



**Australian Government**

**Australian Institute of  
Health and Welfare**

*Better information and statistics  
for better health and wellbeing*

DRUG TREATMENT SERIES

Number 11

# **Review of the Alcohol and Other Drug Treatment Services National Minimum Data Set**

**January 2011**

Australian Institute of Health and Welfare  
Canberra

Cat. no. HSE 94

**The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is *better information and statistics for better health and wellbeing.***

© Australian Institute of Health and Welfare 2011

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced without prior written permission from the Australian Institute of Health and Welfare. Requests and enquiries concerning reproduction and rights should be directed to the Head of the Communications, Media and Marketing Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

This publication is part of the Australian Institute of Health and Welfare's Drug treatment series. A complete list of the Institute's publications is available from the Institute's website <[www.aihw.gov.au](http://www.aihw.gov.au)>.

ISSN 1447-6746

ISBN 978-1-74249-104-2

### **Suggested citation**

Australian Institute of Health and Welfare 2011. Review of the Alcohol and Other Drug Treatment Services National Minimum Data Set. Drug treatment series no. 11. Cat. no. HSE 94. Canberra: AIHW.

### **Australian Institute of Health and Welfare**

Board Chair

Hon. Peter Collins, AM, QC

Director

David Kalisch

Any enquiries about or comments on this publication should be directed to:

Nadia August

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

Phone: (02) 6244 5129

Email: [Nadia.August@aihw.gov.au](mailto:Nadia.August@aihw.gov.au)

Published by the Australian Institute of Health and Welfare

Printed by Bluestar Print

**Please note that there is the potential for minor revisions of data in this report. Please check the online version at <[www.aihw.gov.au](http://www.aihw.gov.au)> for any amendments.**

# Contents

- Acknowledgments..... iv**
- Abbreviations..... v**
- Foreword ..... vii**
- Summary ..... viii**
- Background.....1**
- Methodology .....10**
- Literature review .....14**
- Consultation .....37**
- Thematic analysis .....49**
- Conclusions and potential solutions .....74**
  - Next steps .....80
- Appendixes .....83**
  - Appendix 1: AODTS-NMDS Working Group terms of reference and operating principles.....83
  - Appendix 2: Health reporting structure .....87
  - Appendix 3: Analysis of current data elements .....88
  - Appendix 4: Literature review search terms .....106
  - Appendix 5: List of stakeholders consulted .....107
  - Appendix 6: Consultation documentation – stakeholder consultation questionnaire.....108
  - Appendix 7: Scope of review of the Alcohol and Other Drug Treatment Services National Minimum Data Set.....115
- Bibliography.....116**
- Index .....123**

# Acknowledgments

The author of this report was Nadia August, of the Drug Surveys and Services Unit at the Australian Institute of Health and Welfare (AIHW).

Thank you to Amber Jefferson, who provided guidance, advice and support throughout the project and to Kristina Da Silva and Carey Sebbens for their administrative and technical support.

The author would also like to thank and acknowledge the contributions made by several areas of the AIHW, with expertise in the subjects including, but not limited to, Aboriginal and Torres Strait Islander peoples, mental health, homelessness, metadata, prisoner health, data linkage, governance and privacy.

Many thanks to the stakeholders who gave their time and expertise through the consultation process and provided valuable information to inform this report.

This project was funded by the Australian Government Department of Health and Ageing.

# Abbreviations

ADCA	Alcohol and Other Drugs Council of Australia
AHMAC	Australian Health Ministers Advisory Council
AIHW	Australian Institute of Health and Welfare
ANCD	Australian National Council on Drugs
AOD	alcohol and other drugs
AODTS-NMDS	Alcohol and Other Drug Treatment Services National Minimum Data Set
ASCDC	Australian Standard Classification of Drugs of Concern
BBV	blood-borne virus
DATIS	Drug and Alcohol Treatment Information System
DoHA	(Australian Government) Department of Health and Ageing
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
GAP	Global Assessment Programme on Drug Abuse
HIV	human immunodeficiency virus
IDU	injecting drug use/r
IGCD	Intergovernmental Committee on Drugs
MCDS	Ministerial Council on Drug Strategy
NCETA	National Centre for Education and Training on Addiction
NDARC	National Drug and Alcohol Research Centre
NDS	National Drug Strategy
NDSHS	National Drug Strategy Household Survey
NFP	not-for-profit (organisation)
NGO	non-government organisation
NGOTGP	Non Government Organisation Treatment Grants Program
NHHRC	National Health and Hospitals Reform Commission
NHIA	National Health Information Agreement
NHISSC	National Health Information Standards and Statistics Committee
NHMRC	National Health and Medical Research Council
NIDA	National Institute on Drug Abuse
NIDISC	National Indigenous Data Improvement Support Centre
NIDS	National Illicit Drug Strategy
NMDS	national minimum data set
NOPSAD	National Opioid Pharmacotherapy Statistical Annual Data
NSP	needle and syringe program
OATSIH	Office of Aboriginal and Torres Strait Islander Health

SAMHSA	Substance Abuse and Mental Health Services Administration (USA)
SLK	statistical linkage key
STI	sexually transmissible infection
TDI	Treatment Demand Indicators (European Union)
TEDS	Treatment Episode Data Set (USA)
UNODC	United National Office on Drugs and Crime
USA	United States of America
WHO	World Health Organization

# Foreword

The role of data has always been a priority in the National Drug Strategy, to improve the understanding of licit and illicit drug issues and to inform the development of policies and programs. For over a decade, the Australian Institute of Health and Welfare (AIHW) has worked with the Australian Government, states and territories, research centres and non-government agencies to collect, analyse and report high-quality data on publicly funded alcohol and other drug treatment. In cooperation with these stakeholders, this review has undertaken to assess the Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS-NMDS) as an information source for services policy development, data gaps, and options for future development within the collection. It has also been fortuitously timed, 10 years after the collection's inception and with the pending release of the new National Drug Strategy 2010–2015.

Treatment for alcohol and other drug (AOD) use is a key issue on the government agenda and occurs in a complex system of service delivery that encompasses issues of social disadvantage, homelessness, and mental illness and the broader issue of health reform. It is within this context that this review has been undertaken; specifically, addressing the scope of the current collection and examining how appropriate this is to provide evidence to support policy makers.

In the current health environment, it is critical that policy makers have access to up-to-date, high-quality data that can answer important policy questions. From the literature review and through stakeholder consultations, it became clear that we have an opportunity to consider new concepts such as housing and homelessness status and psychological comorbidity. We can also work to improve consistency with existing collections in each state and territory and to incorporate statistical techniques, such as data linkage, to estimate the number of clients accessing treatment.

To provide sound data to inform policy, the AODTS-NMDS must have leadership, supported by sound governance processes. All stakeholders supported a strengthened governance structure, to guide the collection through the challenging health environment by translating the broad policy concepts into specific policy questions, thereby ensuring that policy and program design is evidence based.

I would like to thank the Intergovernmental Committee on Drugs (IGCD) for taking the initiative to review this collection and the Australian Government Department of Health and Ageing (DoHA) for funding the review and this report. The AIHW looks forward to working with the IGCD, the DoHA and each state and territory on any and all developments and changes that may be implemented as a consequence of this review.

Penny Allbon  
Director

# Summary

The Review of the Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS-NMDS) was conducted by the Australian Institute of Health and Welfare (AIHW) at the request of the Intergovernmental Committee on Drugs (IGCD), funded by the Australian Government Department of Health and Ageing (DoHA).

## **Purpose and process**

The purpose of the review was to assess the AODTS-NMDS as an information source for services policy; data gaps; and options for future development within the collection.

The project was undertaken in four parts: a literature review; consultation with stakeholders in the alcohol and other drugs (AOD) sector, including policy makers, researchers and treatment agencies; analysis of the common themes between the literature review and the consultations; and reporting of the findings.

## **International and domestic context**

The literature review identified potential lessons from the international experience, including different kinds of data collections and their development processes. Of particular interest was the United Nations Office on Drugs and Crime work on internationally standardised data collection in the AOD treatment field and the collections of countries with similar treatment models, such as Canada. Domestically, changes to AOD service provision, as a result of potential changes to the national health system, are challenging to anticipate and the implications for health data collection, monitoring and reporting are unknown. There is, however, increasing interest in collecting more information about specific populations considered to be 'at risk', such as those people experiencing homelessness and/or mental illness, Aboriginal and Torres Strait Islander peoples, injecting drug users and families.

## **Common themes**

The most common theme of the review was the need for a common understanding of AOD treatment in the context of the AODTS-NMDS, to clarify the purpose, scope and content of the collection and strengthen the governance arrangements through the DoHA and the IGCD. Stakeholders also identified concepts that they would like to see captured in the collection, such as primary caring status, treatment history, mental health status and many other concepts, though there was no consensus on which concepts were most important. The ability to estimate the number of unique individuals was considered important by all stakeholders, however the use of a statistical linkage key was not. Similarly, stakeholders agreed that while capturing more information about clients and agencies would be beneficial for service planning and policy setting, it must be balanced with the administrative burden on agencies and the resources required by states and territories to report these data.

## **Governance and strategic direction**

This review supports the roles of the DoHA and the IGCD to provide strategic direction and guidance for the development of the AODTS-NMDS, including negotiating the relationships between relevant stakeholders. As the AODTS-NMDS was originally designed to assist with the evaluation, monitoring and reporting of the National Drug Strategy (NDS), it is appropriate for the collection to be governed by the same bodies that implement the strategy. As the IGCD has representation from all states and territories, it is also an appropriate body

to discuss and negotiate issues that may arise within jurisdictions that impact on the collection, including the role of treatment agencies, sector peak bodies and research centres and to manage these relationships.

### **Scope**

To better meet policy needs and accurately reflect contemporary practice, the scope of the AODTS-NMDS may need to change. Common scope issues that were raised by stakeholders include the paucity of data on treatment in correctional facilities, clients on opioid pharmacotherapy and AOD services provided in non-specialist settings, such as crisis accommodation and sobering-up shelters. This review recommends that the IGCD and the DoHA determine the appropriate scope for the collection in line with the pending NDS.

### **Other concepts**

All stakeholders expressed interest in collecting more information than is currently captured by the AODTS-NMDS. The concepts raised can be broadly categorised into information about clients, the treatment being provided and the treatment agency. Examples of client-level information include their housing status, mental health status and caring responsibilities (if they have children). Examples of treatment-level information were treatment intensity, activities and an outcome measure; and agency-level information such as capacity to deliver, funding source or treatment philosophy. There are various appropriate methods for capturing these concepts, including introducing new data elements and/or implementing data linkage.

### **Analysis of current elements**

In addition to longer term planning and decision making, this review has identified many tasks that may be undertaken immediately, at the direction of the DoHA and the IGCD. Enhancements could be made to current data elements and/or implementation of existing data elements from the National Health Data Dictionary or the Community Services Data Dictionary, to improve the comprehensiveness, consistency and quality of the collection.

### **How to change the collection**

All changes to national minimum data sets, whether intended for voluntary or compulsory collection by jurisdictions, require endorsement by the National Health Information Standards and Statistics Committee, a subcommittee of the Australian Health Ministers' Advisory Council.

### **Products and processes**

Stakeholders were generally supportive of the products emanating from the collection. The online data cubes were used by treatment agencies and researchers while all stakeholders appreciated the availability of the printed annual report and state and territory bulletins. Suggestions were made to improve the profile of the collection, including producing inserts for conferences and advertising the data request process to a wider variety of users.

### **Privacy and consent**

Pending the release of draft legislation regarding the harmonisation of Australian privacy arrangements, as a result of the Australian Law Reform Commission review, privacy and consent processes should be reviewed by each state and territory to ensure compliance with current relevant legislation.

## **Conclusion**

This review provided an opportunity to examine not only the operation of the collection within the AOD sector, but also to consider the wider operation, program and policy context of AOD treatment. It has highlighted the importance of a comprehensive, robust and consistent data collection about AOD treatment and that the AODTS-NMDS remains a key component of the data toolbox available to inform government, service provision and the public on AOD issues in Australia.

# Background

## About the Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS-NMDS)

### Purpose of this review

In 2008, the Australian Institute of Health and Welfare (AIHW) undertook a project with funding from the Australian Government Department of Health and Ageing (DoHA) to investigate and pilot a statistical linkage key and an indicator of psychological comorbidity within the collection. The Alcohol and Other Drug Treatment Services National Minimum Data Set Enhancement Project (the Enhancement Project; AIHW 2008) consisted of consultation with identified stakeholders, the development of metadata and elements for capturing information on mental health and the statistical linkage key, and piloting these elements in selected alcohol and other drug (AOD) treatment agencies.

Statistical linkage was selected because the current inability to estimate the number of clients within the collection has been considered by stakeholders to be extremely limiting for policy makers, program administrators and service planners. The National Comorbidity Initiative and the associated Improved Services for People with Drug and Alcohol Problems and Mental Illness Measure (the Improved Services Measure) provided the policy context for testing the feasibility of a mental health indicator within the collection. The final report of the Enhancement Project was tabled at the Intergovernmental Committee on Drugs (IGCD) meeting of September 2009 and the committee questioned the impetus for such projects and changes. Before changes to the collection could be considered, the IGCD agreed that a review of the collection be undertaken to assess its usefulness as an information source for drug services policy, data gaps and options for development.

### History of the collection

In 1995, the Alcohol and Other Drugs Council of Australia (ADCA) held a national forum 'Treatment and Research – Where to from here?' which highlighted the paucity of data about AOD treatment in Australia and the negative consequences for effective service provision. Consequently, from 1997 to 1999, the then Commonwealth Department of Health and Family Services funded the National Drug and Alcohol Research Centre (NDARC) to undertake a project to assess the state of data collections in the AOD sector, identify the barriers between treatment and research, and pilot a set of data elements that may comprise a national collection. The final report of The National Minimum Data Set Project (Rankin & Copeland 1997; see also Box 1) set out a justification for a collection to provide baseline data useful in the subsequent evaluation of treatment programs. Following this project, the then National Health Information Management Group (NHIMG) endorsed the first Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS-NMDS) for collection to commence on 1 July 2000.

### **Box 1: What is a national minimum data set (NMDS)?**

A national minimum data set (NMDS) is a minimum set of data elements agreed for mandatory collection and reporting at a national level (AIHW 2010a). It consists of elements, which are the common data collected in each state and territory and are reported according to nationally agreed protocols. An NMDS is contingent upon a national agreement to collect data and to supply it as part of the national collection, but does not preclude agencies and service providers and other authorities from collecting additional data to meet their own specific needs. Without agreement between all relevant parties, an NMDS does not exist. In the health sector, this agreement is exemplified by the National Health Information Agreement (NHIA).

An NMDS agreement includes specified data elements as well as the scope of the application of those data elements. These are described in each element's metadata (AIHW 2010b).

The AODTS-NMDS was established to assist in the evaluation, monitoring and reporting of the National Drug Strategy and in particular to provide (IGCD Working Group meeting minutes 1999):

- information on the harms caused by drug use
- data that may be useful for evaluating achievements against objectives and treatment priority areas
- evidence-based practice in treatment
- information about emerging trends and problems in the treatment sector.

In the most recent *Specifications and collections manual* (2010–11; AIHW 2010a) the purpose of the collection is described as follows:

...to combine standardised Australian Government, state and territory data so that national information about clients accessing AOD treatment, service usage and treatment programs can be reported. It is also expected that the collection will provide agencies with access to basic data relating to drug problems and treatment responses in their areas. The data derived from the national collection are used, with information from other sources (e.g. admitted-patient data and national surveys), to inform debate, policy decisions and strategies that occur within the AOD treatment sector.

## **Development of the AODTS-NMDS**

In 2001, the AIHW prepared a report on the development and implementation of the AODTS-NMDS, including a review of data collections that contained information about AOD use and consequences that existed at the time (Grant & Petrie 2001). This review, ten years on, is to assess the collection's compliance with the original intentions as described in the 2001 report.

The statement of purpose for the AODTS-NMDS was developed by the IGCD AODTS-NMDS Working Group (the Working Group) in 1999 and was subsequently endorsed by the IGCD. It reads:

There is an urgent requirement for data development and collection implementation which will provide timely and accurate data to support the delivery of AOD treatment

services in Australia. The information strategy will be developed under the National Health Information Agreement and will be designed to monitor and evaluate the key objectives of the National Drug Strategic Framework, and to assist states and territories in the planning, management and quality improvement of services. (IGCD Working Group meeting minutes 1999)

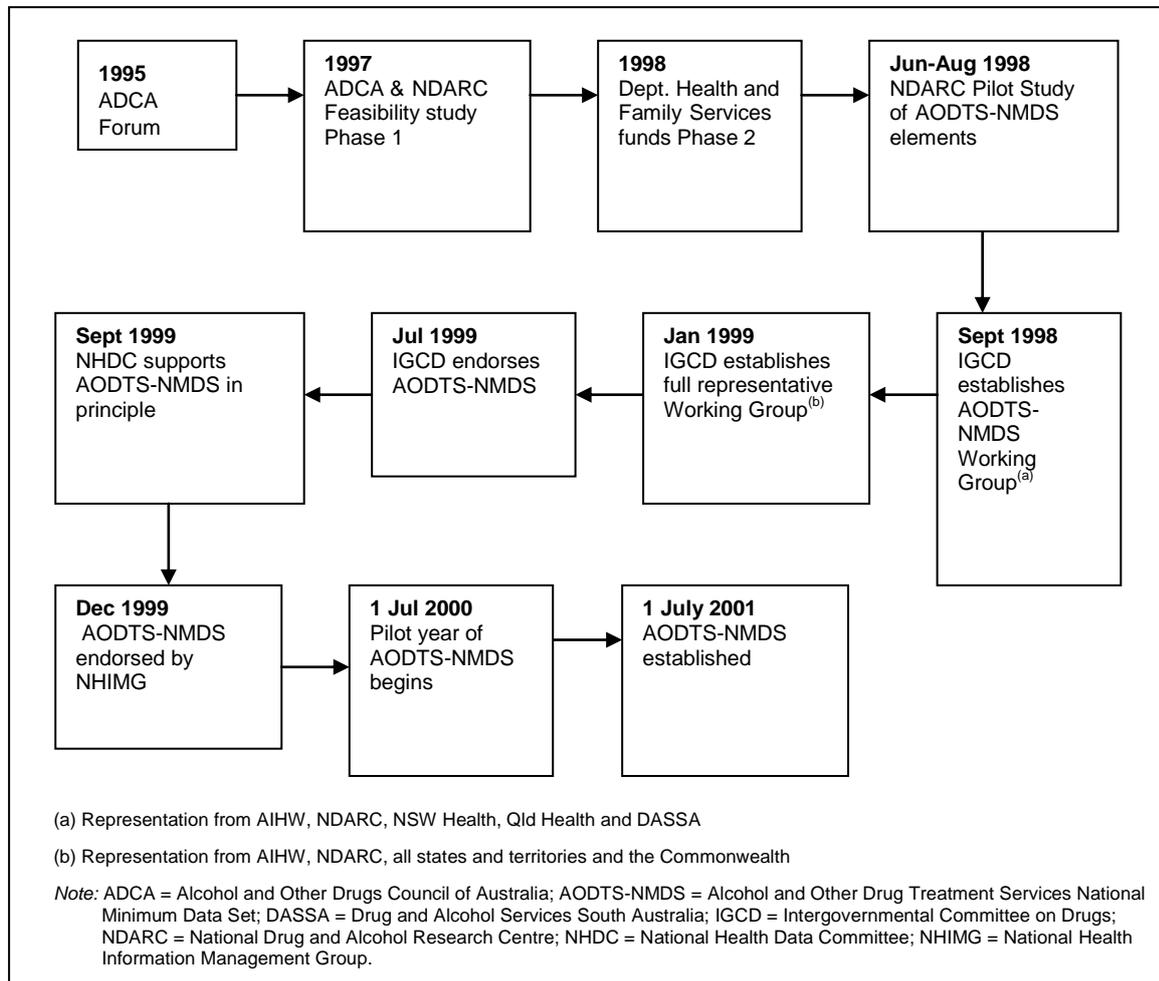
The Working Group identified four aims of the collection in addition to the statement of purpose:

1. monitor broad patterns of service utilisation by clients
2. monitor access to services for specific population groups
3. inform planning and development of service delivery strategies
4. support the development of strategies for benchmarking.

The extent to which the collection has met these aims and statement of purpose is a core aspect to this review and is examined in detail in the consultation and thematic analysis of this report.

Throughout the development, implementation and subsequent maintenance of the AODTS-NMDS, various issues related to the scope, content and analysis of the collection have been raised. Some of these were identified in the 2001 report and others through minutes of Working Group meetings since January 1999. A number of these issues are very similar to those discussed in the consultation and thematic analysis sections of this report and emphasise the need to urgently resolve these concerns.

The events leading up to the inception of the AODTS-NMDS are illustrated in Figure 1.



**Current collection scope**

**What the collection captures**

The AODTS-NMDS contains 20 data items and has two parts (Box 2). The first part contains information about establishments – the actual organisations (or parts thereof) that provide AOD treatment services. This information is very basic, comprising geographical and sector data. The second part is client-level information, collected about each client that accesses AOD treatment at an in-scope agency during a collection period. These data are explained in detail in the *Specifications and collection manual*, produced before each collection period. The collection captures demographic information about each client, some administrative information and some other information.

<b>Box 2: AODTS-NMDS data elements</b>	
<b>Establishment information</b>	
Establishment – organisation identifier (Australian)	
Service delivery outlet – geographical location	
<b>Client information</b>	
Client type	Person identifier
Country of birth	Preferred language
Date of birth	Principal drug of concern
Indigenous status	Reason for cessation
Injecting drug user (IDU) status	Sex
Main treatment type	Source of referral
Method of use (principal drug of concern)	Treatment cessation date
Other drug/s of concern	Treatment commencement date
Other treatment type	Treatment service delivery setting

These data items were initially agreed because they were considered to be necessary for delivering treatment services; that is, these data would already be collected in the course of providing AOD treatment. For this reason, there is a mixture of information about the clinical aspects of treatment (such as method of use and principal drug of concern) as well as contextual information important to service delivery, such as the source of referral.

**The agencies and clients captured by the collection**

The AODTS-NMDS does not capture the full array of agency- or client-level data elements that some may consider relevant to AOD treatment. The current scope of the collection as it appears in the *Specifications and collection manual* (AIHW 2010a) is below.

*Included:*

- all publicly funded (at state, territory and/or Australian Government level) government and non-government agencies that provide one or more specialist alcohol and/or drug treatment services, including residential and non-residential agencies
- acute care hospitals or psychiatric hospitals, if they have specialist alcohol and drug units that provide treatment to non-admitted patients (for example, outpatient services)

- Aboriginal or mental health services may also be included if they provide specialist alcohol and other drug treatment.

*Excluded:*

- agencies whose sole function is to prescribe and/or provide dosing for opioid pharmacotherapy treatment – these services are excluded only because of the complexity of the service delivery structure, and the range of agencies and practitioners in private and general practice settings
- agencies that provide primarily accommodation or overnight stays such as ‘halfway houses’ and ‘sobering-up shelters’
- agencies that provide services concerned primarily with health promotion (for example, needle and syringe programs)
- treatment services based in prison or other correctional institutions
- alcohol and drug treatment units in acute care or psychiatric hospitals that only provide treatment to admitted patients
- private treatment agencies that do not receive public funding
- the majority of Australian Government-funded Indigenous substance use services or Aboriginal primary health care services.

A complete list of data elements in the AODTS-NMDS and their summarised metadata (see Box 3) can be found at Appendix 3.

### **Box 3: Why do we need metadata?**

The drivers for standard development arise from the need for better statistical, administrative, clinical or other information (AIHW 2010b). Metadata standards describe the expected meaning and acceptable representation of data for use within a defined context. The need for consistency of meaning is vital to facilitate information sharing among primary and secondary users of the data. Much of the work involved in establishing a data collection is in the development of metadata standards to ensure comparability and consistency of the data collected and produced from the collection (AIHW 2010b).

## **How the collection is governed**

From inception, the AODTS-NMDS (see Box 4) has been a project of the now Australian Government Department of Health and Ageing (DoHA; formerly, the Department of Health and Family Services and the Department of Health and Aged Care). The DoHA undertook responsibility for the development of the collection in 1997 and, in September 1998, the IGCD, a committee of the Ministerial Council on Drug Strategy (MCDS), recommended the establishment of an interim working group (the Working Group) to implement the collection. This Working Group originally comprised representatives from the AIHW, NDARC, DoHA, New South Wales Department of Health, Queensland Department of Health, Victorian Department of Human Services and Drug and Alcohol Services South Australia.

In the last 10 years, the Working Group has become a permanent body that oversees the technical and strategic development and maintenance of the collection. The group is accountable to the IGCD and its terms of reference may be found at Appendix 1.

Figure 2 illustrates the Australian Health Ministers' Advisory Council (AHMAC) committee structure in relation to the IGCD and Figure 3 illustrates the roles, responsibilities and communication flows of the parties involved in governance of the AODTS-NMDS.

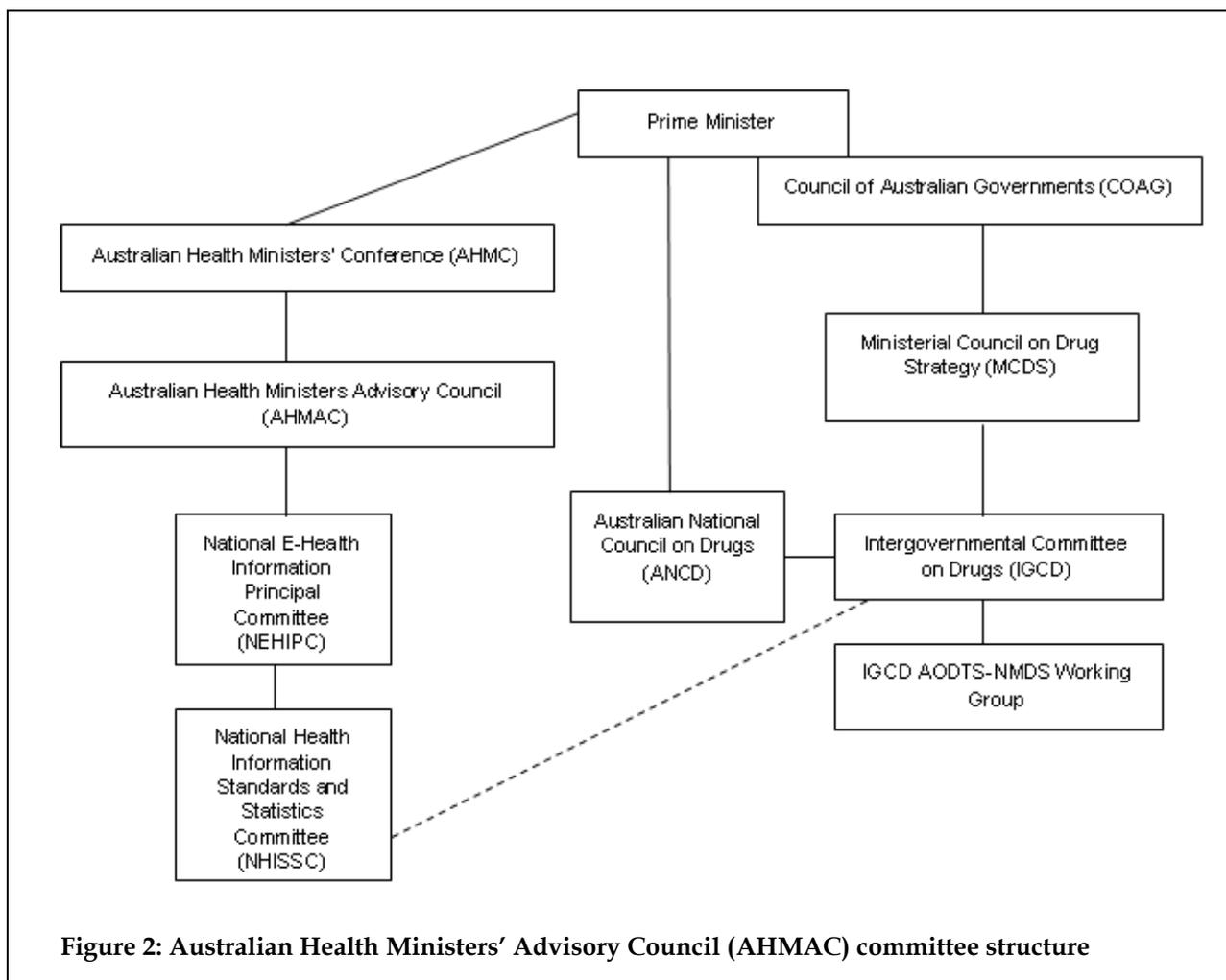
**Box 4: How is an NMDS created?**

There are several steps required in the development of a national minimum data set (NMDS), the first being sufficient demand for a nationally consistent data collection. To begin or change data that are collected, a list of data elements or items are developed to describe the collection and the elements within it. These metadata are agreed to by all states and territories as required under the National Health Information Agreement (NHIA). The National E-Health and Information Principal Committee (NEHIPC) oversees implementation of the NHIA and the National Health Information Standards and Statistics Committee (NHISSC) is the national registration authority for all health metadata standards, replacing the National Health Information Management Group (NHIMG) that originally endorsed the AODTS-NMDS. The NHISSC commits each jurisdiction to the collection and reporting of data items.

When the NHISSC agrees to endorse an NMDS, each state and territory is obliged to collect and report the agreed data items. Alternatively, where jurisdictions agree to a set of data items but are not in a position to begin collection and reporting, the NHISSC may agree to include the items in a data set specification (DSS). A DSS ensures that where the elements contained within it are collected and reported, they are done so in a nationally consistent way, based on the metadata. Making changes to any part of an NMDS requires approval from the NHISSC, to ensure national consistency, transparency and efficiency are maintained (AIHW 2010b).

The National Health Information Standards and Statistics Committee (NHISSC) was formed in 2008 and has assumed roles previously undertaken by the Statistical Information Management Committee (SIMC) and the Health Data Standards Committee (HDSC). It is a standing committee of the National E-Health and Information Principal Committee (NEHIPC); one of several principal committees that report to the AHMAC. The role of the NHISSC is to:

- provide strategic advice to the NEHIPC on issues relating to health information standards
- endorse national information standards for the health sector
- endorse specifications for statistical collections of national health information.



A complete figure of the health reporting structure including AHMAC can be found at Appendix 2. Details of the National Health Information Agreement (NHIA) are provided in Box 5.

**Box 5: National Health Information Agreement (NHIA)**

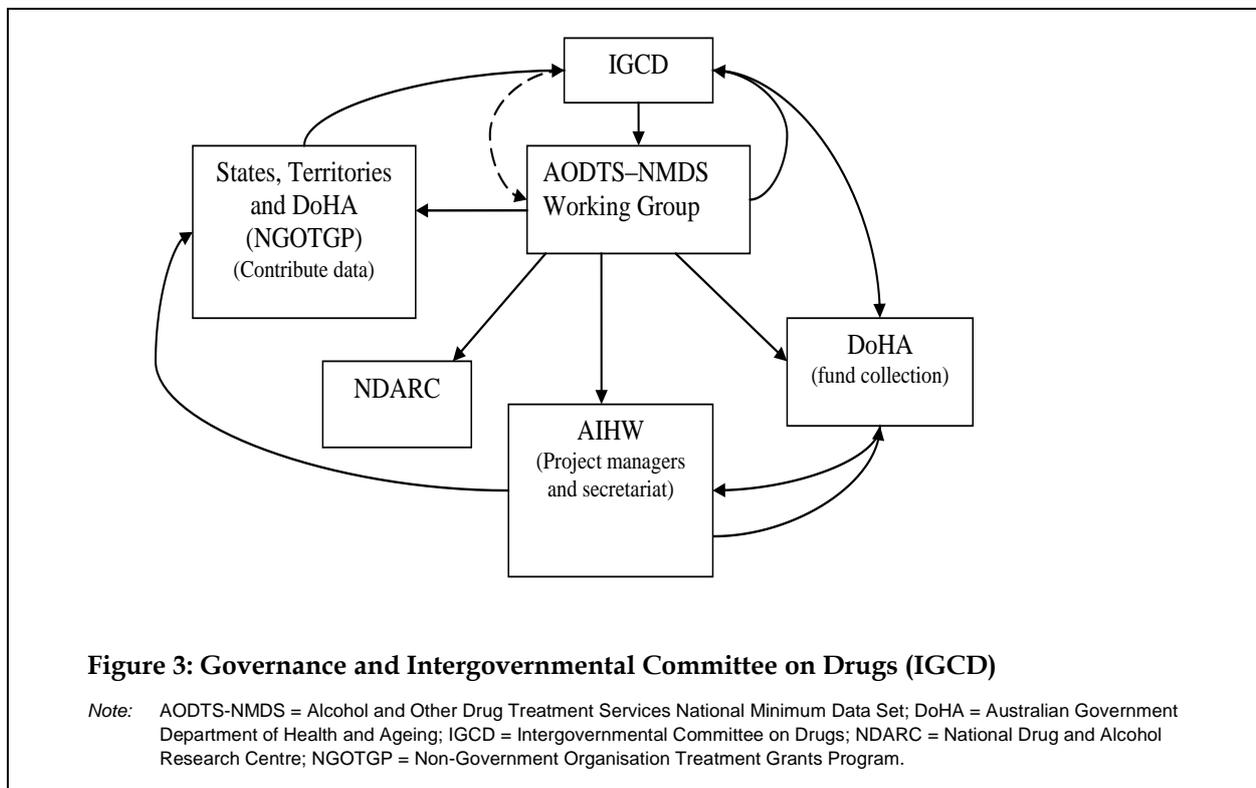
The NHIA is a collaborative agreement between jurisdictional agencies responsible for health policy and service delivery as well as statistical agencies. As the national repository for many health data sets, the AIHW is a party to the NHIA with the Australian Government and state/territory government health authorities, the Australian Bureau of Statistics (ABS), the then Health Insurance Commission (now Medicare Australia), and the Department of Veterans' Affairs.

The objectives of the NHIA are to:

- promote the collection, compilation, analysis and dissemination of relevant, timely, accurate and reliable health information concerned with the full range of health services and of a range of population parameters (including health status and risks), in accordance with nationally agreed protocols and standards
- develop and agree on projects to improve, maintain and share national health information
- cooperate in the provision of resources necessary to address national health information development priorities efficiently and effectively

- provide the information required to research, monitor and improve health and the delivery of health services
- provide the information required to facilitate nationally agreed projects which promote the development and reform of the health care system in accordance with the priorities of the AHMAC
- promote the extension of the range of national health information and encourage other groups and individuals in government and non-government sectors to participate by making available information that they hold
- work towards improving consistency in data definitions, classifications and collections between health, community services and housing assistance. (AIHW 2010b)

At an operational level, the collection is a project of the IGCD. A Working Group reporting to the IGCD was formed at the collection's inception (as discussed above) while the AIHW provides technical and secretariat support. The relationship between these bodies is outlined in Figure 3. The terms of reference for the Working Group are at Appendix 1.



- The Working Group is accountable to the IGCD.
- The Working Group provides the IGCD with an annual work plan and updated strategic plan. The IGCD has the opportunity to comment on these documents.
- The AIHW provides the DoHA with project reports (progress, financial etc) and advice on technical development of the collection.
- The DoHA funds the AIHW to perform secretariat functions as well as other activities such as data development, ad hoc data requests and agency forum participation.

- States, territories and the DoHA have representation on the IGCD. Working Group members generally brief their representative on issues related to the collection.
- The AIHW liaises with data contributors to ensure consistency and accuracy of data for the AODTS-NMDS and fulfil data requests.
- As data contributors, each state, territory and the DoHA have the opportunity to comment on the intended publication contents and new analyses.

## How does this fit into the health information environment?

Initial development of the AODTS-NMDS was undertaken by the Working Group and it was this body that submitted the metadata for approval through the then health information approval process. Under the current AHMAC structure (as outlined in Figure 2), the Working Group would, at the direction of the IGCD, prepare a business case for data development, which the IGCD would submit to the NHISSC for consideration.

## Structure of this report

This report is divided into five parts. **Methodology** describes the way in which the components of the project were undertaken. The **literature review** explores the alignment of the collection with international, national and local policies, strategies and research, from the broader health sector and the AOD sector specifically. The literature review was designed to inform the consultation process, which forms the second substantial component of the review report. The **consultation** process was broad and the analysis has been structured to highlight the common themes identified by the majority of stakeholders, organised by sector. These are further discussed in the **thematic analysis** before **conclusions and potential solutions** and **next steps** are proposed.

# Methodology

The methodology employed in this review differs from that used in a number of similar projects, including evaluations, in that it relies predominantly on the views of stakeholders. Therefore, this review utilises thematic analysis techniques that are designed to identify and categorise common subjects, explore the literature that supports or opposes them, draw conclusions and provide potential solutions.

## Review scope

The scope of the review was determined in consultation with the DoHA and was initially described in terms of a review of the aspects of data collection; namely, the influences and national initiatives that impact the collection, the collection scope, the policy objectives and monitoring capacity of the collection, data development activities, the processes of data transmission, cleaning, analysis and reporting, and the outputs from the collection.

These concepts were then used to form the basis of a broader set of categories that could be used to assess several aspects of the collection concurrently. This was important as many themes cross multiple criteria – for example, capturing information about family and living situation crosses *alignment*, *efficacy* and *prospect* criteria and is discussed later in this report in detail.

The seven criteria of the review scope are:

1. **alignment** with current strategies and initiatives, nationally and in each state and territory
2. **efficacy** in meeting policy objectives and monitoring
3. **limitations** of the collection and supporting/complementary data sets
4. **prospects** for data development
5. **efficiency** and transparency of processes in transmission, cleaning, analysis and meeting requests
6. **usefulness** and value of outputs such as reports, bulletins and data cubes
7. **opportunities** to improve governance of the collection and clarify the roles of stakeholders.

## Literature review

This literature review informed the consultation process of the wider review of the AODTS-NMDS. The fundamental premise was to explore the extent to which the collection captures relevant aspects of contemporary clinical practice in AOD treatment and services, based on the available literature, including current government strategies and policies, treatment guidelines, meta-analyses and similar review and evaluation studies.

Instead of identifying areas where more research is required, this review identifies common themes or principles for AOD data collections that should be considered when embarking on any change process in the AODTS-NMDS.

To ensure consistency and maintain focus, this literature review was designed to adhere to the same scope as the wider review. To this end, literature was sought on the usefulness of

current data collections, their utility as information sources for drug services policy, identified data gaps, and options for the future data development.

Neither the literature review nor the overall review itself assesses best practice or clinical efficacy. Instead, the intention is to ascertain the extent to which the collection captures information about contemporary practice, how well information is reported and how useful it is for policy and program planning, and to make recommendations for improvements.

## Literature identification

A preliminary literature search was undertaken using the DoHA's website to identify relevant documents using a key word search. The key words used are included at Appendix 4.

Documents were assessed for relevance by the number of references to (in descending order): the AODTS-NMDS, AOD treatment, health data collections, data collection reform/review and strategies or plans for future development. The references contained in each document were sourced and assessed using the same criteria.

Policies, strategies and guidelines were sourced from each state and territory for program- and service-specific information. Research papers from the Australian National Council on Drugs (ANCD), the NDARC, The National Drug Research Institute (NDRI) and the National Centre for Education and Training on Addiction (NCETA) were identified using a similar key word search, as were documents from the United Nations Office on Drugs and Crime (UNODC) and the World Health Organization (WHO). Meta-analyses were sourced from the Cochrane Collaboration through a search of *alcohol and other drug treatment*. Again, references contained in each document were sourced and assessed for relevance.

Literature has been broadly categorised as follows:

- international environment
- national agendas, policies and strategies
- AOD-specific agendas, policies and strategies.

## Consultation

Broad consultation was undertaken as part of this review. Stakeholders from the treatment, research and other non-government AOD services were approached to provide their comments, suggestions, compliments and concerns about the AODTS-NMDS.

### Who was consulted?

A list of stakeholders was identified by the AIHW during the project's initial stages and was agreed to by the DoHA. As consultations progressed, a number of additional stakeholders were identified and approached to provide input. A complete list of stakeholders consulted can be found at Appendix 5. Private AOD treatment facilities, private health insurance agencies, primary and community care and health promotion and community development organisation do not currently fall in the scope of the collection and were not consulted as part of this review.

## **Method of consultation**

In early March 2010, letters were sent to each stakeholder – directly or through the IGCD secretariat – informing them of the review and its purpose and inviting them to participate in the consultation process. Following this correspondence, a Stakeholder Consultation Document (Appendix 6), was circulated before meetings. This document outlined the scope of the review and was designed to gather feedback on specific characteristics of the AODTS-NMDS, including the process of data collection, transmission, and validation and reporting. Included in this document was a response matrix to assess the utility of the current collection and explore data gaps.

Face-to-face meetings and telephone discussions were undertaken from late March to the end of April 2010. Written submissions were also accepted. All stakeholders were encouraged to invite other attendees whom they thought could contribute to the review process. Some IGCD representatives chose to have policy, program, clinical and/or technical personnel present and some peak bodies invited representatives from non-government treatment agencies in management, technical or clinical positions. Given the diversity of the sector, a decision was made not to approach specific treatment agencies directly. Instead, peak bodies were asked to circulate information about the review to their member agencies and those who expressed interest in participating were able to attend the consultation or provide their responses to the consultation document in writing. Organisations with multiple sites, programs and funding sources, especially those that operate in two or more jurisdictions, were sought to assess the administrative complexity of delivering AOD services across Australia.

The AIHW circulated a call for submission through the ADCA Update web service. The consultation document was circulated to a small number of individuals and responses were incorporated into the relevant section of the report (researchers, peak bodies and so forth). Some respondents declined to provide further feedback as their organisation had already participated in previous discussions.

Notes from each consultation were circulated to respondents for comment. Publications, reports and position papers were provided by some respondents and these have subsequently been included in the literature review.

## **Thematic analysis**

To identify the common themes in both the literature review and the consultation process, several techniques were used. First, information and responses were categorised by the aspects of the collection outlined in the consultation document; namely, familiarity/utility, definition, breadth and volume of treatment, treatment setting, issues pertinent to treatment provision, data management processes, strategic direction and privacy.

Information and responses were then ranked according to frequency and broad categories developed to refer to these responses. Where a data concept has been suggested for development and inclusion in the collection, the concept is assessed against the extent to which it can inform current policies. Limitations in its collection, analysis and ability to inform policy are also analysed.

Current data elements have been analysed separately and can be found at Appendix 3.

## **Conclusions and potential solutions**

Recommendations do not form part of this review. Instead, a series of conclusions drawn from the available information are provided, accompanied by numerous potential solutions. In this way, a course of action may be decided according to the purpose of the collection.

## **Next steps**

This section is presented in three broad parts, differentiating between the immediate and longer term decision. These steps are not a recommended course of action but a suggestion as to the main areas of work.

# Literature review

## International environment

Substance use and associated harms have formed part of the international consciousness for the greater part of the 20th century and into the 21st. The complex relationship between substance use, social consequences, criminal activity and legitimate medicinal use have created numerous actions worldwide, each in response to specific cultural and social contexts. Treatment for substance use takes as many different forms as there are approaches to substance use. For example, where substance use is considered primarily to be a breach of existing laws, punitive measures within the justice system may be employed. Conversely, where substance use is considered to be at least in part a health issue, treatments may focus on these aspects. The scope limitations of this project did not allow for a comprehensive assessment of international approaches to AOD treatment, however some core documents were identified.

### The World Health Organization

In 1949, the Economic and Social Council of the World Health Organization (WHO) requested that the Secretary General of the WHO communicate to all governments that habit-forming substances should be placed under control. This constitutes the first recognisable international acknowledgment of substance dependence and addiction in the context of its potential health, social and economic impacts. Consequently, the WHO established the Expert Committee on Drugs Liable to Produce Addiction, and this evolved to the Expert Committee on Addiction Producing Drugs in 1957 and the Expert Committee on Drug Dependence in 1969.

### United Nations Office on Drugs and Crime

The United Nations Office on Drugs and Crime (UNODC) was established in 1997 and supports the treatment of drug use and addiction as any other health disorder. In practice, this means the implementation of prevention programs and dependence treatment and care services which are based on scientific evidence and on ethical standards (UNODC 2006).

Two major initiatives of the UNODC are the joint program on drug dependence with the WHO and the Global Assessment Programme on Drug Abuse (GAP) and International Network of Drug Dependence Treatment and Resource Centres. The latter is designed to enhance and disseminate evidence on community-based treatment, treatment in correctional and prison settings, human immunodeficiency virus (HIV) prevention and care and sustainable rehabilitation and reintegration. Turning Point Drug and Alcohol Centre in Victoria is the Australian centre participating in this initiative.

### Global Assessment Programme on Drug Abuse (GAP)

The GAP was developed by the UNODC, in collaboration with the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), to reduce the negative health and social consequences of drug abuse.

The GAP toolkit consists of eight modules that assume the absence of any data collection within the AOD context, primarily for developing countries. Module eight of the toolkit

'Guidance for the measurement of drug treatment demand', specifically addresses the lack of standardised data (including methods and tools) on AOD treatment.

According to the GAP, the three main concepts that require clarification before a data collection can be established are:

1. What is being measured?
2. What is treatment?
3. What agencies should be included?

Once these decisions have been made, the GAP module progresses through six milestones, from foundation building to maintenance and evaluation of the collection. The UNODC recommends using the GAP process to design, implement and maintain data collections and may be useful when considering potential changes to the AODTS-NMDS.

## Comparable countries

A limited scan of the international environment identified three countries and one union considered comparable with Australia in terms of their approach to AOD treatment and their associated data collections.

### United States of America

Two main sources of information on AOD treatment were identified as relevant in the United States of America (USA). These were the Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Institute on Drug Abuse (NIDA), both part of the United States Department of Health and Human Services. These bodies form the research and implementation organisations respectively of the American national response to substance abuse.

#### Substance Abuse and Mental Health Services Administration

Of the SAMHSA data collection activities, the most relevant and similar to the AODTS-NMDS is the Drug and Alcohol Services Information System (DASIS). This collection is an inventory of all public and private substance use treatment facilities, treatment admissions and discharges.

The DASIS consists of three components:

1. *Inventory of Substance Abuse Treatment Services* (I-SATS) – a listing of all known public and private substance abuse treatment facilities in the USA and its territories.
2. *National Survey of Substance Abuse Treatment Services* (N-SSATS) – an annual survey of all facilities in the I-SATS with information on location, characteristics, services offered and utilisation.
3. *Treatment Episode Data Set* (TEDS) – a compilation of demographic and substance abuse characteristics on the admissions to (and more recently, on discharges from) substance abuse treatment. The data are routinely collected by state administrative systems and then submitted to SAMHSA in a standard format.

The AODTS-NMDS does not contain a complete list of AOD treatment facilities in Australia and its coverage of those publicly funded agencies is difficult to determine. The bulk of the AODTS-NMDS is, however, similar information to that found in the TEDS. A comparison is found in Table 1.

**Table 1: Comparison of SAMHSA TEDS and AODTS-NMDS data elements**

<b>SAMHSA TEDS minimum data set elements</b>	<b>AODTS-NMDS data elements</b>
Provider identifier	Establishment identifier
Client or co-dependent	Client—type 1 or 2
Transaction type	Not applicable (N/A)
Date of admission	Date of commencement
Type of service at admission	Main treatment type
Date of birth	Date of birth
Sex	Sex
Race <sup>(a)</sup>	N/A
Ethnicity (Hispanic origin)	N/A
Number of treatment episodes	N/A
Education	N/A
Employment status	N/A
Principal source of referral	Source of referral
Substance problem (primary, secondary, tertiary)	Principal and other drug of concern
Usual route of administration (all substances)	Method of use (principal drug of concern only)
Frequency of use (all substances)	N/A
Age of first use (all substances)	N/A
Medication-assisted opioid therapy (pharmacotherapy)	N/A

(a) This element is no longer recorded or reported.

Note: AODTS-NMDS = Alcohol and Other Drug Treatment Services National Minimum Data Set; SAMHSA = Substance Abuse and Mental Health Services Administration; TEDS = Treatment Episode Data Set.

Source: OAS (2008).

There are differences in the definitions for each element, however they are broadly comparable. The TEDS also contains all elements apart from living status (contained in the supplementary data set) that are recommended by the UNODC for minimum data collection in treatment settings.

Unlike the AODTS-NMDS, clients in the TEDS must have completed an assessment or intake process and been formally admitted for treatment. That is, the assessment itself is not recorded as a completed treatment episode and all treatments are considered to consist of a formal assessment procedure. Discharges are recorded separately and transfers between agencies are recorded at the beginning of the episode.

Counselling, case management and support, and information and education are not considered treatment in this collection. Changes in service type do not automatically close an episode in the TEDS. That is, where a client receives different services in the course of treatment for a single substance of abuse, the episode is considered to be continuous. In practice, this means that episodes may last for several years as clients progress from detoxification to rehabilitation and aftercare services. The options for sources of referral are fewer than in the Australian collection but include the options of school and employer/employee assistance program (EAP) providers. Similar to the AODTS-NMDS, the TEDS uses a classification for coding substances for which clients seek treatment, however this classification also identifies the problematic use of over-the-counter (OTC) medications and non-prescription methadone, which is also problematic in the AODTS-NMDS.

Clients receiving opioid pharmacotherapy and individual clients are counted through the TEDS, though the number of episodes is also reported.

In addition to the minimum data set, the TEDS has a supplementary data set that contains additional, more detailed information. Table 2 outlines these additional items.

**Table 2: Comparison of supplementary TEDS and AODTS-NMDS data elements**

<b>TEDS supplementary data elements</b>	<b>AODTS-NMDS data elements</b>
Detailed drug code (primary, secondary and tertiary)	Principal and other drug of concern
Diagnostic Statistical Manual (DSM) diagnosis	Not applicable (N/A)
Psychiatric problem in addition to AOD problem	N/A
Pregnant at time of admission	N/A
Veteran status	N/A
Living arrangements	N/A
Source of income/support	N/A
Health insurance	N/A
Expected/actual primary source of payment (for the episode)	N/A
Detailed not in labour force	N/A
Detailed criminal justice referral	N/A
Marital status	N/A
Days waiting to enter treatment	N/A
Number of arrests in 30 days prior to treatment	N/A
Frequency of attendance at self-help programs 30 days prior to treatment (AA, NA etc.)	N/A

*Note:* AA = Alcoholics Anonymous; AODTS-NMDS = Alcohol and Other Drug Treatment Services National Minimum Data Set; NA = Narcotics Anonymous; TEDS = Treatment Episode Data Set.

*Source:* OAS (2008).

The TEDS employs disclosure analysis, a process similar to data linkage, to provide access to de-identified data for researchers. In terms of processes, treatment facilities complete the TEDS using the information and communication systems of their jurisdiction. These records are then submitted to the SAMHSA for national reporting; a very similar process to that used for the AODTS-NMDS.

## **Canada**

Similar to the federation of Australian states and territories, Canada comprises provinces and territories with autonomous governments and a variety of health information systems.

The Canadian Centre on Substance Abuse (CCSA) has a legislated mandate to:

provide national leadership and evidence-informed analysis and advice to mobilize collaborative efforts to reduce alcohol- and other drug-related harms. (CCSA 2009)

In October 2008, Canada's National Treatment Strategy Working Group released the National Treatment Strategy, which identified a lack of national data as a priority area for development. The working group stated that 'optimally, data collection across Canada should be coordinated by means of a national information system' that incorporated the existing episode-based collections of the provinces into a client-level collection similar to the AODTS-NMDS. The strategy goes on to outline the common elements from each jurisdiction

that would form the basis of the national collection; also similar in scope to the Australian collection. The purpose of the Canadian collection is to monitor and measure system performance, with a great emphasis placed on linking aggregate and individual data within and between sectors related to AOD treatment.

To allow a comparison between existing data collected in Canada and the AODTS-NMDS, the province of Ontario was selected for more detailed review. The Drug and Alcohol Treatment Information System (DATIS) is the AOD information system of Ontario. It contributes to the understanding and enhancement of problem gambling and addiction treatment through the ongoing development and maintenance of a comprehensive, province-wide client information system (CAMH 2009). Unlike the AODTS-NMDS, which is an administrative, episode-based collection, the DATIS draws information directly from client and patient files from many sources including hospitals.

No data dictionary for the system could be located; however, cross-referencing statistical reports yielded the data items shown in Table 3, compared with the AODTS-NMDS.

**Table 3: Comparison of DATIS data items and AODTS-NMDS data elements**

DATIS data item	AODTS-NMDS data element
Gender	Sex
Age group	Date of birth
County of residence	Not applicable (N/A)
Local Health Integration Network (LIHN) of client residence	N/A
Pregnancy status	N/A
Relationship status	N/A
Highest level of education	N/A
Employment status	N/A
Source of income	N/A
Legal status	N/A
Treatment mandated/required by	N/A
Substances used in the past 12 months	N/A
Presenting problem substances	Principal drug of concern
Prescribed methadone/opioid substitute use	N/A
Intravenous drug use	Injecting drug user (IDU) status
Referral sources	Source of referral
Outgoing referrals	N/A
Physical and mental health problems	N/A

*Note:* AODTS-NMDS = Alcohol and Other Drug Treatment Services National Minimum Data Set; DATIS = Drug and Alcohol Treatment Information System.

*Source:* CAMH (2010).

Though less than one-third of elements are common between the collections, it is important to recognise that more information is likely to be available and not reported, as this is a client management-based system.

## European Union

Within the European Union, there is a variety of AOD treatment and data collection systems. Some countries maintain centralised systems of referral, treatment, monitoring and reporting while others have decentralised systems with minimal reporting requirements. Some interesting characteristics of the various systems are:

- The Treatment Demand Indicators (TDI) system is used in many countries for planning purposes in lieu of a treatment data set
- Denmark has mandated a response time of no longer than 14 days for clients to be admitted to treatment
- Ireland uses a methadone client register to monitor utility as well as to recompense health practitioners
- France uses health insurance data to inform data on methadone prescriptions
- Latvia maintains a completely centralised treatment system where all named client records are located in the statutory authority
- Luxembourg operates a comprehensive register and monitoring system for all clients in addiction treatment and persons in contact with law enforcement authorities for drug use offences (Regional Drug Information Centres, Norway; RELIS) – this includes specialised in- and outpatient treatment centres, counselling centres, some general hospitals as well as law enforcement agencies and national prisons
- Hungary collects data using an online system from treatment agencies, hospitals and prisons but not general practitioners
- The Dutch Alcohol and Drug Information System (LADIS) covers 95% of AOD treatment outpatient services in the Netherlands – contact episodes of individual clients can be linked over time with a unique code made anonymous by encryption.

The TDI is used by EMCDDA and captures information on the number of people entering treatment in a given year. It does not capture information on clients returning to or continuing treatment. The definition of treatment in the TDI excludes contact with social services where drug use is not the primary reason for seeking assistance, contact with friends or family of the person using drugs, services concerned only with the physical complications of drug use or contact by letter or telephone only. The complete TDI protocol also defines each element and provides guidance as to which episodes, agencies and treatments should be counted. Interestingly, the TDI does not capture data where alcohol or tobacco is the primary drug for which treatment is being sought. The core elements that comprise the TDI are shown in Table 4.

**Table 4: Comparison of TDI elements and the AODTS-NMDS data elements**

TDI elements	AODTS-NMDS data elements
Treatment centre type	Not applicable (N/A) but can be derived from main treatment type and treatment delivery setting
Date of treatment	Date of commencement
Ever previously treated	N/A
Source of referral	Source of referral
Gender	Sex
Age	Derived from date of birth
Year of birth	Date of birth
Living status (with whom)	Not applicable (N/A)
Living status (where)	N/A
Nationality	Country of birth
Labour status	N/A
Highest educational level completed	N/A
Primary drug	Principal drug of concern
Already receiving substitution treatment	N/A
Usual route of administration	Method of use
Frequency of use	N/A
Other drugs currently used	N/A
Ever injected/currently injecting (last 30 days)	Injecting drug use status

Note: AODTS-NMDS = Alcohol and Other Drug Treatment Services National Minimum Data Set; TDI = Treatment Demand Indicator.

Source: EMCDDA (2009).

From this information, the AODTS-NMDS is fairly comparable to the European Union TDI. It should be noted, however, that some elements appear comparable but are not, such as 'other drugs currently used' in the TDI and 'other drugs of concern' in the AODTS-NMDS. The former is a measure of other currently used substances while the latter is a measure of those drugs that the client considers to be of concern to them, which are different concepts.

Though the Australian collection has been recognised by stakeholders as an unsuitable measure of demand for many reasons, the feasibility of collecting, analysing and reporting the collection in such a way may be considered.

## New Zealand

Information from the New Zealand Health Information Directorate indicates that there is no national data collection on AOD treatment services in New Zealand. The data that are collected are drawn from a number of national surveys and a national minimum data set that contains demographic and clinical data on all discharges of publicly funded inpatients and day patients of hospitals and mortality data.

## **Elements required for evaluation of programs**

To draw the common elements of this literature together, a search was done on the Cochrane Collaboration database of meta-analyses. The purpose of this search was to identify the elements common to study reviews based on the premise that evaluation of Australian treatment programs would require similar characteristics too. While the collection is not solely for research purposes, it is valuable to align research, administrative and clinical information.

Six AOD treatment related meta-analyses were reviewed. Elements identified by the reviewers as important to assess effectiveness of AOD interventions are:

- clearly stated intention for the intervention
- outcome of the intervention
- access (geographical, economic and social acceptability)
- ability to follow up clients/participants
- employment and education status of clients
- concurrent and consecutive treatments
- number of contacts in an intervention and treatment intensity
- identifying subtle differences in the setting of the intervention delivery.

The AODTS-NMDS relies on broad definitions of treatment type and treatment delivery setting and does not currently provide the ability for analysis of access, consecutive and concurrent treatments, the number of contacts, treatment intensity or education and employment status. Most notably, the collection does not contain an intended outcome measure, though there have been analyses done using reason for cessation and interpretations of treatment type and duration as proxies.

## **National agendas, policies and strategies**

### **National health environment**

Recently, there have been several major changes proposed in the area of national health policy and service delivery. These are outlined in a number of important documents including the National Health and Hospitals Reform Commission report on health and hospital reforms, the Preventative Health Taskforce report, new National Healthcare agreements between the Commonwealth, states and territories, the national e-health agenda and Australia's first national primary health care strategy.

These documents were reviewed to ascertain how the AOD treatment sector is proposed to fit into the national health policy landscape and to identify areas where AOD service reporting can better align with the data collection and reporting practices of the mainstream health services sector.

### ***A healthier future for all Australians—the final report of the National Health and Hospitals Reform Commission (NHHRC)***

The final report of the NHHRC made 123 recommendations from prenatal care through to aged care and grouped recommendations into five broad categories: Aboriginal and Torres Strait Islander Health, Mental Health Treatment, Rural and Remote, Dental and Public

Health. Though there is only one specific reference to AOD treatment (see Recommendation 88.1), the AODTS-NMDS may be relevant to informing the first three of these groupings.

The specific reference to AOD services exists in Recommendation 88.1, which states that:

The Commonwealth Government would assume full responsibility for the policy and public funding of primary health care services. This includes all existing community health, public dental services, family and child health services, and alcohol and drug treatment services that are currently funded by state, territory and local governments. (NHHRC 2009)

The consequences of such a change are difficult to anticipate. The recommendations of the report have been considered as part of this review to determine the extent to which the AODTS-NMDS has the capacity to respond to such changes and continue to capture service activity. Should these changes also include modifications to current administration and information infrastructure, which may be out of the sector's control (that is, it may become part of a broader set of health services), more attention may need to be paid to the content of the collection. For this reason, the key recommendations made by the NHHRC in this report and relevant to the AODTS-NMDS are outlined below:

- public reporting of health status, health service use and health outcomes
- regular national reporting on health inequity
- access to evidence-based, consumer-friendly information
- introduction of a personal electronic health record
- increased support for carers
- multidisciplinary services for chronic health conditions and special populations
- increased shared care arrangements
- integration of primary health care services with Federal Government control
- data linkage between hospitals (public and private), the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS)
- expansion of outreach services, especially in rural and remote areas, including telephone counselling and referral services
- youth-friendly community-based services for mental and sexual health screening
- linked hospital-based mental health care and community support
- government provision of stable housing for clients exiting mental health care
- use of specialists in community settings
- that national data sets focus on safety and quality including reporting on patient outcomes and experiences.

Generally, the report identifies the smart use of data, information and communication as an integral lever to support health system reform, making care patient centred and efficient.

### ***A National Health and Hospitals Network for Australia's future—delivering better health and better hospitals***

The Australian Government response to the NHHRC report, the National Health and Hospitals Network report was released in April 2010 (DoHA 2010a). This document outlines reforms to the funding and governance of the public health and hospital system, the way that health services are delivered and immediate improvement in quality and care for patients.

The government response draws on numerous other strategies in prevention, early intervention, primary care and 'e-health' which aim to address health service delivery at every point in the public system. Activity-based funding is core to the reforms and the implications of this in the AOD sector are unclear. AOD treatment is referred to as a subset of mental health services and the operational implications of this are also unclear as mental health and AOD are integrated in some jurisdictions but remain completely separate in others.

The AODTS-NMDS is well placed to inform public and national reports, to contribute to exercises in data linkage, monitor and report on the expansion of outreach counselling and referral services and the use of specialist community settings. This is due to the nationally consistent and regular reporting of these and similar elements in the existing collection as well as the potential for data development to capture those concepts not already part of the collection. Further, the value of the AODTS-NMDS can be increased if this reform package introduces commonality in clinical practices, from service models to evidence-based interventions, as collection and coding practices become less variable. Though the AODTS-NMDS is not mentioned, nor is AOD treatment singled out in the report, it is important to ensure that it is aligned as much as possible with the principles and recommendations.

### ***Australia: the healthiest country by 2020—preventing alcohol-related harm and tobacco control***

The National Preventative Health Taskforce (the Taskforce) was established in 2008 to develop a prevention strategy targeted at reducing obesity, alcohol-related harm and controlling tobacco in Australia. The strategy was designed to:

prevent hundreds of thousands of Australians dying prematurely, or falling ill and suffering, between now and 2020. (Preventative Health Taskforce 2009)

The strategy acknowledges the unequal distribution of health in Australia, recognises the social gradient and the impending burden on the public health system as a result of obesity, alcohol and tobacco use.

Of specific relevance to the AODTS-NMDS collection are the technical papers on reducing alcohol-related harm and tobacco control.

#### **Reducing alcohol-related harm**

The Taskforce regarded data on alcohol consumption trends and patterns as the most useful information, though not readily available (Preventative Health Taskforce 2009). The ability to identify possible opportunities for intervention is difficult when the diverse data sources use incomparable concepts, inconsistent methods of collection and irregular collection and reporting periods.

The strategy identifies the three subpopulations of pregnant women, Indigenous Australians and young people as those where the greatest opportunity to effect behaviour change exists. Unfortunately, this is in part due to the greater burden of harm that is prevalent in these populations.

Australia's adoption of a harm minimisation approach (harm, demand and supply reduction) to substance use provides the framework for the seven types of interventions advocated in the strategy. Treatment and early intervention is ranked as the fourth most effective approach to reducing alcohol-related harm. Within this intervention, the following six approaches were rated as policy relevant and their evidence base, cross-cultural acceptance and cost were evaluated:

- brief interventions in primary health care settings
- alcohol problem treatment
- thiamine supplementation
- workplace interventions
- mutual/self-help attendance (for example, 12-step, Smart Recovery)
- mandatory treatment of repeat drink drivers.

### **Tobacco control**

Like alcohol, data related to tobacco use and harms form the central tenet of the tobacco control strategy. The strategy draws largely on the 2004 National Tobacco Strategy which relied on seven agreed national policies to reduce tobacco smoking in Australia. Two of the policies relate to treatment and research, including evaluation, monitoring and surveillance.

A core component of the Tobacco Control Strategy is improved services and treatment for smokers, including pharmacotherapies and withdrawal programs, counselling and a holistic approach to smoking cessation through program implementation in the wider health system.

The AODTS-NMDS currently contains information on alcohol and tobacco as the principal and other drugs of concern as well as the treatments being received for use of these substances. Tobacco use has never been a focus of the collection, however, and there are opportunities to capture more information related to tobacco use and cessation attempts. By aligning with the policies outlined in these strategies, there may be an opportunity for the AODTS-NMDS to position itself as an information source in the evaluation and monitoring of these strategies.

### **National Primary Health Care Strategy**

The Australian Government released the Draft National Primary Health Care Strategy in August 2009 (DoHA 2008). The role of primary health care has been recognised to be critical to the effective functioning of the health and hospital system, as identified by the NHHRC report *A national health and hospitals network for Australia's future – delivering better health and better hospitals* (DoHA 2010a).

The increased role of primary health care providers in identifying and treating AOD issues, as well as the placement of specialist services in primary care settings and integrated services intended to provide 'seamless' care for patients, will all impact on the ability of the AODTS-NMDS to capture relevant AOD information about clients and the agencies that provide treatment. Currently, publicly funded services in primary health care settings do not report to the AODTS-NMDS and while this is a potentially rich source of data, the practicalities of collecting these data are unknown. Further, the details of the reporting systems that would support such services have yet to be released.

### **E-health**

The plan for the e-health record in Australia is to provide a means for patients to control and track their own health information. The initiative was identified as part of the NHHRC report and supported by the National Primary Health Care Strategy and the National Preventative Health Strategy. In September 2008, The Australian Government released the National E-Health Strategy and the National E-Health Transition Authority (NEHTA) was established by all Australian governments to develop the required foundations, coordinate the solutions to accelerate the adoption of and provide leadership in e-health. In addition,

the Australian Government announced a \$466.7 million e-health package as part of the 2010–11 Federal Budget.

How the implementation and operation of individual and health services' e-health records will be undertaken is unclear but it is anticipated that this will have some consequences for existing health data collections, including national minimum data sets. Consequently, retaining a focus on the relevance, consistency and accuracy of the collection will position it to respond positively to changes in the information environment.

## **Social inclusion**

The whole-of-government approach to social inclusion is designed to address existing inequalities in people's opportunities in education, employment, community participation and social, civic and economic engagement. The agenda consists of eight broad priority areas that span government departments and agencies and consequently require action by multiple players, with a renewed focus on the data that underpin these actions.

The six social inclusion priorities relate to (Australian Government 2010):

- preventing long-term disadvantage for children through education, health and family support services
- assisting with sustainable employment for families with children
- focusing on locational disadvantage [sic] and tailoring responses accordingly
- assisting in the employment of people with a disability and/or mental illness
- addressing the incidence of homelessness and
- closing the gap for Indigenous Australians with respect to life expectancy, child mortality, access to early childhood education, educational achievement and employment outcomes.

As the agenda is broad in scope, the AODTS-NMDS is well placed to provide targeted information on the AOD treatment services available in specific areas and provide demographic information. There are also opportunities to develop improved ways of capturing information about clients and agencies to better inform this agenda and associated policies. Examples of the kind of information that are not currently collected and that would contribute to this government initiative are housing status, child rearing/caring responsibilities, employment, mental health status and educational achievement.

### ***The road home: the Australian Government white paper on homelessness***

Released by the Australian Government in 2008, the homelessness white paper (FaHCSIA 2008) describes the current prevalence of people experiencing homelessness, unstable or substandard housing and recognises that the experience of homelessness is not solely a housing problem. The impact of domestic violence and relationship breakdowns, long-term unemployment, mental health issues and substance use are addressed through three strategies that constitute the Australian Government's response to homelessness and with the agreement of state and territory governments, two headline goals have been set to guide the long-term response:

- to halve overall homelessness by 2020
- to offer supported accommodation to all rough sleepers who need it by 2020.

The three strategies are:

1. *turning off the tap*: services will intervene early to prevent homelessness, including a policy of 'no exits to homelessness' from statutory and custodial care and health, mental health and drug and alcohol services
2. *improving and expanding services*: services will be more connected and responsive to achieve sustainable housing, improve economic and social participation and end homelessness for their clients
3. *breaking the cycle*: people who become homeless will move quickly through the crisis system to stable housing with the support they need so that homelessness does not recur.

As substance use has been identified as a primary cause of homelessness and unstable housing, the role of AOD treatment services as well as the provision of AOD support services within the housing and homelessness sector will be increasingly important. To support the high-quality delivery and expansion of these services, nationally consistent and accurate data will be required. The AODTS-NMDS is well placed to fulfil this need. Further, the policy of 'no exit to homelessness' may have a substantial impact on the practices of AOD treatment services that is important to capture in a national collection.

### **Health information of Aboriginal and Torres Strait Islander peoples**

Two key national documents with specific relevance to the AODTS-NMDS were identified.

Health researchers accept the cultural social norms that influence the collection, analysis and reporting of health information of Aboriginal and Torres Strait Islander peoples and that the consequences have a direct impact on the planning, delivery, monitoring and evaluation of health services for Indigenous Australians (NHMRC 2003). In recognition of these biases, guidelines for conducting Aboriginal and Torres Strait Islander health research and collecting Indigenous status in health data sets have been developed.

The *National best practice guidelines for collecting Indigenous status in health data sets* (AIHW 2010c) highlight data quality issues that arise from under-identification of Aboriginal and Torres Strait Islander peoples in data sets due to high 'not stated' rates for Indigenous status. The AODTS-NMDS collection could be improved through the application of the guidelines and of the National Health and Medical Research Council's *Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research* (NHMRC 2003).

### **Other important policies and agendas**

Also considered relevant to the AODTS-NMDS are three of the strategies that aim to reduce the transmission of sexually transmissible infections (STIs) and blood-borne viruses (BBVs) in Australia, and the research report from the Productivity Commission on the contribution of the not-for-profit sector.

### **Sexually transmissible infections and blood-borne viruses**

The three strategies from the STI and BBV suite that contain references to AOD use are the:

- Third National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy 2010–2013 (DoHA 2010e)
- Third National Hepatitis C Strategy 2010–2013 (DoHA 2010d)
- Sixth National HIV Strategy (DoHA 2010c).

Each strategy identifies injecting drug use as a risk factor in transmission and aims to reduce the prevalence of injecting drug use as well as reducing the incidence of injecting drug users re-using and sharing injecting equipment.

Though the AODTS-NMDS contains an element on the injecting drug use status of clients, this element is conditional, has a high 'not stated' response rate and has limited utility as it is a proportion based on the treatment population, not all injecting drug users. However, there is potential for data development to improve the collection's efficacy in informing these strategies.

### **Contribution of the not-for-profit sector**

Approximately half of all AOD treatment agencies that contribute data to the AODTS-NMDS are from the non-government organisation (NGO) sector and are not-for-profit (NFP) organisations. Though they vary in their source of funding – that is, some are entirely funded by government grants while others have philanthropic sources, participate in fundraising or other business activities – they all have similar regulatory requirements. The bulk of the NFP sector consists of health and health-related services, of which AOD treatment is one (Productivity Commission 2010).

The Productivity Commission's report examined the role of the NFP sector and the constraints to their effective, efficient and transparent operation. Key points outlined in this report relevant to the AODTS-NMDS and the AOD treatment sector in general were:

- the need for a nationally agreed measurement and evaluation framework for NFP organisations
- reform to meet 'best practice' principles in good evaluation practice and to assemble and disseminate evaluations based on the agreed measurement framework
- a national registrar for NFP organisations
- greater clarity about funding commitments, streamlining of mandatory vetting requirements and potential portability between agencies and across jurisdictions would reduce one source of costs
- urgent review of the ways in which governments engage with and contract NFP organisations.

While the AODTS-NMDS collection is nationally consistent, from consultations it is clear that the methods of collection and reporting vary within and between jurisdictions; in some cases duplicating processes and increasing the administrative and cost burden for services. Consequently, data quality may be compromised or incomplete, reducing the value of a national collection.

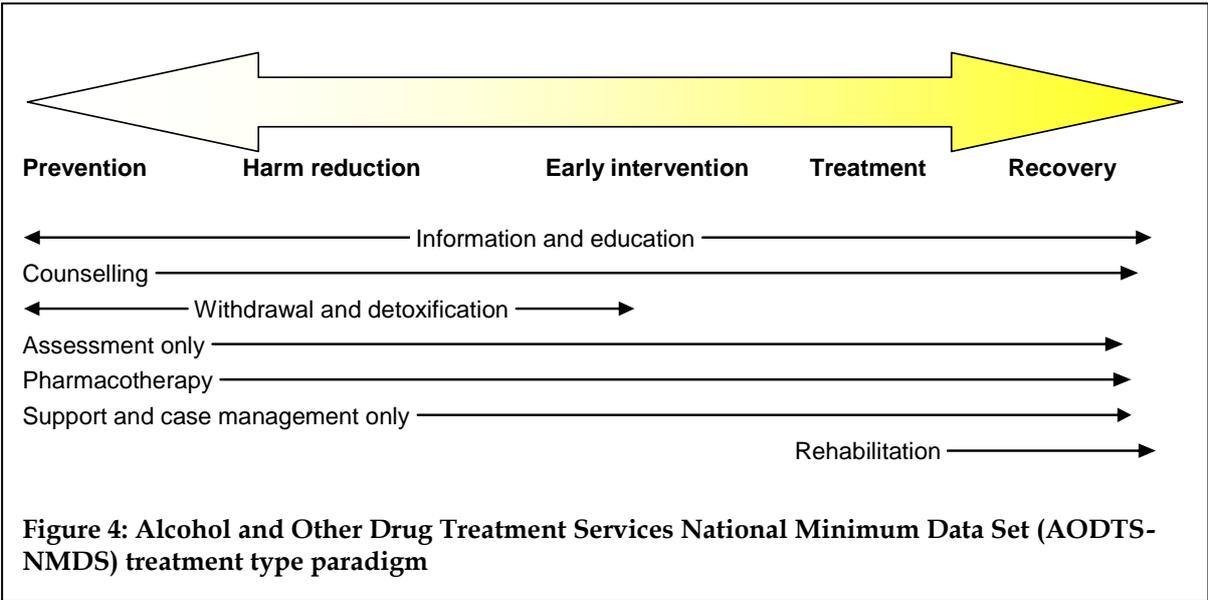
### **AOD-specific agendas, policies and strategies**

Australia operates within the harm minimisation paradigm in its approach to substance use. A fundamental premise of harm minimisation is coordinated action between the health, criminal justice and education sectors. The three basic pillars of harm minimisation are reductions in supply, demand and harm. Treatment and other AOD interventions are commonly categorised as harm and demand reduction initiatives. Harm reduction interventions are those policies, programs and practices that aim to reduce the harms associated with the use of psychoactive drugs in people unable or unwilling to stop (IHRA 2010). They include policies such as decriminalising the administration of specific substances or practices such as injecting (one's self or another) and active criminal diversion for the use

of specific substances and actions such as providing sterile injecting and using equipment, disposal facilities and safe areas for using drugs such as supervised injecting facilities and education resources to teach safe using and sexual practices. Demand reduction generally focuses on public education of drug harms, such as warnings on cigarette packets. Other activities include preventing initiation through education in school-based programs, early intervention to prevent further use through diversion and counselling services and treatment programs that encourage controlled use or abstinence (IHRA 2010).

The AODTS-NMDS captures information from interventions that may not be exclusively understood and categorised as treatment. For example, in Victoria, treatment is a term that indicates interventions at a specific point in an individual’s substance-using career, specifically when they have an established condition, such as dependence (VDHS 2007). As the AODTS-NMDS contains no such references to the level of use of clients, nor for what severity of substance use the treatment is being offered/ accessed, the treatment types are not categorised. Treatment types within the AODTS-NMDS are illustrated in Figure 4 and are broadly based on the response areas identified by the EMCDDA (2000) that incorporate the concepts of the Victorian model.

As states and territories move towards increasingly integrated and holistic approaches to substance use policy and agencies provide a variety of models of care, the scope of treatments being delivered in the AOD sector is increasing (VDHS 2007). ‘Scope creep’ is a fundamental issue for the AODTS-NMDS and will be discussed in detail later in this report.



**What is treatment?**

In 1992, the National Campaign Against Drug Abuse Working Party on Future Directions for Drug Treatment Programs in Australia (the Working Party) released a monograph considering the future of Australia’s approach to treating AOD use (Ali et al. 1992). The report defines treatment as:

any person-to-person intervention which is designed to identify and minimise hazardous, harmful or dysfunctional drinking/ drug taking behaviour.

The authors argue that prevention and treatment are at either end of a continuum, that strategies and interventions cannot be categorised as one or the other and that each share

important elements. Consequently, they argue that any definition of treatment is arbitrary and useful only for administrative purposes (Ali et al. 1992).

Given the AODTS-NMDS is an administrative collection, a definition of treatment is necessary and vital for the validity and accuracy of collecting and reporting data.

As the Working Party relies on a broad definition of treatment, the discussion of future directions of substance use treatment in Australia follow equally broad directions. What the Working Party did support was the assessment of treatment goals against the treatment objectives and measurement of the goals in terms relevant to the audience – the client, the society and the government. For example, the objective of detoxification may be to maintain a specified time free of a specific drug and the outcome measure may be whether or not this occurred. The measurement may be the number of days free of substance use (for the client), the decreased burden of health, social, economic and law enforcement costs (for society) and the return on investment for the treatment service (for government). This argument is not without pitfalls, however, as treatment goals may be defined to prevent failure; for example, designing detoxification programs with no intention of effecting lasting changes in the client's substance use.

Another document that defines treatment, albeit from the perspective of health professionals and not specifically a policy approach, is *Alcohol and other drugs: a handbook for health professionals* (NCETA Consortium 2004). The Handbook was developed by a consortium with representatives from the fields of general practice, addiction medicine and nursing, with cooperation from the Centre for Addiction and Mental Health (CAMH) in Canada. The handbook defines treatment as specific activities intended to change a person's substance use and includes interventions such as:

- screening
- assessment
- information and advice
- brief interventions for tobacco, alcohol and, to a lesser extent, cannabis
- detoxification, including home detoxification
- pharmacotherapy for tobacco, alcohol and opioid dependence
- counselling, including motivational interviewing, and relapse prevention
- referral to clinicians with specialist skills in drug and alcohol issues
- follow-up monitoring and care coordination.

Some of these interventions are included in the AODTS-NMDS but not all. This handbook also addresses specific substances and associated treatment techniques that are evidence based and could provide the basis for further discussion on the types of treatment considered to be appropriate for substance use and misuse; an issue discussed further in sections on purpose, scope and content of the AODTS-NMDS.

### **National Drug Strategy and the National Illicit Drug Strategy**

The National Drug Strategy (NDS) 2004–2009, was externally evaluated in 2009, before the initial development of the 2010–2015 NDS. When the AODTS-NMDS was implemented in 2000, its principal objectives were to:

monitor and evaluate the key objectives of the National Drug Strategic Framework.  
(Grant & Petrie 2001)

The National Illicit Drug Strategy (NIDS) forms part of the NDS and is predominantly a mechanism for funding programs, services and campaigns aimed at reducing the demand

and harm caused by the use of illicit drugs (Australian Government 2004). Under NIDS, four programs have been identified (DoHA 2010b):

- The Non-Government Organisation Treatment Grants Program (NGOTGP)
- The Improved Services Measure for People with a Drug and Alcohol Problem and a Mental Illness (Improved Services Measure)
- The National Psychostimulants Initiative
- Supporting Measures for Needle and Syringe Programs (NSPs).

Of these initiatives, services funded under the NGOTGP are most relevant to the AODTS-NMDS, as they are in scope for contributing data to the collection. Some of these services also receive funding under the Improved Services Measure. Both initiatives have been continued under the 2010–11 Federal Budget.

Also falling under the NIDS but administered by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) is the Strengthening Families Program which poses a unique challenge for the AODTS-NMDS, as outlined below.

### **Non-Government Organisation Treatment Grants Program (NGOTGP)**

Organisations funded under this program provide a variety of services. According to information contained on the DoHA's website, these services include counselling, outreach support, peer support, home-based medicated and non-medicated detoxification, therapeutic communities and in/outpatient rehabilitation (DoHA 2010b). Organisations funded under the NGOTGP do not necessarily receive funding from other sources, specifically the state or territory they operate in, and in some jurisdictions this precludes them from submitting their data to the jurisdictional health authority for inclusion in the national collection. Except in Victoria, these agencies submit their data directly to the DoHA either electronically or using paper forms and these data are entered, coded and compiled into a single data set for transmission to the AIHW at the end of each collection period. Whether data collected by NGOTGP agencies contains more information than the AODTS-NMDS is unknown.

Agencies that receive NGOTGP funding are not identifiable through the AODTS-NMDS nor can the episodes within agencies that receive multiple funding sources be attributed to any specific funding source.

### **Strengthening Families<sup>1</sup>**

This program funds organisations, not necessarily in the health or AOD field, to provide services targeted at families where substance use presents a significant issue to the physical, emotional and mental development of children (FaHCSIA 2009). Before the 2010–11 Federal Budget, this program funded services including direct treatment provision such as counselling and case management as well as referral, capacity building and some research projects. Of those agencies funded to provide services that fall in scope of the AODTS-NMDS, it is unclear if they are submitting data to the collection. This is because this funding occurs outside of the federal health portfolio and therefore is not subject to the NHIA.

---

<sup>1</sup> This program has been replaced by the 'Kids in Focus – Family Drug Support' initiative in the 2010–11 Federal Budget. This initiative funds one organisation in each jurisdiction to provide counselling, group workshops and education, aftercare and post-rehabilitation support and pre- and postnatal support for women with dependency problems. The reporting requirements for this program are unclear at this time.

## **Evaluation of the National Drug Strategy (NDS)**

Recommendations from the evaluation of the NDS cover national approaches to the principles of harm reduction, encouraging stakeholder engagement, a strategic approach to the AOD workforce, research and data and the way in which the IGCD operates (Siggins Miller 2009).

The roles of research and data collections were singled out for attention and evaluators recommended increased collaboration between the NDS and researchers and also a strategic review of AOD data sources to ascertain where resources should be channelled for the greatest benefit.

In regards to the AODTS-NMDS, evaluators recommended that capacity to identify the funding sources of agencies be introduced. This was specifically in the context of monitoring the performance of agencies funded under the NGOTGP as the number and characteristics of the episodes funded by this program could not be differentiated from others (Siggins Miller 2009).

## **Australian National Council on Drugs (ANCD)**

Australian drug policy is informed by a number of stakeholders, with the ANCD being the principal advisory body to the Australian Government. From its communiqué of May 2010:

The ANCD consists of representatives from the non-government and government drug and alcohol and related sectors (treatment, research, law enforcement, education etc.) from around Australia.

Council meetings and consultations with people working with drug and alcohol issues are held in a different state or territory every three months. Through these meetings and consultation forums, the ANCD is able to ensure that the views of the sector, in particular non-government, community-based organisations, are considered as part of drug policy advice. (ANCD 2010)

The ANCD also has a dedicated research function and several research reports published by the ANCD in recent times have made specific mention of the AODTS-NMDS, general gaps and deficiencies in data sources and the administrative burden on AOD agencies to comply with reporting requirements.

Seven research reports were selected for this review, as they addressed concepts and concerns common in other pieces of literature and have the greatest relevance to the AODTS-NMDS.

## **Indigenous-specific alcohol and other drug interventions: continuities, changes and areas of greatest need**

The most recent research report that focused on AOD services for Indigenous Australians, specifically specialist Indigenous services and not mainstream programs, found that:

there is no single repository of data on the many AOD intervention projects targeted at Indigenous Australians which are conducted and/or funded by a wide range of Indigenous community-controlled organisations, non-government organisations and government agencies. (Gray et al. 2010)

The AODTS-NMDS contains incomplete information about AOD agencies that are funded and controlled by Aboriginal Health Services and Indigenous specific funding programs through state, territory and Australian Government health authorities.

## Opioid pharmacotherapy

Two recent ANCD research reports focused on the provision of opioid pharmacotherapy in Australia and though the AODTS-NMDS is not designed to capture unit record data from opioid pharmacotherapy clients, there are some concepts raised that are relevant to the collection.

Both publications, *Modelling pharmacotherapy maintenance in Australia: exploring affordability, availability, accessibility and quality using system dynamics* (Chalmers et al. 2009) and *Polygon: the many sides to the Australian opioid pharmacotherapy maintenance system* (Ritter & Chalmers 2009), reference the AODTS-NMDS, but use data from the National Opioid Pharmacotherapy Statistical Annual Data (NOPSAD) Collection. The authors recognised the absence of unit record data on this population limits national policy responses and strategies. This issue is discussed further in the thematic analysis.

## Treatment services

*Mapping national drug treatment capacity* (Siggins Miller 2005) mapped the nature and location of AOD treatment services in Australia. The AODTS-NMDS was a core data source for this project and several limitations of the data set were highlighted in the report. These are listed below:

- agencies who report to the AODTS-NMDS interpret the categories (treatment types) contained in the collection differently, suggesting that the people delivering the services should be directly involved in the choice of a transparent set of descriptors
- the AODTS-NMDS does not differentiate between different programs being run through a single agency
- service use is a poor indicator of underlying need and the AODTS-NMDS only captures treatments accessed
- the geographical location of treatment delivery is difficult to ascertain as the administrative centre may be reported as the location of the service
- the geographical location of clients is unknown
- poor socioeconomic data make service and program planning difficult (income source, employment status, education level)
- the impact of mental health is underestimated and not reflected by current data sources
- there is a lack of data about treatment models or approach, proportion of services catering for specific subpopulations, treatments for specific substances, the source and longevity of service/agency funding, treatment capacity and waiting times, staff profiles and qualifications.

Following this Siggins Miller 2005 report, the *Non-government organisations in the alcohol and other drugs sector: issues and options for sustainability* report (Spooner & Dadich 2009) explored the existence of NGO AOD agencies by examining existing data sets and the mechanisms that fund and support these agencies. The authors contend that it is not possible to know how many NGO AOD agencies there are:

While there are no ready data on the number of organisations that fit [this] criterion, it is anticipated that most of them would be AOD NGOs primarily concerned with treatment, and that most of those concerned with treatment would also have some activities related to prevention, harm reduction and/or advocacy. (Spooner & Dadich 2009)

The criterion referred to are those 'agencies whose core business is AOD treatment, prevention, harm reduction or advocacy'.

This is a concern because it is these agencies specifically that are meant to be captured by the AODTS-NMDS. If any NGO that fits this description does not receive public money, it will fall out of scope of the collection, however the report does not make this distinction, referring to an agency's not-for-profit status as the defining feature. The AODTS-NMDS contains very little information about the actual treatment agencies, save geographical information, which is an acknowledged limitation of the collection.

In 2009, Spooner & Dadich referred to the declining membership of peak bodies, changing expectations from funders and transitional governance arrangements within NGOs as issues that compromised effective service delivery and organisation sustainability. While these issues do not relate to the content of the AODTS-NMDS, they do directly impact on the capacity and motivation for agencies to collect and report data.

### **Families**

The last two ANCD research reports in this literature review focused on the family unit and the implications of substance use for children. The AODTS-NMDS captures information on clients aged 10 years and over, however their relationship to others is not identified and there is no information about accompanying or dependent children within the collection.

The report *Drug use in the family: impacts and implications for children* (Dawe et al. 2007) was published in the same year as the House of Representative inquiry into the impact of illicit drug use on families. This research report recommended that the number of biological children, dependent children, and children living in the households of adults who access AOD treatment, and additional information on current or previous involvement with social services (child protection), should be collected as part of the AODTS-NMDS to allow comparisons to be made across jurisdictions. The report also cited the inability to estimate the number of individuals in treatment as problematic for research purposes.

Similarly, the report *Supporting the families of young people with problematic drug use: investigating support options* (Frye et al. 2008) identifies the inability of the AODTS-NMDS to estimate the number of young people who access publicly funded treatment as a dire limitation. The lack of information about the young person's family situation and relationships and involvement with child protection and other social services limits the potential of policy and program responses to substance use in young people, according to the authors. This report also found that family-oriented therapeutic approaches, such as group counselling and family therapy, are effective in treating substance use in young people, but these treatment types cannot be identified or captured in the current collection.

### **Comorbidity**

Building on the National Comorbidity Initiative, the Improved Services Measure funded NGO AOD treatment services across Australia to build their capacity to identify and manage comorbidity. One activity under this measure was to improve data systems and collection methods within the mental health and AOD sectors to manage comorbidity more effectively (2007).

In 2005, the AIHW undertook a review of data collections relating to people with coexisting substance use and mental health disorders and the AODTS-NMDS was identified as a primary data source. The review acknowledged the paucity of comorbidity information in the AODTS-NMDS, only being indicated by source of referral. Further, the lack of information about the location of clients, social context and participation including living

arrangements, the inability to estimate the number of individuals accessing treatment in the collection period or to link across data sets, and incapacity for measuring unmet need or demand for services ('turnaways') or outcomes were highlighted as areas for potential development (AIHW 2005).

The AIHW also undertook a project to investigate the feasibility of introducing a statistical linkage key and measures of mental health into the AODTS-NMDS in 2008. Specifically, the first two questions that formed part of the *PsyCheck* General Screener, a tool developed with funding from the National Comorbidity Initiative, were piloted. The AODTS-NMDS Enhancement Project (AIHW 2009b) found that the *PsyCheck* questions were an appropriate indicator for affective and anxiety disorders, however limitations of the tool and potentially inconsistent application across agencies made it less useful for introduction into the NMDS. Capturing mental health information is also complicated by the absence of a definition of mental health in the National Health Data Dictionary and the diversity of skills in the AOD workforce that prevent a diagnosis-based collection method.

### **House of Representatives inquiry into illicit drugs**

In February 2007, the House of Representative Standing Committee on Family and Human Services (the Committee) launched an inquiry into the financial, social and personal cost to families who have a member(s) using illicit drugs, including the impact of drug-induced psychoses or other mental disorders; the impact of harm minimisation programs on families; and ways to strengthen families who are coping with a member(s) using illicit drugs. The report titled *The winnable war on drugs: the impact of illicit drug use on families* was released in September of the same year and nine of the recommendations of the report have been identified as having some consequence for the AODTS-NMDS (recommendations 4, 8, 22, 24–27 and 30–31) (House of Representatives Standing Committee on Family and Human Services 2007). These have been grouped into three broad themes.

#### **Measuring outcomes**

The report contained a major focus on supporting treatments and services that aimed for and supported permanent abstinence from substance use. The recommendations in this theme encourage the collection of outcome data on achieving abstinence and funding of agencies based on this information. There is currently no outcome measure within the AODTS-NMDS nor is the intention of treatment types captured.

#### **Capturing information about families and children**

Several recommendations refer to collecting and reporting information on people aged less than 18 years, either as the substance user or as the dependent child of a person using substances. There are also recommendations in support of agencies to provide family inclusive and focused services, including specific services to support relatives of a substance user and treatments that cater for parents with accompanying children in residential and non-residential settings. The recommendation is to fund these agencies through the NGOTGP and all NGOTGP agencies are required to contribute data to the AODTS-NMDS.

Related to this is the recommendation that a standardised assessment tool and consequent referral processes be developed to identify and address the needs of relatives of substance users. There is currently no standard assessment tool for use in AOD treatment agencies and the minority of jurisdictions operate centralised referral systems. There is also debate about services offered to people other than the substance user themselves being considered as treatment, for the purposes of data collection.

## **Mental illness and substance use comorbidity**

The development of treatment services that address both mental illness and substance use is advocated for. There is currently no measure of mental health or wellbeing in the AODTS-NMDS.

## **State and territory strategies**

Each state and territory has developed either AOD-specific strategies and implementation plans or broader, departmental approaches to AOD use and treatment. Where specific AOD strategies exist, they are generally in line with the NDS and the NIDS, however they contain more detail about regional approaches and target populations. The differences between jurisdictions' service systems are stark; for example, in South Australia, the vast majority of treatment agencies are government run, while in Victoria, the entire AOD sector is operated by non-government agencies.

Each state and territory defines treatment, either explicitly or in practice, differently and consequently the nature and scope of services that are delivered in each state and territory differ. Further, as jurisdictions respond to the particular needs of their population, different treatment types, modes and models are developed.

Each state and territory operates their own data collection for AOD services and in all instances these collections contain more information than the AODTS-NMDS. As a result, it is the data in each jurisdiction's collection, the systems that support its collection, analysis and reporting and the support required by services to comply with the jurisdiction's requirements that are referred to in each strategy. Some jurisdictions have specific information strategies, while others have general references to 'evidence informed practice' or 'information for service planning'.

Given that the AODTS-NMDS was not designed to monitor or evaluate the strategies of states or territories, it is unsurprising that there are no references to the national collection in their documents. It is interesting to note that data collection is not prioritised in half of the strategies examined.

## **Ethical issues for research involving injecting drug users**

Given the nature and scope of this collection, the responsibility for developing and maintaining trust is paramount, not only for those people who access treatment but to ensure high-quality data. That is, protecting confidentiality not only reassures participants in data collection but also fosters confidence in the data (AIHW 2010a). The Australian Injecting and Illicit Drug Users' League (AIVL) released a national statement in 2007 addressing the ethical issues presented by research involving those people who inject or use illicit drugs. NHMRC guidelines for ethical standards in human research similarly outline a process for engaging with the injecting/illicit drug using population in a meaningful and beneficial way to inform the development, undertaking, analysis and reporting of research.

This issue has specific relevance to the AODTS-NMDS because the collection contains elements which require information about the clients injecting drug user (IDU) status and method of use for the principal drug of concern. Information from the AIVL and some of its members indicates that many peer-provided services do not feel that they have adequate information to provide to clients explaining why information is being collected, thereby not constituting adequate information for informed consent. Further, as the purpose for collecting these data is unclear, there is some evidence that clients are reluctant to respond or may provide deliberately false information, reducing data quality.

## **Ethnicity and cultural diversity**

The Drug and Alcohol Multicultural Education Centre (DAMEC) is located in Sydney and is a state-wide NFP organisation whose aim is to reduce the harm associated with AOD use within culturally and linguistically diverse (CALD) communities in New South Wales. From the information available on the DAMEC website, its publications and promotional material, the term CALD (as used by the DAMEC) refers to non-dominant cultures and includes, but is not limited to, individuals who were born in a country other than Australia, whose parents were born in a country other than Australia, who speak a language other than English at home or for whom English was not their first language and ethnicity. The DAMEC considers the appropriate identification and reporting of cultural diversity as paramount to delivering culturally appropriate services. Given there is no generally accepted definition of cultural diversity in the context of metadata, it is difficult to capture this concept in a collection. Other issues associated with this concept are the identification of non-ethnic-based cultural identities, such as those based on behaviour or sexuality. Further, the purpose and intended use of these data must be clear before collection. Elements in the current collection that inform cultural diversity within the treatment population are country of birth and preferred language. The DAMEC identifies that these elements have been used in service planning for special populations, funding applications and gaps analysis. For this reason, it is important to ensure that these elements meet policy needs and capture what is intended. Should a broader concept of ethnic and cultural diversity be required, this would require extensive data development.

A complete analysis of the capabilities, limitations and potential for these and other elements is outlined in Appendix 3.

# Consultation

A primary component of this review was consultation with a broad cross-section of the Australian AOD sector relevant to the AODTS-NMDS.

## Themes from consultations

Consultations began by asking participants to identify any issues they would like to cover in regards to the AODTS-NMDS, apart from those outlined in the consultation document (Appendix 6). Participants were also given an opportunity to ask questions about the process of the review as well as the collection in general before commencing.

The consultation document was used to guide discussion and ensure that all aspects of the review scope were covered, though many times additional information was provided by the participants.

Given the structure of the AOD sector and the current governance arrangements of the AODTS-NMDS, priority has been given to the feedback and responses provided by IGCD representatives, followed by national peak bodies and researchers, state and territory peak bodies and AOD treatment agencies. This is not to underestimate or devalue the contribution of AOD treatment agencies but to recognise the operational nature of the treatment agencies' concerns that are the responsibility of their jurisdiction and not the IGCD per se.

The themes identified have been ranked within each section from most to least common. No individual state, territory, organisation or individual has been identified and issues that did not achieve consensus are clearly identified. The AIHW has encouraged agencies to pursue resolution of these issues through existing communication and governance channels.

## Intergovernmental Committee on Drugs

In the majority of consultations with IGCD representatives, the first questions asked of the project team were 'What is the purpose of the collection?' and 'What would the Department like from the collection?' Generally, though IGCD representatives and their support personnel in technical, clinical, policy and program capacities found the collection useful, they rarely used it and all sought clarification on the purpose of the collection. Further, the differences between the national collection and their own were cited as the fundamental reason why the national collection was not used for policy and planning purposes. When potential developments and modifications to the collection were canvassed, representatives were supportive of improvements but questioned the principles behind each suggestion and reiterated the need for a clear purpose for the collection.

### Purpose of the collection

The current stated purpose of the collection contained in the *Specifications and collection manual* (AIHW 2010a), is to inform national debate, policy decisions and strategies in the AOD treatment sector. IGCD representatives expressed that the collection could be more successful in achieving this aim. The original purpose was also described as being too broad as the AODTS-NMDS contains insufficient information to monitor and evaluate the entire NDS. All IGCD representatives supported a renewed focus on AOD treatment services as the

core concept being measured by the collection, with some representatives also supporting a broadened scope to capture other AOD activities in the harm minimisation spectrum.

Related to this overall purpose, IGCD representatives were interested in the DoHA's intentions for the collection: its purpose and uses at the federal level. As each state and territory has its own collection, the national collection is peripheral to their main information sources, however the DoHA has fewer sources to draw on in regards to the AOD services it funds. For this reason, states and territories were interested to know what the DoHA's intentions are for the collection as changes to the national collection impact on all agencies as opposed to changes to state and territory collections which have little or no perceived impact on the AODTS-NMDS.

### **What is treatment?**

While there was support for a renewed focus on treatment and some support for broadening the scope of the collection to include other AOD services, the difference between these two aspects was difficult to ascertain as there was no commonly accepted definition for treatment.

IGCD representatives generally agreed that what is accepted as AOD treatment in Australia is a philosophical issue. Though the principles of harm minimisation form the basis of all national, state and territory strategies addressing AOD use and treatment, the services and programs that form the responses to AOD use are varied. Some jurisdictions do not consider services provided to people other than the substance user themselves as treatment, though they report them as part of the collection. Other jurisdictions consider all interventions that address substance use in some way as treatment, including adjunctive services. The AODTS-NMDS avoids defining treatment, instead defining the treatment episode and thus avoiding any description of what constitutes AOD treatment (AIHW 2010a).

### **Strengths and utility of the collection**

Feedback from IGCD representatives and their colleagues in the state or territory department overseeing AOD service delivery indicated that they rarely use the AODTS-NMDS as their own collections contain more information. When the national collection was used, it was in response to media enquiries after the release of a publication, briefings and other requests. The national collection was rarely, if ever, used to inform agencies of their activity, plan services and programs or to develop responses to emerging issues; primarily because it lacks specific detail and the time lag in receiving national data makes it less useful.

Regardless, each representative acknowledged the need to improve the utilisation of the AODTS-NMDS to inform national policy and direction. Areas suggested for improvement are the general content (expanding data elements to capture more concepts); capacity to adhere to activity-based funding requirements; and more information about the actual treatments provided by agencies that contribute to the collection.

### **Governance and strategic direction**

IGCD representatives identified that there are opportunities to be better engaged with the AODTS-NMDS and to provide greater strategic direction than in the past.

Governance of the Working Group and thus, the collection, has been a matter of discussion since 2000. As the Working Group has never been part of the formal structure of the IGCD, strategic direction has been difficult to secure until recently. In September 2009, the IGCD agreed to provide the Working Group and the AODTS-NMDS generally with greater direction. Further, representatives were supportive of greater IGCD involvement in the

development of strategic and work plans of the Working Group to ensure alignment with current policy decisions and agendas and of a process whereby decisions can be referred to the IGCD for resolution in a timely manner. This appears to continue to be the case.

IGCD representatives expressed some interest in reviewing the terms of reference and operating rules of the Working Group, the requirements for membership to ensure that members had the appropriate level of authority dependent on the outcomes of this review and the intentions of the DoHA. The majority of representatives supported regular auditing of the AODTS-NMDS in line with the NDS.

## **Scope**

The issue of scope is dependent on an accepted definition of AOD treatment for the purposes of data collection. IGCD representatives who supported restricting the scope of the AODTS-NMDS to services that provided treatment according to an accepted definition of treatment also acknowledged that the activity of other AOD services, which may no longer be considered in scope for the collection, should be able to report their services by another means. Representatives who supported a broader scope to include AOD services, not specifically treatment, advocated for defining each intervention to prevent misinterpretation of the categories. Services that do not currently form part of the collection and that representatives felt were important for inclusion in the current data set, or a modified version, were:

- pharmacotherapy for opioid, alcohol and, potentially, nicotine dependence
- sobering-up shelters that provide AOD services in addition to accommodation
- halfway houses, aftercare and transition services
- AOD services delivered in correctional facilities, prisons and other justice settings.

A sensitive area for consideration and a source of frustration for some IGCD representatives was the inclusion of substance use services funded by the Office of Aboriginal and Torres Strait Islander Health (OATSIH) in the AODTS-NMDS. The Working Group first raised the potential benefits of OATSIH representation on the Working Group in 2004. Some OATSIH-funded substance use services do currently report to the AODTS-NMDS, however there are a number that do not. An outcome of the OATSIH review of reporting requirements in 2009 was the development of a new, streamlined paper-based reporting form called the OATSIH Services Reporting (OSR) – capturing relevant information previously reported under the Service Activity Reporting (SAR), Drug and Alcohol Service Report (DASR) and questionnaire for Bringing Them Home (BTH) and Link-Up counsellors. The OSR is an annual data collection of Australian Government-funded Aboriginal and Torres Strait Islander services that captures relevant information on primary health care, substance use-specific rehabilitation and treatment services, and BTH and Link-Up counsellor activities (OATSIH 2009).

OATSIH is currently considering options for including OATSIH-funded Indigenous substance use services in the AODTS-NMDS data collection.

## **Limitations of the current collection**

IGCD representatives identified several concepts that are not captured by the collection. These concepts are related to state, territory and national agendas as well as capacity to evaluate the services provided by AOD treatment agencies.

## **Counting clients**

Since the collection's inception, the rule of counting closed treatment episodes has limited the collection's utility. As it is not possible to differentiate between multiple concurrent and consecutive treatment episodes of individuals, no estimate can be made of the number of individuals who access treatment services within a collection period (Grant & Petrie 2001). Further, the collection provides no basis for estimating the number of individuals accessing treatment between years. All IGCD representatives acknowledged the potential that data linkage would provide the collection in addressing these issues, however there was varied support for its introduction. Most jurisdictions supported data linkage in principle and one cited privacy concerns and opposition within the AOD sector as hindrances to its introduction. All states and territories stated that inclusion of any statistical linkage key to the collection would require a clear statement of purpose from the DoHA, including for what purpose the linked data would and would not be used.

## **Informing policy**

Group and family counselling and brief intervention services are increasingly being adopted by government and non-government agencies, however the level of this activity is inadequately captured by the collection as these episodes may be reported as counselling with no further information, or missed altogether as the mode of delivery does not necessitate the collection of the information in the AODTS-NMDS.

The national focus on decreasing people's experience of homelessness, coupled with many jurisdictions' policies of 'no exit to homelessness' cannot be informed by the AODTS-NMDS as there is no indication of the client's housing status or location.

Similarly, agendas and policies on increasing child safety and supporting parenting cannot be informed as this information is not contained in the collection. The client's mental health status is also not indicated within the collection; limiting adequate information for comorbidity and social inclusion policies and strategies.

While IGCD representatives were open to discussing means to collect and report these data, there was less support for their introduction until an outcome measure is introduced. A complicating factor was that there was no common ideal for what this would be a measure of – the client's, clinician's or service outcome, a measure of reduced use or abstinence or a measure of cost-effectiveness.

Concepts that received some, but not total, support from IGCD representatives were:

- price and source of principal and other drugs of concern
- use of unbranded tobacco
- employment and education status of the client
- income source.

## **Other comments**

There was some support for a national coordinating body dedicated to drawing together all data sources to inform the NDS and related initiatives as well as recommending developments and improvements to those collections. Some IGCD representatives suggested reducing the number of analyses that were reported in the annual publications to encourage better use of the data, including purpose-specific analyses, while others recommended adding greater detail to increase the use of publications and products.

## **National AOD interest organisations**

The national bodies consulted in this review were the Alcohol and Other Drugs Council of Australia (ADCA) and the Australian National Council on Drugs (ANCD), the Australian Injecting and Illicit Drug Users' League (AIVL) and the Association for Prevention and Harm Reduction Programs Australia (ANEX). These bodies represent the broad AOD sector, non-government AOD treatment agencies, peer-provided services, injecting and illicit drug users and harm reduction programs, such as needle and syringe or clean needle programs. As these organisations also undertake research projects, the use of the collection in this context was also discussed.

### **Purpose of the collection**

Like the IGCD, these organisations expressed the desire to have a clear purpose for the collection – not only to understand reporting and analysis but also to convey to agencies and clients. They saw the responsibility of defining the purpose of the collection as that of the DoHA and the IGCD, through consultation with the AOD sector.

### **What is treatment?**

The question 'What is treatment?' had particular resonance with this group of stakeholders, as they represent a wide variety of intervention types on the harm minimisation spectrum. There was broad agreement that the lack of a nationally consistent definition of treatment was problematic as agencies were unsure of their eligibility for funding under certain programs, clients were unsure of the services they were accessing and the community is hesitant about certain services being provided in their area because they have a very specific idea of what 'treatment' looks like.

Though there was agreement that the definition of treatment would in part be informed by the intended purpose of the collection, there was support to broaden the concept of AOD intervention and the idea that 'alcohol and other drug services' may be a more appropriate focus for this collection.

The fact that some agencies were funded to provide specific services that may not be regarded as treatment was raised, given that many are also mandated to report these episodes to the national data collection and differentiating between programs is administratively very difficult, if not impossible. As a result, some episodes that are reported may not be regarded as treatment by some stakeholders, while other episodes that may be funded and provided as treatment (such as brief interventions), may not be reported.

As with the purpose of the collection, reaching consensus on what is and isn't treatment, for the purposes of the AODTS-NMDS, was considered to be a consultative process involving the AOD sector.

### **Strengths and utility of the collection**

The AODTS-NMDS is used by these stakeholders primarily to provide national, headline figures and attempt comparisons between jurisdictions. Again, the lack of detailed information, the inability to estimate the number of individuals and inconsistency with state and territory collections limit its use.

Ideally, these stakeholders wanted to use the AODTS-NMDS to develop national policy positions and undertake national research projects with confidence. They cited inconsistency with state and territory collections, perverse incentives for agencies and the administrative burden as major impediments to high-quality data collection and reporting.

As expressed by these peak bodies, many agencies believe that the collection is already used for monitoring service delivery, benchmarking and performance reporting. Despite this belief, agencies were unlikely to use data from the collection in applications for funding, even where reporting to the AODTS-NMDS is a requirement of funding. They were more likely to use data from their own systems.

### **Governance and strategic direction**

Amongst these stakeholders there was limited knowledge of the governance of the AODTS-NMDS and they did not associate the AODTS-NMDS with the IGCD but rather with the DoHA. All stakeholders were familiar with the IGCD and recognised the policy and strategic direction setting responsibility vested in that committee. There was some surprise that this was the first time that the collection has been reviewed, given developments within the AOD sector and multiple funding programs and rounds. These stakeholders expressed frustration that some services and agencies within the AOD sector appeared to be driving their clinical practice and service delivery to meet reporting requirements though they recognised that the AODTS-NMDS was not the core report for the majority of these agencies. Discussion then focused on potential changes that may be made to the nature of the collection to reflect the agreed practices of agencies; for example, capturing the breadth of treatments they are funded to provide rather than creating a forced choice between the discrete categories that currently exist.

### **Scope**

A common theme from these consultations was frustration felt by agencies who deliver multiple programs of which some fall out of scope of the current collection, and those which identify as, and may be funded as, treatment services but whose entire range of services fall out of scope for the collection. According to these stakeholders, these services were most likely recently funded to provide transition and aftercare services within a continuum of care model, sobering-up shelters, pharmacotherapy services and out/in reach services to prisons and other correctional facilities. Further complicating the issue of scope are several instances where agencies are required by their funding agreement to report to the AODTS-NMDS but their treatment services fall out of scope for the collection; for example, pharmacotherapy induction and withdrawal services. To report this activity, many agencies code this treatment type as rehabilitation.

Stakeholders supported the idea of capturing the full breadth of AOD services provided in the harm minimisation framework and recognised the complexity of such a task. One suggestion was to have several complementary data collections or to develop a suite of subsets that would be completed according to the relevance to the agency.

### **Limitations of the current collection**

The inability to obtain detailed information about specific populations was recognised as a major limitation of the collection. This includes prisoners, young people and young people in state care, and older people. Information regarded as missing included employment status, income source, education level, prisoner status, parenting responsibilities and the use of prescription medicines. Stakeholders felt that the inability to estimate the number of individuals exacerbated this limitation because the information that is currently available is less useful.

The agencies represented by these organisations expressed that if the collection is a measure of service activity, that it should have greater capacity for capturing treatments such as

group counselling, family therapy, brief interventions and pre-treatment engagement, as well as waiting lists and delays in service. Further, the current collection does not contain a measure of treatment intensity, which leads to misinterpretation of some data. For example, where counselling is the main treatment type, there is no record of how many, how long or what kind of counselling sessions were provided or attended, just the length of the entire treatment episode. A similar problem exists for rehabilitation in residential settings and therapeutic communities which are considered more intensive treatments.

While the limitations of the collection were easily named, there was also strong recognition that the collection and reporting of any more information than is currently required would cause an impost on agencies.

## **Other comments**

Other comments made in these consultations and considered important to include concern the increasing differences between state and territory collections and the national collection. These stakeholders supported a coordinated national effort to bring together relevant AOD data in a national treatment strategy and advocated for greater consumer engagement in the data collection process.

There was also agreement that products from the national collection should be promoted more widely and that services related to the collection, such as specific analyses and other data requests, be publicised, especially to agencies who contribute their data to the collection.

## **Research centres**

The three national research centres funded under the NDS, as well as the Queensland Alcohol and Drug Research and Education Centre (QADREC), were consulted to discuss the role that the AODTS-NMDS does and could play in AOD research.

Not all centres utilised the collection for their research projects, primarily because each centre has a different focus within the AOD sector. Of those centres that have or do use the collection, they were most likely to use unit record data requested from the AIHW and the online data cubes for planning research projects.

All centres were concerned about the quality of the data collected and highlighted a number of limitations of the collection within a research context. Generally, researchers were happy with the collection and recognised the balance between quality and quantity of data, acknowledging the difficulty in collecting sensitive information.

Unlike other stakeholders, researchers did not immediately ask what the purpose of the collection was. Instead, they sought definitions of treatment and clarification on the treatment types within the collection. There was also limited discussion on the collection's governance and strategic direction, with the majority of comments and suggestions being about the content of the collection as well as the way in which products and information about the collection are disseminated and publicised.

## **Content**

### **Scope**

All centres identified pharmacotherapy treatment and services delivered in correctional facilities and prisons as omissions from the collection. Further, services provided in private

settings – that is, not publicly funded agencies – were seen as an important component of the collection to provide a comprehensive view of AOD treatment in Australia.

### **The clients**

The most common limitation identified was that the number of individuals accessing treatment could not be estimated. Further, that the person identifiers within the data set could not be used to identify concurrent and consecutive treatment episodes within and between agencies.

Other client-level information that was considered useful was:

- mental health status
- treatment history
- family situation and dependent children
- frequency of use measure
- employment and education status
- living situation and homelessness
- client postcode
- an expanded code set for source of referral, treatment delivery setting and reason for cessation.

This is not an exhaustive list; rather it is a list of the most commonly identified concepts.

Researchers acknowledged the difficulty in collecting some information, especially where clients or services may perceive that disclosure would limit access to services or necessitate the involvement of other agencies, such as child protection.

To support greater use of client-level information, researchers expressed a desire for clearer definitions of data elements, especially treatment types, and consideration of introducing standardised assessment tools for dependence, mental health status and treatment outcome. Further, knowing if a question was not asked was seen to be more beneficial than only having a ‘not stated/inadequately described’ response, as it is not possible to disaggregate this further.

### **The agencies**

The limited information about the agencies that provide treatment services was also identified as a limitation of the collection. Specifically, the philosophy and service delivery model of treatment agencies was considered to be important information as well as the nature of the treatment types they provided. For example, what kind of counselling was provided? This would allow for more informed comparisons in research. The capacity to identify individual treatment agencies in analysis was also considered to be useful.

### **Products**

Researchers appeared to be the biggest users of products from the AODTS-NMDS, including specific data requests and access to the actual data set. General issues identified by researchers relating to the products of the collection were the time required to publish the annual report and make data cubes available online and a lack of citation and referencing information to properly acknowledge online sources when used in research projects and publications. All the stakeholders consulted also suggested ways in which the collection and products could be better advertised in the AOD sector and generally.

In using the data, feedback was that there needs to be clearer guidance on what the data can and cannot be used for; for example, that counting rules mean that the number of clients cannot be estimated. One centre suggested that sample codes for different statistical programs and software be made available so that analyses can be replicated in secondary analysis.

## **State and territory peak bodies<sup>2</sup>**

The AOD sector in each state and territory is generally represented by a peak body, however it should be noted that not all agencies are members of their peak body and membership has been said to be declining (Spooner & Dadich 2009). Having said this, peak bodies were approached because they were considered to be representative of the sector and a single point of information rather than approaching individual treatment agencies.

Through consultation with peak bodies there were five common themes.

### **Peak body and health authority relations**

Each peak body expressed frustration at what they perceived as a lack of engagement and communication with their relevant member on the AODTS-NMDS Working Group and all expressed their desire for more effective, positive relationships between the health authority and their Working Group member.

Another common frustration raised was the perception of a lack of an iterative process with data submission, especially where the peak body plays a significant role in coordinating data submission from NGOs. Peak bodies expressed their desire to receive their data back in a useful format, so they can understand what their sector is doing and identify areas where resources are required so they can better support their members.

Some peak bodies also felt that there is a lack of trust between themselves and their health authority. As a result of this perception, the peak body and their members are less likely to respond positively to requests and developments brought to them by the health authority but appear to be more receptive to national developments that are initiated by the DoHA or at that level (through the AIHW). For example, all peak bodies expressed interest and enthusiasm in developing the AODTS-NMDS but expressed concern with the state or territory health authority having access to greater amounts of personal information. Interestingly, no concern was expressed about the AIHW holding such information and, in several instances, peak bodies suggested that data bypass the state authority and be submitted directly to the AIHW.

### **Complexities of compliance**

The peak bodies' perception of how decisions that impact on the sector are made appears to be dependent on their relationship with their relevant Working Group member and health authority. That is, they have a positive perception when they have a positive relationship with the Working Group and their health authority (self reported) and vice versa. Specific to the AODTS-NMDS, peak bodies perceive that decisions are made with limited consultation with the sector and imposed through funding agreements. While the AODTS-NMDS is

---

<sup>2</sup> At the time of consultation, the Northern Territory (NT) and the Australian Capital Territory (ACT) did not have dedicated AOD peak bodies. The ACT has since established the Alcohol, Tobacco and Other Drug Association. The NT Council of Social Services (NTCOSS) and the ACT Executive Directors of AOD Services Group were consulted instead.

specified as a reporting requirement in some funding agreements, it is more common for the state or territory data collection to be named.

Peak bodies expressed the difficulty in their position trying to support agencies to understand their funding agreements and to comply with the reporting requirements. This is especially difficult where an agency has multiple funding sources and consequently, numerous reports that are required. In most jurisdictions, several versions of the same data are required, including for submission to different areas of the same department, sometimes for different programs in the same area. One example of this is NGOs who receive funding through the NGOTGP and the Improved Services Measure.

The ANCD 2009 report *The burden of submission writing and reporting for alcohol and other drug non-government organisations* (ANCD 2009) explores the issue of reporting compliance in detail. While the AODTS-NMDS is not in itself a tool used for generating applications for reporting on funding, or compliance with contracted activities, it has become apparent that many agencies view it as such and, in some instances, contract managers do too.

Given that in the majority of cases, neither peak bodies nor agencies receive feedback on their data, peak bodies feel that the submission of poor-quality or incomplete data is a symptom of excessive reporting requirements. Exacerbating this is that the data required for compliance are rarely, if ever, the same data required for funding applications and submissions, which pressures agencies to maintain parallel data collections to populate applications.

Where data collection is mandatory, peak bodies support the full funding of sufficient positions to meet these needs, in agencies and at peak body level. They also support the introduction of standardised data collection systems that simplify the process and can provide useful information and reports for the agencies themselves.

## **Privacy**

With the suggestion that any new element could be considered for inclusion in the AODTS-NMDS, peak bodies were concerned about the privacy of the clients accessing treatment agencies and the agencies themselves. Interestingly, no peak body expressed concern at the introduction of data linkage; on the contrary, all were supportive. There was concern about introducing elements that captured information about dependent children, mental health, employment status and income source. In the majority of cases, the concern was about the use of these data at the local level and there was no opposition to reporting it for the national collection. Though all peak bodies were familiar with their privacy obligations under legislation, there were several instances where the integration, co-location and collaboration between NGO and government services blurred this line and it became unclear as to which privacy legislation requirements were applicable. Further complicating this are issues pertaining to the ownership of data and records. Where NGOs have their own information systems, they appear to understand their obligations and often have the capacity to respond to requests for information from clients as well as funders. Where NGOs do not possess their own information systems, whether through a lack of resources or because the state or territory authority has provided one, there is confusion about who owns the information and what privacy legislation applies to it. This is particularly problematic where clients are aged under 18 years (minors) and where records may be subpoenaed. It is unclear to what extent clients are aware of the differences between government and non-government agencies and how their information is treated.

## **Capturing service activity**

In terms of the scope of the AODTS-NMDS, peak bodies were confused as to why the collection did not capture the diversity of AOD services funded in each state and territory and under different federal programs. The definition of treatment was less important to peak bodies than defining the scope of the collection, dependent on its purpose. There was support for widening the current scope to include all interventions on the harm minimisation spectrum, acknowledging that many of these interventions would find it difficult to report the elements required by the AODTS-NMDS. At the same time, many peak bodies said that there are existing services that would not ordinarily ask the questions required by the collection but, as they are mandated to report this information, it is collected.

Peak bodies were frustrated that many of their members do not have the opportunity to report their activity through the collection. That is, the counting rules and treatment types do not provide a comprehensive picture of treatment activity in their jurisdiction. Many peak bodies perceived the collection as a performance measurement tool and in some jurisdictions it is used as such. For this reason, agencies have 'perverse incentives' to inflate the number of treatment episodes they deliver, through varying interpretations of the counting rules. This is often at odds with their model of service delivery which is increasingly a continuum of care, where clients access treatment through a single point though their treatment type may change over the course of an episode.

The inability of the collection to reflect contemporary clinical practice was cited as a major limitation. This includes pre-treatment engagement, waiting times and delays in service, group counselling, insufficient detail in treatment types and insufficient coding options for treatment types.

Peak bodies were particularly concerned about the collection's inability to capture the policy context in which AOD treatment are now being delivered. For example, some jurisdictions have implemented a 'no exit to homelessness' policy where agencies can only discharge a client to safe, stable housing and, consequently, treatment durations may rise or clients may be transferred to other service providers. Currently, there is no way to identify this in the collection as the only detectable change would be the reason for cessation and treatment duration.

There was also strong support for data linkage dependent on services being supported to analyse and interpret their own data, to ascertain the stock and flows in the AOD treatment sector.

## **What data are used for**

Peak bodies want to use the data to answer specific questions and to contribute to the evidence base for treatment provision. For example, one peak body expressed that they would like to answer the question 'How long should a client be in treatment (cumulative duration) for a specific principal drug of concern before a client does not come back to treatment for a specified period of time?'

Some peak bodies had used published data from the collection and most focused on the data for their state. As many of the elements in state and territory collections are more comprehensive than the national collection, peak bodies were frustrated that they could not access breakdowns of treatment types, sources of referral and reasons for cessation that they knew existed in state collections. As a result, they and many of their agencies used data from their own collections for applications, submissions and policy papers and these data did not match that from the national collection.

Peak bodies perceived that the collection is used for benchmarking, performance measurement and measuring outcomes, though could not describe why they thought this. They were concerned that the inaccuracies in the data being submitted by agencies were having a negative impact on funding opportunities.

## **AOD treatment agencies**

Of those treatment agencies who participated directly in the consultation process, their main contributions were related to the purpose and use of the collection, its content and how agencies can be better engaged in the data development, collection and reporting process.

In relation to the purpose and use of the collection, agencies wanted assurances that it could not be used for purposes other than those stated. For example, that the collection could not be used to identify individuals, pursue action in relation to their substance use, child protection or employment, evaluate services or measure their performance, or set benchmarks for service delivery.

Agencies recognised that incorporating more elements into the AODTS-NMDS, while capturing more detail about the activities in the AOD sector, would create greater administrative burden for services. They expressed a desire for balance in what was required of them and what they wanted to report; that is, that agencies would like to report some aspects of their services that funding bodies do not necessarily request, such as capacity and waiting lists. The concepts that agencies would like to see incorporated into the AODTS-NMDS include, but are not limited to:

- BBV/STI status including hepatitis C virus (HCV) and HIV
- sexuality/same sex attraction
- smoking status
- behaviour while under the influence
- the agencies' role in shared care arrangements
- the difference between therapeutic communities and other residential programs, inpatient and outpatient withdrawal support and out/in reach programs in fixed and temporary locations
- new modes of delivery, including web and telephone counselling.

Technically, agencies were concerned that a number of episodes are lost between collection periods because of the counting rules. Currently, episodes that remain open at the end of a collection period are not transmitted as part of that year's data set, however where a client does not make contact with the agency for three months and that episode is subsequently closed, the episode cannot be submitted in the previous year's data set (as it is closed) nor in the next years. This was of particular concern to those agencies who perceived that the AODTS-NMDS was used to measure service activity.

Generally, agencies would like greater support to understand data and its potential. To achieve this, they identified a need for dedicated resources to comply with data collection requirements and an iterative loop between themselves and those to whom they submit data. Making use of relevant data in funding submissions was also identified as a way of increasing data literacy and valuing the data that agencies contribute.

# Thematic analysis

## Common themes

To draw the literature review and consultations together, the main themes have been identified for further analysis and discussion. The discussion examines why the theme is important and its relationship to current international, national and local agendas and policies, as well its importance to the various stakeholders.

## Purpose, scope and content

The common thread through the literature review and all consultations was that data collections require a clear, articulated purpose. While IGCD representatives, researchers, peak bodies and agencies could all describe what they use the national data for (if they use it), there is a plethora of different interpretations of the data. As a result, agencies misunderstand what the data are used for and are wary of reporting requirements, and jurisdictions appear sceptical that development of the data set will bring any benefits if there is no clear purpose.

Without a specific objective for the collection, based on common understandings of what is being captured and why, metadata development, refining of processes and refreshing the look, feel and content of publications and statistical products will be difficult.

Once a more specific purpose for the collection is agreed, the scope, or what is being counted, can be decided. In summary, we need to clearly articulate what we want to know, which agencies and clients we want to know it about and what we want to know about them.

## Purpose

Three broad purposes for health data collections have been identified to frame the discussion about how the purpose and thus the scope of the AODTS-NMDS may be reframed.

## Activity-based funding – what governments pay for

The Activity Based Funding National Framework and Implementation Plan (Australian Government 2008) describes activity-based funding as:

a management tool that has the potential to enhance public accountability and drive technical efficiency in the delivery of health services by:

- a) Capturing consistent and detailed information on hospital sector activity and accurately measuring the costs of delivery;
- b) Creating an explicit relationship between funds allocated and services provided;
- c) Strengthening management's focus on outputs, outcomes and quality;
- d) Encouraging clinicians and managers to identify variations in costs and practices so these can be managed at a local level in the context of improving efficiency and effectiveness; and
- e) Providing mechanisms to reward good practice and support quality initiatives.

As the primary method for funding and data collection in the national health and hospital reform agenda, it is reasonable to assume that, at a minimum, at least some characteristics of this funding model will impact AOD services.

A collection designed to inform activity-based funding contains more information about the cost of delivering services and, as such, may contain less demographic and clinical information than other data sets.

Data collection and reporting on activity-based funding rely on nationally consistent definitions and application of concepts – a core feature of national minimum data sets, including the AODTS-NMDS. Implementation of the national framework is anticipated to have some impact on the AODTS-NMDS as some in-scope services are provided through the public hospital system, which is directly affected by these reforms. Further, the information technology and communication systems that each jurisdiction use may require modifications or enhancements, with flow-on effects to other collections such as the AODTS-NMDS.

### **Establishment information – what agencies provide**

Slightly different to activity-based reporting is establishment information. Data sets of this nature capture information about the characteristics of the agencies funded to provide services, such as their location, what services they offer, their model of service delivery, their workforce and philosophy. Rather than a unit record collection, establishment information is usually aggregate data collected on a regular basis; for example, annually.

Some sectors utilise establishment information to measure progress against specific initiatives and measures, such as those to improve geographical access. They are also considered useful in program planning and funding allocations. What these collections do not do is capture information about what clients actually receive or what these services cost, though they may have capacity to capture some of this information in an aggregate form – for example, the total number of brief interventions, total number of participants in group counselling sessions or the total number of clients with specific characteristics.

### **Clinical and administrative data collection – who the clients are and what services they receive**

The current AODTS-NMDS captures treatment type and quantitative and qualitative data and is considered an administrative data set with some clinical information. Collections like these are client focused and use a combination of administrative sources (information required to deliver the service, such as demographic information) and questionnaires (information not necessary for the delivery of services, but useful) to gather information. These data sets may contain some information about activity, either through a measure of contacts or duration of treatment, but insufficient information to estimate or calculate costs.

Collections of this type are generally used for assessing the effectiveness of particular approaches; for example, a rise in the delivery of a particular treatment type or a greater number of episodes in a specific geographical location. The majority of international and national AOD collections are clinical and administrative data sets and are used to monitor treatment demand, access and completion rates. Some have the capacity to measure outcomes and most complement collections that capture information about other aspects of AOD service delivery, such as agency information.

### **Which is best?**

The kind of collection chosen will determine the type of agencies, services and activities that are considered in scope for reporting. Stakeholders expressed different ideas about what they thought the collection is and should be about.

IGCD representatives and some peak bodies supported an activity-based funding model of reporting and data collection to assist in accounting for and applying for funding. Research centres and agencies supported an expanded clinical/administrative collection and there

was general support for collecting establishment information, in addition to the current collection. The purpose and nature of the collection is primarily a decision for the IGCD.

## Scope

Once the 'what we want to know' has been defined, the agencies and clients providing data must be considered. The issue of scope and 'scope creep' in the collection is of great concern, especially as there are multiple funding sources with different eligibility and reporting requirements.

Given the variety of treatment interventions and types articulated in the literature, especially *Alcohol and other drugs: a handbook for health professionals* (NCETA Consortium 2004), it is obvious that the current treatment types in the AODTS-NMDS do not adequately reflect current practices.

The scope of the collection has not changed since inception, though models of care and treatment types have changed over the past 10 years. All stakeholders expressed concern at the incompleteness of the collection and identified several areas for improvement in data capture:

- **Pharmacotherapy services**, including initiation, stabilising/maintenance and reduction services. Opioid pharmacotherapy is a cornerstone of opioid dependence treatment in Australia and forms a central tenet of BBV strategies (IGCD 2007). Currently, the national collection on opioid pharmacotherapy (NOPSAD) comprises aggregate data and because the operation of opioid pharmacotherapy services in each state differs markedly, there are inconsistent definitions. The diversity in treatment settings, including correctional facilities and private clinics as well as the role of pharmacists and general practitioners in delivering this treatment, place it out of scope for the AODTS-NMDS. However, state and territory health authorities are increasingly funding services to provide specific interventions and support for clients on opioid pharmacotherapy, outside of exclusive prescribing and dosing facilities. Currently, there is no accurate measure of the number of people who are both accessing AOD treatment and are on opioid pharmacotherapy.
- **Halfway/transition and aftercare services** are increasingly being funded as jurisdictions implement policies that prevent discharge to homelessness, emphasise continuity of care and comprehensive health and recovery services. In some instances, agencies for which AOD treatment is not core business have begun to offer these types of services but they are not in scope for this collection. There is evidence that correlates treatment duration and prolonged support with more successful outcomes and collecting these data may assist with verifying this contention in an Australian context (DoHA 2009). To accurately capture the gamut of AOD interventions across the continuum of care, transition and aftercare services should be considered for inclusion to the data set.
- **Brief intervention services** offered in a variety of settings are considered to be an effective use of resources to engage people in therapeutic relationships (NCETA Consortium 2004). Because of the nature of these interventions, it is not always possible to collect all the information required for the AODTS-NMDS, however as services begin to deliver more of this type of treatment, an adequate measure, within an activity, clinical or establishment collection, may be required. This concept also presents an opportunity to capture pre-treatment information, such as engagement before formal assessment for treatment. Given the AODTS-NMDS is intended to capture only those episodes where the client has been formally assessed and accepted for treatment, this concept does not fit neatly into the current collection.

- **Children aged less than 10 years** have not been captured in the collection since its beginning as jurisdictions expressed such small numbers may compromise privacy. As models of care change and there is an increasing policy focus on the impact of substance use on families and children, it may be valuable to begin including data from clients aged less than 10 years. There are several services in each jurisdiction that are specifically designed to provide treatment and support to families, parents with accompanying children and parents who are engaged with the child protection system. The Australian Institute of Family Studies and several ANCD research reports have identified the lack of data on young people and children who are directly engaged with, or have a family member engaged with, substance use treatment (Dawe et al. 2007). Where agencies provide these services, and are able to collect all the relevant elements for children aged less than 10 years, especially where they are receiving services for another's substance use, they should be able to report to the collection. Including data for this population is also relevant for jurisdictions with a younger population, such as the Northern Territory.
- **AOD services provided in correctional facilities and prisons** have been identified by all stakeholders as a growing concern. In terms of scope, the guidelines of the AODTS-NMDS only refer to publicly funded AOD specialist services, which may be interpreted as services funded by any sector, including justice and corrections. The complication is that the AODTS-NMDS is an agreed collection under the National Health Information Agreement (NHIA) to which justice and corrections departments are not party and, therefore, under no obligation to report. The high rates of substance use in many prisons necessitated the introduction of treatment services, from information and education sessions, to counselling and rehabilitation, including therapeutic communities (Black 2004). The UNODC promotes the principle of equivalence which states that 'treatment services available in prisons (be) equivalent to those in the community' and application of this principle naturally extends to the inclusion of these data in the national collection. This principle is supported by the ANCD research report *Supply, demand and harm reduction strategies in Australian prisons: implementation, cost and evaluation* (Black 2004), which found that harm and demand reduction techniques were the least expensive and showed favourable results in prison settings. These interventions included detoxification, opioid pharmacotherapy, needle and syringe availability and exchange programs, as well as continuity of care after release. Opioid pharmacotherapy is also recommended as an approach to minimising BBV transmission in correctional settings by the suite of national strategies to minimise the transmission of STIs and BBVs in Australia (DoHA 2010e). The idea of explicitly widening the scope to ensure reporting by AOD services within correctional settings involves more than the treatment setting and has implications for the reporting of other elements, including treatment type.
- **AOD services funded solely by the Office for Aboriginal and Torres Strait Islander Health (OATSIH)** do not consistently report their service activity in the AODTS-NMDS, as a consequence of their funding and administration arrangements. There are sensitivities surrounding the reporting requirements of these agencies, however the OATSIH is taking steps to improve reporting compliance. Many IGCD representatives expressed frustration at the dearth of data from such agencies because it makes planning other services for Aboriginal and Torres Strait Islander peoples difficult. Researchers have expressed the complexity in triangulating data sources to create an accurate picture of these specific AOD services and the Aboriginal and Torres Strait Islander Complementary Action Plan (complement to the National Drug Strategy) identifies the need for better, coordinated data collection that does not further burden service delivery agencies. The inclusion of data from these services depends on successful negotiation of

processes as well as content. The AIHW acknowledges the continuing discourse between the OATSIH and the Working Group to improve the current state of data collection within OATSIH-funded services.

- **Private AOD services** are expressly excluded from the scope of the collection as there is no mechanism for compelling privately funded and operated agencies to submit their data. From a research planning perspective, data from privately operated AOD services may be useful, especially where different treatment types, settings, modes and protocols are applied. The inclusion of data from private AOD services would have to be considered in the context of available resources. The benefits of inclusion should also be examined given the limited ability of government to effect change within these services, outside of regulatory frameworks of which few exist in the AOD sector and vary between jurisdictions (information from IGCD consultations). There may exist opportunities to engage with private providers, either directly or through representative bodies and health insurers, to ascertain what information is currently collected, assess its utility and begin a discussion about potential inclusion. This would be a decision for policy makers, including the DoHA and the IGCD.
- **Services that are co-located or integrated** with services from another sector may be government or non-government services, or AOD services delivered with homelessness, mental health, primary care or other health-related services. The likelihood of these types of services increasing is great, given the current health reform agenda and the draft national strategy on primary care, which both advocate for streamlined, integrated services. Though the AODTS-NMDS is intended to include specialist AOD services, where these become physically or administratively integrated with other services, the impact on data collection is unclear. Some instances may be simply addressed by introducing new coding options for the agency sector, to indicate an integrated service, though the flow-on effects, such as assigning proportions of treatment episodes, may be affected. The practicality of reporting the collection, should services begin to operate from more general settings, will depend on the information technology of each site as well as the administrative arrangements and obligations. This is especially relevant where a single agency provides multiple services each with a mandatory data collection.

## Content

Content must be determined following a decision on the purpose and scope of the collection. For example, if the purpose is to account for funding (activity-based reporting) for the services that clients receive (clinical/administrative), specific elements like the number of contacts for a specific treatment type may be required.

The literature that discusses the content of data collections is varied as it is dependent on the region of collection, nature and purpose of the collection.

The UNODC GAP recommends a core set of elements for collection in an international context. The concept is similar to that of an NMDS in that jurisdictions may collect more elements than exist in the national collection. These elements are outlined in Table 5.

**Table 5: Core elements of an international data set**

Client level	Drug use (last 30 days)	Treatment
Attributor <sup>(a)</sup>	<u>Primary drug</u>	Treatment centre type
<u>Age/date of birth</u>	<u>Secondary drugs</u>	<u>Date of treatment start</u>
<u>Gender</u>	<u>Method of use<sup>(b)</sup></u>	<u>Source of referral</u>
Race/ethnicity	Frequency of use <sup>(b)</sup>	Prior treatment episodes
Living status	Age of first use <sup>(b)</sup>	
Employment status		

(a) Attributor is an identifier that prevents or minimises double counting.

(b) For primary drug or each drug is possible.

*Note:* elements that are underlined are contained in the current Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS-NMDS).

*Source:* UNODC (2006).

The AODTS-NMDS contains approximately half of these elements (underlined) but their definitions differ slightly. The concept of an international collection creates the same issues for Australia that the national collection creates for each jurisdiction.

Though none of the stakeholders identified compliance with an international data set as a priority during consultations, many of the elements contained within the UNODC GAP were raised as concepts missing from the AODTS-NMDS. Specifically, the person identifier in the AODTS-NMDS does not prevent or minimise double counting, and there is no information about the frequency of drug use before treatment or whether the client has accessed treatment before.

Because data collections are designed to provide specific information for policy and program planning, the variety of elements in other collections should be considered in this context and not as a guide for what the AODTS-NMDS should contain. That is, the purpose and use for the AODTS-NMDS should determine the content, in consultation with stakeholders.

The literature review and consultations both identified similar concepts that would ideally be captured in an AOD collection. These concepts have been organised according to the degree of support they received, from most to least:

1. alignment with the National Drug Strategy (NDS)
2. identification of funding sources
3. description of treatment intensity
4. description of mode of treatment
5. reporting of waiting times and delays in service.

### **Alignment with the National Drug Strategy (NDS)**

At a minimum, stakeholders expressed that the content of the AODTS-NMDS should reflect the priorities of the NDS. This may require more demographic information, changing the counting rules to focus on client registrations or introducing capacity to count individual clients to measure flows.

### **Identification of funding sources**

All stakeholders and the evaluation of the NDS 2004–2009 identified the lack of information about services funded under the strategy as problematic. Almost all stakeholders wanted to

be able to differentiate between the episodes funded by their respective health authority and those funded by the DoHA, as well as some information about what the treatments being funded actually are.

Further, a breakdown of programs offered within single agencies was considered useful, especially where specific treatments have been funded.

Whether it is important to identify specific funding streams or if it is a matter of identifying funding sources in general, is a decision for the DoHA and the IGCD; for example, identifying whether an agency is funded through government grants, philanthropic grants, fundraising or other business activities, or identifying the actual grant programs, such as the NGOTGP or Improved Services Measure.

### **Description of treatment intensity**

The AODTS-NMDS captures the main treatment type and the physical setting in which the treatment is delivered but there is no measure of how intense these treatments are and stakeholders felt this was important to differentiate between different service types and models of service delivery. This concept has utility in an activity-based reporting model and a clinical/administrative model because depending on how the element is defined, it can provide information about contact hours and the resources required (staff, space and so on). Differing intensities of treatment may also be correlated with different treatment goals and outcomes, which may be of interest to the clinician, agency and funders. The ways in which treatment intensity could be captured are dependent on what these data are intended to inform; that is, either for costing or service planning purposes.

### **Description of mode of treatment**

Related to treatment intensity, this concept is about how services are delivered. The combination of treatment type and setting provides no information about how treatment is being delivered.

While at the inception of the collection treatments may have been provided in a limited number of settings and predominantly in person, the use of increasingly diverse media to reach a wider population and engage with specific cultures means that the collection no longer captures adequate information to describe the way in which services are delivered. This lack of information further limits agencies when reporting their services, and where the data are used to inform policy and planning restricts the decisions that can be taken.

This concept could include capturing information such as web, telephone and video conferencing modes of delivery which, in combination with the treatment type and setting, provide greater detail about the treatment being provided. For example, information about counselling offered in a residential treatment setting becomes more useful if we can also see that it was delivered by telephone. In this way, treatment agencies that offer these services need not be physically located where they deliver treatment and resources may be allocated accordingly.

The concept of mode may also provide an opportunity to capture treatment types that are unreported in the collection, such as therapeutic communities. Currently, these services may report their treatment type as rehabilitation in a residential setting and their data are reported the same as less intense services with a different focus. Considering the difference in resources required to operate therapeutic communities, being able to differentiate between these and other data may be useful. Similarly, differentiating between counselling types and outreach services may also be useful and the concept of mode of delivery may be one such way of achieving this.

## **Reporting of waiting times and delays in service**

All stakeholders articulated a need for having information on the time between client contact with an agency and the time when they actually begin treatment. In some jurisdictions this information is collected and the majority of agencies report through their peak body that they also collect this information, however the different service types across the country mean that developing metadata for this concept would be difficult. There is also some requirement for a standardised process of contact and referral. Outsourced or brokered assessment procedures, where services are funded to provide assessments as their primary treatment type, pre-treatment services that aim to keep clients engaged until they are able to enter treatment, and triage practices where agencies support clients to access other services until the agency is able to accept them all, complicate the way in which this concept could be defined. Regardless, some measure of the work that can or cannot be done before clients enter treatment was viewed as valuable for policy and planning purposes.

## **Governance and strategic direction**

This review has created an opportunity to address the governance structure and decision-making processes related to the AODTS-NMDS. Given the pending release of a new NDS, the following discussion outlines the broad aspects of governance and strategic direction.

### **Collection direction**

All stakeholders agreed that the collection should reflect national policy relevant to AOD treatment and that currently, the responsibility for setting this policy rests with the IGCD and the DoHA. Given that each state and territory develops their own AOD and mental health strategies and related data collections, the national collection should reflect the national strategy and provide the DoHA with all the data it requires to make national decisions regarding policy, program and service planning.

As there is the potential for AOD services to become centrally funded under the national health and hospital reform agenda and the impacts of this development on planning are unknown at this time, it is difficult to determine whether policy setting and data requirements will remain the responsibility of the IGCD and the DoHA. What is clear is that the AODTS-NMDS Working Group, as an operational and technical body, is an inappropriate body for setting the strategic direction of the collection without some guidance from a policy setting authority.

### **Relationship between the IGCD and the Working Group**

All IGCD representatives and Working Group members expressed satisfaction with their relationships and this section does not comment on this interaction but rather the formal ties between the two bodies.

The AODTS-NMDS has not, and does not, exist in the formal committee and Working Group structure of the IGCD (National Drug Strategy website). The lack of a technical link and formally recognised relationship makes communication between the bodies complex, and has implications for data development as a recognised national subject matter body is required to submit a business case to the NHISSC for approval of NMDS modifications.

When the IGCD first established the AODTS-NMDS Working Group in 1999, there was an explicit requirement that members of the Working Group be appointed in their capacity to make decisions and commit their jurisdictions to action (AIHW unpublished). Since the collection has been formalised and has continued to operate without major disturbance,

representatives from each jurisdiction have been from increasingly operational areas with varying decision-making capacity. Consequently, there may be many layers of hierarchy between the Working Group member and the IGCD representative.

Given the increasingly operational nature of the Working Group, there has also been a trend for more technical and data management personnel to attend Working Group meetings. This has been supported by changing terms of reference to reflect the then membership of the Working Group instead of dictating it. Members tend to focus on the practical aspects of data development such as systems capacity and lead time as well as the resources required to undertake such changes, before consideration of broader concepts by the IGCD. Though these are important issues to consider, they have become a driving force in Working Group discussions.

There is no formal communication mechanism between the Working Group and the IGCD. The Working Group submits a work plan, reviewed strategic plan and updated terms of reference to the IGCD annually but it is unclear whether these plans are tabled for discussion or noted as no comments are received. The Working Group member for the Department provides an update on IGCD resolutions and discussions, however this is not formalised in the operating rules. It is assumed that should the IGCD wish to engage with the Working Group, it would contact the DoHA, though this is also not formalised and many, but not all, Working Group members are privy to IGCD discussion before Working Group meetings.

IGCD representatives have expressed a need for greater involvement with the Working Group, including setting the strategic direction, approving work plans that operationalise the strategic plan, appointing members and monitoring progress.

### **Communication between the IGCD and the AIHW**

The DoHA funds the AIHW to provide secretariat support to the Working Group as well as expert services and support for data development, analysis and reporting. Since the IGCD established the AODTS-NMDS Working Group in January 1999, the AIHW has had no direct link with the IGCD, using the Working Group member from the DoHA to communicate with the IGCD.

### **Relationship between the Working Group and peak bodies**

The Working Group terms of reference at Appendix 1 describe members as the data custodians or data managers in each jurisdiction and their role to be 'providing data according to agreed formats and timeframes, participating in data development related to the collection and providing advice to the Working Group about emerging issues which may affect the AODTS-NMDS.' It is this last point which requires clarification.

The terms of reference contain no definition for 'emerging issues' nor do they explain what effects on the AODTS-NMDS are considered important to discuss. The ambiguity of this description allows for multiple interpretations.

What has become apparent through recent projects undertaken by the Working Group is that consultation with relevant stakeholders, including peak bodies, agencies and the individuals who access AOD treatment services, is important. The consultation process for this review highlighted areas for improvement in the communication between Working Group members and the peak body in most jurisdictions. The current terms of reference and operating rules do not provide any basis for requiring consultation with, or representation of, these organisations.

As Working Group members are employees of a jurisdictional health authority, they are first and foremost representatives of these organisations. Depending on the structure of the AOD service system in their jurisdiction, they may or may not engage with the non-government sector and to varying degrees. The extent of engagement is usually determined by the funding relationship between the two sectors; that is, where the government funds a non-government service, they have a specific interest in their data, however where they do not they may not have much interest in or knowledge about these services.

At Working Group meetings, members are often asked about the developments in their jurisdictions including about peak bodies and agencies. Through the consultation process, peak bodies expressed that they would like to engage more with their Working Group member and to support them in their role by providing them with information directly from the agencies they represent.

In most jurisdictions, AOD peak bodies are considered to be the major representative body for NGO AOD agencies, though not all agencies in this sector are members of their peak body. In some jurisdictions, the peak body actually participated in the AODTS-NMDS by supporting agencies to report, hosting the software necessary for reporting and assisting agencies with compliance. Through the Improved Services Measure, some peak bodies were funded to enhance their capacity to support agencies in this area.

Currently, unless the Working Group takes a decision to, there is no requirement for Working Group members to consult with stakeholders. Given the crucial role of peak bodies in supporting agencies to comply with reporting requirements and, in some jurisdictions, their actual submission of data, it may be prudent to consider how to engage more effectively with peak bodies.

### **Review, evaluation and auditing**

Given the initial purpose of the collection was to monitor and evaluate the National Drug Strategic Framework, review of the collection in line with the renewal of each NDS would ensure that the collection remains policy relevant. This should be formalised in some way with a mandated review cycle.

### **State and territory collection systems and priorities**

Though not within the control of the AODTS-NMDS and its related governance structures, the national collection is closely linked to those of the jurisdictions because it is a subset of these collections. As a result, the processes that are involved in creating jurisdictional collections have a direct impact on the accuracy, quality and timeliness of the national collection. The international experience is that national and international collections usually comprise the minimum common elements of the states, provinces and countries that contribute their data (EMCDDA 2000; UNODC 2006). They draw on simple processes, usually paper-based systems, for reporting minimum data to a central repository for collation, analysis and reporting. The Australian system also draws on the various collections of jurisdictions and a combination of electronic and paper-based systems, though all data are transmitted to the AIHW as the central repository electronically.

In consultations, stakeholders expressed confusion and concern about the differences between their jurisdictional collection and the national collection, the complicated steps required to access their own data, inaccurate and lost data and the burden of supporting various data collection and reporting methods based on the jurisdiction and the sources of their funding. Peak bodies and agencies spoke of their frustration with the impact that

system changes have on service delivery and confusion as to what are national, state or territory priorities in regards to what is collected.

Some jurisdictions have also experienced difficulty in identifying those agencies that fall within scope and are complying with reporting requirements within and between collection periods. This is due in part to the complexities of Commonwealth and state/territory funding arrangements but also because of inherent complexities with state and territory information systems. Consequently, there is no definitive list of agencies that are expected to report within a collection period.

## **Concepts that require further consideration**

### **Counting clients and data linkage**

The inability to count clients was identified as a limitation before the commencement of the collection, and persists as a limitation of the data set. This means that it is impossible to estimate stocks and flows and carry out person-level analyses. There are multiple ways in which the objective of counting clients may be achieved, however the sensitive nature of this collection, often about clients engaging in illegal behaviour, means that only a few methods will be acceptable to the individuals, agencies, sector and governments.

In 2008, the AIHW undertook a project (the Enhancement Project) to investigate the feasibility of introducing a statistical linkage key to the AODTS-NMDS and concluded that it was possible, however there are political and practical issues, such as privacy concerns and systems capabilities, that need to be addressed (AIHW 2009b). When the report was tabled with the IGCD, the IGCD agreed to in principle support of data linkage (specifically the statistical linkage key 581(SLK-581)) as a means to estimating individuals within the collection, subject to resolution of concerns raised in relation to privacy and resource implications.

Literature on the use of statistical linkage keys has predominantly focused on the aged care, homelessness and other community service sectors, as collections in these areas have implemented a standard statistical linkage key (the SLK-581) and there appears to be greater motivation to utilise the information that data linkage within and across these collections can provide.

There were varying degrees of support amongst review stakeholders for the introduction of statistical linkage; the majority querying the DoHA's potential uses of linked data and the DoHA's intentions rather than specific privacy concerns. Unlike the Enhancement Project, review consultations provided peak bodies and some agencies the opportunity to discuss their views about various aspects, including the concept of data linkage. No-one opposed the introduction; the majority were in support of its introduction as soon as possible, and all were enthusiastic about the analysis potential. There was concern that the data may be used at a state level with unintended negative consequences – for example, the administrative checking of individuals – though advice from the Statistical Linkage unit of the AIHW indicates that the margin of error inherent in the SLK-581 would prevent this. That is, concerns were related to linkage that may occur within the jurisdiction and not nationally. Researchers also supported the introduction of data linkage as a means of estimating individuals' treatment and treatment patterns within and between years among other research potential.

At the IGCD level, some representatives expressed views that data linkage (or counting clients) requires justification at the national level. Representatives may have supported the

concept in principle, as at the IGCD meeting of 10 March 2010, but referred to system limitations, financial burden, limited expertise and unclear purpose as obstacles to national implementation. While most jurisdictions can already estimate or accurately count the number of individuals who access treatment in a given year, some do not and expressed no desire to start. Those that currently have this capacity were happy to provide this aggregate number for national analysis but not the ability to estimate this from unit records. From the consultations, the main reason for reluctance to allow this ability to compare nationally was the general resistance to comparisons between jurisdictions and the potential for misinterpretation related to differences in service delivery models and service systems, including funding, which may become more apparent with this technique.

It is clear from this review that opposition to data linkage is not at the operational or peak body level. The actual elements required for the statistical linkage key are simple and relatively easy to explain (they already exist within the national data registry and are used in numerous other collections), however the argument for national implementation has not been made successfully at the IGCD level.

The process of securing agreement to introduce the elements necessary for the statistical linkage key need not be complex but does require clear direction, demonstration of need and adequate resources to implement it.

### **Relational elements**

Relational elements are those items in the collection that are dependent or antecedent to others. For example, method of use is related to the principal drug of concern. These elements present a special complexity to the AODTS-NMDS because their correct interpretation and collection relies on consistent data collection techniques, including the order in which elements are collected. Therefore, the issue of relational elements is an issue of definition as well as the jurisdictional systems that support data collection.

The AODTS-NMDS is most often a subset of the data collection within a jurisdiction and therefore subject to the collection procedures of the jurisdiction collection. These vary from paper-based systems with uniformly designed documents to electronic client management systems that extract the required data. As a result of this variation, the way in which data are collected, including the order, impacts on the quality of the collection because some elements are considered to be relational when they are not and vice versa.

Where data are collected directly from the client, a questionnaire/interview style is usually used, either with the respondent completing the form or with the clinician/AOD worker filling in the provided answers. How much information and guidance clients are provided with when completing a questionnaire is unknown, as is the degree of interpretation provided by clinicians and AOD workers. Further, some agencies use previously supplied information for subsequent client episodes while others complete the full data collection at each episode; some rely on the clients' responses while others verify them with formal sources of information, such as drug tests and formal referrals.

Related to the way in which the data are collected is the issue of what order they are collected. The elements 1) principal drug of concern, 2) method of use and 3) injecting drug use status (IDU status) are collected for clients seeking treatment for their own drug use. When self-completed in the above order, the client may nominate, for example, heroin as their principal drug of concern, and injecting as their method of use and identify as a current injector. They may have interpreted the IDU status as related to their principal drug of concern and method of use, however should the client nominate alcohol as their principal drug of concern and ingestion as their method of use, they may not identify as a current

injector, because they do not inject alcohol or may not feel their injection of other substances is what is being asked for. If the order is changed, to have IDU status collected before any information about the principal drug of concern and method of use, we may be able to improve reporting accuracy as it is less likely that clients (or clinicians) will associate this element with others. Other similar instances in the current collection are discussed in the element analysis (Appendix 3) and this issue should be considered during discussion of any modifications to the collection.

The complexity that this issue presents for the AODTS-NMDS is that no control of the way in which data are collected can be exercised by any single authority on the national collection; rather consensus must be reached on the best, most practical and consistent way for data to be collected in each jurisdiction. Similar situations have been encountered and addressed by other collections, such as the Disability Services NMDS, where a standard document was developed and implemented by all in-scope agencies (AIHW 2009a). The potential for such an approach in the AOD sector could be considered, though the funding and administration arrangements for AOD treatment differ markedly from disability services.

### **The impact of referring to standard classifications**

The AODTS-NMDS refers to four classifications instead of providing code sets for three elements; specifically the Australian Classification for Drugs of Concern (ASCDC) for the principal and other drugs of concern, the Standard Australian Classification of Countries (SACC) for country of birth, the Australian Standard Classification of Languages (ASCL) for preferred language and the Australian Standard Geographical Classification (ASGC) for location of treatment agencies. Australian Standard Classifications are developed and maintained by the Australian Bureau of Statistics in accordance with international standards.

The benefits of referring to these classifications is that data collectors have the most complete set of codes available for them to capture data accurately and that the data element does not require modification when the classification is updated and comparability across data collections.

The costs of referring to standard classifications are that it is difficult to keep all data collectors abreast of changes to the classifications; it is cumbersome and time-consuming to incorporate changes in some jurisdiction data collection systems; and many jurisdictions have implemented short lists for agencies to use instead of referring to the full classifications.

Using the ASCDC as an example, another problem with referring to classifications is that there are times when they do not remain current and agencies are not able to report on changes within their service delivery as they happen. This feedback was received from some IGCD representatives as well as peak bodies, researchers and agencies who want information about new and emerging drugs, such as mephedrone (colloquially called 'meow' or 'miaow'). Because classifications are not updated as often as new drugs become available, there is lag between the experience of treating clients who are using the substance and the ability to report it. This is further complicated by systems that rely on short lists that categorise substances at the most general level and omit finer detail.

In addition, issues arise if only part of the available code set is used. In the AODTS-NMDS, only the four-digit codes for substances are used, though there are supplementary codes available to indicate the form of the substance that was used. This detail may be considered useful for planning purposes, such as addressing risk and harm reduction, specifically if the form of the substance requires injection as opposed to methods of use considered to be safer.

## **Current element analysis**

A complete analysis of the current collection is provided at Appendix 3.

## **Information relevant to treatment provision**

The literature review and consultations both highlighted areas of the collection where information is lacking. The most commonly raised issues are listed below with a brief discussion of the agendas to which they relate, concepts that underpin them and potential ways of capturing the information.

### **Demographic information**

#### **Education**

The education attainment of clients was considered important by many stakeholders across research organisations, peak bodies and agencies. Many agencies already collect this information but do not report it and no jurisdiction routinely requires this information.

Education status has been linked to treatment outcomes in some literature and may provide information relevant to service planning; for example, the development of information and education in various formats.

There is an Australian Standard Classification of Education (ASCED) which could be utilised to provide consistency and this should be considered in the context of the costs and benefits of referring to a standard classification as discussed earlier. Should this classification be adopted, this element would then be comparable to other data sources.

#### **Employment status and history**

Employment status was raised as an important issue for many stakeholders as an indication of several things. For some stakeholders, a client's ability to maintain employment may indicate their level of functioning relative to their substance use, propensity to engage in risky behaviour to support their substance use and a potential support system. For other stakeholders, employment status may provide information about potential areas of intervention and service delivery as well as interventions and support that could be provided in particular industries.

Employment for families with children and individuals with a disability are specifically identified as priority areas in the social inclusion agenda. Given the complexity between substance use and maintaining stable employment, the AODTS-NMDS is positioned to provide valuable information in this area.

This concept is not routinely collected by jurisdictions, though a small number of agencies indicated that they collect this information internally and do not report it.

Employment status should not be confused with the concept of income source; a more commonly collected data element. If it is income source that is the issue of interest, different metadata would require development to capture sources such as government benefits and annuities, for example.

#### **Location of clients**

While the geographical location of agencies or their administration centres is captured by the AODTS-NMDS, the geographical location of clients is not. This limits the ability for policy makers and program planners to design service responses to meet client needs. The postcode of usual residence is collected by the majority of jurisdictions though the metadata do differ.

A priority of the social inclusion agenda is to address 'locational disadvantage' and without this information AOD treatment services are not able to address this need. Further, the AODTS-NMDS cannot inform analyses on access to services; that is, it is not possible to tell how far an individual travels to access a treatment service.

Postcode may be the most appropriate element to capture this information and an element capturing client-based geographical information has been registered in the health, community services and housing assistance data dictionaries. This element refers to the location of usual residence and is left blank when the client reports an overseas, unknown or no fixed address. Given the limitation of this element to capture homelessness, this element is not ideal. The concept of homelessness is discussed later in this section.

### **Living situation**

This is one of the more complex issues to unravel as there are many interpretations of living situation and purposes for collecting this information. Living situation, family circumstances, children and involvement with child protection were all raised as part of living situation discussions.

The literature review, as well as the current policy environment, has highlighted the dearth of information available on children within the context of substance use, abuse and treatment. Stakeholders expressed that knowing how many dependent children a client had was useful in not only planning their individual treatment but also establishing support after treatment, lobbying for resources to support parents in treatment and to liaise with appropriate services, such as child protection. Another approach is to collect information about children within the context of the risks posed by their parent using substances, conceivably as a flag for child protective services. In some jurisdictions, AOD services are mandated to report parents who access their services and have children who are considered to be at risk. No element is currently registered in the AIHW's METeOR system that captures the concept of dependent child/ren.

Completely different to the idea of capturing information about children, is that of information about the client's living situation. Homelessness is discussed separately to this concept but is closely related. Living situation may be about the other occupants of the client's residence, the number of people they reside with, the relationship between the client and other occupants or the client's marital status. Elements that captured this information were presented to the Working Group in August 2008.

To decide which element would be best for the collection to meet its intended objectives, the purpose of the data to be collected must first be determined. From the available information, data on the number of children in the care of the client accessing treatment appears to have the most policy support and a data element would require development to capture this information. Regardless of the element and purpose selected, a flag for current involvement with child protective services could be developed for implementation in the collection.

### **Homelessness**

The homelessness white paper, social inclusion agenda and the policies of several jurisdictions all aim to minimise the experience of homelessness in the population. All stakeholders regarded the impact of homelessness in the AOD sector as profound; limiting the capacity of clients to access and remain in treatment as well as sustain their intended path of recovery after treatment. Some states have implemented programs to address the white paper policy of 'no exit to homelessness' whereby clients who access government-funded services, including statutory health and correctional facilities and AOD treatment services, must be discharged to stable, medium-term to long-term accommodation. This

requirement means that AOD agencies must provide housing support and referral services as part of their operations – not necessarily as part of their AOD services, but through integration and appropriate referral. As a consistent and core activity, it may be useful to report this at the national level. Though the AODTS-NMDS is not a data source for measuring housing access, it may be considered to be a useful indicator within the AOD sector and particularly for policy responses within the treatment population.

Most jurisdictions collect information on the housing status of AOD clients, and peak bodies and agencies all collect this information, though there are several permutations of the elements and points in time at which these data are collected. There are several existing registered data elements in the community services and health data dictionaries, however not all capture the concept of varying degrees of homelessness.

There is substantial work currently being undertaken as part of the Australian Government's national approach to reducing homelessness (FaHCSIA 2008), including the development of headline indicators to measure success against the goals of halving homelessness and offering supported accommodation to all rough sleepers by 2020. In addition, a new homelessness data collection is being developed, with proposed data linkage capacity, to better understand pathways into and out of homelessness. It is likely that this work will have a significant impact on other collections; for example, requiring measures of homelessness to allow for cross-collection analysis or the capacity to link data sets.

## **Health status**

### *Comorbidity*

The co-occurrence of mental illness and problematic substance use was identified as an important issue for the AODTS-NMDS soon after its inception in 2002. The Improved Services Measure (discussed earlier in this report) as well as the social inclusion and homelessness agendas all recognise the complex relationship between mental health, general wellbeing and social functioning. Stakeholders acknowledged that they desire different information about comorbidity, varying from a general indicator, to results from standardised tools, measures of severity and diagnosis. The Enhancement Project (AIHW 2009b) examined how comorbidity may be reported in the AODTS-NMDS and concluded that a general indicator of mental health may be most useful, given the diversity of practices between agencies. Also, what is required at the national level may be different to the information required by agencies, states and territories. A general indicator, as recommended by the Enhancement Project, could be developed with the capacity to capture all this information.

Inclusion of mental health information in the AODTS-NMDS was not supported by all stakeholders. Stakeholders at various levels were not convinced that national information about mental health has a place in the AODTS-NMDS, especially when elements directly related to substance use are not collected.

### *Pharmaceutical use*

The issue of pharmaceutical use was raised in the literature and by stakeholders as two distinct concepts: the use of pharmaceuticals while accessing treatment, and the problematic use of pharmaceuticals, as opposed to illicit drugs, for which treatment is sought. The former will be addressed in this section while the latter will be discussed in the following section.

Agencies identified the need to know what other medication clients are using when they access treatment, whether or not they consider them to be a drug of concern, for risk management, duty of care and treatment planning purposes. Other stakeholders considered

this information important for policy and planning purposes, especially where the diversion of prescription pharmaceuticals is of concern.

This may have been identified as a need for the collection because the language used to describe other drugs of concern can be difficult to relate to for clinicians/AOD workers and clients, in that other substance use may not be a 'concern'. Also, there may be a need to know what other substances the client is taking, in addition to other drugs of concern.

Not generally identified by stakeholders but apparent in the literature is the use of prescription pharmaceuticals to treat comorbid physical conditions, and subsequent misuse of these substances, especially those that are used to treat pain.

As with all data elements, the purpose for collecting information about the use of prescription pharmaceuticals needs to be clearly established for the correct metadata to be developed.

#### *Blood-borne viruses and sexually transmissible infections*

The BBV and STI status of clients is collected by most agencies but has little support from other stakeholders. The national importance of this information would have to be investigated considering the AODTS-NMDS has not been named as a data source for the indicators developed as part of each national strategy.

#### **Substance use and treatment history**

As a collection about AOD treatment, some stakeholders expressed concern that there is no national measure of substance use within the treatment population and limited information on substance use before seeking treatment. Similarly, for those clients seeking support for the substance use of another person, there is no indication of what substance or how much that person is using. The majority of stakeholders would also like to see some indication of treatment history, in addition to any potential data linkage ability.

#### *Frequency, quantity and recency of use*

Many, though not all, stakeholders expressed interest in having a national indication of how much and how often people who access treatment use their principal drug of concern before entering treatment. Most agencies collect this information to inform treatment plans, especially where risk management is necessary – for example, in withdrawal and detoxification programs – and some jurisdictions have capacity to report it. National clinical guidelines for treatment of alcohol and opioid dependence refer to treatment planning that takes into consideration the level and frequency of the client's use, though the AODTS-NMDS does not contain any measures of these. This concept could refer to the principal or other drug/s of concern depending on the purpose.

There are also treatment types where prior use may be less relevant, such as where the client is seeking support for the use by another person, or a client who is entering rehabilitation or counselling services after a period of abstinence. Local areas and regions within jurisdictions have used similar information to tailor treatment responses and peak bodies state that they have supported agencies in preparing funding applications for specific treatment types and resources using data such as these. Researchers have expressed a keen interest in these data, however the relevance of this information at a national level is unclear.

Categories of frequency and quantity (the value domains) would be dependent on the purpose of the element, however consideration should be given to using the same categories as in other data collections, such as the National Drug Strategy Household Survey (NDSHS). Registered data elements exist for capturing information about the frequency of alcohol and tobacco use but not for other classes and types of drugs.

The temporal aspect of this concept (for which period the information is being collected and when it is collected) requires clarification and raises the idea that the level of substance use during a treatment episode may also be of interest. This information has been flagged as a potential data source for an outcome indicator, where substances use at cessation is compared with that before treatment. Timing of use relates to the length of time between the client accessing treatment and the last time they used a specific substance, usually the principal drug of concern. No metadata exists for this concept.

#### *Prior treatment*

Though data linkage may provide an estimate of the number of individual clients within a specified period, as well as information about how many treatment episodes they have completed either concurrently or consecutively, there are limitations to this technique. Many stakeholders supported the concept of capturing information about clients who have accessed, participated in or completed prior treatment episodes. The limitations of data linkage in this respect are that episodes in agencies that are out of scope of the collection (in patient, private or pharmacotherapy agencies), episodes that have occurred before the introduction of data linkage or in agencies outside of Australia are not captured.

Supporters of this concept advocated a flag for prior treatment with many also supporting more detailed information, such as the principal drug of concern and treatment type of this previous episode and how many previous episodes there have been.

In lieu of data linkage, this flag affords an opportunity to analyse trends for multiple treatment episodes. In addition to data linkage, this information can provide a more comprehensive picture of treatment, especially where it is accessed outside of the scope of the collection.

While some treatment agencies collect these data, they are not collected consistently. There is currently no registered data element that captures this concept and development of metadata would be required.

#### *Source and price of drugs*

This information is usually collected by population surveys, such as the NDSHS. Its utility in the treatment population may be limited by concerns about data quality, given the illegal nature of some substance use. Further, clients may not be able to recollect this information to report accurately. There are currently no registered data elements that capture this information though there are categories in national surveys that could inform metadata development.

#### *Pharmaceutical misuse*

This concept refers to increasing misuse of prescription pharmaceuticals, specifically opioid analgesics (Dobbin 2001). Through appropriate use of the ASCDC, including the full code set, the detail required to capture information about prescription pharmaceutical use may be captured in current elements, such as principal and other drug/s of concern.

#### *Smoking status*

One of the three major foci of the national preventative health strategy is to reduce smoking prevalence. Given this strong national focus and other related activities such as taxation measures and advertising campaigns, the collection of these data may be of sufficient importance to include in the national collection. Agencies wanted to include this element to justify their efforts to secure resources to support clients to cease tobacco use as well as modify their services to become 'smoking unfriendly'. Researchers and IGCD representatives

shared an interest in this element because of the high proportion of AOD treatment seekers who smoke and the associated burden of disease.

There are several data elements that have been registered in the health data dictionary that capture different aspects of smoking status; most include a measure of frequency and some include a measure of quantity.

Adoption of an indicator of smoking status would be in line with current national policy and could draw on existing data elements.

#### *Use of unbranded tobacco*

The use of unbranded tobacco is of interest to some stakeholders because of potential policy implications. If this concept is considered important to capture, there is potential for it to be combined or related to smoking status and a measure of frequency. Where possible, categories should be compatible with other data sets such as the NDSHS. There is currently no registered data element that captures information about unbranded tobacco in any data dictionary and appropriate metadata would have to be developed.

### **Service delivery**

#### *Expanding code sets*

The inconsistency between the AODTS-NMDS and the collections in states and territories was a source of great concern amongst stakeholders, specifically because the number, range and diversity of options that treatment agencies can report for many elements are restricted in the national collection. There is confusion as to why the collections differ so markedly and general unease about data quality given the amount of recoding, mapping and interpretation required to report jurisdiction's data at a national level. Two data elements that presented the greatest cause for concern were 'source of referral' and 'reason for cessation'. These elements are discussed in detail in the current data element analysis (Appendix 3).

Stakeholders were generally supportive of reporting a greater level of detail at a national level, including such referral sources as workplaces, schools and child protection services, and reasons for cessation including unsuitable for service.

Changes to these elements would require the development of new or modified metadata and engagement with NHISSC.

#### *Standardised tools*

Clinical practice within the AOD sector is highly variable and not all agencies utilise standardised tools for many aspects of their treatment practices. As a result, collecting information about treatment practices is difficult. There were mixed responses to the idea of introducing standardised approaches to some practices, such as assessment, as many services as well as their peak bodies viewed this as an encroachment on their autonomy. Further, some services have been funded to provide specific treatment types within identified frameworks and changing their practice would require a renegotiation of their funding arrangements.

The concept of using standardised tools from a data collection perspective is to produce consistent data and remove one variable that impacts on data quality, as all participants are doing the same thing. One step before implementing standardised processes that may provide the desired consistency in data collection is identifying those episodes where a standardised tool has been used.

To assist those agencies and jurisdictions that do use standardised tools, it may be useful to consider developing metadata for these tools to support consistent implementation and reporting, should they choose to do so.

#### *Referrals during treatment*

All peak bodies and researchers and the majority of IGCD representatives support the collection and reporting of referral made during treatment episodes. This information provides detail about the activity of the agency, the services that the client has accessed and the degree of support the client is receiving. This information has also been used to monitor related initiatives such as allied health services, housing and mental health services, which may be accessed during a treatment episode.

While most agencies collect this information in client files, it is rarely reported to the jurisdiction. There is currently no registered data element for this concept though there are elements to capture referrals for housing assistance, ophthalmology (national indicator) and service types in the assisted housing program data collection, which may inform metadata development.

#### *Shared care*

'Support and case management only' is a main treatment type within the AODTS-NMDS and, from consultations and the literature, one of the least understood. Many stakeholders did not consider this to be treatment but a method of coordinating the activities that constitute treatment, however, as many agencies provide these services, they are in scope for the collection.

Shared care is the concept that many services participate in a single treatment plan for an individual. They may provide a variety of services or just one and a client may be accessing multiple agencies at any one time in one episode. Currently, where an agency reports 'support and case management only' as the main treatment type, they are unable to report any 'other treatment types' they may be offering, such as counselling or pharmacotherapy services. Feedback from stakeholders was that this is not an accurate representation of their practices. Some stakeholders also acknowledged that those agencies that provide a single component in a treatment episode of case management are not being identified as participating in a shared care model, contributing to the number of episodes for the same client within a collection.

The idea of flagging those services that are participating in a shared care arrangement was supported by the majority of stakeholders to more accurately reflect the way in which agencies deliver treatment. This information may be useful in informing the planning of different agencies, including their treatment types and locations, to offer a continuum of care or comprehensive model of care.

There is currently no registered data element to capture this concept, however there is substantial metadata for the concept and value domain within the health and community services data dictionaries.

#### *Treatment goals and outcomes*

The most commonly raised concept considered for inclusion to the collection in some form, but that no stakeholder could agree to, was the reporting of treatment goals and outcomes. The diversity of treatment types, modes and philosophies in the AOD sector means that identifying and agreeing on common goals is difficult. Further, the way to capture this information and report it in a meaningful and useful way is even more complex.

There were several peak bodies that were supportive of an outcome measure in principle but not for inclusion to the AODTS-NMDS. Feedback from these stakeholders was that there was potential for this information to be used as a performance management tool within agencies that would incentivise poor reporting practices and compromise data quality. As an alternative, these stakeholders did support measuring outcomes separate to the collection.

Before discussing these concepts, it is important to acknowledge that this is by no means a comprehensive examination of this issue. Indeed, this concept could, and has, become a discrete topic in the literature.

Treatment goals and the extent to which they are met (outcomes) are not captured by the AODTS-NMDS. The closest concept contained in the collection is 'reason for cessation' and may be considered a proxy for outcome by some researchers and services given there is no record of the intention of treatment and the variability inherent with this element (see the current data element analysis at Appendix 3).

The literature suggests that it is important to identify the subject of the outcome, be it the outcome for the client, the society or the government (Ali et al. 1992). Each of these bodies is important and values different things about AOD treatment. There is also variability within each of these sectors, in that there is no single outcome measure that can tell the whole story of the success (or otherwise) of the treatment and this is largely based on an appropriate measure being chosen for the treatment type. For example, the goal of a detoxification episode may be a specified period where the client abstains from use of a specific drug of concern. The outcome of this episode may be success or failure. However, this cannot be applied across other treatment types. For example the goal of counselling may be behaviour change such as anger management related to substance use, and the goal may be reduction in use rather than abstinence, making the outcome measure for this treatment type different to the previous one. Ali et al. (1992) provides a comprehensive examination of this issue with some suggestion as to how to approach identifying goals and establishing outcomes relevant to the AOD treatment sector.

Before a measure of outcome can be discussed, the goal of treatments based on agreed definitions of treatment should be established.

## **Products and processes of the collection**

The process of collation, cleaning, validation, analysis and reporting is the responsibility of the AIHW in cooperation with each jurisdiction. Stakeholders were generally pleased with the products emanating from the collection.

### **Time between data collection and reporting**

All stakeholders acknowledged the considerable time required to make national data publicly available. This is by no means a situation unique to the AODTS-NMDS, which compares favourably to other collections, some of which take in excess of 24 months to produce a national data set from the end of the relevant collection period.

As production of the national data set is entirely dependent on the finalisation of data submission from each jurisdiction, any steps or processes that can minimise iterations and improve accuracy should be considered.

### **Validation of data**

The process to clean and validate data was identified as a major obstacle for timely data submission by jurisdictions. As the AODTS-NMDS is a subset of most jurisdictions'

collections, some mapping and recoding is required. In addition, the AIHW requires data to conform to certain formats for transmission. The AIHW is currently developing a web-based data receiving and validation tool that is intended for use for data submission in future.

## **Products**

Currently, the Working Group, as data custodians, provides advice on the content of products emanating from the collection. Though the majority of stakeholders were pleased with the range of products currently available, consultations have shown that these products may not necessarily meet the needs of all stakeholders and several potential solutions have been proposed. Internationally, data appears to be available online in the form of data sets (SAMHSA 2010), published reports and tables (EMCDDA 2000; UNODC 2008b) and interactive tools such as data cubes and maps. Suggestions included searchable electronic tables and summary reports.

## **Data requests**

Most stakeholders, while not aware of the specific processes involved in making data requests, were aware of the contact point should they require any information about or from the AODTS-NMDS. Generally, stakeholders were satisfied with the process timing and, where relevant, cost of making data requests.

## **Data use in media, briefings, research and published reports**

All stakeholders expressed concern that AODTS-NMDS data have the potential to be misinterpreted and misused. There were suggestions that a brief guide, about what the collection can and can't be used for, be developed and circulated for use, for example, by researchers, journalists and students. Research centres expressed that clearer guidelines for the citation of data, especially data sourced from internet published tables and data cubes, should be developed and circulated.

## **Marketing the collection**

All stakeholders commented that the collection should be better marketed and have a greater profile in the AOD sector. Many suggestions were made including conference presentations and presence, advertising in sector-relevant publications and journals, presentations at agency and sector forums in states and territories, and more prominent media releases.

## **Workforce and agency information**

While information about the operation of AOD treatment agencies does not currently form part of the AODTS-NMDS, many stakeholders identified a need to not only collect and report these data but to recognise and mitigate the consequences that some of these features have on the collection. It is out of the scope of this review to examine these characteristics in detail and only a brief discussion of each follows.

## **Staff turnover**

Like many sectors, AOD services experience a high level of staff turnover which negatively impacts on both service delivery and data collection. Peak bodies and agencies acknowledged the knowledge gap in data collection left by experienced clinicians and workers about data collection when they move on and the unintended impact on agency data collection and reporting. Other stakeholders at various levels also recognised that quantifying this issue may in part assist in addressing it.

## **Qualifications**

While many jurisdictions have embarked on introducing minimum qualifications or quality assurance and compliance programs, there is still great diversity in the qualifications held by workers and clinicians in the AOD sector. Stakeholders considered that some degree of familiarity and training with data led to greater regard and investment in data collection which led to improved data quality. Also, all levels of stakeholders expressed concern with the decreasing number of addiction professionals and tertiary qualified personnel that are interested in working in the AOD sector.

## **Training**

Related to qualifications, training also refers to the learning and development opportunities provided to, and taken up by, AOD workers. In terms of the collection, the need for more tailored training was identified, in combination with data on staff turnover and qualifications.

## **Volunteer numbers**

As approximately half of the AOD treatment agencies that currently report to the AODTS-NMDS are NGOs, it may be interesting to know the proportion of volunteers providing services. This has implications for resourcing agencies as well as investigating what support agencies and individuals require for complying with data collection obligations.

## **Services offered by agencies**

To recognise the increasing diversity of agencies that provide specialist AOD services, having some measure of the services offered by AOD treatment agencies may be useful. This information need not be limited to the treatment types described by the AODTS-NMDS but could include services that are out of scope for the collection, including but not limited to housing assistance, problematic gambling counselling and allied health services.

## **Philosophy of agency**

The influence of an organisation's philosophy on their service delivery was also recognised by stakeholders as a factor in how their service reports data. For example, some philosophies may regard all substances being used as drugs of concern and report them all, though clients may not identify these substances as a concern to them. In the element analysis in Appendix 3, the elements that may be influenced by service philosophy are identified and discussed. Knowing the philosophy of the agency may provide additional information for analysts to interpret their data as well as provide valuable information for policy makers and planners, to ensure a variety of interventions are funded to meet community need.

Information that may not be able to be captured by a suite of data elements may be easier to collect by a free text method that affords room for description. For example, services with abstinence-based philosophies may be recognised as providing different treatment types to harm reduction-based services. Similarly, religious-affiliated services may be funded alongside non-aligned services to ensure clients are able to access treatment appropriate to their needs.

## **Model of service delivery**

Similar to the philosophy of the AOD treatment agency, the model of service delivery may provide valuable information for policy makers and planners. Models of service delivery are generally described in applications for funding and examples are strengths-based case management, therapeutic communities or community integrated rehabilitation.

## **Funding sources**

At an agency level, the identification of funding sources may provide information on the other activities of the agency; for example, fundraising, access to philanthropic trusts and private enterprise.

The inclusion of data on these characteristics has the potential to form a complementary but distinct data collection, should this meet policy objectives.

## **Privacy and consent**

As with all data collection, the issues of confidentiality and privacy are paramount, not only to protect the information of individuals but to enable those who use the data to do so with confidence. Currently, there are four points at which the privacy features of this collection could be publicised, strengthened and enforced.

## **Clients**

For those individuals who access publicly funded treatment to feel comfortable in disclosing sensitive, private information they must be given every opportunity to understand why their information is required, what it will be used for and what rights they are entitled to exercise. Each state and territory has differing legislation on the collection, use and storage of health information and from the consultations with peak bodies and agencies, there is varying understanding of the obligations.

## **Agencies**

Feedback from consultations is that agencies require support to understand and operate under the required privacy obligations relevant to their jurisdiction. Many agencies do not understand the relevant legislation or their obligations and consequently do not convey information to clients correctly. Further, this confusion often places AOD agencies at odds with other services and authorities because they are reluctant to share information about clients, even when this is in the client's interest. The differing legislation between jurisdictions is also difficult for national agencies to negotiate.

## **Jurisdictions**

Peak bodies and agencies expressed that they would appreciate greater support from their relevant authority to comply with privacy requirements. Related to this is the implementation of consent procedures which are required in some jurisdictions and not in others.

## **AIHW**

The *Australian Institute of Health and Welfare Act 1987* provides clear parameters for the collection, storage, analysis and reporting of data. No breaches of confidentiality or privacy have been recorded at the AIHW and all stakeholders expressed confidence in the abilities of the AIHW to comply with relevant legislation and support others to do so.

## **Review of Australian privacy arrangements**

In August 2008, the Australian Law Reform Commission released the report *For your information: Australian privacy law and practice* (ALRC 2008) which recommended 295 changes to the Australian privacy framework. The Australian Government response is in two stages, and the first was released in October 2009.

The first stage response outlines the government's position on 197 recommendations relating to:

- developing a single set of privacy principles
- strengthening and clarifying the Privacy Commissioner's powers and functions
- introducing comprehensive credit reporting and enhanced protections for credit reporting information
- enhancing and clarifying the protections around the sharing of health information and the ability to use personal information to facilitate research in the public interest.

The second stage of the government response will focus on the remaining 98 recommendations, specifically:

- proposals to clarify or remove certain exemptions from the *Privacy Act*
- introducing a statutory course of action for serious invasion of privacy
- serious data breach notifications
- privacy and decision-making issues regarding children and authorised representatives
- handling of personal information under the *Telecommunications Act 1997*
- national harmonisation of privacy laws (partially considered in stage one).

The extent to which these reports and subsequent legislation may affect current practices in each state and territory are as yet unknown. It is also unclear what interaction there may be between privacy legislation harmonisation and the introduction of individual electronic health records as part of the Government's health reform agenda.

Having identified and discussed the main themes, it is apparent that some decisions need to be made before others can be considered. These initial decisions relate to the scope, purpose and content of the collection, from a policy-making perspective; that is, what information is required for the purposes of informing policy. Subsequently, decisions can be made about the actual data elements required, how they will be defined and what policy directions they will inform.

# Conclusions and potential solutions

This review of the AODTS-NMDS has provided an opportunity to examine not only the operation of the collection within the AOD sector but to also consider the wider operation, program and policy context of AOD use and how they relate to data collection and reporting.

The AODTS-NMDS is the only collection of its kind in Australia, capturing information about AOD treatments at a national level, and is valued by stakeholders for research, policy and planning.

What has become apparent during this review is the interaction between policy and the operation of the AODTS-NMDS and that the collection should reflect and report on the policies that frame AOD treatment services. The decisions of policy makers such as the IGCD and the DoHA are outside of the responsibilities of the Working Group and the AIHW; however, these decisions guide the operational activities undertaken by both bodies. In recognition of this relationship, conclusions that are policy based have been separated from those that are operational. Greater detail and discussion of the issues contained in each of these conclusions may be found in the thematic analysis section of this report.

## Policy-related conclusions and potential solutions

### **1. There are multiple, incongruent understandings of what is meant by the term ‘treatment’ in the AOD sector**

From the literature review and consultations, it is clear that there is no single agreed definition for what constitutes treatment for AOD use nor is there national agreement on the activities that comprise treatment and that should be included in the AODTS-NMDS. States and territories have different understandings of AOD treatment and fund accordingly, providing treatments that cater for their local requirements. Creating a nationally consistent definition for treatment, for the purposes of the AODTS-NMDS, is a decision to be made by the DoHA and the IGCD, for which appropriate metadata would need to be developed by the AODTS-NMDS Working Group and the AIHW.

Related to this definition are the issues of scope and content. The decision to expand the scope (the clients and agencies that provide information) and modify content (what information is provided by these clients and agencies) is reliant on the definition of treatment for the purposes of this collection.

### **2. The IGCD and the DoHA are the most appropriate bodies to provide strategic direction and guidance for development of the AODTS-NMDS, including negotiating the relationships between relevant stakeholders**

Given that the purpose and scope of NMDSs are a decision for the policy makers, the IGCD and the DoHA are best placed to govern the collection and set its strategic direction. Related to the governance of the collection is the relationship between stakeholders in the sector, such as treatment agencies and peak bodies, and the AODTS-NMDS Working Group.

Potential solutions for this issue may be found under Governance and strategic direction (7) below.

### **3. It is an appropriate time to consider the purpose, scope and content of the AODTS-NMDS in line with the release of the National Drug Strategy 2010–2015**

All stakeholders supported the idea of a regular review of the AODTS-NMDS in line with the NDS, to ensure that it meets policy requirements and can be modified or developed to inform the objectives of the strategy. With the pending release of the new strategy, this is an appropriate time to make decisions relating to the scope, purpose and content of the collection, to more closely align to the new objectives of the NDS.

### **4. The impact of the health reform agenda on the AODTS-NMDS is currently unknown**

All data development work, including decisions pertaining to the governance and strategic directions, is likely to be influenced by developments in relation to proposed national health reform. The technical infrastructure that will support changes in the public health system is unclear and as the AODTS-NMDS is drawn primarily from health data systems in each state and territory, there may be changes that affect the collection in ways that are currently unknown.

Further to this, the introduction of personal electronic health records may provide opportunities to re-imagine health data collections more broadly and the AODTS-NMDS may be able to capitalise on this new environment.

## **Operational conclusions and potential solutions**

### **1. Analysis of current elements**

The description of the capabilities, limitations and potential of each element currently contained in the AODTS-NMDS provides a starting point for technical examination of the collection (Appendix 3). By addressing the strengths and limitations of each element, the collection may be improved with limited impact on the systems that underpin agency reporting. This approach may also clarify common misunderstandings around the definition of elements and improve data quality. Some suggestions on how to undertake such a task are:

- conduct of a national audit of client files in each jurisdiction, undertaken by the relevant authority, to determine the extent to which information is being correctly recorded and reported
- conduct of a national project using a sample of de-identified client files to examine the differences in recording and reporting as well as the agency processes that create these discrepancies
- assessment of existing elements by the Working Group and communication of any changes using existing channels
- assessment of existing elements by the Working Group and the development of new supporting materials to better communicate the collection requirements.

### **2. Scope, purpose and content**

The scope, purpose and content of the AODTS-NMDS are decisions to be made by bodies such as the DoHA and the IGCD, with advice and assistance from the AIHW on technical aspects of the collection itself.

Three types of data collections have been described (activity-based funding, clinical/administrative and establishment information) to fulfil different purposes and each

would require specific modifications to the current collection, to varying degrees. Once a decision is taken on the purpose of the collection, the Working Group can be directed to undertake the appropriate data development activities.

Given the level of interest by stakeholders and their prominence in current policy discussions, the scope of the AODTS-NMDS could include agencies and services that operate within the AOD sector but do not currently report, such as pharmacotherapy, transition and aftercare, brief interventions, correctional facilities and agencies that treat children. Inclusion of these services would provide a more comprehensive picture of AOD treatment in Australia. Discussions with some stakeholders also suggest that a broader collection – for example, the Alcohol and Other Drug Services National Minimum Data Set – excluding the word ‘treatment’, may be more appropriate to meet the needs of policy makers, capturing more information about services provided (and therefore funded) in the sector.

Under direction, the Working Group can undertake the development of concepts and metadata that will support the inclusion of these agencies and services in preparation of any anticipated data set development.

Similarly, any expansion or change in the content of the AODTS-NMDS would require data development and have potential resource implications.

### **3. Governance and strategic direction**

The DoHA and the IGCD are regarded as the most appropriate bodies to provide strategic direction for the collection. As discussed in the thematic analysis, the governance structures for the collection could be made clearer, taking into account the implications of health reform and consequent changes to other governance structures.

Under direction, the Working Group and the AIHW may be able to provide information on the governance structures and strategic directions of similar working groups in the health information sector, to assist with thinking in this area. Potential actions include:

- inclusion of the AODTS-NMDS Working Group in the IGCD structure with associated formal protocols
- identification of the types of decisions that should be made by the IGCD and development of an agreed protocol for referral by the Working Group for resolution
- submission of the Working Group work plan and strategic plan to the next IGCD meeting for discussion and endorsement
- review of the terms of reference of the Working Group by the IGCD (Appendix 1)
- review of the membership of the Working Group to determine the appropriate level of decision-making ability, in accordance with the role of the Working Group
- review of the membership of the Working Group to consider the inclusion of representatives from peak bodies in accordance with the role of the Working Group
- development of a plan of regular review for the AODTS-NMDS in line with the NDS.

### **4. State and territory collection systems and processes**

State and territory processes related to data collection have a direct impact on the AODTS-NMDS. While they are out of the control of the Working Group and the AIHW, there are steps that can be taken to support greater compliance with national reporting conventions. Through greater engagement with the agencies and peak bodies within each jurisdiction, the AIHW may be able to provide technical support, with regards to data definitions in the national collection as well as supporting materials such as plain English manuals. By

developing these materials in cooperation with jurisdictions, the differences between the national, state and territory collections may be clearer to agencies and promote greater accuracy in data collection which benefits both jurisdictional and the national data collection.

## **6. Concepts that require further consideration**

In addition to these conclusions, there are a few instances where a single concept or approach may be used to address multiple issues. Some of these concepts and approaches are in current use in other collections and, as such, already have developed metadata, analysis and validation. There has already been substantial development work, and often piloting, to establish the most efficient way of addressing the issue.

### *Data linkage (or the use of a statistical linkage key)*

Data linkage using a statistical linkage key presents the greatest potential for addressing multiple issues but is not without limitations; mainly that it is not 100% accurate. The statistical linkage key allows records to be linked within and between data sets; within a single collection period, between different collection periods of the same data set and between different data sets (Karmel 2005). By using the statistical linkage key within a data set, it is possible to estimate the number of unique records (the number of clients) as well as to examine stock and flow information. That is, the trends in concurrent and consecutive service use. Used to link data between different collection periods, data linkage provides greater analytical power. In the AODTS-NMDS, this may be long-term trends in service usage, client characteristics and potentially constructing vignettes that can describe typical and atypical AOD treatment journeys.

Data linkage is most powerful where different data sets are linked to draw on elements specific to different collections providing information to be combined for more informative analyses. For example, by linking the AODTS-NMDS and another collection, say a homelessness data collection, it may be possible to estimate the number of clients that have accessed treatment and supported accommodation services. Similarly, the AODTS-NMDS would have the ability to be linked with other data sets that use the same statistical linkage key and this has the potential to inform national, state and territory policies.

Data linkage between collections thus often allows analyses to be done that would otherwise be impossible unless a raft of new elements were introduced to the collection. Using the previous example, should the experience of homelessness amongst clients of AOD services be identified as a policy priority, data linkage would allow information about this issue to be sourced without introducing specific housing-related elements to the AODTS-NMDS. By limiting the number of new elements that are introduced to the collection, the process of data development, preparation of a business case and the approval process through the NHISSC, the associated resources and costs and undue burden on agencies can be avoided.

The elements required to create a statistical linkage key (SLK) and specifically the SLK-581, previously piloted by the AIHW in the Enhancement Project, are registered in the community services and health data dictionaries. Though the statistical linkage key is not currently used in any health data collection, other forms of probabilistic data linkage have been used in health data sets but the SLK-581 is extensively used in the community services data collections; namely, Aged Care Assessment Program NMDS, Home and Community Care (HACC) NMDS, Juvenile Justice NMDS, Homelessness and Disability Services NMDS, and is being piloted in the Child Protection and Support Services (CPSS).

### *AOD elements in other data sets*

An alternative to data linkage is the introduction of indicators relevant to the AODTS-NMDS to other data sets. There are several things to take into consideration if this approach is selected.

The data sets that are relevant for the collection of AOD information have to be decided by the DoHA and the IGCD as policy makers. From the previous example, if a policy priority is examination of the experience of homelessness by clients of AOD treatment agencies, or the use of AOD treatment agencies by clients experiencing homelessness, the homelessness data collection could be approached to implement AOD-related elements. These may be single indicators, a set of elements or a suite.

Exactly what information is of interest is a policy decision. For example, in the context of the AODTS-NMDS measures of use (lever, frequency or recency), substance use history, AOD treatment history or source of drugs may be considered important.

Regardless of which collections and elements are selected, there is a process of data development and implementation that must be adhered to. The subject matter group (equivalent to the IGCD) may be approached to canvass the potential inclusion of new elements to their collection. The IGCD or its delegates then engage in a process of negotiation on the elements to be included and a business case may be prepared and submitted to the NHISSC before data development can be undertaken. Before implementation, parties from both collections must agree to the content and then the data elements are progressed through the NHISSC process.

This approach has the potential to draw on a diverse range of data sources, however it is likely that the same challenges experienced by agencies as described in this report exist in some form in other sectors, with similar impacts on data quality. Consequently, this approach has limitations in that the IGCD and Working Group have little, if any, control over the implementation within the data collection agencies.

### *Expanding code sets*

Unlike the previous two approaches, expanding code sets can address some data quality issues within the AODTS-NMDS without involving any other national collections. Stakeholders at all levels identified several limitations in the national collection, specifically the inability to report the same level of detail available in states and territories. To capture all the detail that elements in jurisdictional collections contain, this approach would involve expanding the code sets for all elements to include all the options available at the state and territory level. This would make mapping unnecessary and minimise confusion at the agency level because agencies need only code one value. This would mean a greater number of options in several elements, far greater than the current collection.

In practice, changing the code set for any element in the AODTS-NMDS requires consideration by the NHISSC, including the preparation of a business case and engaging the required data development activities. Fortunately, this approach would have minimal impact on jurisdictions, actually decreasing the work required to modify data sets for submission to the national collection.

The elements for which this is relevant are identified in the data element analysis at Appendix 3.

### *Standard classifications and short lists*

Related to expanded code sets is the use of standard classifications and short lists. For those elements that already refer to standard classifications, data quality and accuracy may be improved by strongly encouraging the use of these classifications in preference to short lists.

The advantages of classifications are that they provide the greatest level of detail possible and are comparable between data sources. The disadvantage is that they are not necessarily kept up-to-date; for example, to contain new drugs of concern.

Where new elements are being considered, the potential to utilise a standard classification in lieu of a specially developed code set should be investigated to prevent confusion.

## **7. Structure of data collection**

Stakeholders identified the type of information they would like to see in the collection and these concepts are in the thematic analysis. These concepts are related to current policy that impacts on the AOD sector, such as homelessness, or a wider political agenda such as social inclusion. There may also be additional concepts that become significant as health reform activities begin. Regardless of their source, capturing the issues pertinent to treatment provision is a decision for the DoHA and the IGCD.

For some of these concepts, metadata already exist, while for others, further work needs to be undertaken to determine exactly what is to be collected and the most appropriate way to capture it. Whether current registered elements exist or not, the implementation process through the NHISSC is the same.

Once a decision is taken on the elements to be developed, some potential options are:

### *Data set specification containing currently registered elements*

A business case is prepared by the Working Group for the creation of a data set specification that contains elements that are already registered. This means that should jurisdictions agree to and be in a position to collect this information in the future, the metadata are already agreed to. Jurisdictions may choose to collect and report these data but are not obliged to. A data set specification does not mandate collection and would not change the current collection.

### *Data set specification containing both currently registered and new elements*

A business case is prepared by the Working Group for the creation of a data set specification that contains elements that are already registered and embarks on developing any new elements. As above, this would not require jurisdictions to begin collection and reporting of new elements, unless they chose to.

### *National Minimum Data Set containing currently registered elements*

A business case is prepared by the Working Group for the inclusion of additional data elements that are already registered, actually modifying the AODTS-NMDS. This would mandate the collection and reporting of these new elements.

### *National Minimum Data Set containing both currently registered and new elements*

A business case is prepared by the Working Group for the inclusion of additional data elements that are already registered, and embarks on developing any new elements, actually modifying the AODTS-NMDS. This would mandate the collection and reporting of these new elements.

## **8. Products and processes**

Feedback from stakeholders indicates that there is general satisfaction with the current products from the collection but they require better marketing and dissemination. Though raising the profile of the collection is a strategic direction of the Working Group, assistance to develop a marketing and dissemination strategy may be considered.

Potential actions in this area are:

- develop a marketing and dissemination strategy for publication of the reports
- redesign publications and products to meet a variety of stakeholder needs; for example, a single summary page for data definitions
- pursue opportunities to present AODTS-NMDS information at conferences, seminars and forums
- encourage use of the data by advertising the data request process widely amongst stakeholders
- develop advertising material to inform stakeholders of the products available.

## **9. Agency information**

All stakeholders identified a dearth of information about the agencies that provide AOD treatment. Investigation into the possibilities of capturing this information may be necessary, to determine the best form for such a collection to take. To further investigate the idea of expanding agency-level information, and if this is considered a national priority, the AIHW suggests a separate project be undertaken to assess the need, most appropriate format and technical requirements of such a collection.

## **10. Privacy and consent**

As a paramount concern for the collection, adequate privacy controls and measures are required to engender trust from clients and agencies and instil confidence in researchers and data users.

Pending the release of exposure draft legislation regarding the harmonisation of Australian privacy arrangements, as a result of the Australian Law Reform Commission review, privacy and consent processes should be reviewed by each state and territory to ensure compliance with current relevant legislation. The implications of new legislation will become apparent when it comes into effect.

# **Next steps**

Having considered the conclusions and potential solutions, there are decisions that will have a direct impact on the collection, by changing its current processes, scope, purpose and/or content; and actions that can be taken to support these decisions.

Throughout this report, the IGCD and the DoHA have been identified as the most appropriate bodies to provide strategic direction and make decisions about the AODTS-NMDS collection's future. To this end, the following steps are suggested.

## **Consider this report and its potential uses**

The conclusions and potential solutions are broad and address the variety of concerns, comments and compliments made about the collection, by stakeholders and in the literature.

Because of this breadth, it is possible to identify those aspects of the collection that are priorities for the IGCD and the DoHA, in line with policy direction. For example, areas of priority identified in the new NDS may guide future development and the information needs of health reform activities and e-health have not yet been articulated.

What this review has highlighted is the diversity of opinions on the AODTS-NMDS and the different ways in which information about clients, agencies and treatment may be captured.

## **Differentiate between immediate and longer term decisions**

There are tasks identified in this report that will require strategic direction and deliberation by the IGCD and the DoHA. Deciding the role of the AODTS-NMDS is one such task and central to this decision is a nationally common understanding of what AOD treatment is. The definition of treatment will depend on the purpose the collection is to serve and it is unlikely that a single collection will fulfil the needs of all stakeholders. Defining treatment is also central to the concept of an outcome measure, given what we are measuring must be clearly defined before it can be measured.

To assist with framing the discussion about the role of the AODTS-NMDS and what treatment may mean, three types of collections are explored in this report:

- a) activity-based funding – what government pays for
- b) establishment/agency information – what agencies provide
- c) clinical/administrative – who are the clients and what services do they receive.

Once the purpose of the collection has been decided, the scope of the collection can be defined to meet policy needs. For example, are data required on opioid pharmacotherapy, brief interventions and clients in correctional settings? These requirements may be outlined in the NDS or other health strategies, such as primary care or preventative health.

Within the defined scope, the actual data concepts or content can then be developed, to answer or contribute to answering specific policy questions.

Also in this report are tasks that can be undertaken immediately, to make incremental improvements in the existing collection. Applying the analysis of existing elements, expanding existing code sets and implementing data elements that do not require any data development work are examples of these tasks. It is possible to undertake these simultaneously with the longer term improvement of the AODTS-NMDS.

## **Supporting actions**

To ensure that short- and long-term decisions are supported and implemented efficiently, the report suggests that the relationship between the IGCD and the Working Group is clarified and consolidated. This may be through existing mechanisms or the creation of new ones to ensure that relevant information is provided to the appropriate body and that decisions are made in a timely manner. Stakeholders also expressed interest in strengthening the relationship between the Working Group and national, state and territory peak bodies, especially in the implementation and reporting of data from the AODTS-NMDS.

As the AODTS-NMDS was initially developed to monitor and evaluate the NDS, it is fitting that it too has been reviewed. All stakeholders were supportive of implementing a process of regular review, in line with each new NDS, to ensure that the collection fulfils its purpose and remains policy relevant.

Achieving any or all of the short- and long-term plans for the AODTS-NMDS is dependent on adequate resources being available. Given the multitude of funding arrangements for AOD treatment and the complex relationship between funding and reporting sources at a national and jurisdictional level, priority should be given to clarifying, simplifying and consolidating the resourcing of the collection.

# Appendixes

## Appendix 1: AODTS-NMDS Working Group terms of reference and operating principles

The Alcohol and Other Drug Treatment Services National Minimum Data Set Working Group (AODTS-NMDS WG) aims to support the development, coordination, collection, quality improvement and reporting of the Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS-NMDS).

### Background

- The AODTS-NMDS Working Group was established by the Intergovernmental Committee on Drugs (IGCD) to oversee the development and implementation of the AODTS-NMDS to support the National Drug Strategic Framework.
- The AODTS-NMDS was developed and implemented under the terms of the Australian National Health Information Agreement, under which signatories agree to maintain and provide information in accordance with agreed national minimum data sets.

### Responsibilities

The responsibilities of the WG are:

- to oversee the maintenance and further development of the AODTS-NMDS to ensure good quality and well defined national data for alcohol and other drug treatment services and their clients;
- to identify any information gaps and develop strategies to fill them;
- to maintain the integrity of the collection;
- to provide advice to the IGCD on implementation of the AODTS-NMDS Strategic Plan 2005–06 to 2007–08;
- to develop and carry out an agreed annual work plan (e.g. IGCD AODTS-NMDS Working Group Work Plan 2006–07); and
- to coordinate the collection and publication of data using the AODTS-NMDS and to promote the quality, consistency and comparability of these data.

### Membership

Membership comprises one or more representatives from each of the following organisations or their future equivalents:

- Research, International and Policy Section, Australian Government Department of Health and Ageing;
- Partnerships and Treatment Section, Australian Government Department of Health and Ageing;

- Australian Institute of Health and Welfare;
- Population Statistics Standards, Australian Bureau of Statistics;
- Mental Health and Drug and Alcohol Office, New South Wales Department of Health;
- Drug Policy & Services Branch, Victoria – Department of Human Services;
- Alcohol, Tobacco and Other Drug Unit (ATODU), Queensland Health;
- Drug and Alcohol Office, Western Australia – Health Department;
- Drug and Alcohol Services South Australia, South Australia;
- State-wide Specialist Services, Tasmania–Department of Health and Human Services;
- Alcohol and Other Drugs Program, Northern Territory – Department of Health and Community Services;
- Drug and Alcohol Policy Unit, Australian Capital Territory – ACT Health; and
- The National Drug and Alcohol Research Centre.

The WG may seek the attendance of advisers and other experts to its meetings as needed.

## **Roles of Working Group members**

### **AIHW**

The AIHW is secretariat to the WG and supports the functioning of the group by preparing agendas, agenda papers and minutes, under the guidance of the WG and in consultation with the Chair and Deputy Chair of the WG. The AIHW provides secretariat services to the WG, utilising funding provided by the Australian Government Department of Health and Ageing.

The AIHW supports the group in, and provides expert advice on, data development and data standards and is the custodian and manager of the AODTS-NMDS. The AIHW analyses and produces publications and outputs from the collection, in accordance with the Working Group work plan.

### **State/Territory and Australian Government data providers**

The jurisdictional representatives are data managers and/or data custodians of their respective State, Territory and Australian Government AODTS-NMDS collections. Jurisdictions are responsible for providing data according to agreed formats and timeframes, participating in data development related to the collection and providing advice to the WG about emerging issues which may affect the AODTS-NMDS.

### **Australian Government Department of Health and Ageing (DoHA) contract managers**

DoHA fund the AIHW in their roles as secretariat and data custodian for the AODTS-NMDS. In addition to this contract management role, DoHA's key roles on the WG are to participate in the development of the annual AODTS-NMDS WG Work Plan and to keep the AIHW and the WG informed of major developments relating to national drug and alcohol policy and facilitate liaison with the Intergovernmental Committee on Drugs and the Ministerial Council on Drug Strategy (MCDS).

## **National Drug and Research Centre (NDARC)**

The NDARC are foundation members of the Working Group, having worked on the development and pilot testing of the original AODTS-NMDS collection. Their key role is to provide expert advice to the group on research developments of relevance to the AODTS-NMDS.

## **Australian Bureau of Statistics (ABS)**

The ABS provides expert advice to the WG on population data standards and classifications of relevance to the AODTS-NMDS.

## **Strategic relationships**

The AODTS-NMDS WG was established by the Intergovernmental Committee on Drugs (IGCD) and in the past has reported to it on an annual basis. The relationship between the AODTS-NMDS WG and the IGCD was reviewed in 2004 in the context of new advisory structures for the IGCD. While this review is ongoing, the AODTS-NMDS is recognised as one of a number of National Drug Strategy data collections and the AODTS-NMDS Working Group is recognised by the IGCD as providing important information about treatment.

The WG promotes the use of national data definitions and standards, as agreed by the Statistical Information Management Committee (SIMC) and the Health Data Standards Committee (HDSC). The WG reports to and seeks the endorsement of the SIMC and HDSC as required.

## **Chairing arrangements**

The WG is chaired by a current member of the WG for a period of up to two (2) years. Nominations for Chair and Deputy Chair (DC) are received, seconded and endorsed at WG meetings. This occurs when the Chair resigns or has completed a two year term (which ever comes first). The DC will become Chair directly following their DC term.

When electing the Chair and DC the WG should consider the time since the individual last chaired and the expertise of the individual.

The Chair of the WG is elected as an individual not as a member of the organisation they represent. If the Chair resigns during their term, the organisation they represent does not take over the role of Chair, rather the DC becomes the Chair.

If for any reason the Chair is unable to attend a WG meeting the DC will chair the meeting.

The Chair and DC have the responsibility of facilitating balanced participation and discussion amongst the WG and enabling all views to be heard.

The Chair will work closely with the WG secretariat in organising meetings and setting meeting agendas. The Chair and secretariat for the WG will ensure timely exchange of correspondence and key documents.

## **Working Group meetings**

The WG is scheduled to meet three times a year, twice face-to-face and once via teleconference, or more frequently if so determined by the WG. Face-to-face meetings are to be rotated through Australian capital cities as agreed by the WG. WG meetings will be arranged to ensure that all WG members or their proxies (alternate member) can attend and

fully participate. To facilitate maximum attendance, unless otherwise agreed, WG meetings will be held in the:

- second full week of March (1-2 day meeting in Canberra);
- third full week of August (1-2 day meeting in an agreed capital city other than Canberra); and
- third full week of November (teleconference);

with exact dates to be scheduled at the March meeting each year.

If for any reason a WG member is unable to attend a WG meeting, or that person ceases to be an employee of the organisation they are representing, the organisation may participate through an alternate member by notifying the Chair and/or secretariat of the WG.

Wherever possible, WG meeting agendas will be designed so that it is possible for non-jurisdictional representatives to attend only the agenda items of most relevance to fulfilling their WG role.

## **Working Group decision making procedures**

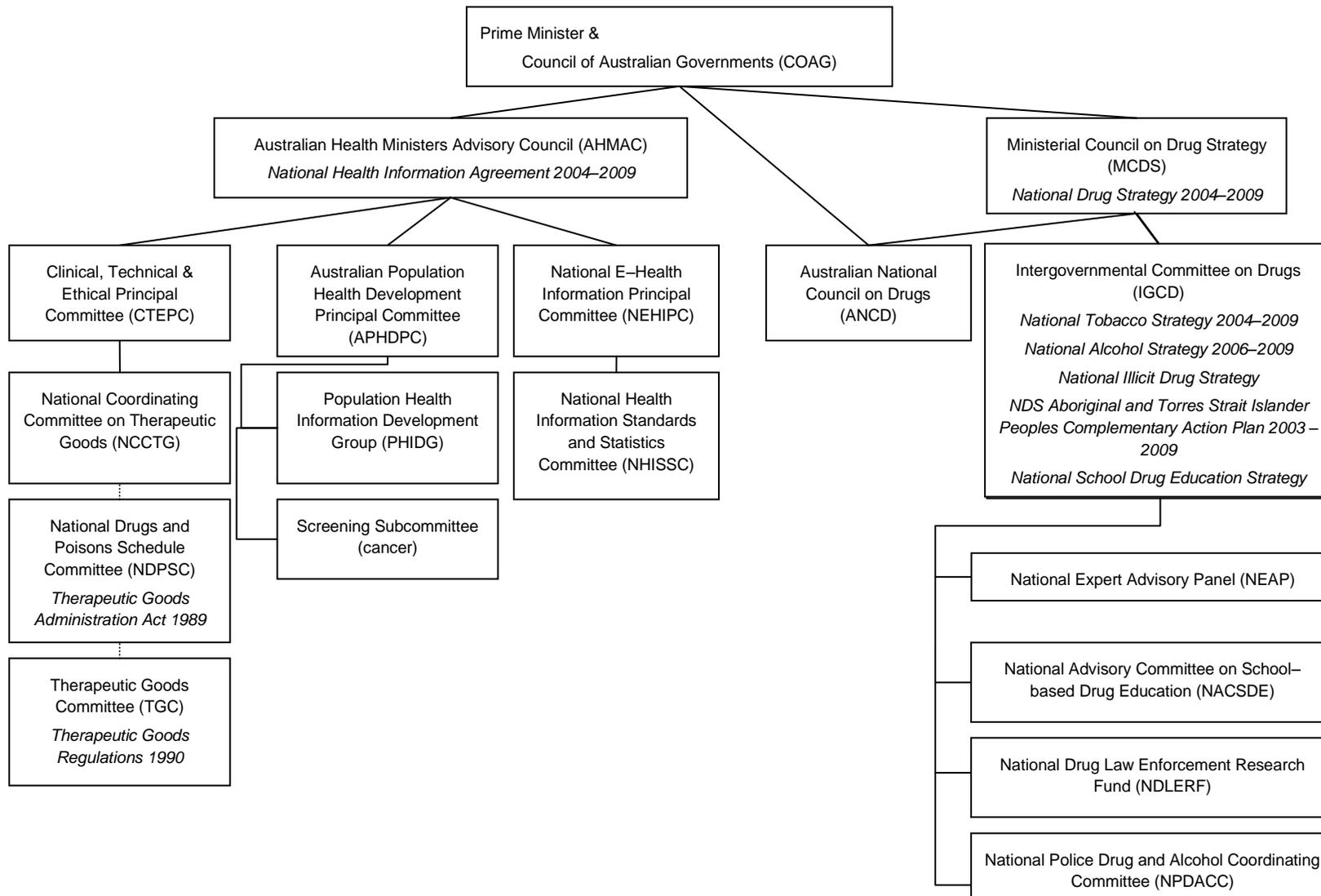
Members of the WG will work cooperatively and seek to achieve consensus in all matters relating to its responsibilities.

If a vote is required, each organisation represented on the WG will have one vote. The voting rights may vary depending on the purpose of the vote. In such instances, the WG should discuss and resolve voting procedures prior to voting.

Absent WG members will have the opportunity to comment on decisions resulting from WG meetings by viewing and commenting on the relevant draft minutes before decisions are finalised. Comments on materials by absent WG members should be timely and should not hinder key WG timetables.

Major issues not able to be agreed by the WG may be referred to the IGCD for resolution.

# Appendix 2: Health reporting structure



## Appendix 3: Analysis of current data elements

### AODTS-NMDS data elements

The AODTS-NMDS comprises two sections, the first being about the establishments that deliver AOD treatment and the second about the clients, principal drugs of concern and treatment/s received. Elements within the collection are categorised as either mandatory or conditional. Mandatory completion signifies that the data element/data set specification must be included. Conditional completion signifies that under specific criteria, a data element/data set specification must be included. Mandatory elements are denoted by a superscripted m (<sup>M</sup>) and conditional elements are denoted by a superscripted c (<sup>C</sup>).

### Establishment level data

Establishment level data in the collection is transmitted to the AIHW from all jurisdictions in a separate file to the episode file. The establishment file comprises two items, the first being a concatenation of four different elements and the second being the geographical location of the establishment.

These are the only data collected about the actual agencies that provide AOD treatment in this collection. Only the establishment identifier is discussed below as the geographical location is determined by the Australian Standard Geographic Classification, a standard prescribed by the Australian Bureau of Statistics and is regarded as the most appropriate classification to use at this time.

### Establishment identifier <sup>M</sup>

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

The establishment identifier is a nationally unique identifier for each AOD treatment agency in the AODTS-NMDS and is assigned by each jurisdiction's health authority. This identifier allows for episodes to be recorded, analysed and reported against the agency in which treatment was provided.

Constructing the identifier requires collection and reporting of four elements:

- Australian state/territory identifier
- sector (public or private)
- region identifier
- organisation identifier

As with other data elements, the multiple steps involved in constructing the identifier create several points at which errors can be made. In the 10 years of the collection, however, there does not appear to be variation in the identifier for agencies unless they have changed their location or the jurisdiction authority has altered the way in which the organisation identifier is allocated. In these cases the AIHW is generally notified of the change.

**Capabilities:**

- provides some information useful in geographical mapping of agency locations, in conjunction with main treatment types, principal drugs of concern and other elements
- consistent organisation identifiers enable changing locations of individual services to be monitored
- clear differentiation between public and private agencies.

**Limitations:**

- differentiation between programs offered by single organisations is not possible
- the identifier may be for an administrative centre rather than the location of the treatment delivery – this is common for organisations that offer multiple services within jurisdictions and those that offer services across numerous jurisdictions
- where services are offered in an outreach setting, there is no record of the location
- some agencies may not have their identifier consistently recorded
- where agencies straddle the public and private sectors through co-location or integration, forced choice creates the potential for inconsistent coding between collections
- there are no components in this element that identify funding source
- the four components have inherent limitations. For example, the region identifier is a code created and maintained by each state and territory and not nationally consistent. It is not apparent from the code if boundaries have changed over time or on what basis the determination of the area or region was made.

**Potential:**

- capture information about funding source
  - the number of funding sources during that collection period
  - identify the actual sources – Commonwealth, state or territory, fundraising, philanthropic donations, private sources and so forth
  - identify the programs providing funding – Non-Government Organisation Treatment Grants Program, Illicit Drug Diversion Initiative, Needle and Syringe Program, Improved Services Measure, Amphetamine Type Stimulants measure and so
  - provide an estimate of the proportion of income by source
- differentiate between the organisation's administrative centre and the site from which treatment is delivered through
  - flagging the administrative site
  - limiting identifiers only to treatment sites
- develop metadata for the treatment delivery site, based on a measure of the treatment provided from there; for example, the hours of operation or staff levels required. This would be in addition to the organisation identifier.

Apart from limiting reporting to treatment sites, metadata development would be required for each of these concepts. Limiting identifiers would have an impact on time series data as there would be a change in the geographical location of some agencies as well as a change in number, though the magnitude of this change is unknown.

Feedback from stakeholders was that this element is not problematic at an agency level however some agencies would like the opportunity to demonstrate the complexity in their organisational structure and funding sources.

## Episode (client) level data

### Client type<sup>M</sup>

**Definition:** the status of a person in terms of whether the treatment episode concerns their own alcohol and/or other drug use or that of another person, as represented by a code.

*Value*    *Meaning*

- |   |                                   |
|---|-----------------------------------|
| 1 | Own alcohol or other drug use     |
| 2 | Other's alcohol or other drug use |

This element describes those clients who are seeking treatment for their own substance use and those who are seeking support because of the substance use of another person. Some stakeholders queried the value of this element given that some definitions of treatment exclude those individuals who are not being treated for their own substance use. Further, there are several elements which are not collected for client type 2; again raising the question of the value of this element.

#### Capabilities:

- for agencies that provide services for both client types, this is an effective way of capturing activity.

#### Limitations:

- some definitions of treatment (including the United Nations Office on Drugs and Crime) exclude services provided to those individuals who are seeking support because of the substance use of another person
- the limited information collected where client type is 2 restricts the use of the data, especially as the principal drug of concern is not recorded
- the main treatment types do not reflect the array of services that may be appropriate for clients of this type
- there is no threshold for the level of contact, intensity or treatment type that determines how episodes for client type 2 are initiated. There has been feedback from some agencies that episodes are created for family members who participate in case management and counselling sessions of the main client, though they are not receiving individual services themselves.

#### Potential:

- ensure the most comprehensive data collection possible, consideration should be given to making all elements mandatory for both client types – some amendments may be necessary to differentiate between the client's own information and the information regarding the 'other's alcohol or other drug use'
- an element that captures the relationship of the 'other' person should be considered

- data for all records where the client is seeking support for another’s alcohol or other drug use could be partitioned into a separate data set for future development. This partitioned section could be expanded to contain information more relevant to this client type, as discussed in the previous sections on issues pertinent to treatment provision.

### **Country of birth<sup>M</sup>**

**Definition:** the country in which the person was born, as represented by a code.

As this element uses the Standard Australian Classification of Countries (SACC) the issues that arise with this element are related to the use of short lists, allowing free text responses and using out-of-date code sets. By educating agencies about the classification and ensuring that information and client management systems support the use of the SACC, data quality for this element could be improved.

### **Date of birth<sup>M</sup>**

**Definition:** the date of birth of the person.

This element was well understood by all stakeholders and its importance agreed. Issues arise where agencies are unable or reluctant to ask for the client’s date of birth. In these instances, sometimes the year of birth is recorded or estimated from the client’s age.

Date of birth is a required element for the introduction of the statistical linkage key 581 (SLK 581).

The most appropriate development for this element would be to introduce an estimate flag, so that it is obvious to analysts that the date of birth contained in that record is an estimate.

### **Date of cessation<sup>M</sup>**

**Definition:** the date on which a treatment episode for alcohol and other drugs ceases.

This refers to the date of the last service contact in a treatment episode between the client and staff of the treatment provider. In situations where the client has had no contact with the treatment provider for 3 months, nor is there a plan in place for further contact, the date of last service contact should be used.

The greatest confusion with this element is the date that should be recorded when a client has failed to contact the treatment agency to notify them of their intention to cease treatment.

#### **Capability:**

- allows the duration of a treatment episode to be calculated.

#### **Limitations:**

- agencies may be confused about which date to record in the event of a forced close; that is, the client has not made contact for three months or longer
- the timing of data submission may cause data to be lost between collection periods because data are submitted before the required 3-month period is complete – this occurs when an episode remains open at the end of the collection period, however, after 3 months, the client has still made no contact and the episode is closed in the previous year
- there is no way of differentiating between episodes that have been closed normally and those that have been administratively or forced closed apart from inferences through the reason for cessation (see limitations for that element).

**Potential:**

- some attempt should be made to quantify the 'lost record' issue between collections periods
- flagging episodes where a client has failed to make contact for 3 months may be useful (in addition to the reason for cessation 'ceased without notice').

**Date of commencement<sup>M</sup>**

**Definition:** the date on which the first service contact occurred within the treatment episode when assessment and/or treatment occurred.

A new treatment episode is deemed to commence when any, some or all of the following occur:

- the client is new
- the client is recommencing treatment after an unplanned absence of 3 months or more
- the principal drug of concern is new or has changed
- the main treatment type has changed
- the treatment delivery setting has changed.

Though this element appears to be one of the simplest items in the collection, agencies in particular have expressed some confusion about what is actually being collected. This is described in limitations below.

**Capability:**

- seasonal trends in commencement may be analysed.

**Limitations:**

- the date of commencement varies according to the service model used by treatment agencies. Feedback from stakeholders is that where pre-treatment engagement or an informal assessment process before treatment is used, these contacts are not always recorded as episodes. Further, some agencies only open an episode subsequent to an assessment and record the episode as the main treatment type for which the client has been assessed
- as counting rules allow for multiple episodes for single individuals to be open simultaneously, even within a single agency, the administrative complexity may impact on the data quality for this element
- for treatments that utilise a continuum of care, agencies and clinicians may not regard a new stage in treatment as a new episode and these components cannot be recorded in the current counting rules
- waiting times between the client's contact and the actual beginning of treatment are not clearly captured and in some instances the waiting time is part of the episode duration.

**Potential:**

- introduce an element to capture assessment date as separate to the treatment commencement date – this date would be the same where 'assessment only' was the main treatment type

- modify this according to any changes made to the triggers for new episodes, should any be made.

### **Indigenous status<sup>M</sup>**

**Definition:** whether a person identifies as being of Aboriginal or Torres Strait Islander origin, as represented by a code.

Though the ‘not stated/inadequately described’ rate of response for this element nationally has remained stable at around 5%, the rate in each jurisdiction varies and there has been a recent rise.

The fundamental limitation of this element exists where agencies and individual clinicians and AOD workers do not ask the client directly, through a lack of understanding of the purpose of the information or reluctance because they do not know how (AIHW 2010c).

Implementation of the *National best practice guidelines for collecting Indigenous status in health data sets* (AIHW 2010c) would be the best approach to addressing this issue.

### **Injecting drug user (IDU) status<sup>C</sup>**

**Definition:** The client’s use of injection as a method of administering drugs, as represented by a code.

<i>Values</i>	<i>Meaning</i>
1	Last injected 3 months ago or less
2	Last injected more than 3 months ago but less than or equal to 12 months ago
3	Last injected more than 12 months ago
4	Never injected
9	Not stated/inadequately described

This element is intended to provide a measure of risk in the treatment population. Though the Australian Needle and Syringe Program (NSP) Survey undertaken by the National Centre in HIV Epidemiology and Clinical Research monitors behavioural indices of risk in addition to prevalence of infection, there is no measure of IDU status in the treatment population.

Consultation regarding this element split stakeholders in terms of its usefulness and importance, based on the purpose of the treatment service and their target population as well as their philosophy. This is a conditional element in the collection and there are a high proportion of ‘not stated/inadequately described’ responses compared with other elements (13%, 2007–08). Most commonly, the element is interpreted as related to the method of use or the principal drug of concern. Feedback from stakeholders was that this element was least likely to be asked where clients were older, seeking treatment for alcohol use or where there was a perceived risk of disclosure to child protection, opioid pharmacotherapy providers and other statutory agencies.

#### **Capabilities:**

- unique measure of risk in the treatment population
- can inform population health interventions as well as individual agency approaches to service delivery

- provides a prompt for agencies to provide advice and/or access to safe injecting information and equipment.

**Limitations:**

- high ‘not stated/inadequately described’ erodes confidence in data
- high risk of misinterpretation due to
  - order of element collection –if asked directly after or close to questions about the principal drug of concern and the method of use
  - philosophy and modes of treatment that do not collect this information as a matter of course, such as relating to older people and alcohol treatment
- some agencies do not collect this element to build trust with clients and minimise the risk of disclosure of information to third parties – there is also fear that disclosure of this information may prevent access to certain services
- this element is not collected for those clients who are seeking treatment for someone else’s substance use and therefore is an incomplete measure of population risk behaviours
- there are unknown duty-of-care implications. Some agencies are unaware of their obligations if they know that a client identifies as a current, recent or previous injector.

**Potential:**

- make collection of this element mandatory to improve data quality
- require collection of this element for both client types
- include a coding option for ‘did not ask’ to differentiate between responses
- make suggestions in the guide for use as to the order of element collection, especially in relation to the collection of principal drug of concern and method of use to prevent confusion
- suggest that comparisons (where possible) are made with population-level data (with appropriate caveats) to improve utility of these data.

**Main treatment type<sup>M</sup>**

Definition: the main activity determined at assessment by the treatment provider to treat the client’s alcohol and/or drug problem for the principal drug of concern, as represented by a code.

<i>Value</i>	<i>Meaning</i>
1	Withdrawal management (detoxification)
2	Counselling
3	Rehabilitation
4	Pharmacotherapy
5	Support and case management only
6	Information and education only
7	Assessment only
8	Other

This element has posed the greatest concern to stakeholders, chiefly because the categories have not been reviewed since the collection's inception. This is also the most complex element to address as the nature of treatment must be addressed before coding options can be discussed; that is, what is treatment?

**Capabilities:**

- the concept that underpins this element can capture what is actually delivered as treatment in the AOD sector
- analyses according to demographic and clinical information, such as principal drug of concern, can be undertaken to inform policy, program and service planning.

**Limitations:**

- there is no agreed definition or understanding of treatment that underpins this element
- the definitions contained in the data guide for each treatment type are broad and open to interpretation. Further, these definitions contain no information about the intensity of treatment or the type of counselling, rehabilitation and so forth
- there are stark differences between the codes available in the national collection and those used in each state and territory – there is detail lost in the mapping process from jurisdictional data sets
- there is confusion at all levels as to whether this element is designed to capture the breadth of treatments or the activity of an agency (that is, for monitoring and evaluation purposes)
- use of the word *only* in the treatment types 'support and case management only', 'information and education only' and 'assessment only' do not reflect contemporary clinical practice – the original intention of these types is unclear
- where agencies are funded for a specific treatment type, they may not repeat what treatment is actually being provided. Conversely, agencies may report that they are providing treatments that they are not, through misinterpretation of the definition. This is likely to be occurring with the treatment type 'counselling'
- the inclusion of pharmacotherapy as a treatment type is problematic as services that only provide this treatment are out of scope for the collection, however the number of agencies providing supported pharmacotherapy services is increasing. It is also not possible to differentiate between initiation, maintenance or reduction programs
- some stakeholders regard the current treatment types as insufficient for capturing the breadth of treatment types actually being delivered
- services such as post-withdrawal residential support, transitional and aftercare services and brief interventions are not adequately captured
- withdrawal management cannot be disaggregated into medicated and non-medicated methods
- the type and intensity of counselling and rehabilitation isn't captured
- in some jurisdictions and agencies, information and education is not regarded as treatment wherein others this main treatment type signifies a compulsory information session through diversion programs or a pre-treatment session where the client's

information can be collected. The problem lies in the definition of the element that requires an assessment before treatment which may not occur in these situations

- there is evidence that the main treatment type ‘assessment only’ is being used where clients have not returned to treatment, even where the intention of the episode was another treatment type; for example, where the assessment was for rehabilitation but the client did not attend
- the main treatment type ‘support and case management’ does not adequately capture the activities that occur within the episode nor does it adequately capture the concept of shared care. There is also debate as to whether the case management activities constitute treatment.

#### **Potential:**

- an agreed definition of treatment is required to determine what categories are best for this element – the definitions of each treatment type should be agreed, including the activities that constitute each
- where clients are currently accessing pharmacotherapy, these records could be flagged. The pharmacotherapy does not have to be provided by the agency providing the treatment episode and would be recorded regardless of treatment type
- a flag for episodes that form part of a shared care agreement could be flagged to differentiate between ‘support and case management’ and other services being provided within this framework
- removing the term ‘only’ from the relevant treatment types should be considered given contemporary clinical practice. A clearer definition for assessment would be required in this instance.

#### **Method of use for principal drug of concern <sup>c</sup>**

**Definition:** the client’s self-reported usual method of administering the principal drug of concern, as represented by a code.

<i>Value</i>	<i>Meaning</i>
1	Ingests
2	Smokes
3	Injects
4	Sniffs (powder)
5	Inhales (vapour)
6	Other
9	Not stated/inadequately described

Information on the client’s method of use for their principal drug of concern is used for minimising specific harms associated with drug use, and is consequently of value for informing treatment approaches.

Researchers expressed the greatest value for this element and some agencies used information from these data to inform their service planning and treatment approaches. This element has been used as a proxy for substance form as there is no record of the substance form elsewhere in the collection.

**Capabilities:**

- informs availability of substance forms; for example, powder heroin is more likely to be injected than brown heroin, which is more suitable for smoking
- used in research
- indicator of risk and provides a prompt for agencies to provide advice and/or access to safe using information and equipment.

**Limitations:**

- may not be relevant to all main treatment types; for example 'rehabilitation
- disclosure may prevent access to some services, specifically for injecting drug users
- assumptions may be made if not asked directly of the client, compromising data quality
- misunderstanding the meaning of each term may cause incorrect coding; for example, the difference between smoking and inhaling
- as with other elements, the 'not stated/inadequately described' response may be being used because the information was not requested
- where a single principal drug of concern is identified but is available in more than one form and the form dictates the method of use, this information cannot be adequately captured; for example, where a substance is available in both liquid and tablet form
- duty of care implications for collecting this element are unclear.

**Potential:**

- statistical linkage could provide information about changes in method of use within a harm reduction paradigm; for example, encouraging a shift from injecting to other methods of use
- identifying those main treatment types or models of service delivery where this element is irrelevant to minimise administrative burden.

**Other drug/s of concern<sup>c</sup>**

**Definition:** a drug apart from the principal drug of concern which the client states as being a concern, as represented by a code (the same codes as principal drug of concern).

Unlike the principal drug of concern, other drug/s of concern is not necessarily the subject of any treatment within the episode. The main treatment type and other treatment types do not have to relate to this other drug, however the existence of other drugs of concern may have a role in determining the types of treatment required and may influence treatment outcomes. Where other drugs are reported, there is currently no way of knowing if the client is receiving treatment for these within the episode.

Similar to the principal drug of concern, this element provides information on the substances for which a person is seeking treatment. Only the capabilities, limitations and potential for this element that are different to those for the principal drug of concern are described.

**Capabilities:**

- the characteristics of polydrug use can be captured at some level
- drugs for which this sort of treatment is not usually sought (nicotine) may be captured
- information about the use of opioid pharmacotherapy may be inferred from this element, though it is considered unreliable.

**Limitations:**

- the order in which drugs of concern are collected is arbitrary and highly dependent on the way in which the information is collected, including the philosophy and mode of service delivery
- polydrug use cannot be accurately captured as the level of use of other drugs is unknown, especially in relation to the principal drug of concern
- inconsistencies in recording this element have the potential to artificially inflate the number of treatment episodes; for example, where agencies record a separate episode for each drug of concern
- as the treatment types may not have any relationship to other drugs of concern, the extent to which this information influences treatment is unknown
- the use of short lists allows for duplication of codes, especially where different forms and subtle differences between drugs cannot be captured; for example, where all amphetamine-type stimulants are reported as amphetamines more broadly instead of different types of amphetamines.

**Potential:**

- The concept of 'other drug/s being used' may be more useful than 'other drugs of concern' and this should be investigated
- Whether the other drug/s of concern are being treated within the episode could be flagged.

**Other treatment type <sup>M</sup>**

**Definition:** all other forms of treatment provided to the client in addition to the main treatment type for alcohol and other drugs, as represented by a code.

<i>Value</i>	<i>Meaning</i>
1	Withdrawal management (detoxification)
2	Counselling
3	Rehabilitation
4	Pharmacotherapy
5	Other

Similar to the main treatment type, this element is intended to provide information about what happens during a treatment episode. It is meant to capture activities that are in addition to, and not a component of, the main treatment type. Other treatment type may not necessarily be for the principal drug of concern in that it may be treatment for other drugs of concern.

**Capabilities:**

- provides greater detail about what happens in a treatment episode
- allows agencies to capture greater breadth of activity information and complexity of service delivery.

**Limitations:**

- it is not possible to determine if other treatments are being applied to the principal drug of concern or other drugs of concern
- the code set for this element differs to that of main treatment type, consequently agencies that provide case management and support services, information and education or assessments for other treatments cannot record this in addition to the main treatment type
- like the main treatment type, the code set for the national collection is less comprehensive than state and territory collections, leading to less reportable detail
- there is some concern that this element does not reflect evidence-informed clinical practice; for example, detoxification and rehabilitation are unlikely to be offered as another treatment
- the definition for pharmacotherapy as another treatment type needs refining as it neglects to refer to non-opioid pharmacotherapies that may be offered, such as acamprosate and nicotine replacement.

**Potential:**

- amendments to this element should be informed by the evidence on treatment service delivery and complement the main treatment type.

**Person identifier<sup>M</sup>**

**Definition:** person identifier unique within an establishment or agency.

The practice of inconsistently assigning person identifiers, within and between agencies, jurisdictions and nationally, limits the utility of this element. Currently, this element cannot be used for estimating the number of unique records or unique individuals at a national level.

The issue of double counting and differentiating between duplicate records and concurrent and consecutive records for individuals can be addressed through the adoption of unique personal identifiers though the current concept of this element may not support this as agencies have the discretion to assign the identifier according to their own system.

**Preferred language<sup>M</sup>**

**Definition:** the language (including sign language) most preferred by the person for communication, as represented by a code. This element uses the Australian Standard Classification of Languages (ASCL).

There was mixed feedback from stakeholders on this element, stemming from confusion about its purpose. Stakeholders expressed that they used this information for:

- securing resources for translating written material
- accessing translation services
- making appropriate referrals
- inferring ethnic and cultural background and designing appropriate programs and services.

Where a client is able to speak fluent English, many agencies stated that they do not collect this information, assuming that English is the client's preferred language.

The purpose of this element is unclear and as it is used for numerous purposes it is timely to review it. Other elements that may be of greater utility in this collection that may be considered are:

- language spoken at home
- first language spoken.

The guide for use within the metadata should be refined to ensure that responses are sought directly from the client. Further, agencies should be supported to become familiar with the ASCL to ensure accurate coding is encouraged in preference to the use of short lists.

### **Principal drug of concern<sup>c</sup>**

**Definition:** the main drug, as stated by the client, that has led a person to seek treatment from the service, as represented by a code.

This is a central element of the collection as it identifies a substance for which the client is seeking treatment. All principal drugs of concern are coded according to the Australian Standard Classification of Drugs of Concern (ASCDC), published by the Australian Bureau of Statistics (ABS). This classification is currently being reviewed by the ABS. This element is used by multiple stakeholders to inform policies for treatment, health promotion and community development, policing and criminal justice and border protection activities.

#### **Capabilities:**

- where the full four-digit code from the ASCDC is used, there is substantial detail in the data set and subtle differences between substances can be recorded.

#### **Limitations:**

- the term 'concern' may be misinterpreted and cause inconsistencies in the data being collected – clients or agencies may not perceive use or particular substances as a 'concern'
- that this element is not collected where the client type is 2 (treatment sought for another's AOD use) reduces the amount of information available
- polydrug use is not adequately captured as only one drug may be selected. Additional drugs may be recorded as other drugs of concern, a new episode or a concurrent episode and this practice is inconsistent across the country
- as polydrug use is not adequately captured, clients or agencies may be forced to choose a principal drug of concern that is incorrect
- the identification of a principal drug of concern is of less relevance, if any, to some treatment types; for example, case management and support services and rehabilitation
- the use of short lists creates inaccuracies as the differences between substances cannot be captured – this is particularly problematic where over-the-counter (OTC) and prescription medications are the drugs of concern
- it is not possible to differentiate between substances used for opioid pharmacotherapy initiation/maintenance/reduction and illicit use, specifically methadone.

#### **Potential:**

- clearer guidance on how to collect this information would be useful, especially to clarify what 'concern' means

- capturing polydrug use either in this element or through another should be investigated, perhaps through a flag
- where the client type is 2 (treatment sought for another's AOD use) it may be possible to collect information about the other's substance use
- those treatment types where this information is not routinely collected should be identified to minimise administrative burden
- a flag for concurrent treatment for other drugs, in the same agency or elsewhere, should be considered to estimate the extent of polydrug use in the treatment population and the current treatment responses
- agencies and jurisdictions should be supported to implement the ASCDC as their sole source of codes for all drugs of concern
- the use of the ASCDC code for the substance form should be investigated.
- the opportunities to collect information on the frequency of use, price paid, source and location of use could be investigated.

### **Reason for cessation <sup>M</sup>**

**Definition:** the reason for the client ceasing to receive a treatment episode from an alcohol and other drug treatment service, as represented by a code.

<i>Value</i>	<i>Meaning</i>
1	Treatment completed
2	Change in main treatment type
3	Change in the delivery setting
4	Change in the principal drug of concern
5	Transferred to another service provider
6	Ceased to participate against advice
7	Ceased to participate without notice
8	Ceased to participate involuntary (noncompliance)
9	Ceased to participate at expiation
10	Ceased to participate by mutual agreement
11	Drug court and/or sanctioned by court diversion service
12	Imprisoned, other than drug court sanctioned
13	Died
98	Other

This data element generated substantial discussion amongst stakeholders. Retention is regarded as a strong correlate to successful treatment and the reasons for leaving treatment are considered important to design and delivery of treatment services.

### **Capabilities:**

- provides a general overview for why clients cease treatment
- can be generally categorised into expected and unexpected/administrative reasons which have been used as proxies for treatment episode outcome.

**Limitations:**

- the number of codes available in the AODTS-NMDS is fewer than those available in some jurisdictions – consequently
  - there is some detail lost in the mapping required for national reporting
  - agencies feel that they are not accurately reporting their activity
- differences in agency philosophy or service delivery model may influence how this is coded; for example, favouring the codes for mutually agreed and treatment completed as opposed to involuntary/without notice/against advice
- the reason for cessation ‘treatment completed’ is problematic because there is no record of the original intention for that episode
- where episodes are forced closed due to unintended lack of contact with the client for 3 months, the reason of cessation may be inconsistently recorded
- from stakeholder consultation, there is reason to believe that some agencies record reason for cessation as ‘transfer to another AOD provider’ and a new episode is opened at the same agency, inflating the number of episodes that that agency provides
- where a client is receiving treatment for more than one drug and these have been coded as separate episodes (principal drugs of concern) the reason for cessation ‘change in the principal drug of concern’ is unlikely to be used. This is also a method of inflating the number of treatment episodes provided by an agency
- the reason ‘change in the delivery setting’ poses administrative problems, especially for some treatment types such as counselling and outreach case management where contacts may occur in several different locations during a single episode. This characteristic of the collection appears unmanageable for continuum of care models of treatment services
- some agencies perceive this element as a measure of efficacy and tend to code for ‘treatment completed’ regardless of the actual reason for cessation
- where the main treatment type is assessment only, there is no information on the result of that assessment.

**Potential:**

- the current code set could be expanded to include all possible reasons for cessation from state and territory collections to preserve accuracy and minimise errors through mapping
- consideration should be given to removing the ‘change in treatment setting’ as a trigger for the closure of episodes and as a reason for cessation
- consideration should be given to incorporating a measure of client satisfaction; for example, if their expectations of the treatment were not met
- the outcome of an assessment could be incorporated as a reason for cessation, especially for assessment-only episodes; for example, assessed inappropriate for service, assessed but no capacity for service and so forth
- the definitions for each code require refining to minimise room for misinterpretation.

**Sex<sup>M</sup>**

**Definition:** the biological distinction between male and female, as represented by a code.

<i>Value</i>	<i>Meaning</i>
1	Male
2	Female
3	Intersex or indeterminate
9	Not stated/inadequately described

The AODTS-NMDS does not use code three within the collection and stakeholders expressed concern that this was not an available option, especially given the literature regarding sexual identity and problematic substance use. Nationally, there are also specialist AOD services for intersex and sexually indeterminate persons. Serious consideration should be given to the inclusion of code 3 in the collection to accurately capture demographic information of the clients of treatment services.

### **Source of referral<sup>M</sup>**

**Definition:** the source from which the person was transferred or referred to the alcohol and other drug treatment service, as represented by a code.

<i>Value</i>	<i>Meaning</i>
1	Self
2	Family member/friend
3	Medical practitioner
4	Hospital
5	Mental health care service
6	Alcohol and other drug treatment service
7	Other community/health care service
8	Correctional service
9	Police diversion
10	Court diversion
98	Other
99	Not stated/inadequately described

This element is very similar to the element 'reason for cessation' in its purpose and form. In part, this element provides information for the analyses of inter-sectoral patient/client flow and for health care planning. It is also useful for comparing those episodes from various diversion programs with corresponding diversion data.

#### **Capabilities:**

- information from this element can identify those sectors where efforts could be focused in increasing referrals to AOD treatment
- services for specific groups, such as family and friends, can be designed.

#### **Limitations:**

- how this information is captured greatly influences the response; for example, asking 'How did you hear about us?' is different to 'What caused you to seek treatment' or accepting a formal referral from another agency

- jurisdictions use a greater number of codes within their collection and detail is lost in reporting at the national level
- factors such as the philosophy or mode of service delivery, privacy concerns, having multiple referral sources or not finding the appropriate code in the existing set all influence the collection of these data
- some jurisdictions and agencies differentiate between formal and informal referrals. Where no formal referral exists, they may code this element as 'self'.

**Potential:**

- the AODTS-NMDS could expand the code set for this element to include all sources of referral that exist in other collections. Examples of additional options include referrals from schools, workplace, primary care and needle and syringe programs
- the difference between formal and informal referrals should be clarified and a decision taken about which to capture and how.

**Treatment delivery setting<sup>M</sup>**

**Definition:** the main physical setting in which the type of treatment that is the principal focus of a client's alcohol and other drug treatment episode is actually delivered irrespective of whether or not this is the same as the usual location of the service provider, as represented by a code.

<i>Value</i>	<i>Meaning</i>
1	Non-residential treatment facility
2	Residential treatment facility
3	Home
4	Outreach setting
8	Other

This is a fundamental element as it captures something about the physical environment in which the treatment is being delivered. The intention of this element is to capture where the actual contacts within an episode have occurred – not the setting of the treatment service or the intention of the treatment. This element is meant to be coded at the end of episode and should be the setting in which *most of the main type of treatment* was received by the client during the treatment episode. For example, where an outreach service has been funded to operate as such, episodes may occur within the client's home and the episode should be coded as such, not as outreach.

**Capability:**

- inferences about treatment intensity may be made using this element in conjunction with treatment type and duration of episode.

**Limitations:**

- as with many other elements, the options for coding responses in each state and territory are more comprehensive than the AODTS-NMDS and some detail is lost in the national report – this also causes confusion in some agencies
- in-reach services and services delivered in correctional facilities are not captured

- the level of misinterpretation is considered to be high given agencies may not differentiate between an outreach, home and other setting. Further, they may not understand that it is the location of the actual treatment, not the agency
- the trigger to close an episode where the treatment delivery setting changes is problematic as it does not make sense in some treatment types and modes and creates additional administrative burden
- though this element provides some measure of intensity, it is not possible to differentiate between rehabilitation activities in a residential setting and a therapeutic community which may operate with greater intensity
- as this element should be collected at the end of the episode, agencies may have difficulty in determining what the main setting was, and this capacity will in part be determined by their client management and information systems.

**Potential:**

- the AODTS-NMDS could expand the code set for this element to include all treatment delivery settings that exist in other collections – examples of additional options include corrections/prison settings and schools
- the definition may require clarification to emphasise that the location of the actual treatment delivered is what should be reported
- the definition of ‘most of the main treatment type’ should be clarified, perhaps incorporating a threshold for contacts during the episode
- the option of coding secondary treatment settings may add value to this element and should be investigated.

## **Appendix 4: Literature review search terms**

Alcohol

Drugs

Dependency

Data

Data collection

Privacy

Evaluation

Drug strategy

Treatment

Addiction

Rehabilitation

Counselling

Comorbidity

Illicit drugs

AOD

Treatment guidelines

Review

MCDS

IGCD

NMDS

## Appendix 5: List of stakeholders consulted

Representatives from each of the organisations named below participated in the consultation process of this review.

- Alcohol and other Drugs Council of Australia (ADCA), Canberra
- Alcohol and Other Drugs Program, Northern Territory  
Department of Health and Community Services, Darwin
- Alcohol and Other Drugs Treatment Strategy Unit, Queensland Health, Brisbane
- Alcohol, Tobacco and Other Drugs Council of Tasmania (ATDC), Hobart
- Association for Prevention and Harm Reduction Programs Australia (ANEX),  
Melbourne
- Australian Capital Territory Health, Canberra
- Australian Capital Territory Executive Directors of Alcohol and Other Drug Services  
Group, Canberra
- Australian Customs and Border Protection Service, Canberra
- Australian Federal Police, Canberra
- Australian Injecting and Illicit Drug Users' League (AIVL), Canberra
- Australian National Council on Drugs (ANCD), Canberra
- Drug and Alcohol Office (DAO), Western Australian Department of Health, Perth
- Drug and Alcohol Services South Australia (DASSA), South Australia Department of  
Health, Adelaide
- Mental Health and Drug and Alcohol Office (MHDAO), New South Wales Department  
of Health, Sydney
- Mental Health and Drugs Division, Victorian Department of Health, Melbourne
- National Centre for Education and Training on Addiction, Flinders University, Adelaide
- National Drug and Alcohol Research Centre (NDARC), University of New South Wales,  
Sydney
- National Drug Research Institute (NDRI), Curtin University, Perth
- Network of Alcohol and Other Drug Agencies (NADA), Sydney
- Office for Aboriginal and Torres Strait Islander Health (OATSIH), Australian  
Government Department of Health and Ageing, Canberra
- Queensland Alcohol and Drug Research and Education Centre (QADREC), University of  
Queensland, Brisbane
- Queensland Network of Alcohol and Other Drug Agencies (QNADA), Brisbane
- South Australian Network of Drug and Alcohol Services (SANDAS), Adelaide
- State-wide and Mental Health Services, Tasmanian Department of Health and  
Human Services, Hobart
- Turning Point Drug and Alcohol Drug and Alcohol Centre, Melbourne
- Victorian Alcohol and Drug Association (VAADA), Melbourne
- Western Australian Network of Alcohol and Other Drug Agencies (WANADA), Perth

# Appendix 6: Consultation documentation— stakeholder consultation questionnaire

## Introduction

The Alcohol and Other Drug Treatment Services National Minimum Data Set (AODTS-NMDS) enables reporting of nationally consistent information about clients accessing alcohol and other drug treatment services. The data derived from the national collection are used, with information from other sources (e.g. admitted-patient data and national surveys), to inform debate, policy decisions and strategies that occur within the alcohol and other drug treatment sector.

At the Intergovernmental Committee on Drugs (IGCD) meeting of September 2009, members noted that a review paper will be provided to the next IGCD meeting that will outline: the usefulness of the current NMDS as an information source for drug services policy; data gaps; and options for the future development of the AODTS-NMDS.

The review of the AODTS-NMDS is intended to explore the current utility of the collection as an information source for drug services policy; to ascertain data gaps and canvass options for future development of the collection.

## Purpose

This document is designed to gather your feedback on some specific characteristics of the AODTS-NMDS, including the process of data collection, transmission, validation and reporting.

**Part A** is intended to encourage your thinking about the issue and the examples given are not an exhaustive list. It will form the basis for the consultation and you can provide as much or as little information as you like. If you think of anything after the consultation, or would prefer to write, please feel free to do so.

**Part B** is a formal response matrix about the content of the collection. There are blank rows included for you to suggest any other data elements you may feel are important to be considered in the collection. If you already collect any of the information, or if you would like to add clarification, please note this in the comment column.

In either case, if you think there are issues that have been missed, please feel free to include them in your responses. Write as much as you like as all responses will be considered to inform the final report.

In addition to your completed questionnaire, you will be able to raise other issues during the consultation phase of the project. Any issues, questions or comments you have regarding the collection can be made in confidence, to the project manager.

All feedback and contributions from the consultations and questionnaires will be used to inform the final report presented to the IGCD. Individual responses will not be identified.

## AODTS-NMDS publications and reports

Data from the collection is used to prepare publications:



collection period to ensure that collection is as accurate, consistent and efficient as possible. The most recent specifications may be found here, <<http://www.aihw.gov.au/publications/phe/phe-113-10726/phe-113-10726.pdf>>.

## **Important points to note about the collection**

### **Agencies and clients included in the collection**

- all publicly funded (at state, territory and/or Australian Government level) government and non-government agencies that provide one or more specialist alcohol and/or other drug treatment services
- all clients who had completed one or more treatment episodes at an alcohol and other drug treatment service that was in scope during the period 1 July to 30 June the subsequent year.

### **Agencies and clients excluded from the collection.**

- agencies whose sole activity is to prescribe and/or dose for opioid pharmacotherapy treatment
- clients who are on an opioid pharmacotherapy program and who are not receiving any other form of treatment that falls within the scope of the AODTS-NMDS
- agencies for which the main function is to provide accommodation or overnight stays such as halfway houses and sobering-up shelters
- agencies for which the main function is to provide services concerned with health promotion (for example, needle and syringe exchange programs)
- treatment services based in prisons or other correctional institutions and clients receiving treatment from these services
- clients solely receiving support from (the majority of) Australian Government-funded Indigenous substance use services or Aboriginal primary health care services that also provide treatment for alcohol and other drug problems
- people who seek advice or information but who are not formally assessed and accepted for treatment
- private treatment agencies that do not receive public funding
- clients aged under 10 years, irrespective of whether they are provided with services, or received services from agencies included in the collection.
- admitted patients in acute care or psychiatric hospitals.

A full list of collection features and data elements (including metadata) can be found in the data specifications document. Throughout the consultation process, you may have comments or questions about these scope issues, so please feel free to raise them for discussion.

## **Review scope**

To guide the consultation, please consider the collection's:

1. Alignment with current strategies and initiatives, nationally and in each state and territory
2. Efficacy in meeting policy objectives and monitoring
3. Limitations of the collection and supporting/complementary data sets
4. Prospects for data development
5. Efficiency and transparency of processes in transmission, cleaning, analysis and meeting requests
6. Usefulness and value of outputs such as reports, bulletins and data cubes
7. Opportunities to improve governance of the collection and clarify roles of stakeholders.

These are the seven areas of investigation that are the focus of the review. Your comments in each of these areas are welcomed during the consultation phase of the project.

## **Consultation questions**

### **Familiarity/utility with the collection**

1. What do you use the AODTS-NMDS for?

For example:

- Statistical reporting
  - Comparisons/benchmarking
  - Research
  - Policy advice/development
  - Program planning
  - Measuring outcomes
2. How often do you use it?
  3. What level of data do you use?
    - National only
    - State and territory
    - Geographical breakdowns
    - Specific data requests for client-level data
    - Confidentialised Unit Record Files (CURFs) and interactive data cubes
  4. Are you familiar with the data specifications/collection manual?
  5. How often would you access it and how?
  6. How easy are they to understand?
  7. How well do you think they are applied within agencies?
  8. Are there other standards that you use; for example, state or territory specifications?

### **Comments**

#### **What is treatment?**

1. What do you consider alcohol and other drug (AOD) treatment?
2. Is this a shared understanding within your organisation/service?

3. Is it defined/ documented anywhere?
4. Are there circumstances where the definition of treatment changes? If so, when?
5. What do you not consider treatment and why?

### **Comments**

### **Breadth and volume of treatment**

Familiarity with the data specifications is required for the following sections.

The AODTS-NMDS data specifications currently contain the following treatment types:

- Withdrawal management (detoxification)
- Counselling
- Rehabilitation
- Pharmacotherapy
- Support and case management only
- Information and education only
- Assessment only
- Other

1. Do these terms adequately capture the current array of treatment types?
2. Do any definitions need refining (not additions but amendments)?
3. Are there treatments that are captured:
  - a. Inadequately?
  - b. Not at all?

The AODTS-NMDS is based on counting closed treatment episodes.

4. Is there treatment activity not captured adequately or at all because of the counting rules?
5. Is there a current estimate for uncaptured treatment episodes?
6. Are there current plans to trial, expand or cease any specific treatment types?
7. Will specific treatments be offered/recommended for specific drugs/demographics etc?

### **Comments**

### **Treatment setting**

The AODTS-NMDS data specifications currently contain the following treatment settings:

- Non-residential treatment facility
- Residential treatment facility
- Home
- Outreach setting
- Other

1. Do these terms adequately capture the current array of treatment settings?
2. Are some treatments offered only in some specific settings?
3. Are there plans to increase/decrease/otherwise change where treatments are offered?

4. Would different coding of treatment setting allow for greater data capture?
5. Do you have co-located services? (these are two or more services in the one physical location that offer AOD treatment services)
  - How do you currently record these settings?
  - Are treatment episodes recorded for each setting?
6. Do you have the capacity to report AOD treatment activity in more services, e.g. primary care?

### **Comments**

### **Issues pertinent to treatment provision**

The AODTS-NMDS data specifications currently contain data elements that capture demographic and clinical information, such as country of birth and principal drug of concern.

1. Are there outstanding uses, i.e. not covered by previous questions, related to data capture?

\* This is an opportunity to suggest elements that you may collect but do not form part of the current national collection or that you would be interested in seeing as part of the national collection. Knowing the element name is not necessary, a description of the concept is sufficient.

### **Comments**

### **Data collection, transmission, reporting and data requests**

1. A flow chart of the data collection process can be found in the background of this document. The following questions are based on the practice in your jurisdiction/organisation/service. Is data collection electronic/manual?
2. When does collection occur and who enters the data? Are there multiple data collectors or steps?
3. Is training provided to data collectors?
4. How often are data submitted and to whom? What are the processes/iterations?
5. Are there any lessons that can be learned from state/territory/service collection processes?
6. If you have made any data requests, how did you find the process? (clarity, timeliness, accuracy)
7. Are you aware of the agency survey and have you completed one?

### **Comments**

### **Strategic direction and decision making**

1. Who do you think makes decisions about the AODTS-NMDS, including its strategic direction?
2. How do you think changes are made to the collection?
3. Do you know who to contact for information regarding the AODTS-NMDS?
4. Do you know who to contact to make suggestions or comments about the collection?

### **Comments**

## **Privacy and consent**

1. Are you aware of the National Privacy Principles, the National Health Privacy Principles, and Information Privacy Principles, Privacy legislation or the current Australian Law Reform Commission Privacy Legislation Review?
2. Do you have privacy concerns about the collection, transmission or use of NMDS data? Please explain.
3. Do you seek informed consent from clients when collecting information? How?
4. To your knowledge, has a client ever refused/withdrawn consent?

## **Comments**

If you have any comments, questions or suggestions about any of the above topics, or the collection in general, please write them in the space below.

## **Appendix 7: Scope of review of the Alcohol and Other Drug Treatment Services National Minimum Data Set**

*The following excerpt is taken from the Schedule between the Department of Health and Ageing and the AIHW to undertake the review of the AODTS-NMDS.*

At the September 2009 meeting of the Intergovernmental Committee on Drugs (IGCD) members:

- Agreed to provide direction to the AODTS-NMDS working group for the future development of the AODTS-NMDS.
- Noted the findings of the AODTS-NMDS Enhancement Project.
- Noted that a review paper will be provided to the next IGCD meeting that will outline the usefulness of the current NMDS as an information source for drug services policy; data gaps; and options for the future development of the NMDS.

### **Review scope**

Influences/ national initiatives

Collection scope

Policy objectives/ monitoring

Data development

Processes

Outputs

Collection governance/ roles and responsibilities

# Bibliography

ACT Health (Australian Capital Territory Department of Health) 2004. Australian Capital Territory Alcohol, Tobacco and Other Drug Strategy 2004–2008. Canberra: ACT Government.

ACT Health 2010. Draft Alcohol, Tobacco and Other Drug Strategy 2010–14: draft for community consultation. Canberra: ACT Government.

AIHW (Australian Institute of Health and Welfare) 2005. National comorbidity initiative: a review of data collections relating to people with coexisting substance use and mental health disorders. Drug statistics series no. 14. Cat. no. PHE 60. Canberra: AIHW.

AIHW 2008. Linking SAAP, child protection and juvenile justice data collections: a feasibility study. Data linkage series no. 5. Cat. no. CSI 5. Canberra: AIHW.

AIHW 2009a. Disability Services National Minimum Data Set collection: Data guide  
Canberra: AIHW. Viewed 10 February 2010  
<[http://www.aihw.gov.au/disability/ds\\_nmds/09-10\\_data/data\\_guide\\_09-10.doc](http://www.aihw.gov.au/disability/ds_nmds/09-10_data/data_guide_09-10.doc)>

AIHW 2009b. Enhancing the Alcohol and Other Drug Treatment Services National Minimum Data Set: counting clients and reporting comorbidity. Bulletin no. 69. Cat. no. AUS 112. Canberra: AIHW.

AIHW 2010a. Alcohol and Other Drug Treatment Services National Minimum Data Set 2010–11: specifications and collection manual. Drug statistics series no. 24. Cat. no. PHE 125. Canberra: AIHW.

AIHW 2010b. Metadata Online Registry (METeOR). Canberra: AIHW. Viewed 1 February 2010, <<http://meteor.aihw.gov.au/content/index.phtml/itemId/181162>>.

AIHW 2010c. National best practice guidelines for collecting Indigenous status in health data sets. Cat. no. IHW 29. Canberra: AIHW.

AIVL (Australian Injecting and Illicit Drug Users' League) 2007. National statement on ethical issues for research involving injecting/illicit drug users. Canberra: AIVL.

Ali R, Miller M & Cormack S (eds) 1992. Future directions for alcohol and other drug treatment in Australia. National Campaign Against Drug Abuse, Monograph series no. 17. Canberra: Australian Government Publishing Service.

ALRC (Australian Law Reform Commission) 2008. For your information: Australian privacy law and practice. ALRC report 108. Sydney: ALRC.

ANCD (Australian National Council on Drugs) 2009. The burden of submission writing and reporting for alcohol and other drug non-government organisations. ANCD general report. Canberra: ANCD.

ANCD 2010. May communiqué. Viewed 15 May 2010.  
<<http://www.ncnd.org.au/communiqués/communique-may-2010.html>>

Australian Bureau of Statistics 2000. Australian Classification of Drugs of Concern 2000. ABS cat. no. 1248.0. Canberra: Australian Bureau of Statistics.

Australian Government 2004. National Drug Strategy. Canberra: Commonwealth of Australia. Viewed February 2010, <<http://www.nationaldrugstrategy.gov.au>>.

- Australian Government 2007. National Comorbidity Initiative. Canberra: Commonwealth of Australia. Viewed 1 February 2010, <<http://www.health.gov.au/internet/mentalhealth/publishing.nsf/Content/national-comorbidity-initiative-2>>.
- Australian Government 2008. Activity Based Funding National Framework and Implementation Plan. Canberra: Commonwealth of Australia. Viewed 1 May 2010, <[http://www.federalfinancialrelations.gov.au/content/national-partnership\\_agreements/HE003/ABF\\_National\\_Framework\\_and\\_Implementation\\_Plan.pdf](http://www.federalfinancialrelations.gov.au/content/national-partnership_agreements/HE003/ABF_National_Framework_and_Implementation_Plan.pdf)>.
- Australian Government 2010. Social inclusion agenda. Canberra: Commonwealth of Australia. Viewed 1 March 2010, <<http://www.socialinclusion.gov.au/Pages/default.aspx>>.
- Black E 2004. Supply, demand and harm reduction strategies in Australian prisons: implementation, cost and evaluation. Australian National Council on Drugs (ANCD) research paper. Canberra: ANCD.
- CAMH (Centre for Addiction and Mental Health) 2009: Drug and alcohol treatment information system. Viewed 12 February 2010 <[http://www.camh.net/About\\_CAMH/Guide\\_to\\_CAMH/Corporate\\_Services/guide\\_data.html](http://www.camh.net/About_CAMH/Guide_to_CAMH/Corporate_Services/guide_data.html)>
- CAMH 2010. Substance abuse statistical tables. Toronto: CAMH. Viewed 12 February 2010, <<http://www.datis.ca/pub/reports/DATIS%20SA%20Statistical%20Tables%200910.pdf>>.
- CCSA (Canadian Centre for Substance Abuse) 2009. Statistics. Viewed 1 April 2010, <<http://www.ccsa.ca/Eng/Statistics/Pages/default.aspx>>.
- Chalmers J, Ritter A, Heffernan M & McDonnell G 2009. Modelling pharmacotherapy maintenance in Australia: exploring affordability, availability, accessibility and quality using system dynamics. Australian National Council on Drugs (ANCD) research paper. Canberra: ANCD.
- Council of Australian Governments 2010a. Intergovernmental Agreement on Federal Financial Relations: Schedule C Public Accountability and Performance Reporting. Viewed 1 April 2010, <[http://www.coag.gov.au/intergov\\_agreements/federal\\_financial\\_relations/docs/IGA\\_FR\\_ScheduleC\\_Public\\_accountability\\_and\\_performance\\_reporting.rtf](http://www.coag.gov.au/intergov_agreements/federal_financial_relations/docs/IGA_FR_ScheduleC_Public_accountability_and_performance_reporting.rtf)>.
- Council of Australian Governments 2010b. National Healthcare Agreement. Canberra: Commonwealth of Australia.
- Dawe S, Frye S, Best D, Moss D, Atkinson J, Evans C, Lynch M & Harnett P 2006. Drug use in the family: impacts and implications for children. Australian National Council on Drugs (ANCD) research report 13. Canberra: ANCD.
- Deloitte 2008. National E-Health Strategy. National E-Health and Information Principal Committee. Developed on behalf of the Australian Government by Deloitte Consulting. Viewed 1 February 2010, <<http://www.health.gov.au/internet/main/publishing.nsf/Content/National+E-health+Strategy>>.
- Dobbin M 2001. Temazepam injecting in Victoria: a discussion paper. Melbourne: Victorian Department of Human Services.

DoHA (Australian Government Department of Health and Ageing) 2008. Towards a national primary health care strategy: a discussion paper from the Australian Government. Canberra: Commonwealth of Australia.

DoHA 2009. Guidelines for the treatment of alcohol problems. Canberra: Commonwealth of Australia. Viewed 18 March 2010, <<http://www.health.gov.au/internet/alcohol/publishing.nsf/Content/treat-guide>>.

DoHA 2010a. A national health and hospitals network for Australia's future: delivering better health and better hospitals. Canberra: Commonwealth of Australia. Viewed 12 April 2010, <<http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/content/report-redbook>>.

DoHA 2010b. Illicit drugs: programs and publications addressing the use of illicit drugs. Canberra: Commonwealth of Australia. Viewed 1 March 2010, <<http://www.health.gov.au/internet/main/publishing.nsf/Content/health-publth-strateg-drugs-illicit-index.htm>>.

DoHA 2010c. Sixth National HIV Strategy 2010–2013. Canberra: Commonwealth of Australia. Viewed 1 April 2010, <[www.health.gov.au/internet/main/publishing.nsf/Content/ohp-national-strategies-2010-hiv/\\$File/hiv.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-national-strategies-2010-hiv/$File/hiv.pdf)>.

DoHA 2010d. Third National Hepatitis C Strategy 2010–2013. Canberra: Commonwealth of Australia. Viewed 1 May 2010, <[http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-national-strategies-2010-hcv/\\$File/hcv.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-national-strategies-2010-hcv/$File/hcv.pdf)>.

DoHA 2010e. Third National Aboriginal and Torres Strait Islander Blood Borne Virus and Sexually Transmissible Infections Strategy 2010–2013. Canberra: Commonwealth of Australia. Viewed 1 May 2010, <[www.health.gov.au/internet/main/publishing.nsf/Content/ohp-national-strategies-2010-atsi-bbv/\\$File/atsi.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-national-strategies-2010-atsi-bbv/$File/atsi.pdf)>.

Donato-Hunt C & Grima K 2009. Counting diversity: indicators of cultural diversity used by drug and alcohol workers in Australia. Sydney: The Drug and Alcohol Multicultural Education Centre.

Drug and Alcohol Office 2005. Western Australian Drug and Alcohol Strategy 2005–2009. Perth: Government of Western Australia.

Drug and Alcohol Treatment Information system (DATIS). Viewed 1 March 2010, <<http://www.datis/ca>>.

EMCDDA (European Monitoring Centre for Drugs and Drug Addiction) 2000. Treatment demand indicator: standard protocol 2.0. Lisbon: EMCDDA. Viewed 1 April 2010, <[http://www.emcdda.europa.eu/attachements.cfm/att\\_65319\\_EN\\_EMCDDA\\_Treatment%20demand%20indicator,%20standard%20protocol%202.pdf](http://www.emcdda.europa.eu/attachements.cfm/att_65319_EN_EMCDDA_Treatment%20demand%20indicator,%20standard%20protocol%202.pdf)>.

EMCDDA 2009. Treatment demand indicator (TDI). Lisbon: EMCDDA. Viewed 12 April 2010, <<http://www.emcdda.europa.eu/themes/key-indicators/tdi>>.

FaHSCIA (Australian Government Department of Families, Housing, Community Services and Indigenous Affairs) 2008. The road home: the Australian Government white paper on homelessness. Canberra: Commonwealth of Australia. Viewed 18 February 2010,

<<http://www.fahcsia.gov.au/sa/housing/progserv/homelessness/whitepaper/Pages/default.aspx>>.

FaHCSIA 2009. Strengthening Families Projects – National Illicit Drug Strategy. Canberra: Commonwealth of Australia. Viewed 1 April 2010, <<http://fahcsia.gov.au/about/news/2009/Pages/kidsinfocus.aspx>>.

Ferri M, Amato L & Davoli M 2009. Alcoholics Anonymous and other 12-step programmes for alcohol dependence. *Cochrane Database of Systematic Reviews*, issue 3 (art. no. CD005032).

Frye S, Dawe S, Harnett P, Kowalenko S & Harlen M 2008. Supporting the families of young people with problematic drug use: investigating support options. Australian National Council on Drugs (ANCD) research paper. Canberra: ANCD.

Gates S, McCambridge J, Smith LA & Foxcroft D 2009. Interventions for prevention of drug use by young people delivered in non-school settings. *Cochrane Database of Systematic Reviews*, issue 1 (art. no. CD005030).

Grant B & Petrie M 2001. Alcohol and other drug treatment services: development of a national minimum data set. AIHW cat. no. HSE 12. Canberra: AIHW.

Gray D, Stearne A, Wilson M & Doyle M 2010. Indigenous-specific alcohol and other drug interventions: continuities, changes and areas of greatest need. Australian National Council on Drugs (ANCD) research paper. Canberra: ANCD.

Hesse M, Vanderplasschen W, Rapp R, Broekaert E & Fridell M 2009. Case management for persons with substance use disorders. *Cochrane Database of Systematic Reviews*, issue 2 (art. no. CD006265).

House of Representatives Standing Committee on Family and Human Services 2007. The winnable war on drugs: the impact of illicit drug use on families. House of Representatives Standing Committee on Family and Human Services, September 2007. Canberra: Commonwealth of Australia.

IGCD (Intergovernmental Committee on Drugs) 2007. National pharmacotherapy policy for people dependent on opioids. Canberra: Commonwealth of Australia. Viewed 1 April 2010, <[http://www.health.gov.au/internet/drugstrategy/publishing.nsf/Content/98126046E0AEF093CA2575B4001353A6/\\$File/pharm07.pdf](http://www.health.gov.au/internet/drugstrategy/publishing.nsf/Content/98126046E0AEF093CA2575B4001353A6/$File/pharm07.pdf)>.

IHRA (International Harm Reduction Association) 2010. London: IHRA. Viewed 1 May 2010, <<http://www.ihra.net>>.

Kaner EF, Dickinson HO, Beyer FR, Campbell F, Schelsinger C, Heather N, Saunders JB, Burnand B & Pienaar ED 2009. Effectiveness of brief alcohol interventions in primary care populations. *Cochrane Database of Systematic Reviews*, issue 4 (art. no. CD004148).

Karmel R 2005. Data linkage protocols using a statistical linkage key. Data linkage series no. 1. AIHW cat. no. CSI 1. Canberra: AIHW.

Marsh A, Dale A & Willis L 2007. Evidence based practice indicators for alcohol and other drug interventions: summary (second edition). Perth: Drug and Alcohol Office, Western Australia.

Ministerial Council on Drug Strategy 2003. National Drug Strategy: Aboriginal and Torres Strait Islander Peoples Complementary Action Plan 2003–2006. Canberra: Australian Government Department of Health and Ageing.

National Treatment Strategy Working Group 2008. A systems approach to substance use in Canada: recommendations for a national treatment strategy. Ottawa: National Framework for Action to Reduce the Harms Associated with Alcohol and Other Drugs and Substances in Canada.

NCETA (National Centre for Education and Training on Addition) Consortium 2004. Alcohol and other drugs: a handbook for health professionals. Canberra: Australian Government Department of Health and Ageing.

Network of Alcohol and Other Drug Agencies 2009. NGO drug and alcohol and mental health information management project: determining the treatment outcomes data collection set. Sydney: Network of Alcohol and Other Drug Agencies.

New South Wales (NSW) Government 2009. A way home – reducing homelessness in NSW: NSW Homelessness Action Plan 2009–2014. Sydney: NSW Government.

NHHRC (National Health and Hospitals Reform Commission) 2009. A healthier future for all Australians: final report June 2009. Canberra: Commonwealth of Australia. Viewed 18 November 2010,  
<<http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/nhhrc-report>  
Canberra: Commonwealth of Australia>.

NHMRC (National Health and Medical Research Council) 2003. Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research. Canberra: Commonwealth of Australia.

NIDA (National Institute on Drug Abuse) 2009. Bethesda: NIDA. Viewed 1 April 2010,  
<<http://www.nide.nih.gov>>.

NIDA 2010. Principles of drug addiction treatment: a research based guide, second edition. Washington, DC: NIDA. Viewed 1 April 2010,  
<<http://www.drugabuse.gov/podat/podatindex.html>>.

Northern Territory Department of Health and Community Services. Strategic directions 2007–09. Darwin: Northern Territory Government.

NSW Health (New South Wales Department of Health) 2007a. Drug and Alcohol Plan 2006–2010: a plan for the NSW Health Drug and Alcohol Program. Sydney: NSW Government.

NSW Health 2007b. Drug and alcohol treatment guidelines for residential settings. Sydney: NSW Government.

NSW Health 2008. Co morbidity framework for action. Sydney: NSW Government.

OAS (Office of Applied Studies) 2008. The Treatment Episode Data Set (TEDS). Washington, DC: Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA). Viewed 12 November 2010,  
<<http://www.oas.samhsa.gov/2k2/TEDS/TEDS.cfm>>.

OATSIH (Office for Aboriginal and Torres Strait Islander Health) 2009. Stakeholder feedback: review of reporting requirements for OATSIH funded organisations. Canberra: OATSIH. Viewed 1 May 2010,  
<[http://www.health.gov.au/internet/main/publishing.nsf/Content/90168BD3BB8176FBCA2574E900041101/\\$File/stakeholder\\_feedback\\_report.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/90168BD3BB8176FBCA2574E900041101/$File/stakeholder_feedback_report.pdf)>.

Perry A, Coulton S, Glanville J, Godfrey C, Lunn J, McDougall C & Neale Z 2008. Interventions for drug-using offenders in courts, secure establishments and the community. Cochrane Database of Systematic Reviews, Issue 3 (art. no. CD005193).

Preventative Health Taskforce 2009. Australia: the healthiest country by 2020. Technical report no. 3. Preventing alcohol-related harm in Australia: a window of opportunity. Canberra: Commonwealth of Australia. Viewed 18 November 2010, <<http://www.health.gov.au/internet/preventativehealth/publishing.nsf/Content/tech-alcohol-toc>>.

Productivity Commission 2010. Contribution of the not-for-profit sector. Research report. Canberra: Commonwealth of Australia. Viewed 1 April 2010, <<http://www.pc.gov.au/projects/study/not-for-profit/report>>.

Queensland Department of Health 2006. Queensland Drug Strategy 2006–2010. Brisbane: Queensland Government.

Rankin J & Copeland J 1997. The national minimum data set project for alcohol and other drug treatment services. Technical report no. 46. Sydney: National Drug and Alcohol Research Centre (NDARC), University of New South Wales.

Ritter A & Chalmers J 2009. Polygon: the many sides to the Australian opioid pharmacotherapy maintenance system. Australian National Council on Drugs (ANCD) research paper. Canberra: ANCD.

Roche AM & Pidd K 2010. Alcohol and other drugs workforce development issues and imperatives: setting the scene. Adelaide: National Centre for Education and Training on Addiction (NCETA), Flinders University.

SAMHSA (Substance Abuse and Mental Health Services Administration) 2010. Rockville: SAMHSA. Viewed 19 April 2010, <<http://www.samhsa.gov>>.

Shand F, Gates J, Fawcett J & Mattick R 2003. Guidelines for the treatment of alcohol problems. Sydney: National Drug and Alcohol Research Centre, University of New South Wales.

Siggins Miller 2005. Mapping national drug treatment capacity. Australian National Council on Drugs (ANCD), research paper. Canberra: ANCD.

Siggins Miller 2009. Evaluation and monitoring of the National Drug Strategy 2004–2009: final report. Canberra: Commonwealth of Australia.

Smith LA, Gates S & Foxcroft D 2008. Therapeutic communities for substance related disorder. *Cochrane Database of Systematic Reviews*, issue 3 (art. no. CD005338).

South Australian Department of Health 2005. South Australian Drug Strategy 2005–2010. Adelaide: Government of South Australia, Department of Health, Drug Policy and Programs Branch.

Spooner C & Dadich A 2009. Non-government organisations in the alcohol and other drug sector: issues and options for sustainability. A report prepared by the Social Policy Research Centre, University of New South Wales, for the Australian National Council on Drugs (ANCD), April 2008. ANCD research paper 17. Canberra: ANCD.

Tasmanian Department of Health and Human Services 2005. Tasmanian Drug Strategy 2005–09. Hobart, Tasmanian Government.

Tasmanian Department of Health and Human Services 2008. Alcohol, tobacco and other drug services: Future service directions – a five year plan 2008/09 – 2012/13. Hobart, Tasmanian Government.

UNODC (United Nations Office on Drugs and Crime) 2006. Guidance for the measurement of drug treatment demand. Global Assessment Programme on Drug Abuse (GAP) Toolkit Module 8. Vienna: United Nations. Viewed 1 March 2010, <<http://www.unodc.org/unodc/en/GAP/index.html>>.

UNODC 2008a. Principles of drug dependence treatment. Discussion paper. Vienna: UNODC. Viewed 1 March 2010, <[www.unodc.org](http://www.unodc.org)>.

UNODC 2008b. Drug dependence treatment: community based treatment good practice. Viewed 1 March 2010, <[http://www.unodc.org/docs/treatment/CBTS\\_AB\\_24\\_01\\_09\\_accepted.pdf](http://www.unodc.org/docs/treatment/CBTS_AB_24_01_09_accepted.pdf)>.

Van de Gaag K 2007. Identifying ethnicity: representation in drug and alcohol treatment services data. Sydney: The Drug and Alcohol Multicultural Education Centre (DAMEC).

VDHS (Victorian Government Department of Human Services) 2005. Dual diagnosis: key directions and priorities for service development 2005. Melbourne: VDHS.

VDHS 2006. Improving health, reducing harm: Victorian Drug Strategy 2006–09. Melbourne: VDHS.

VDHS 2007. Towards a new blueprint for alcohol and other drug (AOD) treatment services: a discussion paper. Melbourne: VDHS. Viewed 1 March 2010. <<http://www.dhs.gov.au/drugservices/pubs/blueprintdisc>>.

VDHS 2008. Shaping the future: the Victorian alcohol and other drug quality framework 2008. Melbourne: VDHS.

World Health Organization 2009. Guidelines for the psychosocially assisted pharmacological treatment of opioid dependence 2009. Geneva: World Health Organization.

# Index

- Aboriginal and Torres Strait Islander people, iv, 26
- access, 21, 22
- activity, 14, 22, 33, 38, 39, 40, 42, 47, 48, 49, 50, 51, 52, 53, 55, 64, 68, 75, 90, 94, 95, 98, 102, 109, 110, 112
- Activity Based Funding, 49, 50, 116
- ADCA, 1, 12, 41, 107
- administrative, iv, 4, 5, 12, 15, 18, 21, 27, 29, 31, 32, 41, 48, 50, 53, 55, 75, 81, 89, 92, 97, 101, 102, 105
- agency, 4, 9, 31, 32, 33, 42, 46, 48, 50, 53, 55, 56, 68, 70, 71, 72, 75, 78, 80, 81, 88, 89, 90, 91, 92, 93, 95, 96, 99, 101, 102, 103, 105
- AHMAC, 6, 7, 8, 9
- alcohol, 4, 5, 11, 17, 19, 22, 23, 24, 26, 29, 31, 32, 39, 41, 60, 65, 83, 84, 90, 91, 93, 94, 98, 101, 103, 104, 108, 110, 111, 115, 117, 118, 119, 120, 121
- ANCD, 11, 31, 32, 33, 41, 46, 52, 107, 115
- annual report, 44
- AODTS-NMDS, viii, x, 1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 15, 16, 17, 18, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64, 65, 67, 68, 69, 70, 71, 74, 75, 76, 77, 78, 79, 80, 83, 84, 85, 88, 102, 103, 104, 105, 108, 109, 110, 112, 113
- assessment, 14, 16, 29, 34, 44, 51, 56, 67, 92, 94, 96, 102
- BBV, 26, 48, 52, 65
- brief interventions, 24, 29, 41, 43, 50, 51, 76, 81, 95
- burden, 23, 27, 31, 41, 48, 52, 58, 60, 67, 97, 101, 105, 115
- Canadian Centre on Substance Abuse, v, 17
- child, 22, 25, 33, 34, 40, 44, 48, 52, 63, 67, 93, 115
- children, 25, 30, 33, 34, 44, 46, 52, 62, 63, 73, 76, 116
- classifications, 8, 61, 79, 85
- clinical, 50, 67, 81, 93
- comorbidity, 1, 33, 35, 40, 64, 115, 116
- co-located, 53, 112
- confidentiality, 35, 72
- consent, ix, 35, 72, 80, 113
- correctional facilities, 39, 42, 43, 51, 52, 63, 76, 104
- counselling, 19, 22, 23, 24, 28, 29, 30, 33, 40, 43, 44, 47, 48, 50, 52, 55, 65, 68, 69, 71, 90, 95, 102
- culturally and linguistically diverse, 36
- data, vii, viii, x, 1, 2, 4, 5, 6, 8, 9, 10, 11, 12, 14, 15, 16, 17, 18, 19, 21, 22, 23, 24, 25, 26, 27, 29, 30, 31, 32, 33, 34, 35, 36, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64, 65, 66, 67, 68, 69, 70, 71, 72, 73, 75, 76, 77, 78, 79, 80, 81, 83, 84, 85, 88, 89, 90, 91, 92, 93, 94, 95, 96, 97, 100, 101, 103, 104, 108, 109, 110, 111, 112, 113, 115, 118, 120
- data linkage, iv, vii, 17, 40, 59, 64, 66, 77
- demand reduction, 27, 52
- demographic, 4, 15, 25, 50, 54, 95, 103, 113
- detoxification, 16, 29, 30, 52, 65, 69, 94, 98, 99, 112
- disability, 25, 61, 62
- domestic violence, 25, 91
- Drug and Alcohol Services Information System, 15
- DSS, 6
- education, 16, 18, 21, 25, 27, 30, 32, 40, 42, 44, 52, 62, 94, 95, 99, 112
- eHealth, 6, 21, 24, 116
- employment, 16, 18, 21, 25, 32, 40, 42, 44, 46, 48, 54, 62
- European Union, 19, 20
- families, 25, 30, 33, 34, 52, 62, 117, 118
- family, 10, 19, 22, 25, 33, 34, 40, 43, 52, 63, 90, 103, 116
- Federal Budget, 25, 30
- follow up, 21
- funding, 1, 5, 12, 22, 23, 27, 29, 30, 31, 32, 34, 36, 38, 41, 42, 45, 46, 48, 49, 50, 51, 52, 53, 55, 58, 59, 60, 61, 65, 67, 71, 72, 75, 81, 84, 89, 90, 110
- geographical, 4, 21, 50, 62, 63, 89
- governance, 6, 10, 22, 33, 37, 42, 43, 56, 58, 74, 75, 76, 111
- halfway houses, 5, 110
- harm minimisation, 23, 27, 34, 38, 41, 42, 47

Hepatitis C, 26, 117  
 homelessness, 25, 26, 40, 44, 47, 51, 53, 59,  
 63, 64, 77, 78, 79  
 housing, 8, 22, 25, 26, 40, 47, 63, 64, 68, 71, 77  
 IGCD, viii, 1, 2, 3, 5, 6, 8, 9, 12, 31, 37, 38, 39,  
 40, 41, 42, 49, 50, 52, 53, 56, 57, 59, 61, 66,  
 68, 74, 75, 76, 78, 83, 85, 86, 106, 108  
 Improved Services Measure, 1, 30, 33, 46, 55,  
 58, 64, 89  
 Indigenous Australians, 23, 25, 26, 31  
 injecting drug users, 27, 35, 97  
 integrated, 23, 24, 28, 53, 71  
 jurisdictions, 6, 12, 23, 27, 30, 33, 34, 35, 38,  
 40, 41, 46, 47, 49, 51, 52, 53, 56, 57, 58, 59,  
 60, 61, 62, 63, 64, 65, 68, 69, 71, 72, 77, 78,  
 79, 88, 89, 91, 95, 99, 101, 102, 104  
 location, 15, 32, 33, 40, 50, 61, 62, 63, 88, 89,  
 101, 104, 105, 112  
 mental health, iv, 1, 5, 18, 22, 23, 25, 26, 32,  
 33, 34, 35, 40, 44, 46, 53, 56, 64, 68, 103,  
 115, 118  
 mental illness, 25, 35, 64  
 meta analyses, 21  
 metadata, iv, 1, 2, 5, 6, 9, 36, 49, 56, 62, 65,  
 66, 67, 68, 74, 76, 77, 79, 89, 100, 110  
 modes, 35, 48, 53, 55, 68, 94, 105  
 National Drug Strategy, 2, 29, 39, 40, 43, 52,  
 54, 75, 76, 85, 115  
 National Health and Hospitals Network, 22  
 National Health and Hospitals Reform  
 Commission, 21  
 National Health and Medical Research  
 Council, 26, 119  
 National Illicit Drug Strategy, 29  
 National Survey on Drug Use and Health, v  
 NCETA, 11, 51, 118, 120  
 NDARC, 1, 5, 11, 85, 107, 119  
 NDRI, 11, 107  
 NGO, 27, 32, 33, 46, 58, 118  
 NGOTGP, 30, 31, 34, 46, 55, 89  
 NHIA, 2, 6, 7, 52  
 NHISSC, 6, 9, 56, 67, 77, 78, 79  
 non-government, 4, 8, 12, 27, 31, 35, 40, 41,  
 46, 53, 58, 88, 110, 115  
 Non-Government Organisation Treatment  
 Grants Program, 30  
 OATSIH, 39, 52, 107, 119  
 opioid, 5, 16, 17, 29, 32, 39, 51, 52, 65, 66, 81,  
 93, 97, 99, 100, 110, 120, 121  
 outcome, 21  
 outcome measure, 21, 29, 34, 40, 69  
 performance, 18, 31, 42, 47, 48, 69  
 pharmaceutical, 64, 66  
 pharmacotherapy, 5, 16, 17, 29, 32, 42, 43, 51,  
 52, 66, 68, 76, 81, 93, 95, 96, 97, 99, 100,  
 110, 116, 120  
 policy, vii, viii, x, 1, 2, 7, 10, 11, 12, 21, 22, 24,  
 26, 28, 29, 31, 32, 33, 36, 37, 38, 39, 40, 41,  
 42, 47, 52, 54, 55, 56, 62, 63, 65, 67, 71, 72,  
 74, 75, 76, 77, 78, 79, 81, 84, 95, 108, 110  
 prescription, 16, 42, 65, 66, 100  
 Preventative Health Taskforce, 21, 23  
 primary care, 24  
 prior treatment episodes, 66  
 privacy, ix, 12, 40, 46, 52, 59, 72, 73, 80, 104,  
 113  
 products, 40, 43, 44, 49, 69, 70, 80  
 publications, 32, 36, 40, 44, 49, 70, 80, 84,  
 108, 109  
 quality, 3, 22, 23, 26, 27, 32, 35, 41, 43, 46, 49,  
 58, 60, 66, 67, 69, 71, 75, 78, 79, 83, 91, 92,  
 93, 94, 97, 116, 121  
 referrals, 18, 60, 68, 99, 103, 104  
 reform, 8, 11, 22, 23, 49, 53, 56, 73, 75, 76, 79  
 rehabilitation, 14, 16, 30, 39, 42, 43, 52, 55,  
 65, 71, 95, 96, 97, 99, 100, 105  
 resources, 8, 28, 31, 45, 46, 48, 51, 53, 55, 57,  
 60, 63, 65, 66, 77, 99  
 SAMSHA TEDS, 16  
 scope, 2, 3, 4, 10, 11, 12, 14, 18, 25, 28, 29, 30,  
 33, 35, 37, 38, 39, 42, 43, 47, 49, 50, 51, 52,  
 53, 59, 61, 66, 68, 70, 71, 74, 75, 76, 81, 95,  
 110  
 smoking, 24, 66, 67, 97  
 sobering-up shelters, 5  
 social inclusion, 25, 40, 62, 63, 64, 79, 116  
 states and territories, 6, 17, 28, 38, 40, 64, 67,  
 70, 78  
 statistical linkage, 1, 34, 40, 46, 47, 59, 60, 65,  
 66, 77, 78, 118  
 STI, 26, 48, 65  
 strategic direction, 12, 38, 42, 43, 56, 57, 74,  
 76, 80, 113  
 Strengthening Families Program, 30, 117  
 Substance Abuse and Mental Health  
 Services Administration (SAMHSA), 15  
 TEDS, 15, 16, 17  
 therapeutic communities, 30, 43, 48, 52, 55,  
 71  
 tobacco, 19, 23, 24, 29, 40, 65, 66, 67

treatment, viii, x, 1, 2, 4, 5, 10, 11, 12, 14, 15,  
16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27,  
28, 29, 30, 32, 33, 34, 35, 36, 37, 38, 39, 40,  
41, 42, 43, 44, 45, 46, 47, 48, 50, 51, 52, 53,  
54, 55, 56, 57, 59, 60, 61, 63, 64, 65, 66, 67,  
68, 69, 70, 71, 72, 74, 76, 77, 78, 79, 80, 81,  
83, 85, 88, 89, 90, 91, 92, 93, 94, 95, 96, 97,  
98, 99, 100, 101, 102, 103, 104, 105, 108,  
110, 111, 112, 113, 115, 118, 119, 120, 121

Treatment Demand Indicators, 19  
Treatment Episode Data Set, 15  
UNDOC, 11  
waiting lists, 56  
WHO, 11, 14  
working group, 2, 3, 5, 8, 9, 17, 38, 39, 45, 53,  
56, 57, 58, 63, 70, 74, 75, 76, 78, 79, 80, 83,  
84, 85, 86, 118  
XE treatment, 14