

Primary Mental Health Care Minimum Data Set FAQs for consumers

This FAQ was developed for PHNs and their commissioned service providers to share with clients to explain the Primary Mental Health Minimum Data Set and how data are collected, stored and used.

Questions	Answer
Q1. Why are my data collected and how are they used?	<p>As part of providing services to you, your mental health service provider will collect some information about you and the services you are accessing. This will be kept by the provider and will be primarily used to keep up-to-date details about your needs. This data also helps your service provider understand how their mental health services are being used, so they can work to improve those services.</p> <p>Your personal information will not be shared with anyone apart from you, your service provider, and your Primary Health Network (PHN), which funds your service provider. Your information will not be disclosed to any other person, organisation or agency, unless you consent, or where disclosure is authorised or required under privacy law (such as in the case of a medical emergency).</p> <p>Your service provider stores data to ensure they can provide the best possible services. If you give consent, your de-identified data will be provided to the Australian Government Department of Health (Health) to help them monitor and evaluate the services that are provided to you. They may also use your data to help improve the planning and future funding of mental health care services by the PHN and Health.</p>
Q2. What is a Primary Health Network (PHN)?	<p>PHNs were established by Health to fund health services in your local community, including your mental health service provider. More information about PHNs can be found on the Health website at: https://www.health.gov.au/initiatives-and-programs/phn</p> <p>PHNs collect data about the services you receive to help with future planning for health services, and to improve the quality of mental health services in your local area.</p>

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<p>Q3. What happens to my data?</p>	<p>If you have given consent, your data will be provided electronically to Health through the Primary Mental Health Care Minimum Data Set (Data Set). The data are de-identified by removing personally identifying information, such as your name and address, before they are provided to Health.</p> <p>The data are stored securely in Australia by an IT organisation called Strategic Data, which has been contracted by Health to manage the Data Set securely on its behalf.</p> <p>For further details about the de-identification of data, please see question 11.</p> <p>If you do not consent for your data to be included in the Data Set, certain information about your service will still be collected and used in summarised reports. Health use this information to understand the overall number and types of services being provided. You will not be able to be identified from these reports.</p>
<p>Q4. Who can access it?</p>	<p>Your data can be accessed by:</p> <ul style="list-style-type: none"> • Your mental health service provider – The organisation who is providing your care. They work in partnership with your local Primary Health Network (PHN). • Your local PHN – This organisation is funded by Health to engage mental health services from suitable health service providers in your local area. They are responsible for ensuring services are effective, efficient and meet clients' needs. • Health – From time to time, Health may share the data with third parties for the purpose of program evaluation. Where this is the case, additional protections are put in place to ensure your privacy. • Strategic Data – This organisation manages the secure IT system where your data are stored and protected. Your data is stored securely in Australia. Trained and authorised analysts at Health use the data by accessing this secure IT system.
<p>Q5. Can I change my consent?</p>	<p>Yes. You can choose to change or withdraw your consent for Health to access your data through the Data Set at any time. Please contact your service provider if you wish to change or withdraw your consent.</p>
<p>Q6. What data are collected?</p>	<p>When your data are added to the Data Set, Health collects and securely stores information from your service provider about: your service provider organisation, the practitioner who is delivering services to you (not including their name), and the services they provided. This may also include the following information about you:</p> <ul style="list-style-type: none"> • Your date of birth • Your gender • Your marital status • Whether or not you identify as Aboriginal and Torres Strait Islander • Your country of birth and main language spoken at home • Your postcode and type of residence • Information about your employment and source of income, including if you receive any pensions or benefits • Whether you have a health care card, or are participating on the National Disability Insurance Scheme (NDIS) • Date of your referral and who referred you

	<ul style="list-style-type: none"> • Whether you have a GP Mental Health Treatment Plan (if applicable) • Your main mental health diagnosis, and any other diagnoses • Whether or not you are taking certain types of medications for a mental health condition. <p>Your service provider may also provide your results from one (or more) outcome questionnaires, which will help to determine if their services are working for you.</p>
Q7. Can I refuse to answer any questions?	Yes. Even if you have provided consent for your data to be shared with Health, you do not have to provide any information you don't feel comfortable with sharing. This includes using a pseudonym (a made-up name), if you wish.
Q8. Can I still access services if I do not consent to sharing my data?	Yes. You do not have to provide consent to share your data in order to receive services. If you prefer not to have your data shared, please contact your service provider. Your service provider will continue to provide services to you, even if you choose for your data to not be provided to Health.
Q9. Where does my data go?	When your data are sent to the Data Set, they are held in a secure data storage system (managed by Strategic data) which is housed in Australia. Only authorised people will be able to see your data.
Q10. What is the role of the Australian Government?	The Australian Government, through Health, funds PHNs to commission health services in your local area. The Australian Government uses data about PHN funded service delivery to monitor and evaluate whether PHNs are achieving their goals, and to assist in improving mental health services in Australia.
Q11. What does it mean that my data are de-identified? Can I be identified from my data?	<p>When your data are de-identified, this means that information with direct identifiers such as your name, address and Medicare number are excluded, and only information like your date of birth, gender, and the types of services you received records are collected.</p> <p>Removing this information makes it extremely unlikely that you will be identified, however that does not mean there is no possible way for you to be identified. To provide additional protections, Health has a range of security controls in place to protect its data from unauthorised access such as restricted IT security and only providing access to authorised users for approved purposes. Health puts protections in place to ensure any use of the data does not seek to identify you.</p>
Q12. Who do I contact if I have any questions?	If you have any questions about the use of your data, please contact your service provider.
Q13. Can I have my data removed/deleted from the Data Set?	Yes. If you withdraw your consent, no further information will be added to the Data Set. However, as data in the Data Set does not contain information that can be used to identify you, only your service provider can remove or edit your individual data.
Q15. What is good about agreeing to provide data?	The data that are collected through the Data Set plays an important role – it helps plan services and programs to improve mental health care in Australia. The data are also used to evaluate programs and services, to find out how well they are working and what needs to be done to make them work better.
Q16. What does 'informed consent mean'?	In this context, informed consent means that you clearly understand why your information is being collected and how it will be handled. It also means that you agree to your data being provided to the Data Set.

	<p>Providing consent for your data to be provided to Health should always be voluntary. It is important that you are given adequate information about the use of your information before you provide consent. If you are under the age of 18, your service provider will be able to determine your capacity to consent. Informed consent for people under the age of 15 must be obtained from a parent or authorised caregiver. Please ask your service provider if you need any further information to make an informed decision.</p> <p>If you do not consent for your data to be included in the Data Set, certain information about your service will still be collected and used in summarised data reports. These reports help Health understand the overall number and types of services provided. You will not be able to be identified from these reports.</p>
<p>Q17. Where are my data stored?</p>	<p>Your data may be stored in up to four places, depending on who you consent to sharing your data with, including:</p> <ul style="list-style-type: none"> • In a secure client information management system. This is a type of medical/health records system owned either by your PHN or mental health service provider. • In your PHN's secure data storage systems • In Strategic Data's secure data storage systems • In Health's secure data storage systems (only if you consent). <p>All data held by Brisbane North PHN, Health and Strategic Data are stored in Australia</p>