Guidance on client consent for the provision of PMHC MDS data to the Department of Health and Aged Care and state and territory health departments/agencies

Version 2, updated 30 April 2024

In 2023, the department undertook an updated Privacy Impact Assessment (PIA) for the Primary Mental Health Care Minimum Data Set (PMHC MDS) to support the implementation of data sharing commitments outlined in National Mental Health and Suicide Prevention Agreement (clause 90). The PIA made several recommendations including:

- establishing data sharing agreements with the states and territories
- updating the current consent guidance to reflect state and territory access to the data as well as the use of personal information to generate an alpha-numeric linkage key which can be used to facilitate research and statistical analysis by linking de-identified PMHC MDS data with other de-identified data.
- the development of a new Data Access Protocol.

PHNs, intake providers, service providers, the department and state and territory health departments/agencies are each subject to their own obligations under the Privacy Act in relation to the collection, use and disclosure of the personal information of clients.

This guidance is mainly concerned with the access to data for the Commonwealth and state and territory health departments/agencies, and the role that PHNs play in facilitating this.

The department and state and territory health departments/agencies require access to information about clients to produce statistical reports and help improve the planning and funding of mental health care services funded by the Commonwealth and State and Territory Governments. Given that PHN intake and service providers are best placed to collect personal information from clients, the department relies on PHNs to facilitate access to required information by obtaining client consent and notifying the clients of certain matters as required by APP 5.

General guidance in relation to specific issues commonly raised is provided below. It must be noted that this is general guidance only and PHNs are advised to seek their own legal advice in relation to their obligations under the Privacy Act, if required.

(a) Can PHNs collect the required MDS data?

Under APP 3, an organisation can collect sensitive information (e.g. health information) where it is reasonably necessary for, or directly related to, its functions or activities, and the individual concerned consents to the collection, or another exception applies.

The “primary purpose” for which PHNs originally collect personal information about clients in the PMHC MDS can be broadly expressed as supporting the role of PHNs managing commissioned services. Use or disclosure by the PHNs of personal information for the secondary purpose of national information would require the individual’s consent.

As commissioners and regional planners, PHNs require a range of data to remunerate service providers as well as monitor overall regional service provision and plan future service improvements. These are all core functions of PHNs and require that PHNs collect and analyse data on what services are delivered, to what clients, at what costs and with what outcomes. Without data, PHNs cannot undertake these functions.

Additionally, most PHNs have set up centralised referral coordination points to which the GP or other referrer forwards client and referral details. This centralised function allows referrals to be processed and services selected to match the client's needs as well as giving the PHN an efficient method for managing demand.

In line with the Privacy Principles and the PIA, the department expects that the PHNs will continue to collect and upload all non-consented client data into the regional data repository. The department and State and Territory health departments do not have access to the personal information in the regional data repository, only summary reports.

(b) Can PHNs supply the data to the Department of Health and Aged Care and state and territory health departments/agencies?

Provision of information to the department and state and territory health departments/agencies is necessary for governments to undertake their role in funding, monitoring and planning future service delivery.

Supply of personal information collected by PHNs to the department and state and territory health departments/agencies is governed by APP 6 which regulates how an organisation may use and disclose the health information that it collects. Under APP 6, if an organisation collects health information for a particular or 'primary purpose', it generally cannot use or disclose that information for a 'secondary purpose' unless an exception applies. A specific exception under APP 6 allows personal information to be used or disclosed for a 'secondary purpose' where there is client consent.

To comply with APP 3, the department is required to obtain the consent of clients before collecting health information. The department relies on PHNs to obtain this consent from a client. An item is included in the PMHC MDS to confirm that client consent for supply of their personal information to the department and state and territory health departments/agencies has been obtained. Any personal information attached to clients for whom the consent flag is not checked as 'yes' will not be passed to the department or state and territory health departments/agencies.

PHNs should therefore, by **30 April 2024**, ensure that the consent documents and processes they establish include client consent to the provision of personal information to the Australian Government Department of Health and state and territory health departments/agencies.

It is important to note that consent is not required where data supplied by PHNs to the department and state and territory health departments/agencies does not include personal information. This applies, for example, to PMHC MDS Standard Reports that present aggregated, summary statistics on activities commissioned by each PHN.

Consent

Guidance on the definition and approach to consent is provided at **Attachment A** and derived from APP guidelines.

Suggested wording for obtaining consent

Generally, consent is obtained by the referrer, and in some cases, the health practitioner to whom the patient is referred. However, specific responsibilities for this will vary according to the referral and service delivery arrangements established within each region. Consent must be current and specific.

PHNs should ensure that their referral and other forms created to obtain client consent includes wording along the following lines:

> *"I consent to my personal information being provided by [insert PHN name] to the Department of Health and Aged Care, and state and territory health departments/agencies to be used for statistical and evaluation purposes designed to improve mental health services in Australia. I understand that this will include details about me such as date of birth and gender but will not include my name, address or Medicare number. I understand this includes the use of personal information to generate a unique key, which can be used to link my de-identified data to other de-identified data to facilitate research. I understand that my personal information will not be provided to the Department of Health and Aged Care or state and territory health departments/agencies if I do not give my consent.*
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> *I also understand that my consent is not required for the Department of Health and Aged Care and state and territory health departments/agencies to include data about my use of services, combined with information about other clients, in summary reports about the activities funded by (insert PHN name) because these do not require personal information."*
>
> *"For more information on how the Department of Health and Aged Care and state and territory health departments/agencies use your data please refer to the consumer FAQ [insert link]"*

The above consent is intended to cover the department's collection of personal information, and to facilitate this, the PHN's disclosure of that information to the department and state and territory health departments/agencies.

Suggested wording for informing clients of APP 5 matters

APP 5 concerns the notification of the collection of personal information and requires the department to take reasonable steps to ensure that clients are notified of the matters listed in APP 5.2 before collecting personal information (e.g., the purposes for the collection, any other entity to whom the information is disclosed).

Many PHNs have consumer information brochures that explain the services offered. These provide a useful format to assure the client about the confidentiality of their information and its protection under Australia's privacy laws, and notify clients of APP 5 matters. The department is aware that several PHNs have used their information brochures in this way.

Where advice about privacy and confidentiality are included on information brochures, or as part of the consent process, the department suggests the following wording as possibly suitable for local use or adaptation to suit your PHN referral and data collection arrangements. This suggested wording is intended to complement the PHN's existing information (in relation to the Departmental use of the data), not replace it.

> *"Your GP/(other referrer) has referred you to the (PHN name) for services to support your mental health and wellbeing. Services provided under this program will require your GP/(other referrer) to provide some information to (PHN name) and health professionals involved in your care to ensure that you are referred to the service that best suits your needs. Your consent is required for this to occur.*
>
> *Mental health services funded through the (PHN name) undergo regular review and evaluation by the Department of Health Aged Care which are aimed at informing ongoing service improvements.*

This is a requirement of all Primary Health Networks across Australia. To enable the Department of Health and Aged Care and state and territory health departments/agencies to conduct the regular review and evaluation of mental health services, (PHN name) provides data about services and clients to the Department of Health Aged Care.

Some of the data provided to the Department of Health Aged Care includes personal information such as date of birth and gender. The information provided does not include your name, address or Medicare number. Your personal information will only be provided by [PHN name] to the Department of Health and Aged Care and state and territory health departments/agencies if you give your consent. If you do not give your consent your personal information will not be provided.

The Department of Health and Aged Care and state and territory health departments also uses data collected by (insert PHN name) to facilitate data linkage and produce statistical and evaluation reports, which are based on summary statistics for our region. These statistical reports contain only combined information from many clients and will not identify any individual. Your consent is not required for the Department of Health and Aged Care and state and territory health departments to include your data in these summary statistics.

Protecting your privacy

(PHN name) is committed to providing you with the highest level of service and confidentiality, and this includes protecting your privacy. (PHN name) is bound by the Commonwealth Privacy Act 1988 and the Privacy Amendment (Private Sector) Act 2000, which outlines the principles concerning the protection of your personal information.

Attachment: APP Guidelines on Consent

The APP guidelines (https://www.oaic.gov.au/agencies-and-organisations/app-guidelines/) while not legally binding outline how the Office of the Australian Information Commissioner (OAIC) interprets the Australian Privacy Principles when exercising powers under the Privacy Act.

According to APP guidelines, *Chapter B: Key Concepts, Consent* - The four key elements of consent are:

1. The individual is adequately informed before giving consent
2. The individual gives consent voluntarily
3. The consent is current and specific, and
4. The individual has the capacity to understand and communicate their consent.

Guiding principles relating to consent are as follows:

- Express consent is given explicitly, either orally or in writing. This could include a handwritten signature, an oral statement, or use of an electronic medium or voice signature to signify agreement.
- It should not be assumed that an individual has given consent on the basis alone that they did not object to a proposal to handle personal information in a particular way.
- An APP entity should generally seek express consent (as opposed to implied consent) from an individual before handling the individual's sensitive information, given the greater privacy impact this could have.
- An APP entity should ensure that an individual is properly and clearly informed about how their personal information will be handled.
- Information should be written in plain English, without legal or industry jargon.
- An APP entity should seek consent at the time the information is collected.
- Do not seek a broader consent than is necessary for its purposes.
- An individual may withdraw their consent at any time, and this should be an easy and accessible process.
- An individual must have the capacity to consent. The entity may presume that an individual aged 15 and over has capacity to consent unless there is something to suggest otherwise.

Verbal consent is a form of express consent where a person or a person responsible for another person, says, for instance, they consent to *information being provided by [insert PHN name] to the Department of Health*. Verbal consent should be documented and witnessed in the event that consent is contested, and if possible, verbal consent should be followed up with written consent at a later date.

Written consent is where a person or a person responsible for another person, provides written evidence of their consent to do something or for something to happen, for instance written evidence of their consent to *information being provided by [insert PHN name] to the Department of Health* through signing a consent form.