



**Treatment
Service
Users Project
Final Report**



The *Australian Injecting and Illicit Drug Users League (AIVL)* is the national peak organisation for state and territory peer-based drug user organisations and represents issues of national significance for people who use or have used illicit drugs. Its mission is *'to promote and protect the health and human rights of people who use or have used illicit drugs'*.

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Preface

'... Involving the community in decision making about their own health, as well as the planning and management of health services is integral to effective health promotion and illness prevention...'

Better Health Outcomes for Australians,
1994, Commonwealth Department of Human Services and Health

For well over a decade now, health bureaucracies and services in Australia and around the world have acknowledged the value of consumer input to service planning, operations and evaluation. Governments around Australia now recognise consumer participation as an essential component of quality health care.

Unfortunately, for too long now many drug treatment service providers have looked on from the sidelines at the developments in involving communities and consumers in the planning and delivery of services.

This innovative project represents a great collaboration between an important national research centre of excellence and AIVL as the peak organisation representing drug users and drug user groups from around the country. Without doubt the findings and recommendations of this study represent a significant contribution to the development of improved strategies for consumer involvement with alcohol and other drug service providers.

We know that people who use drugs illicitly experience widespread discrimination within the health system. This level of discrimination actively reduces the effectiveness of treatment services and acts as a barrier to health care. If drug treatment services around Australia can rise to the challenge of involving consumers in service planning and delivery, as well as seeing these consumers as legitimate participants in their own health care, then we will see significant improvements in the efficacy of treatment and the quality of life for all Australians.

Michael Lodge

President

Australian Injecting and Illicit Drug Users' League (AIVL)

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The author of this report is the **Australian Injecting and Illicit Drug Users League (AIVL)**.

This report was written collaboratively by staff of the **Australian Injecting and Illicit Drug Users League (AIVL)** and the **National Centre in HIV Social Research (NCHSR)** including:

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Members of the **TSU Project Advisory Committee** also provided an invaluable contribution to the writing of the final report through comments, editing and authorship for the Forward. A complete list of the Advisory Committee members is at Appendix 2.

Production of the report was assisted by funding from the **Drug Strategy Branch of the Australian Government Department of Health and Ageing**. The Drug Strategy Branch provided the principle funding for the TSU Project. The AIVL Executive Committee and the Department of Health and Ageing provided comments and final approval for the report.

AIVL would like to acknowledge the support of the **Australian National Council on Drugs (ANCD)** in gaining funding for this project, for its participation in the TSU Project Advisory Committee and for its ongoing support of the project.

AIVL wishes to acknowledge the contribution made by the **National Centre in HIV Social Research (NCHSR)** to the overall success of the TSU Project, and for its contribution to the writing of this report. This work was undertaken by the Centre in a largely unfunded capacity in the interests of furthering collaboration with drug user organisations and promoting new research among drug treatment consumers.

AIVL would also like to acknowledge the support of the **state and territory peer-based drug user organisations** in promoting and participating in the TSU Project.

Finally, AIVL and the NCHSR would like to acknowledge all of the **individual treatment consumers and the treatment services** who participated in this research project. Without the investment of their time and expertise, this project and report would not have been possible.

Definitions

All references to 'treatment service users' in this document should be read to mean people who are currently accessing services that offer treatment for illicit drug use. This project does not address the needs of alcohol-treatment service users per se but will address alcohol as part of the needs of people with poly drug-use issues as appropriate within the project parameters.

The terms 'service users' and 'service consumers' or 'consumers' have been used interchangeably throughout the report.

❖ Objectives of the Australian Injecting and Illicit Drug Users League (AIVL)

The Australian Injecting and Illicit Drug Users League (AIVL) is the national peak organisation for the state and territory drug user organisations and represents issues of national significance for illicit drug users.

The organisational philosophy of AIVL is user-centred and peer-based with the dual aims of reducing drug-related harm and promoting and protecting the health and human rights of people who use / have used illicit drugs.

AIVL operates within a health promotion framework as articulated in the *Ottawa Charter for Health Promotion* (1986). With this overall framework in mind, AIVL undertakes a broad range of health promotion and disease prevention activities and programs.

One of the primary aims of the organisation is to prevent and reduce the transmission of blood borne viruses amongst people who inject illicit drugs – such as hepatitis B and C and HIV – and to ameliorate the negative impact of such conditions amongst those already infected.

In addition to disease prevention activities, AIVL also works to promote the provision of high quality, accessible and relevant services to people who use / have used illicit drugs throughout Australia, including drug treatment services.

Although AIVL represents and addresses issues affecting all illicit drug users, AIVL and its member organisations maintain a priority focus on injecting drug users and injecting drug user issues due to the higher levels of harm and marginalisation routinely experienced by people who inject drugs.

AIVL believes that people who use illicit drugs have the right to be treated with dignity and respect and be able to live their lives free from discrimination, stigma and health and human rights violations.

Further information about the aims, objectives and work of AIVL can be found at: www.aivl.org.au

Abbreviations

| | |
|-------|--|
| ACT | Australian Capital Territory |
| ADCA | Alcohol and Other Drugs Council of Australia |
| AHCA | Australian Health Care Agreements |
| AIDS | acquired immune deficiency syndrome |
| AIVL | Australian Injecting and Illicit Drug Users League |
| ANCD | Australian National Council on Drugs |
| AOD | alcohol and other drugs |
| APSU | Association of Participating Service Users |
| ATCA | Australasian Therapeutic Communities Association |
| ATODS | Alcohol, Tobacco and Other Drugs Services |
| BBV | blood borne virus |
| CAHMA | Canberra Alliance for Harm Minimisation and Advocacy |
| CAG | Consumer Advisory Group |
| CCRG | Community/Consumer Reference Group |
| CDA | Centre for Drug and Alcohol |
| CDHA | Commonwealth Department of Health and Ageing |
| CHF | Consumers' Health Forum of Australia |
| CPSS | Consumer Participation in Staff Selection |
| DHAC | District Health Advisory Councils |
| DHS | Department of Human Services Victoria |
| DoHA | Department of Health and Ageing |
| HR | Human Resources |
| HREC | Human Research Ethics Committee |
| HIV | human immunodeficiency virus |
| MHCA | Mental Health Council of Australia |
| NAMHS | Northern Area Mental Health Service |

| | |
|---------|--|
| NCADA | National Campaign Against Drug Abuse |
| NCAG | National Consumer Advisory Group |
| NCCF | National Consumer and Carer Forum |
| NCHSR | National Centre in HIV Social Research |
| NDS | National Drug Strategy |
| NEPOD | National Evaluation of Pharmacotherapies for Opioid Dependence |
| NGO | non-government organisation |
| NHS | National Health Service |
| NOAC | Network of Australian CAGs |
| NRCCPH | National Resource Centre for Consumer Participation in Health |
| NSW | New South Wales |
| NT | Northern Territory |
| NTA | National Treatment Agency |
| NUAA | New South Wales Users and AIDS Association |
| ORPACS | Opioid Replacement Pharmacotherapies Advice and Complaints Service |
| PAMS | Pharmacotherapies Advocacy, Mediation and Support Service |
| QIC | Quality Improvement Council |
| QLD | Queensland |
| RAAV | Rheumatism and Arthritis Association of Victoria |
| RHH | Royal Hobart Hospital |
| SA | South Australia |
| SHARC | Self Help Addiction Resource Centre |
| SWSAHS | South Western Sydney Area Health Service |
| TAS | Tasmania |
| TC | Therapeutic Community |
| TSS | Treatment Support Service |
| VIC | Victoria |
| VIVAIDS | Victorian Drug Users Group |
| WASUA | Western Australian Substance Users Association |
| WSAHS | Western Sydney Area Health Service |
| WHO | World Health Organisation |
| TSU | treatment service user |
| WA | Western Australia |

Foreword

The UN Convention on the Rights of the Child enshrines the principle of 'participation'. It is seen as crucial in meeting the needs of children and young people, and echoes the title of the report of the Canadian HIV/AIDS Legal Network 2005: *Nothing about us without us*. While the convention applies to children, it would almost seem to be self-evident that it should be a feature of most interventions for most conditions that are associated with pain and suffering. Even hospitals tend to emphasise patient participation in their treatment as helpful in healing. There is almost an obsession with 'satisfaction' surveys; albeit more to satisfy quality control assessors and funders than to actually be the basis of service change to better meet needs.

While 'satisfaction' may be on the radar of some agencies, it has been of concern that there appears to have been minimal attention given to meaningful and active 'participation' by drug treatment service users in a full range of activities involved in providing such services. What exists could be regarded as at the 'low degree' end of a participation continuum.

There are many myths around participation. Some of these myths include:

- treatment service users are not capable of full participation;
- confidentiality concerns preclude participation other than at 'lower levels' (eg designing health promotion materials or making suggestions about the program); and
- treatment service users just want to get on with their recovery and do not want to participate in activities such as program and staff review.

This timely study debunks most of these myths. Of course, there can be kernels of truth in some, but most do not stand up to scrutiny. This study clearly demonstrates that most treatment service users want to be involved as much as practicable, and fully recognises that there are some areas where full participation may require some restriction. The study stimulates a wonderful discussion of opportunities available to maximise participation, and to the development of effective strategies to deal with possible barriers and obstacles.

In addition to myths, there is a darker element in the resistance to consumer participation in treatment services. There is often an undercurrent of mutual distrust and antagonism between treatment providers and consumers. The community, treatment providers and consumers themselves conceptualise drug use as deviance, with implications of guilt, blame, and punishment confusing the relationship between providers and consumers. Consumer participation in service planning and delivery is a constructive, if challenging, approach to defining treatment as a health intervention, rather than a system of punishments and rewards.

The study provides a cogent rationale for increased consumer involvement, and identifies that a significant number of the treatment service users and providers surveyed are ready and waiting to work together to achieve better health outcomes. The study has also identified that leadership and policy at all levels is essential to create a facilitating environment within which active and meaningful opportunities for participation can be fostered and develop.

Of course, one cannot just say 'OK, let's increase participation'. For this to be achieved a great deal has to be done in addition to the development of facilitating policy and leadership. The study recognises the need for pilot strategies based on available literature and current good or promising practices. It also highlights the need to educate and train both treatment service users and providers to see opportunities and jointly develop strategies to increase participation and, of course, to make available adequate funds for this to occur.

We welcome this ground-breaking study and, as representatives of both treatment service users and service providers (both in government and non-government agencies), trust that service users, treatment providers, policy makers and funding bodies take seriously the recommendations so that together we may improve the quality of treatment and its outcomes for those who have often been marginalised and had their voices silenced.

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Executive Summary

This project sought to describe the current arrangements for consumer participation and to determine the extent of support for consumer participation in the planning and delivery of drug treatment services in Australia.

Specific Objectives

The key objectives of the project were to:

- Describe the opportunities, as documented in policy, for consumer participation in the planning and delivery of a range of health services including, drug treatment services.
- Describe service consumers' and provider's experiences of, knowledge about, and attitudes towards consumer participation, and to explore their opinions about the barriers to conducting or participating in consumer participation.
- Describe the current activities of consumer representative organisations that relate to consumer participation and to determine their vision for future consumer participation at both the individual and organisational/political level.
- Determine the extent of support for consumer participation among key government, non-government and expert stakeholders, and obtain opinions about how consumer participation could most effectively be implemented in terms of policy, funding and leadership.

Definition

'Consumer participation' is broadly defined as 'the process of involving health consumers in decision making about health service planning, policy development, setting priorities and quality issues in the delivery of health services' (Commonwealth Department of Health and Aged Care 1998).

The TSU Project uses a model of consumer participation that was developed in consultation with the health consumer literature and from examples of consumer participation in other health services (including mental health services). Consumer participation models generally feature varying degrees of involvement in service planning and delivery, with the lowest level being concerned with providing information to or receiving information from consumers. Middle-level consumer participation involves consumers in more active roles that encourage participation but do not involve decision-making. The highest degree of consumer involvement grants consumers decision-making roles in the planning and delivery of services.

Method

The project employed five methods of investigation:

- **Policy audit:** An audit of national, state/territory and some international policy relating to consumer participation in health service planning and delivery was undertaken.
- **Interviews with service providers:** Structured interviews were conducted via telephone with a sample of 64 randomly selected service providers. Each service provider represented a single service. All services were located in New South Wales, Victoria or Western Australia.
- **Interviews with service consumers:** Structured interviews were conducted face-to-face with 179 service consumers. Service consumers were clients at one of 14 services that were selected as recruitment sites for consumers. These services were located in New South Wales, Victoria or Western Australia. A service provider from each of the 14 services also participated in the service provider component of the project to allow some comparison between providers and consumers.
- **Consultation with consumer organisations:** A workshop was held with consumer advocates from the state/territory and national peer-based drug user organisations. In addition, a brief written survey was conducted of managers of the state/territory peer-based drug user organisations.
- **A survey of key government, non-government and policy stakeholders:** A nine-item survey was distributed via email to people identified as key representatives of government and non-government organisations (other than consumer organisations), and people identified as expert advisors.

Key Findings

- While areas such as mental health and disability have consumer participation policies, there are few examples of this in the drug treatment area in Australia.
- Consumer representative organisations emphasised a need for education of both consumers and providers and the facilitation of open and meaningful communication. They expressed beliefs that, if adequately resourced, consumer organisations are well-positioned to facilitate such education.
- Considerable communication gaps exist between consumers and providers regarding currently available consumer participation activities, with consumers knowing little about activities available at the services they attend. For example, while all consumers attended services that had a complaints process, only half (54.2%, n=97) knew about it.
- There is high support from both consumers and providers of drug treatment services with, for example, 71.9% (n=46) of providers and 70.4% (n=126) of consumers reporting that they definitely, probably or possibly would support having consumer representatives involved on decision-making committees. Providers were less supportive of 'high degree' activities in which consumer representatives would have decision-making roles in activities relating to staff (training, recruitment, performance appraisal).
- There is a strong belief amongst some providers that consumers are not interested in taking part in consumer participation activities. Similarly, some consumers expressed the view that other consumers are not interested in consumer participation. This contrasts sharply with reports from consumers themselves, many of whom say they would be willing to take part in consumer participation activities.

- There is a lack of awareness about the meanings and practices of consumer participation in the drug treatment sector, with many providers reporting that the main reason why they had not conducted consumer participation activities in the past was because they had simply never thought about it. This suggests a need to raise awareness about the benefits of consumer participation and how it might work in practice.
- A number of resourcing and capacity issues were identified as obstacles to implementing consumer participation activities. Service providers reported inadequate funding and time restraints as reasons why they had not or would not be willing to support consumer participation at their services. Consumers reported beliefs that they lacked the necessary skills and confidence.
- The culture of some drug treatment services was identified, in various ways, as an obstacle to implementing consumer participation activities. A small number of study participants (including service providers, consumers, and other key stakeholders) expressed beliefs that it is not the appropriate role of consumers to have decision-making responsibility with regard to service planning and delivery, which may reflect the way that consumers' roles are often construed in terms of being passive or lacking (Treloar & Holt 2006). Moreover, the study findings identify that consumers have fears around participating in such decision-making activities, worrying that doing so might negatively impact their treatment or cause trouble for them in other ways.
- Other stakeholders (including representatives from key government and non-government organisations, and expert policy advisors) expressed overall support for consumer participation, identifying it as a priority issue for drug treatment services in Australia. Also, they generally agreed that any consumer participation initiative should be accompanied by specific, extra funding, and should include AIVL and/or its state/territory based members as either leaders or key players in its implementation.
- Many services in Australia already conduct 'low degree' consumer participation activities that are concerned with providing information to or receiving information from consumers. For example, close to two-thirds (64.1%, n=41) of services reported conducting a survey within the previous 12 months that asked consumers specifically for their views on service planning and delivery.

Key Recommendations

The following recommendations are grouped according to four priority action areas to guide the implementation of consumer participation in drug treatment services. All of the recommendations have been informed by the findings of the study. These recommendations aim to provide an implementation framework in relation to consumer participation in drug treatment services for all key stakeholders. Some recommendations require collaboration and partnership between a number of key stakeholders while others will need leadership from a single stakeholder group such as government, drug treatment services or consumer organisations.

Priority Action Area 1: Education and Training for Consumer Participation

- R1: Develop a National Consumer Participation Demonstration Project to design, pilot and evaluate practical models of consumer participation in a range of drug treatment contexts.*
- R2: Based on the outcomes from the above project, produce a National Consumer Participation Toolkit for service providers and consumers covering practical strategies and guidance on initiating and maintaining consumer participation in drug treatment services.*
- R3: Given the number of services currently conducting 'low degree' consumer participation activities, it is recommended that services should document and evaluate these existing activities and*

develop strategies to ensure consumers are aware of these activities.

- R4: Consumer participation in drug treatment services should be identified as a priority theme during Drug Action Week and AIVL and its member organisations should be supported to take a leadership role in designing, implementing and promoting consumer focused activities in order to raise awareness of the importance of consumer involvement.*
- R5: Encourage relevant national and local publications such as the Drug and Alcohol Review, Of Substance, ADCA News, Junkmail and the local drug user organisation magazines to regularly publish discussion pieces, articles, papers and commentaries on the issue of consumer participation in drug treatment services.*
- R6: Provide training and education for drug treatment consumers to build skills, capacity and confidence in relation to consumer participation.*
- R7: Provide training and education for service providers to build skills and capacity in relation to consumer participation.*

Priority Action Area 2: Policy Framework for Consumer Participation

- R8: Develop and promote a nationally agreed definition of consumer participation in drug treatment services to be used at the policy and service delivery levels.*
- R9: Incorporate principles of, and outcome indicators for, consumer participation in drug treatment services into the national and state/territory drug strategies.*
- R10: At the state/territory level, develop specific policy frameworks to support consumer participation in drug treatment services in addition to policies relating to consumer participation in general health settings.*

Priority Action Area 3: Funding for Consumer Participation

- R11: Consider conducting a national consultation on the effectiveness, advantages and disadvantages of including outcome indicators in relation to consumer participation in all drug treatment service funding agreements.*
- R12: Consider establishing a 'start-up' funding initiative to support drug treatment services to initiate consumer participation activities and incorporate them into mainstream service practices.*
- R13: As a principle consumers should be remunerated for their involvement in consumer participation activities.*

Priority Action Area 4: Leadership for Consumer Participation

- R14: All stakeholders should commit to working together to build and sustain consumer participation in drug treatment services.*
- R15: Support consumer organisations to take a leadership and developmental role in relation to consumer participation in drug treatment.*
- R16: Establish a National Drug Treatment Consumers' Round Table. The group would be facilitated by AIVL and function as an advisory and leadership body to progress issues in relation to consumer participation in drug treatment services. Once established the Round Table could also be responsible for developing and disseminating strategic discussion papers on key issues in relation to consumer participation. It would include representation from a diverse range of drug treatment consumers and other relevant stakeholders (including Therapeutic Communities Association, ANCD, peak NGO agencies etc).*

❖ Chapter 1: Background

1.1 Introduction

The National Treatment Service Users (TSU) Project is a peer-driven research project of the Australian Injecting and Illicit Drug Users League (AIVL). The project aimed to investigate the support for, and feasibility of, involving consumers in the planning and delivery of drug treatment services in Australia. Consumer participation in service planning and delivery operates to varying extents in other health service settings in Australia, but is thought to be uncommon within drug treatment settings. This project involved consultation with a broad range of stakeholders in the drug treatment sector, including service consumers and providers, relevant consumer organisations and representatives, representatives from the alcohol and other drug (AOD) sector, non-governmental organisations, government officers and expert policy advisors. In December 2003, AIVL presented the basic concept for the TSU Project to the Australian National Council on Drugs (ANCD) and with the support of the ANCD secured funding for the study from the Drug Strategy Branch of the Australian Government Department of Health and Ageing in June 2005.

1.2 Consumer Movements

The shift towards involving consumers in the planning and delivery of health services has emerged from the broader social reform movements of the last 50 years, such as the women's and civil rights movements. These movements have the concepts of human rights as a central feature and argue that each individual is entitled to, amongst other things, self-determination. The idea of entitlement to determine the nature of one's own health care has been taken up and incorporated into health consumer movements in Australia. Concerned initially with improving the individual experience of receiving medical treatment, the health consumer movement in Australia now has a broader reach to include issues of health care policy and planning, service planning and delivery and research and evaluation (Consumers' Health Forum www.chf.org.au). The concept of rights has been fundamental to this movement and is used to lobby on behalf of, and validate the views of, health consumers (Consumers' Health Forum www.chf.org.au). These rights include the right to satisfaction of basic needs, to safety, to be informed, to choose, to be heard, to redress, to be educated about services, and to a healthy environment (Consumers' Health Forum www.chf.org.au).

The consumer movement has developed significantly in Australia, with the backing of a considerable body of academic and policy-oriented literature. Here consumer participation is broadly defined as 'the process of involving health consumers in decision making about health service planning, policy

development, setting priorities and quality issues in the delivery of health services', (Commonwealth Department of Health and Aged Care 1998); or in more ideological terms as 'more sharing, not only of information and opinion, but also of decision making power. Real participation means joint problem- solving, joint decision-making, joint responsibility.' (National Resource Centre for Consumer Participation in Health 2002).

The consumer movement has been successful in gaining representation on government advisory bodies and committees. Consumer groups routinely make submissions to government inquiries into health care and consumer representatives appear before parliamentary committees and meet regularly with parliamentarians. For over 10 years in Australia there have been positions for health consumers on numerous government and ministerial committees, including the National Health and Medical Research Council, the Australian Health Minister's Advisory Council, Ministerial Advisory Committees on AIDS and Hepatitis, and the Australian Institute of Health and Welfare. Consumer involvement in service planning and delivery has also developed at the local service level in various health service settings (Commonwealth of Australia 2001); including mental health services (Commonwealth Department of Health and Ageing 2002) and government area health services (Western Sydney Area Health Service 2002).

A 'consumer-oriented' movement for people who use or have used illicit drugs has developed in parallel to the health consumer movement. In the late 1980s, largely in response to the emergence of the global HIV/AIDS epidemic, peer-based drug user organisations were established in Australia. Over the past five years a number of local peer-based drug user organisations have gained funding for dedicated drug treatment consumer representative positions and/or projects within their organisations. These have enhanced the capacity of peer-based drug user organisations to represent consumers of treatment services. Nevertheless, the development of a strong consumer movement for people who use or have used illicit drugs is challenging, largely because of the comparative marginalisation of people who have used illicit drugs and the illegal nature of drug use. The funding for this project can be considered a significant step towards the development of a strong consumer voice within drug treatment services. The project will provide knowledge that will inform future initiatives aimed at having consumers of drug treatment services involved in service planning and delivery. This will provide drug treatment consumers with the rights and standards that are widely accepted in other areas of health service delivery and will also improve treatment – and therefore improve treatment retention rates.

1.3 Unique Issues for Consumers of Drug Treatment Services

The reasons why consumers of drug treatment services have not been encouraged to participate in service planning and delivery to the same extent as other health consumers are unknown, but likely relate to the unique contextual features of drug treatment. Anecdotal evidence suggests that there is a perception that people who access drug treatment services do not have the capacity and/or interest to participate in service planning and delivery. Moreover, people who access drug treatment services often enter such services at a time when they are extremely vulnerable and may have health, social, financial and legal issues to manage (Treloar et al 2004), which creates challenges for people in articulating and asserting their needs and rights. For consumers of pharmacotherapy services, it may be particularly difficult to assert rights and feel comfortable participating in higher level planning and decision-making because they are often fearful of being denied access to the treatment if they are seen as a 'difficult client'. Finally, a significant contextual difference facing consumers of drug treatment services compared to other health consumers is that illicit drug use marginalises, isolates and stigmatises people and this

can act as a significant barrier to the formation of relationships based on trust and mutual understanding between service providers and consumers of drug treatment services (Treloar et al 2004).

1.4 Why was the TSU Project Needed?

There have been a number of recent research projects examining treatment issues for people who have used or use illicit drugs (Treloar et al 2004; Complex Vulnerabilities Adjunct Study 2006; Mattick et al 2001 National Evaluation of Pharmacotherapies for Opioid Dependence [NEPOD] Study). These have been extremely valuable in identifying the range of issues for drug treatment services and those who use them – such as service access, treatment options and treatment efficacy. However, these studies have not focused on the needs of treatment service consumers as ‘service consumers’. That is, they have focused on issues for the individual treatment consumer rather than on the rights of all treatment service consumers to have their say in the policies, planning and delivery of services.

As such, there was a belief within AIVL that there is a need to learn about the extent of support for, and feasibility of, involving consumers in the planning and delivery of drug treatment services. The reasons for this belief included the following:

- There has never been a formal national consultation to identify the extent of support for, and feasibility of, involving consumers in the planning and delivery of drug treatment services.
- Evidence in other areas of health service delivery has highlighted the value of consultation with consumers and the way in which it can lead to improved planning, targeting and provision of services.
- People who use drug treatment services have a positive contribution to make in relation to service planning and delivery.
- People who use drug treatment services have a right to be consulted in relation to their service needs.
- Drug treatment service providers are keen for consumers to play a more active role in the planning and delivery of services.
- A number of countries including the United States, the United Kingdom, Canada and France had already developed national drug treatment consumer organisations to provide expertise on the needs of treatment service users.

Existing consumer participation models in general health settings were used to provide a comparative benchmark for developing consumer participation models in the drug treatment context. AIVL believes that the way in which consumers of other health care services participate should in essence be no different for people accessing drug treatment services. Consumer participation within drug treatment services will ensure parity with consumers that are currently being achieved within other areas of health care provision.

1.5 Purpose and Scope

The main aim of the project was to describe the current arrangements for consumer participation and to determine the extent of support for consumer participation in drug treatment services in Australia. The project involved consultation with a broad range of stakeholders in the drug treatment sector, including service consumers and providers, relevant consumer organisations and representatives, representatives from alcohol and other drugs (AOD) sector non-governmental organisations, government officers and expert policy advisors. The specific purpose of each component of the project was:

1. **Policy audit** – to describe the opportunities, as documented in policy, for consumer participation

in the planning and delivery of a range of health services including drug treatment services.

2. **Interviews with service consumers and providers** – to describe service consumers' and providers' experiences of, knowledge about, and attitudes towards consumer participation, and to explore their opinions about the barriers to conducting or participating in consumer participation.
3. **Consultation with consumer organisations and other stakeholders** – including staff from consumer representative organisations, government officers, representatives from non-governmental organisations and expert policy advisors. For consumer representative organisations – to describe the current activities relating to consumer participation and to determine their vision for consumer participation at both the individual and organisational/political level. For other stakeholders – to determine the extent of support for consumer participation, and to obtain opinions about how consumer participation could most effectively be implemented in terms of policy and funding.

The TSU Project is the first study of its kind in Australia. Thus it is intended to provide preliminary insight into the current arrangements for, and overall interest in, consumer participation in drug treatment services. For the purposes of the project, 'drug treatment services' were defined as services that conducted pharmacotherapy treatment, residential rehabilitation or residential detoxification treatment (although the consultation with service consumers and providers involved a small number who were involved with *non-residential* rehabilitation and detoxification treatment – see Chapter 3, p. 45). The project did not consult stakeholders who were associated with services that offered treatment exclusively for alcohol users. Due to the limited amount of resources available for the project, AIVL decided to target the scope of the research and focus on drug treatment services for illicit drug use, with alcohol use included in the project only as a poly-drug use issue for people who use illicit drugs. The research methods of the project were devised to ensure representation from the diversity of perspectives involved in drug treatment services. This involved consulting with stakeholders in government and non-government or private services, and those in regional locations.

1.6 Research Partnership

While the TSU Project is a project of the Australian Injecting and Illicit Drug Users League (AIVL), a unique collaboration was formed at the commencement of the project with the National Centre in HIV Social Research (NCHSR) which has greatly enhanced both the research process and outcomes from the project.

Through this partnership, AIVL and the NCHSR have worked collaboratively on all aspects of the project including engagement of participants, data collection and analysis, report writing and dissemination. The research partnership between AIVL and the NCHSR has produced benefits for both organisations, including:

- capacity building for AIVL in relation to conducting peer-driven research projects;
- ensuring the right balance of consumer experience and research expertise within the project;
- strengthening collaboration between drug user organisations and national research centres;
- expanding the scope of research being undertaken by the NCHSR; and
- increasing the opportunities for future research and partnerships for both AIVL and the NCHSR.

1.7 Advisory Committee

AIVL recognises that the issues regarding consumer participation in drug treatment services are complex and highly sensitive for some stakeholders. To ensure that the perspectives of all stakeholders were adequately represented, a multidisciplinary advisory committee was established to have direct input into the research design, questionnaires, data interpretation, and drafting of the final report. The membership of the committee was carefully selected to ensure the inclusion of all perspectives and included:

- three treatment service user representatives from different backgrounds and treatment experiences;
- two service provider representatives;
- one representative from a relevant recognised research institution;
- one representative from a relevant organisation with health consumer expertise;
- one representative on behalf of the drug treatment sector;
- one representative from the Australian Government Department of Health and Ageing, Drug Strategy Branch;
- one representative from the Australian National Council on Drugs;
- one representative from the Intergovernmental Committee on Drugs;
- AIVL Executive Officer, AIVL Treatments and Policy Manager, and AIVL TSU Project Worker; and
- NCHSR project investigators.

A full list of members of the Advisory Committee is provided in Appendix 2.

The diverse membership of the Advisory Committee was highly successful in ensuring the inclusion of various consumer and provider perspectives. In particular, it allowed for an appropriate balance of views and issues in relation to the different types of drug treatment services including detoxification, rehabilitation, therapeutic communities and pharmacotherapy services.

❖ Chapter 2: Policy Audit

2.1 Introduction

It is difficult to pinpoint the first response to consumer participation in health in Australia. We know that, for example, in as far back as 1964, Dr Les Koadlow, a Melbourne based rheumatologist and Medical Director at Royal Talbot Hospital, established the Rheumatism and Arthritis Association of Victoria (RAAV) in response to a need among his patients with rheumatoid arthritis for support and information.

At the national level, in May 1985 a petition of reform was addressed to the federal Health Minister. This petition called for a formal system of public participation to be built into the national health system. A review of community participation was conducted by the Department of Health in 1985–86. The review recommended that a health forum be established with representation from community and consumer groups to provide a consumer perspective on health issues. It is this action that established the Consumers' Health Forum (CHF) and funds were made available within the 1986–87 budget to support its establishment. The Consumer Health Forum stated that;

'Consumer participation is well recognised by many politicians, policy makers and service planners. Although considerable gains have been made in many areas for the benefit of health consumers, the need for effective consumer participation is not universally accepted.'

[CHF, www.chf.org.au/our_chf/history.asp]

This statement has great resonance for people who are engaged within drug treatment services. Within many other areas of healthcare, consumer participation is valued and seen as a crucial component of health care provision. Within drug treatment services however there is still a great deal of work to be done to ensure consumer participation is not only valued but viewed as a standard aspect of quality service provision.

Consumer participation is multi-faceted. There are many models and views with which health care consumers can engage, with differing activities and involvement. Bastian (1998) suggests that consumer activism in health derives from six broad strands:

1. groups that form around local geographical interests, generally in response to a single issue of local public concern;
2. groups that form among people sharing the same health condition or experience;
3. groups that are forged among people with a shared experience of being harmed by a product (or by people advocating a particular treatment or practice);
4. groups that protest about particular practices or developments on an ideological basis;
5. population groups with a shared identity who came together to represent their concerns and interests; and
6. generic groups and coalitions that are formed to advocate on behalf of the whole population. (Bastian 1998)

It is acknowledged that consumer and carer participation can occur across many levels including:

1. participation in treatment and care;
2. employment of consumers by services as consultants and advocates;
3. participation in service delivery and evaluation;
4. participation in policy and planning;
5. participation in education and training; and
6. participation in staff recruitment.

While these levels represent the opportunities for consumer and carer participation, in practice participation does not occur in all of these areas, all of the time. Opportunities to develop and implement consumer and carer participation are greatly effected by context, environment and the attitudes of those who provide the services. The Mental Health Council of Australia (MHCA) has also identified the importance of service provider attitudes in relation to effective consumer participation:

'The relationship between attitudes and consumer and carer participation is circular: inappropriate attitudes can act as a barrier to genuine participation; when participation is lacking, inappropriate attitudes are not challenged or changed.'

(MHCA 2000)

This current policy audit aims to broadly document existing consumer participation policy frameworks at the national and state/territory government levels in relation to general health settings and drug treatment services. By outlining the key policy and strategic documents we hope to highlight the extent to which such policies are being implemented at the service delivery level within drug treatment services. This audit has not attempted to document the many consumer participation projects and programs at the local level within government and non-government health services as this was beyond the scope and resources of the project. To establish what policies, guidelines and discussion documents exist in relation to consumer participation at the government level the audit has focused on gathering evidence from the following contexts:

- international;
- national; and
- state and territory.

A variety of different research mechanisms were utilised:

- website/Internet searches;
- research reports, discussion papers and policy position statements;
- state and federal policies; and
- direct contact with relevant individuals.

The following themes were utilised to frame the audit:

- rationale for consumer participation;
- success of consumer participation;
- consumer participation in general health settings – policy frameworks;
- consumer participation in drug treatment services – policy frameworks; and
- consumer participation in drug treatment services – conclusions.

While all care was taken throughout the policy audit to include relevant documents, we acknowledge that some documents may have been omitted.

2.2 Rationale for Consumer Participation

The delivery of health care services has historically been a passive engagement. The patient, who is ill, seeks the services of the expert doctor (who is highly regarded by society) to be 'cured'. The doctor, who knows best, prescribes the 'cure' and the patient complies. In his work on doctor-patient relationships, Talcott Parsons worked from the assumption that illness was a form of dysfunctional deviance and saw four norms governing the sick role:

1. The individual is not responsible for their illness.
2. The sick are exempt from normal obligations until they are well.
3. Illness is undesirable.
4. The ill should seek professional help. (Childress & Siegler 1984)

For Parsons, the physician's role is to represent and communicate these norms to the patient to control their 'deviance'. Such views are still held today within the health sector and are particularly prominent within some drug treatment services. The entrenched medical culture is seen as a barrier to effective consumer participation. Ms Hilda Bastian, chairperson of the Consumers' Health Forum of Australia in 1999, said:

'Doctors have failed to grasp the implication of societal change. The medical language is jargonistic and littered with derogatory and hurtful terms about patients... If real improvements in health care are to be achieved, the government, health professionals, consumer groups, and patient organisations must work more closely together in a much more equitable way. At the moment we are still moving in parallel universes.'

(Bastian 1999)

Nevertheless, over the past two decades a shift has occurred as to how health services are both accessed and utilised. For example, the Internet has allowed the inquisitive 'lay' person to gain insight into health that previously was available only to the experts. This, alongside the development of human rights and civil liberties movements, has ensured that health consumers now have greater status and are considered to have their own expertise to share with health care providers. Health consumers are valued for the knowledge and expertise that they can bring.

Such change to the way in which health care is being delivered includes the work of the World Health Organisation (WHO) which has a dedicated health and human rights agenda. WHO states that *'Promoting and protecting health and respecting, protecting and fulfilling human rights are inextricably linked'* (WHO www.who.int/hhr/en/). WHO recognises that access to and outcomes from engaging in health services are not equitable to all in society and are best summarised by Koffi Annan, former United Nations Secretary General 1997–2006, *'It is my aspiration that health will finally be seen not as a blessing to be wished for; but as a human right to be fought for'* (ibid).

As is discussed in the section of this report that explores the development of social movements and their impact on health, it was the disparity in health care provision and outcomes from such engagements that have ensured the increasing role and rationale for consumer participation in health. Within Australia, due to the increase in consumer movements, both government and non-government funding bodies now expect levels of consumer participation to be included as standard practice within most areas of health care provision. It appears from the available literature that the overarching agreed rationale for consumer participation is as follows:

- Active consumer participation leads to more accessible and effective health services.
- Effective consumer participation in quality improvement and service development activities leads to better targeting and uptake of services.
- Effective consumer participation facilitates participation by those traditionally marginalised by mainstream health services and therefore improves health outcomes across the community. (Consumer Collaboration 2001)

2.3 Success of Consumer Participation

The available literature cites many benefits and successful outcomes from consumer participation in health services. In broad terms it is stated by the National Resource Centre for Consumer Participation in Health (NRCCPH) that the successes of consumer participation include:

- improvements in the quality of health care;
- improvements in health outcomes;
- more appropriate public policy;
- better use of public funds;
- better understanding and targeting of consumer issues and needs;
- increased consumer control over health and health services; and
- improved communication between service providers and consumers. (NRCCPH 2004)

More specifically, a report by the Victorian Government Department of Human Services (DHS), Southern Health Breast Services (DHS 2004) evidenced that nurses, nurse unit managers and social workers respondents reported that consumers play a 'significant' and 'essential' role at the service delivery level. DHS identified several specific service developments where consumer involvement improved services or enabled health professionals to better target service delivery, or where it supported health professionals working for changes to service delivery. One respondent commented that the expectation of scrutiny from interested consumers also plays a role in the working relationship between consumers and staff, encouraging staff to 'routinely evaluate plans with a consumer in mind'.

An *Evaluation of the Consumer Participation in Staff Selection (CPSS) Strategy* at the Northern Area Mental Health Service in Victoria (NAMHS 2003) showed that:

'Since its introduction late in 2000, the CPSS has been a highly successful strategy and an innovative example of collaborative partnership between consumers and providers of mental health services. The unique perspective of consumers which, rather than being 'at odds' with the key selection criteria developed by staff/senior managers, was complementary. Evidence of consumer empathy, insight and comfortable interaction were an important set of values and skills which sat comfortably alongside considerations of appropriate qualifications, training and experience'.

The evidence supporting consumer participation is strong. Alexander and Hicks, who presented a model for involving consumers, community members and health service staff in strategic planning for resource allocation, concluded that 'developing an understanding of people's values provides important information to support more equitable and effective decision-making for health services planning' (Alexander & Hicks 1998).

In 2001, the Australian Government funded the Consumer Focus Collaboration Project which concluded that:

- Effective consumer participation in quality improvement and service development activities is achieved through the adoption of a range of methods.
- Effective consumer participation uses methods that facilitate participation by those traditionally marginalized by mainstream health services.
- Active involvement of consumers at all levels of the development, implementation and evaluation of health strategies and programs is integral to their success.

One of the best examples of successful consumer participation in the Australian health service context is the work that has been carried out in the area of mental health service delivery. There is a wealth of information available regarding consumer participation in mental health services. This includes documentation that refers to policy, research guidelines and tools that have been developed to assist in the inclusion of consumer participation for specific services. To explore all of the models that exist would exhaust this report. However, two documents that explore a specific successful model of consumer participation in mental health have been considered. These are:

1. *Project Report – Development of a New Consumer Participation Model based on the National Consumer and Carer Forum*, August–November 2004; and
 2. *Consumer and Carer Participation Policy* – National Consumer and Carer Forum, 2004.
1. ***Project Report – Development of a New Consumer Participation Model based on the National Consumer and Carer Forum***

This project, carried out during August–November 2004, reviewed the existing models of consumer and carer participation throughout Australia and internationally with a view to recommending the best working model for consumer and carer participation at the national level. It plots historically the processes that have been undertaken within the mental health sector in developing consumer participation. The report documents the following key milestones in consumer and carer participation in mental health at the national level in Australia:

- The *First National Mental Health Plan 1993–98* included a commitment to consumer participation by committing to establish a National Consumer Advisory Group (NCAG). The state and territories followed by committing to establish state-based Consumer Advisory Groups (CAG). During 1993–98, these advisory structures were established and provided direct consumer input into policy discussions and were able to disseminate information throughout the broader community, liaise with other sectors, provide governments with the consumer perspective and develop partnerships between mental health providers and consumers.
- The *Evaluation Report of the First Mental Health Plan* emphasised the important contribution of consumer participation. It stated that;

‘Consumers and carers now have a place at the policy table, yet only have limited influence on local services, even when it concerns their personal treatment. It is essential that a national group of consumers and carers be maintained to signal the policy agenda is far from complete’.

(Commonwealth Department of Health and Ageing 2002)

- The *Mental Health Council of Australia* (MHCA) was established in 1997 and the National Consumer Advisory group was disbanded. This was due at the time to an understanding that consumer representation would exist within the MHCA. However, at the same time a national network for the jurisdictional Consumer Advisory Groups was established – the Network of Australian CAGs (NOAC). Funding for the NOAC ceased in 2001 and has continued as in informal alliance and has representation on the MHCA Board.
- In 2001 initial agreement was made to establish the *National Consumer and Carer Forum*.
- In 2001 the *International Mid Term Review of the Second National Mental Health Plan for Australia* stated that there needed to be an enhanced consumer and carer network to ensure the ongoing involvement in policy programming and also to fund any necessary administrative capacity.
- 2002 saw the establishment of the *National Consumer and Carer Forum (NCCF)*. This was undertaken by:
 - the Mental Health Council of Australia;
 - peak consumer and carer groups; and
 - the Australian Health Ministers' Advisory Council National Mental Health Working Group.

The NCCF is resourced and supported by MHCA, which is funded by the Australian Government with jurisdictional contributions. The role of the NCCF is to:

'...provide a medium for mental health consumers and carers to come together to foster partnerships, provide input into activities of the MHCA and, through the auspice of the Council, input into the reform of mental health policy and service delivery in Australia.'

(MHCA 2002)

- The National Mental Health Report 2002 discusses the role of NCCF and states:

'...This forum offers the opportunity for consumer and carer groups to work in partnership not previously seen in Australian health care system.'

2. Consumer and Carer Participation Policy – a framework for the mental health sector, developed by the National Consumer and Carer Forum

The NCCF developed this framework in 2004 as a guide for all organisations involved in mental health within the public, private and non government sectors, to utilise the development and implementation of consumer and carer participation policies. It is a fully encompassing document detailing participation at individual, local, state and national levels and deconstructs consumer participation by the development of a series of principles:

- core principles for the participation of consumers and carers;
- principles for *defining* participation roles;
- principles for *selection* of consumer and carer representatives; and
- principles for *employment* of consumer and carer representatives.

In addition, the document details components for inclusion in a Consumer and Carer Participation Policy together with a 21 point checklist.

This document provides evidence that the experience and successes that the mental health sector has in implementing consumer participation and its principles are such that they can easily be transferred to the drug and alcohol sector.

Copies of the documents referred in this section of the report can be found at: <http://www.mhca.org.au/Resources/NCCF/index.html>

2.4 Consumer Participation in the General Health Setting – Policy Frameworks

Across the various areas of health care provision there is an abundance of literature relating to consumer participation policy, frameworks, discussion papers and projects. To document it all goes beyond the scope of this policy audit. This section however, does attempt to outline the key policy frameworks identified at the national and state/territory levels in relation to consumer participation in general health settings. By documenting the existing consumer participation policy frameworks, we can see the level of government commitment to consumer participation in health and understand how these frameworks can be used in context of drug treatment service delivery.

2.4.1 National

Consumer participation is referred to within national strategies as well as within specific initiatives that have been undertaken to address consumer participation. Some of the key national approaches to consumer participation include:

- ***Australian Health Care Agreements.*** While these agreements are not focused on consumer participation per se, they are the basis upon which all funding for general health services, including public hospitals is negotiated between the Australian Government and the state and territory governments. The Australian Health Care Agreements (AHCAs) contain a number of requirements for funding including the incorporation of the *Public Patients Hospital Charter* into any patient or consumer rights frameworks at the state and territory level. In this way, the AHCAs form the principle policy framework supporting consumer participation at the national level.
- ***Healthy Horizons Outlook 2003–2007: A framework for improving the health of rural, regional and remote Australia.*** This national policy framework includes priorities that focus on people in rural, regional and remote Australia being involved in decisions about their own health, their local health services, and social and economic developments that may affect their health. It also includes community members, health professionals and others who work in rural, regional and remote communities working together to determine priorities for local action.
- ***Consumer Focus Collaboration.*** This was established in 1997. The Commonwealth Department of Health and Aged Care funded a range of projects to strengthen consumer participation in health through its *Consumer Focus Strategy*. These projects are overseen by the Consumer Focus Collaboration, which is made up of consumer organisations, professional organisations, Commonwealth, state and territory health departments and private sector representatives. The Collaboration works to increase effective consumer participation at all levels within the Australian health care system. The aim is to strengthen the focus on consumers in health service planning, delivery, monitoring and evaluation in Australia.
- ***National Mental Health Plan 2003–2008.*** There are numerous national strategies in relation to almost all major health issues affecting the Australian population and, while not all, some of these strategies contain specific policy commitments to support consumer participation. One such example is the *National Mental Health Plan* (2003–2008) which builds on the priorities of both the first and second plans. In relation to consumer participation, the plan commits to:
 - ensure consumer rights; and
 - assure the rights of people with mental disorders.

- **National Mental Health Statement of Rights and Responsibilities.** This was endorsed by the Australian Health Ministers in July 2003. This statement addressed consumer rights to information, education, training, treatment and available services, participation in decision making regarding the development of mental health policy and provision of mental health consumer interests. The statement builds on, and aims to support in practice, the core policy commitment to consumer participation in the *National Mental Health Plan*.
- **National Strategic Framework for Aboriginal and Torres Strait Islander Health Context July 2003.** This is another example of how consumer participation has been incorporated into national policy frameworks/strategies. The framework includes Aboriginal Community Controlled Health Services, including increasing Aboriginal and Torres Strait Islander participation in the operations of mainstream health services and enhancing their control over services specifically for Aboriginal and Torres Strait Islander peoples.
- **National Disability Services Standards.** These were developed by a working party comprising Commonwealth and state government representatives, plus three each of consumer and service provider representatives. They were the subject of wide consultation nationally. Social welfare ministers from all states and territories endorsed the eight national standards, and the purposes, principles and elements of standards monitoring. The standards included minimum requirements for services in relation to consumer participation. The following provides an example of one of the standards, which outlines the minimal requirements for disability agencies in relation to consumer involvement in policy development and service planning:

'Agency has developed, in consultation with consumers, written policies and procedures on planned approaches to meeting individual needs.'

www.familiesandcommunities.sa.gov.au

- **National Resource Centre for Consumer Participation in Health.** On 1 October 2004 the National Resource Centre for Consumer Participation in Health closed. Commonwealth Department of Health and Ageing funding ended on 30 June 2004 and the Centre was unsuccessful in securing new sponsors. Nevertheless, the website www.participateinhealth.org.au remains as a national resource to the healthcare sector. It includes information relating to consumer participation in, for example:
 - introduction to frameworks;
 - practical tools and practice examples;
 - methods and models; and
 - evaluation.
- **Engaging Consumers in Health Policy: Assessing Models and Outcomes.** The Australian Institute of Health Policy Studies' 3rd National Health Policy Roundtable focused on *Engaging Consumers in Health Policy: Assessing Models and Outcomes* (November 2005). This discussion paper argues the need to think more clearly about consumer participation and more rigorously assess the evidence for its benefits.
- **Education and Training for Consumer Participation in Health Care,** Commonwealth of Australia 2000. This report states that, *'Building a safe, high-quality health care system means that people managing and working in the system need to work together with consumers and the community to achieve sustainable improvements and maintain public confidence in the system'* (Commonwealth of Australia 2000). The report covers many of the areas for consideration for training on consumer participation including the training of consumers.

2.4.2 State and Territory Jurisdictions

At the level of state and territory governments there is now a commitment to ensuring that consumers and potential consumers of health services are provided with choice, information and an opportunity to play an active role in their own health care. As discussed above, fully documenting all of the areas of health service delivery that include consumer participation activities goes beyond the scope of this report. However we have attempted to provide a broad overview of some of the key government consumer participation policies, guidelines and discussion papers in relation to general health services at the jurisdictional level.

Victoria – The Victorian Department of Human Services has a range of initiatives which aim to promote and support consumer involvement in decision-making about their own treatment and care, in service development and quality improvement, and in health policy developments. These initiatives have been broadly grouped under what is called the Consumer Participation and Information Program. The key policy underpinning the program, *Doing it with us not for us: Participation Policy 2006–09* (DHS 2006) focuses on the stakeholder groups of consumers, carers and the community working together with their health services and the Department of Human Services to improve service accessibility and quality. The policy sets out priority actions across four levels of the health service system including the individual level, program and department level, health service organisational level and the Department of Human Services level. The *Doing it with us not for us: Participation Policy* aims to provide strategic direction for all policy stakeholders on participation and a model to continuously improve participation in action. Other initiatives under the Department's Consumer Participation and Information Program include the Health Issues Centre, which is funded to support and promote consumer participation, and the Cochrane Consumers and Communication Review Group, funded to identify evidence-based improvements to clinical practice focusing on consumer interactions with health care professionals, services and researchers.

Queensland – As part of a range of health reforms, in August 2006 Queensland Health released a discussion document entitled *Developing a Consumers' Health Council for Queensland: engaging Queensland consumers in health care* (Qld Health 2006). This document was published as part of an overall strategy to develop better ways for consumers to engage with government about improving health services. Along with the discussion document, the Health Quality and Complaints Commission has established a Consumer Advisory Committee and a review is currently being conducted of the Queensland Health Consumer Complaints Management Policy. The discussion paper presents a possible model for a future Consumers' Health Council in Queensland.

Australian Capital Territory – In late 2002, the ACT Health Minister appointed the ACT Health Council as the peak community reference group charged with planning and evaluation of health services in the ACT. The Health Council was established to engage consumers, the community and clinicians at the highest level of decision-making within ACT Health including providing policy advice and giving direction on health service delivery. The Health Council guides and monitors the progress of health policies and plans, with particular emphasis on the *Health Action Plan* (ACT Health 2002). The ACT Health Council publishes progress reports against the *Health Action Plan* and reports from public forums such as *How Do We Know the Health System is Performing?* – a public forum held in December 2005. ACT Health has also established a Community/Consumer Reference Group (CCRG) to provide high level input into

the Department's health policy and planning processes. The CCRG is the capacity for the community to have direct input into macro-policy decisions, broad resource allocation and priority setting.

New South Wales – NSW Health has developed a comprehensive and strategic approach to ensuring better consumer participation in all areas of health service delivery. The NSW Health website has dedicated an area for consumer participation, called 'NSW Health Participation Website'. It states that:

'NSW Health has identified community involvement as a priority and is committed to working in partnership with health services and the community to ensure that there is true involvement, at the earliest opportunity, in the planning and evaluation of health services'.

www.health.nsw.gov.au/policy/participate/index.html

In 2001, the NSW Health Consumer and Community Participation Implementation Group produced a report entitled *Partners in Health* (NSW Health 2001) which includes a wide range of recommendations in relation to involving consumers and community members as equal partners in the health team. To support consumers participating at a local level, NSW Health has established Area Health Advisory Councils which aim to facilitate the involvement of health service providers, consumers and community members in the development of the Area Health Services' policies, plans and initiatives. Each of the Area Health Advisory Councils have taken a different approach to consumer participation but broadly their strategies include regular council meetings, community consultations on specific health/service delivery issues, partnerships with local organisations/groups and consumer/community representatives on health service committees etc. Other Area Health Services have developed specific consumer participation policies or guidelines to guide action in this area, for example, *Help Us Make a Difference* (WSAHS 2002) – a set of consumer participation guidelines developed by Western Sydney Area Health Service in 2002.

South Australia – The South Australian Department of Health has developed a charter for South Australian public health system consumers entitled *Your Rights and Responsibilities* (SA Department of Health 2005). This charter aims to represent a commitment from the South Australian Government to support the rights and needs of individuals using the public health system and covers all of the health regions and all health services. The charter also aims to provide a commitment to service on the part of the public health system and to ensure that services are accessible and that they meet the needs of individuals. The charter sets out consumer rights in relation to access to information, consent to treatment, confidentiality and the right to receive appropriate care. It also outlines how consumers can participate in decision-making and looks at responsibilities for consumers. *Your Rights and Responsibilities* incorporates the Public Patients Hospital Charter, which is required under the Australian Health Care Agreement between the South Australian and Commonwealth Governments.

Western Australia – All government health services in WA are required to have a consumer charter that assures consumers are treated fairly, equitably and with dignity. An example of such a charter is the *WA Public Patients' Hospital Charter* (WA Department of Health 2002) which provides information to consumers on their rights and responsibilities and how they can have input into public hospital services. WA Health has also established District Health Advisory Councils (DHACs) through the WA Metropolitan Health Services and the WA Country Health Service. The aim of the DHACs is to represent the community and ensure that health consumers can have input into health policy and the development of local health services. DHACS are being established in health regions across the state.

Northern Territory – In *Building Healthier Communities – A Framework for Health and Community Services 2004–2009* (NT Department of Health and Community Services 2004), the NT Government set priorities to create better ways to work with services and the community. An outcome of these priorities was the establishment of the Health Advisory Council to provide advice to government on policy, planning and delivery of services. The Council is comprised of consumers, service providers and professionals residing in urban, rural and remote areas. Specific advisory structures have also been established for family and community services and disability services. The Family and Community Services Advisory Council provides strategic advice to the NT Government in areas such as child protection, family wellbeing, alcohol and drug use, mental health needs in the community, raising and supporting young people and ways to improve the system. The Disability Advisory Council provides advice to the NT Government on the policy, planning and delivery of disability services in the Northern Territory. Both councils include consumer representation. The *Building Healthier Communities Framework* has also identified the need to involve consumers and carers more across the whole health and community services system in the NT in the future.

Tasmania – This audit was unable to identify a specific strategy or overarching framework or approach in place to guide the development and implementation of consumer involvement in health services planning and delivery in Tasmania. However the Tasmanian Government has recently released a new *Royal Hobart Hospital (RHH) Development Plan Study* (Conrad Gargett Pty Ltd 2006). The Royal Hobart Hospital has a long history of consumer participation through many different forums. In 1994 a Consumer Reference Group was established. The role of this group is to:

- Provide a forum for consumers to provide input into quality issues in the delivery of health services at the Royal Hobart Hospital.
- Provide an opportunity for hospital staff to tap into community views and encourage a process of two-way exchange of information.
- Foster and develop communication links between the Royal Hobart Hospital and health consumers to enable them to participate effectively.
- Promote the benefit of consumer participation/partnerships and co-ordinate consumer involvement in quality improvement activities.
- Assist in the development of appropriate evaluation tools to monitor and measure the activities where there is consumer participation.

The new Development Plan for the RHH also identifies the importance of continuing consultation with stakeholders to support the development of integrated hospital and community based health services across the state.

2.5 Consumer Participation in Drug Treatment Services – Policy Frameworks

2.5.1 International Experience

At the international level, consumer participation with people engaged in drug treatment services is gaining in momentum. While the UK and New Zealand have taken a lead on consumer participation in the drug treatment context, other countries such as Canada, the United States and some European

countries are also following suit. The UK and New Zealand have two of the most comprehensive government policy frameworks to support consumer participation in drug treatment services. Some of the key aspects of the UK and New Zealand policy responses are described below.

Consumer participation in drug and alcohol services in the UK

One of the turning points for drug treatment services in the UK came in an independent review of drug treatment services in England entitled *Task Force to Review Services for Drug Misusers 1996* which was produced for the Department of Health. This report noted that the way in which services were delivered lacked quality and also highlighted the fact that people accessing treatment services were entitled to health care provision equitable to other areas of the National Health Service (NHS). This catalyst saw the future development of quality frameworks such as *QuADS: Organisational Standards for Alcohol and Drug Treatment Services* in 1999 by Alcohol Concern and the then-named Standing Conference on Drug Abuse (now known as DrugScope). These standards have a whole section dedicated to consumer participation in drug treatment services. This was followed in 2001 by the passing of the Health and Social Care Act 2001 which states that:

'It is a requirement that every NHS body, including drug treatment services, undertakes the involvement of patients and the public in its activities, not just when a major change is proposed, but in the development of proposals and in ongoing service delivery.'

The Act states further that consumers should be able to contribute to:

- the planning of drug treatment services;
- developing and considering proposals for changes in the way services are provided; and
- decisions which affect how services operate.

Involving users and carers is not an end in itself, but a way of achieving three fundamental objectives:

- strengthened accountability to all stakeholders;
- services that genuinely respond to the needs of users and carers; and
- a sense of ownership and trust. (NHS 2001)

At the same time, the development of the National Treatment Agency (NTA) in 2001 was undertaken and it is from here that consumer participation in drug and alcohol services gained in momentum.

The NTA is a special health authority, created by the UK Government to improve the availability, capacity and effectiveness of treatment for drug use in England. It is the first time that the UK Government has developed an organisation at the national level to oversee drug and alcohol issues. Parallel structures have been established with the Scottish Executive and the Welsh and Northern Ireland Assemblies. The NTA states that:

'... it wants to build an equal partnership with treatment service users and drug users because they recognise that those in treatment and those who have identified a need for treatment have the right to become involved in activities that affect their health and well-being.'

The NTA also states that it *'respects the unique expertise and experiences of people who use drugs and understand the health, esteem and other personal benefits which involvement can bring. The NTA has worked with individual users and user groups and have put in place processes and a structure for involving users at the regional and national level'*.

To ensure that consumer participation activities take place at national, regional, commissioning and service provider level, with users and carers being actively involved in planning, delivering and evaluating service provision, the NTA has developed a series of policies and resources that address the following issues:

- what user and carer involvement means;
- the need for user and carer involvement;
- when and where to involve users and carers;
- understanding the user's perspective;
- planning in partnership;
- consequences of partnership planning;
- local action;
- strategy and planning;
- training, support and development;
- engagement and inclusion;
- collaboration and partnership;
- results and impact; and
- treatment plans.

The NTA has also developed a framework for drug treatment consumer involvement, as shown in Figure 1.

Figure 1: UK National Treatment Agency framework for involvement

| | Information | Feedback | Influence |
|------------|--|---|--|
| Individual | Information to service users and carers about treatments and services | Feedback on service user experience | Shared decision making between service users, carers and professionals |
| Collective | Information to the wider public about how well the organisation is doing | Trends in complaints, PALS issues, etc Feedback on service user experience | Involvement in policy and planning |

Source: National Treatment Agency for Substance Misuse 2004.
PALS: Patient Advice and Liaison Service.

At the 17th International Conference on the Reduction of Drug Related Harm held in Vancouver, Canada in May 2006, *the Alliance* (formerly the Methadone Alliance – a user-led organisation in the UK which provides advocacy, training and helpline services to those who are accessing or have accessed drug treatment) gave a presentation on the their involvement in the NTA approach from the consumer perspective (Garratt 2006).

While the Alliance definitely acknowledged the role of the NTA in establishing a clear policy framework for consumer participation in drug treatment services, it also stated that from the consumer perspective there is some level of disparity in the 'aims of the approach' compared to the 'consumer experience' of the approach. For example on a positive note it believes that the national and regional meetings that are held for consumers are busy and well utilised; however on a more negative level, it stated that the consumer involvement workers that have been employed around the country are not necessarily representative of people who have been or are engaged in treatment.

Consumer participation in drug and alcohol services in New Zealand

To understand the developments in relation to consumer participation in the drug treatment sector in New Zealand it is necessary to first understand consumer participation in the area of mental health services. The reason for this is that in New Zealand alcohol and other drugs (AOD) is situated within mental health and the funding for AOD activities comes from the Mental Health Directorate section of the New Zealand Ministry of Health.

One of the problems consumers in New Zealand have identified in relation to AOD coming under the mental health umbrella is that the approach may have created barriers to the development of the AOD consumer workforce in some District Health Board (DHB) areas. This is due to the fact that in some DHB areas, Mental Health Consumer Advisors are responsible for all areas of consumer advocacy including undertaking the role of AOD Consumer Advisors. Some DHBs In this context, some DHB areas are reluctant to spend resources on engaging a specialist AOD Consumer Advisor when they have a Mental Health Consumer Advisor who, in their view, can carry out all consumer roles.

Another significant issue than can be created by this approach is the problem of how available resources are allocated between the issues of mental and AOD consumer initiatives. Given the mainstream nature of mental health issues, there can be a risk of the bulk of resources being directed to specific mental health consumer initiatives without necessarily seeing a corresponding commitment to AOD consumer employment, projects, research, etc. It can also cause problems with the composition of advisory groups and committees where the balance of representation can favour mental health rather than AOD.

As in Australia, the New Zealand mental health consumer workforce has existed for a lot longer than the consumer workforce in relation to drug treatment issues and its work has lead the way in the area of consumer health and advocacy. The New Zealand AOD consumer workforce acknowledges that it has learnt a great deal from the mental health consumer workforce but they feel there is still some work to be done before they are acknowledged and seen as equals, in a parallel process of workforce development rather than as an adjunct to mental health.

In New Zealand there is also a 'watchdog' organisation, the Mental Health Commission, which is one of the major players when it comes to influencing government policy. It is a consumer-focused organisation, although it has only taken on an active role in advocating for the AOD sector in recent years. There are a range of relevant materials available on their website at <http://www.mhc.govt.nz/publications>.

In relation to the government policy framework to support consumer participation in drug treatment services, in 1995 the New Zealand Ministry of Health published *A Guide to Effective Consumer Participation in Mental Health Services*. This document was intended as a guide for providers of mental health services including doctors, nurses, health workers, caseworkers, and caregivers, providers of other services utilised by consumers and consumers themselves. The Guidelines was one of the first documents to formally highlight the value of consumer expertise and acknowledge the unified call by consumer groups and mental health workers for participation of consumers in planning implementation and evaluation of mental health policies and programmes.

The Ministry outlined the main rationale and advantages for consumer involvement as:

1. efficient and effective services which meet consumer needs: Resources can be better targeted if services reflect actual needs
2. ethical reasons: People's ability to take responsibility and control over their lives is central to their quality of life
3. Health reasons: Participation by consumers in mental health services has been shown to be

empowering to both the individuals and the organisations involved.

The Guidelines highlighted three levels that consumers can have input into services:

- The individual level: input into treatment and services used as an individual
- The organisational level: input into provider agencies and organisations
- The policy level: contributing to policy development of purchasing or policy agencies

The major ways in which consumer participation can be realised in practice were identified as:

- Consumers join groups or networks that are controlled by their members and become active in advisory and/or advocacy roles
- Consumers, as individuals or in partnerships or groups, work together with providers on mental health issues
- Consumers set up or become involved in consumer-run and consumer-managed enterprises

(Taken from: Health Research Council, 2005, *Mental Health Consumer Advisor Resource Kit*) This can be ordered from www.hrc.govt.nz

There are a range of government documents containing references to consumer participation in mental health and AOD services and these can be obtained by contacting the New Zealand Mental Health Commission at www.mhc.govt.nz and the New Zealand Ministry of Health www.moh.govt.nz

New Zealand has a range of models by which consumers participate in alcohol and drug services. The first Consumer Advisor positions in the AOD sector were employed by the Alcohol and Drug Association (ADA), an NGO based in Christchurch.

ADA is contracted by the six South Island District Health Boards to provide regional Consumer Advisor positions. It employs two Consumer Advisors to bring consumer perspectives to drug and alcohol services in the South Island. This is done through regular meetings with consumers and consumer groups around the South Island and reporting back to service providers.

CADS (Community Alcohol and Drug Services) Auckland was the first District Health Board AOD service to employ a fulltime Consumer Advisor to work with its counselling, detox and methadone services, and now has a team consisting of a fulltime Consumer Advisor and three part-time Consumer Liaisons.

Increasing the number of service users as advisors to DHBs is a strategy to improve the quality and responsiveness of mental health services. Funding and employment arrangements for consumer advisors vary, as does the positioning of the roles within services.

Two other DHB AOD services employ specific AOD Consumer Advisors: Northland and Bay of Plenty. Under this model, the consumer workers are situated within the services rather than sitting outside services as in the South Island.

NGOs and residential AOD services are slowly developing consumer participation through the part-time employment of consumer representatives and are utilising consumer groups in relation to planning and evaluation.

In the mid-Central region of the North Island a group of consumers has established *Te Punawai Whanuitanga* based on the Maori *Te Whare Tapa Wha* concept to “empower people in recovery to their pathway to wellness”. Essentially this is a peer support model but is less focused on the individual with

the AOD issue focused instead on including the wider *whanau* (extended family) in its activities. (Further information on *Te Punawai Whanuitanga* can be found at: http://www.alac.org.nz/FileLinks/8804_TF_TePunawaiWhanuitanga.c38f70a6.pdf)

The Mental Health Commission's *Service User Workforce Development Strategy* is an important contribution to mental health workforce development in New Zealand and is closely aligned with the planning for the alcohol and other drugs (AOD) consumer workforce development being undertaken by the National Treatment Centre for AOD Workforce Development.

All consumer participation in AOD services rests upon the National Mental Health Sector and Alcohol and Other Drug Sector Standards which both have as a standard:

"Consumers will be/Consumers are involved in the planning, implementation and evaluation at every level of the mental health service to ensure services are responsive to the needs of individuals."

(Ministry of Health, 2001 and Ministry of Health, 2003)

The criteria by which attainment of this standard is measured are:

- 9.1 The mental health service has policies and procedures related to the consumer participation, which are used to maximise their role and involvement in the service, and where applicable includes their employment.

This may include but is not limited to:

- (a) A range of advice is sought when developing consumer participation processes from consumers, consumer groups and people who are using the service.*

- 9.2 The mental health service includes participation from consumers in decisions relating to policies, protocols, planning, implementation, and monitoring.

This may include and is not limited to:

- (a) strategic planning*
(b) quality committee
(c) quality improvement projects
(d) service development
(e) staff selection and training
(f) policies and procedures
(g) advisory groups at service/team levels
(h) involvement in inquiries

- 9.3 The mental health service assists with training and support for consumers and staff to maximise consumer participation in the service.

This shall include and is not limited to:

- (a) training for staff on working with colleagues who are consumers;*
(b) supervision, debriefing and peer support.

- 9.4 Consumers and consumer groups who work in planning, implementation and evaluation of

mental health services are appropriately reimbursed for expenses and/or paid for their time and expertise.

- 9.5 Consumers and consumer groups who work in planning, implementation and evaluation of mental health services have clear terms of reference and/or position descriptions.

This may include and is not limited to:

(a) *their roles and responsibilities are clearly outlined and include areas such as accountabilities, confidentiality, and conflicts of interest.*

- 9.6 The mental health service established mechanisms and feedback processes that involve consumers in contributing to the collective view at service and team/unit levels.

This may include and is not limited to:

(a) *consumer forums*

(b) *consumer satisfaction surveys*

(c) *consumer advisory groups*

(d) *focus groups*

(e) *consumers networking with local people receiving the service and consumer groups*

(Excerpt: Standard 9: From National Mental Health Sector Standards/ He Whariki Oranga Hinengaro, Ministry of Health 2001)

Consumer participation in drug and alcohol services in Canada

'Nothing About Us Without Us' – Greater, Meaningful Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative (Canadian HIV/AIDS Legal Network, 2005) states that within the Canadian context *'... it is time to move from supporting the meaningful involvement of people who use drugs in principle to ensuring their greater involvement in practice.'* Within this document, Australia is singled out as a successful example of the involvement of people who use illicit drugs. This however is in relation to involvement in HIV/AIDS and hepatitis C and not in relation to drug treatment services. Although *Nothing About Us Without Us* is not a government policy framework, it is included in this policy audit because it is a landmark community-initiated policy document with the potential to greatly influence the future of consumer participation in Canada. Following the release of this document, Canada Health sponsored for the first time in 2006 a national meeting of drug user and treatment consumer representatives from across Canada to discuss the formation of a national network and other future policy objectives. It is too soon to tell whether the Canadian Government will respond to the outcomes of this national meeting with a coherent policy framework for consumer participation in drug related services.

2.5.2 National

Within Australia there is limited literature available on consumer participation policy frameworks in relation to drug treatment services. Within the limited resources of this policy audit we were unable to conduct in-depth research into whether every drug treatment service or every area health service or health region has an existing consumer participation policy. We did however conduct an extensive search through available databases and Internet sites to gain an overall picture of existing consumer participation policies at the national and state/territory levels.

National Drug Strategy – In 1985 the Federal Government launched the National Campaign Against

Drug Abuse (NCADA) followed in 1993 by the development of a series of national drug strategies and strategic frameworks. These policy frameworks outlining Australia's core policy responses to both licit and illicit drug use were formed with strong bipartisan political support across all political parties, all state and territory governments and in partnership with the non-government sector.

The current *National Drug Strategy: Australia's Integrated Framework 2004–2009* states the following commitment to consumer participation:

- improved access to quality treatment – through the involvement of consumers and drug user organisations; and
- a coordinated, integrated approach – through a commitment to partnership.

Other than broadly identifying the issue of consumer participation as shown above, the current National Drug Strategy (NDS) does not outline a framework or approach to guide and support the implementation of consumer participation in relation to drug related services and programs. In addition, outside of the general requirements under the Australian Health Care Agreements relating to patients of public hospitals, there remain no specific policies or guidelines at the national level to support consumer participation in drug treatment services.

It is important to note here that, while the NDS does not currently outline a comprehensive policy approach to consumer participation in drug services, there are a whole range of national strategies targeting other health issues that have played a role in building the existing consumer responses within drug treatment services. For example there are the national initiatives of the Australian Government Department of Health and Ageing in relation to HIV/AIDS, Hepatitis C and other related diseases which include:

- *National HIV/AIDS Strategy 2005–2008: Revitalising Australia's Response;*
- *National Hepatitis C Strategy 2005–2008;*
- *National Sexually Transmissible Infections Strategy 2005–2008;* and
- *National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy 2005–2008.*

While these initiatives and strategies (that are duplicated at the state and territory level in most jurisdictions) are not exclusively focused on issues relating to drug treatment service delivery, they do demonstrate a strategic commitment on behalf of the Australian Government to the involvement of 'affected communities' or 'consumers' at the national level. These strategies have been built on the *Partnership Approach* which recognises the central importance of the affected communities in developing the policy response and in shaping the planning and delivery of services. Historically, these strategies have also supported the development of grass-roots organisations that are managed by the affected communities – including the development of the national and state/territory peer-based drug user organisations.

Given the link between blood borne viruses (BBVs) and injecting drug use, the provision of drug treatment services has been a key feature of Australia's national policy response to the prevention and treatment of BBVs. The lack of an equivalent policy framework within the NDS to support the active participation of drug treatment service consumers in the planning and delivery of drug treatment services has meant that the policy response to BBVs has in many ways acted as a 'de facto' policy framework for consumer participation in drug treatment services.

It is here that the role of peer-based drug user organisations is given value in relation to consumer participation in drug treatment services. Drug user organisations provide peer-based education, services and support, and have played a significant role in representing their community in relation to government policy development and in services planning and delivery. At the national level this role has been undertaken by the Australian Injecting and Illicit Drug Users League (AIVL) and through the AIVL member organisations at the state and territory level. Under the guises of the Hepatitis C and HIV/AIDS strategies, AIVL and its members have developed capacity in relation to consumer participation and demonstrated the skills and knowledge that drug treatment service users have to offer.

Accreditation Processes – Although service accreditation processes are not consumer participation policy frameworks, they are included here because in the absence of clear national or jurisdictional consumer participation policies, they can provide a structural framework to support consumer participation at the service delivery level. Many drug and alcohol treatment services are now engaging in accreditation processes and there are a number of different accreditation bodies across the country. The Quality Improvement Council (QIC) is an Australasian body with over 20 years' experience in overseeing accreditation processes in health and community services. According to their strategic plan the QIC aims to:

'... promote continuous quality improvement in health and community services through the provision of standards, accreditation programs, and developmental resources, and undertaking projects for the benefit of service users, service staff and the wider community'. (2005– 08 QIC Strategic Plan)

QIC recently developed a set of standards for the drug treatment sector called the *Alcohol, Tobacco, and Other Drugs Services (ATODS) Standards Module*. The recently completed ATODS Module applies to the full range of services in this field including counselling, rehabilitation and residential services. There are eight standards and a set of supplementary evidence questions covering subjects like harm reduction, continuity of care, relationship with service consumers, assessment and individual service planning. At this stage, these standards omit consumer participation.

Towards Better Practice in Therapeutic Communities (ATCA 2004) – This was published by the Australasian Therapeutic Communities Association (ATCA) as part of the Illicit Drug Strategy, in recognition of the need to improve the capacity and accountability of therapeutic communities in Australia, and to demonstrate the effectiveness of the therapeutic community (TC) approach. The report states that:

'Aspects of program delivery (reflecting the components of intervention experienced by residents of TCs) include encouraging community spirit and a sense of belonging and that encouraging a sense of participation in and belonging to the community is critical to the effectiveness of the TC approach. Work is used to enhance the sense of community, to build self-esteem and social responsibility, and to develop communication, organisational and interpersonal skills.'

The report outlines activities that residents of such services are required to participate in to:

- take responsibility for orienting, guiding and supporting new residents; and
- conduct important peer management functions such as preparing work rosters, organising and running house meetings.

These activities have been noted within the TSU Project as consumer participation activities. What differs here is that the aims of and motivations for participation are therapeutic rather than aspiring to meet consumer participation principles.

2.5.3 State and Territory Jurisdictions

Although, as stated above, it was beyond the resources available for this audit to document all consumer participation policies at the local level, it should be noted that most area health services/regional health authorities etc do have general health consumer participation policies in place. These have been documented in section 2.4.2 above on state and territory consumer participation policy frameworks in the general health setting. However, the specific needs of drug treatment consumers are not always identified within these policies. Outside of these broad consumer health policies, we identified two examples of specific consumer participation policies for drug treatment services at the state and territory level. These are described below.

A Guide to Consumer Participation in NSW Drug and Alcohol Services – In 2005 the Centre for Drug and Alcohol (CDA) within NSW Health commissioned this unique publication. Many stakeholders contributed to this document, including consumers. It is a comprehensive guide that was developed to provide assistance to drug and alcohol services to implement appropriate consumer participation initiatives at the local level. While the guide acknowledges that there are many readily available resources about consumer participation in a general sense, it expressed that there was a *'dearth of information available about the involvement of consumers specifically in Drug and Alcohol services'* (NSW Health 2005).

The guide includes the following areas of concern for consumer participation in drug and alcohol services:

- who is a consumer and why involve consumers?
- issues relating to the involvement of consumers in drug and alcohol services;
- guiding principles;
- planning for undertaking consumer participation;
- a framework for consumer participation;
- strategies to consider;
- resources; and
- examples of consumer participation in a drug and alcohol service.

The guide highlights the sensitivities and complexities that can present some challenges to involving consumers, for example:

- low literacy;
- lack of self confidence; and
- pharmacotherapy clients fearing reprisals from both staff and other clients, including cessation of their medication if they make an official complaint or criticise the service and/or staff.

The guide also highlights the issues that staff of treatment services face:

- lack of experience of working with clients in the drugs and alcohol sector;
- doubts about the ability of their clients to contribute honestly and effectively; and
- negative views about illicit drug use.

The guide provides useful principles relating to consumer participation for treatment service users. Some of the recommendations that the guide makes for drug treatment services include the following:

- Think about consumers in the broadest sense.
- Involve consumers as early as possible.
- Effective consumer participation requires leadership and support.
- Be clear about the purpose of consumer participation initiatives.

- Involve consumers in relation to a range of issues and across different settings.
- Organisational culture must demonstrate support and encouragement for consumer participation.
- Support and assistance needs to be provided to consumers to assist their participation.

The guide did not have an implementation strategy which would be necessary to ensure that the principles and recommendations outlined in the publication are implemented in practice with the NSW drug treatment sector.

South Western Sydney Area Health Service (SWSAHS) has an active community participation framework that not only encompasses general health but also includes blood borne virus and drug and alcohol treatment service users. It states that:

'Participation of the community in health service planning, development, service delivery and evaluation is fundamental and essential to the provision of effective health services'.

The service has identified a range of measures to engage the community and:

'...gain community input and feedback, such as: developing formal partnerships, inviting public comment through public meetings, forums and documents for consultation; conducting focus groups, surveys, interviews and workshops; forming community councils, advisory and consultative committees; developing networks of consumers, carers and community representatives; and appointing representatives to health committees'.

Although the SWSAHS example above does not represent a consumer participation 'policy' but is instead a 'program', we have documented it in this audit because it was one of the few examples of an area health service developing a framework to support consumer participation in the drug treatment setting.

Although some state and territory mental health, drugs and/or blood borne virus (BBV) strategies make mention of 'working in partnership with affected communities' or 'involving and consulting with consumers', the absence of detailed policy frameworks to guide this action has meant that consumer participation in drug treatment services at the state/territory level remains, for the most part, an ad hoc process.

The only peer-based drug user organisations that are specifically funded to undertake drug treatment consumer projects under the auspices of the state/territory drugs and/or BBV policy frameworks are:

- **VIVAIDS – the Victorian Drug Users Group** which is funded to conduct the *Pharmacotherapies Advocacy, Mediation and Support* (PAMS) Service through the Victorian Department of Human Services.
- **WA Substance Users Association** (WASUA) which is funded to conduct the *Opioid Replacement Pharmacotherapies Advice and Complaints Service* (ORPACS) through the WA Health Department.

Under the auspices of the National Drug Strategy, NGO Treatment Grants Program (ACT Regional Office) the ACT peer-based drug user organisation are:

- **Canberra Alliance for Harm Minimisation and Advocacy** (CAHMA) which was funded to conduct the *Treatment Support Service* (TSS) Project. The TSS Project was a consumer-based project providing peer support, information, advocacy and referral for people accessing drug treatment services in the ACT. This project was defunded at 30 June 2006 and has been replaced with a non-peer based project at a mainstream AOD service.

In addition to PAMS, ORPACS and TSS at the peer-based drug user organisations in Victoria, WA and ACT, Victoria also funds the:

- **Association of Participating Service Users** (APSU) which is a non-government service funded through the Victorian Department of Human Services to provide a voice for drug treatment service users and have input into all aspects of the drug treatment service system. APSU is a project of *Self Help Addiction Resource Centre* (SHARC).

It should be noted that peer-based drug user organisations in other states and territories, although not specifically funded to conduct consumer-based drug treatment projects, do carry out work in this area often as part of a broader health promotion agenda and sometimes in an unfunded capacity. More specific policy frameworks at the state and territory level aimed directly at supporting consumer participation in drug treatment service (such as the *Guide to Consumer Participation in NSW Drug and Alcohol Services* above) are needed to shift consumer participation efforts in this area from a series of isolated projects to a more strategic and integrated approach.

2.6 Consumer Participation in Drug Treatment Services – Conclusions

Commitment to consumer participation in the general health setting from governments and communities has evolved at the international, national and local levels as a result of the evidence that shows that consumer participation improves health outcomes. The evidence to support consumer participation as a positive and helpful tool is also plentiful. It has been acknowledged by both consumers and providers that being involved with your own healthcare from the early stages has numerous advantages including extending the level and length of contact with health services.

Based on the experiences and progress made in other areas of health care, consumer participation is gaining wider acceptance as an approach that is fundamental to good practice and high quality service delivery. Examples provided in this audit from Victoria and New South Wales show the effectiveness of consumer participation in health services and demonstrate how greater consumer participation can be achieved in practice. There is still a great deal of work that needs to be done to address the major gaps in policies and guidelines to support consumer participation in drug treatment services. Governments at the national and state/territory levels need to include principles for consumer participation into key policy and strategic documents to create the frameworks to support consumer participation in action.

While it is encouraging to find several different examples of consumer participation and involvement at the government policy level, there are fewer examples of where these policies have been operationalised within service delivery. The audit shows that, at the service level, more work needs to be done to engage consumers in service planning and delivery. Some examples of engaging consumers in drug treatment services could include the following practices, to name just a few:

- including consumer representatives on service planning committees;
- consulting consumers in relation to staff recruitment and appraisal processes;
- involving consumers in staff training; and
- developing mechanisms for consumer input into service planning and development.

The evidence has also highlighted that consumer participation programs in health services, regardless of the type of health service, have a range of core or guiding principles in common including that:

- Consumers need to be engaged and involved from the beginning.

- Effective consumer participation requires leadership, funding and support.
- The purpose of consumer participation programs/initiatives need to be clear from the outset.
- Consumer participation initiatives should:
- involve a range of different consumers;
- provide support and encouragement for consumers to participate; and
- provide practical assistance to consumers to enable them to participate fully.

Consumer participation in other areas of health service delivery has been shown to be successful. Consumer participation in drug treatment services can be equally successful if there is a commitment to implementing existing policy, addressing the policy gaps and to engaging with consumers to support their participation. As the *Guide to Consumer Participation in NSW Drug and Alcohol Services* states:

'Generally, the principles that underpin consumer participation in Drug and Alcohol Services are no different from those for other parts of the health system. Whilst some may need greater emphasis due to the context, all of the guiding principles are applicable to any health service.'

(NSW Health 2005)

❖ Chapter 3: Results – Consultation with Service Consumers and Providers

3.1 Definition of ‘Consumer Participation’

This study uses a model of consumer participation that was developed in consultation with the health consumer literature and from examples of consumer participation in other health services, such as mental health services (Commonwealth Department of Health and Ageing 2002), and government area health services (Western Sydney Area Health Service 2002). The literature shows how consumers can have varying degrees of involvement in service planning and delivery (National Resource Centre for Consumer Participation in Health 2004). The lowest level of consumer participation, according to this literature, is concerned with providing information to or receiving information from consumers. Examples of ‘low degree’ consumer participation activities are complaints systems, satisfaction surveys, consumer councils, suggestion boxes, or producing newsletters or other printed materials that inform consumers of service planning and delivery issues (Figure 2). Middle level consumer participation involves consumers in more active roles that encourage participation but do not involve decision-making. Examples of these types of activities include supporting consumers to produce their own printed educational resources or involving consumers in particular aspects of staff training (Figure 2). The highest degree of consumer involvement grants consumers decision-making roles in the planning and delivery of services. Here, consumer representatives are selected to have membership on boards or management committees that make key organisational decisions (Figure 2).

Figure 2: Treatment Service Users’ Project model of consumer participation

| Degree | Type of participation activity | Example |
|--------|--|---|
| HIGH | Consumer participation built in to values, philosophies and policies of organisation | Consumer participation incorporated into vision or mission statement; patient charter; partnership with drug users organisation |
| | Activities in which consumers play a <i>decision-making</i> role | Consumer representatives have membership on service planning committees, attend staff meetings, advise on staff performance appraisal and recruitment |
| | Activities in which consumers play a non- <i>decision-making</i> role | Consumer representative involved in staff training, in resource development |
| | Activities that promote and support consumer participation | Consumers are supported to conduct their own group activities; service displays consumer advocacy group publications (<i>Junkmail, Users News</i>) |
| LOW | Activities concerned with providing information to or receiving information from consumers | Consumer councils, patient forums, surveys, suggestion box, complaints system, in-house newsletter for clients |

Following are definitions for each consumer participation activity used in this study. These were the definitions provided to respondents in order to aid their understanding of questions.

Produce resources for consumers that include information about service planning – in the previous 12 months, the service has written or produced its own brochures, fact sheets, newsletters, magazines that specifically include information about changes to the policies and programs of the service.

Survey – surveys that took place within the previous 12 months that specifically asked consumers for their opinions about how programs and services could be improved.

Consumer council – committees or groups of consumers that met within the previous 12 months whose role it was to advise the service about how services and programs are run.

Consumer forum – open meetings held within the previous 12 months in which consumers could express their views about how services or programs are run.

Display of consumer representative group publications – in the previous 12 months, the service has displayed or made available in other ways the publications of the drug user organisations (NUAA, VIVAIDS, WASUA).

Consumers supported to conduct own group activities – service has ways to help consumers facilitate and run their own support groups (eg fitness groups, mums' and dads' groups) such as through providing space, training or transport.

Consumer involvement in resource development – consumers involved in writing or reviewing written materials such as brochures, fact sheets, newsletters, magazines or educational resources.

Consumers involved in staff training – consumers involved in determining the content of in-service training that is directly relevant to consumers and their treatment.

Consumer representatives attend staff meetings – in the previous 12 months the service has had a consumer representative regularly attend staff meetings.

Consumer representatives on decision-making committees – in the previous 12 months the service has had a consumer representative as a member of any committee that plans or makes decisions about services or programs.

Consumer representative involved in staff recruitment – in the previous 12 months the service has had a consumer representative involved in the employment process of new staff at the service. Respondents were provided with examples of having a consumer representative contribute to interview questions or sit on an interview panel.

Consumer representative involved in staff performance appraisal – in the previous 12 months the service has had a consumer representative involved in assessing staff job performance. Respondents were provided the example of having consumer representatives meet with the nurse unit manager to give feedback on staff performance.

Consumer charter of rights – a document outlining client/patient rights and the guarantees that specify service conditions.

This model and its definitions are used in this study to define 'consumer participation' as it might take place in practice, in order to structure the survey questions and provide a framework through which the results of the study are interpreted.

3.2 Method

3.2.1 Participants

To be included in the study, service providers and consumers were required to be from pharmacotherapy, residential rehabilitation and detoxification services. Rehabilitation and detoxification services concerned exclusively with alcohol use were excluded. A small number of services that conducted non-residential rehabilitation were included because in regional areas of particular states residential services are uncommon. All services were located in New South Wales, Victoria or Western Australia. A 'key informant' from each service was invited to answer questions on behalf of the service they worked for. Key informants were usually nurse unit managers or equivalent service managers. Each key informant represented a single service. Service consumers were people aged 18 years or older who were accessing treatment at eligible drug treatment services.

3.2.2 Data Collection

A list of eligible treatment services was constructed using a report published by the Australian National Council on Drugs (ANCD 2005). Approximately 110 services were randomly selected, with the expectation that 65–85 would ultimately participate. Random selection of services was stratified by state to ensure representation from each state. The ANCD list of services did not contain telephone or mailing address information. Web-based directories (including government service directories and yellow pages) were used to obtain telephone numbers for each of the selected services. Each service was telephoned to obtain a mailing address and contact name of the nurse unit manager or equivalent. At this stage, services were asked to verify that they met the study's criteria of offering pharmacotherapy, residential rehabilitation or detoxification services. Services were excluded from the sample if there was inadequate contact information, if the service no longer operated or had amalgamated with another service, or if the service no longer offered the kinds of services that made it eligible for inclusion in the study (pharmacotherapy, residential rehabilitation or detoxification). After this verification, a final sample of 78 eligible services remained.

Each of the remaining 78 services was mailed a letter inviting the nurse unit manager or equivalent to take part in a 20–30 minute structured interview by telephone. One to two weeks following this, nurse unit managers were telephoned to determine their willingness to participate and to set a time for the interviewer to phone back and conduct the interview. Most participants agreed to an interview at the first phone call. Those that were difficult to contact were phoned a total of three times before being designated as a refusal. A total of 64 service providers completed a telephone interview, providing a final response rate of 82%.

From the 64 services included in the provider sample, 14 sites were chosen as locations from which to recruit consumers. The 14 sites were selected using purposive sampling to ensure an adequate representation across the three states, from regional and metropolitan areas, government and non-government services, and from the three types of eligible services. Recruitment posters were placed in prominent locations at each service inviting consumers to phone and book an appointment for an interview. Each of the 14 participating services offered a private space in which to conduct the interviews. Between three and 25 consumers were recruited from each of the 14 services.

Data was collected using interviewer-administered questionnaires. Separate questionnaires were developed for consumers and providers, but were structured to allow comparison between the two groups. Questionnaires were piloted (n=7 consumers, n=8 providers) to evaluate the clarity and sensitivity of survey questions and to determine the time required to complete the interview.

Most survey questions were closed format; however, a small number of questions were open-ended and coded into categories after data collection. Questions collected data about:

1. current opportunities for consumer participation at services and consumer's knowledge and experiences of those opportunities;
2. service providers' beliefs about the main barriers to conducting consumer participation activities;
3. service consumers' beliefs about the main barriers to participating in consumer participation activities;
4. willingness to conduct or participate in consumer participation activities in future;
5. attitudes towards consumer participation;
6. beliefs about staff and consumers; and
7. demographic and other descriptive information.

Interviews with providers were conducted over the telephone by a member of the NCHSR research team. Interviews with consumers were conducted face-to-face by trained peer interviewers. All interviews took approximately 20–30 minutes to complete. The peer interviewing method was used because it has been shown to facilitate recruitment and reduce biases because of a sense of shared norms, values and meanings (Kelsall & Kerger 2001; Williams & Roche 1999). All consumer participants provided written consent and were offered \$20 to cover travel and other expenses.

3.2.3 Data Analysis

Data entry was conducted using Microsoft Access and all data was checked and validated before analysis. Because the purpose of the study is primarily descriptive, most data is presented as proportions or percentages. A secondary aim of the project was to compare responses across types of treatment services. For this purpose four categories were required: pharmacotherapy, residential rehabilitation and detoxification, and a fourth category for services that offered a combination of two or more of these. Once broken down to service type categories, the provider data had small cell sizes. To accommodate this, tests for statistical differences across these groups were conducted by combining all residential services (residential rehabilitation and detoxification, and combination services) compared to pharmacotherapy services. Differences between these two groups were determined using χ^2 . Analyses were conducted using *Statistical Package for the Social Sciences version 14*.

3.3 Ethical Approval

The study has ethical approval from the Human Research Ethics Committee (HREC) at the University of New South Wales and all relevant area and state ethical review boards, including one HREC from Victoria, one from WA and nine from NSW. The process of gaining ethical approval began in November 2005 and was completed by May 2006.

3.4 Characteristics of Service Providers and Consumers

Of the 64 participating services, half (50.0%, n=32) were located in New South Wales, 32.8% (n=21) in Victoria and 17.2% (n=11) in Western Australia. Key informants were most commonly directors or general managers (40.6%, n=26) or nurse unit managers (32.8%, n=21), followed by service coordinators (18.8%, n=12) or individuals who held other positions (7.8%, n=5).

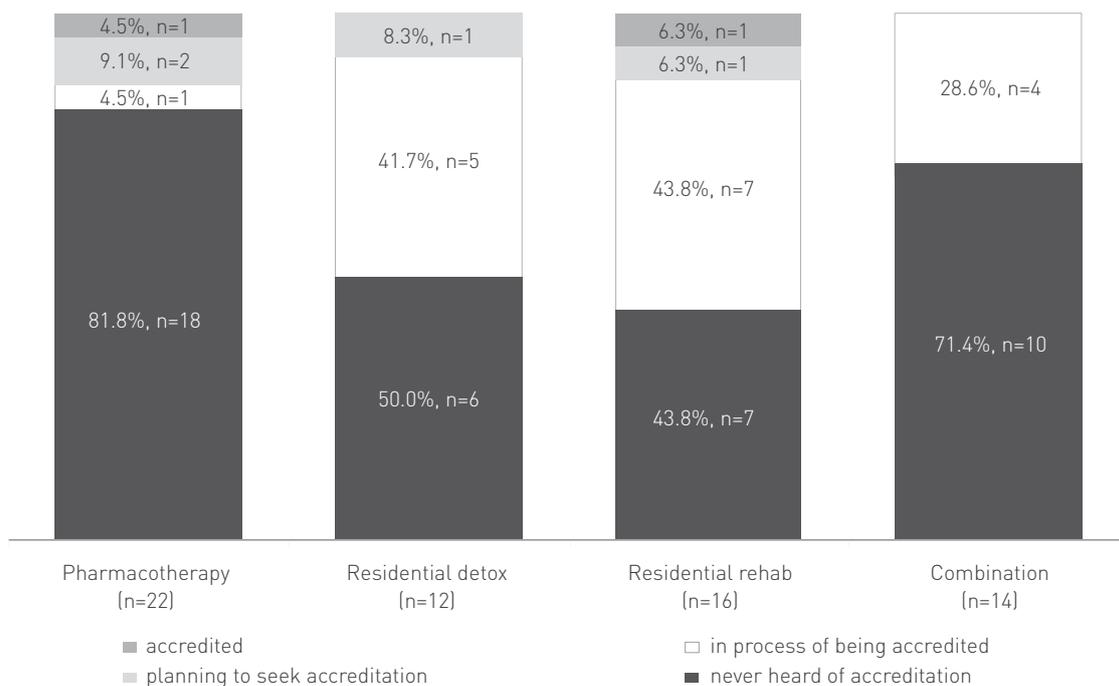
Participating services included 22 pharmacotherapy services (34.4%), 16 residential rehabilitation services (25.0%), 12 residential detoxification services (18.8%) and 14 combination services (21.9%). Services ranged widely in size, from small regional or rural-based services treating a single consumer, to large metropolitan services treating up to 850 consumers (Table 1). This demonstrates the success of the random sampling method in recruiting a widely representative sample of Australian treatment services.

Table 1: Size of services – estimated number of consumers, by service type (n=64)

| | Total (n=64) | Pharmaco- therapy (n=22) | Residential detox (n=12) | Residential rehab (n=16) | Combination of services (n=14) |
|--------|-----------------|--------------------------------|--------------------------------|--------------------------------|--------------------------------------|
| Median | 30.0 | 150.0 | 10.0 | 15.5 | 50.0 |
| Range | 1–850 | 5–850 | 1–80 | 6–39 | 12–600 |

At the time of data collection, most services (64.1%, n= 41) had received accreditation or were in the process of being accredited (26.6%, n=17). A small number were planning to seek accreditation (6.3%, n=4) or had never heard of accreditation (3.1%, n=2). Stage of accreditation across the different types of services is presented in Figure 3. Levels of accreditation were different between pharmacotherapy service (n=22) and residential services (n=42) (residential rehabilitation, detoxification and combined services) with significantly more pharmacotherapy services reporting that they had received accreditation (81.8%, n=18 versus 54.8%, n=23, $\chi^2=4.59$, $p<0.05$).

Figure 3: Stage of accreditation, by service type (n=64)



Of the 179 participating consumers, 59.2% (n=106) were receiving treatment from services located in NSW, 21.2% (n=38) in Victoria and 19.6% (n=35) in WA. The average age of consumers was 35.4 years (range 18–59 years) and more than half (59.8%, n=107) were men. The largest proportion (60.3%, n=108) of consumers were receiving pharmacotherapy treatment, 19.0% (n=34) were in residential rehabilitation programs, 11.7% (n=21) were in residential detoxification programs, and 8.9% (n=16) were receiving other types of services (for example, non-residential rehabilitation counselling). Participants attending pharmacotherapy services had been doing so for a median time of 36 months (range 0–240 months). As expected, consumers attending residential rehabilitation and detoxification services had been doing so for a much shorter period of time, a median of 35 days (range 1–540 days) and 6 days (range 1–21 days) respectively.

3.5 Current Opportunities for Consumer Participation in Drug Treatment Services

3.5.1 Opportunities Offered by Services

Data shows that many services conduct what can be considered 'low degree' consumer participation activities; that is, activities concerned with providing information to or receiving information from consumers (Table 2). For example, close to two thirds (64.1%, n=41) of all services reported conducting a survey within the previous 12 months that asked consumers specifically for their views on service planning and delivery. While this suggests that some services are concerned with incorporating consumers' views about service quality, this was largely limited to low degree activities. As the degree of consumer involvement increased, the proportion of services engaging in consumer participation decreased, with only a small proportion of services reporting that consumer representatives were involved in decision-making activities (Table 2). The least commonly reported activities were those that involved consumer representatives in matters relating directly to staff, such as staff training, staff performance appraisal, staff recruitment or having consumer representatives attend staff meetings. Nevertheless, it is encouraging to find that at least one example of each type of consumer participation activity was found among the 64 participating services. This demonstrates that consumer participation at every level of involvement is viable.

While 'high degree' activities were largely uncommon, most services (85.9%, n=55) reported having a consumer charter of rights (Table 2). Services reported that the charter of rights was most commonly provided to consumers in the form of an induction or orientation package (61.8%, n=34). Some services reported giving consumers a copy of their rights as part of a signed treatment agreement or contract (32.7%, n=18) and/or posting it in common areas (38.2%, n=21). Part of the reason that such a large proportion of services have a charter of rights, but not other features of 'high degree' consumer participation, is that a charter is often required for accreditation.

Certain kinds of consumer participation activities were more common in some services than others. Pharmacotherapy services were more likely than residential services to display or distribute publications from consumer representative organisations (such as NUAA, VIVAIDS and WASUA) (77.3%, n=17 versus 38.1%, n=16, $\chi^2=8.87$, $p<0.05$). On the other hand, residential services (n=42) were more likely to have conducted consumer councils or forums compared to pharmacotherapy services (n=22) (22.7%, n=5 versus 54.8%, n=23, $\chi^2=6.02$, $p<0.05$). This is likely because it is a strong feature of some residential rehabilitation services to conduct regular open meetings at which consumers can offer their opinions about service delivery. While these meetings are certainly aimed at engaging consumers in group decision-making activities, such meetings may not necessarily constitute 'consumer councils'.

Services that reported that they did not conduct consumer participation activities were asked to provide the main reasons why they did not (Table 3). In the main, reasons given regarding low or mid degree activities were focused on resourcing and capacity issues, both for the service and consumers. For example, services commonly reported a belief that staff were too busy to facilitate such activities or that consumers lacked the necessary skills to participate. There was also a strong belief amongst services that consumers would not be interested in taking part in consumer participation activities. Moreover, many services had simply never thought about involving consumers, which suggests that raising awareness about consumer participation in treatment services is important.

With higher degree activities, the reasons given focused on concerns about confidentiality for both staff and consumers. Service providers believed that consumers would be reluctant to take part in staff performance appraisal and recruitment because staff would know the identity of those consumers involved. Likewise, service providers felt that staff would feel equally that the details of their recruitment and appraisal should be kept confidential from consumers. These concerns about confidentiality may relate to the way that these activities challenge the existing roles and relationships between service providers and consumers. Notably, providers again expressed the belief that consumers are not interested in consumer participation.

Table 2: Current arrangements for consumer participation in drug treatment services, by service type

| Degree | Type of activity | Example | Total (n=64) | | Pharmaco therapy (n=22) | | Residential detox (n=12) | | Residential rehab (n=16) | | Combination of services (n=14) | |
|---|--|--|--------------|------|-------------------------|------|--------------------------|------|--------------------------|------|--------------------------------|------|
| | | | n | % | n | % | n | % | n | % | n | % |
| HIGH | Consumer participation built into values and policies of organisation | Incorporated in Mission Statement | 12 | 18.8 | 4 | 18.2 | 1 | 8.3 | 3 | 18.8 | 4 | 28.6 |
| | | Consumer Charter of Rights | 55 | 85.9 | 19 | 86.4 | 11 | 91.7 | 14 | 87.5 | 11 | 78.6 |
| | Activities in which consumers play a decision-making role | Consumer rep involved in staff performance appraisal | 4 | 6.3 | 1 | 4.5 | 1 | 8.3 | 2 | 12.5 | 0 | 0.0 |
| | | Consumer rep involved in staff recruitment | 7 | 10.9 | 1 | 4.5 | 1 | 8.3 | 4 | 25.0 | 1 | 7.1 |
| | | Consumer rep on decision making committees | 13 | 20.3 | 2 | 9.1 | 0 | 0.0 | 7 | 43.8 | 4 | 28.6 |
| | | Consumer rep attend staff meetings | 6 | 9.4 | 1 | 4.5 | 0 | 0.0 | 5 | 31.3 | 0 | 0.0 |
| Activities in which consumers play a non-decision-making role | Consumers involved in staff training | 2 | 3.1 | 2 | 9.1 | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 | |
| | Consumers involved in resource development | 20 | 31.3 | 5 | 22.7 | 1 | 8.3 | 11 | 68.8 | 3 | 21.4 | |
| Activities that promote consumer participation | Consumers supported to conduct own group activities | 30 | 46.9 | 10 | 45.5 | 3 | 25.0 | 11 | 68.8 | 6 | 42.9 | |
| | Display of consumer representative group publications | 33 | 51.6 | 17 | 77.3 | 3 | 25.0 | 7 | 43.8 | 6 | 42.9 | |
| LOW | Activities concerned with providing info to or receiving info from consumers | Consumer councils/ forums (<12 months) | 28 | 43.8 | 5 | 22.7 | 2 | 16.7 | 14 | 87.5 | 7 | 50.0 |
| | | Survey (<12 months) | 41 | 64.1 | 13 | 59.1 | 10 | 83.3 | 10 | 62.5 | 8 | 57.1 |
| | Produce resources for clients including service planning | 18 | 28.1 | 8 | 36.4 | 0 | 0.0 | 7 | 43.8 | 3 | 21.4 | |
| | Complaints process | 61 | 95.3 | 21 | 95.5 | 11 | 91.7 | 15 | 93.8 | 14 | 100.0 | |
| Suggestion box | 45 | 70.3 | 17 | 77.3 | 9 | 75.0 | 9 | 56.3 | 10 | 71.4 | | |

Table 3: Reasons for not undertaking consumer participation activities – services

| Degree of consumer participation | Type of activity | Reason given | n | % |
|--|--|---|------|------|
| LOW | Consumer councils/ forums (n=36) | Staff too busy | 12 | 33.3 |
| | | Clients not interested | | |
| | | Inadequate funds | | |
| | | Viewed as not valuable, not a priority | 7 | 19.4 |
| | | Not practical for this type of service | 4 | 11.1 |
| | | Staff lack necessary skills/experience | 3 | 8.3 |
| | | Clients reluctant due to confidentiality (identified to staff) | 2 | 5.6 |
| | | Clients reluctant due to confidentiality (identified as treatment user) | 2 | 5.6 |
| | | Clients don't want to mix with other clients | 2 | 5.6 |
| | | Rural service difficult to get clients together | 2 | 5.6 |
| | | Practical issues eg space limitations | 2 | 5.6 |
| MID | Consumers involved in resource development (n=25) | Never thought about it | 8 | 32.0 |
| | | Staff too busy | 7 | 28.0 |
| | | Clients not interested | 4 | 16.0 |
| | | Clients lack necessary skills | 4 | 16.0 |
| | | Not practical for this type of service | 4 | 16.0 |
| | | Viewed as not valuable, not a priority | 3 | 12.0 |
| | | Inadequate funds | 2 | 8.0 |
| | | Drug users organisations produce resources for consumers | 2 | 8.0 |
| | Staff not interested | 1 | 4.0 | |
| | Consumers involved in staff training (n=55) | Never thought about it | 13 | 23.6 |
| | | Staff too busy | 9 | 16.4 |
| | | Clients lack necessary skills | 8 | 14.5 |
| | | Training is external thus difficult to involve clients | 8 | 14.5 |
| | | Clients not interested | 7 | 12.7 |
| Viewed as not valuable, not a priority | | 6 | 10.9 | |
| Inadequate funds | | 4 | 7.3 | |
| Clients need to focus on their treatment | | 4 | 7.3 | |
| Staff reluctant to have clients involved in their training | | 2 | 3.6 | |
| Not practical for this type of service | | 1 | 1.8 | |
| Training clients would be difficult | 1 | 1.8 | | |
| HIGH | Consumer representatives on committees, employment process, staff performance appraisal (n=47) | Not practical for this type of service | 12 | 25.5 |
| | | Clients reluctant because they would be identified to staff | | |
| | | Tasks viewed as confidential and should not be accessible to clients | | |
| | | Clients not interested | 11 | 23.4 |
| | | Need to have clear role and selection criteria | 8 | 17.0 |
| | | Clients lack necessary skills | 7 | 14.9 |
| | | Never thought about it | 7 | 14.9 |
| | | Staff reluctant to have client reps | 6 | 12.8 |
| | | Viewed as not valuable, not a priority | 5 | 10.6 |
| | | Staff too busy | 3 | 6.4 |
| | | Training clients would be difficult | 1 | 2.1 |
| | | Inadequate funds | 1 | 2.1 |

Note: Data is not shown for suggestion boxes, complaints processes, and surveys because a large proportion of services reported that they already conducted these activities. Shading signifies three most commonly reported reasons.

3.5.2 Consumers' Knowledge of and Participation in Available Consumer Participation Activities

Overall, consumers had low levels of knowledge about the consumer participation activities that were available at their treatment service (Table 4). For example, while all consumers attended services that had a complaints process, only half (54.2%, n=97) knew about it (Table 4). Less than half of consumers (43.5%, n=70) were aware that a suggestion box was available at their service, and only 19% (n=12) knew about the existence of consumer councils or forums (Table 4). Moreover, while knowledge about 'low degree' activities was low, very few consumers knew about the existence of 'high degree' activities such as consumer representation on decision-making committees, involvement in staff performance appraisals and recruitment, and attendance at staff meetings. An exception was the high level of knowledge about consumer charters of rights, with most consumers (70.9%, n=127) knowing about these (Table 4).

For consumers that knew about participation activities at their service, involvement in those activities was high, with approximately three quarters of consumers reporting that they took part in surveys (78.7%, n=37) or councils (75.0%, n=9) (Table 4). This data contradicts providers' beliefs that consumers aren't interested in taking part in 'low degree' consumer participation activities (Table 3).

In contrast to surveys and councils, consumers were less likely to use existing suggestion boxes and complaints systems. Of the 97 consumers who reported knowing about existing complaints systems, only 17.5% (n=17) had ever made a formal complaint (Table 4). While many others reported that they had not wanted or needed to make a complaint (53.6%, n=52), a considerable proportion (28.9%, n=28) reported that they had wanted to make a complaint but hadn't carried this out. The most commonly reported reasons for consumers not complaining when wanting to related to fears of creating trouble for themselves (46.4%, n=13) or that a complaint would negatively impact on the treatment they received (42.9%, n=12) – and beliefs that nothing would happen as a result of the complaint (25.0%, n=7) (Table 5).

Table 4: Consumers' knowledge of and participation in available consumer participation activities

| Degree | Type of activity | Example | Consumers at services that conduct activity | | Consumers who know that activity exists | | Consumers who have participated in activity (% of those who know about activity) | |
|---|--|--|---|------|---|----|--|----|
| | | | n | % | n | % | n | % |
| HIGH | Consumer participation built into values and policies of organisation | Consumer Charter of Rights | 179 | 70.9 | 127 | na | na | na |
| | Activities in which consumers play a decision-making role | Consumer rep involved in staff performance appraisal | 15 | 6.7 | 1 | nc | nc | nc |
| | | Consumer rep involved in staff recruitment | 23 | 4.3 | 1 | nc | nc | nc |
| | | Consumer rep on decision making committees | 28 | 0.0 | 0 | na | na | na |
| Activities in which consumers play a non-decision-making role | Consumer rep attend staff meetings | 19 | 0.0 | 0 | na | na | na | |
| | Consumers involved in staff training | 0 | na | na | na | na | na | |
| LOW | Activities that promote consumer participation | Consumers involved in resource development | 72 | 13.9 | 10 | 2 | 20.0 | |
| | | Consumers supported to conduct own group activities | 75 | 29.3 | 22 | nd | nd | |
| | Activities concerned with providing info to or receiving info from consumers | Display of consumer advocacy group publications | 105 | 42.9 | 45 | nd | nd | |
| | | Consumer councils/forums | 63 | 19.0 | 12 | 9 | 75.0 | |
| | | Survey | 126 | 37.3 | 47 | 37 | 78.7 | |
| | | Complaints process | 179 | 54.2 | 97 | 17 | 17.5 | |
| Suggestion box | 161 | 43.5 | 70 | 28 | 40.0 | | | |

na: not applicable.

nc: not calculated due to small cell size.

nd: no data collected.

Note: Data for this table was calculated by comparing survey answers from the 'key informant' at each of the 14 services from which consumer data was collected, to survey answers from the consumer at each of those locations.

Table 5: Reasons for consumers not using complaints process (n=28)

| Reason given | n | % |
|--|----|------|
| Didn't want to cause trouble for myself | 13 | 46.4 |
| Worried that it would negatively impact my treatment | 12 | 42.9 |
| Believe that nothing would happen anyway | 7 | 25.0 |
| Worried about reaction from other clients | 6 | 21.4 |
| Didn't want to make a fuss | 4 | 14.3 |
| Didn't want to cause trouble for staff | 3 | 10.7 |
| Worried that staff would know it was me | 3 | 10.7 |
| Too busy | 2 | 7.1 |
| Didn't want to be identified as a treatment user | 1 | 3.6 |

Note: shading signifies three most commonly reported reasons.

3.5.3 Extent of Informal Consumer Participation: Conversations, Letters and Meetings

Almost all providers reported engaging in conversations with consumers about service quality, by either asking consumers or being offered advice from them (Table 6). Many consumers also reported engaging in such conversations. Also, data shows the extent to which consumers discuss service quality amongst themselves, with more than three quarters reporting that they had talked to other consumers at their service about service improvement (Table 7). However, consumers' discussions about service quality were not well-translated into more formal practices such as writing letters or having meetings with staff (Table 7). This could be related to a consumer's fear of creating trouble for themselves or beliefs that nothing would happen as a result, as reported in Table 5. This data suggests that most consumers have opinions about service quality and that providers want to hear them. These informal practices can provide building blocks upon which official models of consumer participation can be established.

Table 6: Informal communication about service quality – providers and consumers

| Participants who reported that: | Providers (n=64) | | Consumers (n=179) | |
|---|------------------|------|-------------------|------|
| | n | % | n | % |
| Providers initiated conversations with consumers about how services could be improved | 60 | 93.8 | 78 | 43.6 |
| Consumers offer advice to providers about how services could be improved | 61 | 95.3 | 79 | 44.1 |

Table 7: Participation in informal consumer participation activities – consumers

| Consumers who reported that they had: | n | % |
|--|-----|------|
| Talked to other consumers about how services could be improved | 139 | 77.7 |
| Written a letter to staff about how services could be improved | 14 | 7.8 |
| Had a formal meeting with staff about how services could be improved | 22 | 12.3 |

3.6 Support for and Opinions about Consumer Participation

3.6.1 Extent of support from service providers

Apart from determining the current opportunities for consumer participation, the study also aimed to determine the extent to which providers and consumers supported the idea of conducting or taking part in consumer participation activities. Many providers stated that the management and staff at their service definitely or probably would be willing to conduct consumer participation activities (Table 8). Over 60% felt that conducting councils or forums or involving consumers in resource development (such as writing or reviewing educational materials) would be supported by the management and staff at their service (Table 8). Fewer services expressed willingness to conduct 'high degree' activities, particularly those that directly involved consumer representatives in decision-making about staff (recruitment, performance appraisal, and training). Notably, however, more than 70% stated that their service definitely, probably or possibly would be willing to have consumer representatives sit on decision making committees (Table 8).

Providers who reported that the management and staff at their service would be unlikely to support the 'mid degree' activity of involving consumers in staff training most commonly cited reasons relating to beliefs about feasibility and capacity of services and consumers. They expressed the view that staff were too busy to facilitate consumer involvement in staff training (17.6%, n=3) or that it was simply not practical (29.4%, n=5) (Table 9). It was also believed that consumers lacked the necessary skills to be involved in this type of activity (17.6%, n=3) (Table 9). Providers who reported that the management and staff at their service would be unlikely to support 'high degree' activities cited reasons that:

- involving consumers in such activities was viewed as inappropriate;
- such activities are confidential and should not be accessible to consumers; and
- consumers lack the necessary skills.

This pattern is similar to that reported in Table 3 and shows how involving consumers in such activities might challenge beliefs about the existing roles and relationships between staff and clients at drug treatment services.

Willingness in relation to consumer participation exists from both service providers and consumers. Knowledge and understanding of programs that could be implemented, as well as advice on how to go about implementing these strategies, seems to be an obvious next step given this generally high degree of willingness.

Table 8: Support for consumer participation – providers

'In future, would the management and staff at the service you work for be willing to ...'

| Degree | Type of activity | Example | Definitely/probably | | Possibly | | Unlikely/no | | Don't know | |
|--------|---|--|---------------------|------|----------|------|-------------|------|------------|-----|
| | | | n | % | n | % | n | % | n | % |
| HIGH | Activities in which consumers play a decision-making role | have a consumer rep involved in staff recruitment? | 12 | 18.8 | 14 | 21.9 | 34 | 53.1 | 4 | 6.3 |
| | | have a consumer rep involved in staff performance appraisal? | 14 | 21.9 | 20 | 31.3 | 27 | 42.2 | 3 | 4.7 |
| | | have a consumer rep on decision making committees? | 33 | 51.6 | 13 | 20.3 | 15 | 23.4 | 3 | 4.7 |
| | | involve consumers in staff training? | 26 | 40.6 | 15 | 23.4 | 17 | 26.6 | 6 | 9.4 |
| LOW | Activities in which consumers play a non-decision-making role | involve consumers in resource development? | 43 | 67.2 | 11 | 17.2 | 9 | 14.1 | 1 | 1.6 |
| | | hold consumer councils/ forums? | 39 | 60.9 | 13 | 20.3 | 9 | 14.1 | 3 | 4.7 |
| | | conduct a survey on consumers' opinions about service quality? | 57 | 89.1 | 5 | 7.8 | 2 | 3.1 | 0 | 0.0 |
| | | have a suggestion box? | 53 | 82.8 | 7 | 10.9 | 4 | 6.3 | 0 | 0.0 |

Table 9: Reasons for unwillingness to support select consumer participation – services

| Degree of consumer participation | Type of activity | Reason given | n | % |
|--|---|--|-----|------|
| LOW | Consumers involved in staff training (n=17) | Not practical for this kind of service | 5 | 29.4 |
| | | Staff too busy to facilitate client involvement | 3 | 17.6 |
| | | Clients lack necessary skills | 3 | 17.6 |
| | | Training is determined externally thus difficult to involve clients | 3 | 17.6 |
| | | Staff reluctant to have clients involved | 2 | 11.8 |
| | | Clients not interested | 2 | 11.8 |
| | | Viewed as not valuable | 2 | 11.8 |
| HIGH | Consumer rep on decision making committees (n=15) | Staff are reluctant to have clients sit on committees | 5 | 33.3 |
| | | Not practical for this kind of service | 4 | 26.7 |
| | | Clients lack necessary skills | 3 | 20.0 |
| | | Clients not interested | 2 | 13.3 |
| | | Clients would not want to be identified to staff | 2 | 13.3 |
| | | Decisions made on committees should be confidential, not accessible to clients | 2 | 13.3 |
| | | Viewed as not valuable | 2 | 13.3 |
| | | Staff too busy to facilitate client involvement | 1 | 6.7 |
| | | Training clients for this would be difficult | 1 | 6.7 |
| | Not considered a priority | 1 | 6.7 | |
| | Consumer rep involved in staff performance appraisal (n=27) | Clients lack necessary skills | 8 | 29.6 |
| | | Viewed as not valuable, inappropriate, not client's role | 8 | 29.6 |
| | | Staff are reluctant to have clients assess job performance | 5 | 18.5 |
| | | Decisions made about staff performance should be confidential, not accessible to clients | 5 | 18.5 |
| | | Believe clients have own agendas | 5 | 18.5 |
| Clients not interested | | 2 | 7.4 | |
| Clients would not want to be identified to staff | 1 | 3.7 | | |
| Not considered a priority | 1 | 3.7 | | |
| Not practical for this kind of service | 1 | 3.7 | | |

Table 9 continued

| Degree of consumer participation | Type of activity | Reason given | n | % |
|----------------------------------|--|--|----|------|
| HIGH | Consumer rep involved in staff recruitment (n=34) | Viewed as not valuable, inappropriate, not client's role | 11 | 32.4 |
| | | Clients lack necessary skills | 9 | 26.5 |
| | | Decisions made in employment process should be confidential, not accessible to clients | 8 | 23.5 |
| | | Staff are reluctant to have clients involved in employment process | 7 | 20.6 |
| | | Not practical for this kind of service | 5 | 14.7 |
| | | Clients would not want to be identified to staff | 3 | 8.8 |
| | | Difficulties implementing with HR | 3 | 8.8 |
| | | Clients not interested | 2 | 5.9 |
| | | Not considered a priority | 2 | 5.9 |
| | | Training clients for this would be difficult | 1 | 2.9 |
| | | Never thought about it | 1 | 2.9 |
| | | Inadequate funds | 1 | 2.9 |
| | | Believe clients have own agendas | 1 | 2.9 |

Note: Data is not shown for suggestion box, survey, consumer councils/ forums and resource development because most services said they would be willing to conduct these activities. Shading signifies three most commonly reported reasons.

3.6.2 Extent of Support from Service Consumers

Most consumers stated that, in future, they would be willing to be involved in consumer participation activities, with at least 70% stating they definitely, probably or possibly would be willing to take part at each level of participation, including 'high degree' activities (Table 10). This shows the high level of interest that consumers have in consumer participation and, again, contradicts the views expressed by providers that consumers would not be interested.

The small group of consumers who expressed unwillingness to participate cited reasons that were similar across the degrees of involvement (Table 11). Consumers expressed beliefs that they do not have the necessary confidence or skills to take part in consumer participation. A reason that was given in relation to every activity was that consumers wanted to concentrate on their treatment and not become involved in extra activities. This is a pattern that is likely common in other health service contexts, where recruiting consumers into participation activities can be limited by consumers' commitments to treatment. It is also important to recognise that a certain proportion of people will opt out of activities simply because they are not interested.

With higher degree activities, consumers continued to say that they wanted to concentrate on their treatment. However they also expressed views that it is not their place to be involved in decision-making activities (Table 11). This belief is likely to be related to consumers' lack of confidence and, more broadly, to their beliefs about existing roles and relationships within treatment service. Here, consumers may be expressing a view similar to that articulated by providers, that the role of consumers within treatment service should not include decision-making about service planning and delivery. This provides insight into the culture that exists within drug treatment services in which consumers are often positioned as passive recipients of treatment. Finally, with some higher degree activities, consumers reported fears that participating in certain activities could negatively impact their treatment (Table 11). This is similar to consumers' reported reasons for not using official complaints processes (Table 5) and shows the fears that some consumers experience in relation to their treatment.

Table 10: Support for consumer participation – consumers

| | | ‘In future, would you be willing to...’ | | | | | | | | | | | |
|--------|--|--|---------------------|------|----------|------|-------------|------|------------|-----|--|--|--|
| Degree | Type of activity | Example | Definitely/probably | | Possibly | | Unlikely/no | | Don't know | | | | |
| | | | n | % | n | % | n | % | n | % | | | |
| HIGH | Activities in which consumers play a decision-making role | be a consumer rep involved in staff recruitment? | 106 | 59.2 | 18 | 10.1 | 51 | 28.5 | 4 | 2.2 | | | |
| | | be a consumer rep involved in staff performance appraisal? | 117 | 65.4 | 22 | 12.3 | 35 | 19.6 | 5 | 2.8 | | | |
| | | be a consumer rep on decision making committees? | 97 | 54.2 | 29 | 16.2 | 51 | 28.5 | 2 | 1.1 | | | |
| LOW | Activities in which consumers play a non-decision-making role | be involved in staff training? | 105 | 58.7 | 20 | 11.2 | 52 | 29.1 | 2 | 1.1 | | | |
| | | be involved in resource development? | 112 | 62.6 | 31 | 17.3 | 34 | 19.0 | 2 | 1.1 | | | |
| | Activities concerned with providing info to or receiving info from consumers | attend consumer councils/ forums? | 123 | 68.7 | 28 | 15.6 | 24 | 13.4 | 4 | 2.2 | | | |
| | | fill out a survey? | 160 | 89.4 | 9 | 5.0 | 6 | 3.4 | 4 | 2.2 | | | |
| | | use a suggestion box? | 156 | 87.2 | 13 | 7.3 | 10 | 5.6 | 0 | 0.0 | | | |

Table 11: Reasons for unwillingness to support select consumer participation – consumers

| Degree of consumer participation | Type of activity | Reason given | n | % |
|--|--|--|----|-------------|
| LOW | Consumer councils/ forums (n=24) | Believe that nothing would happen anyway | 8 | 33.3 |
| | | Not interested | 7 | 29.2 |
| | | Just want treatment, not interested in anything else | 7 | 29.2 |
| | | Don't feel confident | 7 | 29.2 |
| | | Councils and forums are tokenistic | 4 | 16.7 |
| | | Worried it would negatively impact my treatment | 3 | 12.5 |
| | | Too busy | 2 | 8.3 |
| | | Worried that staff would think I am a troublemaker | 2 | 8.3 |
| | | Worried that staff would treat me differently | 2 | 8.3 |
| | | Feel that we wouldn't get any feedback anyway | 2 | 8.3 |
| | | Not my place | 1 | 4.2 |
| | | Wouldn't want to be identified as a treatment user | 1 | 4.2 |
| MID | Consumers involved in resource development (n=34) | Just want treatment, not interested in anything else | 13 | 38.2 |
| | | Feel I don't have necessary skills | 10 | 29.4 |
| | | Don't feel confident | 9 | 26.5 |
| | | Too busy | 7 | 20.6 |
| | | Not interested | 6 | 17.6 |
| | | Not my place | 4 | 11.8 |
| | | Feel that this is not relevant to this type of service | 3 | 8.8 |
| | | Believe that it would be tokenistic | 2 | 5.9 |
| | | Wouldn't want to be identified as a treatment user | 2 | 5.9 |
| | | Worried it would negatively impact my treatment | 2 | 5.9 |
| | Consumers involved in staff training (n=52) | Just want treatment, not interested in anything else | 16 | 30.8 |
| | | Feel that this is not relevant to this type of service | 15 | 28.8 |
| | | Not my place | 13 | 25.0 |
| | | Feel I don't have necessary skills | 13 | 25.0 |
| | | Too busy | 8 | 15.4 |
| | | Don't feel confident | 8 | 15.4 |
| | | Worried it would negatively impact my treatment | 7 | 13.5 |
| | | Feel staff don't want to learn from us | 5 | 9.6 |
| | | Believe that it would be tokenistic | 4 | 7.7 |
| | | Not interested | 4 | 7.7 |
| Wouldn't want to be identified as a treatment user | 2 | 3.8 | | |

Note: Shading signifies most commonly reported reasons.

Table 11 continued

| Degree of consumer participation | Type of activity | Reason given | n | % |
|---|---|---|--|------|
| HIGH | Consumer rep on decision making committees (n=51) | Not my place | 10 | 19.6 |
| | | Just want treatment, not interested in anything else | 10 | 19.6 |
| | | Believe that nothing would happen anyway | 9 | 17.6 |
| | | Too busy | 9 | 17.6 |
| | | Don't feel confident | 9 | 17.6 |
| | | Worried about being blamed for wrong decisions by clients | 8 | 15.7 |
| | | Not interested | 7 | 13.7 |
| | | Worried it would negatively impact my treatment | 7 | 13.7 |
| | | Believe that it would be tokenistic | 5 | 9.8 |
| | | Don't know what my role would be | 5 | 9.8 |
| | | Worried about being blamed for wrong decisions by staff | 4 | 7.8 |
| | | Don't have necessary skills | 4 | 7.8 |
| | | Fear reprisal from other clients | 4 | 7.8 |
| | | Live too far away to attend meetings | 2 | 3.9 |
| | | Wouldn't want to be identified as a treatment user | 2 | 3.9 |
| | | Consumers involved in staff performance appraisal (n=35) | Just want treatment, not interested in anything else | 19 |
| | Feel that this is not relevant to this type of service | | 10 | 28.6 |
| | Not my place | | 8 | 22.9 |
| | Worried it would negatively impact my treatment | | 8 | 22.9 |
| | Not interested | | 5 | 14.3 |
| | Too busy | | 5 | 14.3 |
| | Believe that it would be tokenistic | | 4 | 11.4 |
| | Worried about being blamed for wrong decisions by staff | | 4 | 11.4 |
| | Worried about being blamed for wrong decisions by clients | | 3 | 8.6 |
| | Don't feel confident | | 3 | 8.6 |
| | Don't like mixing with other clients | | 2 | 5.7 |
| | Wouldn't want to be identified as a treatment user | | 1 | 2.9 |
| | Don't know what my role would be | 1 | 2.9 | |
| | Consumers involved in staff recruitment (n=51) | Not my place | 20 | 39.2 |
| | | Feel that this is not relevant to this type of service | 15 | 29.4 |
| | | Just want treatment, not interested in anything else | 12 | 23.5 |
| | | Don't feel confident | 10 | 19.6 |
| | | Not interested | 9 | 17.6 |
| Worried about being blamed for wrong decisions by clients | | 9 | 17.6 | |
| Too busy | | 8 | 15.7 | |
| Worried about being blamed for wrong decisions by staff | | 6 | 11.8 | |
| Don't know what my role would be | | 6 | 11.8 | |
| Worried it would negatively impact my treatment | | 5 | 9.8 | |
| Believe that it would be tokenistic | | 2 | 3.9 | |
| Wouldn't want to be identified as a treatment user | 1 | 2.0 | | |

Note: Shading signifies most commonly reported reasons.

Table 12: Providers definitely/probably/possibly willing to support consumer participation, by service type

| Degree | Type of activity | Example | Total (n=64) | | Pharmaco therapy (n=22) | | Residential detox (n=12) | | Residential rehab(n=16) | | Combination (n=14) | |
|--------|--|---|--------------|------|-------------------------|-------|--------------------------|-------|-------------------------|------|--------------------|-------|
| | | | N | % | n | % | n | % | n | % | n | % |
| HIGH | | Consumers involved in staff recruitment | 26 | 40.6 | 8 | 36.4 | 3 | 25.0 | 7 | 43.8 | 8 | 57.1 |
| | Activities in which consumers play a decision-making role | Consumers involved in staff performance appraisal | 34 | 53.1 | 11 | 50.0 | 5 | 41.7 | 10 | 62.5 | 8 | 57.1 |
| | | Consumer reps on decision making committees | 46 | 71.9 | 11 | 50.0 | 8 | 66.7 | 15 | 93.8 | 12 | 85.7 |
| | Activities in which consumers play a non-decision-making role | Consumers involved in staff training | 41 | 64.1 | 11 | 50.0 | 10 | 83.3 | 11 | 68.8 | 9 | 64.3 |
| | | Consumers involved in resource development | 54 | 84.4 | 18 | 81.8 | 9 | 75.0 | 15 | 93.8 | 12 | 85.7 |
| LOW | Activities concerned with providing info to or receiving info from consumers | Consumer councils/ forums | 52 | 81.3 | 18 | 81.8 | 11 | 91.7 | 10 | 62.5 | 13 | 92.9 |
| | | Survey | 62 | 96.9 | 22 | 100.0 | 12 | 100.0 | 14 | 87.5 | 14 | 100.0 |
| | | Suggestion box | 60 | 93.8 | 21 | 95.5 | 12 | 100.0 | 13 | 81.3 | 14 | 100.0 |

Table 13: Consumers definitely/probably/possibly willing to support consumer participation, by service type

| Degree | Type of activity | Example | Total (n=179) | | Pharmaco-therapy (n=108) | | Residential detox (n=21) | | Residential rehab (n=34) | | Combination (n=16) | |
|--------|--|--|---------------|------|--------------------------|------|--------------------------|-------|--------------------------|-------|--------------------|-------|
| | | | N | % | n | % | n | % | n | % | n | % |
| HIGH | | Consumer rep involved in staff recruitment | 124 | 69.3 | 77 | 71.3 | 14 | 66.7 | 22 | 64.7 | 11 | 68.8 |
| | Activities in which consumers play a decision-making role | Consumer rep involved in staff performance appraisal | 139 | 77.7 | 86 | 79.6 | 15 | 71.4 | 28 | 82.4 | 10 | 62.5 |
| | | Consumer rep on decision making committees | 126 | 70.4 | 72 | 66.7 | 15 | 71.4 | 28 | 82.4 | 11 | 68.8 |
| | | Consumers involved in staff training | 125 | 69.8 | 74 | 68.5 | 15 | 71.4 | 23 | 67.6 | 13 | 81.3 |
| | Activities in which consumers play a non-decision-making role | Consumers involved in resource development | 143 | 79.9 | 91 | 84.3 | 16 | 76.2 | 25 | 73.5 | 11 | 68.8 |
| LOW | Activities concerned with providing info to or receiving info from consumers | Consumer councils/forums | 151 | 84.4 | 91 | 84.3 | 15 | 71.4 | 33 | 97.1 | 12 | 75.0 |
| | | Survey | 169 | 94.4 | 99 | 91.7 | 21 | 100.0 | 33 | 97.1 | 16 | 100.0 |
| | | Suggestion box | 169 | 94.4 | 99 | 91.7 | 20 | 95.2 | 34 | 100.0 | 16 | 100.0 |

3.6.3 Support for Consumer Participation Across Types of Treatment Services

For the most part, providers from pharmacotherapy, residential rehabilitation and detoxification services did not feel differently about whether their management and staff would be willing to conduct consumer participation (Table 12). There was fairly high support across all degrees of consumer involvement for each type of service. As an exception, more providers from residential services (n=42) than pharmacotherapy services (n=22) expressed support for consumer representatives on decision-making committees (83.3%, n=35 vs. 50.0%, n=11, $\chi^2=7.94$, $p<0.05$). This may be because joint decision-making is already a prominent feature of some kinds of residential services, namely rehabilitation, as discussed earlier.

Similarly, consumers from pharmacotherapy, residential rehabilitation and detoxification services generally did not feel differently about whether they would be willing to take part in consumer participation activities, with high support across all degrees of participation (Table 13). As an exception, more consumers from residential services (n=71) than pharmacotherapy services (n=108) expressed the view that they would be willing to participate in surveys (98.6%, n=70 versus 91.7%, n=99, $\chi^2=3.90$, $p<0.05$) and use a suggestion box (98.6%, n=70 versus 91.7%, n=99, $\chi^2=3.90$, $p<0.05$). However, it is important to note that almost all consumers (ie greater than 90%) from both residential and pharmacotherapy services reported they would be willing to carry out these activities.

3.6.4 Views About Consumer Representatives

The concept of a consumer representative is central to the model of consumer participation used in this study. Consumer representatives would be responsible for making decisions on behalf of, and in the best interest of, all consumers within the treatment service. As such, it was important for this study to gain consumers' and providers' opinions about who is best positioned to act as a consumer representative.

Almost 80% of consumers believed that consumer representatives should be people who are current or ex clients of the service (or another drug treatment service). In comparison, very few consumers felt that general patient representatives could adequately represent them. (General patient representatives are consumers or patients of health services other than drug treatment services. For example, at community-based hospitals consumer representatives represent all service users, including drug treatment service consumers).

Providers largely agreed with the views of consumers (Table 15), although it appears that more providers feel that general patient representatives could act as consumer representatives within drug treatment services. Also, many providers (18.8%, n=12) suggested consumers' family members could act as consumer representatives; however virtually no consumers (0.6%, n=1) suggested this.

This data strongly demonstrates that, if consumer representation were to be implemented within drug treatment services, these representatives should be current or ex clients of drug treatment services. This may reflect the belief that consumers of drug treatment services have unique circumstance and experiences that would not be well-represented by people who had not had this experience themselves.

Table 14: Who should be a consumer representative? – consumers’ views (n=179)

| | Strongly agree/ agree | | Neither agree nor disagree | | Disagree/ strongly disagree | |
|---------------------------------|-----------------------|------|----------------------------|------|-----------------------------|------|
| | n | % | n | % | n | % |
| Current clients of service | 141 | 78.8 | 19 | 10.6 | 18 | 10.1 |
| Ex-clients of service | 142 | 79.3 | 16 | 8.9 | 20 | 11.2 |
| State drug-users’ organisation | 79 | 44.1 | 80 | 44.7 | 16 | 8.9 |
| General patient representatives | 25 | 14.0 | 25 | 14.0 | 128 | 71.5 |

Table 15: Who should be a consumer representative? – providers’ views (n=64)

| | Strongly agree/ agree | | Neither agree nor disagree | | Disagree/ strongly disagree | |
|---------------------------------|-----------------------|------|----------------------------|------|-----------------------------|------|
| | n | % | n | % | n | % |
| Current clients of service | 45 | 70.3 | 7 | 10.9 | 12 | 18.8 |
| Ex-clients of service | 58 | 90.6 | 3 | 4.7 | 5 | 7.8 |
| State drug-users’ organisation | 28 | 43.8 | 16 | 25.0 | 20 | 31.3 |
| General patient representatives | 25 | 39.1 | 11 | 17.2 | 28 | 43.8 |

3.6.5 Opinions About Consumer Participation, Clients and Staff

The vast majority of consumers (89.9%, n=161) and providers (84.4%, n=54) agreed that service quality would be improved if consumers’ opinions about services were included, demonstrating the enormous support for the principle of consumer participation among these key groups (Table 16). Moreover, the majority of both consumers and providers agreed that having client representatives on committees or holding open meetings for clients are some of the ways that consumer participation could work in practice.

Providers and consumers generally held positive views about consumers, namely that consumers’ complaints were usually reasonable, that they would be reliable participants in service planning and delivery, and that they would have time to take part. Many providers (31.3%, n=20) felt that consumers were not interested in participating in service planning and delivery, as did many consumers (40.8%, n=73) (Table 16). While it is clear from other data in this study that providers believe consumers are not interested in participating, it is notable to find that a large proportion of consumers also believe this. This is especially noteworthy in view of the fact that consumers state very strongly that they would be interested in participating (Table 10). This suggests that consumers may feel isolated in their interest to participate, since they say that they themselves would be willing but simultaneously believe that other consumers would not.

Providers and consumers held contrasting views about whether staff want clients to be involved in service planning and delivery. While two thirds of providers stated they believed staff wanted consumers to be involved, less than 30% of consumers believed this (Table 16). A further 27.4% of consumers were undecided or unsure whether staff wanted them to be involved (Table 16). Again, this shows the isolation that consumers appear to feel about their participation. While they want to be involved, they believe that other consumers don't want to be involved and that staff do not want them involved. This data suggests that consumers are disengaged not only from staff but also from each other.

❖ Chapter 4: Consultation with Consumer Organisations and Other Key Stakeholders

The consultations with consumer organisations and other stakeholders included staff from consumer representative organisations, government officers, representatives from non-governmental organisations and expert policy advisors. For the consumer representative organisations, the consultation provided an opportunity to describe their current activities relating to consumer participation and to determine their vision for consumer participation at both the individual and organisational/political level. For the other stakeholders the consultation provided an opportunity to determine the extent of support for consumer participation and to obtain opinions about how consumer participation could most effectively be implemented in terms of policy and funding.

4.1 National Consultation with Consumer Organisations

The TSU project sought the opinions of consumers employed in the state and territory based drug user organisations. This was achieved by conducting a face-to-face consultation workshop and the completion of an email questionnaire by the managers of the organisations.

4.1.1 National Consultation Workshop

The workshop was held in Adelaide, South Australia in December 2005. AIVL was able to bring together staff and volunteers to explore the drug-user organisation perspective on consumer participation in drug services. While AIVL does not have member organisations in Tasmania and Queensland, individual representatives attended from these states. To guide the consultation a series of questions were developed in consultation with the NCHSR. This process ensured that the national consultation complemented the consumer and provider data collection tools. Three such questions framed the consultation:

1. As a consumer organisation, what would you ideally like to see your advocacy role to be?
2. What are your views on how consumers at an individual level can be involved in service delivery?
 - a. How do we get consumers involved?
 - b. What are some roles and responsibilities consumers can take on?
 - c. How do we know we are not just hearing the loudest voices?
 - d. Do we know how consumers would like to participate?
 - e. How will the organisation support those consumers who provide their time and expertise?
3. What are the barriers to involvement for both organisational and individual consumers?

Discussion

As expected, several recurring themes presented themselves throughout the workshop. Participants highlighted some vital requirements that will need to be met in order for consumer participation to be successful. The importance of bringing together consumers and service providers in a non-threatening environment for both parties was seen as essential. Also seen as imperative to the success of consumer participation was the need to educate both consumers and service providers. It was stated that service providers views and ideas of drug users could be seen as judgemental and their ability to understand the client perspective was limited. Representatives from the state and territory drug user organisations felt it necessary that service providers be better educated to understand not only the needs and requirements of service users but also recognise that drug users have unique skills and expertise that could be valuable and enhance service provision. It was also seen as important to educate consumers about their rights and responsibilities and about the way that the system works in relation to processing complaints. Participants felt that there is a need to support and empower consumers as representatives and that with adequate resourcing drug user organisations were best placed to provide advocacy, support and training for consumer representatives as well as service providers.

It was also noted that there is a need for ongoing consultation between service providers and consumers. Liaison should not only take place when there are complaints or grievances but there should be ongoing networking at all times. Consumer advocates also felt it important that both positive and negative feedback be given to service providers. They felt this would ensure the development of a culture of ongoing positive and meaningful communication between service users and service providers. Participants stated that conducting this type of advocacy work on behalf of drug treatment consumers is one of the most valuable roles that consumer organisations could undertake. A small number of drug user organisations are currently funded to conduct formal advocacy and mediation projects in relation to drug treatment consumers. These projects have demonstrated their value not only in advocating good outcomes for individual consumers but also in building stronger and more positive relationships between consumer organisations and service providers. Ideally all consumer organisations should be funded to conduct this important advocacy and relationship building role within the drug treatment area.

A key issue raised during the consultation was that of the need for a process to be developed to enable clients to feel safe about being involved in consumer participation activities. It was noted that a major barrier to involvement for clients could be the fear of punishment for speaking up. Concerns were strongly expressed in regards to punitive repercussions for those who vocalise issues and complaints as a barrier to getting involved. It was stated that pharmacotherapy clients often do not make complaints for fear that they will lose their place at pharmacotherapy clinics or community pharmacies, be refused take-away doses or be treated unfairly by staff. It was stressed that these are not just fears or perception but also 'real' concerns as there have been instances where clients have experienced these outcomes after making complaints or speaking up for themselves. Other barriers to involvement were funding issues, reluctance of service providers to properly engage with and consult consumers, and staff not recognising the skills and expertise of service users as valuable.

It was considered important that people engaged in consumer participation activities be remunerated for their input and participation. Drug user organisations deem that financial payment for time and expertise is essential. This view was also supported in the consultation with other stakeholders (see page 73). Remuneration was also seen as vital to clients giving their time. Such an issue has been addressed in other areas of health service delivery where participants are seen as experts.

There was agreement that incentives for providers to get involved are essential. Current successful models that can be promoted as models of good practice (evidencing examples of positive outcomes and the benefits of consumer involvement to service providers) may encourage services to involve consumers. It was also suggested that as a requirement of funding it should be necessary for services to have consumer representatives sit on committees and take part in all aspects of service provision.

Finally the need for formalisation of such a process was also seen as vital, with quality assurance standards and policy and guidelines to be set nationally so that each state and territory operated in compliance with each other. This national approach was seen as crucial.

4.1.2 National Consultation Questionnaire

The managers from each of AIVL's member organisations were sent (by email) a questionnaire that was developed in partnership with the NCHSR. The aim of this questionnaire was to gain an understanding of:

- drug-user organisation involvement in accreditation standards development;
- which consumer participation activities were being undertaken by jurisdictional drug-user organisations;
- existing policy knowledge;
- current funding for consumer participation activities; and
- committee and working group involvement in relation to consumer participation.

Results

The national consultation questionnaire was sent to the managers/convenors of all seven AIVL member organisations. (These are listed on page 118.)

Involvement in the standards and accreditation of treatment services

Out of the seven consumer organisations only two respondents reported having any involvement in the development of standards and accreditation for drug treatment services in their state/territory. These two organisations described their involvement as:

- contributing to state/territory drug strategies and their evaluations;
- reviewing initial standards for accreditation of pharmacotherapy treatment centres;
- informal engagement, for example feedback by telephone on service quality; and
- committee membership relating to planning of services and programs.

Awareness of policies relating to consumer rights

Six of the seven consumer organisations reported that they had some awareness of policy. This included knowledge of:

- the rights and responsibilities of consumers engaged in drug treatment (drug treatment

contracts);

- complaints procedures;
- principles held within jurisdictional and national drug strategies;
- a guide to consumer participation in drug and alcohol treatment;
- consumer participation frameworks;
- privacy guidelines.

Funding

This question was asked in three parts:

1. Was funding received to undertake consumer participation activities?
2. How much funding was received?
3. What consumer participation activities were being undertaken?

Two consumer organisations reported that they were funded to specifically undertake consumer participation activities in relation to drug treatment services. The respondents also reported that where government funding is received, there is an assumption that advocacy and representation roles in relation to drug treatment will be undertaken, regardless of which government department is funding. For example, drug user organisations may be funded by communicable diseases or blood-borne viruses funding but there is still an expectation that the organisation will undertake consumer activities in relation to drug treatment. While drug user organisations attempt to fulfill these expectations regardless of the funding they receive, the funding does reflect a lack of recognition for the key role that drug user organisations can play in developing and implementing consumer participation models within individual services. Some of AIVL's member organisations do carry out individual advocacy relating to complaints and mediation.

Consumer Participation Committee membership

Only four respondents reported their membership to committees relating to consumer participation. These included, for example:

- policy guidance advisory committees;
- research advisory committees;
- regulatory reviews;
- treatment program advisory committees; and
- related consumer organisation steering groups.

Drug treatment services complaints

The level of complaints that are managed by jurisdictional drug user organisations and how complaints policy could be improved were explored. Six respondents reported managing individual complaints against treatment providers. The following are examples of suggestions for improving complaints policies and procedures:

- Make the process less complicated.

- Focus more on empowering consumers and educating them about their right to complain.
- Formally fund drug user organisations to be involved in the process.
- Advertise the complaints policies and procedures to consumers.
- Develop Charters of Rights for consumers in treatment.
- Monitor and improve responses from related boards such as the boards of area or regional health services, medical boards etc.

4.1.3 Conclusions

The key themes identified through the consultation with the consumer organisations included the fact that both consumers and service providers will need education and training if consumer participation in drug treatment services is to develop. In particular, the consumer organisations felt there was a need to educate service providers about the value and benefits of consumer participation and to educate consumers about their rights and responsibilities in the context of treatment service provision. Drug user organisations believed they have a key, and in many ways unique, role to play in educating both service providers and consumers but stressed the need for adequate resourcing to allow them to properly undertake this work.

Other themes included the need to develop pathways to support more positive and constructive communication between consumers and service providers. Practical models for ongoing consultation and liaison were considered the best way to achieve meaningful communication between consumers and service providers and it was felt that this might be an effective strategy to reduce consumer fears about participation and 'speaking up'.

Overall, consumer organisations believe their unique knowledge and expertise means they are well placed to provide advice, education and skills development in a number of areas related to consumer participation including service accreditation processes, policy development, development of practical models and complaints and mediation mechanisms. They highlighted, however, that these roles could only be effectively fulfilled if drug user organisations are adequately funded and resourced.

4.2 National Consultation with Other Stakeholders

The national consultation of other stakeholders sought the opinions of individuals who were thought to have influence over the policy and funding aspects of drug treatment services in Australia. Participants were representatives of government and non-government organisations (both national and state), and expert policy advisors. A survey was used to determine their level of support for consumer participation at drug treatment services, and to gain their opinions regarding how a consumer participation program might be implemented in drug treatment services in terms of policy, funding and key leading organisations.

4.2.1 Definition

This survey used the same definition for 'consumer participation' as the consumer and provider survey described in Chapter 3 (Figure 1).

4.2.2 Data Collection

Thirty potential participants were identified. A survey consisting of nine questions was emailed to each, with a request that participants return survey answers via reply email. Two weeks after the initial email, participants who had not returned a survey were emailed a single reminder. The survey consisted of nine closed-response questions. For each question, participants were invited to add commentary around their response. Questions collected data assessing the degree of support for consumer participation, and opinions regarding how consumer participation could be implemented effectively in terms of funding, policy and key leading organisations.

In total, 14 surveys were returned, providing an overall response rate of 46.7%. The highest response came from representatives of national non-governmental organisations (NGOs) (80.0%), while the lowest was from state government departmental officers (12.5%).

4.2.3 Ethical Approval

The study has ethical approval from the Human Research Ethics Committee at the University of New South Wales in May 2006.

4.2.4 Support for Consumer Participation

There is high support among respondents for low or mid degree forms of consumer participation, with over 85% of stakeholders reporting that they definitely or probably would support consumer involvement in activities that are concerned with information sharing or involving consumers in non-decision-making activities (Table 17). However, there was less support for high degree activities in which consumers play decision-making roles, with only approximately a quarter of stakeholders saying that they definitely or probably would support the implementation of these in Australian drug treatment services (Table 17). These views are similar to those expressed by service providers (Chapter 3) and demonstrate the discomfort that exists with involving consumer representatives in decision-making that relates directly to staff.

Table 17: Extent of support for select consumer participation activities among key stakeholders (n=14)

| Degree | Type of activity | Example | Definitely/ probably | | Possibly | | Unlikely/ no | |
|--------|---|--|-------------------------|-------|----------|------|-----------------|------|
| | | | n | % | n | % | n | % |
| HIGH | Consumer participation built into values and policies of organisation | Consumer participation built into mission statement | 13 | 92.9 | 1 | 7.1 | 0 | 0.0 |
| | | Consumer rep involved in staff recruitment | 3 | 21.4 | 9 | 64.3 | 2 | 14.3 |
| | | Consumer rep involved in staff performance appraisal | 4 | 28.6 | 5 | 35.7 | 5 | 35.7 |
| | | Consumer rep on decision making committees | 9 | 64.3 | 5 | 35.7 | 0 | 0.0 |
| LOW | Activities in which consumers play a non-decision-making role | Consumer rep involved in staff training | 12 | 85.7 | 2 | 14.3 | 0 | 0.0 |
| | | Consumers involved in resource development | 12 | 85.7 | 2 | 14.3 | 0 | 0.0 |
| | | Consumer councils/ forums | 13 | 92.9 | 1 | 7.1 | 0 | 0.0 |
| | | Survey | 14 | 100.0 | 0 | 0.0 | 0 | 0.0 |

Commentary provided by respondents suggests that their concerns about consumer involvement in staff recruitment and staff performance appraisal activities relate to concerns about confidentiality and beliefs about appropriateness:

'Performance appraisal is an activity which is confidential, involving only supervisor/s and employee.'

'I don't think it is appropriate to have consumers/clients involved in staff performance appraisals. I think there is a conflict of interest here.'

Concerns about confidentiality and appropriateness were also expressed by service providers (see Chapter 3). These concerns may relate to the way that involving consumer representatives in these activities challenges the existing roles and relationships in drug treatment services. Some respondents also expressed the view that many consumers do not have the skills that would be necessary to take part in staff recruitment or performance appraisals:

'Employing new staff is a very sensitive issue. Involves establishing confidence, a deep understanding of a person's capabilities, and weaknesses. I think this should be restricted to a very small group with experience and expertise. People who have to live with the decision, supervise the person and if necessary terminate that person's employment.'

'Performance appraisal is very difficult, demanding and testing for all concerned. There are high levels of sensitivity. I don't think consumers can appreciate these issues adequately. For example, the Chairman of the Board has very high levels of accountability – publicly, to the organisation and elsewhere. Very few consumers would have any idea of these complexities or issues.'

Respondents' recognition that consumers lack such skills highlights the importance of training and education for consumers who wish to take part in such activities. With appropriate training, support and guidance, consumers should be able to gain suitable appreciation for the sensitive issues surrounding staff recruitment and performance appraisal.

Despite these concerns, it is evident that there is support for consumer participation in staff-related matters, especially when considering that a further 64.3% (n=9) and 35.7% (n=5) reported that they possibly would support consumer representatives involvement in staff recruitment and performance appraisal, respectively (Table 17). The large proportion of respondents who indicated possible support for these activities might reflect the need of these stakeholders (and indeed other stakeholders) for more information about how consumer participation might work in practice. For example, involvement of consumer representatives in staff recruitment can take many forms, from asking consumer representatives to contribute interview questions to having consumer representatives sit on interview panels and contribute to decision-making. The need to raise awareness about the benefits of consumer participation and how it might work in practice is a theme that is also evident in data collected from service providers (see Chapter 3). Respondents in this component of the project expressed a need to better understand what type of consumer participation process would be introduced:

'[It] really depends upon the type of process that would be introduced. I think a few particular things need to be taken into consideration – including: Definition of 'consumer' – is this someone 'in treatment' (briefly, long-term) or 'out of treatment' or in 'ongoing treatment'...?....Critical to have guidelines to inform how consumer participation occurs – and to avoid tokenistic involvement...

Adequate support and training for consumers if they're to participate in committees and boards (without support, being on committees can be intimidating for some)... Selection of consumer 'representatives' – national or state guidelines need to provide boundaries around ethical ways to engage consumers in service delivery and planning.'

4.2.5 Policy Needs in Relation to Consumer Participation

Almost all stakeholders (92.9%, n=13) believed that changes to current policy activities would be necessary in order to implement a consumer participation initiative in drug treatment services. Most suggested that consumer participation be included in national and jurisdictional drug strategies (64.3%, n=9) and/or that discussion papers be developed (64.3%, n=9). Many also supported the idea of developing national and jurisdictional position papers (42.9%, n=6). In the main, respondents' believed that consumer participation would be best implemented by using an 'across the board' approach to ensure the principle is embedded in strategic policy, and that there are clear implementation guidelines:

'Discussion papers and position papers might provide mechanisms to achieve the goal or references for its proper working, but to be serious the principle needs to be embodied in strategies.'

'While it is important that policy is developed to drive and promote consumer participation – such policy is likely to be ineffectual if clear guidelines around the implementation of the policy is not carefully considered.'

Respondents were asked whether they believed policy changes should begin at the national, state/territory or regional level. Opinion was split, with 21.4% (n=3) suggesting changes should first be made to national policy, 28.6% (n=4) suggesting state/territory policy, and 7.1% (n=1) suggesting area or regional policy (14.3%, n=2 stated that no policy changes were necessary). Those that supported the introduction of consumer participation into national policy did so out of a belief that Commonwealth government policy is most wide-reaching in relation to its impact on consumers. Alternatively, starting at the state/territory level was viewed as more effective since drug treatment is primarily the responsibility of the state/territory governments. A further 28.4% (n=4) of respondents left the question blank, instead suggesting that policy would be best implemented simultaneously, across jurisdictions.

4.2.6 Funding Needs for Consumer Participation

Most respondents (64.3%, n=9) felt that a consumer participation initiative should be supported by extra, specific funding, although some respondents (21.4%, n=3) reported feeling unsure about whether extra funding was necessary and a small proportion (7.1%, n=1) felt that there should be no extra funding. Those who believed extra funding was necessary expressed the view that the type of funding would depend on the nature of the initiative and also that any funding would likely be in the form of 'start up' funding because of funding restraints:

'Given the pressures on funding, any new initiative is unlikely to get full support unless it attracts specific funding at least until such a time as the initiative becomes the 'norm' (part of business as usual).'

Several respondents also commented that some funding should be available to compensate consumers for their time and effort:

'Consumers' time ought to be reimbursed – and at a standard rate, preferably nationally, at the very least at a statewide level.'

'We get paid for our time. If we truly value client participation then we should pay for it as well.'

'Consumer reps deserve to be compensated for their efforts but this may not always be possible from existing budgets.'

Respondents believed that the extra funding required for a consumer participation initiative should come from governments, either national or state/territory (Table 18). A smaller proportion felt that the non-governmental sector were well-positioned to fund such an initiative. However, many respondents left the question blank (Table 18) and instead wrote commentary suggesting that cost-sharing arrangements may be more suitable.

Table 18: Which sector should be primarily responsible for funding?

| At national level? | n | % | At state/territory level? | n | % |
|---|---|------|--|---|------|
| Drug Strategy Branch | 7 | 50.0 | State/territory government Departments of Health | 7 | 50.0 |
| Non-governmental sector | 2 | 14.3 | Non-governmental sector | 4 | 28.6 |
| Did not answer | 4 | 28.6 | Did not answer | 3 | 21.4 |
| Consumer participation should not be funded at national level | 1 | 7.1 | | | |

(Respondents were allowed to choose only one from each list.)

Respondents who stated that governments should primarily be responsible for funding, did so because they believed that governments are the primary policy bodies and, therefore, are best positioned to be the primary funding bodies:

'Ties it to national initiatives and consistency across country.'

'Government has a responsibility to take the lead in incorporating consumer participation more effectively into current drug strategies and national and statewide policies. Integral to such strategies and policies is funding – and it is government responsibility to create a funding stream for consumer participation into the budget on alcohol and other drug related harm.'

Those stakeholders who suggested that the non-governmental sector should act as the primary funding body believed this because they felt NGOs had 'more freedom' and could work more effectively with consumers:

'I think the peaks could work directly with the consumer groups and would be more culturally appropriate as funding bodies.'

Respondents were asked whether they would support having service funding linked to mandatory requirements of consumer participation. Opinions were divided, with 35.7% (n=5) stating that they definitely or probably would support this; 21.4% (n=3) stating they possibly would; and 35.7% (n=5) stating that they would be unlikely to. Those that supported the idea did so because they believed consumer participation is an aspect of service quality, or because they believed this is the only way it would work:

'It is an aspect of quality service provision and therefore funding should be contingent upon these processes occurring.'

'Needs to be built into service guidelines and funding arrangements/contracts to have relevance and to work.'

Respondents who were unsure about linking consumer participation to funding felt that doing so created the danger of consumer participation becoming tokenistic:

'I think there needs to be some caution in just heading directly down the path of mandatory consumer participation... the involvement of consumers in a mandatory context led to tokenistic engagement or engaging consumers in ways that wasn't supportive or respectful.'

Respondents who reported that they would not support linking consumer participation to funding suggested that services already had too many conditions attached to their funding:

'Adding yet another mandatory condition on funding on organisations which are already stretched is not pragmatic.'

'There are too many conditions for organisations already which bear little relationship to the needs in the community or the real effectiveness of organisations. Of course if an organisation/program included consumers in real and meaningful way I would be impressed and be very sympathetic to funding that organisation... but that does not mean I would set it as a condition or requirement for funding.'

4.2.7 Key Organisations to Drive the Implementation of Consumer Participation

Respondents generally believed that the development and implementation of a consumer participation initiative should involve collaboration amongst all relevant organisations (Table 19). Opinions about who should act as the *lead* organisation in such an initiative were generally split, with a similar proportion of respondents suggesting that leadership should be provided by drug user organisations or the non-governmental sector (Table 20). Notably, a considerable proportion of respondents left the question blank (Table 20) and instead commented that a partnership between organisations might be most effective.

Table 19: Which organisations should be involved in implementing a consumer participation initiative?

| At national level? | | | At state/territory level? | | |
|-------------------------|----|------|--|----|------|
| | n | % | | n | % |
| Drug Strategy Branch | 8 | 57.1 | State/territory government Departments of Health | 9 | 64.3 |
| Non-governmental sector | 11 | 78.6 | Non-governmental sector | 11 | 78.6 |
| AIVL | 10 | 71.4 | based drug user organisation | 10 | 71.4 |
| Consumer Health Forum | 9 | 64.3 | State/territory Consumer Health Councils | 9 | 64.3 |

(Respondents were allowed to choose all that apply.)

Table 20: Which organisation should lead the implementation of a consumer participation initiative?

| At national level? | | | At state/territory level? | | |
|-------------------------|---|------|--|---|------|
| | n | % | | n | % |
| Drug Strategy Branch | 1 | 7.1 | State/territory government Departments of Health | 1 | 7.1 |
| Non-governmental sector | 4 | 28.6 | Non-governmental sector | 3 | 21.4 |
| AIVL | 4 | 28.6 | State-based drug users organisation | 4 | 28.6 |
| Consumers Health Forum | 1 | 7.1 | State/territory health consumer councils | 1 | 7.1 |
| Did not answer | 3 | 21.4 | Did not answer | 3 | 21.4 |

(Respondents were allowed to choose only one from each list.)

Respondents who believed drug user organisations should play a lead role did so with the caveat that this would be best achieved in partnership with government:

'Ideally, AIVL and the state based drug user organisations should take the lead in such an initiative. However, the level of support from relevant government departments would need to be considerable. A partnership model may be more pragmatic.'

Other respondents expressed concerns that a large proportion of consumers of alcohol and other drug treatment services were not illicit or injecting drug users and thus suggested the possibility of collaboration between drug users organisations and other consumer groups:

'I think broad consumer representation is vital... It's critical to note that illicit and injecting drug users form only a portion of the broader consumer population seeking treatment – and if any consumer body were to effectively 'represent' the consumer population, some way to encompass those not covered by illicit and injecting would need to be determined. This is particularly vital – given that alcohol-related problems are the most prevalent of drug-related issues for consumers when presenting for treatment in either generalist or specialist agencies.'

Because the TSU Project included only those services that treat people who use illicit or injecting drugs, it is not possible to determine the extent of support for consumer participation initiative amongst service providers and consumer of alcohol services. If it were the case that there was support among these services, and a consumer participation initiative were to be implemented, then collaboration amongst consumer groups would be useful.

4.2.8 Conclusion

This consultation sought the opinions of those individuals thought to have influence over the policy and funding aspects of drug treatment services in Australia. It shows that there is overall support for consumer participation in drug treatment services. There is agreement that policy changes would be necessary and that such policy initiatives should be accompanied by specific, extra funding. In doing so, respondents identified consumer participation as a priority issue for drug treatment services in Australia. It is also clear that the implementation of such an initiative should be a collaborative and inclusive project and that consumer representative organisations such as AIVL and/or its state-based members should lead the initiative, or, at the very least, be key players in partnership with others.

❖ Chapter 5: Discussion

5.1 Scope of the Study

From the consumer perspective there are many potential issues of investigation and research in relation to drug treatment service delivery. Other national research projects in the recent past such as *National Evaluation of Pharmacotherapies for Opioid Dependence* (NEPOD) (Mattick et al 2001) and the *Barriers and Incentives to Drug Treatment for Illicit Drug Users* (Treloar et al 2004) have examined a range of issues in drug treatment service delivery including the range of treatment options available, the availability of treatment places, treatment affordability and accessibility, the impact of service models and philosophies, and personal and interpersonal barriers and incentives to treatment.

Building on this growing body of evidence, the Treatment Service Users (TSU) Project was a small, targeted research project which aimed to investigate one specific aspect of drug treatment service delivery – that is, the issue of consumer participation in drug treatment services. In this context, the TSU Project did not aim to research issues in relation to treatment availability, treatment accessibility or treatment flexibility. While these are without doubt very pressing issues for many drug treatment consumers, the issue of consumer participation in drug treatment services is also an extremely important issue in the context of drug treatment service delivery and outcomes.

Consumer participation in the planning and delivery of health services is supported in the available literature as a highly effective way of not only improving service planning, targeting and delivery but also of improving health outcomes for health consumers. The policy audit conducted as part of the TSU Project identifies a strong track record of consumer participation activities in a range of mainstream and targeted health and social service areas including mental health, disability services, aged care, youth services and women's health. The relative lack of established policy frameworks and documented activity in relation to consumer participation in drug treatment services however, highlighted the need to further investigate the issue of consumer participation in drug treatment services.

5.2 Defining 'Consumer Participation'

To provide a framework for understanding and assessing consumer participation in drug treatment services, a strict definition of 'consumer participation' was developed and applied within the TSU Project. This definitional framework identified levels of consumer participation with a range of specific consumer participation activities within each of the three levels. (see Chapter 3, Figure 2, page 45.) There are other models of consumer participation, and the findings and outcomes of the TSU Project should be viewed within the context of this specific definition of consumer participation.

5.3 Support for Consumer Participation

The study findings reflect strong support for consumer participation in the planning and delivery of drug treatment services from all stakeholders, including service providers, consumers, AIVL member organisations and other key stakeholders. Many services indicated that they already engaged in some types of consumer participation activities, although these were mostly low to mid degrees of consumer involvement. The findings also show there is a considerable amount of informal communication about service quality already taking place between consumers and providers, and amongst consumers themselves. This encouraging support and the fact that some services are already conducting low level consumer participation activities provide a strong foundation upon which to build future formalised consumer participation policies and programs in Australian drug treatment services. These foundation activities show that involving consumers in service planning and delivery is possible, that consumers are interested and capable of making valuable contributions to the services they use, and that communication between consumers and providers is achievable.

There was less support among some service providers and other stakeholders (government officers, key experts and representatives from non-government AOD organisations) for consumer participation in *higher degree* activities in which consumers have decision-making roles particularly in relation to staff matters. This may reflect the reluctance of staff to have consumers involved in decision-making matters that relate directly to their work practices (such as performance appraisal, training and recruitment). In this situation, however, it is possible that staff may become more comfortable with having consumers in these roles once they have had experience with consumers in this capacity. The study found that residential services were more likely to support the idea of having consumers involved in decision-making roles, which may be because residential services were more likely to already engage consumers in joint decision-making activities. As such, staff understand how consumer participation works and have fewer concerns or fears around it. Overall, however, the majority of service providers reported that they would at least consider consumer involvement in decision-making activities. The reluctance of some service providers may simply derive from their lack of knowledge about how consumer participation might work in practice.

5.4 Challenges to Consumer Participation

Despite the very strong support for consumer participation in drug treatment services from all stakeholders, a range of challenges to the practical implementation of consumer participation activities were identified. These include communication problems, lack of awareness about what consumer participation actually means, beliefs about consumers' level of interest, cultural issues regarding the roles and relationships between providers and consumers, and inadequate resourcing.

5.4.1. Communication Issues

The data reflects a significant gap in communication between consumers and providers in relation to knowledge of current consumer participation activities. While many services indicated they already engaged in some types of consumer participation, interviews with consumers at these services show that they knew very little about these activities. These communication issues can be easily addressed through the active promotion of consumer participation activities, as the consumer data also shows that once consumers are aware of consumer participation activities they are keen to participate in those activities.

Communication issues were also highlighted in the national consultation with the AIVL member organisations, with consumer advocates identifying the importance of ongoing consultation between service providers and consumers. The consumer organisations stressed the importance of networking and liaison to avoid the perception that providers and consumers only communicate when there are complaints or grievances.

5.4.2. Lack of Awareness about Consumer Participation

The study findings suggest that there is a lack of understanding on the part of providers and consumers about what consumer participation means in practice. For example, when asked for reasons why a service had not engaged in certain types of activities, some service providers stated they had 'never thought about' conducting these activities, suggesting a need for education and training on the role and potential benefits of consumer participation.

Providers' lack of awareness about consumer participation has implications for how consumer participation might be implemented in future, but also in how current consumer participation efforts are acted upon. For example, the study found that most services were accredited (or in the process of gaining accreditation) but were nevertheless not engaging in many consumer participation activities. Such a high level of accreditation might suggest there would be equally high levels of certain kinds of consumer participation activities since these are often mandatory parts of receiving accreditation. The fact that most services had only minimal or low level consumer participation activities suggests a possible lack of understanding about the potential benefits of consumer participation. This lack of formal consumer involvement in accreditation processes is also evidenced at the policy level, with only two AIVL member organisations reporting any involvement in the development of accreditation standards for drug treatment services.

The national consultations with AIVL member organisations and other key stakeholders also identified quality assurance and accreditation processes as 'critical' in ensuring more consistent or 'standardised' definitions of consumer participation. They identified that by including consumer participation in service accreditation, such processes had the potential to promote a better understanding of consumer participation and its role in quality service provision. If accreditation processes were to play this role, they could potentially make a significant contribution to raising awareness of the practical benefits of consumer participation in drug treatment service delivery. From this perspective however, further work needs to be carried out to ensure that mandatory quality assurance and accreditation processes really do promote a better understanding of consumer participation activities rather than simply encouraging tokenistic approaches towards consumer participation in order to gain the 'required' accreditation.

Another example of differences in definitions and interpretations of consumer participation is reflected in the high number of services that reported having a Consumer Charter of Rights. The widespread presence of Charters of Rights might show how making certain practices mandatory can introduce new concepts to services. The fact that many services have Charters of Rights could be used as building blocks to further develop and implement more formalised consumer participation activities. Importantly, however, the study did not collect information about the content of each service's Charter. It is essential that Charters of Rights be consistent across services, and reflect the meaning and spirit of the Consumer Charter of Rights as it is defined in the consumer participation literature (Consumers' Health Forum). www.chf.org.au/public_resources/consumer_rights.asp

Often consumers' rights as listed in treatment contracts can be interpreted more as consumers'

responsibilities toward the service, and less as the consumers' rights within the service, which is often how individual treatment contracts in NSW can be construed.

Further linked to the lack of awareness of what consumer participation is in practice, is the comment made by some service providers that they were unwilling to support mid and higher level consumer participation activities because such activities were 'not practical for this kind of service'. It is likely these responses are a combination of fears or concerns about consumer participation for some services and an expression of genuine service limitations for others. For example, comments on the limitations that different types of services may experience in relation to implementing certain types of consumer participation activities were not only made by service providers. The national consultation with AIVL member organisations highlighted the genuine restrictions that could be inherent in certain types of treatment programs and services. Consumer organisations identified that consumers of inpatient detoxification services may simply be too unwell to participate in some high level consumer participation activities. The nature of the service, such as some very short term treatment programs, could also mean that consumers are not in contact with the service long enough to establish ongoing consumer involvement.

Like providers, some consumers also seemed to have a lack of knowledge about the meaning of consumer participation. The most common reason given by consumers for being unwilling to participate in consumer participation activities was a general lack of confidence related to a perception of 'not having the necessary skills'. While many consumers will have 'actual' skills deficits in relation to certain consumer participation activities, it is also important to recognise that some consumers could simply 'assume' they do not have the necessary skills and capacities because they don't have an adequate understanding of what consumer participation involves. Consumer projects conducted within drug user organisations have demonstrated that when educated about consumer participation in drug treatment services, consumers do develop the confidence to participate and have perspectives to offer that can lead to improvements in both policy and service delivery (Thompson 2002).

This is consistent with the views expressed by the AIVL member organisations in the national consultation workshop. As consumer representatives, the AIVL member organisations hold a belief that a lack of recognition of the skills and expertise of consumers creates a barrier to involvement for consumers. The consumer organisations believe that services need to undertake education to not only understand the needs of consumers but to also recognise that consumers come to services with a unique set of skills and expertise that could be utilised to enhance service provision and improve treatment outcomes. This is a view also supported in the policy audit in relation to the value of consumer involvement in other areas of health service delivery (Consumer Collaboration 2001).

5.4.3. Beliefs about Consumers' Level of Interest in Consumer Participation

Both providers and consumers held incorrect beliefs about consumers' levels of interest in relation to consumer participation. Some service providers reported that the reason they had opted not to conduct consumer participation activities was because they believed that consumers would not be interested in participating. Likewise, some consumers held the belief that other consumers would not be interested in participating. Yet the study findings clearly show that the majority of consumers supported the principle of consumer participation, would be willing to participate in such activities in future, and displayed high levels of actual participation when given the chance to be involved (and were informed about available activities).

Consumers' beliefs that other consumers are not interested in participating could either demonstrate a lack of effective communication and cohesion amongst consumers or a sense of optimism about one's own ability to participate compared to others. Although many consumers reported talking to each other about service quality, a considerable proportion held incorrect understandings about the views of other consumers – that is, they incorrectly believed that other consumers did not want to be involved. In order to facilitate proper and meaningful consumer participation, it seems likely that a degree of cohesion will need to be facilitated amongst consumers. Moreover, given providers' views that consumers do not want to be involved, it seems clear that consumers' advocates themselves (such as AIVL's member organisations) are best positioned to encourage participation through education, training and other development initiatives.

Understanding the factors informing such beliefs among consumers is complex and multi-faceted. As a highly marginalised group within the community, consumers' beliefs about their own interests and skills and those of others often stem from years of stigmatisation and internalisation of the negative beliefs of others. Indeed, as highlighted in the policy audit for this study, other areas of health service delivery to marginalised communities (such as mental health consumers) have identified that the relationship between attitudes and consumer participation is circular, and that negative attitudes on behalf of service providers can act as a barrier to genuine consumer participation (MHCA 2000). Like all areas of health service provision, there will always be consumers who are disinterested in consumer participation activities or who simply want to focus on their treatment. However, it is also important that rather than basing the design and availability of consumer participation activities on assumptions and beliefs, no matter how strongly they are held, services need to ensure they have accessible mechanisms in place to regularly ask consumers what they would like in relation to involvement and participation. Similarly, organisations representing drug treatment consumers need to be supported to build cohesion and confidence among consumers and empower consumers to make use of participation opportunities provided by services.

5.4.4. Roles and Relationships Between Service Providers and Consumers

A small group of stakeholders (including service providers, consumers, and other key stakeholders) expressed beliefs that it is not the role of consumers to have decision-making responsibility with regard to service planning and delivery. The respondents' concerns about what are *appropriate* consumer roles within services highlights how the culture of drug treatment services acts to position providers and consumers as active/passive or as having/lacking skills (Treloar & Holt 2006). Involving consumers in decision-making activities appears to challenge providers' beliefs about the roles and capacities of consumers within drug treatment services. Moreover, there is strong evidence to show that consumers have fears around participating in such decision-making activities. They fear repercussions from services, which is why they do not take full advantage of certain existing activities such as complaints processes, and why they are not willing to take part in higher degree activities in future.

Providers appeared to be particularly reluctant to involve consumers in activities that relate directly to staff (recruitment, performance appraisals and training). However, it may be the case that once providers have more information about how this might work in practice, their fears may be alleviated. For example, consumer participation in staff recruitment and appraisals could involve gradual degrees of participation, making the activity easier for both service providers and consumers. Consumer representatives could have input into the drafting of position descriptions for new positions, or could provide structured feedback on the performance of case managers. Such participation activities may be more amenable to providers and alleviate concerns about consumers' roles.

Providers' concerns about the capacity for and appropriateness of consumer participation are challenged by the experience of service providers in the mental health sector. An evaluation of a Consumer Participation in Staff Selection (CPSS) Strategy at a mental health service showed that the strategy had been highly successful. It identified that rather than being at odds with each other, staff, senior managers and consumers had complementary perspectives on issues such as key selection criteria for staff positions. The evaluation also highlighted that the values and skills of consumers such as empathy, insight and comfortable interaction sat well alongside considerations of appropriate qualifications, training and experience (NAMHS 2003).

Importantly, not all service types were concerned about consumers being involved in decision making roles to the same extent or in the same way. For example, residential service providers expressed more support than pharmacotherapy services for consumer involvement in decision making roles. One of the reasons for this may relate to the existing roles that consumers play as part of the treatment process in many residential rehabs where consumers can be part of joint decision-making processes in relation to practical operational issues within the service (work schedules, menus, cleaning rosters, and house rules). The more experience services have had with consumers in decision-making roles, even if they are limited to operational issues, the more comfortable they seem to be with the concept of expanding that role. Another reason for the difference in support between service types could relate to the fact that pharmacotherapy services dispense restricted medications, which are dependency forming, in a security-oriented environment which inevitably leads to the establishment of more formal, hierarchical structures and a far more passive role for consumers than in residential rehabs and therapeutic communities. Indeed at the 'theoretical' level, the entire premise for residential therapeutic communities is that there should be no formal distinction between 'clients' and 'staff'. While this does occur in practice in some services working on the therapeutic community model, it is also the case that other services have gradually moved away from this model into more formalised roles between 'clients' and 'staff'.

A small number of consumers also expressed a reluctance to be involved in some higher degree consumer participation activities because they felt it was not their place to do so. Consumers reported fears of retribution and/or feelings that participation in certain activities would impact negatively on their treatment. This was reported most strongly in relation to the use of complaints processes. Consultation with AIVL's member organisations also highlighted the critical role that consumers' fears play in determining their willingness to become involved in decision-making activities. Fears of punitive repercussions such as losing one's place in a pharmacotherapy program, being refused dosing or take-aways and being treated unfairly by staff were identified by AIVL's member organisations as major concerns for consumers. The significance of this issue in preventing active consumer involvement is also highlighted in the NSW Health *Guide to Consumer Participation in NSW Drug and Alcohol Services*. The guide is designed to be a practical document aimed at supporting consumer participation in NSW drug treatment services and highlights fear of reprisals if seen to be critical of the service and/or staff as one of the challenges that needs to be addressed when seeking to involve consumers in drug treatment services (NSW Health 2005).

The level of fear expressed by individual consumers and highlighted by both consumer organisations and NSW Health appears at odds with the views of service providers in this study. For example, the majority of service providers stated they believed that client's complaints about the quality of services are usually reasonable and that they want clients involved in the way services and programs are run. However, the vast majority of consumers did not seem to believe this and instead reported that they believed service providers did not want them involved.

It is important to address the reasons why consumers are fearful of involvement. Such fears will prevent some consumers from participating in certain activities. Changing the culture of drug treatment services to support more meaningful consumer participation will require a willingness and commitment from policy makers, service providers, consumers and their representatives to work together to develop practical and workable models. It is clear that as long as traditional roles and relationships within drug treatment services are maintained, consumers will continue to feel isolated and under-valued and any dialogue that does occur between providers and consumers will be hampered by fear and mistrust on both sides.

5.4.5. Lack of Adequate Resourcing and Skill Capacity

Some service providers identified a lack of adequate funding as a main reason why they had not engaged in consumer participation, or why they would be unwilling to do so in future. Equally, both consumers and providers identified the need for increasing skill capacity to undertake consumer participation, which would inevitably require funding.

The respondents in the key stakeholder consultation were specifically asked about a range of funding issues in relation to consumer participation. The majority of respondents supported the need for dedicated extra funding, in addition to current treatment services funding, at the very least to allow services to 'start up' or establish consumer participation activities within their services. There was a general recognition of funding pressures within the drug treatment area and for this reason some key stakeholders felt that a 'start-up initiative' would support services until consumer participation activities became part of 'business as usual'.

Developing funding models to resource consumer participation activities within drug treatment services will require extensive dialogue between all levels of government, drug treatment services and relevant non-government organisations. Initiating such discussions rests with government and will need to occur as a matter of urgency if the strong support for consumer participation evidenced in this study is to be realised at the service delivery level.

The issue of providing compensation or remuneration for individual consumers engaged in consumer participation activities was also raised in the key stakeholder and AIVL member organisation consultations. Some key stakeholders and all of the consumer organisations felt that reimbursing consumers for their time and expertise is an essential component of developing effective consumer participation approaches. The remuneration of consumers for their time, expertise and out-of-pocket expenses is regarded as standard practice in many areas of health service delivery and is one of the core consumer participation principles in the *AIVL National Statement on Ethical Issues in Research Involving People Who Use Illicit Drugs* (AIVL 2004). Ensuring proper remuneration for individuals engaged in consumer participation activities will require a commitment from governments, services and non-government organisations to incorporate such principles into their policies, programs and funding arrangements.

Consultations with the AIVL member organisations also identified a lack of resourcing as one of the main reasons why they struggle to effectively coordinate consumer participation efforts across the drug treatment sector. Despite the fact that all AIVL member organisations and AIVL itself routinely undertake consumer participation activities in relation to drug treatment service delivery, only two AIVL member organisations specifically identified that they were funded on an ongoing basis to undertake these activities. The consumer organisations referred to the 'assumptions and expectations' of funding

bodies, drug treatment services and key stakeholders in relation to their role in coordinating consumer participation activities regardless of whether they are receiving any specific funding. Overall there seems to be a lack of recognition of the fundamental role that peer-based drug user organisations must play in relation to the development and implementation of consumer participation policy frameworks and targeted activities at the service delivery level. Along with funding for drug treatment services to develop and implement consumer participation initiatives, it is also necessary for peer-based drug user organisations to be provided with funding to effectively fulfill both the strategic and targeted demands on them in this area.

5.6 Implementing Consumer Participation in Practice

The 'take home' message from the consultation and data collection phase of this project is that stakeholders strongly support the principle of consumer participation in drug treatment services. While there are challenges to implementing consumer participation in this context – with communication gaps, awareness levels, resourcing problems and the culture of services needing to be addressed – the focus should remain firmly on developing strategies to achieve consumer participation 'in practice' rather than focusing on barriers or areas of difference. The key to the future successful development of consumer participation in drug treatment services will depend on the willingness and commitment of all stakeholders to address the above challenges and expand the opportunities for consumers to reduce their fears, isolation and marginalisation. Meaningful consumer participation will only truly develop within the drug treatment sector if there is commitment to a range of key components. These are considered in the following sections.

5.6.1 Education and Training

The need for education and training sessions to support effective consumer participation in drug treatment services was identified at various stages throughout the consultation phase by a range of different stakeholders. Stakeholders believed that education and training was needed to fulfill a range of outcomes including to:

- raise awareness of consumer participation among all key stakeholders;
- reach consensus on what consumer participation is in practice;
- develop effective and practical models for drug treatment environments;
- explore differences in consumer participation models for different types of services; and
- support all stakeholders (including consumers) to develop the skills and capacity they need to participate without fear.

The idea of demonstrating effective and practical consumer participation models was supported in the study by comments made during the consultations with the AIVL member organisations. The concept of providing 'incentives' for service providers to get involved in consumer participation activities was suggested in the form of promoting successful models of good practice to show how consumer participation in services can result in positive outcomes and benefits for both the service and treatment consumers.

The study shows that different treatment services are at different levels of development in relation to their attitudes towards and experience with consumer participation activities. It will be crucial

therefore that this diversity of experience is taken into account in the development of any future model of education and training aimed at building support for consumer participation in drug treatment services. A demonstration or pilot approach will ensure this, with the development and evaluation of consumer participation models suitable for services unsure about or with no experience of consumer participation as well as providing more advanced models for those services willing to expand their existing consumer participation activities.

A series of practical demonstration projects will not only provide guidance and tools for treatment services to put consumer participation into practice in their specific context, but will also raise awareness and build skills, capacity and confidence in consumer participation among consumers and providers of drug treatment services. As evidenced by the outcomes of training programs implemented in the general health care sector, this next step will be vital in taking consumer participation from a theoretical concept to an action-oriented strategy capable of having a direct and positive effect on the quality of services and individual treatment outcomes (Commonwealth Department of Health & Ageing 2000).

Finally, when asked for their opinion regarding which organisations should be involved in further developing and implementing a consumer participation initiative, stakeholders identified a key leadership role for AIVL and its member organisations. Given that AIVL and its member organisations hold unique expertise stemming from the TSU Project and other consumer-oriented work, it would make sense for these organisations to take a key role in the development of any follow-up demonstration or pilot projects in relation to consumer participation in drug treatment services.

5.6.2 Development and Implementation of Policy Framework

The role of policy, standards and guidelines in providing leadership and strategic direction for consumer participation in drug treatment services was also identified in the TSU Project consultation. While the role of policy in relation to consumer participation was not explored in the formal data collection phase with service providers and individual consumers, the need to make changes to the current policy framework was explored and supported by almost all respondents in the key stakeholder survey. The consultation with AIVL member organisations also explored and identified the crucial role for national policy guidelines in supporting consistency and compliance at the national and local levels in relation to consumer participation.

Although opinion was split as to whether policy change needed to be initiated at the national, state/territory or regional level, as a first step towards embedding consumer participation within the policy framework, there was significant support for the inclusion of consumer participation into national and jurisdictional drug strategies. In addition to providing a clear statement that governments are 'serious' about consumer participation in drug treatment services, it was felt that the inclusion of consumer participation principles and standards into the national policy framework through the National Drug Strategy would also provide the basis for an 'over-arching' consistency of approach and the capacity to effectively evaluate whether the principles in the strategy are being implemented. To achieve this, any inclusion of consumer participation in the National Drug Strategy would need to move beyond 'motherhood' statements of broad support for consumer participation in drug treatment services to include concrete, measurable and achievable outcome indicators.

The overall lack of understanding of consumer participation and how it works in practice, definitional inconsistencies and confusion about whether compulsory and therapeutic activities constitute 'genuine'

consumer participation all suggest the need for national and jurisdictional policy frameworks to support more consistency in consumer participation approaches and to provide strategic direction. Indeed, the move to embed consumer participation into the national policy framework is consistent with other areas of health service delivery with highly effective approaches to consumer participation including the National Mental Health Plan 2003–2008, the National Strategic Framework for Aboriginal and Torres Strait Islander Health Context 2003 and the National Disability Services Standards.

5.6.3 Funding Support for Consumer Participation

Key stakeholders surveyed for this study expressed a range of opinions on whether funding for consumer participation initiatives in drug treatment services should come from government or non-government sources. The important link between government policy frameworks and associated funding initiatives was also highlighted as a reason why governments should take primary responsibility for funding consumer participation initiatives. The increased flexibility that the non-government sector has to administer and apply funding particularly in relation to working with consumers was also raised as a basis for supporting non-government funding sources.

It should be highlighted however, that the extremely limited funding available to the non-government treatment sector, coupled with the fact that governments are currently the main source of funding for drug treatment services makes it extremely unlikely that strategic responses to consumer participation in this context will be developed without the commitment of government funding support. It is possible that some of the opinions expressed by key stakeholders on this issue relate more to the method of 'administering' available funding for consumer participation activities (ie through the non-government sector to provide more flexibility) rather than necessarily viewing the non-government sector as a 'source' of funding support.

The issue of linking funding to mandatory requirements of consumer participation was explored with key stakeholders. The majority of responses were roughly divided between those who thought consumer participation should be included in funding agreements as an aspect of delivering a quality service (along with other outcome indicators) and those who did not support the concept out of concern that such a move could either lead to tokenistic approaches to consumer participation or simply place further pressure on already stretched services. While this issue will need further discussion among all stakeholders to identify the most effective model to support increased consumer participation in drug treatment services, as part of that process it may well be worth reviewing other areas of health service delivery where mandatory requirements for consumer and community participation have been utilised effectively, including the provision of health services for Aboriginal and Torres Strait Islanders (NATSIHC 2003).

5.6.4 Leadership and Consumer Participation

A range of views were expressed across respondents to the questions about who should be involved and take a leadership role in building and sustaining consumer participation within drug treatment services. While respondents generally believed that there needed to be a collaborative partnership-based approach to the development and implementation of consumer participation involving government, the non-government sector, drug user organisations and individual consumers, some respondents identified specific partners for particular roles.

When asked, consumers overwhelmingly wanted either current or ex consumers to act as consumer representatives on their behalf. In contrast to service providers, very few consumers were in favour of 'generalist' health consumer representatives or family members being involved in advocating on their issues in relation to drug treatment services. There needs to be further discussion on the definitional issues surrounding the concept and role of the 'current consumer' and the 'ex-consumer', particularly within different types of drug treatment services. It is vital that these discussions are led and owned by drug treatment consumers with input from service providers and other stakeholders, to ensure that any approaches developed adequately represent the actual rather than perceived needs of drug treatment consumers.

The majority of respondents in the key stakeholder survey believed that AIVL, its state/territory member organisations and the non-government sector generally should lead on the implementation of consumer participation initiatives within drug treatment services. In expressing this support in relation to leadership however, a number of comments were also raised about the importance of these leaders adopting a pragmatic partnership-based approach and the need to ensure broad consumer representation. As the TSU Project only sought to investigate the issues of consumer participation in the context of drug treatment services for illicit drug use, there is future work that needs to be done to examine the participatory and representational needs of alcohol and other non-illicit treatment service consumers. Having said this however, it is imperative that the impetus, awareness and goodwill created through the TSU Project in relation to consumer participation in drug treatment services does not get lost while we discuss the above issues.

The TSU Project has commenced an important dialogue between treatment service consumers and service providers. The project was initiated by a particular group of consumer representatives through AIVL who, over many years, have built themselves to a position where they are ready to work in partnership with stakeholders on these issues. The project has been a success precisely because of the willingness of all involved to work in collaboration and listen to the needs, concerns and aspirations of the other stakeholders. In order to build on the success and learnings of the TSU Project we have a responsibility to build and expand the diverse voices and experiences of treatment consumers while at the same time to seek to make progress on those areas of strong agreement and common ground identified in this first stage.

❖ Chapter 6: Recommendations

The following recommendations are grouped according to four priority actions areas to guide the implementation of consumer participation in drug treatment services. All of the recommendations have been informed by the findings of the study. These recommendations aim to provide an implementation framework in relation to consumer participation in drug treatment services for all key stakeholders. Some recommendations require collaboration and partnership between a number of key stakeholders while others will need leadership from a single stakeholder group such as government, drug treatment services or consumer organisations.

All of the recommendations are directed towards the main findings of the study which were that, although there is a strong level of support for the concept of consumer participation in drug treatment services, a number of challenges exist that will need to be addressed if consumer participation is to be implemented 'in practice'. The recommendations can be conceptualised as a series of 'building blocks' that, if implemented will create a strong foundation upon which the broad-based support for consumer participation in drug treatment services can be realised.

Priority Action Area 1: Education and Training for Consumer Participation

***R1:** Develop a National Consumer Participation Demonstration Project to design, pilot and evaluate practical models of consumer participation in a range of drug treatment contexts.*

***R2:** Based on the outcomes from the above project, produce a National Consumer Participation Toolkit for service providers and consumers covering practical strategies and guidance on initiating and maintaining consumer participation in drug treatment services.*

***R3:** Given the number of services currently conducting 'low degree' consumer participation activities, it is recommended that services should document and evaluate these existing activities and develop strategies to ensure consumers are aware of these activities.*

***R4:** Consumer participation in drug treatment services should be identified as a priority theme during Drug Action Week and AIVL and its member organisations should be supported to take a leadership role in designing, implementing and promoting consumer focused activities in order to raise awareness of the importance of consumer involvement.*

***R5:** Encourage relevant national and local publications such as the Drug and Alcohol Review, Of Substance, ADCA News, Junkmail and the local drug user organisation magazines to regularly publish discussion pieces, articles, papers and commentaries on the issue of consumer participation in drug treatment services.*

R6: Provide training and education for drug treatment consumers to build skills, capacity and confidence in relation to consumer participation.

R7: Provide training and education for service providers to build skills and capacity in relation to consumer participation.

Priority Action Area 2: Policy Framework for Consumer Participation

R8: Develop and promote a nationally agreed definition of consumer participation in drug treatment services to be used at the policy and service delivery levels.

R9: Incorporate principles of, and outcome indicators for, consumer participation in drug treatment services into the national and state/territory drug strategies.

R10: At the state/territory level, develop specific policy frameworks to support consumer participation in drug treatment services in addition to policies relating to consumer participation in general health settings.

Priority Action Area 3: Funding for Consumer Participation

R11: Consider conducting a national consultation on the effectiveness, advantages and disadvantages of including outcome indicators in relation to consumer participation in all drug treatment service funding agreements.

R12: Consider establishing a 'start-up' funding initiative to support drug treatment services to initiate consumer participation activities and incorporate them into mainstream service practices.

R13: As a principle consumers should be remunerated for their involvement in consumer participation activities.

Priority Action Area 4: Leadership for Consumer Participation

R14: All stakeholders should commit to working together to build and sustain consumer participation in drug treatment services.

R15: Support consumer organisations to take a leadership and developmental role in relation to consumer participation in drug treatment.

R16: Establish a National Drug Treatment Consumers' Round Table. The group would be facilitated by AIVL and function as an advisory and leadership body to progress issues in relation to consumer participation in drug treatment services. Once established the Round Table could also be responsible for developing and disseminating strategic discussion papers on key issues in relation to consumer participation. It would include representation from a diverse range of drug treatment consumers and other relevant stakeholders (including Therapeutic Communities Association, ANCD, peak NGO agencies, etc).

Appendix 1

October 2005

National Treatment Service Users Project



TREATMENT SERVICE USERS PROJECT

- AIVL has received government funding to look at consumer health and advocacy issues for people in drug treatment.
- AIVL is working with the National Centre in HIV Social Research
- Areas of Investigation

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and representatives from the Australian National Council on Drugs ANCD), Inter-governmental Committee on Drugs (IGCD) and the Drug Strategy Branch.

Why is this project important?
Over the past few years there have been a number of national research projects which have focused on the drug treatment issues for people who use illicit drugs including Barriers and Incentives to Drug Treatment (and Adjunct Study) and the National Evaluation of Pharmacotherapies for Opioid Dependence (NEPOD) Study. While these studies have been extremely valuable in identifying a range of broad issues and needs for both drug treatment services and those who use them, they have not focused on the needs of treatment service users as 'service consumers'.

Currently there is a lack of information at the national and local levels in relation to the consumer health and advocacy needs of drug treatment service users. While the recognition of the rights and advocacy needs of health consumers has become the norm in other areas of health service delivery such as mental health and disability services, the same recognition has not occurred within drug treatment services. For this reason, AIVL believes there was a need to conduct a formal consultation process to identify the consumer health and advocacy needs of drug treatment service users in Australia. Evidence in other areas of health service delivery have highlighted the value of consultation with health service consumers and models overseas are showing that involving consumers in service delivery and planning is of great benefit to all stakeholders.

Welcome to the TSU Project. This is an exciting and pioneering project which has been funded by the Australian Government Department of Health and Ageing, Drug Strategy Branch. This project is for all stakeholders within the drug treatment sector and aims to increase the understanding of consumer health and advocacy needs of people accessing drug treatment services. In addition it will provide an opportunity for all stakeholders to gain a better understanding of the potential role that service users can play in the planning and delivery of high quality services.



Who will be involved in the project?
AIVL and the National Centre in HIV Social Research have forged an exciting partnership bringing together the right balance of consumer experience and research expertise to make this project a success. This project is a great opportunity for the sector to work together. We are keen to ensure that both the research process and the final project outcomes are supported by both treatment service users and treatment service providers.

As part of the funding agreement with the Drug Strategy Branch, AIVL has agreed to establish a multidisciplinary advisory committee to provide ongoing advice on the development and implementation of all stages of the project. The TSU Advisory Committee will have direct input into all research questionnaires, review data collected and have input into the final project report. The proposed members of the TSU Advisory Committee includes service user and service provider representatives; researchers, health consumer

What are the key themes that the project will investigate?

- Consumer consultation processes and policies;
- Consumer participation and input into service planning and delivery;
- Consumer feedback mechanisms and complaints processes;
- Values and attitudes of service providers;
- Consumer rights and responsibilities;
- Advocacy and representation;
- Peer support and community development.
- Standards and accreditation;
- Workforce development and training;
- Other related issues raised during the consultation phase.

How will the project be conducted?

The preliminary research phase

This phase will consist of an audit and review of existing consumer participation policies at the national, state/territory and area/regional health service levels. The policy audit will help to determine what formal policies exist and to inform the development of the consultation tools. A brief literature search will also be conducted to collect available international and Australian research, consultations, project reports and articles in relation to the consumer health and advocacy needs of drug treatment service users.

The Consultation Phase

A range of consultation strategies will be employed to identify and examine the consumer health and advocacy needs of treatment service users including:

- Interviews with a selected sample of drug treatment services in WA, VIC and NSW
- Interviews with a sample of service users from the selected treatment services
- National Consultation Workshop with relevant consumer organisations and representatives and
- A Self-complete survey with other relevant stakeholders.

Ethical approval from all relevant Health Departments is presently being sought.

Dissemination Phase

Copies of the final report will be provided to all services and service users who were interviewed for the project and all consumer organisations and all other stakeholders who were consulted. The final report will also be sent to all relevant services, organisations and committees with an interest in the consumer health and advocacy needs of treatment service users. Articles for publication in consumer magazines, peer reviewed journals and presentations for conferences will also be developed.

What can drug treatment services gain from this project?

AIVL recognizes that consumer health and advocacy needs are a new area for consideration. Both consumers and providers will learn together as a result of this project about how best to build on current activities and develop new initiatives that can increase consumer involvement in the delivery and planning of services. AIVL looks forward to hearing from all of the stakeholders and ensuring that everyone's voice is heard and considered. This project is about enhancing drug treatment provision and bridging the gap between providers and consumers. By recognizing the expertise of all involved, services can only improve.

***Alone we can do so little; together we can do so much.
- Helen Keller***

❖ Appendix 2: List of TSU Advisory Committee Members (2005–06)

| | |
|----------------------------------|---|
| Ms Annie Madden | Executive Officer, Australian Injecting and Illicit Drug Users League (AIVL) – Chairperson |
| Dr Joanne Byrant | Research Associate, National Centre in HIV Social Research (NCHSR) |
| Ms Nicky Bath | Treatments Program and Policy Manager, Australian Injecting and Illicit Drug Users League (AIVL) |
| Ms Lin Lordi | TSU Project Worker, Australian Injecting and Illicit Drug Users League (AIVL) <i>September 2005 – January 2006</i> |
| Ms Suzanne Robinson | TSU Project Worker, Australian Injecting and Illicit Drug Users League (AIVL) <i>March – September 2006</i> |
| Ms Melissa Saxton | Research Officer, National Centre in HIV Social Research (NCHSR) |
| Dr Carla Treloar | Deputy Director, National Centre in HIV Social Research (NCHSR) |
| Dr Martin Holt | Research Fellow, National Centre in HIV Social Research (NCHSR) |
| Ms Karen Price | Director, Research, International and Policy Section, Drug Strategy Branch, Australian Government Department of Health and Ageing |
| Ms Louise Grant | Consumer Representative |
| Ms Sarah Lord | Consumer Representative |
| Ms Dayle Stubbs | Consumer Representative |
| Dr James Bell | Director, Langton Clinic, Sydney South East Area Health Service |
| Dr John Howard | Director Clinical Services, Training and Research, Ted Noffs Foundation |
| Mr Garth Pople | Member, Australian National Council on Drugs (ANCD) |
| Ms Ros Carter | Representative, Inter-Governmental Committee on Drugs (IGCD) |
| Ms Helen Hopkins | Executive Director, Consumer Health Forum of Australia |
| Ms Anita Rodrigues Macias | Policy Officer, Alcohol and Other Drugs Council of Australia (ADCA) |

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❖ Appendix 4: Documents for Consumer Participants

Approval No HREC 05278

THE UNIVERSITY OF NEW SOUTH WALES PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

National Treatment Service Users (TSU) Project

[Participant selection and purpose of study]

You are invited to participate in a study looking at the opportunities for, attitudes towards and experiences of client participation in the planning and delivery of drug treatment services in New South Wales, Victoria and Western Australia. We hope to learn about the ways in which clients are involved in the planning and delivery of the treatment services they receive. You were selected as a possible participant in this study because you are a client at this treatment agency, which has been selected as a site for this study.

[Description of study and risks]

If you agree, we will ask you to participate in a 20-30 minute interview. We will ask you questions about your views, knowledge and experiences of participating in the planning and delivery of drug treatment services. The interview is entirely confidential and all answers you provide will be anonymous.

We cannot and do not guarantee or promise that you will receive any benefits from this study.

[Confidentiality and disclosure of information]

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission, except as required by law. Study data will be treated confidentially and will be securely stored in a locked cabinet at the National Centre in HIV Social Research at the UNSW.

If you give us your permission by signing this document, we plan to release the results in a report co-produced by the National Centre in HIV Social Research and the Australian Injecting and Illicit Drug Users League (AIVL). The report will be available to relevant Australian government bodies and consumer organisations (such as NSW User's and AIDS Association, the Western Australian Substance Users Association, and the Victorian Drug Users Group). Also, we will present the results in academic journals and at conferences, and in AIVL's national policy magazine *Junkmail*. Copies of the study's final report will be available to you and other participants on-line at AIVL's website (<http://www.aivl.org.au>) or in paper copy by asking the staff at this treatment agency. In any publication, information will be provided in such a way that you cannot be identified.

This study is funded by the Australian Government Department of Health and Aging, Drug Strategy Branch. Any complaints about this study may be directed to the Ethics Secretariat, The University of New South Wales, SYDNEY 2052 AUSTRALIA (phone 9385 4234, fax 9385 6648, email ethics.sec@unsw.edu.au).

edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

[Recompense to participants]

As compensation for your time and expenses we will give you \$20.

[Your consent]

Your decision whether or not to participate will not prejudice your future relations with The University of New South Wales or the agency at which you receive treatment. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

If you have any questions, please feel free to ask us. If you have any additional questions later, Dr Joanne Bryant, (02) 9385 6438 will be happy to answer them.

You will be given a copy of this form to keep.

**THE UNIVERSITY OF NEW SOUTH WALES
PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)**

National Treatment Service Users (TSU) Project

You are making a decision whether or not to participate. Your signature indicates that, having read the Participant Information Statement, you have decided to take part in the study.

.....
Signature of Research Participant

.....
Signature of Witness

.....
(Please PRINT name)

.....
(Please PRINT name)

.....
Date

.....
Nature of Witness

.....
Signature(s) of Investigator(s)

.....
Please PRINT Name

REVOCAION OF CONSENT

National Treatment Service Users Project

I hereby wish to **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with The University of New South Wales, or the agency at which I receive treatment.

.....
Signature

.....
Date

.....
Please PRINT Name

The section for Revocation of Consent should be forwarded to Dr Joanne Bryant, National Centre in HIV Social Research, University of New South Wales, Sydney, NSW, 2052.

❖ Appendix 5: Documents for Provider Participants

Date

Name

Street

Suburb

NSW

Postcode

Dear

name

RE: National Treatment Service Users (TSU) Project; Approval No HREC 05278

You are invited to participate in a study looking at the opportunities for, attitudes towards and experiences of client participation in the planning and delivery of drug treatment services in New South Wales, Victoria, and Western Australia. We hope to learn about the ways in which clients are involved in the planning and delivery of the services they receive.

You were selected as a possible participant in this study because you are a Nurse Unit Manager (or equivalent service manager) at a drug treatment agency in New South Wales, Victoria, and Western Australia. The names and contact details of possible participants were obtained from drug and alcohol service directories.

We will contact you by telephone approximately one week to determine whether you would be willing to participate.

If you choose to participate, we will ask you to complete a 20-30 minute questionnaire. You can do this by whatever means is most convenient to you, including 1) arranging a time for us to conduct a telephone interview, or 2) completing the questionnaire yourself and returning it to us by email.

The questionnaire/interview will ask a structured set of questions about current opportunities at your service for client participation in service planning and delivery, as well as your values towards and experiences with client participation. ***We would like you to complete a questionnaire/interview even if you believe your service does not have any client participation practices.***

All information that you provide will be treated with utmost confidentiality. None of the information will ever be published or released in a form that could identify you.

An information sheet about the study is attached. Please feel free to telephone me if you have any questions about the study.

If you choose not to participate you can detach the slip from the enclosed information sheet and return it in the reply paid envelope. Alternatively you may decline to participate when we contact you by

telephone. Participating in the study is entirely voluntary.

This study has been approved by the Human Research and Ethics Committees of the University of New South Wales.

Sincerely,

Dr Joanne Bryant
National Centre in HIV Social Research
Level 2, Robert Webster Building
The University of New South Wales
Sydney, NSW 2052
Tel: (02) 9385 6438
Email: j.bryant@unsw.edu.au

Approval number HREC 05278

THE UNIVERSITY OF NEW SOUTH WALES PARTICIPANT INFORMATION STATEMENT

National Treatment Service Users (TSU) Project

[Participant selection and purpose of study]

You are invited to participate in a study looking at the opportunities for, attitudes towards and experiences of client participation in the planning and delivery of drug treatment services in New South Wales, Victoria, and Western Australia. We hope to learn about the ways in which clients are involved in the planning and delivery of the treatment services they receive. You were selected as a possible participant in this study because you are a Nurse Unit Manager (or equivalent service manager) at a drug treatment agency in New South Wales, Victoria, and Western Australia.

[Description of study and risks]

If you agree, we will ask you to complete a 20-30 minute questionnaire. We will ask you questions relating to the current opportunities at your service for client participation in service planning and delivery, as well as your values towards and experiences with client participation. **We would like you to complete a questionnaire/interview even if you believe your service does not have any client participation practices.**

We will telephone you in approximately a week to determine if you would be willing to participate. If you choose not to participate you can detach the slip at the bottom of this sheet and return it in the reply paid envelope. Alternatively you may decline to participate when we phone you.

We cannot and do not guarantee or promise that you will receive any benefits from this study.

[Confidentiality and disclosure of information]

Any information that is obtained in connection with this study and which can be associated with you will remain confidential and will not be disclosed without your written permission, except as required by law. Study data will be treated confidentially and will be securely stored in a locked cabinet at the National Centre in HIV Social Research at the UNSW.

The study findings will be published in a report co-produced by the National Centre in HIV Social Research and the Australian Injecting and Illicit Drug Users League (AIVL). The report will be available to relevant Australian government bodies and consumer organisations (such as NSW User's and AIDS Association, the Western Australian Substance Users Association, and the Victorian Drug Users Group). Copies of the study's final report will be available to you and other participants on-line at AIVL's website (<http://www.aivl.org.au>). Also, we will present the results in academic journals and at conferences, and in AIVL's national policy magazine *Junkmail*. In any publication, information will be provided in such a way that **you cannot be identified.**

This study is funded by the Australian Government Department of Health and Aging, Drug Strategy Branch. Any complaints about this study may be directed to the Ethics Secretariat, The University of New South Wales, SYDNEY 2052 AUSTRALIA (phone 9385 4234, fax 9385 6648, email ethics.sec@unsw.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

[Your consent]

Your decision whether or not to participate will not prejudice your future relations with The University of New South Wales. If you decide to participate, you will be free to withdraw your consent and to discontinue participation at any time without prejudice.

If you have any questions about the study at any time, Dr Joanne Bryant (9385 6438) will be happy to answer them.

Do not return this form if you are willing to allow us to contact you by telephone

I do not wish to participate in the study *National Treatment Service Users (TSU) Project*.

Name:

Address:

.....

References

- ACT Health 2002, *Health Action Plan*, ACT Government, Canberra.
- Alcohol Concern and SCODA 1999, *Quality in Alcohol and Drug Service (QuADS): Organisational Standards for Alcohol and Drug Treatment Services*, Alcohol Concern and Standing Committee on Drug Abuse, London, UK.
- Alexander, K & Hicks, N 1998, 'Sailing without Radar: an excursion in resource allocation', *Australian Health Review*, 2:2, pp.76–99.
- Australasian Therapeutic Communities (ATCA) 2004, *Towards Better Practice in Therapeutic Communities*, ATCA, Australia.
- Australian Health Ministers 2003, *National Mental Health Plan 2003–2008*, Australian Government, Canberra.
- Australian Injecting & Illicit Drug Users League (AIVL) 2004, *National Statement on Ethical Issues in Research Involving People Who Use Illicit Drugs*, Canberra.
- AIVL Australian Institute of Health Policy Studies 2005, 3rd National Health Policy Roundtable, *Engaging Consumers in Health Policy: Assessing Models and Outcomes*, Roundtable Monograph, AIHPS, Canberra.
- Australian National Council on Drugs (ANCD) 2005, *Mapping National Drug Treatment Capacity: a report prepared for the Australian National Council on Drugs*, ANCD, Canberra.
- Bastian, H 1998, 'Speaking Up for Ourselves: the evolution of consumer advocacy in health care', *International Journal of Technology Assessment in Health Care*, 14(1), pp. 3–23.
- Bastian, H 1999, 'Australia's Consumer Champion', *British Medical Journal*, 319:730, 18 September 1999.
- Canadian HIV/AIDS Legal Network 2005, *Nothing About Us Without Us – Greater Meaningful Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative*, Canadian HIV/AIDS Legal Network, Canada.
- Childress, J & Siegler, M 1984, 'Metaphors and models of doctor–patient relationships: Their implications for autonomy', *Theoretical Medicine and Bioethics*, Netherlands, Springer, 5:1, pp. 17–30.
- Commonwealth Department of Health and Aged Care 1998, *Consumer Focus Collaboration*, Commonwealth of Australia, Canberra.
- Commonwealth Department of Health and Ageing 2000, *Education and Training for Consumer Participation in Health Care*, Commonwealth of Australia, Canberra.
- Commonwealth Department of Health and Ageing 2002, *National Mental Health Report 2002: 7th Report: Changes in Australia's Mental Health Services in the First Two Years of the Second National Mental Health Plan 1998–2000*, Commonwealth of Australia, Canberra.
- Commonwealth Department of Health and Ageing 2004, *National Drug Strategy: Australia's Integrated Framework 2004–2009*, Australian Government, Canberra.

Commonwealth Department of Health and Ageing 2005, *National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy 2005–2008*, Australian Government, Canberra.

Commonwealth Department of Health and Ageing 2005, *National Hepatitis C Strategy 2005–2008*, Australian Government, Canberra.

Commonwealth Department of Health and Ageing 2005, *National Sexually Transmissible Infections Strategy 2005–2008*, Australian Government, Canberra.

Commonwealth Department of Human Services and Health 1994, *Better health outcomes for Australians: national goals, targets and strategies for better health outcomes in the next century*, Australian Government Publishing Service, Canberra.

Commonwealth of Australia 2000, *Education and Training for Consumer Participation in Health Care* – see Commonwealth Department of Health and Ageing 2000.

Commonwealth of Australia 2001, *Conference Proceedings: Improving Health Services through Consumer Participation*, Commonwealth of Australia, Canberra.

Community Resources Inc. 2005, *Guiding Principles for Consumer Participation: A Resource Document for Psychiatric Support, Disability Support Services and Consumers*, Victoria, Consumer Participation Project.

Conrad Gargett Pty Ltd 2006, *Royal Hobart Hospital Development Plan Study*, Hobart, Tasmanian Government.

Consumer and Carer Participation Policy – National Consumer and Carer Forum, 2004 – see National Consumer and Carer Forum of Australia 2004.

Consumer Focus Collaboration 2001, *The Evidence Supporting Consumer Participation in Health*, Commonwealth Department of Health and Aged Care, Canberra.

Consumers' Health Forum of Australia, www.chf.org.au accessed 06/10/06.

Consumers' Health Forum of Australia, *History of the Consumer Health Forum*, www.chf.org.au/our_chf/history.asp, accessed 13/10/06.

Consumers' Health Forum of Australia, *Public Resources, Consumer Charter of Rights*, www.chf.org.au/public_resources/consumer_rights.asp, accessed 08/09/06.

Department of Human Services (DHS) 2006, *Doing it with Us Not for Us: Participation Policy 2006 – 2009*, Melbourne, DHS.

DHS, 2004 – see Southern Health Breast Services.

Garratt, D 2006, *Conference Abstract: Developing a National Model of Peer-Led Advocacy*, in the Major Session: Users Working with Government, abstracts available at: www.harmreduction2006.ca

Guide to Consumer Participation in NSW Drug and Alcohol Services – see NSW Health 2005.

Health Research Council, 2005, *Mental Health Consumer Advisor Resource Kit: Development of Competencies, Employment Guidelines, Training Needs Assessment and Training Programme for Mental Health Consumer Advisors – Project Overview*, Mental Health Workforce Development Programme, HRC, New Zealand.

Holt, M, Treloar, C, McMillan, K, Schultz, L, Schultz, M & Bath, N (forthcoming), *Barriers and incentives to treatment for illicit drug users with mental health co-morbidities and complex vulnerabilities*, National Drug Strategy Monograph Series., Australian Government Department of Health and Ageing, Canberra.

Kelsall, J and Kerger, M 2001, 'Hepatitis C Peer Education', in Crofts, N, Dore, G, and Locarnini S (eds), *Hepatitis C: An Australian Perspective*, pp. 323–41, IP Communications, Melbourne.

Mattick, RP et al 2001, *National Evaluation of Pharmacotherapies for Opioid Dependence (NEPOD): Report of Results and Recommendations*, National Drug and Alcohol Research Centre, Sydney.

Mental Health Commission, 2004, *Service User Workforce Development Strategy for the mental health, addictions and anti-discrimination sectors 2004 – 2009 - Draft for Consultation*, Unpublished, New Zealand.

Mental Health Council of Australia 2000, *Enhancing Relationships between Health Professionals and Consumer and Carers*, MHCA, Canberra, p. 22.

Mental Health Council of Australia 2002, *The Orientation Kit for NCCF Representatives*, MHCA, Canberra.

Mental Health Council of Australia 2004, *Project Report – Development of a New Consumer Participation Model Based on the National Consumer and Carer Forum*, www.mhca.com.au

Ministry of Health, 1995, *A Guide to Effective Consumer Participation in Mental Health Services*, Wellington: Ministry of Health, New Zealand.

Ministry of Health, 2003, *National Alcohol and Other Drugs Sector Standards*, Wellington: Ministry of Health, New Zealand.

Ministry of Health, 2001, *National Mental Health Sector Standards/He Whariki Oranga Hinengaro*, Wellington: Ministry of Health, New Zealand.

National Aboriginal and Torres Strait Islander Health Council 2003, *National Strategic Framework for Aboriginal and Torres Strait Islander Health – Framework for Action by Governments*, NATSIHC, Canberra.

National Consumer and Carer Forum of Australia 2004, *Consumer and Carer participation Policy: A Framework for the Mental Health Sector*, National Consumer and Carer Forum, Canberra.

National Disability Services Standards – see National Standards for Disability Services.

National Drug Strategy: Australia's Integrated Framework 2004–2009 – see Commonwealth Department of Health and Ageing 2004.

National Health Service 2001, *Health and Social Care Act 2001*, UK Government, United Kingdom.

National HIV/AIDS Strategy 2005–2008: Revitalising Australia's Response, Australian Government, Canberra.

National Mental Health Report 2002 – see Commonwealth Department of Health & Ageing 2002.

National Resource Centre for Consumer Participation in Health 2004, *Consumer and Community*

Participation Self-Assessment Tools for Hospital, www.participateinhealth.org.au

National Resource Centre for Consumer Participation in Health 2002, *Fact Sheet No 2: Methods of Consumer Participation*, www.participateinhealth.org.au

National Resource Centre for Consumer Participation in Health, 2002, *Information Series: an Introduction to Participate in Health*, www.participateinhealth.org.au

National Standards for Disability Services, www.familiesandcommunities.sa.gov.au, accessed 04/09/06.

National Treatment Agency for Substance Misuse 2004, *NTA Guidance for Local Partnerships on User and Carer Involvement*, National Health Service, London, UK.

NEPOD Study, 2004 – see Mattick.

Northern Area Mental Health Service (NAMHS) 2003, *Evaluation of the Consumer Participation in Staff Selection (CPSS) Strategy*, Northern Area Mental Health Service, Victoria.

NSW Health 2005, *A Guide to Consumer Participation in NSW Drug and Alcohol Services*, NSW Government, Sydney.

NSW Health Department 2001, *Partners in Health – Sharing Information and Making Decisions Together*, Report of the Consumer and Community Participation Implementation Reference Group, NSW Government Action Plan, Sydney.

NSW Health, Health Participation Website, www.health.nsw.gov.au/policy/participate/index.html, accessed 13/10/06.

NT Department of Health and Community Services 2004, *Building Healthier Communities: A Framework for Health and Community Services 2004-2009*, NT Government, Darwin.

Quality Improvement Council (QIC), 2005, 2005–08 Strategic Plan, QIC, Victoria.

Queensland Health, 2006, *Developing a Consumers' Health Council for Queensland: Engaging Queensland Consumers in Health Care*, Qld Government, Brisbane.

SA Department of Health 2005, *Your Rights and Responsibilities*, SA Government, Adelaide.

Southern Health Breast Services 2004, *Consumer Participation Project: Evaluation Report*, Victorian Government Department of Human Services, Victoria.

Talcott Parsons – see Childress & Siegler.

The Task Force to Review Services for Drug Misusers 1996, Report of an Independent Review of Drug Treatment Services in England, Department of Health, UK.

Thompson, N 2002, 'We Have Rights and We Know How to Use Them!', *Junkmail*, issue 3, Australian Injecting and Illicit Drug Users League (AIVL), Canberra.

Thornicroft, G & Betts, V 2002, *International Mid Term Review of the Second National Mental Health Plan for Australia*, Mental Health and Special Programs Branch, Department of Health and Ageing, Canberra.

Treloar, C & Holt, M 2006, 'Deficit models and divergent philosophies: Service providers' perspectives on barriers and incentives to drug treatment', *Drugs: Education, prevention and policy*, 13(4), pp. 367–82.

Treloar, C et al 2004, *Barriers and Incentives to Treatment for Drug Users*, Monograph Series No.53, Commonwealth Department of Health and Ageing, Australia.

WA Department of Health 2002, *WA Public Patients Hospital Charter*, WA Government, Perth.

Western Sydney Area Health Service 2002, *Help Us Make a Difference: Western Sydney Area Health Service Consumer Participation Guidelines*, WSAHS, Sydney.

Williams, M & Roche, A M 1999, 'Young People's Initiation into Injecting Drug Use: The role of peer interviewers in risk reduction research', *Health Promotion Journal of Australia*, 9, pp. 219–24.

World Health Organisation, *Health and Human Rights*, www.who.int/hhr/en/, accessed 13/10/06.

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