



Programme for the Integration of Mental Health Data



MANATŪ HAUORA

Information and utility resource

Influencing the broader sector and workforce to improve the quality of the data collected in Programme for the Integration of Mental Health Data (PRIMHD)

Purpose

This resource will help improve the consistency of the collection, input and use of Project for the Integration of Mental Health Data (PRIMHD) data. It is designed to be used as a resource for those delivering PRIMHD training in district health board (DHB) and non-government organisation (NGO) settings, as well as for the workforce directly involved with collecting, inputting and using PRIMHD data.

Sections 1 and 2 of this resource were compiled and written by Cara Thomas and Paul Hanton from Te Pou o Te Whakaaro Nui. Section 3 was compiled and written by Phillipa Gaines (Platform Trust), Malcolm Stewart (Clinical Psychologist and Consultant - Thrive Psychology, Auckland) and Patrick Firkin (Auckland DHB).

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Note that the terms 'tangata whai ora' and 'tāngata whai ora' (plural) are used throughout this resource, and are intended to be incorporate all other terms used to describe people who access services, including service users, clients and consumers.

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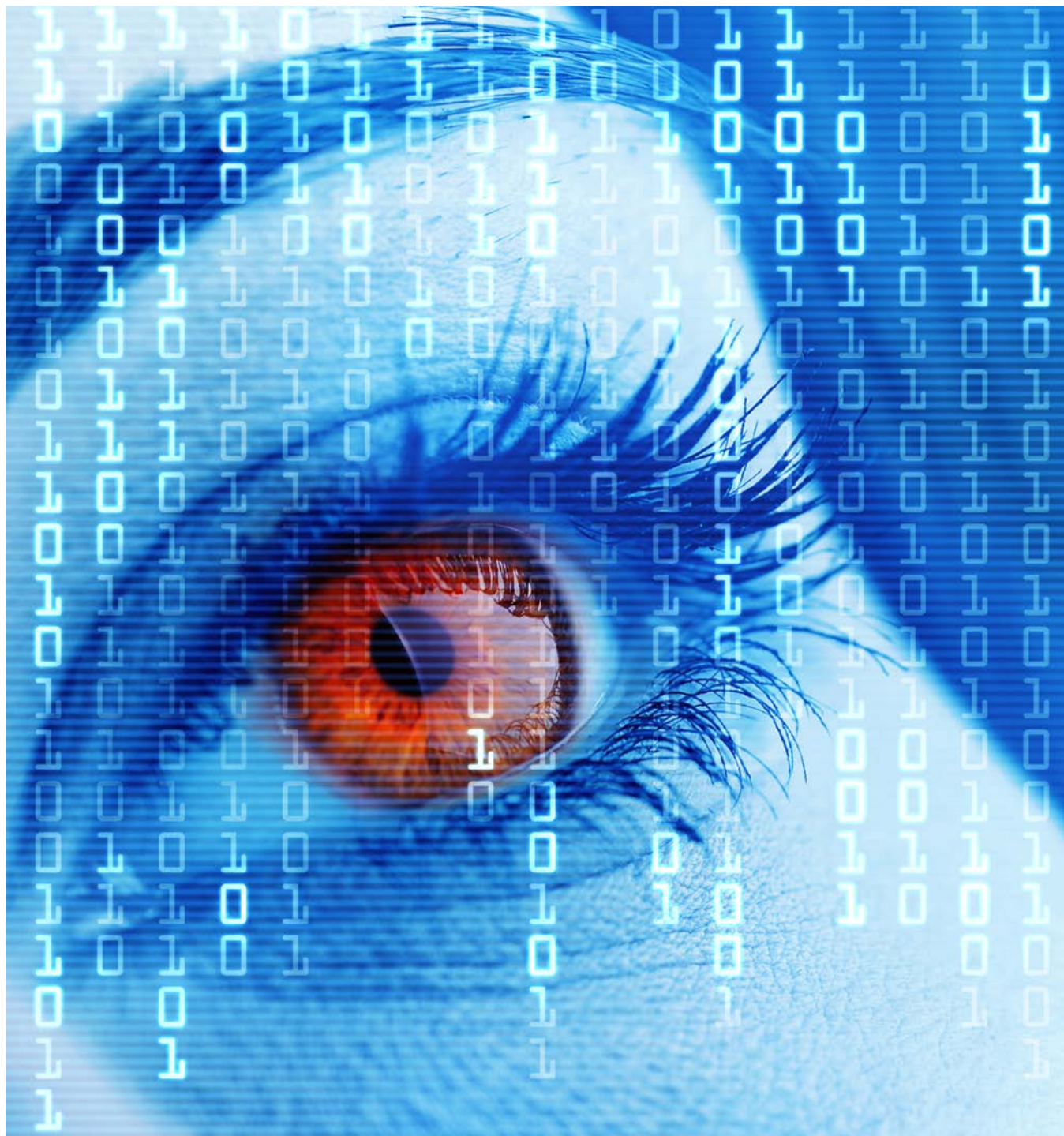
Overview

This resource has been specifically designed to help the workforce better understand the way their work with tātanga whai ora is mirrored in PRIMHD, how this information is collected, and used for the benefit of tātanga whai ora.

Where appropriate, this resource also gives definitions, clarifies business rules and provides links to additional recommended resources that will help improve understanding and consistency of PRIMHD data.

It is recognised that there are variations to practice, based on local, regional and information system variance. Trainers are encouraged to use and promote this resource when delivering training and apply to their local context.

This resource has a central infographic to enable users to easily find the information that is relevant to them.



Section 1: PRIMHD

The purpose of PRIMHD

The Programme for the Integration of Mental Health Data (PRIMHD) is a tāngata whai ora-centric database, designed to capture a range of services (interventions or activities) that are being delivered to tāngata whai ora by contracted mental health and addiction providers. The primary objective of PRIMHD is to obtain a national picture of the services being delivered to tāngata whai ora and how this pattern is changing over time.

PRIMHD data is also used to report on what outcomes are being achieved for tāngata whai ora across New Zealand's mental health and addiction sectors. These reports enable better quality service planning and decision-making by mental health and addiction service providers at the local, regional and national levels.

PRIMHD represents only those activities that are clinically or otherwise significant to a tāngata whai ora service journey. It is not a contract or performance monitoring database. Individual provider information systems may have the capacity to collect a broader range of staff activities, for example the travel time associated with an activity. PRIMHD does not capture information about everything that a staff member does while they are at work.

The vision for PRIMHD at a systems level is to help improve the health outcomes for all mental health and addiction tāngata whai ora in New Zealand, by providing a single data source of national mental health and addiction information that can be used for multiple purposes.

Historical development

PRIMHD was developed by the Ministry of Health to combine data from the legacy Mental Health Information National Collection (MHINC) database with a separate collection of local DHB outcome data (aka MH-SMART).

All DHBs and all eligible mental health and addiction NGOs have been required to submit data to PRIMHD since 1 July 2008. Given that many eligible NGOs did not have the necessary infrastructure to collect and submit data straight away, any analysis that relies on data for the 2008 to 2012 period needs to take into consideration the fact that the national collection was going through a significant process of redevelopment. Data quality has improved in recent years as both DHBs and NGOs have gained experience in collecting and using PRIMHD data, particularly as a result of the benchmarking activity undertaken under the auspices of the National Key Performance Indicator Programme.

PRIMHD goals

The PRIMHD data can be aggregated and used to inform, shape and improve planning, funding and delivery of mental health and addiction services. Some of the questions that PRIMHD data can help answer or inform are:

- What health care services are being provided around the country?
- How well integrated are these services?
- Are the services being provided to the people who most need them?
- What are the outcomes for tāngata whai ora who are seen by these services?
- Is the national policy direction for these services still relevant?

Some PRIMHD basics

Who collects the information?

The frontline workforce collects most of the data that is entered into PRIMHD. Administrative staff may also collect some data that is not related to direct service delivery, such as tāngata whai ora National Health Index (NHI), demographic and domicile information.

What information is collected?

Mental health and addiction services must comply with the business rules and specifications set out in the Ministry of Health's PRIMHD documentation. See [recommended links and resources](#) for details of these requirements.



PRIMHD information includes (but is not limited to):

- demographic data (age, ethnicity, gender, location)
- referral details (date and referral source, plus any onwards referral information)
- diagnosis
- service activity in relation to the types of service provided to the person (such as face-to-face sessions, telephone calls, bed nights and leave)
- outcome data (currently focused on outcome measures, such as the Health of the Nation Outcome Scale (HoNOS) and the Alcohol and Drug Outcome Measure (ADOM))
- Social Outcome indicators for tāngata whai ora.

All of the above information is collected using PRIMHD 'codes'. Please refer to *The Guide to PRIMHD Activity Collection and Use* for further details.



What information is not collected?

PRIMHD collects data about those services that are provided to tāngata whai ora and their whānau. There are other important activities that staff are engaged in which are not captured in PRIMHD (such as community liaison activities or training). For this reason, many organisations have patient management systems (PMS) that collect local data for their own service planning and improvement purposes that is not reported to PRIMHD.

When is information collected?

Information is collected at various stages throughout the tangata whai ora journey, commencing at the point of referral to a service. Service activity data is subsequently collected at each point of contact with the tangata whai ora until such time as they are discharged from the service. It should be noted that tāngata whai ora can be receiving services from more than one organisation concurrently, and that all information is captured.

Mapping process

Each organisation is unique in the way its service or services are configured, and what PRIMHD codes are used to map those services. In order to match the organisation's teams and services to the national PRIMHD code set, the organisation will have completed a PRIMHD mapping document. This document is developed in agreement with their planner, funder or portfolio manager and, where relevant, a site coordinator or PRIMHD champion. A PRIMHD site coordinator or champion is someone who has demonstrated expertise in PRIMHD and he/she is used as a local resource.

When is information entered?

Each service or organisation will be aware of when the information needs to be entered to ensure it is forwarded to PRIMHD (and by proxy, funders) within the expected timeframes (generally monthly).

Who uses the PRIMHD information?

- Service providers.
- The Ministry of Health.
- DHB planners and funders.
- Researchers.
- The National KPI Programme.

What does your organisation do with the data?

Other uses of the data that is collected in your organisation's own PMS include:

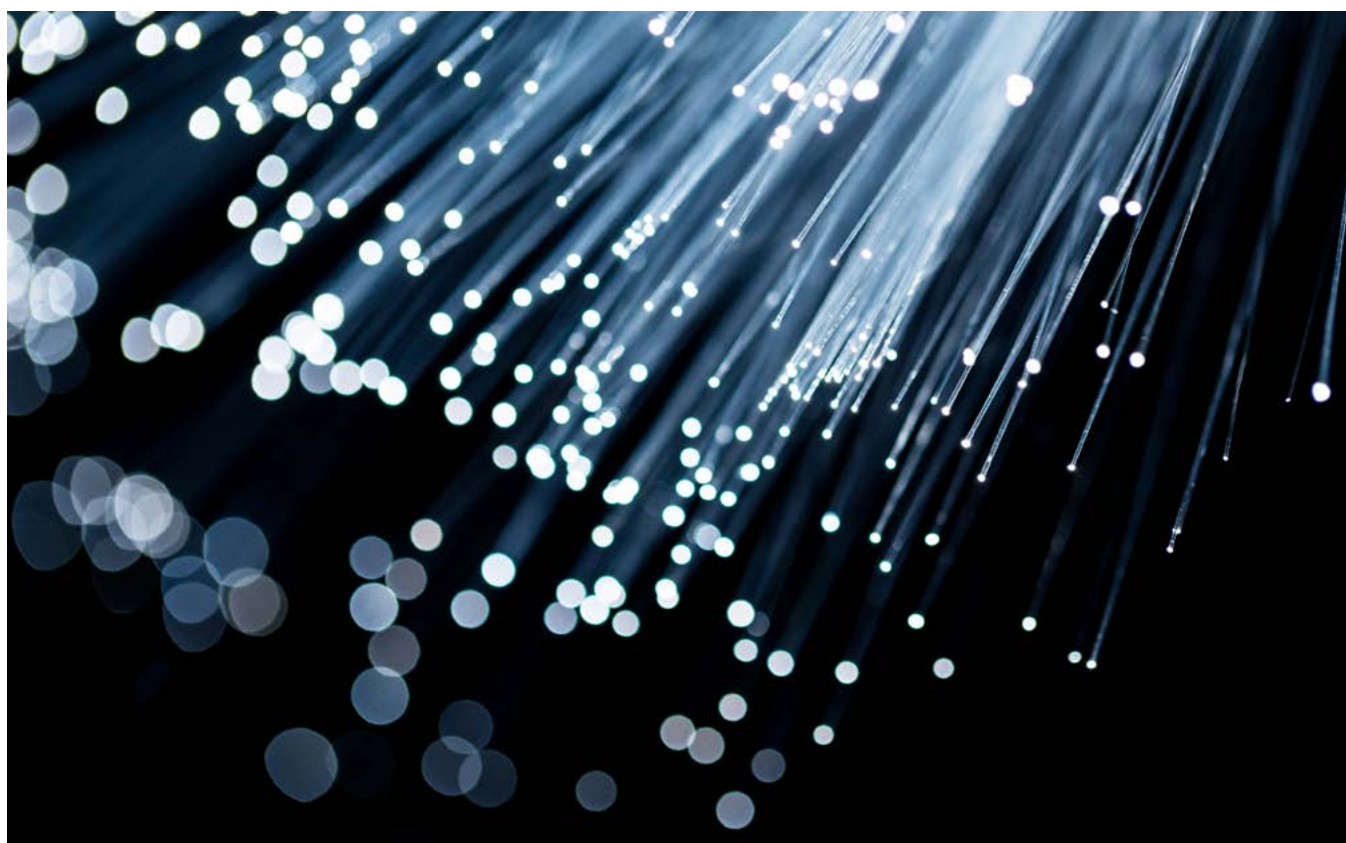
- as an audit trail of information directly related to the care of tāngata whai ora
- for organisational board reports, organisational service planning, monitoring, evaluation and service improvement
- to meet DHB reporting and other accountability requirements (such as PRIMHD or Ministry of Social Development contracts and key performance indicators (KPIs)).



Underpinning principles

Some fundamental principles/rules apply when recording and submitting data to PRIMHD.

1. Recording is always about the tangata whai ora service journey and not the clinician's input.
2. All recorded contacts and activity must be attached to the mental health or addiction team that provided the care.
3. Only activity that is clinically significant and tangata whai ora-centred should be recorded. Patient management systems are not primarily for maintaining time sheets or monitoring clinicians/practitioners. Activity that is not clinically significant does not get recorded, for example; insignificant telephone calls, note taking, reading or computer time. Some organisations may record this additional information, but it should not be included in PRIMHD data. Please refer to *The Guide to PRIMHD Activity Collection and Use* for further details.
4. Wherever practical, all clinically significant activity that occurs and is recorded in a paper or electronic file should be matched with an appropriate contact or activity record in your patient management system.
5. Where several things occur at once (in the same visit or event), choose the most appropriate or significant purpose of the contact. For further information refer to *The guide to PRIMHD activity, collection and use*.
6. Where multiple practitioners from the same team are present at the same time, only one will record the contact on behalf of themselves and the others.
7. Where multiple practitioners from different teams are present at the same time, the contact should be recorded separately against each team's referral.
8. Contacts and activity should ideally be recorded on the day that they occur, or at the most within three working days.
9. If a contact is by telephone, the location must be recorded as 'telephone', regardless of who you are talking to or where the telephone call was made to or from. The activity type code selected will indicate who the contact was with, for example, T42 is recorded when the contact is with the client, and T08 when the contact is with an outside agency. Using any other location than telephone is likely to be reported both in local systems and to the Ministry of Health as a face-to-face contact, which is incorrect.



Organisational checklist

Every organisation will have its own patient management system, and its own data management policies and processes. The following checklist will give staff a better idea of the resources that are available to them within their own organisation.

1. *Is there someone within your organisation who is responsible for generating reports?*

Ask to see some example reports for your organisation.

2. *Are you able to access PRIMHD-related reports in your organisation?*

☐

Yes

☐

No

Do you know how?

☐

Yes

☐

No

3. *Who can you talk to within your organisation if you want to know more about the questions that you have that can be addressed with existing data?*

4. *What other resources are available within your organisation that can help you use in-house data more effectively (e.g. data use guidelines, FAQs, information sheets, etc).*

Other resources

National Key Performance Indicator Programme: <http://www.mhakpi.health.nz>

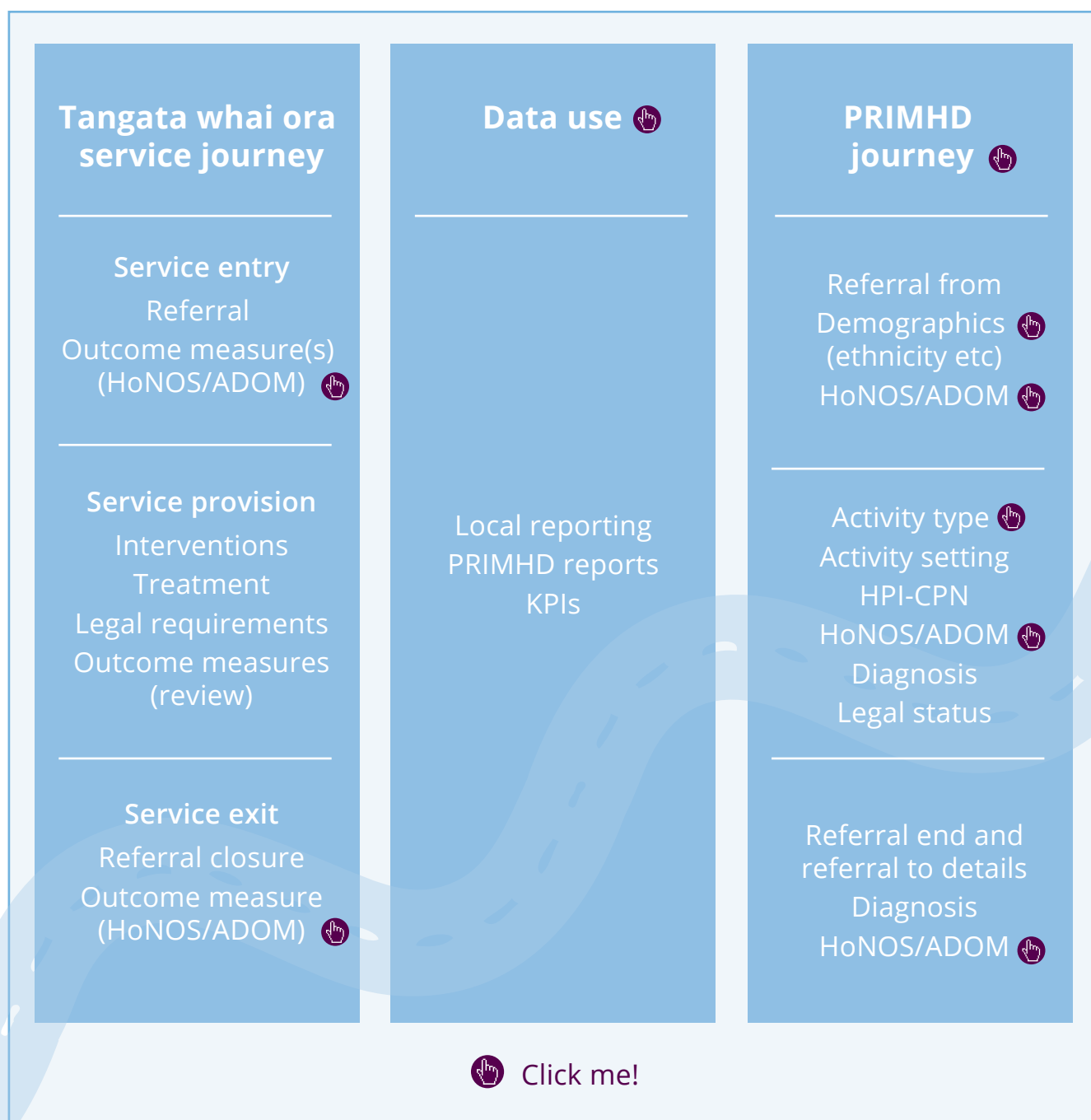


The tāngata whai ora service journey in relation to PRIMHD

The infographic below illustrates the process for interactions with tāngata whai ora and their whānau, from a service journey perspective, and demonstrates the correlation between service activity and data collection. While the details of the process may differ slightly in each locality, the essential elements will remain the same.

You can use the links in this infographic to find out more about each area.

Note that the left-hand side of the infographic, representing the tangata whai ora service journey, correlates with the right-hand side, representing the PRIMHD journey. PRIMHD data is collected throughout the process, and can be used at any point in the journey in different ways.



Section 2: PRIMHD data collection

Categories of codes

Most of the PRIMHD codes fall into one of two categories.

1. Demographic codes – these are codes or values that are used throughout the health sector, such as codes for ethnicity or organisation name. These need to be used consistently.
2. Specialty specific codes – these are specific to mental health and addiction services (such as service activity and outcome measures). The outcome data currently consists of the HoNOS family of measures and ADOM, but there are plans to extend the data collection to include a few measures relating to the social determinants of health, such as employment, training or education, and housing.

Collection points

PRIMHD data is collected at three main points of the tangata whai ora service journey:

1. at service entry
2. during service provision
3. at service exit.

Service entry

Referral from

PRIMHD description: the 'Referral from' code identifies groups of services or people who are sources of mental health and addiction referrals. Use the code to record the date and details of referrals to the service.

Team type + setting

PRIMHD description: a code that categorises the primary function of the healthcare team. Use the 'Team setting' to indicate where the team is based, e.g. community residential, respite etc.

Team code

PRIMHD description: the 'Team code' is assigned by the Ministry of Health and uniquely identifies each mental health and addiction services team.

Demographics

Demographic codes include (but are not limited to) the following data elements, which can be found in the PRIMHD code data set.

- National health index (NHI) number – every New Zealand resident who uses a public health service has an NHI number.
- Date of birth.
- Ethnicity – a classification of the individual's ethnicity data is sourced directly from the NHI, under the Ministry of Health's ethnicity data protocols.
- Sex – a classification of the tangata whai ora sex, including male, female, unknown, indeterminate. Note that transgender is not included in PRIMHD.

Outcome measure(s)

An outcome is a change in health, wellbeing or circumstances over time. Initial outcome data from HoNOS and ADOM are entered into PRIMHD.

Information on the HoNOS suite of outcome measures for mental health can be found at: www.tepou.co.nz/outcomes-and-information/mental-health-outcome-measures/28

Information on ADOM can be found at:

www.tepou.co.nz/outcomes-and-information/alcohol-and-drug-outcome-measure/117

Other codes

The code set listed below is included for reference purposes only. The PRIMHD data for these codes is sourced directly from the National Health Index.

Diagnosis or diagnoses

PRIMHD description: a code that groups clinical codes or indicates the priority of a diagnosis.

Legal status

PRIMHD description: a code describing a tangata whai ora/consumer's legal status under the appropriate section of the Mental Health (Compulsory Assessment and Treatment) Act 1992, the Alcoholism and Drug Addiction Act 1966, the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, the Criminal Procedure (Mentally Impaired Persons) Act 2003. The mapping document will define whether your organisation is required to collect legal status information.

NGO's collection requirements for PRIMHD is different from that of DHBs; it includes all of the data captured for DHBs, with the exception of:

- diagnoses
- legal status
- HoNOS outcome data
- information on primary mental health services provided by GPs or primary health organisations.

It is recognised that NGOs may still collect this information in local systems.

Recommended links and resources for service entry collection and codes

The PRIMHD file specification document will be the principal reference for all:

- providers who submit data to PRIMHD
- business and data quality analysts involved in supporting and maintaining PRIMHD collection
- vendors and software suppliers who are developing or delivering the technical capability for PRIMHD to DHBs or NGOs.

See: www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/primhd-mental-health-data/primhd-file-specification



NGO PRIMHD online training manual and user guide: www.health.govt.nz/system/files/documents/pages/primhd_online_training_manual_and_user_guide_v2.1_160614.pdf

Portal page to access and download the national PRIMHD standards, including:

- PRIMHD Data Process Standard (HISO 10023.1 V3.1)
- PRIMHD Data Set Standard (HISO 10023.2 V3.1)
- PRIMHD Code Set Standard (HISO 10023.3 V3.1).

See: <http://healthitboard.health.govt.nz/hiso-10023-project-integration-mental-health-data-primhd>

Contact details of people and teams who can assist an organisation with PRIMHD-related matters: www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/primhd-mental-health-data/who-contact-and-what

Ministry of Health information about PRIMHD mental health data: www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/primhd-mental-health-data

See also: <http://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/primhd-mental-health-data/ngo-and-vendor-reference-information>

Service provision

For the tangata whai ora journey, codes are collected relating to:

- interventions and treatment
- legal requirements
- outcome measures (review collection(s)).

For the PRIMHD journey, codes are collected relating to the following.

Activity setting

PRIMHD definition: the 'Activity setting' code indicates the type of physical setting or contact channel where the activity took place, such as in the community, in a residential setting or on the telephone.

Activity type

PRIMHD definition: The 'Activity type' codes classify the types of healthcare activity provided to the tangata whai ora. The codes are known as t-codes, and describe the type of service the tangata whai ora received each time they were seen by a service provider. For example a 'T42' would be used to record an individual tangata whai ora treatment meeting. Given the complexity of service delivery, it is not possible to provide staff with a complete list of codes that covers everything they do on a day-to-day basis. As a result, these activity codes are often the most problematic, as not everyone will interpret them in the same way.

The Guide to PRIMHD Activity Collection and Use

This resource is designed to improve the consistency of how t-codes are used. The guide covers each t-code in detail, including scenarios for their use.



Activity T-code quiz

The Te Pou website provides an online tool for the workforce to assess their knowledge in relation to activity t-codes through scenario-based multi-choice questions.



Outcome measures

PRIMHD definition: a code that identifies the outcome tool, and version of that tool, that is being used for a particular outcome collection. The two main outcome tools used in mental health and addiction are the HoNOS suite of measures (for mental health) and the ADOM (for addiction). The data entered at this point is considered 'review' data.

Information on the HoNOS suite of outcome measures for mental health can be found at: www.tepou.co.nz/outcomes-and-information/mental-health-outcome-measures/28

Information on ADOM can be found at: www.tepou.co.nz/outcomes-and-information/alcohol-and-drug-outcome-measure/117

Recommended links and resources service provision collection and codes

The PRIMHD file specification document will be the principal reference for all:

- providers who submit data to PRIMHD
- business and data quality analysts involved in supporting and maintaining PRIMHD collection
- vendors and software suppliers who are developing or delivering the technical capability for PRIMHD to DHBs or NGOs.

See: www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/primhd-mental-health-data/primhd-file-specification

NGO PRIMHD online training manual and user guide: www.health.govt.nz/system/files/documents/pages/primhd_online_training_manual_and_user_guide_v2.1_160614.pdf

Portal page to access and download the national PRIMHD standards, including:

- PRIMHD Data Process Standard (HISO 10023.1 V3.1)
- PRIMHD Data Set Standard (HISO 10023.2 V3.1)
- PRIMHD Code Set Standard (HISO 10023.3 V3.1).

See: <http://healthitboard.health.govt.nz/hiso-10023-project-integration-mental-health-data-primhd>

Service exit

For the tangata whai ora journey, codes are collected relating to:

- referral closure
- outcome measure (treatment end).

For the PRIMHD journey, codes are collected relating to the following.

Referral end code

PRIMHD definition: this code describes the discharge of a tangata whai ora from a mental health or addiction service.

Referral to

PRIMHD definition: this code identifies groups of services or people who are destinations of mental health and addiction referrals.

Recommended links and resources for service exit collection and codes

Portal page to access and download the national PRIMHD standards, including:

- PRIMHD Data Process Standard (HISO 10023.1 V3.1)
- PRIMHD Data Set Standard (HISO 10023.2 V3.1)
- PRIMHD Code Set Standard (HISO 10023.3 V3.1).

See: <http://healthitboard.health.govt.nz/hiso-10023-project-integration-mental-health-data-primhd>



Section 3: The use of PRIMHD data

Introduction

Rising to the Challenge: The Mental Health and Addiction Service Development Plan 2012–2017 (Ministry of Health, 2012) provides the strategic direction for mental health and addiction services in New Zealand. The intention is to increase the consistency of mental health and addiction service access, quality and outcomes nationwide, for tāngata whai ora, their whānau, and local communities. The information collected in PRIMHD will be used to this end.



Graphic adapted from Erickson, Crompton and Peplinkhouse (2008).

The main purpose of collecting data about mental health and addiction services is to provide information that is useful to make services as effective, sustainable, and responsive as possible to the wants and needs of tāngata whai ora and their whānau.

To gain these benefits, the information we gather needs to be accurate, useful, and used. We also need to develop a mind-set of being curious about this information, and what it can (and cannot) usefully tell us.

This section gives a brief introduction to some of the questions that PRIMHD data can help us to answer and how we might use the data to explore these questions. It also provides important guidance on how PRIMHD data is used.

How is the data used?

PRIMHD data is used in different ways at different levels in the mental health and addiction system to help provide good care and quality services.

Users of data at each level will have access to different amounts and types of information. At a tāngata whai ora level, (particularly from outcome measures) the information can contribute to help guide the care for that individual and monitor progress toward recovery. In contrast, at the level of the healthcare organisation and the Ministry of Health, data is aggregated across groups of tāngata whai ora and organisations, and can be used to explore questions that guide service improvement and accountability (Mellsop & O'Brien, 2000).

How data is used depends on whether it is individual or aggregated data.

- **Individual data:** the data for an individual tangata whai ora, or his or her whānau, is used on its own. Some individual data is collected at a single point in time only. Demographic data is an example of this. Other data (called longitudinal data) is collected at different points. Longitudinal data is used to explore change, and this data is often easier to understand if it is presented as a graph, rather than as a series of numbers. Individual data that is presented in this way does not usually require statistical analysis (Te Pou o Te Whakaaro Nui, 2009).

Individual data is used by practitioners and teams working with tāngata whai ora to improve assessment, clinical decision-making and treatment planning. It can also be used in discussions with the tangata whai ora.

- **Aggregated data:** The data for a number of tāngata whai ora (for example, all the clients of a particular service) is analysed as a group and presented in a summarised format. This approach often requires some statistical analysis to help make the data more interpretable. This data can be used by clinical and support teams, health and social service organisations, and the government to help understand the characteristics of tāngata whai ora and their wants and needs; to identify good practice; and to improve the ability of services to produce good outcomes.

Most analyses of PRIMHD data use aggregated data. As a result, this training resource focuses solely on the presentation of aggregated data.

Information can be used in many different ways

The figure below summarises some of the main applications of PRIMHD data.



Clinical practice

Clinicians and practitioners in the mental health and addiction sectors are interested in providing optimal support and treatment services, and improving outcomes for tāngata whai ora. By using standard measures of assessment and recovery, practitioners can help identify tāngata whai ora problems and needs, find solutions, provide better support and carry out effective recovery planning (Te Pou, 2009).

Quality improvement

At an aggregated national level, the data that is collected in PRIMHD is used to produce national key performance indicators (KPIs), which form part of the national benchmarking programme. In this benchmarking programme, DHBs and NGOs use nationally comparable indicators of service performance in order to improve quality and performance across the sector.

Te Pou routinely provides a suite of quarterly reports based on PRIMHD data which are fed back to each DHB and can be used for quality purposes. Standardised reports for NGOs in relation to ADOM are being developed.

Individual teams within NGOs and DHBs can also use their standard measure results to create practice-based evidence. Practice-based evidence involves teams using their own data to better understand what they are doing and achieving, and using this knowledge to help guide improvements in the effectiveness, efficiency and sustainability of their service. This activity improves satisfaction for tāngata whai ora, whānau and the staff working in the service.



Use existing data first

Because data collection can take a lot of time and effort, it is important for an organisation to know it is obtaining the best value from its in-house data before deciding to seek out additional information.

PRIMHD data is generally a sub-set of the in-house data that is collected by every organisation to guide how it delivers treatment and support services and manages its business. As such, it is not regarded as an additional data set.

Balestracci (2009) points out that if an organisation requires additional information, over and above its existing data collection, it should be able to justify the cost of collecting that information in terms of the increased value that the information will give to the organisation.

Examples of PRIMHD reports

This training resource includes four examples of reports that show how data from routinely collected measures can be used to guide better service delivery. These examples are summarised in the table below.

| Example report | | Relationship to the tangata whai ora journey | Relationship to PRIMHD and other data collection |
|----------------|--|---|--|
| 1 | Tāngata whai ora needs | Point of entry to the service | <ul style="list-style-type: none">• NHI• Demographic information• Clinical measures at admission |
| 2 | Percentage of 'did not attends' | Services that are provided during the period that the tangata whai ora is registered with the service | <ul style="list-style-type: none">• Type of service activity |
| 3 | Tāngata whai ora outcomes at discharge | Exit from the service | <ul style="list-style-type: none">• Service activity• Discharge information• Re-referral information |
| 4 | WHOQOL ratings | Point of entry and discharge | <ul style="list-style-type: none">• NHI• Outcome data |

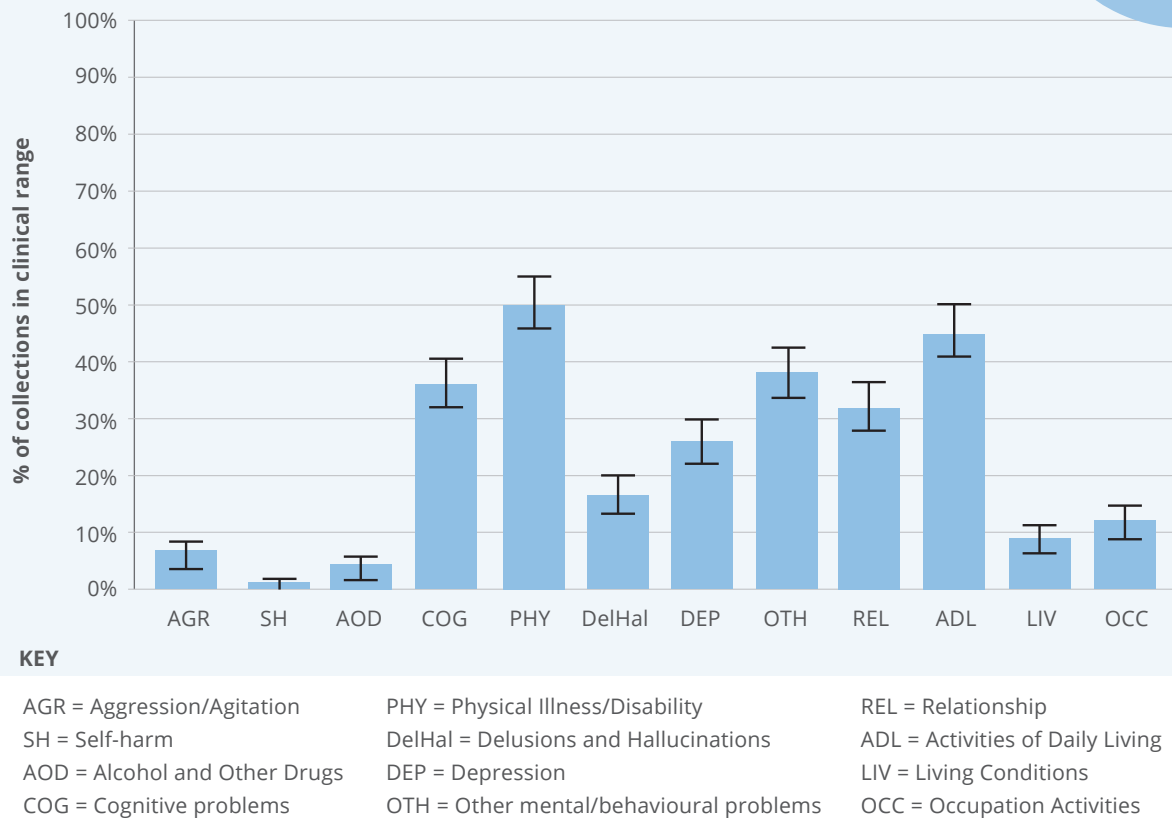
The first three example reports show how staff might interpret PRIMHD-related reports. Our objective is for all staff to be able to use PRIMHD data within their own services to better understand their particular model of service delivery and to improve tāngata whai ora outcomes.

In addition, we have included a fourth example report that shows tāngata whai ora outcomes at discharge based on the World Health Organisation Quality of Life (WHOQOL) measure. Although WHOQOL is not part of PRIMHD, this example shows how data available within organisations can supplement PRIMHD information to provide a broader and richer understanding of outcome and service delivery. Ideally, organisations should be able to map their service activity data from PRIMHD with their locally collected service user outcome data (e.g. from ADOM, WHOQOL, etc.). This sort of mapping would offer insights into the relationships between the different mix and intensity of service provision, and the outcomes that are achieved by different groups of tāngata whai ora.

Report one – Tāngata whai ora needs

What are the characteristics of people that attend our service? What are their needs?

Graph 1: Percentage of community service collections in the clinical range on each HoNOS65+ Item (review collections) for one DHB. April 2013 - March 2014.



The data in the graph above was collected by a mental health for older people's service and shows the proportion of tāngata whai ora who had clinically significant difficulties (i.e. mild, moderate, or severe difficulty) on each item on the HoNOS65+ scale when they had been with the service for at least three months (i.e. at a review collection point).

The top of each solid bar shows the proportion of people who were rated in the clinical range on that item. If the error bars (the black lines shaped like an "I") that straddle the top of each bar don't overlap (i.e. the bottom of the error bar for one item is higher than the top of the error bar for another item), then the two items are statistically significantly different.

So for example, physical problems can be seen to be statistically significantly more common than cognitive problems for people in this service, because their error bars don't overlap. In contrast, the difference between the proportion of people in the clinical range for the aggression or agitation item and the alcohol and other drug item is not significantly different because the error bars overlap.

What this information shows

This graph shows that physical difficulties are the most common clinically significant problem experienced by the people in this service, with problems with the activities of daily living being the next most common problem. It shows that alcohol and drug issues and self-harm issues are relatively uncommon for people who use this service. It also shows that significant depression is more common than difficulties with hallucinations and delusions. It shows that approximately one-third of people using the service have clinically significant relationship difficulties.

The 'other mental/behavioural' item covers a broad range of difficulties (e.g. anxiety, sleep, stress, sexual difficulties). Further analysis could be undertaken to find out which of these difficulties were common.



Interpretation

This data provides a simple needs assessment of the people using this service. It shows that physical health needs are very common, thereby prompting the service to be well-integrated with physical health services and to do what it can to ensure that people's physical health needs are addressed. The high prevalence of problems associated with the activities of daily living suggests that strategies to address these problems, such as more provision of occupational therapy, will also be important. The relatively high frequency of relationship difficulties may lead the service to consider whether it is adequately set up to address this issue at present.

Why is this useful?

This type of analysis will sometimes identify areas of frequent difficulty that are getting overlooked because of the focus on other areas of need. For example, the prevalence of relationship difficulties may be overlooked, yet may be very significant in terms of supporting recovery.

This data can help to identify the training required for the team to best meet the needs of tāngata whai ora. The question can be asked if the team is equipped to address areas of relatively high need, and if the answer is no, then training can be sought.

This data can also help to identify workforce needs. For example, the relatively high level of problems associated with the activities of daily living may lead the service to recruit additional occupational therapy input.

A similar analysis of admission and discharge data will show which items change, and which don't, over time. It will also help to identify areas of high need (high scores at admission), and areas of recovery (improvement from admission to discharge) or non-recovery (no change or worsening from admission to discharge).

Comment

In the process of aggregating and analysing data, some information is often lost. In this case, the categories of mild, moderate, and severe clinical difficulties were simplified into one category of 'clinically significant'. This kind of simplification is often necessary to allow data to be easily understood. However, to answer other relevant questions (e.g., "What are the most common severe difficulties for people using our service?"), other analyses can be undertaken.

This data could also be further analysed using other PRIMHD data. For example, the HoNOS65+ data could be used with ethnicity data to explore how the profile of tāngata whai ora needs varies among different ethnic groups. This understanding could then be used to make services more responsive to people of different ethnicity.



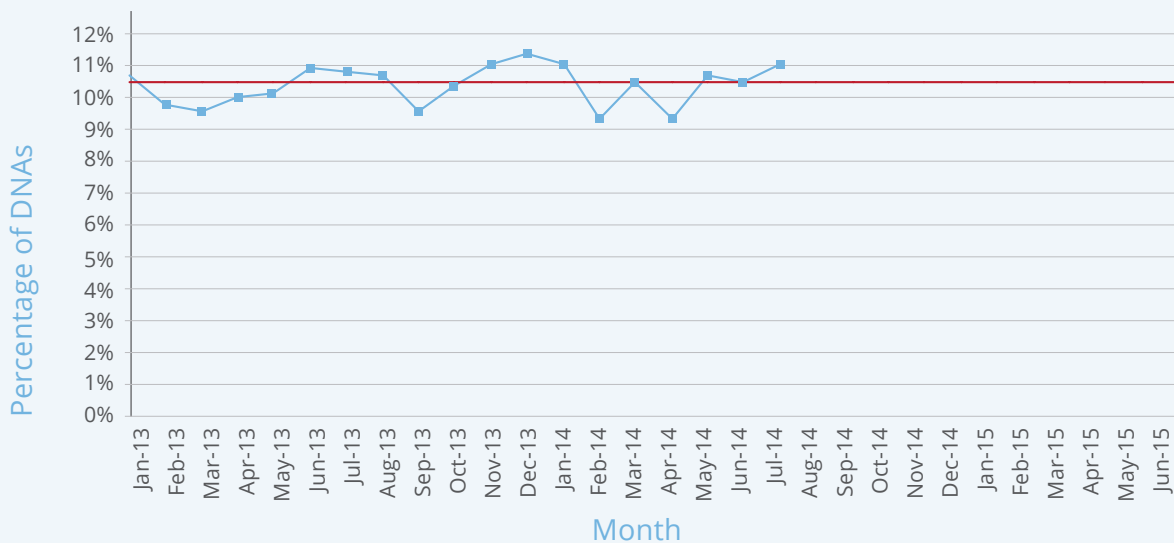
Report two – percentage of ‘Did not attends’

What drives the rate of ‘did not attends’ in our service? What can we do that will make a difference in our ‘did not attend’ rate?

A community mental health service was concerned about the rate of ‘did not attends’ (DNAs), because DNAs reduce the quality of care for people using the service, increase risk, and reduce how effectively staff can use their time. DNAs were defined as the number of occasions each month where tāngata whai ora did not participate in pre-arranged meetings, appointments, programmes or activities.

To understand the DNAs better, the service needed data. At the time, the service had access to monthly DNA data from PRIMHD for period from January 2013 until September 2014. This data is shown on the graph below.

Graph 2: DNA Rate for Total F2F Contacts per Month - PRE Text Reminders



The graph shows the number of appointments that were considered to be DNAs over the reference period (January 2013 to September 2014). The solid line through the middle of the data is the median of all data points.

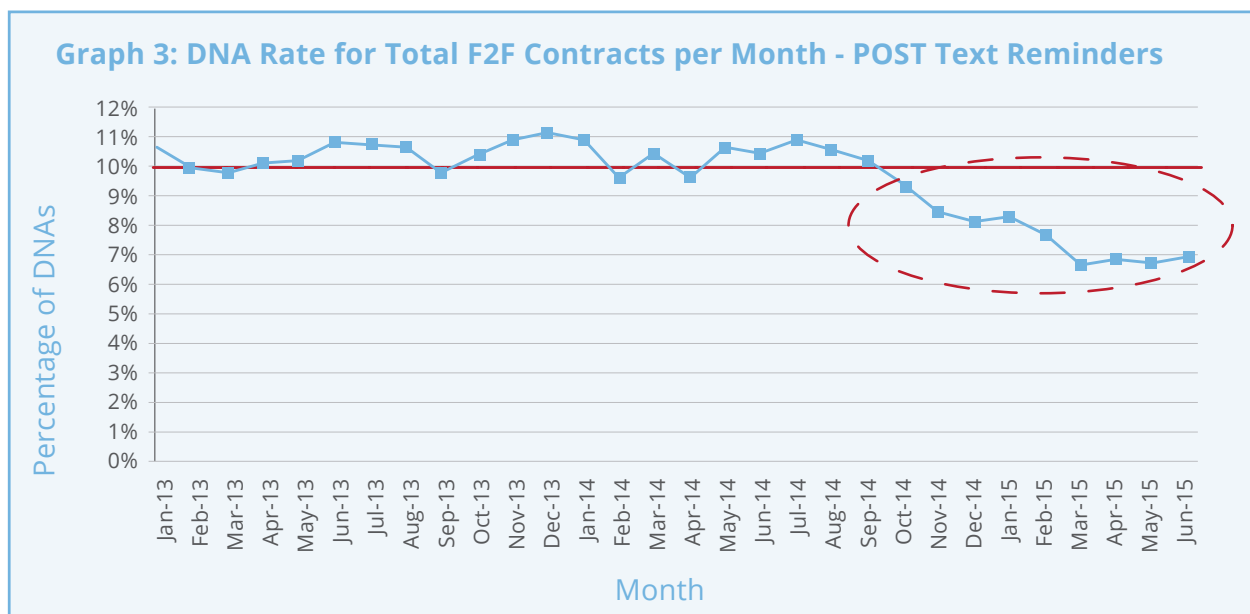
Interpretation

The rate of DNAs at a number of different community mental health services had been reported to range between 10 per cent and 30 per cent. Even though the service was performing well when compared with this range, given the cost and risk associated with DNAs, they wanted to see if it could reduce the DNA rate further. The key objective of the analysis shown in the graph was to help staff at a particular service obtain a better picture of what the DNA rate was for their service, based on the PRIMHD data rather than anecdote. This information helped staff to develop a hypothesis about why people weren't turning up for their scheduled appointments. Based on the outcome of this analysis and subsequent discussion about the problem, the service decided that sending text reminders to tāngata whai ora 24-hours before their appointments might help to reduce DNAs.

Once this course of action had been decided on, staff wanted to check if it would actually make a difference. They decided to undertake a Plan-Do-Check-Act cycle. The first steps in the cycle were to plan how to introduce the text messaging for all clients (plan), and then implement their plan (do). After several months, they wanted to see if the text messaging had made a difference (check). They could then stop doing it if it made no difference, or, if it helped, they could continue it as well as make improvements based on what they had learnt from going through the cycle (act). This would enable them to answer the question: “How do we know that we are making a difference when we

introduce a change?”

To be able to check whether it was successful or not, staff needed the monthly DNAs data from PRIMHD for several months after they started the texting. The graph below shows the data for before and after text reminders were started (period from October 2014 to July 2015).



Staff reviewed the data from October 2014 to July 2015 and compared it to the earlier data. To be sure that there was a significant difference they used two commonly used criteria: a trend of 7 data points all going in the same direction; or an unbroken line of 8 data points that were situated below the median for all data.

If it data showed one of these patterns, Balestracci (2009) suggests that this indicates that the strategy had been successful and has resulted in real service improvement. However, corroborating information might also be required to support this type of statistical result, for example, staff might enquire if the text reminders were helpful for the tāngata whai ora and their whānau, who have previously struggled with attending appointments.

Why is this useful?

When a tāngata whai ora does not attend a scheduled appointment, or cancels so late that the time slot cannot be reallocated to someone else, there is a cost to the health care system in terms of staff time, extended waiting lists, and the loss of potentially beneficial services to that person and other tāngata whai ora who could have used the time.

This example report shows a good idea (text reminders) that helped to reduce DNA rates. However, many good ideas do not actually end up producing the improvements we think and hope they will. This example shows a service taking the next step of not only implementing its good idea, but also using data they already collect to ensure that it did actually make a difference. This process also allows us to identify ways of refining the good idea to make it even better.

There is some evidence to suggest that DNAs may be more likely among certain demographic groups, such as young adults, adults who have young children, people with a lower socioeconomic and educational status, and those with larger families. Moreover, geographical distance from the site of the appointment, the inability to obtain transport, or both, have been found to impede appointment keeping. Other factors include issues with communication, and the role of certain attitudes, such as the extent to which the tāngata whai ora views the appointment as important, urgent or helpful. Interventions to address these other causes of DNAs could be introduced later, and could similarly be evaluated using a Plan-Do-Check-Act cycle. It is generally best to set up one innovation at a time, or it becomes impossible to know what has, or hasn't, made a difference.

Comment

A quality improvement initiative that focuses on reducing the rate of DNAs will not only increase the productivity of staff and the efficiency of the service, but it will also provide evidence of effective engagement with tāngata whai ora and delivery of appropriate services to the population.

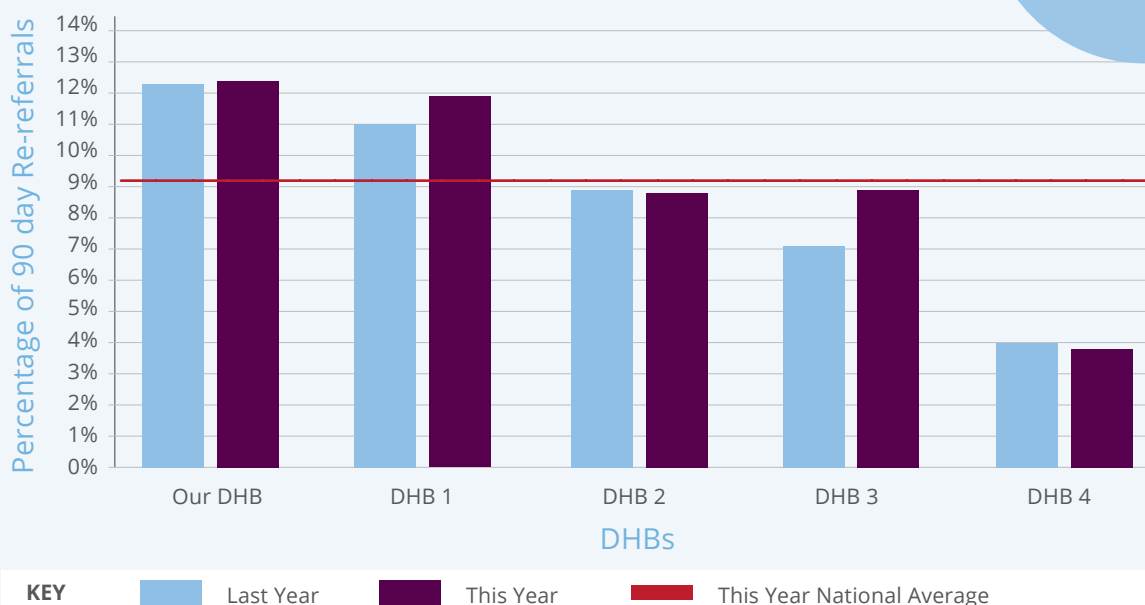
Balestracci (2009) recommends that services do not use highly aggregated data summaries (e.g. annual rates) or rolling averages (for instance where the data point for each month is made up of the average of the data points for the last three months) for their quality improvement initiatives. A good quality improvement process relies on people being able to see (and act) on the smallest unit of performance that makes sense to them, and he is of the view that aggregated data summaries obscure variation rather than highlight it. For this reason, in the example report, the data about the percentage of DNAs is presented month by month.



Report three – tāngata whai ora outcomes at discharge

What are the outcomes for tāngata whai ora when discharged from our service?

Graph 4: 90 day Re-Referral Rate - National CAMHS KPI Data



As part of the shift towards more episodic-orientated care, a DHB child and adolescent mental health service (CAMHS) wanted to know if it was establishing effective follow-up arrangements for the tāngata whai ora it was discharging.

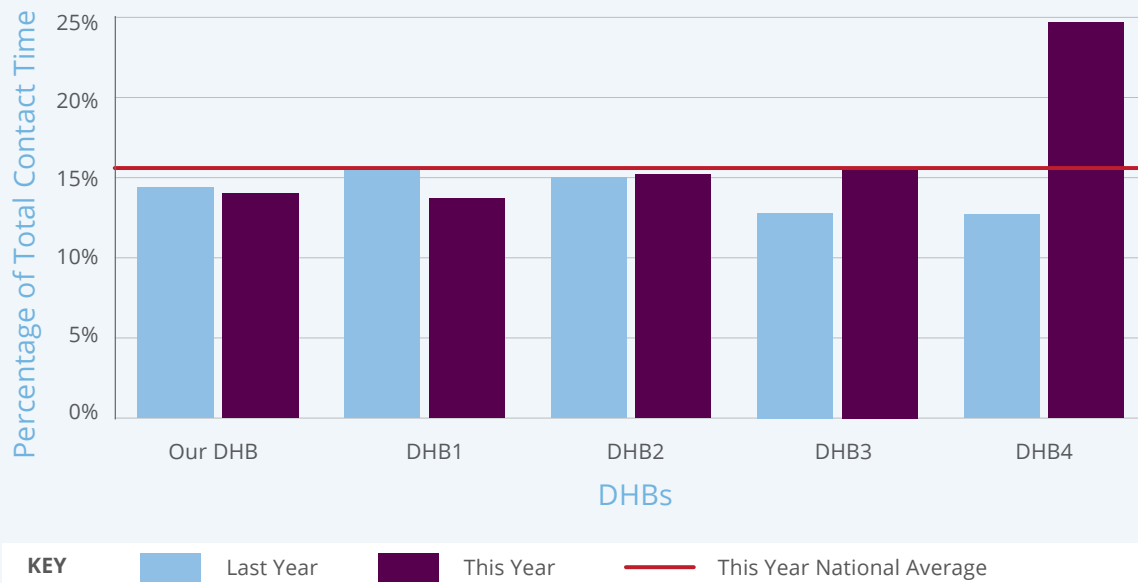
As a first step, the team looked at its performance in relation to other DHBs, using the National CAMHS KPI Project data. The most relevant indicator seemed to be the 90 day re-referral rate. As a result of what this showed, they also looked at data on the average number of community treatment days that tāngata whai ora received each quarter, and the percentage of total contact time that was face-to-face with clients.

What this information shows

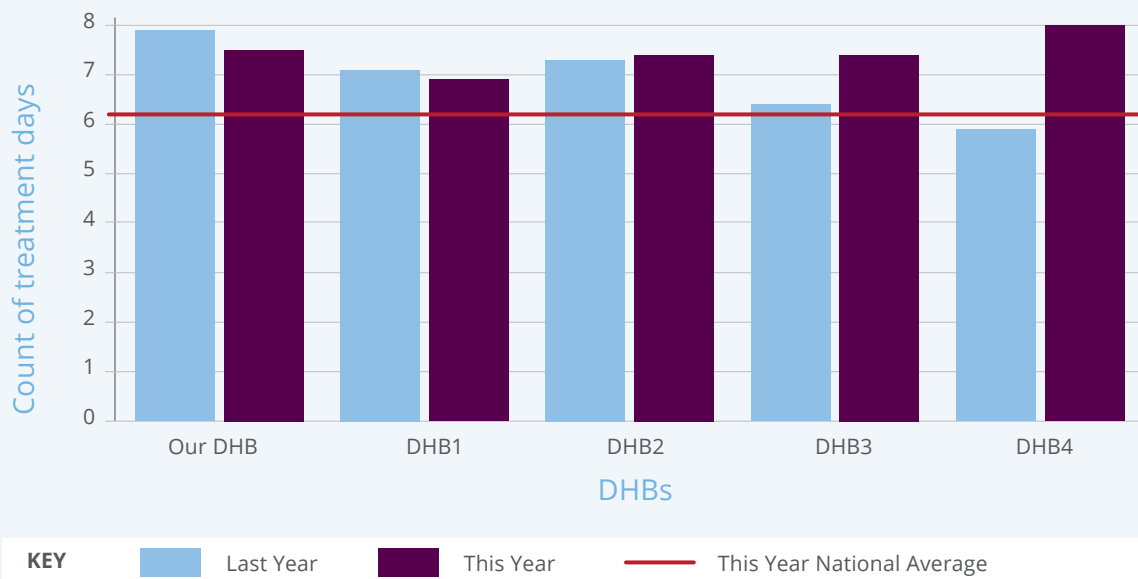
The graph for 90 day re-referrals (above) showed the team that their service had a consistently higher re-referral rate over the past two years compared to similar DHBs. This prompted the team to wonder if the service they were delivering was radically different from these other DHBs.

To answer this, they looked at the graphs of the next two indicators (below), which seem to show that their service was not too different from other similar DHBs in relation to these measures. In doing this, the team demonstrated the importance of not seeing indicators in isolation and instead looking at them in clusters of related measures.

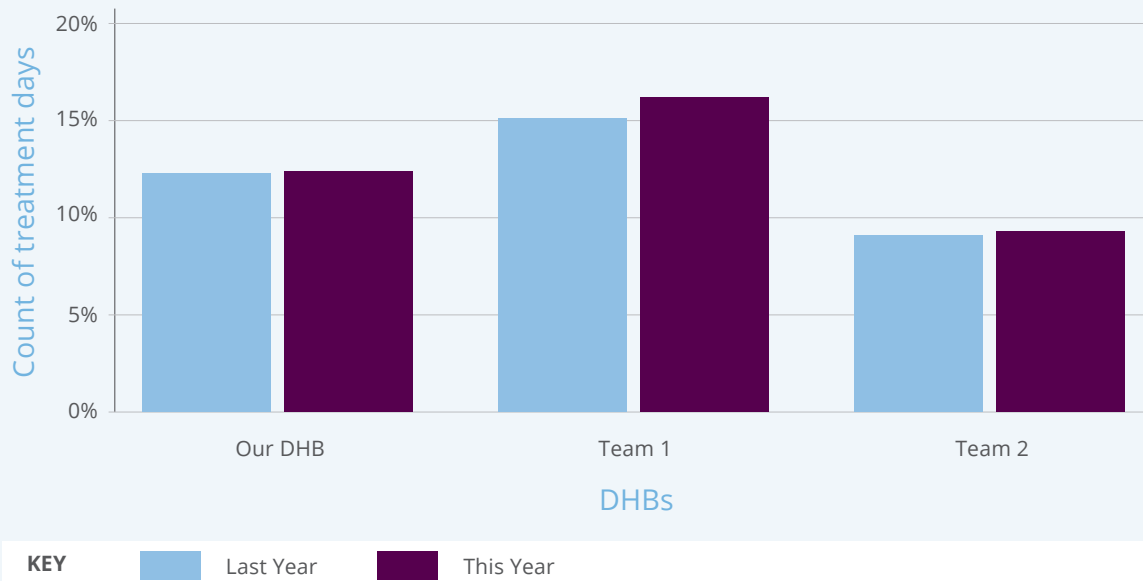
Graph 5: Percentage of Total Contact Time that is Face-to-Face and Involving Tāngata Whai Ora



Graph 6: Average Treatment Days per Tangata Whai Ora each Quarter



Graph 7: 90 day Re-Referral Rates - Our DHB Teams



Interpretation

Because the DHB provided services through two separate CAMHS teams, they decided to look at the data for 90 day re-referrals for each team. The graph showing this comparison (above) highlights the very different 90 day re-referral rates for each team.

High levels of unplanned 90 day re-referrals are regarded as reflecting possible deficiencies in the service, problems with the follow-up arrangements that are being put in place to support people in the community, or inadequacies in the functioning of the overall system of care. As such, they may indicate less than ideal outcomes for tāngata whai ora.

Why is this information useful?

Breaking down the aggregated DHB data suggests that 90 day re-referrals may be driven by different team processes, with Team 1 having a much higher rate than Team 2 over both years.

Given this, the obvious question for the DHB to ask becomes: “Why is there such a difference between the two teams?” This is a good example of how data can often help us to ask better questions, rather than answering all of our questions.

This new question requires further analysis. Now a variety of quantitative and qualitative methods (see glossary) can be used to try to understand the difference between the two teams and other similar services elsewhere, to identify how to improve how the services work.

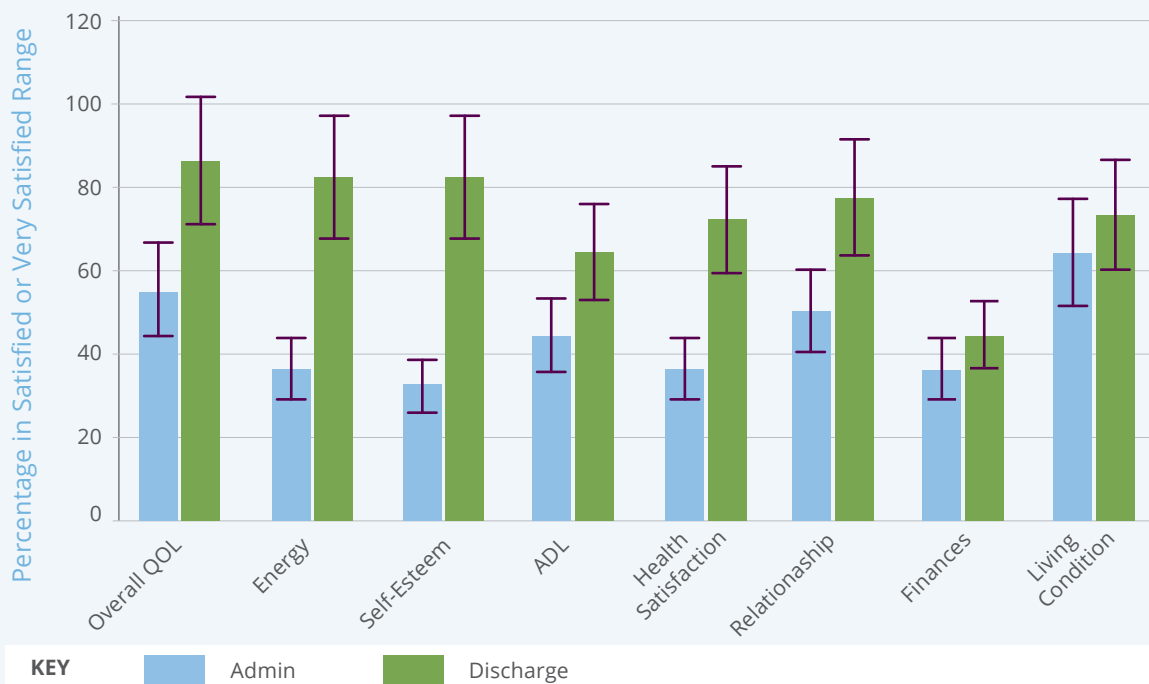
For example, staff from both teams could get together to compare how they operate and discuss what factors might be contributing towards the difference. If this is done in a non-defensive way, it could yield very useful results for both services. Also, other PRIMHD data, such as ethnicity, or other in-house data, such as whether the tāngata whai ora had a formal discharge planning meeting involving both the family and community services, might be analysed to see if this was related to, and might possibly explain, the difference.

Comment

This example report shows why it is a good idea to delve into any aggregated data that is based on the performance of more than just one team or one service. It also illustrates the importance of using more than one variable, and the value of adding a qualitative approach to help gain insights and better understand an issue.

Report four – WHOQOL ratings

Graph 8: WHOQOL Ratings at Admission and Discharge



The data in the graph above comes from a primary health setting, and shows the proportion of tāngata whai ora who described themselves as being ‘satisfied’ or ‘very satisfied’ on items from the World Health Organisation Quality of Life (WHOQOL) measure, before and after receiving individually tailored psychological therapy for anxiety or depression.

The top of each solid bar shows the proportion of people who rated themselves satisfied or very satisfied. If the error bars (the black lines shaped like an ‘I’) that straddle the top of each admission bar don’t overlap the error bars for the corresponding discharge bar (i.e. the bottom of one error bar is higher than the top of the other error bar), then the item shows a statistically significant difference between admission and discharge. For example, the overall quality of life (QOL) of respondents increased significantly between admission and discharge because the error bars don’t overlap, while the area of ‘finances’ didn’t change significantly, because the error bars do overlap.

What this information shows

Over the course of the intervention, the tāngata whai ora who participated in the therapy reported significant improvements in their overall quality of life, their energy levels, their self-esteem, their health satisfaction and their relationships. They did not show improvements in their finances or living conditions. Activities of daily living (ADL) appear to have changed substantially between admission and discharge, but the fact that the error bars overlap indicates that the change cannot be considered to be significant.

Interpretation

These results indicate that, overall, tāngata whai ora undertaking this intervention showed statistically significant gains in a range of areas related to their quality of life. They also showed significant gains in depression and anxiety, but these are not shown here. The areas that did not change (finances and living conditions) are areas that were not focused on by this intervention, and therefore might not be expected to change.

Why is this useful?

These are the slightly modified results of a real study that set out to evaluate the outcomes of an innovative programme of introducing brief psychological therapy into a GP practice. While it seemed like a useful and sensible thing to do, it was important to evaluate the outcomes to make sure that introducing this innovation did contribute to positive outcomes for tāngata whai ora. As there was no control group (i.e. a group of people not receiving the therapy), we cannot be absolutely sure that the effect seen was due to the innovation, but having this data does provides some evidence that the innovation is useful.

Comment

For more information see Dath, Sables, Yang Dong and Stewart (2014).

Other things to consider when interpreting data

Working with aggregated data

Aggregated data is useful to inform service providers and policy makers about the bigger picture with a view to answering Leginski, Croze and Driggers (1989) question: ‘Which groups of services users are receiving what services, from whom, at what cost, and to what effect?’

However, there are obvious dangers in looking at only aggregated data when making decisions about the quality of service delivery, because aggregation often hides important factors, such as the different characteristics of the target population, variations in resourcing, the overall complexity of the system and the quality of the source data. This means that, while often very useful, aggregated data doesn’t always automatically generate accurate conclusions about service characteristics or about individuals. Rather, it is often necessary to ask questions about the data itself, so that its usefulness and limits in terms of the specific situation are more apparent.

For example, as discussed in example report 3, just because one team shows a larger change on an outcome measure than another team, this does not necessarily mean it is more effective – there may be other factors that explain the difference. Similarly, overall results showing larger outcomes for one intervention compared to another, may not mean that a particular individual or subgroup (such as Māori) will gain the most from that one intervention.

For these reasons, decision-making in the real world of mental health and addiction service delivery should take into account information from a number of different data sources, including qualitative information that incorporates the experience of tāngata whai ora and their whānau. Often the greatest value of the information is to help users to pose better questions about service delivery, more than to provide the answers to questions (Te Pou, 2009).

In addition, data should not be aggregated and reported when working with very small numbers, due to confidentiality issues in small populations and the lack of data reliability associated with a very small number of events.

Data and context

“Data have no meaning apart from their context”

Dr Walter Sherwhart quoted in Wheeler (1993)

Providing enough context so that people can accurately understand the information they are given is very important.

A good example is provided the Google Flu Trends debate, which resulted when Google released some new data based on an algorithm it had created to figure out, from Google searches and those searchers’ locations, how many Americans had the flu (Ernst, 2013). In addition, the company used the algorithm to create Google Flu Trends, a tool that compiled a number of ‘good indicators’ to estimate ‘flu activity’.



The magazine *Nature* found inaccuracies with Google's data, reporting that it was double the number estimated by the Centres for Disease Control and Prevention. However, Google's data was about the number of people who searched for information about the flu (possibly because they thought that they might have it or they thought that a family member or friend might have it). *Nature* thought that Google was predicting exactly how many people had the flu.

There was some backlash against Google for releasing its data and its flu algorithm. The company obviously has tons of great data sets, but Google's mistake was releasing that data without any context. Basically, all that Google was saying was: 'Here's our data, draw your own conclusions.' However, without enough context information, it was impossible to draw valid conclusions from the data.

This is a perfect example of why data needs context, and that the correlation between two data points doesn't necessarily imply anything more. Google isn't alone. This is a perfect example of why data needs context. A degree of correlation between two data points doesn't necessarily mean that one thing causes the other; It just means they are related to one another in some way.

Conclusion

In this section of the guide we have explained, and shown examples of, a few ways that PRIMHD data and other routinely collected mental health and addiction information can be used to help develop services that better assist and provide more efficient recovery of tāngata whai ora. There are many other ways that this data can be used to achieve this goal and thereby improve the satisfaction of tāngata whai ora, their whānau, service providers and service funders. For more examples see Te Pou (2009).

However, the most important ingredient in making this data valid, useful, and used is for people who work in the mental health and addiction services to adopt a mindset of curiosity about the data and think about the questions they would like their data to answer. Sometimes you may need to ask your manager, mental health information site co-ordinator/champion, clinical quality manager (or someone in a similar role) to identify who can best help you to use the data for your service.



Accessing standard PRIMHD reports

The Ministry of Health has developed a set of standard PRIMHD reports to help meet the common requirements of a number of different stakeholders.

Information about how to access and run standing order reports, or how to create ad hoc reports from the PRIMHD datamart using Infoview and Business Objects, can be found in the following document:

<http://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/primhd-mental-health-data/primhd-reporting-end-user-guide>

Infoview is the most commonly used mechanism for accessing NGO reports, particularly for those NGOs that are using PRIMHD online.

Further information

For further information, the following links and resources are recommended:


- useful link to mental health and addiction-related statistics: <http://www.health.govt.nz/nz-health-statistics/health-statistics-and-data-sets>
- the Institute for Healthcare Improvement's guide to Run Charts. Registration is required to download the charts: <http://www.ihi.org/resources/Pages/Tools/RunChart.aspx>
- document outlining the core information needed to run PRIMHD reports, from the PRIMHD datamart, using Infoview and Business Objects: <http://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/primhd-mental-health-data/primhd-reporting-end-user-guide>



Glossary

| Term | Definition |
|---|---|
| Alcohol and Drug Outcome Measure | The Alcohol and Drug Outcome Measure (ADOM) is a client-rated, practitioner-facilitated three-part measure including: drug and alcohol use and frequency; health and wellbeing; and recovery-orientated questions. This measure is mandated for use in adult community alcohol and drug services from 1 July 2015. |
| Benchmarking | Benchmarking involves measuring aspects of how your organisation is performing and comparing that to the best-performing comparable organisation(s). The concept of benchmarking is based on the Japanese word Dantotsu, meaning 'striving for the best of the best' (Bank, 2000, p. 43). The term benchmarking encompasses everything from the production of league tables through to a complex process of continuous quality improvement, based on the identification of those processes and practices that are thought to be major contributors towards superior performance. |
| Client Management System | CMS – See Patient Management System (PMS). |
| District Health Board | DHB. Organisations established by the New Zealand Public Health and Disability Act 2000, ensuring health and disability services within a defined geographical area. |
| Discharge | The relinquishing of tāngata whai ora/consumer care/support in whole or in part, by a healthcare provider or organisation. |
| Encoded | To put electronic data into a standard formatted code (in computer science). |
| Health Information Standards Organisation | Health Information Standards Organisation. HISO. See: www.ithealthboard.health.nz/hiso-2010 |
| Health of the Nation Outcome Scale | <p>The Health of the Nation Outcome Scale (HoNOS) is an outcome tool measuring behaviour, impairment, symptoms and social functioning. This tool forms part of the mandatory reporting under PRIMHD for all DHBs, and is completed by a health professional as part of a routine clinical assessment. A few NGOs also collect the HoNOS in situations where they are contracted to provide clinical support, but it is not a mandatory requirement for all NGOs.</p> <p>The HoNOS family of measures consists of a suite of measures designed for different population groups:</p> <ul style="list-style-type: none"> • HoNOS for adults aged 18-64 years • HONOSCA for children and adolescents aged 4 – 17 years • HoNOS65+ for adults aged 65 and over • HoNOS-LD for adults who have a learning disability and receive specialist services • HoNOS-secure for adults receiving specialist forensic services • ADOM – alcohol and drug outcome measure for all community-based outpatient adult and addiction services |



| Term | Definition |
|---|--|
| Key Performance Indicators | A key performance indicator (KPI) is a metric that is used to measure the performance of services, based on some important operational or strategic goal. |
| New Zealand Mental Health KPI Framework | The New Zealand Mental Health and Addictions KPI programme was developed to enable mental health and addiction services to learn about those practices that lead to improved outcomes for tāngata whai ora. |
| Legal status | Information that describes a healthcare user's legal status under the appropriate section of the Mental Health (Compulsory Assessment and Treatment) Act 1992, the Alcoholism and Drug Addiction Act 1996, the Intellectual Disability (Compulsory Care and Rehabilitation) Act or the Criminal Procedure (Mentally Impaired) Act 2003. |
| Non-government organisation | Non-government organisation. NGO – not for profit organisation independent of government that provides social care and treatment provisions. |
| National Health Index | The National Health Index (NHI) is a unique identifier assigned to every person who uses health and disability support services in New Zealand that is stored in a secure format. An NHI allows health professionals involved in a person's care to share health information without using their name and address. This further protects privacy. See: http://www.health.govt.nz/our-work/health-identity/national-health-index |
| Patient Management System | Patient management system. (PMS) This is an information technology term that is generally applied to any software that collects and organises information specifically related to a tangata whai ora. It is designed to include details about the tangata whai ora and their treatment plan, as well as specific details about their treatment (essentially it is an electronic medical record). Variations of a PMS (containing more or less clinical information) include a patient administration system, client information system and clinical information system. |
| PRIMHD Online | The online application used by some NGOs to enter data directly into PRIMHD. |
| Qualitative Methods | Extrapolating evidence for a theory from what people say or write (ref from Andy Reid – disconing statistics. 2013, Sage, London) |
| Quantitative Methods | Inferring evidence for a theory through measurement of variables that produce numeric outcomes. |
| Referral | Referral may take several forms, most notably a request for management of a problem or provision of a service, such as a request for an investigation, intervention or treatment. The common factor in all referrals is a communication whose intent is the transfer of care or support, in part or in whole. |
| Service activity | An intervention provided by a mental health or addiction practitioner to a tangata whai ora and/or his or her whānau. |
| Team | A team consisting of a person or functionally discrete grouping of people providing mental health and addiction services within a service provider. Please refer to <i>The Guide to PRIMHD Activity Collection and Use</i> for further details.  |
| World Health Organisation Quality of Life | The WHOQOL (World health organisation quality of life) assessment developed by the WHOQOL Group with fifteen international field centres, simultaneously, in an attempt to develop a quality of life assessment that would be applicable cross-culturally. |

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Programme for the Integration of Mental Health Data



MANATŪ HAUORA