Enhancing the Alcohol and Other Drug Treatment Services National Minimum Data Set

Counting clients and reporting comorbidity

Summary

The Enhancement Project of the Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS–NMDS) was funded by the Australian Department of Health and Ageing. It examined the feasibility of introducing a statistical linkage key and one or more indicators of mental health into the AODTS–NMDS to answer three specific questions:

1. How many clients across Australia receive treatment for alcohol and other drug use?

2. How many of those clients have a co-existing mental health problem?

3. How do we protect the privacy of these clients?

A statistical linkage key (SLK) is an alphanumeric code that identifies unique records. It consists of a combination of letters and numbers, represented by a code, from an individual's first and last names, their sex and date of birth. This combination of components is highly unlikely to be the same for any two people and therefore it is possible to count unique records without the individual's actual identity being disclosed.

Contents

bulletin 69

The project consisted of four parts:

1. An initial consultation with jurisdictions—to ascertain the feasibility of the project aim and their technical capacity to participate at the time of the project.

2. A feasibility consultation with treatment agencies—to gather information about current practice, capacity and willingness to implement new data items.

3. Piloting the new data elements in alcohol and other drug treatment agencies—to observe how the elements are accepted by staff and clients, the accuracy of information gathered and technical aspects of collection, transmission and analysis.

4. Final Report—to inform the possible implementation of the SLK and mental health indicator items and future development of the AODTS–NMDS.

This report presents the findings of this project.

Major findings

- Introduction of the components of the Statistical Linkage Key 581 to the collection are feasible and should be introduced nationally. This will allow the estimation of the number of clients who access alcohol and other drug (AOD) treatment, providing both point-in-time and flow data and information about patterns of service usage.

- The first two questions of the General Screener of the *PsyCheck* tool (Lee et al. 2007), are appropriate items to indicate the prevalence of affective and anxiety disorders in clients of AOD services. Further discussions with mental health epidemiologists may be required to make this information more robust and capture a greater range of mental health disorders within this population. When analysed with the SLK, an estimation of the number of people who have a co-existing mental health and substance use problem may be made.

- Implementation of new data elements into the NMDS would vary between jurisdictions according to their existing data collection, reporting systems and subject to national agreement[1]. A minority of jurisdictions currently collect the components of the SLK581 while the majority of jurisdictions would have to redesign data collection systems to collect these components. Similarly, some jurisdictions have implemented the *PsyCheck* tool as part of clinical practices while others would have to incorporate these elements into their collections in order to report them.

- Privacy is a critical issue to address in the development of the AODTS–NMDS and will require ongoing attention by the AODTS–NMDS Working Group and the AIHW.

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1 All modifications and enhancements to national minimum data sets require national agreement sought through a process overseen by the Australian Health Ministers Advisory Council and its subcommittees.

Background

Australia has an existing national collection of publicly funded treatment episodes in alcohol and other drug treatment agencies. This collection commenced nationally on 1 July 2000, is an initiative of the Intergovernmental Committee on Drugs (IGCD) AODTS–NMDS Working Group and is coordinated by the Australian Institute of Health and Welfare (AIHW).

The purpose of the AODTS–NMDS is to aggregate standardised unit record data from state, territory and Australian governments so that national information can be reported about clients accessing alcohol and other drug treatment and the services they receive. The collection was designed with the expectation that it would provide service providers and funders with access to basic data relating to client profiles, drugs of concern and treatment responses, to inform policy decisions and for the purposes of service planning.

Current collection products include a national annual report, national annual bulletin, state and territory bulletins and online interactive data cubes. The AIHW also manages a range of requests for access to the national database and specific requests for data tables from the AODTS–NMDS. These requests are managed according to established and agreed data access protocols.

This collection (AODTS–NMDS) is based on closed (completed) episodes, which does not allow for an estimation of the number or profile of clients who access treatment services, or patterns of service usage.

Further, the Australian Government's National Comorbidity Initiative has emphasised the importance of identifying and effectively managing those clients who are experiencing both a substance use disorder and a mental health disorder in treatment settings. As no information is currently collected about mental health in the AODTS–NMDS, the feasibility of introducing at least one indicator of comorbidity has been investigated.

In combination, the concepts of statistical linkage and an indicator of comorbidity may provide detailed information useful in formulating policy and service planning for the AOD treatment sector.

The alcohol and other drug sector

The environments in which AOD treatment agencies operate nationally are diverse and vary between jurisdictions. Funding models and data collection methods vary between states and territories, with numerous modes of service delivery across both the government and non-government sectors. Acknowledging this diversity is important as this project seeks to inform how implementation of these new data elements *may* proceed; however each jurisdiction may have different experiences.

The complex environment in which treatment services operate is evident in their governance and reporting systems. These complexities affect the ways in which data collection can occur and be developed.

According to the annual report of the AODTS–NMDS, 633 agencies delivered 147,325 closed treatment episodes in 2006–07 (AIHW 2008). Approximately half these agencies are government-run and the other half are publicly funded non-government services. Almost two-thirds of these agencies were located in major cities and the treatment types provided according to geographic location varied. These factors and many others, such as client profile and principal drugs of concern, impact on the capacity of agencies to make changes to their data collection. The AOD sector has become established as an integral part of the public health system and therefore needs to be supported by useful data.

Consultation

Enhancement of the AODTS–NMDS requires the participation and understanding of those people who work in AOD treatment agencies. Throughout this project there has been a concerted effort to communicate with agencies in the sector to seek their opinions and advice on the proposed new data elements. A detailed questionnaire was distributed to agencies in participating jurisdictions and was followed by another questionnaire after piloting the new data elements. A comparison of these two surveys informed the analysis of the pilot data and will be important in the design of future developments to the collection.

Counting clients

As a unit of measurement, the 'closed treatment episode' cannot provide information on the number of clients who access publicly-funded alcohol and other drug treatment, nor can it provide information on the extent of concurrent, sequential or recurrent service usage (Box 1). This is because it is possible for a single individual to access more than one service at a time, for different treatments and for different substance use problems. The introduction of a SLK, for the purposes of probabilistic record linkage, will allow an estimation of the number of clients accessing treatment. An SLK would also facilitate more powerful analysis to provide information on patterns of service usage, treatment pathways and the characteristics of groups of clients and agencies.

Statistical linkage

Statistical linkage provides the ability to link records with a high degree of probabilistic certainty (95%) **without** needing an individual's identity (Box 2). In this collection statistical linkage is proposed for statistical purposes only, not for the management of clients or services.

Linkage for the purposes of statistical analysis, research and informing policy is designed to provide information on the *patterns* of service usage, by *groups* of individuals. For example, by linking records, we can determine the average number of assessments provided to groups of clients with a specific profile before they move on to another treatment. This information is important to plan service delivery and gain a better understanding of the health issues faced by this population.

Very early in this project, the particular sensitivities related to the population included in this collection were considered, most notably that a large proportion of treatment episodes are for the use of illicit substances. Statistical linkage keys are used in a number of other collections, some where sensitive issues such as domestic violence, substance use and gambling form part of data collection (for example, the Supported Accommodation Assistance Program collection). The SLK does not require an individual's identity to be collected or reported. Therefore it was considered appropriate to pilot this SLK in the AOD sector.

By linking records within the collection it is possible to reduce double counting, to estimate the number of concurrent treatment episodes and provide a more accurate estimate of the number of people who access publicly-funded alcohol and other drug treatment services each year.

Box 1: Defining closed treatment episodes

The main unit of measurement in the AODTS–NMDS is the closed (completed) treatment episode. This concept has been used because it best reflects clinical practice within the AOD sector and captures quality information on service use. A closed treatment episode may be for a specific treatment that forms part of a longer term treatment plan, for example withdrawal management (detoxification) or it may not, for example information and education only.

Data reported for each treatment episode includes the commencement date, principal drug of concern, treatment type and cessation date. A new treatment episode begins when a different principal drug of concern is identified, a new treatment type begins, the treatment setting changes or an individual has had no contact with the treatment agency for three months (unless planned). With this understanding, it is possible for an individual to have concurrent treatment episodes for different substances, or different treatment types or in different settings. For example, a person may be seeking withdrawal management for alcohol use, and also receiving counselling for benzodiazepine use. These may be two separate treatment episodes and will appear as separate records in the collection. Further, an individual may access a service (or several) more than once in a collection period and each of these episodes will be reported.

As a consequence of these counting rules it is not possible to estimate the number of people who access AOD treatment within a reporting period or the pattern of service usage. This limitation also prevents research into how different treatment types fit together to form a treatment plan or pathway.

Box 2: Statistical Linkage Key 581

The components of the SLK581 are:

 – *second, third and fifth letters of the client's last name*

 – *second and third letters of the client's given name*

 – *date of birth (8 digits)*

 – *sex of the client (1–male, 2–female).*

For example, Joan Smith, female, born 11th May 1972, would have an SLK of: **MIH OA 11051972 2**

Piloting the SLK

As the AODTS–NMDS already contains date of birth and sex as data items, the two remaining components were piloted in Tasmania, the ACT and the NT, as these are small jurisdictions with the ability to make systems changes more readily than larger states. Three months treatment episode data containing the elements required to construct the SLK581 were transmitted to the AIHW for analysis. Some results from these analyses are presented below.

Table 1: Summary of pilot data records

Element	Total
Letters of first name	1,494
Letters of last name	1,494
No recorded response	779
Total valid episodes	1,281
Number of different SLKs	1,402
Total complete records	1,494
Total records	2,060

There were 2,060 records in the pilot data, of which 1,494 (73%) had the complete components of the SLK581. The records which did not contain the components were largely for episodes that commenced before the pilot began and the information could not be inferred from other records. Of the 1,494 complete records, there were 1,402 different SLKs which approximates to 1,402 'countable' individuals who accessed treatment during the pilot period. It is not possible to ascertain how many individuals there were in the entire data set as not all records contained the components of the SLK581, though the number will be higher than the 1,494 counted here. Of the 1,402 different SLKs, there were approximately 87 that appeared more than once in the dataset, some appearing three, four or more times. Unfortunately the pilot data set was not large enough to undertake analyses of different groups' patterns of service usage.

Apart from constructing the SLK581 to estimate the number of individuals and patterns of treatment, the Enhancement Project also undertook to examine if there were any tendencies for particular subgroups to decline to provide their information to construct the SLK (letters of their name). Specifically, it was hypothesised that those individuals who identified as Aboriginal and/or Torres Strait Islander and those people who identified as current injecting drug users (IDU) might be more reluctant to disclose this information.

Records that contained the variables for Indigenous status and IDU status were analysed. There appeared to be no difference between the response rate for individuals according to their Indigenous or IDU status. The rate of 'not stated/inadequately described' must be considered though, as individuals may choose to provide the components of the SLK and not their Indigenous or IDU status. A greater number of episodes are required for sensitivity and significance testing of this kind.

Information about the legislated privacy policies and procedures at the Australian Institute of Health and Welfare was provided to agencies and jurisdictions to allay any fears of individuals being identified or their information being disclosed to third parties.

This project found that the SLK581 appears feasible to implement into the AODTS–NMDS, given appropriate time and resources. Agencies and jurisdictions expressed no great concerns about aspects of the elements, their implementation or use. The data also showed that consistent and accurate collection is possible.

As jurisdictions have different data collection systems, implementation of the SLK may vary. In some instances changes can be made to underlying data collection software with no overt changes necessary to clinical practice or extra effort on behalf of the agencies. In other jurisdictions, complex information technology database changes will be required, with extensive training to be provided to agencies, their staff and volunteers.

Comorbidity

In this project, the term comorbidity refers to the co-existence of an alcohol or other drug problem and a mental health disorder. Research suggests that 10% of the Australian population experience a substance use disorder together with a mental health condition in a 12-month period; and 20–30% of Australians will experience comorbidity at some time in their lives (ABS 1998; Jablenski et al. 2000; Todd 2002). Further, it has been estimated that up to 80% of clients in AOD treatment have a co-occurring mental health condition (Burns & Teesson 2002). The 2007 National Survey of Mental Health and Wellbeing estimates are higher. The 12-month prevalence of a mental disorder was estimated at 20% and lifetime prevalence at 45% (ABS 2008). Given this increase in population prevalence estimates, we would expect a corresponding increase in prevalence in the AOD treatment population.

The National Comorbidity Initiative emphasises the importance of identifying and effectively managing those clients who are experiencing a substance use problem as well as a mental health disorder in treatment settings. The AODTS–NMDS currently contains no information on the mental health status of clients accessing alcohol and other drug treatment services and therefore cannot inform policy direction that would support the effective service provision to those clients.

Determining mental health status

The consultation phase of the project was used primarily to determine what information agencies already collected about mental health in the course of providing treatment. Over 80% of agencies currently collect mental health information, though method of collection varies. Most agencies ask the client directly about their mental health, including medication used and consultations with mental health professionals; some agencies use referral paperwork (Box 3)and contact with the client's doctor or medical practitioner; and others use observation and professional judgment. However, for implementation in the national collection, two questions were selected from the *PsyCheck* General Screener (Box 4).

Through the initial consultation, the AODTS–NMDS Working Group highlighted that the collection of mental health data should be done as sensitively and as accurately as possible. The selection of two questions from the *PsyCheck* General Screener satisfied both these concerns as they have been designed for use in AOD treatment services and had been statistically validated.

Box 3: Referrals to AOD treatment from mental health services

Since the beginning of the collection, there has been a steady proportion of referrals to treatment from mental health services (Figure 1). Referrals from psychiatric or other hospitals have been between 3–4% and referrals from community mental health services have been between 1.5–2.5% nationally.

Note that the source of referral category 'psychiatric and other hospitals' became 'hospitals' in the 2004–05 collection and a slight drop in the proportion of referrals from this source can be seen. A corresponding rise in the number of referrals from community mental health services may be an artefact of jurisdictional policy or a real change in service delivery; however, the combined proportion of referrals from mental health services remained steady. Clients with mental health problems may also self-refer or be referred from other sources so this element is not an accurate source of information for the mental health status of clients.

Per cent

Figure 1: Closed treatment episodes by source of referral

Box 4: The piloted mental health indicators

'PsyCheck: Responding to mental health issues within alcohol and drug treatment' is a tool developed by Turningpoint Drug and Alcohol Centre in Victoria, with funding from the Department of Health and Ageing. The evidence-based tool consists of four parts: screening, treatment, training and supervision guidelines and program implementation guidelines.

The first two questions of the PsyCheck General Mental Health Screener used in the Enhancement Project of the AODTS–NMDS are:

1. Have you ever seen a doctor or psychiatrist for emotional problems or problems with your "nerves"/anxieties/ worries? (Yes/No)

2. Have you ever been given medication for emotional problems or problems with your "nerves"/anxieties/ worries? (Yes/No)

Both these questions have been validated within AOD treatment settings and were found to be significantly correlated with the presence of an affective or anxiety disorder within the past month.

Given that the majority of agencies already collect mental health information, it was not surprising that, during the feasibility consultation, most agencies were supportive of using the *PsyCheck* questions. Of the agencies consulted, many were familiar with the tool and/or used it in practice already.

Metadata was developed to assist with piloting the new data elements. It was developed in the AIHW's online metadata registry, METeOR, with defined concepts, definitions and code sets. This development was undertaken with advice from the National Data Development and Standards Unit of the AIHW.

Of the 2,060 treatment episodes that constitute the pilot data, there were 970 records that contained a legitimate response code for question one and 953 records that contained a legitimate response code for question two. A legitimate response code is considered to be either an affirmative or a negative response to the question being asked and not a 'not stated/inadequately described' response in this instance.

Of the 970 records that contained a legitimate response code for question one and the 953 records that contained a response code for question two, 952 records contained both. A break down of these responses is shown in the table below.

Table 2: Indicator of mental health cross tabulation

Element	Never been given medication	Given medication in the past	Currently given medication	Total
Seen a doctor/psychiatrist	53	153	355	561
Not seen a doctor/psychiatrist	364	19*	8*	391
Total	**417**	**172**	**363**	**952**

* These cells contain the number of responses that are discordant with current understandings of mental health practice.

From these responses, there were 355 records where the client could be regarded as having a current mental health problem, e.g. they had seen a doctor or psychiatrist and were currently being given medication. As an affirmative response to one indicator alone has a statistically significant correlation with having an affective or anxiety disorder, an affirmative response to both questions is highly significant. Conversely, there were 364 episodes for clients who had never seen a doctor and had never been given medication for a mental health problem.

The challenge in interpreting these data lies in the combination of never having seen a doctor for an emotional problem and either having been given medication in the past or currently being given medication. These records are discordant with current understandings of mental health practice and are denoted by an asterisk in Table 2. It is recognised that these questions do not capture the difference between being given over-the-counter or alternative medications, nor do they capture those individuals who seek advice from an alternative health practitioner.

Though the SLK581 was piloted simultaneously, data quality prevented a reasonable estimate of the number of individuals who had a mental health problem within the data set.

The inclusion of a mental health indicator in the AODTS–NMDS has the potential to inform service planning. For clients who have a mental health disorder it will be possible to provide information on important variables such as the most common principal drugs of concern, treatment types provided and episode length. Analytical power will be increased in combination with the SLK581 as it will then be possible to estimate the number of people who access AOD treatment and have a mental health disorder.

Some concern was expressed during the project that the selected indicators will become less useful over time as new tools are developed in the field. As this collection consists of administrative by-product data and the majority of agencies already collect mental health information, the emphasis in this project has been on standardising the element rather than condoning a clinical practice. Should a more appropriate data element to capture mental health status become available, the AODTS–NMDS Working Group will consider implementing it.

Privacy

Given the sensitivities identified early in the course of this project, the AIHW undertook a Privacy Impact Assessment (PIA). The assessment was completed in accordance with guidelines from the Office of the Privacy Commissioner and included aspects of Commonwealth, state and territory law (Box 5). Members of the AODTS–NMDS Working Group were invited to contribute to the development of the assessment and the final report was provided to agencies during the feasibility consultation process.

While not compulsory, the PIA provided a sound basis for exploring and addressing aspects of privacy legislation upon which the success of the project rested and acceptance of increased data collection relied. By undertaking the assessment, the Working Group acknowledged the diversity in privacy legislation between jurisdictions and became familiar with the requirement of each state and territory for new elements to be introduced to the collection.

In general, the minimum requirement for the collection of information in the AODTS–NMDS is compliance with the National Privacy Principles (NPPs). In most states, the consent of clients for the information to be collected, stored and disclosed for specific purposes is required.

The PIA:

* indicated that current practices within jurisdictions are adequate to protect the privacy and confidentiality of individuals in the national collection
* confirmed that each state and territory maintain primary responsibility for appropriate privacy measures to be met by AOD treatment agencies
* outlined that, where appropriate, the AIHW will provide supplementary information on the privacy requirements under *The Australian Institute of Health and Welfare Act 1987*.

There are several other national collections which include what may be considered sensitive or personal information, specifically the name and date of birth components of the SLK581; for example, the Commonwealth State and Territory Disability Agreement collection (CSTDA), the Home and Community Care (HACC) collection and the Supported Accommodation and Assistance Program (SAAP) collection. These collections use a variety of consent procedures, the majority using an opt-out model where a minimum of information is collected should consent not be given. Due to contractual arrangements in the AOD treatment sector, it is not possible to impose a national model of consent on states and territories. The Working Group and the AIHW will keep abreast of changes in privacy legislation to ensure that data being provided for the collection is compliant.

Box 5: Sources of information about privacy

A PIA generally involves several steps, from scoping the issue to examining information flows and considering a privacy management strategy. A complete guide to Privacy Impact Assessments can be found at the website of the Office of the Privacy Commissioner: <www.privacy.gov.au/publications/pia06/index.html>.

The Australian Institute of Health and Welfare operates under specific privacy legislation to maintain excellent standards of privacy and confidentiality. This information, as well as the ethics approval processes of the Institute, may be found on the AIHW website: <www.aihw.gov.au/dataonline/privacy_of_data.cfm >.

Conclusions

Based on the findings from this project and the experience of other collections managed by the AIHW, the following conclusions have been drawn:

* It appears feasible to implement the SLK581 and indicators of comorbidity into the AODTS–NMDS as agencies are receptive and the elements are valid and reliable.

* Data from the SLK581 has the potential to answer important policy questions about how many people access treatment, how often and which treatment types as well as facilitating greater statistical analysis of other variables such as client characteristics.

* In line with the National Comorbidity Initiative, indicators of mental health should be included in the collection and the *PsyCheck* questions are appropriate for this purpose.

* Future analysis and reporting of data from the collection, if the SLK581 is implemented, must take into account the National Privacy Principles and consent procedures should be revisited regularly to maintain compliance with legislation and best practice within the collection.

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Acknowledgments

Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AOD	alcohol and other drug
AODTS–NMDS	Alcohol and Other Drug Treatment Services National Minimum Data Set
IDU	injecting drug use/user
PIA	Privacy Impact Assessment
SLK	statistical linkage key

bulletin 69