



National Network of Private Psychiatric Sector Consumers and Carers

SUBMISSION ON THE REVIEW OF THE MEDICARE AND PHARMACEUTICAL BENEFITS PROGRAMS PRIVACY GUIDELINES

*ISSUES PAPER
NOVEMBER 2004*

INTRODUCTION

The *National Network of Private Psychiatric Sector Consumers and Carers* (National Network) represents Australians who contribute to private health insurance funds and who receive treatment and care for mental illnesses and disorders delivered within the Australian private sector.

The National Network welcomes this opportunity to make a submission to the *Review of the Medicare and Pharmaceutical Benefits Programs Privacy Guidelines* (the Guidelines). It also represents an opportunity to raise issues of concern for people directly involved in the receipt of services covered under Medicare and who receive their medications by way of the Pharmaceutical Benefits Schedule (PBS).

Privacy of sensitive health information is a basic right for all Australians and we believe the Privacy Commissioner, through this Review, is responding accordingly to concerns that have been raised. The National Network understands that, while privacy is of the utmost importance, it must be balanced against the prospect of better treatments and research into the efficacy of such treatments.

The National Network would welcome the opportunity to discuss any of the issues raised in this Submission and would like to work together with the Office of the Federal Privacy Commissioner (OFPC) in a positive way to ensure that those who will be most affected by the Review have direct input into it.

As a consumer and carer organisation, the first impression of the Issues Paper is that it is potentially too complicated to obtain proper input from the people that it is going to affect most. However, the National Network believes that we are in a position to speak on behalf of private mental health consumers and their carers.

The general view of the National Network is that the present provisions and privacy guidelines seem adequate. Our more specific comments on *Section D: Issues for Consideration*, are set out below.

SECTION D: ISSUES FOR CONSIDERATION

The health environment

The National Network holds concerns regarding the increasing use of electronic data collection and storage processes. We believe the greatest threat to the security and integrity of the information any database contains rests with the network administrators and the data custodians who administer such databases. As the health care sector is introducing faster, more powerful and more accurate computers and software packages, the need to safeguard the collection of an individuals' health information is of major concern to us, particularly for those people suffering from a mental illness. Sadly, mental health problems and disorders are still stigmatised and discriminated against by our society.

Separation of the databases

The National Network supports the functional separation of the Medicare claims database and PBS claims database. The National Network opposes any general linkage of the data contained in these databases or any co-location of these databases on the same computer. There must be restricted access to each respective database so that any one data custodian does not have access to both databases. If this is not presently included in the technical standards of the Health Insurance Commission (HIC), we strongly recommend amendments be made to ensure this security procedure is adopted.

The National Network notes that the HIC is required to specify the security procedures and controls, which have been included in each database, or in the system, to prevent unauthorised comparison or merging of records held in either database about the same consumer. We support these requirements.

In those situations where data linkage may be necessary, we believe that the technical requirements need to identify who has the capacity to link the two databases and specify under what special conditions the two databases can be linked. Further, we believe all access to linked data must be audited so that the following is clearly identified.

- The person or agency accessing linked data.
- When linked data was accessed.
- What period of time was this information in a linked format.

The National Network is concerned that weaknesses in database systems often stem from inadequate design of security processes and procedures. We seek reassurance that sufficient safeguards are present to address this in relation to the Medicare and PBS databases.

The National Network notes that, in the Issues Paper, reference is made to the fact that:

...generally, it is not possible to identify an individual's specific condition from Medicare claims data, which indicates visits to a health provider, but does not identify the medical condition.

Currently, one of the most discriminatory and sensitive requirements under Medicare relates to Medicare Benefits Schedule Item Number 319. Under this Item, the diagnosis of mental health consumers, who receive intensive long-term psychotherapy

treatment from highly trained psychotherapists, is provided to the Health Insurance Commission. This is particularly sensitive mental health information, which is not required for other diagnoses or conditions. The consumers treated under Item 319 quite rightly feel discriminated against. We seek the assistance of the Privacy Commissioner to address this situation, as this requirement serves no constructive purpose. The National Network believes it should cease immediately.

The other point we wish to bring to the Privacy Commissioner's notice is the reference in the Issues Paper to the fact that:

...it would not usually be possible to accurately determine from the HIC data alone, an individual's precise medical condition from PBS claims information data.

Again, the National Network believes that authorisation for the provision of particular medications, or particular doses of medication, is required to state a diagnosis for authorisation for that medication to be processed. We feel that this is a particular privacy issue that needs to be addressed by the Privacy Commissioner immediately.

The National Network considers that the restriction on the HIC to retain linked data for a three month period should be maintained in its present form. However, we also consider that in specific research circumstances and under very strict privacy guidelines, that an extension to the three months would allow for greater flexibility in relation to research into the efficacy of treatment processes, particularly in the mental health area.

Secondary uses of information

The National Network considers that privacy is of the utmost importance, but this must be balanced with the prospect of better treatment. We therefore consider that any information used for secondary purposes must be de-identified in all circumstances.

We support the basic privacy principle that personal and sensitive information should only be used for the purpose for which it was obtained.

If the secondary purpose is to track the efficacy of particular treatments, or monitor adverse side effects of medications detailed in the PBS data, or for any other purposes, then the consumer's written informed consent must be obtained prior to this occurring. We believe that the Guidelines could be amended to specific secondary uses of the information with this written informed consent as the security for such purposes.

Community attitudes

The National Network's constituency are consumers who suffer from a mental illness or disorder and their carers. Therefore, by the very nature of the health condition of our members and the people we represent, stigma is often present in some form or another. A mental health consumer's health information is highly sensitive and any disclosure can, and indeed often does, result in discriminatory practices. We need to safeguard people with mental illness and reassure them that information detailed in the Medicare and PBS databases will be secure now and in the future. If we don't, then people may fail to disclose critical information to health professionals, thereby increasing the risk of possible harm to themselves or others.

Consent and access

The submission of claims for Medicare and the dispensing of medications under the PBS and the data collected for this purposes takes the National Network back to the grass roots issue of privacy of health information. We believe this is a very important issue and needs further discussion.

We wish to bring to the attention of the Privacy Commissioner that, for people with certain mental illnesses and during the acute exacerbation of a mental illness, obtaining properly informed consent may be impossible. Under these circumstances, consumers do not have the capacity to understand the implications of what they are consenting to. Under each Australian State and Territories mental health acts, consumers can be admitted involuntarily for treatment and care against their will. With the expectation that consent could be sought from these consumers at this time would be a gross misunderstanding of the mental health sector.

The National Network agrees with the Issues Paper in that the key elements to consent are that it must be voluntary, the individual giving consent must be adequately informed and they must have the capacity to understand, provide and communicate their consent. This understanding of the mental health sector and the application of this principle to the recipients of that care is crucial.

Data retention

The National Network recognises that legal claims associated with this information make a case for the retention of de-identified data for a longer period than the five years at present. We also recognise that the very nature of the care received in the mental health sector can be very long and protracted. Indeed some consumers receive psychiatric care for many years, far beyond the five year limit noted in the Issues Paper for this situation. The Privacy Commissioner also needs to be aware that the very nature of the therapeutic relationship between the therapist and the consumer in psychiatric care is unique to health care. It is, therefore, quite possible that legal implications surrounding psychiatric care could indeed extend for a far greater period of time. The National Network does, however, believe that as the records are stored in the Department indefinitely, then the retention of data by the HIC beyond the five years is not required. Should there be a case for the extension of the period beyond the five years, then the National Network would want implicit reassurance that the safety and control of the information is not corrupted.

Ease of use of the Guidelines

The National Network considers that any Guidelines should follow the principle of plain English, simple and explicit explanation of the issues and that consumers have a proper understanding of their rights and how their privacy is maintained.