Australian
Private Hospitals
Association

APHA Submission

Data Availability and Use: Productivity Commission Issues Paper

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Executive summary

The Australian Private Hospitals Association (APHA) would like to thank the Productivity Commission for the opportunity to comment on their Issues Paper regarding the availability and use of data.

APHA is the peak industry association for the private hospital and day surgery industry, representing around 70% of the private hospital sector in Australia. The members of APHA run both for-profit and not-for-profit hospitals and day surgeries.

This submission addresses a number of issues relating to private hospitals data, its availability and use. Primarily, the APHA highlights that current restrictions around personal, health and sensitive information should be maintained to safeguard patients' privacy.

Additionally, restrictions need to be maintained or put in place to maintain commercially in confidence and commercially sensitive information as well.

Should government agencies wish to expand linkage and publication of currently held data, the APHA advocates for strong guidelines around using private sector data. Government agencies will need to demonstrate relevance of publication/use to policy objectives, adequate consultation with stakeholders, and a better understanding of the differences between the purpose of data collection and what they want to do with the data.

Whilst the APHA is involved with or represented on several government health data and statistics groups, and have some very positive experiences with consultation by government agencies, this is not always the case. Consultation with the APHA is important when activities are proposed pertaining private hospitals data directly, but also more broadly regarding health sector data. The private sector is sometimes overlooked, and policy decisions affecting the private sector are made based exclusively on public data or public processes.

The APHA encourages further consultation and conversations around the availability and use of private hospitals data.

The Productivity Commission should not hesitate to follow up with the APHA regarding this submission, should they have any queries.

Introduction

Regulation of information in the health sector

Information and data are heavily regulated in the health sector, and all private health service providers must comply with the *Privacy Act 1988* when handling personal information of patients.

'Health service' is defined under the *Privacy Act 1988* to mean (s 6(1)):

a. an activity performed in relation to an individual that is intended or claimed (expressly or otherwise) by the individual or the person performing it:
    i. to assess, record, maintain or improve the individual's health; or
    ii. to diagnose the individual's illness or disability; or
    iii. to treat the individual's illness or disability or suspected illness or disability; or
b. the dispensing on prescription of a drug or medicinal preparation by a pharmacist.

The *Privacy Act 1988* requires all health service providers (regardless of turnover) that handle personal information to comply with the 13 Australian Privacy Principles.

Additionally, in New South Wales, Victoria and the Australian Capital Territory, state and territory health privacy laws also apply to private operators.

Public and private data

Whilst data from the private hospital sector would not be considered 'public sector data' by the private hospital sector itself, the Productivity Commission definition of 'public sector data' could be interpreted to include datasets held by public sector agencies.

The *Productivity Commission Issues Paper on Data Availability and Use* defines 'public sector data' as:

> Australian governments ***collect***, create and produce a wide variety of data including legal, administrative, regulatory, ***business***, economic, geographic and meteorological data. (…) Australian governments make some of their data publicly available (emphasis added).

The private hospital sector generates a large amount of data which is shared with and stored by various government agencies. Provision of data to government agencies is often required through legislative instruments to populate national collections. Some data is provided voluntarily under agreed conditions limiting the use, publication and release of data collected (for example, the Independent Hospital Pricing Authority's Private Sector National Hospital Cost Data Collection).

Private hospital data which are held by government entities and statutory agencies include, but are not limited to:

- **State and Territory Health Departments** collect morbidity data about private patient episodes
- **Australian Institute of Health and Welfare** receive the above morbidity data and collate the National Hospital Morbidity Database (NHMD)
- **Department of Health**
    - collects private patient episodes for the Private Hospital Data Bureau (PHDB)
    - holds patient episodes, charges and benefits information in the Hospital Casemix Protocol (HCP) collection
- **Independent Hospital Pricing Authority** receives voluntarily provided cost data for their Private Sector National Hospital Cost Data Collection (NHCDC)
- **Australian Bureau of Statistics** collects information about the activities, staffing and finances of all private hospitals in Australia for the Private Health Establishments Collection (PHEC)
- **Medicare** collects data on medical services and pharmaceuticals provided through the Medicare Benefits Schedule (MBS) and the Pharmaceuticals Benefits Scheme (PBS).

Not all of the data held by these agencies are currently made publicly available.

Privacy and personal information

Privacy in relation to health information and data is extremely important, as it deals with information about an individual and their person, making it sensitive and personal. Additional to health information potentially being embarrassing or confidential to the individual if published, there are also real risks of identity theft if data is not secure or kept private.

The added security needed regarding health information is recognised in the *Privacy Act 1988*, which defines 'personal information', 'health information' and 'sensitive information' narrowly.

According to the Office of the Australian Information Commissioner[1], the following definitions apply to private health providers seeking to interpret the *Privacy Act 1988*:

Personal information

'Personal information' is defined as any 'information or an opinion about an identified individual, or an individual who is reasonably identifiable:

- whether the information or opinion is true or not; and
- whether the information or opinion is recorded in a material form or not' (s 6(1)).

[1] https://www.oaic.gov.au/agencies-and-organisations/app-guidelines/chapter-b-key-concepts#_Toc380575639

Health information

'Health information' is defined to mean:

- information or an opinion, that is also personal information, about:
    - the health or a disability (at any time) of an individual, or
    - an individual's expressed wishes about the future provision of health services to him or her, or
    - a health service provided, or to be provided, to an individual, or
- other personal information collected to provide, or in providing, a health service, or
- other personal information about an individual collected in connection with the donation, or intended donation, by the individual of their body parts, organs or body substances, or
- genetic information about an individual in a form that is, or could be, predictive of the health of the individual or a genetic relative of the individual (s 6(1)).

Sensitive information

'Sensitive information' is a subset of personal information and is defined as:

- information or an opinion (that is also personal information) about an individual's:
    - racial or ethnic origin
    - political opinions
    - membership of a political association
    - religious beliefs or affiliations
    - philosophical beliefs
    - membership of a professional or trade association
    - membership of a trade union
    - sexual orientation or practices, or
    - criminal record
- health information about an individual
- genetic information (that is not otherwise health information)
- biometric information that is to be used for the purpose of automated biometric verification or biometric identification, or
- biometric templates (s 6(1)).

Additional to privacy of the individual being essential in handling personal health information, it is worth highlighting that in the private sector, health data and information is also commercially in confidence and commercially sensitive.

It is the position of the APHA that any information about a private hospital or their operations is both commercially in confidence and commercially sensitive, as this information has economic value to the private hospital and could cause economic harm if used or disclosed inappropriately.

Questions on collection and release of public sector data

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?

The current processes and decision-making tools in place by government agencies are unknown to the private sector. This is an issue of concern in itself particularly when the 'public' data in question has been sourced from the private sector.

The APHA is currently represented on the National Health Information Standards and Statistics Committee, however, there is no forum in which the issue of data linkage and use are discussed by private and public sector stakeholders.

Lack of consultation with the private sector regarding the release of what private hospitals see as their data is one of the main issues the APHA has encountered with government agencies.

Additionally, government agencies do not always understand the context, sensitivity and the sometimes competitive nature of the private sector, especially in times of renegotiation of funding contracts. Frequently, private hospitals and private health insurers are combined in stakeholder consultations regarding private hospitals data. This is not appropriate.

At the very least, government agency criteria relating to the public release of data should include:

- relevance to government policy objectives
- adequate consultation with stakeholders including specific consultation with the providers of data held by government
- satisfaction of the conditions under which data was originally provided.

Processing should include:

- sufficient processing and verifying of the data to ensure that no personal/ business or commercially sensitive information can be identified
- adequate notification should be given to the original providers of the publication, linkage and release of the data. This notification needs to be sufficient to allow those providers to request access to the data themselves and/or prepare a response to the data publication/ release.

Questions on data linkage

How can Australia's government agencies improve their sharing and linking of public sector data?

Whilst data from the private hospital sector would not be considered 'public sector data' by the private hospital sector itself, the Productivity Commission definition of 'public sector data' could be interpreted to include datasets held by public sector agencies.

Health data linkage could occur in three ways;

- to facilitate research
- to project demand and service planning
- to build tools to inform consumers.

Whilst the APHA is not against data linkage per se, it believes that sensitivities of data providers must be taken into account.

Sharing and linking of data must protect commercially sensitive data

The APHA urges the Productivity Commission to carefully consider issues around the ownership and sensitivity of data when considering datasets pertaining to or originating from the private hospital sector held by government.

It is the past experience of the APHA that not all government entities understand the commercial sensitivity of private hospital sector originated data. APHA is of the view that any dataset that allows identification of an individual hospital is commercially sensitive in as much as it allows assessment of that hospital's operations.

Sharing and linking of data must be planned in consultation with data providers

Many private hospitals publish data about their performance either independently or via the Australian Government's MyHospitals Website, however, they do so on a voluntary basis. It is not appropriate to publish, share or link private hospital data as a blanket rule without being consulted regarding its use. Government must weigh the advantages of increased data sharing and linkage against the need to provide appropriate protections in order to maintain the cooperation of data providers.

The ownership of data is complicated, especially when a dataset has several points of data entry. An example is the Hospital Casemix Protocol (HCP). The HCP data collection was established in 1995 to monitor the deregulation of the private health industry. It is supported by the *Health Insurance Act 1973*.

The HCP data flow starts with an admission to hospital. Data is collected for that admission by the private hospital and entered into the hospital administration dataset. Information on the patient's episode, charges and benefits is forwarded to the patient's health insurer. Health insurers add information to the patient's data record and forward the new data record on to the Australian Department of Health for inclusion in the HCP data collection.

The HCP includes data that is highly sensitive for both commercial and personal reasons including details of benefits claimed and paid, the identity of the patient and treating clinician, medical diagnoses, medical interventions and complications.

Sharing and linking of data must recognise the limitations of pooling data from multiple sources

Notwithstanding extensive work to establish agreed data definitions and specifications for statutory health sector data collections, there are still many sources of inconsistency between data pooled from multiple sources.

Some of these inconsistencies arise from definitions and conventions applied by the states and territories. Some of these inconsistencies arise because of variations in clinical and administrative processes in both public and private hospital sectors. The further removed the point of analysis is from the point of data collection, the greater the likelihood of such inconsistencies arising and the greater the risk of these inconsistencies being overlooked, misunderstood or misinterpreted.

Questions on high value private sector data

What would be the public policy rationale for any associated government intervention? What benefits would the community derive from increasing the availability and use of private sector data?

Various stakeholders have argued for greater access to private sector data for purposes of research, particularly where private organisations are publically funded to provide health services.

The APHA notes that much of the extensive data already provided by private hospitals is currently available to researchers under controlled conditions (including de-identification of datasets, ethics approval, etc.).

To the extent that there are specific areas of research that cannot be pursued within current limitations, the APHA would welcome opportunities for open dialogue between the private hospital sector and the research community and greater opportunities for collaborative research.

Questions on access to private sector data

Are there any legislative or other impediments that maybe unnecessarily restricting the availability and use of private sector data? Should these impediments be reduced or removed?

Currently, data in the private hospital sector (and the health sector more widely) is regulated through a number of legislative tools. Health data and information are considered 'sensitive' information, and have additional strict protections in place to protect the privacy of patients.

De-identification and linkage of data in the health sector are carefully managed to ensure the privacy of the individual. Privacy instruments for the individual are covered in legislation such as:

- the *Privacy Act 1988*
- the *Health Insurance Act 1978*
- the Australian Privacy Principles.

It is the view of the APHA that maintaining these restrictions on the availability and use of data are important and should not interfere with the privacy and anonymity of patients.

What are the reasonable concerns that businesses have about increasing the availability of their data?

Additional to maintaining patient privacy, the APHA would like to highlight two issues of concern that need to be considered before increasing the availability of data.

Commercially-in-confidence data

Any data that gives one hospital competitive advantage over another, or data that would place one hospital in a less beneficial position when negotiating contracts with health insurers, would be considered commercially-in-confidence by the private hospital sector. This would include data in respect to activity, costs, volume, price and quality.

This may be data that is publishable in the public sector (such as the number of separations a hospital provides annually) which in the private sector should only be published as a sector-wide aggregate.

Strong caveats and guidelines around publication, de-identification, linkage and accessibility of data are needed before the sector would feel comfortable with increasing the availability of data.

Data needs to be fit-for-purpose

Data can be misused, misinterpreted and misrepresented, especially when caveats and limitations of datasets are not provided or not understood. Data that are collected for one purpose are not always appropriate to utilise for another purpose, although such inappropriate utilisation often occurs.

For example, the Australian Commission on Safety and Quality in Health Care (ACSQHC) developed a group of core hospital-based outcome indicators (CHBOIs). These were developed to help hospitals to "routinely monitor and review" their practices. The purpose was for these indicators to provide hospitals with the tools to improve the safety and quality of their own hospital.

In 2014, however, due to pressure from health insurers on private hospitals to provide CHBOIs, it became necessary for ACSQHC to reiterate that these indicators were not appropriate for public reporting or external performance measurement.

To what extent can voluntary data sharing arrangements—between businesses/ between businesses and consumers/ involving third party intermediaries—improve outcomes for the availability and use of private data? How could participation levels be increased?

Data sharing arrangements between private hospitals and businesses can occur in one of three ways:

- between purchasers (e.g. health insurers) and suppliers (e.g. hospitals). In this case sharing is generally subject to contractual provisions.
- between hospitals and other supply chain participants (e.g. credentialed medical practitioners) which are subject to terms agreed between the parties.
- between competitors in strictly controlled circumstances, for example benchmarking against quality and safety indicators. In this instance, controls are essential to avoid anticompetitive behaviour and to ensure trust between participants.

Ideally, these arrangements should be driven by competitive innovations directed at achieving better outcomes for consumers.

It is notable that in recent years, consumer demand for information has led to a number of voluntary initiatives in the private hospitals sector including voluntary participation in the publication of data on the MyHospitals Website and independent disclosure of quality and safety indicators on many private hospital websites.

Government can play a role in ensuring that consumers have access to independent data, that the data is of good quality, and fit for purpose. One such example is the website privatehealth.gov.au which provides information on private health insurance products to assist consumers making product comparisons. The APHA has elsewhere argued for the extent of this information to be

enhanced, and for the website to be made more accessible, this service remains an essential source of impartial information.

Would such voluntary arrangements raise competition issues? How might this change if private sector information sharing were mandated? Is authorisation (under the Competition and Consumer Act 2010 (Cth)) relevant?

Authorisations (under the *Competition and Consumer Act 2010*) can be relevant where the sharing of information would support collusion or other anticompetitive activity. However, current regulation focuses on the risks involved on the side of service providers and leaves unaddressed the potential for purchasers to use data to unfairly increase their market power.

The APHA regards it as important that contractual parties have recourse to protection from unreasonable demands for information sharing particularly when these demands entail:

- use of data for a purpose for which it was not intended and not designed
- administrative processes which impose an undue burden
- disclosure of data that is not relevant to the services being contracted
- disclosure of data through mechanisms that amount to third-line forcing.

One area where mandatory data provision could be useful is where there is acknowledgement by all stakeholders of the requirement for a minimum level of disclosure and where there is benefit to all stakeholders in establishing consistency in the data collected.

Private hospital sector information sharing has been mandated through the HCP, discussed above. One advantage of the HCP has been that data requirements have been standardised across the industry and with the help of industry, and protocols regarding this disclosure of data have been agreed.

Who should have the ownership rights to data that is generated by individuals but collected by businesses? For which data does unclear ownership inhibit its availability and use?

Private hospitals collect data from individuals in the following ways:

- Personal and confidential information is requested during the admission process to support administrative and clinical processes. Here private hospitals must meet their obligations under Commonwealth as well as state and territory (where applicable) privacy legislation.
- During a hospital admission, clinical data is gathered in the patient's medical record including test results, clinical observations and comments, decisions and directions recorded by treating clinicians.
- Advances in digital health mean that it is increasingly possible for individuals to use or wear devices that generate and/ or record clinical observations. The implications of such technologies in relation to data ownership and use have yet to be fully worked through

and are the subject of work currently being undertaken by the Australian Privacy Commissioner[2].

Individuals already have the right to request what data is collected or held about them from businesses under the Australian Privacy Principles. They can change or amend faulty data, however, they cannot necessarily have their data deleted.

Private hospitals need to collect data for treatment purposes, and to hold data for safety and quality and funding purposes. The ownership of this data is clear at collection, but may become murky as it is transferred on to health insurers or government-held collections. For these reasons it is imperative that the principles that govern the initial collection/ generation of data are adhered to as the data is transferred and subsequently used elsewhere.

Questions on consumer access to, and control over, data

Are regulatory solutions of value in giving consumers more access to and control over their own data?

The APHA believes that the current arrangements for consumer access under the Australian Privacy Principles (principle 12) are strong and should be maintained, subject to review of the cost of compliance as the quality and nature of data changes.

Related issues also arise through implementation of MyHealth Record. Several APHA members run private hospitals within the trial sites for the 'opt-out' approach (Northern Queensland and the Nepean Blue Mountains areas). The APHA may have further comment on this issue following completion of the trial process and as associated policies are further developed by the Australian Government.

[2] https://www.oaic.gov.au/individuals/faqs-for-individuals/health/access-to-health-information-in-the-private-health-sector#further-information

Questions on privacy protection

What types of data and data applications (public sector and private sector) pose the greatest concerns for privacy protection?

As raised in the Productivity Commission Issues Paper, one of the most acute privacy issues in health data is re-identification of individuals through data linkage.

The APHA agrees that it is essential to ensure the privacy of patients, and no relaxation in privacy measures should be agreed to around sensitive (health) data.

How can individuals' and businesses' confidence and trust in the way data is used be maintained and enhanced?

It is essential that government agencies responsible for data collection, linkage and sharing consult effectively with business prior to scoping and implementing new initiatives. Ideally these issues should be discussed between public and private sectors at both a strategic and an operational level. Central to every consultation should be the protection of commercially sensitive data and adherence to the terms under which data was originally provided.

Therefore, the APHA must be included in the development of a framework for any increased use, sharing or linkage of private hospital data, to ensure that private hospitals are consulted prior to data being distributed more widely.

Questions on other restrictions

Is there need for a more uniform treatment of commercial-in-confidence data held by the Australian Government and state and territory governments?

Any commercially-in-confidence data should not be published other than at an aggregate level. Data must be appropriately de-identified and no small cell sizes can be published. As indicated previously, the APHA regards any data that can be identified as pertaining to an individual hospital or corporate group as commercially sensitive.