

**The National Minimum Data Set Project for
Alcohol and Other Drug Treatment Services:
report on the pilot study and
recommended set of data definitions**

Andrew Conroy and Jan Copeland

NDARC Technical Report No. 65

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NDARC Technical Report No. 65
ISBN No. 0 7334 0473 1

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Contents

List of figures and tables	3
Acknowledgments	4
1. Introduction	5
1.1 The National Minimum Data Set Project.....	6
1.2 Purpose and method of the pilot study.....	7
1.3 Summary of findings.....	8
1.4 Issues in national implementation.....	9
1.5 The format and content of this report.....	10
2. Evaluation of the pilot study data items	12
2.1 Establishment identifier.....	13
2.2 Date episode commenced.....	14
2.3 Person identifier.....	16
2.4 Client status.....	17
2.5 Date of birth.....	20
2.6 Sex.....	22
2.7 Country of birth.....	24
2.8 Indigenous status.....	25
2.10 Source of income.....	27
2.11 Type of usual accommodation.....	29
2.12 Living situation.....	31
2.13 Previous treatment for alcohol and other drug 2.14 problems.....	33 35
2.15 Source of 2.16 referral.....	37 40
2.17 Presenting problem 2.18 drug.....	42 44
2.19 Secondary problem drug.....	45
2.20 Method of use for presenting problem 2.21 drug.....	46 48
2.22 Method of use for secondary problem drug.....	50
2.23 Agency program 2.24 type.....	52 54
2.25 Main type of service provided.....	56
2.26 Other type of service provided.....	57
Reason for treatment termination.....	
3. Referral to further care	58
3.1 Problem drug treated.....	59
3.2 Methadone dose.....	59
3.3 Date episode terminated.....	60
Recommended data items and definitions	
Establishment identifier (Agency code).....	

Agency program type.....	
Date episode commenced.....	
3.4 Person identifier (Client code).....	60
3.5 Client status.....	60
3.6 Date of birth.....	61
3.7 Sex.....	61
3.8 Country of birth.....	61
3.9 Preferred language.....	62
3.10 Indigenous status.....	63
3.11 Source of income.....	64
3.12 Type of accommodation.....	65
3.13 Living arrangement.....	66
3.14 Prior use of alcohol and other drug services.....	67
3.15 Source of referral.....	67
3.16 Primary drug of concern.....	68
3.17 Method of use for principal drug of concern.....	69
3.18 Other drugs of concern.....	70
3.19 Injecting drug use.....	71
3.20 Main service provided.....	71
3.21 Other services provided.....	72
3.22 Reason for termination of episode.....	72
3.23 Referral to another service.....	73
3.24 Date episode terminated.....	73
4. Feedback from staff of participating agencies.....	74
4.1 Feedback on specific data items.....	75
4.2 Other feedback from participants.....	83
5. Appendices.....	88
5.1 Client episode form.....	89
5.2 Feedback questionnaire.....	92
5.3 Pilot study protocol.....	97
References.....	102

List of figures and tables

Figures

Figure 1: Episode lengths for different program types (≤ 31 days).....	13
Figure 2: Code name used for CARA Collection System (NSW Health).....	15
Figure 3: Code used for SAAP client form (SAAP/AIHW).....	16
Figure 4: Age distribution of clients.....	19
Figure 5: Mean age & age range for presenting problem drugs.....	20
Figure 6: Source of income.....	27
Figure 7: Presenting problem drug (most prevalent categories).....	37
Figure 8: Secondary problem drug (most prevalent categories).....	40

Tables

Table 1: Client status.....	17
Table 2: Sex.....	21
Table 3: Type of usual accommodation.....	29
Table 4: Living situation.....	30
Table 5: Previous treatment for alcohol and other drug problems.....	32
Table 6: Source of referral to agency.....	34
Table 7: Presenting problem drug.....	38
Table 8: Method of use for presenting problem drug.....	41
Table 9: Method of use for secondary problem drug.....	43
Table 10: Agency program type.....	44
Table 11: Main type of service provided.....	46
Table 12: Other type of service provided.....	47

Table 13: Reason for treatment
termination.....
Table 14: Referral to further
care.....
Table 15: Problem drug
treated.....

Acknowledgments

● **The following agencies took part in the pilot study, on a voluntary basis. Thank-you to the staff of the agencies for handling the extra work involved.**

ADFACT Men's Halfway House, Canberra
Alcohol & Other Drug Services, Casuarina
Alcohol & Drugs Service(North/North-West)Tasmanian Dept Community & Health Services
Alcohol & Drug Service - Community Teams, Prince Charles Hospital & District Health Service
Alcohol, Tobacco & Other Drug Services, Cairns
Alcohol, Tobacco & Other Drug Services, Townsville
Community Unit, Alcohol & Drug Program, ACT Community Care
Council for Aboriginal Alcohol Program Services (CAAPS)
Drug & Alcohol Department, Royal Prince Alfred Hospital (Sydney)
Kamira Farm
Kuitpo Community, Adelaide Central Mission
'Missiondale', Launceston City Mission
Moreland Hall
Salvation Army, St Kilda
South Metro Community Drug Service Team (Palmerston Association)
Sunraysia Community Health Services
Warrnambool & District Base Hospital
Western Australian Alcohol & Drug Authority
Youth Drug & Alcohol Service, Wollongong

● **Thanks also to those Advisory Group members & others who provided advice and assistance for this study.**

Dr Felicity Allen, Drug Treatment Services Unit, Victorian Dept of Human Services
Ms Ros Carter, Drug Treatment Services Unit, Victorian Dept of Human Services
Mr Peter Connie, Network of Alcohol & Drug Agencies
Ms Skye Fraser, Alcohol and Drug Services, Tasmanian Dept of Community & Health Services
Assoc Prof Margaret Hamilton, Turning Point Alcohol and Drug Centre
Mr John Leary, Alcohol & Drug Services, Tasmanian Dept of Community & Health Services
Mr Chris McDonald, Western Australian Network of Alcohol & Other Drug Agencies
Mr Barry Masterton, Alcohol, Tobacco & Other Drug Services, Queensland Health
Ms Jan Parr, Alcohol, Tobacco and Other Drug Services, Queensland Health
Ms Julie Perrin, Alcohol & Drug Program, ACT Community Care
Dr Janis Shaw, Australian Institute of Health and Welfare
Mr Greg Swensen, Western Australian Drug Abuse Strategy Office
Ms Mitch Trevena, Alcohol & Other Drugs Program, Territory Health Service
Ms Pat Ward, Drug Treatment Services Unit, NSW Health
Mr Malcolm Wares, Commonwealth Dept of Health & Aged Care

1. Introduction

This introduction provides background information about the National Minimum Data Set Project for Alcohol and Other Drug Treatment Services and an overview of the pilot study. The overview includes an explanation of the purpose and methodology of the study and a summary of the findings of the study. This section also outlines the key issues that remain for the national implementation of the data set, and describes the content of the body of the report.

1.1 National Minimum Data Set Project for Alcohol and Other Drug Treatment Services

1.1.1 Purpose of the NMDS-AODTS

The National Minimum Data Set Project for Alcohol and Other Drug Treatment Services (NMDS-AODTS) was conducted in response to a demand for a national collection of data about the clients and activities of alcohol and other drug (AOD) agencies. The aim of the project was to develop the framework that is required before the collection of this data could occur. This framework includes data definitions and guidelines for the collection and use of the data.

The purpose of collecting the NMDS-AODTS is to provide information that is useful for developing services and policies throughout Australia. A national data set could contribute, in conjunction with other information sources, to an evidence-based approach to national policy development. A greater availability of comparable and consistent data would enhance the capacity of the AOD sector to advocate for particular types of services and different target groups. It would also provide agency coordinators with access to basic data relating to particular types of communities, drug problems and interventions that are relevant to their own circumstances. The data items that comprise the set are also intended to be relevant to the management of individual AOD interventions.

1.1.2 Background

A national forum conducted by the Alcohol and Other Drugs Council of Australia (ADCA) in 1995 created the initial impetus for this project. This forum examined barriers between research and practice within the alcohol and other drug sector. The forum participants, including agency staff, researchers and administrators, agreed that a lack of comparable data on clients and interventions was impeding the development of the sector. A recommendation to work towards the establishment of an agreed minimum data set and national implementation strategy was strongly supported (ADCA, 1995).

In response to this recommendation, a study was conducted by the National Drug and Alcohol Research Centre (NDARC) in 1997, which examined the feasibility of establishing a national minimum data set. This study reviewed existing data collection practices in all States and Territories.

It found that in spite of differences and inconsistencies between regions and programs, the data that is collected by treatment agencies generally contains the categories of client and service delivery information that would be required to develop a national minimum data set (Rankin, 1997). A proposal for the current project was subsequently developed.

1.1.3 The current project

The current project has been included as part of the *National Health Information Work Program*, an official work program that occurs as a result of the National Health Information Agreement. The *National Health Information Agreement* was signed by Commonwealth, State and Territory governments in 1993 - "to ensure that the collection, compilation and interpretation of national information are appropriate and are carried out efficiently" requiring "agreement on definitions, standards and rules of collection of information and on guidelines for the coordination of access, interpretation and publication of national health information" (AHMAC, 1994). The National Health Information Work Program includes any activities that occur within the terms of this agreement.

Within this project the main work has involved the development of a standard set of data items, and the methods for the national collection of these items. Data items are basic categories of data (e.g. sex, age, date of birth) that may provide information about a person, an organisation or an event. For the NMDS-AODTS, these data items are drawn from the questions that appear on client registration forms and other forms used by alcohol and other drug agencies. Because of the lack of established data standards in the AOD sector, the development of data items has required extensive consultation as well as the testing of data items within agencies. For the data set to fulfil its purpose all of the data items have to be relevant and appropriate to the day-to-day work of AOD agencies.

1.1.4 Project coordination and consultation

The project team for the NMDS-AODTS is based at the National Drug and Alcohol Research Centre. With the cooperation of all States and Territories the project team established a National Advisory Group to assist in the development of the data set. This group comprised government and non-government representatives from the different jurisdictions. With the assistance of the National Advisory Group, the staff at NDARC have conducted a series of activities to gain input from the AOD sector. This consultation process has formed the basis for designing the data items that were used in the pilot study.

As part of the process of developing the pilot data items, NDARC conducted a national survey, a series of forums and also maintained other forms of dialogue with the treatment field. The national survey provided the opportunity for input from a range of service providers and administrators. There was a strong response to the survey, with over one hundred surveys returned from the 230 that were mailed out. A broad mix of government, non-government and private services were represented in the responses, comprising hospital-based services, residential and non-residential community services (including specialised services for particular target groups), information and referral services and methadone prescribers. The content of the responses was generally very thorough, with most respondents completing all sections of the survey and offering detailed comments and suggestions.

Forums have been held in various capital cities, including Perth, Sydney, Adelaide, Brisbane, Canberra, Melbourne and Darwin. These forums were arranged to provide an opportunity for people, from a variety of sectors in different jurisdictions, to discuss design and implementation issues for the data set. Additional methods have been employed to promote awareness of the project, including service newsletters, conference papers, e-mail notices and announcements at a variety of meetings.

There were also efforts made to utilise established data standards. The project team has looked into existing standards for the development of the data set definitions, such as the Australian Bureau of

Statistics demographic codes and the International Classification of Diseases, as well as some specialist classification systems. There is, however, less opportunity to define data according to established systems within the alcohol and other drug sector than there is within mainstream health services.

In order to learn from the experiences of others, there has been an examination of established AOD data sets in several countries, including Holland, the United Kingdom, Germany, the United States, Canada and Hong Kong, as well as some ongoing dialogue with some of the research bodies responsible for the development of these data sets. Although there are quite different circumstances in terms of the drug problems and treatment policies and services between the different countries, the technical considerations and many of the issues encountered in the development of the data sets are the same (Ogborne, 1998; Crabbe, 1995).

Support and coordination of this project is also being provided by the Australian Institute of Health and Welfare (AIHW). The AIHW is the principal national body for health and welfare data development. Its role in the project is primarily one of providing technical expertise and collaborating with other health and welfare sectors. This collaboration involves ensuring that there is a unified approach to the development of data elements that are relevant to different sectors.

1.2 Purpose and method of the pilot study

The pilot study for the NMDS-AODTS involved the collection of standardised client and service data by nineteen agencies nationally, over a six week period between June and August in 1998.

This data was composed of a set of data items (questions) covering basic registration information, socio-demographic information, 'problem' drugs, methods of drug use, services provided to the client, and referral and separation information. Because of the lack of established data standards in the alcohol and other drug sector, these data items were designed through a process of consultation with agency staff, administrators and researchers.

The purpose of the pilot study was to assess the validity of the data set items and definitions, the ability of agencies to collect this data consistently, and the type of support and systems required to collect and compile this data nationally. The pilot was designed to inform any necessary modifications to the data set, and contribute ideas towards a plan for its implementation.

In all jurisdictions, except South Australia, representatives of government departments, and in some instances non-government peak bodies, assisted in the coordination of the NMDS-AODTS pilot study. This assistance included the recruitment of agencies, the dissemination of information and materials to these agencies and the compilation of the data forms.

Among the nineteen agencies that participated, 11 were government services, comprising two hospital and nine community agencies. The remaining eight agencies were non-government organisations, including two therapeutic communities, as well as specialist agencies for indigenous Australians, women and men. There was a total of 1395 cases recorded by these agencies during the six week period.

All of the agencies that took part in the pilot study were sent a protocol (set of guidelines - see section 5.3) for the conduct of the study and a briefing kit to support on-site briefing sessions for

the agency staff. They also received copies of a standard paper form (client episode form) for recording the data. The data was recorded in paper format in all instances, due to the short term nature of the pilot.

These forms were accompanied by a set of definitions for the data items. The definitions included explanations for each of the data items, in regard to their meaning and the rationale for their collection, as well as a copy of the coding scheme (such as a drug coding scheme) for each item.

As outlined in the protocol for the project, the data was to be collected by each of the agencies at the time when a client was registered with the agency, and when the period of treatment or contact with the agency had ended (treatment termination). The NMDS-AODTS data was to be collected in these situations for all clients.

1.3 Summary of findings

1.3.1 Summary of pilot data findings

The vast majority (95%) of clients that were included in the study were presenting in relation to their own drug issue (primary clients), rather than on behalf of another person. The average age for these primary clients was 32 years, and 30% of them were female. The majority (84%) were Australian-born. This figure includes clients that were of a different cultural and/or linguistic background, since it does not distinguish between 'second-generation' residents (those who were born in Australia of migrant parents) and other people born in Australia. A further 10% were indigenous Australians; this figure may be relatively high due to the participation of a specialist Aboriginal service in the study.

The most common presenting problem drugs were alcohol (36.4%) and heroin (28.9%). Opiates as a combined group (including heroin, methadone and other opiates) exceeded alcohol in prevalence as a presenting problem drug. Tobacco (10%) and cannabis (14.2%) were the most common secondary problem drugs. While about 47% of primary clients consumed their 'presenting problem drug' orally, a further 37% indicated that they injected the drug (as their usual method of administration). Nearly half (49%) of all primary clients who indicated a secondary problem drug usually smoked this secondary drug.

Over a third (41.5%) of clients were self-referred. Brief interventions were common, with 28% receiving only assessment or information and education with at least 17% of interventions being conducted within a single day. Inpatient or residential withdrawal services accounted for 17.5% of all of the principal services provided. Counselling comprised 9% of the principal services and 20% of the other services provided. Around one in three (29%) of the episodes were still in progress at the end of the pilot study.

1.3.2 Use of the client episode forms and design issues for the data items

The client episode forms that were provided for the agencies were similar in their general content to the forms already being used by most of the participating agencies. Consequently, most of the staff involved had some degree of familiarity with the general task of collecting client information. The greatest difficulty experienced was with the data collection workload, with the staff of some of the agencies having to conduct a double collection of data, for their existing system and for the NMDS-AODTS pilot study.

Nearly all of the forms received from the agencies were completed satisfactorily, with only a small proportion of them containing minor errors. The most common problems with the use of the forms involved the selection of multiple items, where the question allowed the selection of one

option only in accordance with NHDD conventions. The multiple selection of options occurred mainly for the items: 'previous treatment for alcohol and other drug problems', 'main type of service provided', and to a lesser extent the 'presenting problem drug' and 'secondary problem drug'. These problems occurred as a result of faults with the design of the form and also as a result of inadequate training for specific items.

It was shown through the experience of the pilot study that, for the items 'previous treatment for alcohol and other problem drugs' and 'secondary problem drugs', there is often more than one category that is significant for a client. In response to this fact, these items have been redesigned to allow for multiple options. In some cases data for particular items were omitted, most commonly the 'person identifier'. In regard to this item, the omissions may have been due in part to agencies having no established method for generating an identifier, and agency staff not learning of the item's meaning or purpose.

The greatest proportion of missing data occurred due to the time limitation of the study, rather than as the result of errors. Due to the short duration of the pilot study (6 weeks) there was a high percentage of incomplete cases, and cases commenced prior to the pilot study. These two factors resulted in the omission of the data to be completed on registration and the data to be completed on termination, respectively.

The language used for some of the items, such as 'establishment identifier', 'person identifier', 'treatment', and 'problem drugs' was found by some agency staff to be unclear or inappropriate. Some of this terminology had been directly sourced from NHDD data items, which had been developed for use within predominantly institutional settings. The data items containing this language have been modified accordingly within this report (see section 3).

1.4 Issues in national implementation

Before the proposed NMDS-AODTS can be implemented, it requires formal approval by government representatives in every jurisdiction, including those responsible for AOD services as well as those responsible for the management of health information.

The National Health Information Committee (NHDC) is the peak body responsible for reviewing the data items and approving their inclusion in the National Health Data Dictionary, together with their annual compilation by the Australian Institute of Health and Welfare (NHDC, 1997). In order to gain approval by the NHDC, the definitions must conform to established data management and ethical principles. In the instances where AOD data items are to be used by other health and welfare sectors, the definitions must also be consistent with the needs of these other sectors (AHMAC, 1994).

The Inter-governmental Committee on Drugs (IGCD) is the peak body responsible for approving the implementation of the data set within the government-funded AOD sector. This committee must formally auspice the NMDS-AODTS before the collection of the data set can be approved by the NHDC. The IGCD has formed a working group to develop formal guidelines regarding the collection and specific purposes of the data set.

If the proposed data set (or a portion of the proposed data set) is approved by these groups, the collection of data may commence in July 1999. There has also been some provision made for the

further development of the data set; each of the data items would be subject to ongoing review on the basis of the value and reliability of the data collected.

1.5 The format and content of this report

The remainder of this report comprises an examination and re-working of the NMDS-AODTS data items. Section 2 reports on the data items that were used in the pilot study, section 3 consists of a revised set of data items and definitions, and section 4 contains the feedback from the agency staff who collected the data.

Section 2, the 'evaluation of the data items', examines each of the data items separately. The review of each data item includes the definition of the item that was used in the pilot study, a preliminary analysis of the aggregate data from the study, and a review of the data item based on the quality of the data collected as well as feedback on the use of the item by agency staff. The aggregate data in this section relates only to primary clients (those presenting in regard to their own drug use), unless otherwise stated. The percentages that are given are valid percentages (i.e. percentages that exclude missing data), unless otherwise stated.

The revised data set in section 3 is based on the data item reviews contained in Section 2. The feedback in section 4 was primarily drawn from a questionnaire that was sent out to all participating agencies. A copy of the questionnaire is contained in an appendix (section 5.2) of this report.

2. Evaluation of the pilot study data items

Within this section each of the data items that were used in the pilot study are examined. The definitions that were used in the pilot study are provided. For each item, there is also an analysis of the data collected, and a review of the data item based on the quality of the data and the feedback received from participants. Each review comments on proposed changes to the data item arising from the pilot study.

2.1 Establishment identifier

2.1.1 Pilot data definition

Definition: Identifier for the establishment in which episode or event occurred. Each separately administered health care establishment to have a unique identifier at the national level.

Comment: An establishment is considered to be separately administered if managed as an independent institution for which there are financial, budgetary and activity statistics. Will enable linkage of services to one episode of care.

2.1.2 Preliminary findings from the pilot data

There is no breakdown of data by agency (establishment) for this pilot study, given the scope and constraints of the study. There was no regional analysis due to the small scale of the study. Consequently, this data item was only used for the purpose of data administration within the pilot study, and there is no data to present for this item.

'Establishment identifier' is one of two 'establishment-level' data items used in this pilot study, meaning that it provides information about the agency as a whole. (The other item is 'agency code'). There was no nationally consistent identifier used for this pilot. Agencies used existing identifiers or created ones for the purpose of the pilot study.

2.1.3 Review of the data definition

The definition in the National Health Data Dictionary (NHDD) specifies that the identifier is to be composed of:

N - State identifier

N - Establishment sector

A - Region code

NNN - Establishment number

The first two components (state identifier and establishment sector) are sourced from a coding list provided in the NHDD. 'State identifier' is comprised of a 9 code list and 'establishment sector' is merely comprised of 'public', 'private' and 'repatriation'. The region code is to be specified by the individual states and territories, presumably based upon area health services or local government areas. 'Establishment number' is a 3-character identifier for the actual agency, unique within the state or territory. Again, this number would be formulated at the state/territory level. In combination with the other components, it would form a unique identifier at the national level.

From discussions within the NMDS-AODTS project, it is anticipated that this identifier would only be used for administrative purposes at the area or state/territory level.

Agencies may have their own internal coding to specify different client groups. It has also been suggested that the establishment number could reflect the type of agency, to allow an assessment of how the activities and clients of an agency correspond with its defined role.

It is agreed that concepts such as "establishment identifier" could be expressed in a simpler way., and it may be better to use a more recognisable term, such as "agency code", on the client forms. The code for an agency could be pre-printed on all of the agency's forms.

2.2 Date episode commenced

2.2.1 Data definition used in the pilot study

Definition: Date on which a client commences an episode of care.

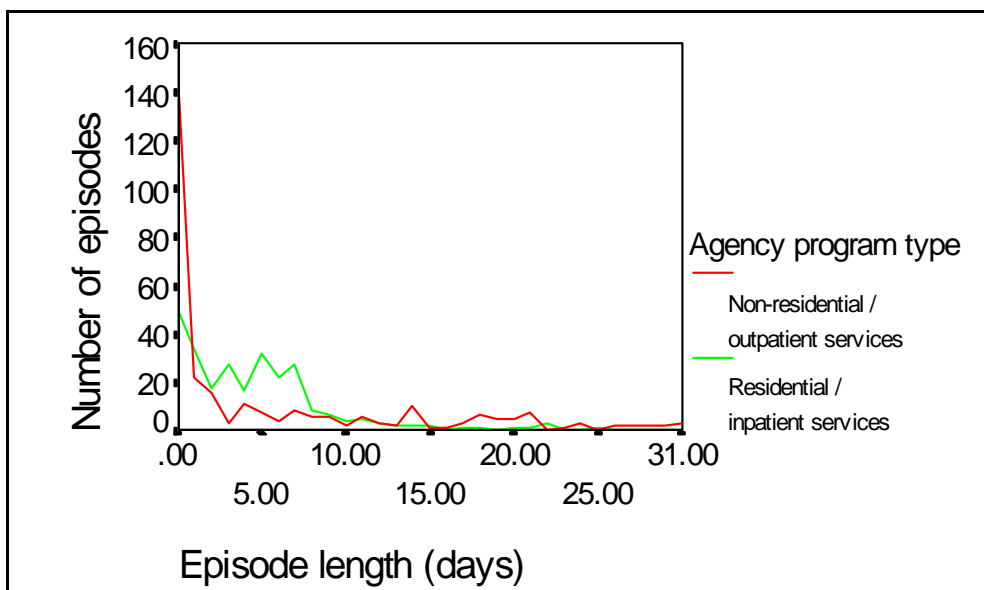
Context: Required for discerning different episodes of care and the analyses of general trends. It also enables the analyses of the progress of persons through different episodes of care, including the calculation of intervals between different episodes (in conjunction with 'Date episode terminated').

2.2.2 Preliminary findings from the pilot data

The application of this item is limited within the context of the pilot study, because the duration of the study only covered a six week period, and consequently does not allow for the analysis of trends or patterns of service utilisation or drug issues.

This item is used in conjunction with 'date episode terminated' to define the length of an episode. There were no missing cases for this item. There were some cases where the commencing date was not properly completed and a commencing date was derived from the terminating date.

The episode length ranged from same day episodes to an episode of nearly three and a half years. Figure 1 shows the number of episodes of different lengths (up to 31 days) for residential/inpatient and non-residential/outpatient programs.



There were 616 cases where the episode length was missing; these cases were largely because of missing termination dates, which were mostly due to incomplete episodes. For all cases relating to primary clients, the most common episode length was less than one day (222 cases or 17% - including missing cases). More than a third (40%) of episodes were of a duration of 10 days or less. Less than one in ten episodes (7.5%) were of a duration of more than 30 days. The high proportion of incomplete episodes (29%), however, may affect these figures. Also, these figures vary greatly between residential and non-residential programs. As expected, there were far more same day episodes for outpatient/non-residential programs than for inpatient/residential and therapeutic communities (25% compared to 16%). There were, however, more residential interventions that were completed within 10 days (82.5% compared to 41%). About nine out of ten (89.5%) residential withdrawal interventions were completed in 10 days or less. Nearly all interventions of this type (98%) were completed in less than one month.

2.2.3 Review of the data item

It is not the role of the currently proposed data set to record the entire workload of alcohol and other drug agencies. This type of information can be derived, as part of further developments, from 'establishment-level data' that records the general activities and resources of agencies without any connection to the details of specific clients. The role of the current client-based set is to develop a descriptive analysis of the clients and programs of agencies. Consequently, it is only appropriate to record agency contact with clients in cases where a client has been registered with a service (including an assessment of the client) and an intervention program is adopted in response to the information gained from the registration process. This excludes a great deal of outreach work, where it is impracticable to record the details of clients. The necessary omission of this type of information within client-based data does not preclude maintaining a 'count' of such contacts and also obtaining qualitative data. (The 'outreach' category included in 'agency program type' refers to mobile services provided for rural and remote communities).

The use of the concept of an episode, although imperfect, does allow for the progress of a specific intervention to be followed. Episode-based data also facilitates a clearer assessment of trends relating to drug use issues and service utilisation, by defining the time frame of separate interventions.

2.3 Person identifier

2.3.1 Data definition used in the pilot study

Definition: Person identifier unique within establishment or agency.

Context: This item could be used for editing at the establishment or collection authority level and, potentially, for episode linkage. There is no intention that this item would be available beyond collection authority level.

Guide

for use: Individual establishments or collection authorities may use their own alphabetic, numeric or alphanumeric coding systems. However, a recommended method of deriving a consistent identifier is by using the person's first three letters of their surname, their date of birth, and the code for their sex (see 'Sex' data element) eg FEH3109731.

2.3.2 Preliminary findings from the pilot data

There are no data to report for this item. This category of data is for the use of area health services and jurisdictions, and is not for reporting at the national level.

2.3.3 Review of the data item

Any identifier used should fulfil the primary requirement of maintaining the anonymity of the de-identified client record (a record that is stripped of information that explicitly identifies the client, such as name and address). As a secondary consideration, it should provide a code that is unique and reliable as possible, so that the use of services by distinct or 'unique' clients can be discerned.

The person identifier suggested in the pilot study definition (using first 3 characters of first name, first three characters of surname, date of birth and the code for the person's sex) was based upon a system used within an existing client data set. A variety of other systems for creating a person identifier have been reviewed during the course of this project. Some of these involve different

configurations of the letters of the person's names and initials, and are less reliant on other identifying components, such as birth date and sex. These systems involve a more complex arrangement of characters, which makes the resulting identifier more difficult to 'decode', but also requires greater care by the worker constructing it. The figures below provide some examples of identifier systems that have been used. The code name represented in figure two was used within the Clients at Residential Agencies (CARA) database by the Drug and Alcohol Directorate of the



CODE NAME	—	— — — —	— —
	1st character	1st 4 characters	1st 2 characters
	2nd GIVEN	of SURNAME	of 1st GIVEN
	FORENAME		FORENAME



ALPHA CODE	2ND & 3RD	1ST & 2ND	LAST LETTER	M/F FOR
	LETTERS	LETTERS OF	OF SURNAME	MALE
	OF FIRST NAME	SURNAME		OR FEMALE

New South Wales Health Department. The CARA database was comprised of client data, collected

on admission and discharge, from 23 non-government residential agencies. Figure 3 shows the code system used on the client forms for the Supported Accommodation Assistance Program (SAAP). The SAAP data set, managed by the Australian Institute of Health and Welfare(AIHW), is comprised of data from these forms and related sources.

It is proposed that the suggestion put forward by one of the participating agencies be adopted within the revised data definition, pending a further review. The suggested system has the advantage of being simple to derive, and is similar to the model suggested in the pilot study definition, while providing greater anonymity. It comprises the first two letters of the surname, the first two letters of the first name and the year of birth (see the example provided in the feedback section - 4.1.3). It is yet to be determined how unique or reliable this system would be within a larger data set.

Because this item of data is not to be available beyond the collection authority level, the choice of systems used is the prerogative of the individual states/territories or area health services. As with the 'establishment identifier', it is proposed that a simpler name, such as 'client code' be provided for this data item on the forms used.

2.4 Client status

2.4.1 Pilot data definition

Definition: The status of the person in relation to the drug use problem being treated, in terms of whether it is their own drug use problem or the problem of another person.

Context: Required to differentiate between primary and secondary clients, given the significant proportion of secondary clients presenting to alcohol and other drug treatment agencies.

Data Domain:

- 1 Own drug use problem
- 2 Other's drug use problem
- 9 Not known

2.4.2 Preliminary findings from the pilot data

Primary clients (those presenting for their 'own drug use problem') formed the overwhelming majority of cases. Secondary clients (those presenting for another's drug use problem) comprised only 5% of the pilot sample. Within a full national data set, however, the data pertaining to secondary clients could be analysed within regions with a greater prevalence of these clients. There were only 7 cases with (.5%) missing data.

	n	Percent
Own drug use problem	1318	95.0
Other's drug use problem	66	4.8
Not known	4	.3

2.4.3 Review of the data item

As recommended in the feedback received from agency staff (section 4.1.4), the word 'problem' should be deleted from this item, to leave the categories as 'own drug use' and 'other's drug use'.

This item was included in the data set at the request of the staff of several different agencies, who stated that 'secondary clients' (those presenting about another person's drug use) form a considerable proportion of the interventions of some agencies, particular those within remote or rural communities. As for primary clients, only those cases where the client is registered, and there was some form of intervention comprising at least an assessment, would be included within this client-level data set.

Furthermore, it was worthwhile defining these client groups for the purpose of reporting on the data, so that the data items that were more significant and reliable in relation to primary clients could be analysed appropriately through the separation of cases that pertain to this group of clients.

At 5% of the total client group for this sample, it is suggested that the issue of secondary clients requires further consideration, and should be retained pending further review. The use of this item within a fully implemented data set, on a national or even a state-wide scale, should provide a clearer indication of its utility, given the participation of a greater number of rural and remote services within such a set.

2.5 Date of birth

2.5.1 Data definition used in the pilot study

Definition: The date of birth of the person.

Context: Required to derive age for demographic analyses and analysis by age at admission or separation.

Guide

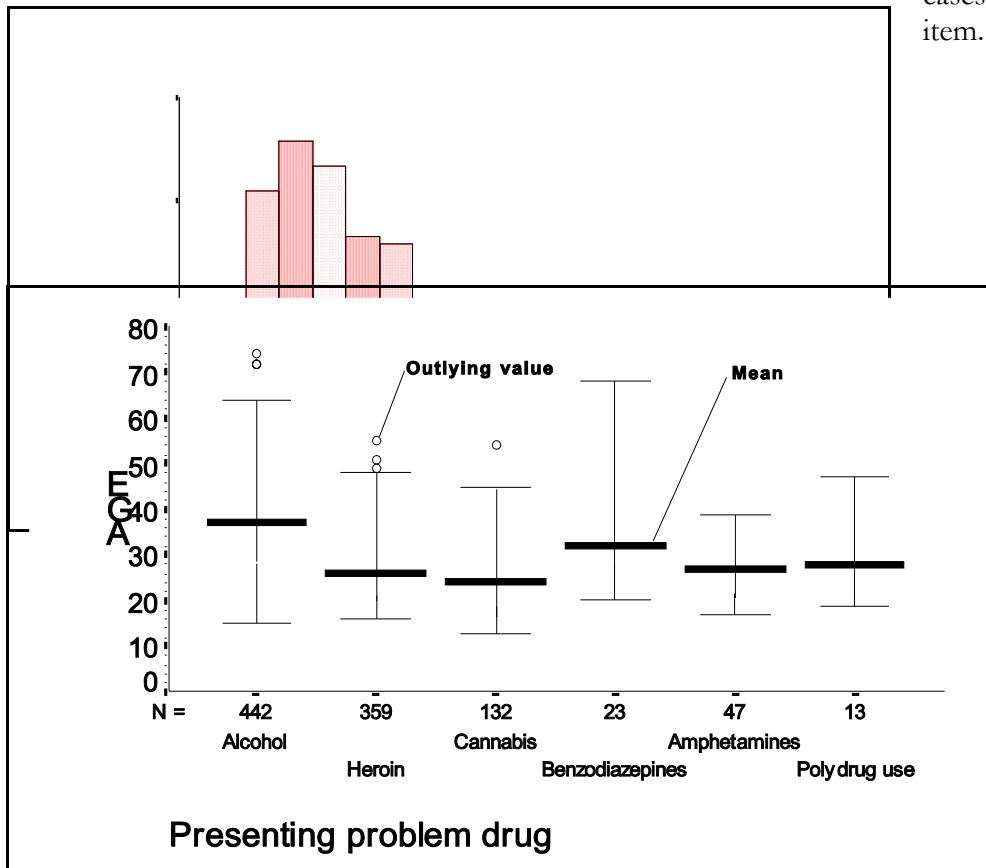
for use: If date of birth is not known, provision should be made to collect age (in years) and a date of birth derived from age.

2.5.2 Preliminary findings from the pilot data

This item is used to calculate the age of people at the time of the occasion of service (commencement or termination of episode). It also may be used as a component of the 'person identifier'.

The age of all primary clients ranged from 12 to 74 (distribution in figure 4), with the average age being 32 years. The age characteristics of clients varied greatly in relation to the 'presenting problem drug', as well as other factors. Figure 5 shows the mean age and the age range for clients presenting for different problem drugs. The mean age for alcohol was the highest, at 37 years. Clients presenting for cannabis had a mean age of 26 years, which was the lowest out of all the of the common presenting problem drugs.

There were 49 missing cases (3.7%) for this item.



2.5.3 Review of the data item

It is proposed that this item should be retained in its current form. Staff training should highlight the importance of recording the date of birth for all clients, or a date of birth derived from the person's age if the date of birth is unattainable.

2.6 Sex

2.6.1 Data definition used in the pilot study

Definition: The sex of the person.

Context: Required for analyses of service utilisation, needs for services and epidemiological studies.

Data domain:

- 1 Male
- 2 Female
- 9 Not stated/inadequately described

2.6.2 Preliminary findings from the pilot data

70% of primary clients presenting to the services in the pilot study were male. The proportion of female clients differed significantly according to the 'presenting problem drug'. A larger percentage of females presented with amphetamines as their 'presenting problem drug' (44%) than presented with heroin (30%) or alcohol (29%). This is consistent with the findings of other studies of the clients of alcohol and other drug services. There were 33 (2.5%) missing entries.

	n	Percent
Male	902	70.2
Female	380	29.6
Not stated/inadequately described	3	.2

2.6.3 Review of the data item

The recently revised definition for the National Health Data Dictionary states that:

"The term 'sex' refers to the biological differences between males and females, while the term 'gender' refers to the socially expected/perceived dimensions of behaviour associated with males and females - masculinity and femininity. The ABS [Australian Bureau of Statistics] advises that the correct terminology for this data element is sex. Information collection for transsexuals and people with transgender issues should be treated in the same manner. To avoid problems with edits, transsexuals undergoing a sex change operation should have their sex at time of hospital admission recorded."

It is proposed that the definition in use for the NMDS-AODTS remain as 'sex', so that the question may be used in the most simple and consistent manner possible, and conform with common practice throughout the health and welfare sectors.

The current NHDD definition also suggests the following format for data collection:

What is your (the person's) sex?

Male

Female

It is thought to be necessary to record the sex of the person because of gender issues affecting the nature and consequences of drug use, and appropriate forms of intervention.

2.7 Country of birth

2.7.1 Data definition used in the pilot study

Definition: The country in which the person was born.

Context: Health services: Ethnicity is an important concept, both in the study of disease patterns and in the need for and provision of services. Country of birth is the most easily collected and consistently reported of possible ethnicity data items.

Comment: As defined in the ABS Directory of concepts and standards for social, labour and demographic statistics, 1993.

Data

Domain: Australian Standard Classification of Countries for Social statistics (ASCCSS)
4-digit (individual country level). ABS catalogue no. 1269.0

Guide

for use: Write down the person's stated country of birth - to be coded subsequently.

2.7.2 Preliminary findings from the pilot data

The country of birth for overseas-born clients varied widely and was not concentrated within any single region. In total, 16.2% of the agencies' clients were born overseas. It is important to recognise that these figures understate the proportion of clients who were from a different ethnic background, because it only accounted for first generation residents. Some of the agencies indicated that second generation residents form a far greater proportion of their clients than first generation residents.

Clients born overseas were far more likely to be homeless than their Australian-born counterparts (10% 'no usual residence' for overseas-born compared to 5% for Australian-born) and are more likely to live alone (28% compared to 23%). A greater proportion of these clients were male, at 78.6% compared to 68.3% of Australian-born clients.

Nearly one in ten of the clients (9.5%) were born in non-English speaking countries (countries where the principal language is not English).

2.7.3 Review of the data item

Given the considerable number of first-generation migrants appearing within this sample, it is proposed that this item be retained. It is also proposed that an item for 'preferred language' be added to the data set, to gauge the need for interpreter services. This additional item will also assist in gauging the proportion of clients who are from different cultural or linguistic backgrounds including those born in Australia.

2.8 Indigenous status

2.8.1 Data definition used in the pilot study

Definition: An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives (High Court of Australia in *Commonwealth V Tasmania* (1983) 46 ALR).

Context: Given the gross inequalities in health status between indigenous and non-indigenous peoples in Australia, the size of the Aboriginal and Torres Strait Islander populations and their historical and political context, there is a strong case for ensuring that information on indigenous status is collected for planning and service delivery purposes and for monitoring Aboriginal and Torres Strait Islander health.

Data Domain: 1 Indigenous - Aboriginal but not Torres Strait Islander origin

- 2 Indigenous - Torres Strait Islander but not Aboriginal origin
- 3 Indigenous - Aboriginal and Torres Strait Islander origin
- 4 Not indigenous - not Aboriginal or Torres Strait Islander origin
- 9 Not stated

2.8.2 Preliminary findings from the pilot data

10% of clients were indigenous Australians; 109 (8.6%) were Aboriginal, 6 (0.5%) were Torres Strait Islanders and 12 (0.9%) were of both Aboriginal and Torres Strait Islander origin.

The indigenous clients within this study tended to have different social circumstances and different drug issues from the non-indigenous clients. The 'presenting problem drug' was alcohol for 60% of indigenous clients compared to 34% for non-indigenous clients. In contrast, heroin was less prevalent for indigenous people, with 13% presenting on account of this drug, compared to 30% of non-indigenous people. In regard to cannabis, however, the proportions were the same for indigenous and non-indigenous people, at 11% for both groups. Indigenous clients were less likely to be employed (12%) than non-indigenous clients (20%).

Around one in five (19%) of indigenous clients had no usual residence, compared to 4.4% of non-indigenous clients. Indigenous people were less likely to complete a program of treatment (28% compared to 45%), and were more likely to be imprisoned (2% and 1% respectively) during the period of contact with their alcohol and other drug agency.

2.8.3 Review of the data item

As stated in the feedback received from agency staff (section 4.1.8), the coding as presented on the 'client episode form' for this pilot was too clumsy. There are, however, numerous cases of clients who are of both Aboriginal and Torres Strait Islander descent. It is proposed that three options be provided in response to the question of origin, in the following manner, as suggested in the revised NHDD definition:

Aboriginal or Torres Strait Islander origin?

1 No

2 Yes - Aboriginal

3 Yes - Torres Strait Islander

If the person is of both Aboriginal and Torres Strait Islander descent, then multiple options may be selected.

The reason for collecting the question is as outlined in the definition provided to the pilot agencies (under 'context'), which is provided in section 2.8.1 (above).

2.9 Source of income

2.9.1 Data definition used in the pilot study

Definition: The person's main source of income, comprising fifty percent or more of their total income.

Context: Provides an indication of the person's socio-economic status and risk factors that relate to their source and type of income.

Guide for use: Should be based upon the personal source of income, not another person's source of income. If the person is reliant upon another for their income, use 'Dependent on others'.

Temporary Benefit refers to government payments provided on a limited basis including Newstart Allowance (unemployment benefit), Youth Training

Allowance, Sickness Allowance, Special Benefit, Widow Allowance, Mature Age Allowance (granted on or before 1st of July, 1996).

Pension includes government payments on a permanent basis such as Age Pension, Disability Support Pension, Disability Wage Supplement, Carer Pension, Wife Pension, Widow Pension (Class B) Bereavement Allowance, Mature Age Allowance (granted before 1st of July 1996), Mature Age Partner Allowance, Sole Parent Pension.

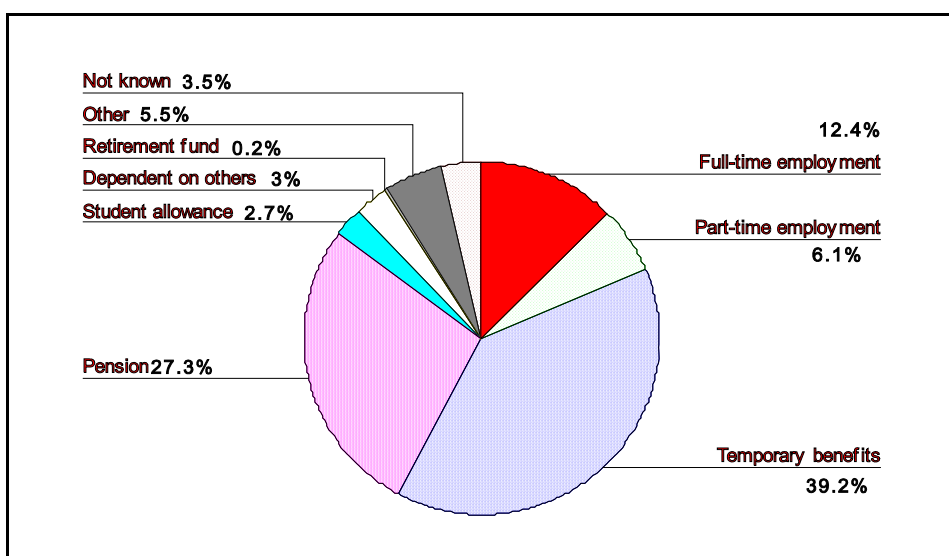
Data Domain:

- 01 Full-time employment
- 02 Part-time employment
- 03 Temporary benefit
- 04 Pension
- 05 Student allowance
- 06 Dependent on others
- 07 Retirement fund
- 98 Other
- 99 Not known

2.9.2 Preliminary findings from the pilot data

Only 18.5% of the people presenting to agencies were in any form of paid employment, and only a further 2.7% were engaged in full-time study (with the support of a student allowance). The levels of employment varied considerably between groups of people with different 'problem drugs'.

There were 63 missing cases for this item. Most of these would be for episodes that commenced earlier than the pilot study (lacking registration data).



2.9.3 Review of the data item

It is proposed that the categories of benefits and pensions be amended so that their meanings are more explicit and easier to distinguish. This may be done simply by using the category titles 'Temporary benefit (e.g. unemployment)' and 'Pension (e.g. age, disability)'. Furthermore, it is important for staff training to provide a clear explanation of this item, as per its definition.

It has been a finding of consultations with the AOD sector that it is worthwhile to maintain the distinction between part-time and full-time employment, given the significant numbers of clients in either category and the different issues that pertain to them.

The potential categories 'self-employed' and 'casual', suggested in the staff feedback, conceptually overlap with 'full-time employment' and 'part-time employment', and are more closely related with the concept of 'employment status' than 'source of income'. From consultations with the AOD sector during this project, it was decided that 'source of income' provided more useful information about a client's immediate economic circumstances than 'employment status'.

2.10 Type of usual accommodation

2.10.1 Data definition used in the pilot study

Definition: The type of physical accommodation that the person lived in immediately prior to the commencement of the episode of care.

Context: The person's physical accommodation can have a bearing on the types of treatment and support required by the person and the outcomes that result from their treatment. Different types of accommodation can be associated with particular risks or opportunities for the client.

Guide

for use: If the response is 'other', please specify the type of usual accommodation. Also note that it is important to distinguish between physical accommodation and location of residence (e.g. a house at a remote outstation should be listed as a house for the purpose of this question).

Data Domain:

- 01 House or flat
- 02 Boarding house
- 03 Hostel (supported accommodation)
- 04 Psychiatric home/hospital
- 05 Nursing home
- 06 Alcohol and other drug treatment residence
- 07 Shelter/refuge
- 08 Prison/detention centre
- 09 Caravan on serviced site
- 10 No usual residence
- 98 Other
- 99 Not known

2.10.2 Preliminary findings from the pilot data

Twenty percent of clients presenting to the alcohol and other drug agencies were not living in an independent private dwelling (house or flat). While many were living in some form of supported or institutional accommodation, 6% of clients had no usual residence.

2.10.3 Review of the data item

The category 'no usual residence' is intended to include homelessness. It is proposed that the category be renamed 'no usual residence/homeless' to make its meaning more explicit.

The category house/flat contains a very large number of cases compared to the other categories,

	n	%
House or flat	999	79.2
Boarding house	44	3.5
Hostel	37	2.9
Psychiatric home/hospital	1	.1
Alcohol/other drug treatment residence	12	1.0
Shelter/refuge	18	1.4
Prison/detention centre	20	1.6
No usual residence	73	5.8
Other	21	1.7
Not known	37	2.9

and also, the other categories imply more about a person's social or economic status. Consequently, it is proposed that this category be divided into 'rental house/flat' and 'own house/flat', on a provisional basis. These categories can readily be combined to map with other data sets if necessary.

It is also proposed that the definition be changed from the type of accommodation 'immediately prior to the commencement of the episode' to that which 'the person lived in during the three months preceding' the commencement of the episode. This response may more accurately reflect the person's usual residence, as opposed to the residence that may be chosen as a consequence of seeking assistance from an AOD agency. The word 'physical' is also being removed from the definition, as the characteristics of the accommodation types go beyond their physical properties.

2.11 Living situation

2.11.1 Data definition used in the pilot study

Definition: The person's living situation in terms of whom they are living with immediately prior to the commencement of their episode of care.

Context: The type of social relationships, responsibilities and support within a person's living situation are of great significance to their well-being, and are likely to influence the outcomes of treatment received. The living situation may be ~~that~~ when deciding between different treatment and support options for the client.

Guide for use: If the client is living as part of an extended family with a spouse or partner, class as *Spouse/Partner* or *Spouse/partner and child(ren)* if they have any children. If the client is living in an extended family situation without a spouse or partner, class as *Relative(s)* or *Friend(s)/parent(s)/relative(s) and child(ren)* if they have any children.

Data Domain:

- 01 Alone
- 02 Spouse/partner
- 03 Alone with child(ren)
- 04 Spouse/partner and child(ren)

- 05 Friend(s)
- 06 Parent(s)
- 07 Relative(s)
- 08 Friend(s)/parent(s)/relative(s) and child(ren)
- 98 Other
- 99 Not known

2.11.2 Preliminary findings from the pilot data

The greatest proportion of clients (24.2%) were living alone prior to their contact with an AOD service. A large proportion were living with their parents; it is possible that part of this figure is due

	n	%
Alone	303	24.2
Spouse/partner	200	16
Alone with child(ren)	58	4.6
Spouse/partner and child(ren)	85	6.8
Friend(s)	120	9.6
Parent(s)	272	21.7
Other relative(s)	47	3.8
Friend(s)/parent(s)/relative(s) and children	43	3.4
Other	77	6.2
Not known	46	3.7

to the incidence of people moving back home with their parents as part of a 'pathway' towards seeking to change their drug using behaviour, and a preliminary step for presenting to an AOD agency. It may also be due, in part, to the large proportion of younger people (32% under the age of 25 years) among those presenting to agencies. In total 14.8% of people presenting to agencies had children in their care.

2.11.3 Review of the data item

The item was shown in the pilot to be practical and relevant. It is proposed that it be retained in its present form, except for one minor change. The definition should be modified to specify that 'children' refers to dependent children, so that the categories are interpreted consistently.

2.12 Previous treatment for alcohol and other drug problems

2.12.1 Data definition used in the pilot study

Definition: Any type of service received by the person at an alcohol and drug treatment agency prior to the episode of care.

Context: The previous treatment received by a person can affect the type of treatment and support that are most appropriate for their current treatment episode. This item can also be used to gauge long term patterns of drug use problems and treatment for an individual.

Guide for use: Includes previous treatment within any agency including the agency providing the current episode of care. Should be based upon the clients' own response, as well as agency records and referral information where applicable.

Data Domain:

- 01 Assessment only
- 02 Detoxification/Withdrawal
- 03 Residential rehabilitation
- 04 Drug substitution/maintenance
- 05 Non-residential rehabilitation (including counselling)
- 06 No previous treatment
- 98 Other

12.2 Preliminary findings from the pilot data

The majority of people presenting to alcohol and other drug agencies had received some level of service from an agency on a previous occasion. Less than a third (27%) of clients had no previous alcohol/other drug treatment. However, a further number (11.5%) had received only an assessment on their previous encounter with an agency. Some of these occasions of 'assessment only' occurred within the same agency, and a proportion of these assessments would have immediately preceded the current occasion of service. The number of people who are 'new' clients is therefore likely to

	n	%
Assessment only	143	11.5
Detoxification/withdrawal	294	23.6
Residential rehabilitation	84	6.7
Drug substitution/maintenance	120	9.6
Ambulatory rehabilitation	64	5.1
No previous treatment	337	27
Any combination including drug substitution/maintenance	34	2.7
Any combination not including drug substitution/maintenance	67	5.4
Other	51	4.1
Not known	52	4.2

be greater than indicated by the 'no previous treatment' category. The proportion of clients with 'no previous treatment' varied considerably according to the type of drug issue being addressed and the age of the clients.

2.12.3 Review of the data item

It is proposed that the title of this item be renamed 'Prior use of alcohol and other drug services'. 'Ambulatory' can be replaced by 'non-residential' in the coding list.

The item may also be made easier to use and of more value if the code list is altered to conform with the other 'service' code lists in the data set ('main service provided' and 'other services provided'). Furthermore, due to the large number of multiple responses to this item in the pilot study, reflecting the typical pattern of service utilisation, it is proposed that multiple options be allowed.

2.13 Source of referral to agency

2.13.1 Data definition used in the pilot study

Definition: Source from which the person was transferred/referred

Context: To assist in the analyses of intersectoral client flow and health care planning.

Data Domain:

- 01 Self
- 02 Relative/Friend
- 03 Drug treatment service
- 04 GP/Medical Officer/Specialist
- 05 Hospital
- 06 Community health service
- 07 Mental health service
- 08 Family and child protection service
- 09 Welfare/community service organisation
- 10 Correctional service
- 11 Educational institution
- 12 Workplace
- 98 Other
- 99 Not known

2.13.2 Preliminary findings from the pilot data

Self-referrals to AOD agencies (42%) constitute by far the largest segment of all referrals. Other major referral sources are alcohol and other drug agencies (11%) and correctional services (12%).

	n	%
Self	519	41.5
Relative/friend	106	8.5
Drug treatment service	141	11.3
GP/medical officer/specialist	109	8.7
Hospital	36	2.9
Community health service	19	1.5
Mental health service	51	4.1
Family and child protection service	15	1.2
Welfare/community service organisation	32	2.6
Correctional service	147	11.7
Educational institution	4	.3
Workplace	2	.2
Other	61	4.9
Not known	10	.8

2.13.3 Review of the data item

As recommended in the staff feedback (section 4.1.13), the number of categories within this item should be reduced. From the low response levels recorded during the pilot study, it is apparent that some of the categories can be combined. It is proposed that 'educational institution' and 'workplace' can be combined to form one new category.

There are also some other modifications proposed, to make the meaning of various categories clearer. 'Relative/friend' can also include 'family', to remove any ambiguity. 'Drug treatment service' can be changed to 'alcohol and other drug service'. 'GP/medical officer/specialist' can be changed to 'medical practitioner'. The category 'correctional service', to become more adequate in its coverage, can also include 'law enforcement agency' and criminal justice system.'

It is suggested that it may involve too much detail to specify agencies responsible for particular communities or target groups within this data item.

2.14 Presenting problem drug

2.14.1 Data definition used in the pilot study

Definition: The drug that has caused the client to seek treatment, as stated by the client, or the drug indicated in their referral from another service.

Context: The presenting problem drug is a simple and essential indicator of the person's treatment needs. This item also provides a source of epidemiological information.

Guide for use: *Polydrug use* (970) should only be indicated in place of a 'presenting problem drug' if the person's problem arises from the practice of using a mix of different drugs, and there is no single drug that can be identified as constituting a problem in its own right.

Other opioids (029) includes codeine, pethidine, morphine etc. *Other sedatives and hypnotics* (049) includes barbiturates. *Other stimulants and pharmaceuticals* includes MDA, PMA (Fantasy), Ketamine (Special K) and GHB (GBH) etc.

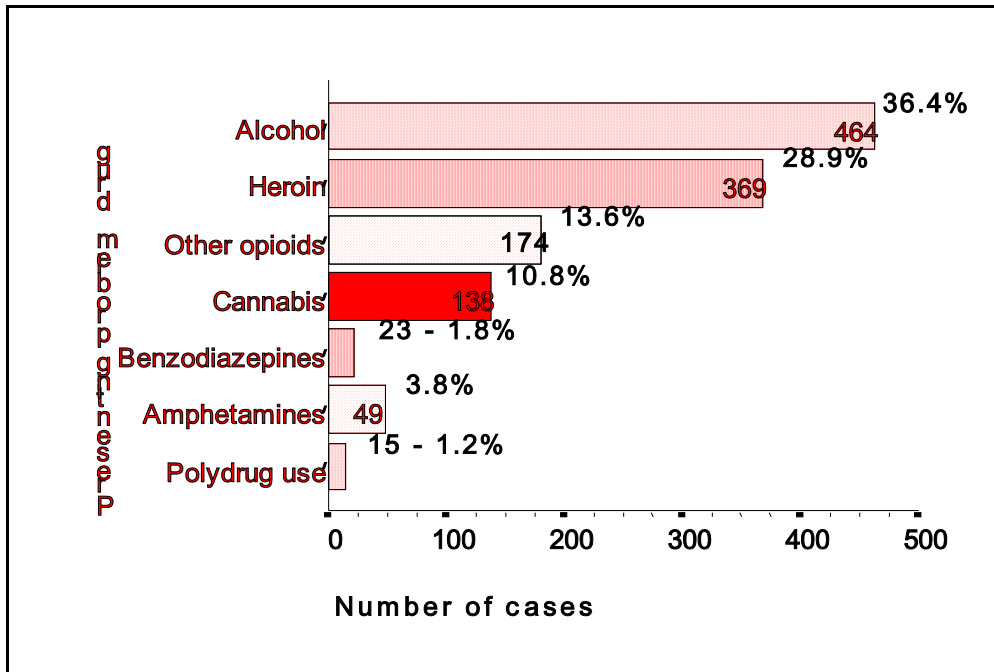
Data Domain:

- 010. Alcohol
- 020. Opioids
 - 021. Heroin
 - 022. Methadone

- 029. Other opioids
- 030. Cannabis
- 040. Sedatives and hypnotics
 - 041. Benzodiazepines
 - 049. Other sedatives and hypnotics.
- 050. Stimulants and pharmaceuticals
 - 051. Amphetamines
 - 052. Cocaine
 - 053. Ecstasy (MDMA)
 - 054. Other stimulants and pharmaceuticals
- 060. Hallucinogens
 - 061. LSD
 - 062. Mushrooms
 - 063. Other hallucinogens
- 070. Tobacco
- 080. Caffeine
- 090. Steroids and related substances
- 100. Volatile solvents/inhalants
- 970. Polydrug use
- 980. Other psychoactive drugs

2.14.2 Preliminary findings from the pilot data

The combined prevalence of all opiates as presenting problem drugs, including heroin, methadone and other opiates, at 42.5% exceeded that of alcohol at 36.4%. (Other opioids, in the graph below of selected categories, includes 'other opioids', 'methadone' and the general category of 'opioids'). The most prevalent presenting problem drugs aside from opiates and alcohol were cannabis (10.8 %) and amphetamines (3.8%). The high prevalence of methadone at 6% raises the issue of the nature of these episodes, whether they are dealing with illicit methadone use or the management of methadone treatment. The type of presenting problem drug varied considerably according to the sociodemographic characteristics of clients. There were 43 missing cases for this item (3.3% of all cases). For discussion of some of these variations, see the 'data' section under the data items 'sex', 'date of birth' and 'indigenous status'.



2.14.3 Review of the data item

The pilot study has shown that the use of use of general category headings (i.e. '020 opioids', '040 sedatives and hypnotics', '050 stimulants and pharmaceuticals', etc.) results in a lack of precision in the selection of drug types. Where agency staff have selected '020 opioids', for example, it is unclear whether this includes heroin or not. It is proposed that these general headings be deleted from the drug code.

In light of the relatively high prevalence of methadone as a 'presenting problem drug', there needs to be clarification of the extent to which these cases are comprised of the use of illicit methadone, as opposed to the management of methadone treatment. It is proposed, therefore, that there is a

distinction made in the drug code between illicit methadone and prescribed methadone.

As recommended in the staff feedback, the title of the element can be renamed to avoid the presumption of a 'drug problem'. The title 'principal drug of concern' is proposed.

In regard to the question of how the 'principal drug of concern' is selected, it is recommended that the guidelines within the existing definition continue to be used. The definition instructs that the drug selected should be the one 'that has caused the client to seek assistance, as stated by the client, or the drug indicated in their referral from another service'.

Any incidences of petrol as a drug issue should be included under 'solvents/inhalants'. Kava should be included under 'other sedatives and hypnotics'. It is also proposed that the definition for this item should provide these specific instructions for coding petrol and kava.

In regard to the question of polydrug use, there is already a polydrug category under 'presenting problem drug'. To be consistent with the definition's explanation of polydrug use, this category should be removed from the data item 'secondary drug problem'. Where there is the use of multiple drugs, as opposed to polydrug use, the revised definition for secondary problem drug ('other drugs of concern') allows for the selection of multiple drug categories.

The definition should also be altered to remove 'fantasy' from the examples of designer drugs, since the street name 'fantasy' has come to refer to a variety of substances.

	n	%
Alcohol	464	36.4
Opioids	59	4.6
Heroin	369	28.9
Methadone	77	6.0
Other opioids	38	3.0
Cannabis	138	10.8
Sedatives and hypnotics	2	.2
Benzodiazepines	23	1.8
Other sedatives and hypnotics	1	.1
Stimulants and pharmaceuticals	6	.5
Amphetamines	49	3.8
Cocaine	2	.2
Hallucinogens	1	.1
Tobacco	7	.5
Volative solvents/inhalants	2	.2
Polydrug use	15	1.2
Multiple responses	21	1.6
Other psychoactive drugs	1	.1

2.15 Secondary problem drug

2.15.1 Data definition used in the pilot study

Definition: Any drugs apart from the 'presenting problem drug', which the client or member of staff perceives as constituting a problem for the client over the past three months.

Context: This item is complementary to 'Presenting problem drug'. The existence of other problem drugs may have a role in determining the types of treatment required and also may influence treatment outcomes.

Guide

for use: Polydrug use should only be indicated in place of a 'secondary problem drug' if the person's secondary problem arises from the practice of using a mix of different drugs, and there is no single drug that can be identified as constituting a secondary problem in its own right.

Other opioids (029) includes codeine, pethidine, morphine etc. *Other sedatives and hypnotics* (049) includes barbiturates. *Other stimulants and pharmaceuticals* includes MDA, PMA (Fantasy), Ketamine (Special K) and GHB (GBH) etc.

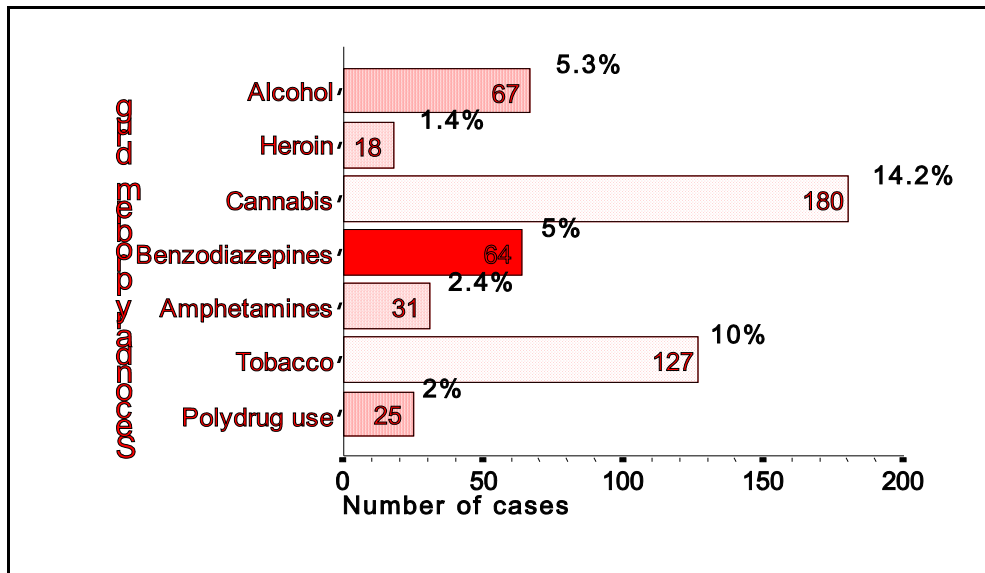
Data Domain:

- 010. Alcohol
- 020. Opioids
 - 021. Heroin
 - 022. Methadone
 - 029. Other opioids

- 030. Cannabis
- 040. Sedatives and hypnotics
 - 041. Benzodiazepines
 - 049. Other sedatives and hypnotics
- 050. Stimulants and related pharmaceuticals
 - 051. Amphetamines
 - 052. Cocaine
 - 053. Ecstasy (MDMA)
 - 054. Other stimulants and related pharmaceuticals
- 060. Hallucinogens
 - 061. LSD
 - 062. Mushrooms
 - 063. Other hallucinogens
- 070. Tobacco
- 080. Caffeine
- 090. Steroids and related substances
- 100. Volatile solvents/inhalants
- 970. Polydrug use
- 980. Other psychoactive drugs
- 990. No secondary problem drugs

2.15.2 Preliminary findings from the pilot data

Cannabis and tobacco are the predominant 'secondary problem drugs' at 14.2 and 10% of all cases respectively (compared to 10.8 and 0.5% as 'presenting problem drugs'). Alcohol and benzodiazepines are the next most prevalent drug types, both at 5%.



2.15.3 Review of the data item

This item does provide worthwhile information, given the prevalence of multiple drug use and the special characteristics of 'secondary drugs' as indicated by the pilot study. Due to the large number of multiple responses to this item, and the feedback received from participants, it is proposed that this item be changed to allow multiple options, and be renamed 'other drugs of concern'. In addition, the category 'polydrug use' should be removed from the coding list for this item, so that the meaning of the category is consistent with the definition provided under 'presenting problem drug' (see section 2.14.1 - 'guide for use').

The other changes recommended for 'presenting problem drug' should also be made for this item, as far as they are applicable.

2.16 Method of use for presenting problem drug

2.16.1 Data definition used in the pilot study

Definition: The client's usual method of administering their presenting problem drug during the last three months, as stated by the client.

Context: Identification of drug use methods is important for minimising specific harms associated with drug use, and is consequently of value for informing treatment and health promotion approaches. By discerning the method of drug use for the

presenting problem drug, a more accurate idea of the relevant harms can be obtained than would be possible from information on drug use methods not associated with any specific drug.

Data domain:

- 01 Inject
- 02 Smoke
- 03 Eat/drink
- 04 Sniff (powder)
- 05 Inhalation (vapour)
- 06 Per rectum/vagina
- 07 Other
- 09 Not known

2.16.2 Preliminary findings from the pilot data

The largest proportion of 'presenting problem drugs' were consumed orally (eat/drink), but the level of injecting drug use was also high at 36.9%. Most of this injecting drug use corresponds to the use of heroin and other opiates. Seventy cases (5.3%) were missing this category of data, these being mostly comprised of terminating episodes commenced prior to the pilot study.

	n	Percent
Inject	460	36.9
Smoke	178	14.3
Eat/Drink	580	46.5
Sniff	2	.2
Inhalation (vapour)	7	.6
Other	7	.6
Multiple indicated	2	.2
Not known	12	1.0

2.16.3 Review of the data item

There is a need to have an item that maps methods of use to a specific drug, most appropriately the principal drug being used, to determine patterns and transitions in methods of use for particular drugs, and the associated harms. There shall be an injecting drug use item included, but this item will incorporate a timeframe of use, with the following categories:

Injecting drug use

- 01 Last injected less than 3 months ago
- 02 Last injected more than 3 months ago
- 03 Never injected
- 99 Not stated/ not known/ inadequately described

It is agreed that 'eat/drink' should be replaced by 'consume orally'. Also, the order of the categories

should be changed so that the most common method of drug use, 'consume orally', appears at the top of the list.

2.17 Method of use for secondary problem drug

2.17.1 Data definition used in the pilot study

Definition: The client's usual method of administering their secondary problem drug during the last three months, as stated by the client.

Context: This item is complementary to 'Method of use for presenting problem drug', and is important for minimising the harm associated with drug use. Significant harms may be associated with a method of use for a particular drug that is not necessarily seen by the client as their main problem drug.

Data domain:

01 Inject

02	Smoke
03	Eat/drink
04	Sniff (powder)
05	Inhalation (vapour)
06	Per rectum/vagina
07	Other
09	Not known

2.17.2 Preliminary findings from the pilot data

Injecting use of the secondary problem drug was far lower than the injecting use of the presenting problem drug. Smoking of the secondary problem drug was far greater than of the presenting problem drug, reflecting the prevalence of both cannabis and tobacco as secondary problem drugs.

	n	Percent
Inject	72	11
Smoke	321	49
Eat/Drink	166	25.3
Sniff	5	.8
Inhalation (vapour)	8	1.2
Other	11	1.7
Multiple indicated	26	4
Not known	46	7.1

2.17.3 Review of the data item

Due to the proposed change to the item 'secondary problem drug' ('other drug issues') into a multiple option item, the present 'method of use for secondary problem drug' will become impracticable and ineffective, as it would be impossible to map the methods of use to specific drugs without the use of a separate 'drug issue' and 'method' question for every individual drug. Consequently, it is proposed that this item be removed from the data set. It is also proposed that there should be a new item in the set concerning injecting drug use (see section 2.16.3).

2.18 Agency program type

2.18.1 Data definition used in the pilot study

Definition: The type of alcohol and other drug treatment program providing the services for this episode of care.

Data Domain:

- 1 Outpatient treatment services
- 2 Inpatient treatment services
- 3 Therapeutic communities
- 4 General practitioners
- 5 Outreach services
- 5 Treatment units in prison
- 9 Other

2.18.2 Preliminary findings from the pilot data

Due to agency program type information being entered at the termination of episodes along with the information about services provided, for the 387 cases in progress at the completion of the pilot study, there was no data recorded for this category. Of the completed episodes, 62.2% were conducted within outpatient/non-residential programs. Aside from the episodes still in progress, 26 cases (around 2% of all cases) were missing data for the agency program type.

	n	%
Outpatient treatment	564	43.7
Inpatient treatment	301	23.3
Therapeutic community	7	.5
General practitioner	1	.1
Outreach service	13	1
Other	19	1.5
(Episodes in progress)	387	30

2.18.3 Review of the data item

It is proposed that this item be retained as is, except for the category 'general practitioner', which is inappropriate for the scope of this project, and consequently should be removed.

2.19 Main type of service provided

2.19.1 Data definition used in the pilot study

Definition: The main type of treatment service provided to the person during this episode of care.

Guide

for use: To be completed at the termination of the episode of care.

All types of service are assumed to include a component of assessment.

Assessment only applies when there is no other service provided.

Information and education is also assumed to be a common component of the other types of service (codes 03 to 12 inclusive) and should only be selected when there is no further service provided.

Data Domain:

01 Assessment only

- 02 Information and education
- 03 Inpatient detoxification
- 04 Outpatient/home detoxification
- 05 Methadone maintenance
- 06 Other drug substitution/maintenance
- 07 Therapeutic (facilitated) groups
- 08 Peer/support groups
- 09 Advocacy
- 10 Counselling
- 11 Other rehabilitation
- 12 Crisis intervention
- 98 Other

2.19.2 Preliminary findings from the pilot data

Detoxification/withdrawal services were predominant at 21% of all cases. The majority of these withdrawal services were inpatient or non-residential. 'Assessment only' comprised 20% of all cases, with 'information and education' accounting for a further 8%. Counselling services were shown to be a major component of the agencies' work (9%). Methadone maintenance was the only form of pharmacotherapy with a significant number of cases in this study (7%). 'Other drug substitution/maintenance' only accounted for 0.1%.

There were 31 missing cases (2.4%). In the instances where multiple items were selected (this did not occur within most agencies), an arbitrary order of precedence was devised for the purpose of recording only a single item. This order consisted of (from the greatest to the least priority): other drug substitution/maintenance, methadone maintenance, inpatient detoxification, outpatient/home detoxification, therapeutic (facilitated) groups, counselling, other rehabilitation, crisis intervention, peer/support groups, advocacy, information and education, assessment only. This hierarchy would have had some effect in skewing the results in favour of those categories at the top of the order of precedence.

	n	%
Assessment only	252	19.6
Information and education	103	8
Inpatient detoxification	225	17.5
Outpatient home detoxification	46	3.6
Methadone maintenance	89	6.9
Other drug substitution/maintenance	1	.1
Therapeutic (facilitated) groups	34	2.6
Peer/support groups	10	.8
Counselling	117	9.1
Other rehabilitation	2	.2
Crisis intervention	8	.6
Other	12	.9
(Episode in progress)	387	30.1

2.19.3 Review of the data item

On the basis of the pilot study findings, it is proposed that the coding list for this item be changed. It is proposed that the coding list suggested in the feedback be adopted (with some modifications), as it accurately describes the mix of services provided by agencies. This list is as follows:

- 01 Intoxication management
- 02 Withdrawal management (residential)
- 03 Withdrawal management (non-residential)
- 04 Counseling
- 05 Information and education
- 06 Crisis intervention
- 07 Case management
- 08 Drug substitution therapy (methadone)
- 09 Drug substitution therapy (other)"

'Case management' may be deleted from the list as this concept relates primarily to administrative activities. 'Crisis management' may also be deleted, on the grounds of the low number of responses for this category in the pilot study.

'Assessment only' should be retained in the list to record those cases, which were common within the pilot study, where the intervention does not proceed beyond assessment. As stated in the definition supplied for the pilot study, assessment is otherwise assumed to be part of the intervention. (If 'assessment only' is selected as the main service, 'no other service provided' should be selected under the item 'other type of service provided').

An additional domain for 'residential rehabilitation' can be added to this list to denote a range of therapeutic activities not covered within the other categories. A domain of 'other' services should be included as well, to enable the adequacy of the list to be assessed.

2.20 Other type of service provided

2.20.1 Data definition used in the pilot study

Definition: Any type of service provided within this episode of care, additional to the *Main type of service*.

Guide for use: To be completed at the termination of the episode of care.

All options are assumed to include a component of assessment. *Information and education* is also assumed to be a common component of the other categories (codes 01 to 10 inclusive).

Data Domain:

- 01 Inpatient detoxification
- 02 Outpatient/home detoxification
- 03 Methadone maintenance
- 04 Other drug substitution/maintenance
- 05 Therapeutic (facilitated) groups

- 06 Peer/support groups
- 07 Advocacy
- 08 Counselling
- 09 Other rehabilitation
- 10 Crisis intervention
- 98 Other
- 99 No other service provided

2.20.2 Preliminary findings from the pilot data

Counselling was the most prevalent form of 'other' services provided, constituting 20%, followed

	n	%
Inpatient detoxification	23	2
Outpatient/home detoxification	10	.8
Methadone maintenance	8	.7
Other drug substitution/maintenance	6	.5
Therapeutic (facilitated) groups	54	4.6
Peer/support groups	5	.4
Advocacy	20	1.7
Counselling	237	20.1
Other rehabilitation	14	1.2
Crisis intervention	12	1
Other	43	3.7
No other service provided	359	30.5
(Episode in progress)	387	32.9

by facilitated or peer group work at 5%.

2.20.3 Review of the data item

It is proposed that the changes outlined for the data item 'main type of service provided' are also made for this item (see section 2.19.3), with some minor exceptions. 'Assessment only' should not be included in the coding list for this item, because it is only to be used if assessment is the main type of service provided, to the exclusion of any other services. 'Other type of service provided' should also include the category, 'no other service provided'.

2.21 Reason for treatment termination

2.21.1 Data definition used in the pilot study

Definition: The reason for the termination of the present episode of care.

Context: Given the levels of attrition within alcohol and drug treatment programs, it is important to gauge the prevalence of different reasons for treatment termination.

Guide for use: *Mutual agreement:* client left program on mutual agreement between themselves and the member of staff, without meeting the original goals of the treatment; *Completed treatment:* the goals of the treatment have been reached; *Left against advice:* client has made a conscious decision to leave the treatment program despite advice to the contrary from a member of staff; *Ceased to participate:* the treatment agency has had no contact with the client for a period of six weeks and has no further plans to contact the client.

Data Domain:

01 Mutual agreement

- 02 Completed treatment
- 03 Referred to another service
- 04 Left against advice
- 05 Ceased to participate
- 06 Hospitalised/medical condition
- 07 Discharged due to non-compliance
- 08 Imprisoned
- 09 Deceased
- 99 Other

2.21.2 Preliminary findings from the pilot data

More than half (55.1%) of clients completed their treatment program through achieving the goals of the program or through mutual agreement between the client and the agency worker. An additional 16.9% were referred to another service, leaving 28% of the clients as not completing

	n	%
Mutual agreement	90	12.6
Completed treatment	304	42.5
Referred to another service	121	16.9
Left against advice	74	10.3
Ceased to participate	66	9.2
Hospitalised/medical condition	4	.6
Discharged due to non-compliance	30	4.2
Imprisoned	7	1
Deceased	1	.1
Other	18	2.5

treatment. About one in five (19.5%) either left the program against the advice of staff or ceased to participate in the program. A further 4.2% failed to complete treatment through non-compliance with the requirements of the treatment program.

2.21.3 Review of the data item

It is proposed that the title of this episode be changed to 'reason for termination of episode', due to the objections to the term treatment on the grounds that it does not adequately reflect the scope of interventions in which agencies are involved.

In addition, it is proposed that the categories 'mutual agreement' and 'completed treatment' be combined (simply replaced by 'intervention completed') due to the lack of a readily comprehensible distinction between them. The same applies to the categories 'left against advice' and 'ceased to participate'. In this instance, 'ceased to participate' can adequately describe both situations.

The category 'discharged due to non-compliance' can be simplified to state 'non-compliance'. It is also proposed that the category 'imprisoned' be expanded to include 'released from prison', to allow for prisoners who are part of an AOD program while in prison.

2.22 Referral to further care

2.22.1 Data definition used in the pilot study

Definition: Referral of the person to further care by the agency.

Context: Allows for the monitoring of interagency linkages and is complementary to the data element 'Source of referral'. May contribute to an assessment of continuity of care.

Data domain:

- 01 Drug treatment service
- 02 GP/Medical Officer/Specialist
- 03 Hospital
- 04 Community health service
- 05 Mental health service
- 06 Family and child protection service
- 07 Welfare/community service organisation

- 08 Education/training organisation
- 09 Employment agency
- 98 Other
- 99 No referral

2.22.2 Preliminary findings from the pilot data

By far the greatest amount of referrals were to a different drug treatment service. A component of these would have comprised referrals between different programs operated by the same organisation. Nevertheless, it suggests a strong relationship between some services. The greatest proportion of referrals outside of AOD services was to medical practitioners. There was also a significant relationship between some AOD services and community health services, mental health services and welfare/community service organisations.

	n	%
Drug treatment service	287	40.4
GP/medical officer/specialist	68	9.6
Hospital	4	.6
Community health service	28	3.9
Mental health service	20	2.8
Welfare/community service organisation	33	4.6
Education/training organisation	1	.1
Other	44	6.2
No referral	225	31.7

2.22.3 Review of the data item

It is proposed that the title of this item be changed to 'referral to another service', to more accurately reflect the nature of referrals within the AOD field.

This item is intended to be used for referrals made on completion of an episode. The definition for this item should specify this to ensure that the use of this item is consistent. The focus upon

referrals made at the end of the episode is considered to be more significant than any concurrent services that the client may use. This is because end-of-episode referrals relate to the issue of the support and alternatives that are provided for a client at the end of an intervention, which may be pivotal to the long-term outcomes for the client.

For ease of use, it is proposed that the coding list for this item be made consistent (as far as possible) with the coding list for 'source of referral'. The changes proposed for the categories under 'source of referral' are also recommended for this item (see section 2.13.3).

2.23 Problem drug treated

2.23.1 Data definition used in the pilot study

Definition: The principal problem drug for which the client has received treatment, as determined by the service provider at the termination of the treatment episode.

Context: This is a means of identifying the drug problems for which treatment resources are allocated. In the course of the treatment process for a single episode of care, the focus of treatment may shift to a drug other than the presenting problem drug.

Guide for use: *Other opioids* (029) includes codeine, pethidine, morphine etc. *Other sedatives and hypnotics* (049) includes barbiturates. *Other stimulants and pharmaceuticals* includes MDA, PMA (Fantasy), Ketamine (Special K) and GHB (GBH) etc.

- 010. Alcohol
- 020. Opioids
 - 021. Heroin
 - 022. Methadone
 - 029. Other opioids
- 040. Sedatives and hypnotics
 - 041. Benzodiazepines
 - 049. Other sedatives and hypnotics
- 050. Stimulants and related synthetic drugs
 - 051. Amphetamines
 - 052. Cocaine
 - 053. Ecstasy (MDMA)
 - 054. Other stimulants and related synthetic drugs
- 060. Hallucinogens
 - 061. LSD
 - 062. Mushrooms
 - 063. Other hallucinogens
- 070. Tobacco
- 080. Caffeine
- 090. Steroids and related substances
- 100. Volatile solvents
- 970. Polydrug use
- 980. Other psychoactive drugs

2.23.2 Preliminary findings from the pilot data

The figures for each drug type for the 'problem drug treated' roughly correspond to those for the 'presenting problem drug', with some minor discrepancies. The data for the 'presenting problem drug' is, however, based upon a far greater number of cases than the information on the 'problem drug treated', due to the number of incomplete episodes (episodes in progress) and fewer missing cases. 461 (35%) cases were missing for this item.

	n	%
Alcohol	285	33.3
Opioids	55	6.4
Heroin	228	26.6
Methadone	53	6.2
Other opioids	34	4
Cannabis	83	9.7
Sedatives and hypnotics	2	.2
Benzodiazepines	14	1.6
Stimulants and 'designer' drugs	5	.6
Amphetamines	24	2.8
Other stimulants and 'designer' drugs	1	.1
Hallucinogens	1	.1
Tobacco	4	.5
Volatile solvents/inhalants	1	.1
Polydrug use	18	2.1
Multiple responses	49	5.7

2.23.3 Review of the data item

The results of the pilot study have shown that the value of collecting this item is questionable. There is a strong similarity between the responses to 'problem drug treated' and the responses to 'presenting problem drug'. Feedback from participants also indicated that the presenting drug was typically the same as the drug treated for interventions within their agency. Consequently, it is proposed that this item be removed from the data set.

2.24 Methadone dose

2.24.1 Data definition used in the pilot study

Definition: The actual dose, recorded in millilitres, for any person currently receiving methadone treatment, at the time of the commencement of this episode of care.

Context: This item allows for patterns of additional service utilisation to be ascertained for clients being prescribed different methadone doses.

Guide

for use: Write down the dose as stated by the client, if the client is receiving methadone treatment, otherwise record as zero (000).

2.24.2 Preliminary findings from the pilot data

Only 89 cases (7%) reported on 'methadone dose'. This is equivalent to the number of cases (89) on methadone maintenance as the main type of service provided, although not all of the cases of clients receiving this service provide a dose level; 29% of these cases were missing data for this item. Also, 120 of all clients in the study had received 'drug substitution/maintenance' as a previous treatment. The mean dose was 55.5 mg and the median dose was 45mg. The stated doses ranged between 2.5mg and 160mg. There was a design error for this item in that the form wrongly instructed millilitres and the accompanying definitions instructed milligrams. It was possible to discern which measure an agency was using, and all measures given in millilitres were converted to milligrams, using 5mg of methadone per ml as a conversion basis.

2.24.3 Review of the data item

It is proposed that this item be removed from the data set as it is perceived by some participating agencies and jurisdictions to be inappropriate to collect within their programs and of limited use within a national data set (refer to the feedback in section 4.1.24). It is suggested that alternative mechanisms for tracking the progress of methadone treatment could be implemented within a data set of methadone providers.

2.25 Date episode terminated

2.25.1 Data definition used in the pilot study

Definition: Date on which a client's episode of care is terminated.

Context: Used in conjunction with 'Date episode commenced' to derive the periods of different episodes of care.

Guide

for use: An episode of care may be terminated in a variety of ways as indicated in 'Reason for treatment termination'.

2.25.2 Preliminary findings from the pilot data

This item is used in conjunction with 'date episode commenced' to discern episodes and trends. missing cases, largely due to incomplete episodes

2.25.3 Review of the data item

It is proposed that this item be retained in the data set, in its current form. See the 'conclusion' section under 'date episode commenced' for a discussion regarding the use of the concept of episodes.

and definitions

This section comprises a recommended set of data items and definitions, which have been developed from the pilot study. The revision of these items was guided by the evaluation of each pilot data item, contained in section 2. It reflects the findings of the pilot study, in terms of the nature of the data obtained and the feedback from the agency workers.

3.1 Establishment identifier* (Agency code)

Definition: Identifier for the establishment in which episode or event occurred. Each separately administered health care establishment is to have a unique identifier at the national level.

Data Domain: Alphanumeric code, comprised of:
N - State identifier
N - Establishment identifier
A - Region code
NNN - Establishment number

Guide for use: If data is supplied on computer media, this item is only required once in the header information. If information is supplied manually, this item should be provided on every form submitted.

May appear on client forms as 'agency code'.

Comment: An establishment is considered to be separately administered if managed as an independent institution for which there are financial, budgetary and activity statistics.
The use of this item will lead to reduced duplication in reporting patient activity and will enable linkage of services to one episode of care.

*(*This data item is already contained in the National Health Data Dictionary. The version shown here has been slightly modified from the original definition.)*

3.2 Agency program type

Definition: The type of alcohol and other drug program providing the services for this intervention episode.

Data domain:

- 01 Outpatient/non-residential services
- 02 Inpatient/residential services
- 03 Therapeutic communities
- 04 Outreach services
- 05 Intervention programs in prison

3.3 Date episode commenced

Definition: Date on which a client commences an intervention episode.

Context: Required for discerning different intervention episodes and the analyses of general trends. It also enables the analyses of the progress of persons through different episodes, including the calculation of intervals between different episodes (in conjunction with 'date episode terminated').

3.4 Person identifier* (Client code)

Definition: Person identifier unique within establishment or agency.

Context: This item could be used for editing at the establishment or collection authority level and, potentially, for episode linkage. There is no intention that this item would be available beyond collection authority level.

Guide for use: Individual establishments or collection authorities may use their own alphabetic, numeric or alphanumeric coding systems. A suggested method of deriving a consistent identifier is by using the first two letters of the surname, followed by the first two letters of the first name, followed by the year of birth.

May appear on client forms as 'client code'.

*(*This data item is already contained in the National Health Data Dictionary item. The 'guide for use' shown here has been altered from the original definition.)*

3.5 Client status

Definition: The status of the person in relation to the drug use issue for which they are presenting, in terms of whether it concerns their own drug use or the drug use of another person.

Context: Required to differentiate between primary (those presenting in regard to their own drug use) and secondary clients (those presenting in regard to another person's drug use), given the significant proportion of secondary clients presenting to alcohol and other drug agencies.

Data Domain:

- 1 Own drug use
- 2 Other's drug use
- 9 Not known

3.6 Date of birth*

Definition: The date of birth of the person.

Context: Required to derive age for demographic analyses, and analysis by age at the commencement or termination of the episode.

Guide for use: If date of birth is not known, provision should be made to collect age (in years) and a date of birth derived from age.

*(*This data item is already contained in the National Health Data Dictionary.)*

3.7 Sex*

Definition: The sex of the person.

Context: Required for analyses of service utilisation, needs for services and epidemiological studies.

Data domain:

- 1 Male
- 2 Female
- 9 Not stated/not known/inadequately described

*(*This data item is already contained in the National Health Data Dictionary.)*

3.8 Country of birth*

Definition: The country in which the person was born.

Context: Ethnicity is an important concept, both in the study of disease patterns and in the need for and provision of services. Country of birth is the most easily collected and consistently reported of possible ethnicity data items.

Comment: As defined in the ABS Directory of concepts and standards for social, labour and demographic statistics, 1993.

Data Domain: Australian Standard Classification of Countries for Social statistics (ASCCSS) 4-digit (individual country level). ABS catalogue no. 1269.0

Guide for use: Write down the person's stated country of birth - to be coded subsequently.

*(*This data item is already contained in the National Health Data Dictionary.)*

3.9 Preferred language*

Definition: The language (including sign language) most preferred by the person for communication. This may be a language other than English even where the person can speak fluent English.

Context: To assist in the development of interpreter services and other supports as part of health and welfare service planning.

Guide for use: The preferred language is to be written down and coded subsequently.

The data domain is that used by the New South Wales Department of Health. It is based on the ABS 2-digit classification of country of birth. Matching codes are used for languages and countries where possible.

Comments: Preferred language is an important indicator of ethnicity, especially for persons born in non-English-speaking countries. It is also a surrogate measure for English language proficiency, which is an important determinant of access to health and welfare services and of effective communication between health professionals and consumers.

*(*This data item is already contained in the National Health Data Dictionary.)*

3.10 Indigenous status*

Definition: An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives (High Court of Australia in *Commonwealth V Tasmania* (1983) 46 ALR).

Context: Given the gross inequalities in health status between indigenous and non-indigenous peoples in Australia, the size of the Aboriginal and Torres Strait Islander populations and their historical and political context, there is a strong case for ensuring that information on indigenous status is collected for planning and service delivery purposes and for monitoring Aboriginal and Torres Strait Islander health.

Data Domain:

- 01 Indigenous - Aboriginal but not Torres Strait Islander origin
- 02 Indigenous - Torres Strait Islander but not Aboriginal origin
- 03 Indigenous - Aboriginal and Torres Strait Islander origin
- 04 Not indigenous - not Aboriginal or Torres Strait Islander origin
- 09 Not stated / not known / inadequately described

Collection methods: The ABS recommends collection of responses in tick boxes, e.g.
Aboriginal or Torres Strait Islander origin?
No
Yes
Yes Torres Strait Islander

*(*This data item is already contained in the National Health Data Dictionary.)*

3.11 Source of income

Definition: The source by which a person derives most (equal to or greater than 50%) of his/her income. If the person has multiple sources of income and none equal to or greater than 50%, the one which contributes the largest percentage should be counted.

Context: The element is an indicator of the needs and circumstances of individuals and is sometimes used in assessment of income equity.

Guide for use: Should be based upon the personal source of income, not another person's source of income. If the person is reliant upon another for their income, use 'Dependent on others'.

“Part-time employment”: applies when the person is working 20 hours a week or less.

Data domain:

- 01 Full-time employment
- 02 Part-time employment
- 03 Temporary benefit (e.g. unemployment)
- 04 Pension (e.g. aged, disability)
- 05 Student allowance (e.g. Austudy, Abstudy)
- 06 Dependent on others
- 07 Other income
- 08 Nil income
- 99 Not stated/not known/inadequately described

3.12 Type of accommodation*

Definition: The usual type of accommodation that the person lived in during the three months preceding the commencement of the intervention episode.

Context: The person's accommodation can have a bearing on the types of intervention and support required by the person and the outcomes that result from their services that they receive. Different types of accommodation can be associated with particular risks or opportunities for the client.

Guide for use: If the response is 'other', please specify the type of usual accommodation. Also note that it is important to distinguish between physical accommodation and location of residence (e.g. a house at a remote outstation should be listed as a house for the purpose of this question).

Data Domain:

- 01 Rented house or flat (public or private)
- 02 Own house or flat
- 03 Boarding house
- 04 Hostel (supported accommodation)
- 05 Psychiatric home/hospital
- 06 Alcohol and other drug treatment residence
- 07 Shelter/refuge
- 08 Prison/detention centre
- 09 Caravan on serviced site
- 10 No usual residence/homeless
- 98 Other
- 99 Not known

(*This data item is related to an existing National Health Data Dictionary item.)

3.13 Living arrangement

Definition: The person's living arrangement in terms of whom they are living with immediately prior to the commencement of their intervention episode.

Context: The type of social relationships, responsibilities and support within a person's living situation are of great significance to their well-being, and are likely to influence the outcomes of an intervention. The living situation may be relevant when deciding between different intervention and support options for the client.

Guide for use: The term 'children' in this definition refers to children who are dependants of the client.

Extended family:

If the client is living as part of an extended family with a spouse or partner, class as Spouse/Partner, or Spouse/partner and child(ren) if they have any children. If the client is living in an extended family situation without a spouse or partner, class as Relative(s) or Friend(s)/parent(s)/relative(s) and child(ren) if they have any children.

Data Domain:

- 01 Alone
- 02 Spouse/partner
- 03 Alone with child(ren)
- 04 Spouse/partner and child(ren)
- 05 Friend(s)
- 06 Parent(s)
- 07 Relative(s)
- 08 Friend(s)/parent(s)/relative(s) and child(ren)
- 98 Other
- 99 Not known

3.14 Prior use of alcohol and other drug services

Definition: The status of an episode in terms of whether it is a first or subsequent admission or service contact.

Context: Will be used to discriminate episodes that are first ever presentations for from those where the person has a previous treatment history. May allow for episodes to be considered within the context of a complete treatment history.

Guide for use: If necessary, multiple service categories may be selected.

Includes previous service contact within any agency including the agency providing the current episode of care. Should be based upon the clients' own response, as well as agency records and referral information where applicable.

Data Domain:

- 01 Intoxication management
- 02 Withdrawal management (residential)
- 03 Withdrawal management (non-residential)
- 04 Counseling

- 05 Residential rehabilitation
- 06 Information and education
- 07 Drug substitution therapy (methadone)
- 08 Drug substitution therapy (other)
- 97 Assessment only
- 98 Other
- 99 Not stated/not known/inadequately described

3.15 Source of referral to agency

Definition: Source from which the person was transferred/referred for this intervention episode.

Context: To assist in the analyses of intersectoral client flow and health care planning.

Data Domain:

- 01 Alcohol/other drug service
- 02 Medical practitioner
- 03 Hospital
- 04 Community health service

05 Mental health service

06 Family and child protection service

07 Welfare/community service organisation

08 Educational institution/Workplace

09 Law enforcement agency/correctional service/criminal justice system

96 Self

97 Family/relative/friend

98 Other

99 Not stated/not known/inadequately described

(*This data item is based on an existing National Health Data Dictionary item.)

3.16 Principal drug of concern

Definition: The drug that has caused the client to seek assistance, as stated by the client, or the drug indicated in their referral from another service.

Context: The principal drug of concern is a simple and essential indicator of the person's treatment needs. This item also provides a source of epidemiological information.

Guide for use: Polydrug use (970) should only be indicated in place of a 'principal drug' if the person's problem arises from the practice of using a mix of different drugs, and there is no single drug that can be identified as constituting a problem in its own right. If polydrug use (970) is selected, then 'No other drugs of concern' (990) must be selected for the question *Other drugs of concern*.

'Other opioids' (029) includes codeine, pethidine, morphine etc. 'Other sedatives and hypnotics' (049) includes barbiturates. 'Other stimulants and 'designer drugs'' includes ecstasy (MDMA), MDA, PMA, Ketamine (Special K) and GHB (GBH) etc.

Petrol should be classed as 'Volatile solvents/inhalants' (100). Kava should be classed as 'other sedatives and hypnotics' (049).

Data Domain:

010. Alcohol

021. Heroin

022. Methadone (prescribed)

023. Methadone (illicit)

029. Other opioids

030. Cannabis

041. Benzodiazepines

049. Other sedatives and hypnotics

051. Amphetamines

052. Cocaine

059. Other stimulants and 'designer' drugs

061. LSD

062. Mushrooms

069. Other hallucinogens

070. Tobacco

080.	Caffeine
090.	Steroids and related substances
100.	Volatile solvents/inhalants
970.	Polydrug use
980.	Other psychoactive drugs

3.17 Method of use for principal drug of concern

Definition: The client's usual method of administering their principal drug of concern during the last three months, as stated by the client.

Context: Identification of drug use methods is important for minimising specific harms associated with drug use, and is consequently of value for informing treatment and health promotion approaches. By discerning the method of drug use for the principal drug of concern, a more accurate idea of the relevant harms can be obtained than would be possible from information on methods not associated with any specific drug.

Data domain:

01	Consume orally
02	Smoke
03	Inject
04	Sniff (powder)
05	Inhalation (vapour)
06	Other
09	Not known

3.18 Other drugs of concern

Definition: Any drugs apart from the 'principal drug of concern', which the client or member of staff perceives as being a health concern for the client over the past three months.

Context: This item is complementary to 'Principal drug of concern'. The existence of other problem drugs may have a role in determining the types of treatment required and also may influence treatment outcomes.

Guide for use: If necessary, more than one category of drug may be selected for this question.

Other opioids (029) includes codeine, pethidine, morphine etc. Other sedatives and hypnotics (049) includes barbiturates. Other stimulants and pharmaceuticals includes MDA, PMA, Ketamine (Special K) and GHB (GBH) etc.

Petrol should be classed as 'Volatile solvents/inhalants' (100). Kava should be classed as 'other sedatives and hypnotics' (049).

Data Domain:

- 010. Alcohol
- 021. Heroin
- 022. Methadone (prescribed)
- 023. Methadone (illicit)
- 029. Other opioids
- 030. Cannabis
- 041. Benzodiazepines
- 049. Other sedatives and hypnotics
- 051. Amphetamines
- 052. Cocaine
- 053. Ecstasy (MDMA)
- 059. Other stimulants and 'designer' drugs
- 061. LSD
- 062. Mushrooms
- 069. Other hallucinogens
- 070. Tobacco
- 080. Caffeine
- 090. Steroids and related substances
- 100. Volatile solvents/inhalants
- 980. Other psychoactive drugs
- 990. No other drugs of concern

3.19 Injecting drug use

Definition: The client's use of injection as a method of administering drugs.

Context: This item is complementary to 'Method of use for principal drug of concern', and is important for identifying and minimising the harms associated with intravenous drug use.

Data domain:

- 01 Last injected less than 3 months ago
- 02 Last injected more than 3 months ago
- 03 Never injected
- 99 Not stated/not known/inadequately described

3.20 Main service provided

Definition: The main type of service provided to the person during this intervention episode.

Guide for use: To be completed at the termination of the intervention episode.

Assessment: All types of service are assumed to include a component of assessment. 'Assessment only' (97) applies when there is no other service provided.

Data domain:

- 01 Intoxication management
- 02 Withdrawal management (residential)
- 03 Withdrawal management (non-residential)
- 04 Counseling
- 05 Residential rehabilitation
- 06 Information and education
- 07 Drug substitution therapy (methadone)
- 08 Drug substitution therapy (other)
- 97 Assessment only
- 98 Other

3.21 Other services provided

Definition: Any type of service provided within this intervention episode, additional to the *Main type of service*.

Guide for use: To be completed at the termination of the episode of care.

If necessary, more than one category of service may be selected for this question.

Data Domain:

- 01 Intoxication management
- 02 Withdrawal management (residential)
- 03 Withdrawal management (non-residential)
- 04 Counseling

- 05 Residential rehabilitation
- 06 Information and education
- 07 Drug substitution therapy (methadone)
- 08 Drug substitution therapy (other)
- 98 Other
- 99 No other services provided

3.22 Reason for termination of episode

Definition: The reason for the termination of the current intervention episode.

Context: Given the levels of attrition within alcohol and drug treatment programs, it is important to gauge the prevalence of different reasons for the termination of an intervention episode.

Guide for use: “Intervention completed”: the goals of the intervention have been reached or the client has left the program on mutual agreement between themselves and the member of staff.

“Ceased to participate”: the alcohol/other drug agency has had no contact with the client for a period of six weeks and has no further plans to contact the client.

Data Domain:

- 01 Intervention completed
- 02 Referred to another service
- 03 Ceased to participate

-
- 04 Hospitalised/medical condition
 - 05 Non-compliance
 - 06 Imprisoned/released from prison
 - 07 Deceased
 - 99 Other

3.23 Referral to another service*

Definition: Referral of the person to another service by alcohol/other drug agency.

Context: Allows for the monitoring of interagency linkages and is complementary to the data element 'source of referral'. May contribute to an assessment of continuity of care.

Data domain:

- 01 Alcohol/other drug treatment service
 - 02 Medical practitioner
 - 03 Hospital
 - 04 Community health service
 - 05 Mental health service
 - 06 Family and child protection service
-
- 07 Welfare/community service organisation
 - 08 Education/training organisation
 - 98 Other
 - 99 No referral

*(*This data item was originally based on an existing National Health Data Dictionary item.)*

3.24 Date episode terminated

Definition: Date on which a client's intervention episode is terminated.

Context: Used in conjunction with 'date episode commenced' to derive the periods of different intervention episodes.

Guide for use: An intervention episode may be terminated in a variety of ways as indicated in the data item, 'reason for termination of episode'.

4. Feedback from staff of participating agencies

Questionnaires were sent to the staff of participating agencies, comprising questions about the design and relevance of the data items, as well questions relating to implementation issues. The comments contained in the completed questionnaires have been transcribed within this section. Any feedback that relates to the data items has been compiled under separate headings for each item. A copy of the questionnaire is appended to this report.

4.1 Specific feedback on data items

4.1.1 Establishment identifier

- “Our agency currently has a number of codes to indicate differing client groups, eg IE - assessment/new referral; IC - corrections referral; IR - readmission. Does this pose a problem for National Data Set? Should it always be the same?”
- “I think some of the wording eg identifier could be put in more simple terms as some people find the jargon complicated to understand.”
- “No difficulty with this element. Can be enhanced with clear guidelines for developing a nationally accepted identifier.”

4.1.2 Date episode commenced

No comments were made about this item in the feedback. There were, however, comments made concerning the concept of an episode:

- “Definition of an 'episode' of treatment was unclear. We interpreted this as the duration of treatment within one treatment modality. However there was some conjecture as to whether or not an episode corresponded to each time the client walked through the door.”
- “One NGO felt that the data set was too clinical and did not allow for a great deal of work

to be counted i.e.drop-in service/non-clinical end of service delivery. Felt that a lot of one-off and anonymous contacts would not be recorded but were also important interventions. Also queried capacity to record outreach work.”

4.1.3 Person identifier

- “Person identifier: That which suggested not used because believe that too much information is divulged. Our agency happier with use of first two letters of surname, first two letters of Christian name and year of birth (eg Joe Smith DOB 5/6/26 -SMJ026).”
- “No difficulties. Can be enhanced with clear guidelines for developing a nationally accepted identifier.”

Participants gave this data item an average rating of 3.5 out of 5 for its relevance to service planning.

4.1.4 Client status

- “Recommend the deletion of the word 'problem' from data domains 1&2. Problem assumes an assessment has already taken place and does not enable this domain to be used for clients seeking information only. Also assumes the drug use is the problem and not a symptom. Domain 3 should be added to enable identification of client who falls into both 1&2 e.g. 3 'Both own and other's drug use'.”
- “Why is there a section under 'client status' that states 'Other's drug use problem?'. It was our understanding that this is in regards to treatment for themselves only. If that is the case then that question would be unnecessary.”

Participants gave this item a rating of 4 out of 5 for relevance to service planning.

4.1.5 Date of birth

There were no concerns raised by the pilot agencies in regard to this item.

This item recieved a rating of 4.4 out of 5 in terms of its relevance both to case management and service planning.

4.1.6 Sex

- “Recommend changing the word 'Sex' to 'Gender' as question is seeking gender identification of the person rather than the biological sex typing. It has been suggested that 'inadequately described' should be deleted from domain 9. It has also been suggested that this is an irrelevant question, that workers should be dealing with people without the need to seek clarification or delineation on the grounds of gender.”

4.1.7 Country of birth

- “This question is of no value or interest in the profile of the client. It is understood that information regarding the ethnicity of the individual may be relevant to matching services. Ethnicity is not able to be determined from the country of birth. It is recommended that if

ethnicity is the data required a question directly related to the information sought should be included. This could take the form of 'Cultural or Ethnic Identity', with the data domain including all the relevant options as would be the case for 'Country of birth'."

- "Country of birth - at times cultural significance. Value for legal referral."

Participants gave this item an average rating of 3.6 out of 5 for relevance to case management and 3.8 out of 5 for relevance to service planning.

4.1.8 Indigenous status

- "Indigenous status - too clumsy. I've never met an aboriginal and torres strait islander - why not aboriginal/non-aboriginal."
- "Most comments have suggested some over detail in this element, but it is understood that the domain here draws on nationally developed and recognised criteria in relation to indigenous people."
- "Reason for needing to ask this question? Many clients take offence at being asked this."

Participants gave this item an average rating of 4 out of 5 for its relevance to service planning.

4.1.9 Source of income

- "Pension could be anything."
- "Could differentiate between unemployment benefits, sole parents pension etc."
- "Employment status - perhaps a category for unemployed."
- "Recommend the inclusion of "self-employed" and "casual" options in the data domain."
- "Need to differentiate between unemployed and temporary benefits."
- "Some confusion as to where UE [unemployment benefits] should go i.e. Temporary benefit, other etc."

Participants gave this item an average rating of 3.3 out of 5 for relevance to case management and 3.2 out of 5 for relevance to service planning.

4.1.10 Type of usual accommodation

- "No provision for homelessness."
- "Doesn't identify if person is renting or owns the house or if it is public housing."

Rating of 3.7 out of 5 for relevance to case management and 3.3 out of 5 for relevance to service planning.

4.1.11 Living situation

- “Some have commented on this element being an improvement on previous systems used. No problems.”

Participants gave this item an average rating of 4.2 out of 5 for relevance to case management and 3.7 out of 5 for relevance to service planning.

4.1.12 Previous treatment for alcohol and other drug problems

- “Most of the clients we see have had several different types of treatments - it was unclear if we were supposed to be circling more than one response (we did anyway).”
- “Found the category 05) Ambulatory rehabilitation confusing. For NT purposes may require inclusion of Methadone Withdrawal Program or Medicated Withdrawal Program, given our government policy and legislation which allows no drug substitution for purposes of addiction for S8 drugs.”
- “There was some strong agreement that the name of this element could be improved. It is recommended that the element be 'Previous alcohol or other drug services used'. Ensure that within the data domain, 05 reads 'Non-residential' as in the definitions document not 'Ambulatory' as was included in the form.”
- “Criticised as not providing an 'holistic' picture of the client's history therefore it requires the ability to select more options. Alternatively, the definition needs to state more clearly that it refers to that treatment *immediately prior* to this access.”
- “Ambiguity due to possibility of multiple options for most clients. Interpreted as most recent treatment prior to this episode.”
- “With some of the questions eg 12 there could be more than one response and it's not clear whether we must just choose one or if more can be chosen.”

Participants gave this item an average rating of 4.3 out of 5 for relevance to case management and 4.2 out of 5 for relevance to service planning.

4.1.13 Source of referral to agency

- “AOD treatment program - same service needed, and brokerage services.”
- “It is recommended that if possible the data domain of this element be reduced to fewer broader categories. Some comments were made suggesting that the level of detail in this element is unnecessary. It has been recommended, however that 'Aboriginal Health Agency' and 'Aboriginal Welfare Agency' be included in the list.”

Participants gave this item an average rating of 3.8 out of 5 for relevance to case management and 4.2 out of 5 for relevance to service planning.

4.1.14 Presenting problem drug

- “Difficulty in interpretation/use for sub-categories. Possibly a training issue.”
- “Primary drug of concern – is this for the client or the counsellor to define this.”
- “Given the specific issues of NT, inclusion of substances such as petrol, kava.”
- “Only two presenting problem drugs are possible with this questionnaire, what about polydrug users?”
- “Questions 14 and 15 should be changed to facilitate their use with polydrug users.”
- “It is recommended that the title of this element be changed to 'Presenting drug issue'. In addition the list of drugs needs some revision. There is no relevance in including the code numbers 020, 040, 050, 060, as these will never be used in entering the data; they are headings for the data items under each of these and therefore do not require code numbers. A single list of items and their code numbers is recommended with classification headings inserted as guiding information in defining this domain only. Also Caffeine and Tobacco are stimulants and should therefore be included under that heading, whilst pharmaceuticals is a broad term that bears no specific relationship to stimulants.”
- “Should methadone be considered a problem drug?”

Participants gave this item an average rating of 5 out of 5 for relevance to case management and 4.9 out of 5 for relevance to service planning.

4.1.15 Secondary problem drug

There are additional comments that relate to this item under 'Presenting problem drug'.

- “Secondary drug problem frequently overlooked – training problem?”
- “Secondary problem drug: important given the prevalence of these in the NT.”

Participants gave this item an average rating of 4.8 out of 5 for relevance to case management and 4.7 out of 5 for relevance to service planning.

4.1.16 Method of use for presenting problem drug

- “Need to include oral/orally.”
- “Should have oral (& sublingual) Eat and drink not a good use of terms. Also this for 17.”
- “Order of priority wrong 1) Oral 2) Smoke 3) Inject. (For 17 as well).”

- “Recommend deleting 'problem' from the title of this element. It is argued that this element has limited relevance. It is clearly understood that the rationale for investigating the route of administration is to ascertain the risk from administration. It is suggested that the biggest issue here is the risk associated with injection and therefore, it would be simpler to have just one element that identified whether the individual previously or currently used drugs by injection. It may well look like this:
16 Injecting drug use
01 Current injecting drug use
02 Past injecting drug use
03 No injecting drug use
09 Not stated”
- “Questions 16 and 17 need to include option 010 various/multiple to allow for polydrug choice in drug problem.”

Participants gave this item an average rating of 4.6 out of 5 for its relevance to case management and 4.2 out of 5 for its relevance to service planning.

4.1.17 Method of use for secondary problem drug

- “If no secondary drug problem, there was no option at question 17 to specify no use.”
- “Feedback comments as per 'Method of use for presenting problem drug'.”

Participants gave this item an average rating of 4.5 out of 5 for its relevance to case management and 4.2 out of 5 for its relevance to service planning.

4.1.18 Agency program type

- “No problems with this element, sufficient range of broad categories.”

4.1.19 Main type of service provided

- “There was some difficulty with this element. It is suggested that the "01 Assessment only" domain item is not valid as assessment never occurs in isolation. By its very nature assessment is accompanied by the provision of information and education in the very least. It has also been commented that none of these items can be exclusive in practice. Workers have great difficulty in confining this element to one item. In some instances it is noted that three or four items were included. It is suggested that it may be useful to shorten this list to 8 or 9 broader items, similar to element 18. This may look like the following:
19. Main type of service provided
01 Intoxication management
02 Withdrawal management (residential)
03 Withdrawal management (non-residential)
04 Counseling

- 05 Information and education
- 06 Crisis intervention
- 07 Case management
- 08 Drug substitution therapy (methadone)
- 09 Drug substitution therapy (other)”

- “Concern was expressed over questions 19 and 20 as also not providing the opportunity to show the complete nature of intervention. In this regard, the data definition information should probably indicate that these questions are not meant to discount or count the huge range of services an organisation might provide a client, but an indication of the greatest focus of treatment.”
- “‘Assessment only’ is problematic especially as ‘assessment’ is not listed under other services provided – assessment is usually the first service activity carried out but is often subsequently not the main service provided.”
- “(a) should be Assessment – ‘only’ should be deleted.”

4.1.20 Other type of service provided

There are additional comments that relate to this item under 'Main type of service provided'.

- “Other type of service provided: would like information/education included as other type of service provided.”
- “Allow for coding of more than one type of service provided.”

4.1.21 Reason for treatment termination

- “There is strong objection to the use of the term treatment, its link to a medical model of intervention being the rationale here. It is suggested that the word treatment can be deleted from the title making it read 'Reason for termination'. In addition there are several changes that have been suggested to the data domain in this element, namely the amalgamation of 01 Mutual agreement and 02 Completed treatment into 01 Service completed then delete 04, 06 and 07. 04 and 07 can be incorporated in 'Ceased to participate' while 06 can be included in 'Referred to another service'. The alternative is as follows:
 01 Service completed
 02 Referred to another service
 03 Ceased to participate
 04 Imprisoned
 05 Deceased
 99 Other”
- “The large number of transfers for the methadone clients both to and from the methadone service did not fit with any of these categories. Would suggest added label “transfer” to the list.”
- “Add completed treatment EPISODE.”

4.1.22 Referral to further care

- “Again there is objection to the term further care. It is suggested that this be deleted from the title so that the title reads 'Referral to' or 'Referral to another agency'. It is also recommended that the domain here be adjusted to match the 'Source of referral to agency' element omitting of course the 'Self' and the 'Relative/friends' items. There also needs to be some clarification about whether the referred to section is on completion of the episode or concurrent to service offered by an agency. If this element is purely for end of episode referrals then there may be a need for a concurrent referral element to be included.”

4.1.23 Problem drug treated

- “It is recommended that the title of this element be changed to 'Drug issue addressed' again removing the assumption of a problem to demonstrate a much more objective perspective. As with presenting and secondary drug lists this list should be amended along similar lines.”
- “All substances of abuse are treated, why this question? Surely “Primary drug of concern” covers this sufficiently.”
- “Problem drug treated - can we circle more than one?”

4.1.24 Methadone dose

- “It is strongly believed that this element is inappropriate in the context of a National Minimum Data Set. Methadone dose is information that will only be relevant to a minority of the users of alcohol and other drug services and to an even smaller minority of clinicians within services. It is clinical information relevant specifically to the medical management of opiate dependent individuals and as such is of limited value to other workers. Methadone programs in all states should incorporate specific data collection and monitoring processes for their purpose and not confuse this process with nationally relevant data on drug use patterns and service utilisation. It is recommended that this element be removed from the Data Set.”
- “Replace with something more relevant to closure of intervention and/or add commencing dose to information at registration and/or dose at completion as separate form.”
- “Conflict between forms and definitions regarding methadone dose (mg/ml). Questionable applicability for all clients commencing on methadone treatment program.”

4.1.25 Date episode terminated

There were no feedback comments that were directly concerned with this item. See 'date episode commenced' for feedback regarding episodes.

4.2 Feedback on other aspects of the project

4.2.1 Specific ways in which the data from the NMDS-AODTS should be used; regional and national planning/policy issues to be addressed

- “It would be good to use data to ascertain issues in particular populations, and the patterns associated with use. This would facilitate better planning”
- “Services should be designed to meet the particular population/s and problem drug use as identified by the NMDS-AODTS - e.g. private/public mix of treatment services – public beds in private detox/public methadone mix with private”
- “Increased funding to service providers”

- “Identifying patterns/trends and then disseminating this information to workers”
- “Regular information and comparisons between states.”
- “Would like to see the data used for 1. identifying target populations and special needs; 2. identifying problem drug use of those presenting perhaps to coordinate with unmet needs; 3. to look at mapping service delivery and ensuring good coverage and identifying gaps.”
- “Coordinating existing services; increasing services for youth/mental health.”
- “To plan for future service requirements of target groups. To identify expanding target groups. To aid in designing more flexible programs. To help evaluate the treatment results of the various models in service in service delivery to clients.”
- “Issues relating to particular population groups eg youth, multiculturally diverse backgrounds, Aboriginal/Torres Strait Islander. Levels and patterns of service use. Mapping client movements between services.”
- “Which groups (i.e. cultural, gender etc) are accessing and accessing services. What types of drugs/patterns of use are most prominent.”
- “Information gathered needs to reflect and determine issues that need to be considered via planning/policy bodies then these are used as a means of prioritising what should/shouldn't be addressed.”
- “I would like to see an annual compilation of data collection.”
- “Need to ensure that we collect data for a purpose, and that it is used to identify trends, funding priorities etc.”
- “Itinerancy of population.”
- “Ages of clients presenting; current drug of choice; past treatments.”
- “Will it make any difference to the availability of funds for services? Will it allow effective non-judgemental public education?”

4.2.2 Support or resources required by agencies for implementation of a national minimum data set (assuming that the national data set would be integrated with existing data forms/systems)

- “Training on how to complete forms, manual for reference. Computerisation rather than hard copy. Access to data reports.”
- “All units would require adequate hardware if computerised. And financial support to modify any existing systems to be able to comply with the NMDS-AODTS.”

- “The efforts/costs of modifying existing paper or computer systems needs to be addressed.”
- “Training – how to use forms, data etc.”
- “Universal system of collation and collection.”
- “Functional computer system.”
- “Specific training to ensure standardised practice.”
- “Computer systems, with training. Time or more human resources.”
- “Unsure. Definite requirement would be a computer for the service.”
- “Training and computer systems.”
- “Training, software. We could certainly make use of any additional computers.”
- “Administrative support/resources to remove this data collection burden from workers whose job it is to assist the client base. Any other requirements outside the sphere of direct service provision affects our ability to meet needs of community. Thank you.”
- “Administrative staff need training, I'm not a computer operator. One that collates all data required so as coal faceworkers can do their jobs without having to organise stats > get it right the first time, do not waste our time. Thank you.”
- “Need to get the data collection/collation process established/trialled before it being implemented. It has been very frustrating trying to report on our state system when it has not been set up properly.”
- “Help the workers on the ground, get rid of the paperwork. Be proactive, computers for staff, programs designed for staff, vetted by staff. Drop down menus, point and click.”
- “Additional funding to cover additional time collecting and collating data unless such data can be extracted from existing data collection systems.”
- “Decrease in duplication of paperwork i.e. one form that does it all.”
- “A client management system adequate to collect and collate all the data fed into it. Enough flexibility in the system for it to adapt to other agency needs and cheap enough for all agencies to afford it.”
- “Generally, completed forms often indicated that workers had not read or understood data elements and definitions. May indicate need for comprehensive training, regular quality assurance exercises/audits and retraining etc.”

4.2.3 Other issues that need to be considered, in regard to the implementation and administration of a national data set.

- “Access to reports. If counsellors are required to provide data, the agency must have access to reports in a timely fashion.”
- “Identifiable/perceived benefit for individual staff and services.”
- “Appropriate feedback.”
- “Quality control of data.”
- “Easily accessible reports from the database.”
- “Confidentiality”
- “Commitment to use the data constructively to plan future services and service delivery.”
- “Continuous monitoring and evaluation of effectiveness.”
- “Would want modification made to current data collection i.e. NT Daisy as opposed to creating extra paperwork.”
- “Confidentiality needs to be paramount at all times.”
- “Need to collect useful data not just data.”
- “A survey of participating agencies of: "are there any question(s) that should be added to the data set? If so, please specify the question(s) and reasons for inclusion.”
- “Consistency in terms of philosophies, operating protocols and service agreements is required to ensure this data collection system is worthwhile.”
- “Not all states follow the same/let alone are governed by the same set of regulations. Also not all states have the same type of service agreements drawn up and this needs to be reflected via flexibility of collection service (data base).”
- “Needs to be registration/episode form; need address and contact number.”
- “Should be standardised for all alcohol and drug services. You can't have a national data set when services are using different reporting mechanism e.g. ADIS, SWITCH.”
- “Questions need to correlate with the registration form, or needs to incorporate name, address etc. If this is going to become a standard process, the form needs to be multi-purpose so that duplication does not occur.”
- “Sure we like helping out, but consider the time down collecting yet another set of stats

from a client base we are already collecting stats from.”

- “This form should be similar to our state form, why not make it the same or change our state form. Why are workers collecting this information. Why haven't the IT technicians made it possible for computer clerks to extract the information from the "multitude" of stats already collected by workers. And do the people who make up these questionnaires trial them first as part of evaluation before releasing it to workers.”
- “Should not be repetitive for coal face workers as time is very valuable.”
- “How long will data be kept in storage and in what format? What happens to the hard copy forms after they have been processed?”
- “Who will have access to the information at the data collection agency, particularly nationally (at the AIHW)?”
- “How will the data be transferred into information for the general public? How might it be published at a national level?”

4.2.4 Other comments or questions about the NMDS-AODTS or the pilot study.

- “Worthwhile exercise but staff complained that it was yet another form for clinical staff to fill in - more work with no more resources.”
- “The comment 'where a question specifies a set of options, please circle one option only' is unclear and ambiguous. We routinely needed to circle more than one option for the following: 12) previous treatment 16),17) method of drug use 20) other type of service.”
- “Importance of accurate recording and input of data needs to be emphasised, especially in terms of all agencies interpreting questions in the same manner - was apparent initially within our agency. Otherwise faced with the dilemma of garbage in - garbage out.”
- “I found participation in the pilot study to be a practical and useful one. It has identified some gaps in this agency's collection of "useful" data.”
- “Thanks for letting us be part of the survey.”
- “This data should be able to be retrieved from the data sent to DHS on quarterly reports, and not duplicated by on the ground workers. All data is inputted to the computer program and should be retrieved from the computer.”
- “Help the worker.”
- “Ensure that data can be extracted from existing computer data collection systems.”

The appendices to this report consist of the instruments that were used to conduct the pilot study, including the client episode form, the feedback questionnaire and the pilot study protocol.

5. Appendices

Appendix 5.1 : Client Episode Form

Alcohol and Other Drug Treatment Services : Client Episode Form

Instructions: Where a question specifies a set of options, please circle one option only. Please fill in a separate form for each new episode of care.

Information to be completed at registration:

1. Establishment identifier: _____

2. Date episode commenced: ___ / ___ / ___

3. Person identifier _____

4. Client status

- 1 Own drug use problem
- 2 Other's drug use problem
- 9 Not known

5. Date of birth

___ / ___ / ___

6. Sex

- 1 Male
- 2 Female
- 9 Not stated/inadequately described

7. Country of birth

8. Indigenous status

- 1 Indigenous - Aboriginal but not Torres Strait Islander origin
- 2 Indigenous - Torres Strait Islander but not Aboriginal origin
- 3 Indigenous - Aboriginal and Torres Strait Islander origin
- 4 Not indigenous - not Aboriginal or Torres Strait Islander origin
- 9 Not stated

9. Source of income

- 01 Full-time employment
- 02 Part-time employment
- 03 Temporary benefits
- 04 Pension
- 05 Student allowance
- 06 Dependent on others
- 07 Retirement fund
- 98 Other
- 99 Not known

10. Type of usual accommodation

- 01 House or flat
- 02 Boarding house
- 03 Hostel
- 04 Psychiatric home/hospital
- 05 Nursing home
- 06 Alcohol/other drug treatment residence
- 07 Shelter/refuge
- 08 Prison/detention centre
- 09 No usual residence
- 98 Other
- 99 Not known

11. Living situation

- 01 Alone
- 02 Spouse/partner
- 03 Alone with child(ren)
- 04 Spouse/partner and child(ren)
- 05 Friend(s)
- 06 Parent(s)
- 07 Other relative(s)
- 08 Friend(s)/parent(s)/relative(s) and children
- 98 Other
- 99 Not known

12. Previous treatment for alcohol & other drug problems

- 01 Assessment only
- 02 Detoxification/withdrawal
- 03 Residential rehabilitation
- 04 Drug substitution/maintenance
- 05 Ambulatory rehabilitation (including counselling)
- 06 No previous treatment
- 98 Other
- 99 Not known

13. Source of referral to agency

- 01 Self
- 02 Relative/friend
- 03 Drug treatment service
- 04 GP/medical officer/specialist
- 05 Hospital
- 06 Community health service
- 07 Mental health service
- 08 Family and child protection service

- 09 Welfare/community service organisation
- 10 Correctional service
- 11 Educational institution
- 12 Workplace
- 98 Other
- 99 Not known

14. Presenting problem drug

- 010. Alcohol
- 020. Opioids
 - 021. Heroin
 - 022. Methadone
 - 029. Other opioids
- 030. Cannabis
- 040. Sedatives and hypnotics
- 050. Stimulants and pharmaceuticals
 - 051. Amphetamines
 - 052. Cocaine
 - 053. Ecstasy(MDMA)
 - 054. Other stimulants & pharmaceuticals
- 060. Hallucinogens
 - 061. LSD
 - 062. Mushrooms
 - 063. Other hallucinogens
- 070. Tobacco
- 080. Caffeine
- 090. Steroids and related
- 100. Volatile solvents/ inhalants
- 970. Polydrug use
- 980. Other psychoactive drugs

041.Benzodiazepines
049.Other sedatives
and hypnotics

substances

15. Secondary problem

010.Alcohol
020.Opioids
021.Heroin
022.Methadone
029.Other opioids
030.Cannabis
040.Sedatives and
hypnotics

drug (select '990' if there is no secondary problem drug)
050.Stimulants and pharmaceuticals
051.Amphetamines
052.Cocaine
053.Ecstasy(MDMA)
054.Other stimulants & pharmaceuticals
060.Hallucinogens
061.LSD
062.Mushrooms
063.Other hallucinogens
070.Tobacco
080.Caffeine
090.Steroids and related substances

100.Volatile solvents/
inhalants
970.Polydrug use
980.Other psychoactive
drugs
990.No secondary problem
drug

041.Benzodiazepines
049.Other sedatives
and hypnotics

16. Method of use for

01 Inject
02 Smoke
03 Eat/drink
04 Sniff (powder)

presenting problem drug

05 Inhalation (vapour)
06 Per rectum/vagina
07 Other
09 Not known

17. Method of use for

01 Inject
02 Smoke
03 Eat/drink
04 Sniff (powder)

secondary problem drug

05 Inhalation (vapour)
06 Per rectum/vagina
07 Other
09 Not known

Information to be completed at the end of the treatment episode:

18. Agency program type

01 Outpatient treatment services
02 Inpatient treatment services
03 Therapeutic communities
04 General practitioners
05 Outreach services
06 Treatment units in prison
09 Other

19. Main type of service provided

01 Assessment only
02 Information and education
03 Inpatient detoxification
04 Outpatient/home detoxification
05 Methadone maintenance
06 Other drug substitution/maintenance
07 Therapeutic (facilitated) groups
08 Peer/support groups
09 Advocacy
10 Counselling
11 Other rehabilitation
12 Crisis intervention
98 Other

20. Other type of service provided

01 Inpatient detoxification
02 Outpatient/home detoxification
03 Methadone maintenance
04 Other drug substitution/maintenance
05 Therapeutic (facilitated) groups
06 Peer/support groups
07 Advocacy
08 Counselling
09 Other rehabilitation
10 Crisis intervention
98 Other
99 No other service provided

21. Reason for treatment

01 Mutual agreement
02 Completed treatment
03 Referred to another service
04 Left against advice
05 Ceased to participate

termination

06 Hospitalised/ medical condition
07 Discharged due to non-compliance
08 Imprisoned
09 Deceased
99 Other

22. Referral to further care

01 Drug treatment service
02 GP/medical officer/specialist
03 Hospital
04 Community health service
05 Mental health service
06 Family and child protection service

07 Welfare/community service organisation
08 Education/training organisation
09 Employment agency
98 Other
99 No referral

23. Problem drug treated

010.Alcohol
020.Opioids
021.Heroin
022.Methadone
029.Other opioids
030.Cannabis

050.Stimulants and pharmaceuticals
051.Amphetamines
052.Cocaine
053.Ecstasy(MDMA)
054.Other stimulants &
060.Hallucinogens
061.LSD
062.Mushrooms
063.Other hallucinogens
070.Tobacco

100.Volatile solvents/
inhalants
970.Polydrug use
980.Other psychoactive
drugs

040.Sedatives and
hypnotics

pharmaceuticals

080.Caffeine

090.Steroids and related
substances

041.Benzodiazepines
049.Other

sedatives and
hypnotics

24. Methadone dose (for patients currently receiving methadone treatment - record in millilitres):

25. Date episode terminated: ___ / ___ / ___

Appendix 5.2 : Feedback question

**National Minimum Data Set Project for
Alcohol and Other Drug Treatment Services (NMDS-AODTS).**

Questionnaire: Feedback on Pilot Study for Participating Agencies.

Please write your answers neatly (type them separately if necessary) and attach additional pages if you run out of space.

1. Have there been any problems encountered with the design (coding or definition) of any questions on the Client Episode Form? (e.g. coding inadequate or too complicated). Please describe these problems and, if possible, provide your suggestions for rectifying these problems.

2. Should any of the questions on the form be **replaced** by an alternative question? If so, please specify which question(s) should be replaced and provide reasons for doing so.

3. Are there any question(s) that should be **removed** from the data set altogether? If so, please specify which questions should be removed and provide reasons for doing so.

Questions Four and Five are concerned with the potential value of different categories of data; they are not concerned with the coding used for the questions on the Client Episode Form.

4. (a) Assuming that reliable data is obtained for the items listed below, rate the value of each item for **case management (planning individual occasions of service)**.
On a scale from 1 to 5: 1 = of no value, 5 = of great value.

	1	2	3	4	5
Date of birth					
Sex					
Country of birth					
Source of income					
Type of usual accommodation					
Living situation					
Previous treatment for alcohol & other drug problems					
Source of referral to agency					
Presenting problem drug					
Secondary problem drug					
Method of use for presenting problem drug					
Method of use for secondary problem drug					
Methadone dose					

- (b) If you wish, provide some comments to accompany the ratings given.

5. (a) Assuming that reliable data is obtained for the items listed below, rate the value of each item for ***planning and developing services within an agency***.
On a scale from 1 to 5: 1 = of no value, 5 = of great value.

	1	2	3	4	5
Person identifier					
Client status					
Date of birth					
Sex					
Country of birth					
Indigenous status					
Source of income					
Type of usual accommodation					
Living situation					
Previous treatment for alcohol & other drug problems					
Source of referral to agency					
Presenting problem drug					
Secondary problem drug					
Method of use for presenting problem drug					
Method of use for secondary problem drug					
Agency program type					
Main type of service provided					
Other type of service provided					
Reason for treatment termination					
Referral to further care					
Problem drug treated					
Methadone dose					

- (b) If you wish, provide some comments to accompany the ratings given.


6. In what specific ways would you like to see the data from the NMDS-AODTS used - what regional and national **planning/policy issues** should be addressed? (e.g. Issues relating to particular populations, problem drugs, levels and patterns of service utilisation, and relationships between different types of services.)

7. What **support** or **resources** (e.g. training, computer systems) do you think would be required by agencies for implementation of a national minimum data set (assuming that the national data set would be integrated with existing data forms/systems)?

8. Are there any other issues that need to be considered, in regard to the **implementation** and **administration** of a national data set?

9. Do you have any other comments or questions about the NMDS-AODTS or the pilot study?

End of Questionnaire.

Thank-you! 

Appendix 5.3 : Pilot study protocol

Protocol for the NMDS-AODTS Pilot Data Collection.

Introduction.

The NMDS-AODTS Pilot Data Collection will involve the collection of standardised client and service data by a small number of agencies nationally, over a six week period from 22 June to 31 July 1998. The purpose of the Pilot Data Collection is to assess the validity of the data set content and definitions, the ability of agencies to collect this data consistently, and the type of support and systems required to collect and compile this data nationally. This pilot will help to inform any necessary modifications to the data set and a plan for its implementation.

It is anticipated that the data will be collected by the agency when the client is registered with the agency, when the period of treatment or contact with the agency has ended, and when the client is referred to other services. The NMDS-AODTS data should be collected in these situations for all clients. Preliminary studies have indicated that the data items (eg 'age', 'sex', 'presenting problem drug') proposed within the data set are collected in some manner by most treatment services. The proposed minimum data set will prescribe a consistent approach to collecting these items of data.

The data items to be collected during this pilot, together with their definitions, will be sent out to agencies by 29 May. The data item definitions include coding schemes (such as a drug coding scheme) where necessary, as well as other guidelines for collecting the data. This information will be accompanied by a standard paper form containing the data items and guidelines. The data may be recorded either in paper or electronic format depending upon the existing system within the agency. Because the data items correspond to data already collected by many agencies, it is expected that in most instances only minor modifications will need to be made to data collection systems and processes. See Attachment 1 for a provisional list of NMDS-AODTS data items.

Collection and transfer of data.

- Services agreeing to participate in the pilot are asked to collect all specified data between 22 June 1998 and 31 July 1998 inclusive.
- Data collected will be forwarded to the State/Territory peak government body in two dispatches, the first comprising the data collected between 22 June 1998 and 12 July 1998, and the second comprising the data collected between 13 June and 31 July. The first dispatch should be sent by 15 July and the second by 5 August, unless a different schedule is negotiated between the agency and the peak government body.
- Data will be forwarded from State/Territory peak government bodies to The National Drug and Alcohol Research Centre, which will be the national collection agency for the pilot.
- Adequate measures will have to be taken to maintain the security and confidentiality of client records in all transfers of data that occur between agencies, peak government bodies and the National Drug and Alcohol Research Centre for this pilot (see attachment two). All parties involved in a transfer of client records shall have responsibility for these measures.

Administrative arrangements within agencies.

- It may be useful for participating agencies to appoint one staff member to be a "Data Officer", to have responsibility for coordinating the pilot within that agency (see relevant protocol items in this section), in conjunction with the State/Territory Coordinator.
- It is advisable that all staff involved in data collection, management or use within an agency attend a briefing session before the commencement of the pilot. Any materials for the briefing session shall be forwarded to them from their State/Territory peak government body, which will provide any other support needed to prepare staff for the pilot.
- Participating agencies will need to make any necessary modifications to their existing data collection procedures or systems before the commencement of the piloting period, so that they

can collect data that conforms to the NMDS-AODTS content and definitions. Any support required for this process should be provided by the respective peak government body. To aid a consistent approach to data collection practices, guidelines will be contained in the definitions of NMDS-AODTS data elements, and with the paper forms supplied.

- Participating agencies should take adequate measures to maintain the security and confidentiality of the client records within the agency (see Attachment 2). Data forwarded from the agency to the peak government body shall not retain any identifying elements (such as name, address) unless this is required as part of an established system within any jurisdiction.

Responsibilities of coordinating bodies.

- The National Drug and Alcohol Research Centre will make available the pilot NMDS-AODTS data elements and definitions to participating agencies by 29 May 1998.
- Peak government bodies within each jurisdiction shall have one person appointed to coordinate the data pilot program within their jurisdiction, this being the NMDS-AODTS National Advisory Group government representative or their delegate. This State/Territory Coordinator should maintain regular contact with the participating agencies within their jurisdiction during the piloting project and preparatory phase (throughout May), and will need to arrange for the collection and compilation of data from these agencies. The Coordinator will also need to make sure that agencies are supported as outlined in this protocol.
- Where possible the peak government bodies shall convert data received from agencies into a standard electronic format and ensure that no data retains any elements that identify a client. If this is not possible in any instance, these tasks shall be performed by the National Drug and Alcohol Research Centre.
- The National Drug and Alcohol Research Centre will need to provide the peak government body in each jurisdiction with any information, advice and written materials necessary to support the pilot. This will include materials for the briefing sessions within pilot agencies, paper forms and supporting documentation for data collection. Briefing session materials will be made available to peak government bodies by 29 May.
- The National Drug and Alcohol Research Centre and peak government bodies will take adequate measures to maintain the security and confidentiality of client data in their possession, in accordance with the relevant State and Commonwealth legislation.

Protocol attachment one : provisional data set content

The data items listed here do not represent the final set of items requested for reporting by participating agencies. This list is currently being revised in accordance with the findings of a national consultation process. It may serve as a rough guide, however, to the types of data that will be collected.

A. Unique identifier and Socio-demographic Information

1. Client identifier
2. Age
3. Sex
4. Ethnicity (Country of birth)
5. Indigenous status (Aboriginality)
6. Employment status/Source of income
7. Living situation

B. Service Contact Information

8. Previous treatment for drug problems
9. Source of referral to agency
10. Type of treatment received
11. Date treatment commenced
12. Date treatment ended
13. Reason for treatment termination
14. Referral to other service
15. Agency code

C. Drug-related Information

16. Presenting drug problem
17. Drug problem treated
18. Secondary drug use
19. Route of administration
20. Methadone dosage

Protocol attachment two : CHASP Standard 6.2 for Alcohol, Tobacco and Other Drug Services.

This standard is taken from the Manual of CHASP Standards for Alcohol, Tobacco and Other Drug Services (1996), developed by the National Community Health Accreditation and Standards Program and Queensland Health. The manual of standards is designed to facilitate service improvement, and is not intended as a set of minimum standards.

Standard 6.2 has been attached to the Protocol for the NMDS-AODTS Pilot Data Collection to serve as a guide, rather than a set of rules, for participating agencies.

Standard 6.2. Confidentiality of client records

– The drug service will ensure the confidentiality of all its client records.

Indicators

6.2.1 Are there adequate security arrangements to prevent loss, defacement and unauthorised ~~use~~ client records (eg a separate lockable space/s, room or cabinet, where all records containing information about clients are stored)? How does this happen?

6.2.2 Are there procedures to make sure that the confidentiality of client records is maintained, if their removal from the service or transport between sites of a service is necessary (eg locked briefcase, registered mail)?

6.2.3 Are there procedures to ensure the confidentiality of material which is faxed? What are these procedures?

6.2.4 Where aspects of the client record system are computerised, how is confidentiality ensured (eg no linkage of client names with information when computers are networked, password)?

6.2.5 Does the service ensure that client records are not left unsupervised (eg on desks, in unlocked filing cabinets) and cannot be read by unauthorised people (eg not having names on front covers)? How does this happen?

6.2.6 Is clients written or verbal consent recorded in their client record when information is sent to other agencies or professionals?

6.2.7 Does the service explain to clients that their client records may be audited or used for data collection? How does this occur?

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