

## Primary Mental Health Care Minimum Data Set FAQs for Clients

These FAQs were developed for Primary Health Networks (PHNs) and their commissioned service providers (KYDS) to share with clients to explain the Primary Mental Health Care Minimum Data Set (PMHC MDS) and how data is collected, stored and used.

Questions	Answer
<b>Q1. Why is my data collected and how is it used?</b>	<p>As part of providing services to you, KYDS will collect some information about you and the services you are accessing. This will be kept by KYDS and will be primarily used to keep up-to-date details about your needs. This data also helps KYDS understand how their mental health services are being used, so they can work to improve those services.</p> <p>Your <b>personal information</b> will not be shared with anyone apart from you, KYDS and your Primary Health Network (PHN), which funds KYDS. 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). KYDS stores data to ensure they can provide the best possible services.</p> <p>If you give consent, your <b>de-identified information</b> will be provided to the Australian Government Department of Health and Aged Care (the department), and state and territory health departments/agencies, to help them monitor and evaluate the services that are provided to you. When your data is de-identified, <b>your name, address and Medicare number are removed</b>. See question 11 for a more detailed explanation of de-identification.</p> <p>The department and state and territory governments may combine the de-identified information provided with other data they hold, but only if this is allowed under privacy and other laws. Your de-identified information may be combined using unique codes. These codes enable information about you from different data sources to be combined without individually identifying you. These bodies will make sure that <b>you cannot be individually identified</b> in any research findings, reports or other outputs from their work.</p>

<p><b>Q2. What is a Primary Health Network (PHN)?</b></p>	<p>PHNs were established by the department to fund health services in your local community, including your mental health service provider. More information about PHNs can be found on the department's website at:  <a href="#">Primary Health Networks   Australian Government Department of Health and Aged Care</a>.</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>
<p><b>Q3. What happens to my data?</b></p>	<p>If you have given consent, your data will be provided electronically to the department and state and territory health departments/agencies through the Primary Mental Health Care Minimum Data Set (Data Set). The data is de-identified by removing personally identifying information, such as your name and address, before they are provided.</p> <p>The department and state and territory governments may combine the de-identified information provided with other data they hold, but only if this is allowed under privacy and other laws. Your de-identified information may be combined using unique codes. These codes enable information about you from different data sources to be combined without individually identifying you. These bodies will make sure that you cannot be individually identified in any research findings, reports or other outputs from their work.</p> <p>The data is stored securely in Australia by an IT organisation called Logicy, which has been contracted by the department to manage the Data Set securely on its behalf.</p> <p>Data may also be stored by KYDS and/or your PHN in their client information systems. If you would like more information about how your data is used and stored, please ask KYDS for more details about their data storage and privacy policies. For further information please refer to the KYDS Privacy Policy at <a href="https://www.kyds.org.au/privacy-policy/">https://www.kyds.org.au/privacy-policy/</a>.</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. The department and state and</p>

	territory health departments/agencies 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.
<b>Q4. Who can access it?</b>	<p>Your data can be accessed by:</p> <ul style="list-style-type: none"> <li>• KYDS - They work in partnership with your local Primary Health Network (PHN).</li> <li>• Your local PHN – This organisation is funded by the Department of Health and Aged Care (the department) to fund 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.</li> <li>• The department – to understand the overall number and types of services being provided and to help improve the planning and future funding of mental health care services. Trained and authorised analysts at the department use the data by accessing this secure IT system. From time to time, the department 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 is protected.</li> <li>• State and territory health departments/agencies – to understand the overall number and types of services being provided and to help improve the planning and future funding of mental health care services.</li> <li>• Logically – This organisation manages the secure IT system where your data are stored and protected. Your data is stored securely in Australia.</li> <li>• The Australian Institute of Health and Welfare (AIHW) – to understand overall number and types of services being provided.</li> </ul>
<b>Q5. Can I change my consent?</b>	Yes. You can choose to change or withdraw your consent for the department and state and territory health departments/agencies to access your data through the Data Set at any time. Please contact KYDS if you wish to change or withdraw your consent and your data will be removed from the Data Set.
<b>Q6. What data is collected?</b>	When your data is added to the Data Set, the department collects and securely stores information from KYDS about: KYDS, the practitioner who is delivering services to you

	<p>(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"> <li>• Your date of birth</li> <li>• Your gender</li> <li>• Your marital status</li> <li>• Whether or not you identify as Aboriginal and Torres Strait Islander</li> <li>• Your country of birth and main language spoken at home</li> <li>• Your postcode and type of residence</li> <li>• Information about your employment and source of income, including if you receive any pensions or benefits</li> <li>• Whether you have a health care card, or are participating in the National Disability Insurance Scheme (NDIS)</li> <li>• Date of your referral and who referred you</li> <li>• Whether you have a GP Mental Health Treatment Plan (if applicable)</li> <li>• Your main mental health diagnosis, and any other diagnoses</li> <li>• Whether or not you are taking certain types of medications for a mental health condition.</li> </ul> <p>KYDS may also provide your results from one (or more) outcome questionnaires, which will help to determine if their services are working for you.</p>
<p><b>Q7. Can I refuse to answer any questions?</b></p>	<p>Yes. Even if you have provided consent for your data to be shared with the department and state and territory health departments/agencies, 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.</p>
<p><b>Q8. Can I still access services if I do not consent to sharing my data?</b></p>	<p>Yes. You do not have to provide consent to share your data 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 the department and state and territory health departments/agencies.</p>
<p><b>Q9. Where does my data go?</b></p>	<p>When your data is sent to the Data Set, they are held in a secure data storage system (managed by Logicy) which is housed in Australia. Only authorised people will be able to see your data.</p>

<p><b>Q10. What is the role of the Government?</b></p>	<p>The Government through the Department of Health and Aged Care (the department) and State and Territory health departments fund PHNs to fund health services in your local area. These Governments use 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.</p>
<p><b>Q11. What does it mean that my data is de-identified? Can I be identified from my data?</b></p>	<p>When your data is 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 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, the department 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. The department puts protections in place to ensure any use of the data does not seek to identify you.</p>
<p><b>Q12. Who do I contact if I have any questions?</b></p>	<p>If you have any questions about the use of your data, please contact KYDS. For further information please refer to the KYDS Privacy Policy at <a href="https://www.kyds.org.au/privacy-policy/">https://www.kyds.org.au/privacy-policy/</a>, contact <a href="mailto:info@kyds.org.au">info@kyds.org.au</a> or phone (02) 9416 0900 and ask for the Privacy Officer.</p>
<p><b>Q13. Can I have my data removed/deleted from the Data Set?</b></p>	<p>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.</p>
<p><b>Q14. Can my data be shared with other departments e.g. Centrelink?</b></p>	<p>The Government may share data reports with other government departments and organisations from time to time. De-identified data may also be linked with other de-identified data as discussed in Q3. However, data is only used for monitoring service performance, and to facilitate research to improve the planning and funding of future mental health services.</p>
<p><b>Q15. What is good about agreeing to provide data?</b></p>	<p>The data that is collected through the Data Set plays an important role – it helps government departments/agencies and PHNs plan services and programs to improve mental health care in Australia. The data is 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.</p>

<p><b>Q16. What does 'informed consent mean'?</b></p>	<p>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> <p>Providing consent for your data to be provided to the department and state and territory health departments/agencies 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, KYDS 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 KYDS 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 the department and state and territory health departments understand the overall number and types of services provided. You will not be able to be identified from these reports.</p>
<p><b>Q17. Where is my data stored?</b></p>	<p>Your data may be stored in several places, depending on who you consent to sharing your data with, including:</p> <ul style="list-style-type: none"> <li>• In a secure client information management system. This is a type of medical/health records system owned either by your PHN or KYDS.</li> <li>• In your PHN's secure data storage systems</li> <li>• In Logicy's secure data storage systems</li> <li>• In the department's secure data storage systems (only if you consent).</li> <li>• In the secure data storage systems of state and territory governments (only if you consent)</li> </ul> <p>All data held by the department and Logicy is stored in Australia.</p> <p>Please contact Sydney North Health Network for additional information.</p>