressive array of sound administrative processes and policies. Together, these place us in a very strong position to receive trust from governments, the health and welfare sectors and the broader community.

The legislative underpinnings of the AIHW Act and the application of the Commonwealth Privacy Act work with national information agreements signed by governments and the AIHW and ABS among others. Together, these specify the agreed way in which data, especially that sourced from third parties, will be managed and the recognised uses to which the information will be put.

Our legislation requires us to have a properly constituted human research Ethics Committee. This provides assurances around the proper use of the information we control and disseminate, for internal analysis and research purposes as well as for those external researchers seeking access to our data.

**Attention to standard-setting**

Recently, I attended a workshop on the national statistical system hosted by the CRC and the ASAC. One issue that caught my attention was the difficulty of comparing the performance of education systems across jurisdictions because they did not have a standard approach to defining, collecting and reporting information.

From our experience across the health and welfare sectors, my one piece of advice to any sector considering information collection would be to clearly and transparently set the standards for information collection that is then expected to be followed by all providers of information, spanning the government and non-government sectors alike. If you do not set a standard, people can and will be very creative around what information they will collect.

Our legislation gives the AIHW a major role in setting data standards across the health and welfare sectors, working with the ABS, and as much as possible having regard to accepted international data standards and conventions.
In carrying out this role, the AIHW has a metadata facility, called METeOR (Metadata electronic Online Registry). METeOR is Australia’s repository for national metadata standards for health, housing and community services statistics and information. METeOR currently contains over 2600 data standards, and these are available free of charge to all users. This facility encourages the use of consistent data standards across our country, supported by Ministerial Council processes.

The reality is that standard setting and standard adherence remains an ongoing challenge, for the AIHW and others. Data standards do need to be continually managed, to ensure standards meet contemporary information needs, add new data requirements, clarify definitions where some unusual local practices have developed and identify non-compliance with national standards.

**Improving the information resource**

Given the substantial costs of data collection, it is necessary to continually review information collections to be sure we are collecting the right information and to seek the most efficient means of collecting quality information. For example, against the backdrop of COAG agreement to new performance reporting and increased transparency and accountability in the health sector, there is also an exercise currently underway to explore opportunities for rationalisation of health information collection and reporting.

Where possible, we strive for single provision of data that is then able to be used for multiple purposes. This would be the most cost-effective outcome.

In the health arena, we are some distance away from achieving this objective – with the outcome that there is currently higher respondent burden on data providers than should be the case and there is also a high risk of inconsistent information being reported. AIHW is actively considering opportunities to limit the extent of information collection and maximise the consistency of information which is reported.

Following the lead of the COAG Reform Council in the Data Quality Statements that have been established for COAG performance reporting, the AIHW is introducing data quality statements across all of our data sets. I hope this will serve two purposes: to help inform users of the information about some of the nuances they need to be aware when they are using the information for particular purposes and to encourage data providers to improve the quality of their information in the future when we transparently point to current issues with their data.

We seek to navigate a tricky balancing course – especially where we do not control the information supply, but through a range of mechanisms seek to influence and encourage good practices. Sometimes, extra resources are made available from governments to improve information, and in these instances the challenge is to make best use of these opportunities in ways that might meet a variety of needs.

The AIHW has utilised a number of information-related committees, drawing together government and non-government representatives, in order to help establish the best way forward, and helping connect the data providers with data users. While this can be a successful approach, there are also times when consensus among the parties will not be possible and the AIHW needs to take on the role of benevolent dictator, weighing up the competing interests, and deciding on a way forward.
Effective presentation of the information

The information resource that is available to us across the health and welfare areas is immense, drawing on our own national data collections and other information sources, such as those provided by the ABS.

So far, I have spoken about the challenge of improving the information resource. Not wanting to diminish the importance of this aspect, nor the fact that there is still more information that we would hope to collect in the future, there is also a challenge to present the information we have in the most effective ways.

Recognising that there are many audiences that have different information needs, and that people receive information in a range of formats, we need to think about the most effective way of communicating our messages to the widest audience. If we were not to pay attention to this aspect, we would diminish the utility of the information that is collected and reduce the potential impact of our work.

As I mentioned earlier, the AIHW has a long and proud history of reporting information, now producing around 150 reports a year. We produce a suite of products, from shorter Overview reports and bulletins through to lengthy data rich publications and more detailed data resources.

With this reporting volume and experience, we should have some expertise in effectively presenting information.

I would note that this does not just happen. It takes effort and drive within the organisation to reform presentation approaches and make use of technological developments such as the pervasiveness of the internet and its interactive nature.

Within this context, we have also invested in developing our writing capability, the way we present information through tables and charts, tailoring information for web presentation, and effective use of colours. The recent release by the AIHW of Mental Health Services On-line provides a contemporary example of what is possible.

Alert to future opportunities

Any organisation that is not moving forward will find itself going backwards, as the environment and client expectations move ahead of them. This would be particularly dangerous for the AIHW that is so reliant upon external funding to keep doing what is expected of us.

The environment that we are working within has been and remains changeable. Governments have recently settled on some major health reforms, agreeing to new performance reporting and increased transparency and accountability of service provision, but with much of the implementation detail still to be determined. In disability and aged care, the Productivity Commission has produced major recommendations for change that governments are considering. Across most of the human services areas, COAG will over the next year be considering reform of the performance monitoring arrangements associated with the national agreements.

One development that I am particularly excited about is the opportunity provided by data integration. Data integration is a set of procedures that combine personal
information from two or more data sources to provide new merged data sets that can be used for socio-economic or clinical research purposes. This enables us to investigate some of the recognised interdependencies between say homelessness, drug use and mental illness, that in turn can contribute to better informed policy choices. The nature of the data sets we currently hold, our robust internal processes that protect privacy and our sound statistical and technical skills mean the AIHW is well placed to contribute to this activity.

Agencies such as the AIHW are constantly challenged because we cannot do all that we would like to do. That is a challenge that we will continue to face, and is just part of life. We need to make choices about where we can best add value, using our scarce resources to have the greatest impact now and in the future.