

Submission to the Productivity Commission Inquiry on Data Availability and Use

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“Aged care as a test case in data availability and use”

Summary

To meet its statutory duty to “to facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstance or geographic location”, the Department of Health needs detailed data on unmet care needs. The same data are needed by providers considering investments in new care facilities.

Many persons seeking aged care, particularly those with few assets or in remote locations, many not currently be able to obtain the aged care they need. Detailed data on unmet needs would help the Department offer grants and subsidies to providers willing to meet special needs

Data on unmet needs would be relatively cheap to collect, and would greatly assist the Department, the providers, and persons seeking care.

Excessive data requirements for the combined income and assets test have slowed admissions to permanent residential care by about a month. Governments should only collect the data they need.

Limited data are currently available on-line from the National Aged Care Data Clearinghouse. More extensive on-line data are proposed, following the development of software to ensure confidentiality. Considerable progress has been made by the Australian Bureau of Statistics in providing access to its data.

Slow access to data greatly reduces its value, as many decision makers only have short windows of opportunity.

Public sector data all come from community sources, and should be given back to the community in full, subject only to confidentiality restrictions.

Inadequate public sector data

Under (1) of its terms of reference, the Commission is to “examine the costs and benefits of options for increasing the availability of public sector data to ... the private sector, research sector, academics and the community”.

The terms of reference appear to assume that public sector data will always be sufficient for its purposes. This is not the case for aged care, where data on residential care approvals and admissions are unlinked, making it impossible to measure unmet needs for residential care.

Public sector data systems can be very costly to establish and update. In areas with rapidly changing legislation, such as social services, superannuation and aged care, it is likely that

public sector data systems will sometimes lag behind, forcing temporary reliance on survey data and guesswork.

Inadequate public sector data, or inadequate access to the data, can be costly for industry. In the aged care sector, lack of data on unmet need increases the risks for providers seeking to build new residential care facilities. This may narrow the regions they choose to invest in, increase their financing costs, or make investment in other industries more attractive. Established providers may have better data than potential new entrants, effectively restricting competition.

Inadequate public sector data can also be very costly for individuals. The present lack of data on unmet need for aged care appears to have led to under-provision of residential care, and to access difficulties for persons without substantial assets.

Excessive public sector data

The terms of reference also appear to assume that public sector data will not be excessive for its purposes. Form SA457, "Permanent residential aged care: request for a combined income and assets assessment", appears to be gathering more data than needed, and to be increasing delays to permanent residential care by about a month.

Form SA457 has to be completed by all persons seeking permanent residential care as from 1 July 2014. It is a 31 page form with 144 questions, many of them requiring multiple answers. Its use appears to have resulted in a 28 day increase from 13-14 to 14-15 in median delay from first ACAT approval to first admission to residential care (Hartland 2016). Respite care, as a proportion of total residential care use, increased from about 1.7% in June 2014 to about 2.8% in June 2015 (ACFA 2016 p2). Providers appear to be using respite care as a way to admit persons before form 457 is fully complete.

Delays associated with form 457 could perhaps be reduced if there was an option for new residents to accept responsibility for the lifetime cap on aged care costs, without having to detail their assets and liabilities. Without such an option, form 457 appears to be a costly data-gathering exercise, perhaps intended to help evaluate higher lifetime caps.

Data needs in the aged care industry

Object (e) of the Aged Care Act 1997 is

"to facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstance or geographic location."

Aged care is provided largely by private organizations, responding to subsidies and grants provided by the Australian government. As far as possible, care is provided locally. The government needs data on unmet demand for aged care services by location, so that it can try to ensure services are available where needed. Some locations are economically unattractive for private providers, and special capital grants or subsidies may be needed for these locations. Government subsidies for the care of different types of person need to be designed to avoid any persons being financially unrewarding for providers.

The government makes no guarantees to providers. Providers are bearing all the financial risks, and need data on the demand for services by location before making capital investments. Providers are likely to specialise in servicing different sectors of the market, and need data on the nature of the persons likely to seek care at each location.

Persons seeking data, and their families, need data on the availability, prices and quality of aged care services near where they live.

In response to legislative changes, the aged care market is changing rapidly. Policy makers and many private users need data updated at least quarterly, if not monthly. Many users have limited ability to pay for data. High data charges are likely to reduce competition, both by providers and by researchers.

Ways in which aged care data needs are met

The Department of Health's Data Access and Release Policy (2015) says in part

"The Australian Government Department of Health (Health) will ensure that the community is able to realise the greatest possible value from data held by Health through better use of existing datasets for research, community information, policy development and policy evaluation..."

Applying a common data access and release policy supported by streamlined processes across the entire Health portfolio will ensure the public has access to a range of useful Health data. The policy objectives are to:

- *improve public benefit from increased data use*
- *timely information release*
- *relevant information release*
- *protect individual privacy*
- *efficient approval, extraction and release processes."*

Some aged care data are published by the Department of Health, as in its "2014-15 report on the operation of the Aged Care Act 1997". Other data are published by the Aged Care Financing Authority (2015). But responsibility for the provision of detailed aged care data appears to rest with the National Aged Care Data Clearinghouse (NACDC), operated by the Australian Institute of Health and Welfare (AIHW). The NACDC was established in 2013, reflecting a recommendation in the Productivity Commission's 2011 report on "Caring for older Australians".

Recommendation 16.1 of the Productivity Commission's report on "Caring for older Australians"

"To encourage transparency and independence in aged care policy research and evaluation, the Australian Aged Care Commission should be responsible for ensuring the provision of a national 'clearinghouse' for aged care data. This would involve:

- *establishing a central repository for aged care data and coordinating data collection from various agencies and departments*
- *making these data sets publicly available in a timely manner for research, evaluation and analysis, subject to conditions that manage confidentiality risks and other concerns about potential data misuse.*

To maximise the usefulness of aged care data sets, reform in the collection and reporting of data should be implemented through:

- *adopting common definitions, measures and collection protocols*
- *linking databases and investing in de-identification of new data sets*

- *developing, where practicable, outcomes based data standards as a better measure of service effectiveness.*

Research findings on aged care and on trial and pilot program evaluations, including those undertaken by the Department of Health and Ageing, should be made public and released in a timely manner.”

Inadequate funding for the aged care data clearinghouse?

In its “Living longer, living better” aged care reform package, in April 2012, the government said

“As part of the Aged Care Reform package, the Government will provide \$9.1 million over five years to increase the availability, accessibility and coordination of aged care data for the community.

This measure will establish a centralised Aged Care Data Clearing House within the Australian Institute of Health and Welfare to improve the availability of data for a range of stakeholders including policy makers, researchers and consumers. The Clearing House’s role will include a focus on geographic and social inequities as well as gender disaggregated data, including analysis of the intersection between gender and cultural diversity.

This measure will also support the expansion of the Australian Bureau of Statistics Survey of Disability, Ageing and Carers and increase its frequency, so that it is conducted every three years rather than every six years from 2014–15. An expanded and more frequent survey will assist policy makers, researchers and consumers, and better inform the deliberations of the Council of Australian Governments.”

Assuming that the Clearinghouse and the 2015 Survey of Disability Ageing and Carers 2015 shared the \$9.1 million of extra funding equally, there would have been less than \$1 million a year available to establish and run the Clearinghouse. This seems a very small level of expenditure, in relation to the \$10-15 billion annual cost of aged care to the Australian government. I have not been able to find actual expenditure on the Clearinghouse each year, presumably because the small amounts are included with other expenditures.

Limited funding seems to have led to a reliance on custom data requests, rather than on capital expenditure on facilities to provide immediate answers

Data sources for NACDC

The following details are from the data quality statement released by AIHW as part of its National Aged Care Places Stocktake Reporting Tool (AIHW 2016a).

“Data included in the AIHW National Aged Care Data Clearinghouse are collected and maintained by the Department of Health (DoH). A sub-set of these data are then provided to the AIHW and are assumed to be as correct as possible. The AIHW has no ability to confirm the correctness and completeness of these data.

The AIHW National Aged Care Data Clearinghouse contains data relating to eight national aged care programs. As such, each of these datasets are outlined in the interpretability, relevance, accuracy, and coherence sections of this data quality statement.

The AIHW National Aged Care Data Clearinghouse (the Data Clearinghouse) is located at AIHW for the purpose of providing aged care data to a range of stakeholders including policy makers, researchers, service providers and general consumers.

The Data Clearinghouse encourages transparency and independence in aged care policy research and evaluation through the provision of data and information in a timely manner for research, evaluation and analysis, subject to data release protocols.

Included in the Data Clearinghouse are data on aged care providers, services, places, residents, care recipients and payments. Specifically, the Data Clearinghouse includes data and information relating to the following:

- Residential Aged Care Services (RACS)
- Community Packaged Care Programs - including the Community Aged Care Package (CACP) program, Extended Aged Care at Home (EACH) program and the Extended Aged Care at Home Dementia (EACHD) program
- Transition Care Program (TCP)
- Aged Care Assessment Program (ACAP)
- Home and Community Care (HACC)
- National Respite for Carers Program (NRCP)
- Community Care Census (CCC)

Data within the DoH Ageing and Aged Care data warehouse are updated and refreshed at varying times. For example, HACC data are submitted to the HACC MDS National Data Repository (NDR) on a quarterly basis. However, claims are submitted by service providers on a monthly basis for services delivered under residential aged care and residential respite care, Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH), Extend Aged Care at Home Dementia (EACHD), and Transition Care.

For consistency, AIHW receives a full refresh of all Data Clearinghouse source data in late September each year.”

Ways in which data are released from the NACDC

The AIHW website says (AIHW 2016b)

“A range of aged care data from the NACDC is accessible through self-service options including the NACDC National Aged Care Places Stocktake Reporting Tool and the aged care data cubes.

The National Aged Care Places Stocktake Reporting Tool provides a quick, user-driven view of the number of operational aged care places in Australia at 30 June from 2006 to 2015. The Stocktake Reporting Tool summarises the number of aged care services and places into interactive graphical representations that enable the user to obtain an overview or to specify the year, aged care planning region, care type, and provider type...

The aged care data cubes include some detailed data relating to residential aged care, community aged care and the Transition Care Program from 2009-2012...

The NACDC also provides customised aged care data to researchers and other stakeholders such as aged care sector and community agencies, and other government agencies.

If you have a specific requirement for data or statistics not covered by any of our published reports or online data, you can request customised aged care data through the AIHW custom data request service.”

Discontinued NACDC online data services

AIHW provides a range of online data services to external users. For example, its General Record of Incidence of Mortality (GRIM) Excel workbooks allow analyses of deaths by cause, with some GRIM books starting at 1907

Online data allow decision makers to respond to emerging opportunities quickly. Researchers can explore complex issues without repeated data costs and delays. Data providers are largely freed of the burden of dealing with custom data requests.

One good example of online data is ABS Tablebuilder, which I have used many times to make analyses of 2011 census data. For example, I have analysed home ownership by sex and 5-year age groups for each of the 2200 SA2s in Australia, as part of the process of synthesizing baseline data for a household microsimulation. Tablebuilder uses data randomisation to ensure confidentiality. ABS charges initial licence fees for Tablebuilder, but there are no subsequent relicensing or use fees.

AIHW has on its website data cubes of residential care admissions and separations in 11-12, and of residents at 30/6/12. The data cube of residents allows tabulations of the numbers of persons in each state, by sex for each five-year age group, of persons with each of the 64 combinations of ACFI domain values. The admission and separation data cubes allow slightly more complex subdivisions, for example by type of region within state. Dr Marijan Jukic and I used these data cubes to estimate transition and mortality rates for residents, as well as the life expectancies of persons entering residential care.

Much better estimates of transition and mortality rates would have been possible given several years of data cubes following 11-12. I understand that lack of flexibility, and some confidentiality concerns, led to the decision not to release the residential care data cubes after 11-12.

NACDC data provision and confidentiality procedures

In response to my query about the future availability of data cubes, AIHW replied

“We are certainly keen to develop some cubes that will improve access to the National Aged Care Data Clearinghouse holdings, consistent with the objectives of the Data Clearinghouse. Accordingly, we are investigating a number of OLAP (that is, on line analytical processing) technologies, including the current SAS ‘data cube’ tool, in order to provide a powerful, user-friendly, contemporary tool that is compatible with the new AIHW website (in development) and that will also allow us to automate some of the confidentialisation methods ... there are a number of factors to consider in delivering it. One such factor is whether we want a straight OLAP tool, or an OLAP function alongside mapping and geospatial analysis capability, providing richer options to users.”

Unlinked data sources

Persons seeking Commonwealth-funded aged care, whether at home or residential, have to be approved through the Aged Care Assessment Process (ACAP). Once admitted to

residential care, the Commonwealth subsidies payable for the person are determined by the Aged Care Financing Instrument (ACFI). AIHW's aged care database has 59 data tables, in all containing 1214 different data fields (AIHW 2015). The AIHW_ASSESSMENT_DETAILS_ACAP table has 177 fields, and the AIHW_ASSESSMENT_DETAILS_ACFI table has 110 fields. There are about 300,000 records of ACAP assessments each year, and about 200,000 ACFI assessments each year. I have worked with large extracts from these ACAP and ACFI tables, and regard the data as of good quality, with many potential government and private uses.

Unfortunately, AIHW has no automatic links between ACAP and ACFI assessments. This appears to reflect the absence of such links in the Department of Health's ACAP and ACFI data. This has serious consequences for the administration of the Aged Care Act 1997.

The current uneven distribution of aged care beds between the 72 Aged Care Planning Regions (ACPRs) suggests that, in some regions, persons needing residential care are not able to find a vacancy. The present lack of links between the ACAP and ACFI data means that there is no easy way to tell if a person with an ACAP approval for residential care is not receiving that care for a valid reason. The limited available evidence suggests that persons with few assets, or with disabilities not giving high ACFI subsidies, may be missing out.

Although the lack of linking between ACAP and ACFI data reflects the data provided to AIHW, persons seeking aged care data sometimes suggest that AIHW use the limited personal information it holds to try to link ACAP and ACFI data. This is likely to be a costly process, not fully successful. A much better solution would be for ACAP teams to remain in contact with persons approved for care until such time as they receive care or an acceptable alternative. Data would then be available promptly on the measures need to help the Aged Care Act meet its objects.

What does the NACDC need to be more effective?

To be more effective, the NACDC needs

- data updated more frequently (at least quarterly)
- more online data released for each aged care planning region
- capital investment in software able to meet online data requests without breaching confidentiality
- capital investment in the creation of confidentialised unit record files and longitudinal files (as recommended by the Productivity Commission in 2011)
- detailed disclosure of confidentiality procedures, so that users understand the limitations of the data they receive, and can make more sensible data requests
- continuity in data releases, so that data can be compared over time
- online disclosure of the nature of data provided in response to custom data requests
- streamlined approval procedures, so that data can be released in time to be useful.

Responses to questions in the issues paper, using aged care as a test case

QUESTIONS ON HIGH VALUE PUBLIC SECTOR DATA

What public sector datasets should be considered high value data to the: business sector; research sector; academics; or the broader community?

Public sector datasets will be of high value to businesses and to individuals if the data help them make important decisions. Researchers and academics will value anything that helps them make money.

What characteristics define high value datasets?

High value datasets will contain up-to-date data, well subdivided by the characteristics that are important to decisions. Data on individuals, showing their behaviour over periods of time, will often be of more value than data on aggregates of individuals. Slow access to data greatly reduces its value, as many decision makers only have short windows of opportunity.

What benefits would the community derive from increasing the availability and use of public sector data?

Opportunities for business, and for services more closely meeting individual needs.

QUESTIONS ON COLLECTION AND RELEASE OF PUBLIC SECTOR DATA

What are the main factors currently stopping government agencies from making their data available?

Inertia, and lack of investment in software to make data freely available without breaching confidentiality.

How could governments use their own data collections more efficiently and effectively?

Collecting all the data governments need, and nothing more, would be a good start. Making frequent use of data would help ensure that it was relevant and reliable.

Should the collection, sharing and release of public sector data be standardised? What would be the benefits and costs of standardising? What would standards that are 'fit for purpose' look like?

Given the many different sources and uses of public sector data, standardisation may have high costs and few benefits. Well-documented approaches to data confidentiality could however be of general value

What criteria and decision making tools do government agencies use to decide which public sector data to make publicly available and how much processing to undertake before it is released?

Any data held by government is potentially of public value. Processing should be used only to reduce access costs, or to protect confidentiality.

What specific government initiatives (whether Australian Government, state, territory or local government, or overseas jurisdictions) have been particularly effective in improving data access and use?

The Australian Bureau of Statistics has been highly effective in developing Tablebuilder to give on-line users great flexibility in table choices, while automatically protecting confidentiality. Its confidential unit record files, particularly the 1% census sample file, also give great flexibility while protecting confidentiality. The recent ability to make inter-censal transition analyses using approximately linked records is another very valuable product. In these areas, ABS is providing much better data than Statistics NZ. The NZ process of allowing elected researchers supervised access to data is slow, expensive and discriminatory.

QUESTIONS ON DATA LINKAGE

Which datasets, if linked or coordinated across public sector agencies, would be of high value to the community, and how would they be used?

This submission has stressed the need to follow individuals who have been recommended for aged care until such time as they receive appropriate care (or die). This could be done approximately by linking separate ACAP and ACFI files. But it would be much better done by frequent followups after ACAP recommendations, as this could allow help to be given quickly to persons struggling to find care.

Which rules, regulations or policies create unnecessary or excessive barriers to linking datasets?

Increasingly, the government is using data linkages to catch welfare cheats and tax evaders. Much the same technology could be used to measure unmet care needs, and to help individuals obtain the care they need. Where the Australian government controls both data sets (as it does with the ACAP and ACFI data), no regulatory problems should arise. It seems high time that death registrations move from state to Australian government control, as gaining permission from eight jurisdictions is slow, and data are not in standard form.

How can Australia's government agencies improve their sharing and linking of public sector data? What lessons or examples from overseas should be considered?

Public sector data all come from community sources, and should be given back to the community in full, subject only to confidentiality restrictions.

Glossary

ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Process
ACFA	Aged Care Financing Authority
ACFI	Aged Care Funding Instrument
ACPR	Aged Care Planning Region
AIHW	Australian Institute of Health and Welfare
GRIM	General Record of Incidence of Mortality
NACDC	National Aged Care Data Clearinghouse
OLAP	On line analytic processing

References

Aged Care Financing Authority (2015) "Third report on the funding and financing of the aged care sector", downloaded on 31/5/16 from <https://www.dss.gov.au/ageing-and-aged-care/aged-care-reform/aged-care-financing-authority/2015-report-on-the-funding-and-financing-of-the-aged-care-industry>

Aged Care Financing Authority (2016) "Report on the impact of the 1 July 2014 financial reforms on the aged care sector", downloaded on 4/6/16 from <https://www.dss.gov.au/ageing-and-aged-care/aged-care-reform/aged-care-financing-authority/report-on-the-impact-of-the-1-july-2014-financial-reforms-on-the-aged-care-sector-quarter-ending-30-september-2015>

AIHW (2015) "AIHW_Metadata_Documentation_v2.0_Final.xls", received September 8

AIHW (2016a) "19794-supplementary-data-tables.xls", downloaded on July 18 from <http://www.aihw.gov.au/national-aged-care-data-clearinghouse/nacp/>

AIHW (2016b) National Aged Care Data Clearinghouse, downloaded on July 18 from <http://www.health.gov.au/internet/main/publishing.nsf/Content/Data-Access-Release-Policy><http://www.aihw.gov.au/national-aged-care-data-clearinghouse/>

Department of Health (2015) "Data access and release policy", downloaded on 25/7/16 from <http://www.health.gov.au/internet/main/publishing.nsf/Content/Data-Access-Release-Policy>

Harland N (2016) "Median delays from first ACTA approval to first admission to residential care for each aged care planning region, 12-13 to 14-15", email May 16