Contemporary Data Governance Challenges and Opportunities
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David W Kalisch
Director (CEO)
Australian Institute of Health and Welfare

It is a pleasure to have been invited to speak at the Health Informatics Society of Australia Conference.

I should start with an open declaration to all of you. I come here as a long term user of data rather than a collector of data or data aficionado. I am not a Health Informatics expert, but I do know good data when I see it and understand where there are some deficiencies.

My background as a researcher, policy adviser and program manager, across many areas of social policy, including health more recently, has been characterised by extensive use and understanding of data, its opportunities and limitations.

I am a long-term evidence-based policy convert, who recognises that good data is the lifeblood of evidence based policy, supporting robust analysis and interpretation and effective communication.

The Australian Institute of Health and Welfare

Since December 2010, I have had the privilege of being the CEO of the Australian Institute of Health and Welfare. AIHW is a national information and statistics agency with a specialist focus on Australia’s health and welfare.

While we are a statutory agency of the Australian Government, and we are established under Commonwealth legislation, we have well-established, robust and necessary relationships with state and territory governments and NGOs that provide us with their trusted information.

We have a long-standing relationship with the ABS, who are also major collectors of health and welfare information through their survey and census processes, and we utilise ABS-sourced data in a number of our information reports.

With our total Budget of around $45 million, largely provided by the Commonwealth government, we:

- Are the national custodian of 14 national minimum data sets, ranging from public hospital and mental health establishments to admitted patient care, admitted and community mental health care, outpatient and emergency department care, and drug treatment services
• Produce around 150 reports a year, presenting information and analysis across health, housing and community services sectors

• Our legislation requires us to produce a major report on Australia’s health and Australia’s welfare every two years – and we also produce a flagship report on the health and welfare of Australia’s Aboriginal and Torres Strait Islander people every two years - with the latest edition released earlier this month and available on our website.

• Are complementing our data collection, data quality and data dissemination activities with further value added activity that includes contributions to performance monitoring and a Closing the Gap Clearinghouse (together with the Australian Institute for Family Studies)

• Are moving to provide more information to the broader public through our website, including managing the MyHospitals website that provides information on all public hospitals and an increasing number of private hospitals.

In the major areas where the AIHW is at the forefront of data collection and information dissemination, in the health and welfare spheres, there are some “market failures” of information provision that makes our information so valuable.

This is due to the significant public sector component of the health and welfare markets, as well as the difficulty for some consumers understanding the technical nature of health and welfare services (and the unwieldy terminology).

The AIHW is well placed to address these market failures through the amount of information that is freely provided to the community and consumers, and the understandability of our information to the broader community.

Our processes to collect, explain and disseminate information about critical aspects of the health and welfare system are a valuable national resource.

This does not just happen. It is delivered largely through the expertise and adaptability of the staff that are working at the Institute, at all levels and across the organisation, as well as the co-operation and contributions we receive from across the health and welfare sector. In addition, our management Board, which comprises independent members and sector representatives, provides sound counsel and direct assistance in achieving our multiple objectives.

In this presentation today, I want to focus on a number of issues:

• The policy relevance of information
• The availability of information for the community
• The need to improve information quality
• The importance of protecting privacy of sensitive information
• The desirability of efficient data collection and dissemination processes, and
• The desirability of maximising the use of information
Policy relevance of information

I want to start with some discussion of why we are seeing some increasing focus and public debate around the concept of evidence-based policy.

Perhaps a good place to start is what is the alternative? The alternative to evidence-based policy is policy determined in the absence of information, when information is either not collected or not adequate nor reliable.

In this scenario where suitable, sufficient and timely information is not available, it is not surprising that policy would need to be designed around assumptions and best guesses.

Several years ago, Australian governments through COAG took an enlightened view to improve the performance information that should be available to Australians on their health system, their education system, disability services, community services and housing services, as some examples. There was also a very strong emphasis on measuring progress towards the COAG Closing the Gap targets for Aboriginal and Torres Strait Islander Australians.

What I think this reflects, at its core, is an expectation and an understanding that the Australian community, that essentially pays for these essential services through their taxes and direct purchase of some services, should be fully informed of how these services are being delivered, whether they are getting value for money, and where there are opportunities for policy and program improvement.

The AIHW is, quite properly, making extensive contributions to this COAG performance monitoring activity.

At a broader level, those of us providing data and information, such as the AIHW, and many other organisations represented in this room, are part of the rich tapestry of organisations contributing to public policy, in a number of ways:

- Contributing quality, timely information so governments can make the most informed policy decisions that they can
- Providing clear advice to policy makers on the quality and shortcomings of any information we supply so they understand any limitations and restrictions on the information and how it should be used
- Adapting and improving data collections to respond to changing policy requirements

One challenge for data agencies is to remain contemporary and relevant. We do not only need to be aware of policy developments, but we need to understand them and their possible implications for the scope and emphasis of our data collections.

Let me be clear – I am not suggesting overt external influence over what information is being collected – but what I am suggesting is that those responsible for maintaining data collections need to continually question and refresh their collections to ensure they are providing answers to the policy questions that matter.

To do this effectively requires some understanding of the policy environment, engagement with policy makers and researchers and, at times, some anticipation of likely future needs, given the long lead-time often between identification of the data need and supply of the information.
One exciting recent development that should lead to better use of data for policy purposes has been the establishment of a Commonwealth framework for data linkage.

The AIHW is embracing this development, particularly as we recognise the opportunities that data linkage across the Institute’s diverse data holdings can bring to better understanding of complex policy dilemmas. The AIHW has some existing experience and expertise in data linkage and this is a capability we are looking to expand in the future.

Availability of information to the community

While our role in contributing to sound public policy is important, there is so much more that we, as data providers, can and should do.

As I mentioned earlier, there are broader community-wide interests in our work, from people who are regular users of health and welfare services, to their families and friends, and not forgetting the interests of taxpayers who ultimately fund these services.

When you look across other types of services, we have seen a significant revolution in the services being offered and now expected by the community.

Not so many years ago, people transacted the majority of their banking with paper records in their passbook, and needed to go into their local bank branch to make withdrawals and deposits.

Now we have much more electronic transfer of payments, including at point of sale.

The community expects to be able to transact their banking over the internet, at an hour of their choosing, and get money from ATMs when they need it.

The term “bankers hours” – notionally 10 am to mid-afternoon – is becoming redundant to a new generation as a result of changes to community expectations and practices, aided by changes in technology and service offers.

Maybe some in this room may have foreseen the developing importance of the Internet to access information and transact business and the role of social networking.

Maybe many of us did not expect its pervasiveness.

Irrespective of how reality matches our prior expectations, the reality of the internet is with us.

This is the contemporary community in which we as data collectors and information providers operate. The challenge for us is to keep up with changes in community expectations and technological possibilities.

In some instances, the community has expectations that exceed what is currently being provided.

For example, in this information age, I suspect many consumers believe that there is already some electronic linkage of their health information.
Instead, the reality is that governments, health providers and the information technology sector are progressing e-health infrastructure in a very measured and steady way, to ensure it has a robust structural base with clear effective national standards and appropriate regard for individual privacy and consumer functionality.

In other instances, we are directly responding to changes in community expectations around what information is available, when and in what format.

For example, at the AIHW, we have:

- Established the MyHospitals website that is providing some standard factual information on what the hospital does and where it is located, and some initial performance information. This facility includes all public hospitals and we are including more private hospitals over time. Work is underway to improve the functionality of the site, to say compare hospital performance and link to national or jurisdictional performance, or to search for hospitals that provide particular services in a nominated region. As noted at the launch of the MyHospitals site just last December, it was always envisaged that the performance information, currently around elective surgery and emergency department waiting times, would be broadened to other important indicators, including the quality and safety and efficiency of hospital services.

- Enhanced our website to make it easier for the community to navigate, our publications available for free through web downloads, and we have started to produce some information that is designed explicitly for easy access via the web. This also assists with earlier provision, and more regular updating, of quality information to the public and policy makers.

- Developed the Validata™ product within the AIHW for use in a number of our collections to enable external data suppliers to undertake more quality assurance checks on data before it is supplied to the Institute. This has enabled us to receive better quality public hospital information from states and territories, which in turn has enabled us to report better quality information quicker to the public and governments. We are extending use of the Validata™ to our new homelessness services data collection, and are considering further applications to other AIHW data collections in the future.

- Taken steps to introduce a Creative Commons (rather than Copyright) licensing to our work, consistent with the expectation we have that our information should be readily accessed and available, with appropriate attribution.

- Continued with our regular process of providing embargoed copies of our publications to media outlets 48 hours prior to their public release, to encourage accurate and more complete media reporting of what can be quite detailed and complex analysis and information contained in our reports.

As indicated above, if we are to be serious about improving information to the community, we need to tackle this on a number of fronts, including accessibility, timeliness and clear presentation of the information.
Improving information quality

For data agencies, there should be a constant focus on assessing and, if possible, improving data quality.

For data and information providers, such as the AIHW, the accuracy and reliability of information is critical to our overall reputation and the respect and attention accorded to our reports.

We pay particular regard to sound internal processes, quality assurance checks and particular attention to the development of and adherence to agreed, sound national standards. Anything less could call into question the core reliability of our reports.

Without clear national standards and explicit data definitions, that are firstly agreed, secondly effectively promulgated and thirdly followed, there is a considerable likelihood of an information morass.

There are risks at each of these stages.

One of the major public resources of the AIHW is our meta-data repository, called METeOR.

This AIHW METeOR product provides a publicly-accessible and rigorously tested set of standards. The expectation is that adherence to these meta-data standards will lead to consistency of content and definition, avoid duplication and diversity of solutions and ultimately also reduce the cost of data development.

In the AIHW context, where we have administrative data sets that cross health, community services and housing sectors, we can utilise the benefits of consistent national standards and definitions across the wide span of our information reach.

In our role as the data custodian of many administrative data sets, we are continually working with jurisdictions to improve the quality of the source information.

At times, this will require adoption of a new data definition or collection standard.

At other times, it will require working with some jurisdictions to improve the quality and timeliness of the information they are collecting through administrative means.

This is a major focus of our attention at the AIHW, and let me be frank with you, there is plenty more scope for improvement in data quality.

But this is not just a role for the AIHW. In the health arena, many of you have the opportunity to contribute to improvements in data quality, adoption of national standards and more efficient information collection, through your local business processes and adoption of data validation checks.

However, we need to be careful not to take this flight to quality to extremes.

As with any activity of government or the private sector, there is not an unlimited amount of funding, and choices need to be made.

For example, in the real life example of a choice between improving the quality of an existing data collection or initiating a new data collection in an area of emerging policy and community interest, where should respective resource priority be given?
Making these choices is a bit more complex than I have just described and we usually have more information and options, but nonetheless this serves the purpose of illustrating the fact that improving data quality is usually not a costless exercise.

The advent of data quality statements, used in the COAG Reform Council performance reporting context, is a useful model that could have broader applicability. The first step in improving data quality is to understand the existing limitations and inconsistencies, before considering opportunities to improve data quality.

Protecting the privacy of an individual’s information

Together with maintaining public confidence in the quality of the information that is supplied, it is equally important to be able to assure the public that their sensitive health information is being treated appropriately and will not be disclosed in a manner that identifies them.

And I should note that it is not just health information that is sensitive, with a strong need to also protect the confidentiality of information about people utilising a wide range of social services.

The AIHW has an exemplary record in maintaining the privacy and security of information on individuals.

To my knowledge, we have never had a privacy “incident”, and we are working hard to ensure this impeccable record is maintained.

Ensuring the privacy and confidentiality of information does not just happen, as if by accident.

It is an outcome of a robust regulatory framework and robust internal practices.

In terms of the regulatory arrangements at the AIHW, we have requirements for the handling and dissemination of information that is prescribed in the Commonwealth Privacy Act, the AIHW Act and AIHW regulations, and a range of other Commonwealth and state/territory legislation which includes provisions to protect the privacy of individuals.

These regulations are very clear about the requirements that need to be met for information to be released.

They also require that the Institute establish a Human Research Ethics Committee which provides further checks and balances on our work and processes.

But regulation by itself is not sufficient. The penalties for non-compliance are a clear, but somewhat delayed, deterrent to poor practice.

We have a view that it is best to adopt and promulgate good practices across the organisation through regular privacy training and awareness.

This is relevant not just for our new staff but for staff that have been at the Institute for some years. Everyone can sharpen up their understandings and processes, supported by senior leadership.
We are currently assessing the robustness of our statistical practices to ensure they meet contemporary confidentiality requirements, as another component of our broader privacy tool-kit.

The bottom line for organisations such as ours is that we survive not just on the funding we receive but the goodwill and confidence of organisations and the broader community that freely provide information to us for compilation and dissemination.

Improving the efficiency of data processes

As I indicated earlier, data collections do not come for free. They have a cost to the community, and an opportunity cost in terms of services that could be provided with these resources.

Let me be clear that this is not just a one-sided issue. I have earlier indicated that there are also benefits from our data collection in terms of a better informed government and community, which should lead to better designed public policy and service delivery.

I would be confident that these benefits of our information would outweigh their costs.

The alternative of not funding such information collections, and not having much of our existing information base, would see wastage of taxpayer money on ineffective or inappropriate programs.

Now that we all have a warm inner glow around the inherent value of what we do, there does need to be a reality check.

As receivers of public money, we should ensure that the public gets value from their contribution.

I can think of a number of ways in which this can be progressed:

We should design data collection processes that pay due regard to the costs of information collection, from respondent burden through to the costs of collecting and cleansing the data and then the reporting of information.

As much as possible, we should adhere to the adage of “Collect once, use often”.

This delivers a clear efficiency gain.

- Governments and the community are getting maximum advantage from the sunk investment involved in data collection.
- There is an efficiency gain in the effective use of scarce staff skilled in the collection and compilation of information, including full understanding of data limitations and possibilities.

This is an area where amateurs should fear to tread, because the risks of providing inaccurate or misleading information can be high, and this is not just a fiscal cost.

Where there are many boutique collection arrangements, there is a clear increased cost being met by the broader community but also a heightened risk that individual data agencies will make some “unique” internal decisions around data standards that reduce the overall usefulness of the national data resource, and reduce the ability to compare progress over time.
Maximising the use of information

One of the significant recent developments in government has been increased attention to open and transparent information to the community.

Freedom of information arrangements have been modified to encourage and require information to be supplied, except in exceptional circumstances.

The Gov 2.0 policy direction of the Commonwealth government is encouraging much more open and technology-enabled processes and services, to the benefit of the community.

Directly related to improving the quantity and relevance of information for the broader community, governments have

- Through COAG, established extensive performance monitoring arrangements in the health, education and skills, community services, housing and homelessness services sectors, to name a few sectors. The COAG Reform Council are the prominent independent body with the role of assessing performance, building upon an extensive data and information infrastructure.
- Introduced the MyHospitals site, the MySchools site, and recently announced that they will establish the MyRegions site
- Delivered an annual Report on Government Services, since the mid-1990s, that provides a stocktake of government services across a wide range of service areas
- Mandated extensive use of the Internet, not just as a free, accessible source of information on government services, but also for people to more easily undertake government service transactions

If I can use the Institute’s compilation and reporting of information on Australia’s hospitals as an example of how we seek to maximise use of data that we receive:

- We provide the core information that is used in the COAG Reform Council health performance reports and the reporting on hospital performance in the annual Report on Government Services, with much of this reporting comparing performance across jurisdictions
- We manage and ensure the quality of information that is presented on individual hospitals, through the MyHospitals website
- The AIHW also has its own suite of regular hospital reports, that provides much more detailed statistical and performance information, that is used by those managing hospitals to managers of hospital systems to the broader community

This not only makes best use of scarce resources devoted to the collection and quality assurance of the hospital information, but it ensures consistency of the information across these respective and different reporting requirements.

At the end, everyone wins from these robust and consistent processes:

- The community and policy makers from more reliable information
• The taxpayer and governments from efficient processes
• Data collection and dissemination agencies also gain from not having to explain apparent data inconsistencies.

If I was to point to an area of considerable further opportunity, it would be to ensure that data collections deliver quality information back to those who are providing the data. When those providing data also receive considerable internal benefits from the supply of information, leading to improved local decision making, information will gain its proper priority among the competing business processes.

Closing remarks

The one final comment I would leave you with is that we have a complex system of health information, where system change can be challenging.

In this presentation I have profiled the role and activity of the Australian Institute of Health and Welfare in contributing to available health information and systematic improvement of these arrangements.

The one aspect that I do need to emphasise is that we manage to achieve great outcomes improving health and welfare data through co-operation and engagement with many other organisations, including government departments, health providers and performance agencies. The insights and contributions of many participants in the health system, from governments, service providers, data experts and evaluators, need to be brought together to achieve further substantive progress.