



Treatment
Service
Users Project
Phase Two
Final Report



Treatment
Service Users
(TSU)
Project: Phase Two
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 and those on opioid pharmacotherapies. 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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This project report and the final project report from the TSU Project: Phase One are both available on the AIVL website at: www.aivl.org.au

❖ 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 people who use illicit drugs and people on opioid pharmacotherapies.

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 — such as hepatitis B and C and HIV — among people who inject illicit drugs, and to ameliorate the negative impact of such conditions among 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 and people on opioid pharmacotherapies, 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 and those on opioid pharmacotherapies have the right to be treated with dignity and respect and to 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
AIVL	Australian Injecting and Illicit Drug Users League
ANCD	Australian National Council on Drugs
AOD	alcohol and other drugs
APSAD	Australasian Professional Society for 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
CDHA	Commonwealth Department of Health and Ageing
CHF	Consumers' Health Forum of Australia
DHS	Department of Human Services Victoria
DoHA	Australian Government Department of Health and Ageing
DPMP	Drug Policy Modelling Program
EOI	Expressions of Interest
HIV	human immunodeficiency virus
HREC	Human Research Ethics Committee
HRV	Harm Reduction Victoria (formerly VIVAIDS)
IGCD	Inter-Governmental Committee on Drugs
MHCA	Mental Health Council of Australia
NADA	New South Wales Alcohol and Other Drugs Association

NAMHS	Northern Area Mental Health Service
NCETA	National Centre in Education and Training on Addiction
NCHSR	National Centre in HIV Social Research
NCOSS	New South Wales Council of Social Services
NGO	non-government organisation
NRCCPH	National Resource Centre for Consumer Participation in Health
NSW	New South Wales
NUAA	New South Wales Users and AIDS Association
ORPACS	Opioid Replacement Pharmacotherapies Advice and Complaints Service
PAC	Project Advisory Committee
PAMS	Pharmacotherapies Advocacy, Mediation and Support Service
SESIAHS	South Eastern Sydney and Illawarra Area Health Service
TAS	Tasmania
TSU	treatment service user
VAADA	Victorian Alcohol and Drug Association
VIC	Victoria
VIVAIDS	Victorian Drug Users Group (now Harm Reduction Victoria)
WA	Western Australia
WANADA	Western Australian Network of Alcohol and other Drug Agencies
WASUA	Western Australian Substance Users Association

Executive Summary

This project was a peer-driven action research project which sought to implement a series of consumer participation demonstration projects in a variety of drug treatment settings in Australia.

The TSU Project: Phase Two follows the implementation of the TSU Project: Phase One research project in 2005-2007, which recommended a series of priority actions to support education and training in relation to consumer participation including:

- To develop a National Consumer Participation Demonstration Project to design, pilot and evaluate practical models of consumer participation in a range of drug treatment contexts;
- To provide training and education for drug treatment consumers to build skills, capacity and confidence in relation to consumer participation; and
- To provide training and education for service providers to build skills and capacity in relation to consumer participation (AIVL, 2008).

Specific Objectives

The key objectives of the TSU Project: Phase Two were:

- To further refine and then apply the model of consumer participation in drug treatment services developed in the TSU Project: Phase One; and
- To conduct an independent evaluation of the suitability and impact of the expanded model within the five selected demonstration sites.

For consistency and to support comparisons across the two project phases, the five demonstration sites were selected from the same states as those who participated in the TSU Project: Phase One – New South Wales, Victoria and Western Australia. The demonstration projects included a range of metropolitan and regional, and government and non-government drug treatment services. The drug treatment approaches offered by the demonstration sites included:

- Pharmacotherapy;
- Inpatient Detoxification; and
- Residential Rehabilitation.

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 Ageing, 1998).

The TSU Project: Phases One and Two used 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 disability and 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.

Following the TSU Project: Phase One, a review and further refinement of the definition and model of consumer participation was adopted for the TSU Project: Phase Two. The main aim was to address a number of conceptual shortcomings identified in the TSU Project: Phase One model and to develop a definition and model of consumer participation that better reflected the complex and multi-layered nature of consumer engagement and stakeholder relationships in the drug treatment context. For a more detailed explanation of the expanded definition and model of consumer participation utilised in TSU Project: Phase Two, see Chapter 2 of this report.

Method

The project included the following components:

- **State and territory forums and project promotion:** These included jurisdictional forums to present the findings from the TSU Project: Phase One and announce the commencement of the TSU Project: Phase Two, and the upcoming expressions of interest process for the demonstration projects. A promotional flyer and articles were also disseminated and published in relevant alcohol and other drugs (AOD) sector publications and online resources;
- **Expressions of interest process:** AOD treatment services in New South Wales, Victoria and Western Australia were invited to submit an 'Expressions of Interest' (EOI) to be selected as one of the demonstration project sites. See Chapter 3 and Appendix 3 for further information;
- **Selection of demonstration sites:** From the EOI process, eligible drug treatment services were invited to submit detailed project plans. Project plans submitted were considered by an assessment panel which selected the five successful demonstration sites. The site selection was confirmed by the Australian Government Department of Health and Ageing (DoHA). See Chapter 3 and Appendix 3 for further information;
- **Establishment and implementation of demonstration projects:** Project agreements, project planning, logframes, and reporting templates were finalised with each site. Basic orientation and training was provided as part of the projects for the consumer representatives and service providers involved. See Chapter 3 and Appendix 4 for further information and project documentation;

- **Evaluation and monitoring of demonstration projects:** This included an ethics approved, process-based evaluation involving a two-stage data collection process at baseline and toward the end of the agreed project timeframe using interviews with service providers and service users at each site. Ongoing project liaison and monitoring was also conducted with key staff at the demonstration sites and the local peer-based drug user organisation. Each project site was required to submit a final project report including project activities and outcomes and self-assessment of the impact and sustainability of the project. See Chapter 4 and 5 and Appendix 5, 6 and 7 for further information;
- **Development of the TSU Project: Phase Two Final Report:** The final project report was developed through a collaborative process involving AIVL, NCHSR and members of the Project Advisory Committee. See Chapter 6 and 7 for further information on project findings and recommendations.

Key Findings

All projects aimed to recruit one or more consumers into consumer representative roles. Although the goals of the projects varied, all demonstration projects experienced problems in achieving their stated outcomes. A number of service and system level issues directly influenced the progress of the projects. Staff and management explanations for this situation included a belief that services are over-stretched and under-resourced. Services also consistently acknowledged that they had underestimated the amount of work involved in implementing the demonstration projects. In analysing the implementation and progress of demonstration projects, a number of inter-connected themes were apparent. Further, the importance and framing of some issues shifted significantly between baseline and evaluation data collection, indicating that the experience of conducting consumer participation projects was somewhat disconnected from initial expectations.

In outlining the findings below, AIVL wishes to acknowledge the complexities and difficulties that can be associated with conducting consumer participation projects in drug treatment settings from the service, staff and consumer perspectives. In presenting these findings, AIVL is seeking to learn from the demonstration projects with the aim of improving the experience of consumer participation for all involved.

Awareness, understanding and interest in consumer participation:

- Levels of awareness and understanding of consumer participation exhibited among consumers across all five sites remained low throughout the project.
- A clear exception was apparent in those instances where consumer representative positions had been created as part of the demonstration project and the consumers fulfilling these roles were able to be interviewed.
- The data suggests that most consumers did value the concept of consumer participation in principle once it had been adequately explained to them.
- Although staff were generally more likely than consumers to be familiar with the term 'consumer participation' and broadly supportive of it, very few had any practical experience of conducting consumer participation activities in drug treatment settings.
- Aside from a minority of staff that remained consistently disinterested, opposition among staff appeared strongest when higher forms of consumer participation (such as staff recruitment or appraisals) were discussed.

Stability:

- The notion of 'stability', initially considered a 'positive' attribution of individuals at baseline, became a means to assess the suitability of services at evaluation. That is, what began as an assessment of the readiness of individuals to take on the responsibilities of consumer participation became, across the project, more of a concern about the capacity of services to run the project.

Who is a consumer? Who can represent treatment service users?

- Not unlike 'stability', the terms 'ex-user' and 'consumer' have become normalised within the taxonomy of drug and alcohol practice and policy. However, like 'stability', these terms are neither neutral nor fixed: their meaning and application varied across treatment settings and between speakers, from senior staff to consumers and across type of service.
- The fluidity (and power) of these terms need to be recognised in the context of this project where each carried considerable currency. These findings suggest that the model of consumer participation needs some further elaboration to account for the possible heterogeneity of treatment services users involved as consumers and consumer representatives.

Expectations of the projects:

- Expectations of the projects remained low to non-existent among consumers due to universally poor levels of awareness about both the projects themselves and the concept of consumer participation.
- The exception was among those consumers who had been recruited specifically into the roles of consumer representatives.
- Staff were mixed in their aspirations for the long-term benefits of consumer participation but a number of staff interviewed noted the positive impact of consumer participation on consumers in relation to gains in self-confidence and empowerment.

Training and capacity building:

- At baseline, staff across most services also believed that they did not require any specific training or education in regard to consumer participation. This led to services, as a whole, being somewhat underprepared in their planning, implementation and management of the demonstration projects.

Power and risks

- The existing culture in most drug treatment settings — including power dynamics between staff and consumers — can result in barriers to communication and trust, which in turn can affect the success of consumer participation in this context.
- There is a need for careful consideration and planning before services taken on the complexities incumbent in consumer participation.

Key Recommendations

The key findings from the five consumer participation demonstration projects have been used to identify five priority areas to act as an overarching framework for the recommendations and actions that follow. Although the key findings have been drawn from the specific issues and outcomes identified by the staff

and consumers of the services involved in the demonstration projects, the key recommendations and actions take a broader 'services and systems' approach. In this regard, AIVL has not sought to make recommendations that would be of relevance and benefit to the services involved in the demonstration projects alone. Instead, the focus has been placed on the overarching themes and lessons learnt from the projects, and AIVL has attempted to interpret these in a way that supports the further development and sustainability of consumer participation in *all* drug treatment settings. It should also be noted that while the recommendations have been clustered as appropriate under one of the five priority areas, there is significant interconnectedness across the areas and recommendations — these linkages have been identified as appropriate. While some of the recommendations and associated actions specify the need for resourcing, it should be taken as read that all of the recommended actions will require appropriate resourcing if they are to be implemented.

Priority Action Area 1: Increasing awareness and understanding of consumer participation

- **Training for staff of drug treatment services:**

Recommendation:

The development of a new consumer participation module within the Certificate IV in Alcohol and Other Drugs (AOD).

Action:

AIVL to approach the National Centre in Education and Training on Addiction (NCETA) and the Drug Strategy Branch, Australian Government Department of Health and Ageing (DoHA) to identify opportunities and pathways for the resourcing, development and implementation of the above module.

- **Training for consumers of drug treatment services:**

Recommendation:

The development of a national consumer participation in drug treatment training program and plan to support the delivery of consumer training at the local level.

Actions:

AIVL to approach the Drug Strategy Branch, DoHA to identify opportunities and pathways for the resourcing development and delivery of the above training program.

Should suitable resources be identified, the program would need to be developed and delivered in partnership with AIVL member organisations, other relevant advocacy groups and local consumer health forums.

- **Ongoing awareness raising in relation to consumer participation:**

Recommendation:

The development of a national communications strategy to address the lack of general awareness and understanding of both the concept and practice of consumer participation within the AOD sector and among drug treatment consumers.

Actions:

AIVL to seek placement of articles and editorial comment on the issue of consumer participation in key national AOD sector publications including, but not limited to, Of Substance, ANEX Bulletin, DANA Newsletter, etc.

AIVL and its member organisations to include articles and discussions on consumer participation and rights in drug user magazines, and provide articles for publications that target treatment consumers produced by other relevant organisations and services.

AIVL to seek a symposium or workshop at the Australasian Professional Society for Alcohol and Other Drugs (APSAD) Conference, which will focus on the definition of consumer participation in drug treatment settings, the value and benefits of consumer participation in this context, and practical strategies for developing and implementing consumer participation.

Priority Area 2: Making consumer participation ‘core business’ for drug treatment services

- **Developing the policy framework to support consumer participation:**

Recommendation:

The development of a national advocacy strategy to promote the need for a policy framework at the national and state/territory levels to provide leadership and underpin support for consumer participation in drug treatment settings.

Actions:

AIVL to develop a brief consumer participation advocacy paper to be disseminated to, and as appropriate used to inform meetings with, the drug policy units of federal and state/territory governments and other government and non-government drug policy and consumer health bodies including the Inter-Governmental Committee on Drugs (IGCD), Australian National Council on Drugs (ANCD), Drug Policy Modelling Program (DPMP), national and state/territory consumer health forums, etc.

AIVL and its member organisations to advocate for the inclusion of principles and outcome indicators to support consumer participation in drug treatment settings in national and state/territory drug strategies and other relevant policy documents.

- **Funding and resourcing consumer participation in drug treatment settings:**

Recommendation:

Federal and state/territory governments to take a leadership role in supporting drug treatment services to incorporate consumer participation into service planning and delivery.

Actions:

Governments should incorporate minimum consumer participation requirements (based on the AIVL Model of Consumer Participation) into performance and funding agreements for drug treatment services.

*[** It should be noted that responsibility for the above action will be with the federal or state/territory health departments, or a combination of the two, depending on the outcomes of national health system reforms currently underway. Based on the outcome of these reforms, this recommendation should be undertaken by the government entity(ies) with primary responsibility for funding government and non-government drug treatment services in the future.]*

Drug treatment services should be appropriately resourced to support and conduct consumer participation in drug treatment settings.

Should the above minimum requirements for consumer participation be incorporated into funding and performance agreements, AIVL and its member organisations should be resourced to provide expertise, partnership and support for drug treatment services in meeting such requirements.

AIVL will seek endorsement and support from the Chapter of Addictions Medicine, the Australasian Therapeutic Communities Association (ATCA), APSAD and other relevant bodies in relation to the above role and in being a recognised source of expertise and support on consumer participation in drug treatment settings.

AIVL will seek to work in partnership with other national and local consumer advocacy organisations as appropriate.

Priority Area 3: Developing a stronger theoretical basis for consumer participation in drug treatment settings

- **Revising the AIVL definition and model of consumer participation in drug treatment settings:**

Recommendation:

To conduct a deeper analysis of the AIVL Definition and Model of Consumer Participation, including an exploration of definitions of 'who is a consumer', the concept of 'stability', 'who should represent consumers' and the significance of 'service type' for consumer participation.

Actions:

The NCHSR and AIVL to produce at least two peer-reviewed papers drawing on the findings and analysis of the TSU Project: Phase Two demonstration projects to further explore the definitions and issues identified above.

AIVL and the NCHSR to incorporate the ideas and thinking in the above peer-reviewed articles into the AIVL Definition and Model of Consumer Participation.

In addition to the above, AIVL and the NCHSR will incorporate a new section into the AIVL Definition and Model of Consumer Participation on 'who should represent treatment consumers' including:

- i. the concept of self-determination in relation to representation for different 'types' of treatment consumers;
- ii. appropriate consultative mechanisms to support the role of consumer representatives; and
- iii. the role of 'past treatment consumers' in the context of consumer participation in inpatient detoxification treatment settings and explore the potential value of other models of consumer participation in acute clinical care settings for application in the detoxification context.

Priority Area 4: Acknowledging and understanding power and empowerment in the drug treatment context

- **Managing dynamics and relationships between staff and consumers:**

Recommendation:

To provide opportunities for staff and consumers to discuss how power and empowerment operates within the drug treatment context and develop positive strategies for acknowledging and managing these dynamics.

Actions:

AIVL to ensure issues of power and empowerment are addressed within the training for staff and consumers outlined in Priority Area 1.

Senior management of drug treatment services to encourage regular reviews of service systems and practices to remove barriers to consumer participation.

- **Managing dynamics and relationships between consumer representatives and other treatment consumers:**

Recommendation:

To empower consumers to take a leadership role in consumer participation activities in order to support the development of consultative consumer participation structures and processes.

Actions:

Drug treatment services should work with consumers to define the role of consumer representative positions and to develop consumer participation structures that support ongoing consultation between consumer representatives and other service consumers.

Consumer participation training for drug treatment consumers should be open to all treatment consumers, not simply consumer representatives.

Priority Area 5: Engaging drug user organisations in consumer participation

Recommendation:

To support the greater involvement of drug user organisations in consumer participation in drug treatment settings.

Actions:

Training for services on working with drug user organisations should be included in funding and performance agreements for drug treatment services (*also see Priority Area 2 for further actions on funding and performance agreements*).

Drug user organisations should be appropriately supported and resourced to participate in consumer participation initiatives in drug treatment settings.

❖ Chapter 1: Background

1.1 Introduction

The National Treatment Service Users (TSU) Project: Phase Two is a peer-driven action research project of the Australian Injecting and Illicit Drug Users League (AIVL) in collaboration with the National Centre in HIV Social Research (NCHSR). The Treatment Service Users (TSU) Project: Phase One Final Report recommended a series of priority actions to support education and training in relation to consumer participation including:

- To develop a National Consumer Participation Demonstration Project to design, pilot and evaluate practical models of consumer participation in a range of drug treatment contexts;
- To provide training and education for drug treatment consumers to build skills, capacity and confidence in relation to consumer participation; and
- To provide training and education for service providers to build skills and capacity in relation to consumer participation (AIVL, 2007).

To progress the above recommendations, AIVL submitted a proposal to the Drug Strategy Branch, Australian Government Department of Health and Ageing (DoHA) in late 2006 to conduct a two-year TSU Project: Phase Two with the primary aim of implementing the above recommendations from the TSU Project: Phase One. The proposed project model for TSU: Phase Two was to implement a series of five demonstration projects in a variety of drug treatment settings in order to:

- Further refine and then apply the model of consumer participation in drug treatment services developed in the TSU Project: Phase One;
- Conduct an independent evaluation of the suitability and impact of the expanded model within the five selected demonstration sites.

In July 2007, AIVL in collaboration with the NCHSR commenced the TSU Project: Phase Two based on the above project plan with funding from the Drug Strategy Branch, DoHA. Originally, the TSU Project: Phase Two included a national workshop as the final project output to develop a national consensus statement on consumer participation in drug treatment settings. In late 2008 however, AIVL negotiated a variation to the funding agreement with DoHA to remove the national workshop and consensus statement from the project outcomes for Phase Two. The main reasons for these changes were a combination of unexpected delays to the establishment and implementation of the demonstration projects, and the lack of sufficient project resources to support the effective delivery of a national workshop.

Following the above agreement variations, the main agreed project outcome was a final project report documenting the process evaluation for the consumer participation demonstration projects. The draft project report was provided to the Drug Strategy Branch, DoHA in June 2009, with the final project report for the TSU Project: Phase Two negotiated for submission in April 2010 following the successful completion and evaluation of the five consumer participation demonstration projects.

1.2 Why was there a Need for a Phase Two of the TSU Project?

Prior to the research conducted in the TSU Project: Phase One, there was very little known about 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. The TSU Project: Phase One employed five methods of investigation to gain a better understanding of consumer participation in the Australian drug treatment context including:

- An audit of local, national and international policy frameworks in relation to consumer participation in health service planning and delivery;
- Interviews with service providers from 64 randomly selected drug treatment services in New South Wales, Victoria and Western Australia;
- Interviews with 179 service consumers selected from 14 of the above drug treatment services;
- Consultation with state and territory drug treatment consumer/drug user organisations; and
- A survey of key government, non-government and policy stakeholders.

The key findings from the above investigations included that:

- 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 was 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 are well-entrenched 'myths' about whether clients are interested in consumer participation with a strong belief among some service providers that consumers are not interested in taking part in consumer participation activities. Similarly, some consumers expressed the view that 'other consumers' were not interested in consumer participation. This contrasted sharply with reports from consumers themselves, many of whom said they would be willing to take part in consumer participation activities.

- There was 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 they had not conducted consumer participation activities in the past was because they had simply never thought about it. This suggested 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 was 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 and Holt 2006). Moreover, the study findings identified that consumers had fears about 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.

The findings from the TSU: Phase One Final Report highlighted the need for further activity in relation to consumer participation in Australian drug treatment settings. While there was a high degree of support from both drug treatment service providers and service consumers for the concept of consumer participation, both groups had little understanding or experience of consumer participation in practice. There was also a clear need to improve communications between drug treatment service providers and service consumers to increase understanding and trust in relation to the purpose and benefits of consumer participation. In short, there was a need for a series of practice—based projects to demonstrate and evaluate whether consumer participation could work effectively in the drug treatment context.

1.3 Purpose and Scope

The main aim of the TSU Project: Phase Two was to independently evaluate the suitability and impact of an expanded model of consumer participation in a variety of drug treatment settings. The project involved the design, implementation and evaluation of five consumer participation demonstration projects in selected drug treatment services in New South Wales, Victoria and Western Australia. The selection of these states and territories ensured the demonstration sites for the TSU Project: Phase

Two were selected from the same jurisdictions as the participating sites that were drawn from the TSU Project: Phase One. Further information on the rationale for the participating jurisdictions and the selection process for the demonstration sites can be found in Chapter 3 of this report.

To ensure the independence of the evaluation and to protect the identity of the participating services and the confidentiality of the service consumers, the five demonstration project sites are not specifically identified in this report. The break-down by service type for the five demonstration projects included:

- **Pharmacotherapy services** including:
 - an inner-metropolitan, non-government service based on a primary health-care service model;
 - a large, metropolitan, government-operated service; and
 - a regional, non-government, community-based service model.
- **A detoxification service** based in an outer-metropolitan, government-operated, multi-disciplinary service model; and
- **A residential rehabilitation service** based on a therapeutic community model.

The project components included:

- **State and territory forums and project promotion:** This included jurisdictional forums attended by state/territory health departments, AOD services, community organisations, consumer groups and other stakeholders to present the findings from the TSU Project: Phase One and announce the commencement of the TSU Project: Phase Two and the upcoming expressions of interest process for the demonstration projects. A promotional flyer was disseminated and articles were also published in relevant AOD sector publications, drug user magazines and online resources;
- **Expressions of interest process:** AOD treatment services in New South Wales, Victoria and Western Australia were invited to submit an 'Expressions of Interest' (EOI) to be selected as one of the demonstration project sites. The EOI process is explained in more detail in Chapter 3. Examples of the documentation from the EOI process are included at Appendix 3;
- **Selection of demonstration sites:** Based on the EOI process, eligible drug treatment services were invited to submit detailed project plans. Project plans submitted were considered by a three-person assessment panel which selected the five successful demonstration sites. The recommendations of the assessment panel were then confirmed by the DoHA. The selection process for demonstration project sites is explained in detail in Chapter 3. Examples of the documentation from the site selection process are included at Appendix 3;
- **Establishment and implementation of demonstration projects:** AIVL project staff worked with each selected demonstration site to finalise project agreements, complete planning for each consumer participation project and develop project logframes, and provided a project reporting template. Basic orientation and training was provided for the consumer representatives and service providers involved in the projects. The establishment and implementation of projects are explained in Chapter 3. Examples of the project agreements, project logframes and reporting template are at Appendix 4;
- **Evaluation and monitoring of demonstration projects:** Formal evaluation for the project included an ethics approved, process-based evaluation involving a two-stage data collection process at baseline and evaluation using interviews with service providers and service users at each site. Ongoing project liaison and monitoring was also conducted with key staff at the demonstration

sites and the local peer-based drug user organisation. Each project site was required to submit a final project report including project activities and outcomes and self-assessment of the impact and sustainability of the project. See Chapter 4 and 5 and Appendix 5, 6 and 7 for further information;

- **Development of the TSU Project:** Phase Two Final Report: The final project report was developed through a collaborative process involving AIVL and NCHSR project staff and the members of the Project Advisory Committee for the TSU Project: Phase Two. See Chapter 6 and 7 for further information on project findings and recommendations.

In addition to continuing to raise awareness of the important role of consumer participation in drug treatment settings, the combined purpose of both TSU Project Final Reports and the associated project documentation in the appendices, is to provide drug treatment services, consumer organisations and other interested stakeholders with information upon which to plan and implement future consumer participation projects. It is important to highlight that the lessons and experience documented through the evaluation process, the individual project reports and the project materials, taken together with the research findings from the TSU Project: Phase One, represent the only significant body of research and practice in the area of consumer participation in the drug treatment services in Australia to date.

1.4 Research Partnership

While the TSU Project is a project of the AIVL, a unique collaboration was formed at the commencement of the TSU Project: Phase One with the NCHSR which has been continued in the TSU Project: Phase Two.

Through this partnership, AIVL and the NCHSR have worked collaboratively on all aspects of the project including project and evaluation design, 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 action research projects and process evaluations;
- Ensuring the right balance of consumer experience and research/evaluation expertise within the project;
- Strengthening collaboration between drug user organisations and national research centres;
- Expanding the scope of evaluative research being undertaken by the NCHSR; and
- Increasing the opportunities for future research and partnerships for both AIVL and the NCHSR.

1.5 Project Advisory Committee

AIVL recognises that the issues regarding consumer participation in drug treatment services are complex and highly sensitive for some stakeholders. To ensure the perspectives of all stakeholders were adequately represented, a multidisciplinary advisory committee was established to have direct input into the project and evaluation design, selection of the demonstration sites, evaluation tools, data interpretation, and drafting of the final recommendations and report. The membership of the committee

was carefully selected to ensure the inclusion of all perspectives and included:

- Two treatment service consumer representatives from different backgrounds and treatment experiences (in addition to the consumer expertise of the AIVL staff involved);
- 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 AOD treatment sector;
- Two representatives from the Drug Strategy Branch, DoHA;
- One representative from the Australian National Council on Drugs (ANCD);
- One representative from the Inter-Governmental Committee on Drugs (IGCD);
- AIVL Executive Officer, AIVL Treatments and Policy Manager, and AIVL TSU Project Worker; and
- NCHSR project investigators.

The Project Advisory Committee (PAC) held two face-to-face meetings across the project in February 2008 and March 2010. A number of written updates were also provided to the PAC during the establishment, demonstration project and data analysis phases of the project.

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

❖ Chapter 2: Model and Definition of Consumer Participation

2.1 Model of Consumer Participation in Drug Treatment Services

This chapter outlines the framework adopted within the project for conceptualising and implementing consumer participation in drug treatment services. While there is a role for consumer participation at a number of levels (individual, local, state/territory and national), the focus of the TSU Project: Phases One and Two were in developing and implementing consumer participation at the level of drug treatment services and not in relation to individual treatment plans. The examples of consumer participation provided in this document are neither exhaustive nor prescriptive, but rather aim to provide a guide for developing and implementing consumer participation in drug treatment services.

Treatment service users are not a single identifiable group or community and therefore individual consumers and consumer groups will want different degrees and forms of consumer involvement (Greater London Authority, 2005). Likewise different drug treatment services will have different needs and capacities, and this will influence the types and levels of consumer participation that are appropriate for an individual service to conduct..

2.2 Definition of Consumer Participation

In much of the available literature, '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 Ageing, 1998).

In the general health context, consumer participation models typically incorporate varying degrees of involvement in service planning and delivery, ranging from the sharing of information and opinions about services to engaging in shared problem-solving and joint decision-making (National Resource Centre for Consumer Participation in Health (NRCCPH), 2002).

As part of the TSU Project: Phase One, a policy audit was conducted to review existing international, national and local policy frameworks to support the implementation of consumer participation in drug treatment settings. This policy audit revealed a number of policy frameworks at the international level, designed to encourage the active participation of consumers in both general health and drug treatment settings.

However, in the Australian context, despite a significant commitment at government and non-government levels to the principles and practice of consumer participation in general health settings,

there was virtually no evidence in the literature of policy frameworks to support consumer participation in the drug treatment context. Further, in the few examples of policies designed to specifically support the involvement of drug treatment consumers, there was little evidence to show how these policies have been implemented in practice (AIVL, 2008, p.43).

Given the strong evidence demonstrating the acceptance and value of consumer participation in general health settings, the TSU Project: Phase One utilised these existing mainstream models when developing the model of consumer participation used. In line with the literature, particular attention was given to developing a model that acknowledged the need for varying levels of consumer involvement in health service planning and delivery from low-level information exchange through to more active decision-making roles at the middle and higher levels respectively (NRCCPH, 2004). As the study was focused on consumer participation in drug treatment settings rather than the general health setting, some minor adaptations were made to the model to reflect examples of participation and involvement with direct relevance for drug treatment consumers.

Despite this, the findings from the TSU Project: Phase One highlighted a number of flaws in the definition and model of consumer participation adopted. In particular, some of the middle and higher level participation activities were found in practice to involve much lower degrees of active participation and/or decision-making than articulated in the model. For example, it was identified that incorporating principles of consumer participation into vision or mission statements or patient charters could, and frequently does, occur without meaningful involvement of service consumers. It was therefore identified that such activity may not involve consumers in decision-making roles at the levels necessary to qualify as high-level participation in accordance with the model (AIVL, 2008, p.45)

Further analysis of the data also identified that involving consumers in a number of the middle to higher level activities in the model, such as the development of information resources or on service committees, could also occur without empowering consumers to have a meaningful role in those processes. The importance of 'how' participation occurs rather than just 'whether' it occurs was the central issue highlighted, and this led to a rethinking of the definition and model of consumer participation adopted within the TSU Project: Phase Two.

The following model adopted in the TSU Project: Phase Two was developed with reference to available literature on consumer participation, findings from the TSU Project: Phase One (AIVL, 2008) and through consultation with the members of the Project Advisory Committee.

2.3 Definition of Consumer in the Drug Treatment Context

In the context of drug treatment services, consumers can be defined as treatment service users, including current and past users of services and people who are contemplating treatment (NSW Health, 2005).

2.4 Steps to Developing and Implementing Consumer Participation Activities in Drug Treatment Services

Drug treatment services need to establish their organisational philosophy before developing a new consumer participation initiative as it may be difficult to develop and implement consumer participation at the level of shared decision-making if the organisation does not already have a range of low-level

consumer participation activities in place, such as mechanisms for feedback, information sharing and recognition and commitment to consumer participation in a vision statement (Greater London Authority, 2005). Consumers and service providers will need to identify what, if any, forms of consumer participation already exist within the service. Identifying existing levels of consumer participation will assist the service in determining what level of consumer participation is most appropriate in the current environment. For example, if a drug treatment service wanted to involve consumers at the higher shared decision-making level the service needs to be able to answer 'yes' to these two questions:

- Does the organisation currently have mechanisms for keeping service users routinely informed about service developments?
- Does the organisation have mechanisms for getting feedback from service users?

Answering 'no' to these questions does not mean the service is not ready for consumer participation per se. However, it does mean the service will need to implement some strategies for sharing information and getting consumer feedback as a first step in the process of implementing and developing meaningful consumer participation. In addition to ensuring there are mechanisms for information and opinion sharing, treatment service users and providers should explore the following questions:

- In what ways would consumers like to participate in the service?
- What kind of skills will be required?
- What are the different levels and possibilities for participation within the service?
- How will the contributions of consumers in terms of time and expertise be supported?
- How will staff be encouraged and supported to engage with new practices of consumer participation?

Services will need to identify the skills already available as well as the necessary skills that need to be built. Training and skills development will be important for consumers, staff and management. For example, a consumer may need training around meeting procedures and business planning in order to participate effectively on a management committee. Staff and management may need training in approaches to communication and information sharing in order to build their capacity to work in a collaborative way with consumers (Greater London Authority, 2005).

2.5 Core Guiding Principles for Consumer Participation in Drug Treatment Services

Some of the fundamental principles that should underpin consumer participation in drug treatment services include:

- Service providers need to acknowledge the benefits of consumer participation and the right of consumers to have input into how services and programs are run;
- Consumers need to be engaged and involved from the beginning;
- Effective consumer participation requires leadership, funding and support; and
- The purpose of consumer participation programs/initiatives need to be clear from the outset.

Consumer participation initiatives should also:

- Involve a range of different consumers;
- Provide support and encouragement for consumers to participate, including providing practical assistance to consumers to enable them to participate fully;
- Allow the form and purposes of consumer participation to evolve over time;
- Ensure appropriate training is available for staff and consumers;
- Support consumers and providers in creating a non-threatening environment for both staff and consumers;
- Establish processes whereby both positive and negative feedback can be conveyed to staff;
- Establish a budget to fund consumer participation activities, including financial remuneration for consumer representatives. Remuneration has both a material and symbolic value;
- Develop mechanisms to ensure that consumer participation does not have adverse effects for the consumers involved;
- Establish and maintain the commitment and capacity for trust and mutual understanding between consumers and providers;
- Acknowledge that consumer participation might involve organisational change, including managers and staff being willing to relinquish decision-making power in order to achieve shared decision-making; and
- Evaluate, review and, where necessary, adapt to ensure consumer participation activities remain responsive to the needs of consumers.

The typology of consumer participation below was used in the TSU Project: Phase One. The diagram recognises varying degrees of consumer involvement, from low-degree information provision and consultation to high-degree involvement, such as shared decision-making between consumers and providers (following Arnstein's ladder of citizen participation, 1969). The model provides examples of consumer activities associated with each degree of consumer participation, ranging from low-level information provision and consultation, to mid-degree involvement of consumers in non-decision-making activities, to high-degree shared decision-making (AIVL, 2007).

Degree of consumer involvement	Type of participation	Example of Activity
HIGH	<i>Activities in which consumers share in decision-making</i>	<p>Consumer representatives involved in service planning committees: The service has had a consumer representative as a member of any committee that plans or makes decisions about services or programs.</p> <p>Consumer representatives attend staff meetings: The service has had a consumer representative regularly attend staff meetings.</p> <p>Consumer representative involved in staff recruitment: The service has had a consumer representative involved in the recruitment process for new staff at the service (e.g. a consumer representative contributed interview questions or was a member of an interview panel).</p> <p>Consumer representative involved in staff performance appraisal: The service has had a consumer representative involved in assessing staff job performance (e.g. consumer representatives meet with the nursing unit manager to give feedback on staff performance).</p>

Degree of consumer involvement	Type of participation	Example of Activity
MID	Activities in which consumers have non-decision-making roles	<p>Consumer involvement in resource development: Consumers involved in writing or reviewing written materials such as brochures, fact sheets, newsletters, magazines or educational resources.</p> <p>Consumers involved in staff training: Consumers involved in determining the content of in-service training that is directly relevant to consumers and their treatment.</p>
	Activities that promote and support consumer involvement	<p>Consumers are supported to conduct their own group activities: A service has ways to help consumers facilitate and run their own support groups (e.g. fitness groups, mums' and dads' groups) such as providing space, training or transport.</p> <p>Service displays user group publications — consumer forum: The service displays or makes available in other ways the publications of drug user organisations (e.g. NUAA, VIVAIDS, WASUA).</p>
LOW	Activities concerned with providing information to or receiving information from consumers	<p>Consumer councils: Committees or groups of consumers whose role it is to advise the service about how services and programs are run.</p> <p>Forums: Open meetings in which consumers can express their views about how services or programs are run.</p> <p>Surveys: Surveys that specifically ask consumers for their opinions about how programs and services could be improved.</p>
		<p>Suggestion box: The service provides a box where consumers can leave written comments regarding their views about how the service or programs are run and suggestions for changes and improvements.</p> <p>Complaints process: The service has put in place a process for consumers to register their complaints about the delivery of the service</p> <p>Produce resources for consumers that include information about service planning: 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.</p>
LOW	Consumer participation built in to the values and policies of the service	<p>Consumer participation incorporated into the vision or mission statement/ consumer charter of rights: A document is produced outlining client/patient rights, responsibilities and expected levels of service.</p>

These levels represent a range of opportunities for consumer participation. In practice, participation does not occur in all of these areas, in all services, or for all consumers all of the time. Opportunities to develop and implement consumer participation are greatly affected by context, environment and the attitudes of those who provide the services and the desires and needs of individual consumers (AIVL, 2007: pp. 23-24). Furthermore, while shared decision-making is a marker of high-level consumer participation it should be noted that information sharing and the inclusion of consumer participation in the values and policies of services (e.g. a consumer charter of rights), are not insignificant. In many cases these lower level activities will provide the basis for the development and implementation of other higher level forms of consumer participation over time.

2.6 Updated Literature Review on Consumer Participation

In addition to reviewing the definition and model of consumer participation applied, AIVL also reviewed the literature on consumer participation available since the publication of the TSU Project: Phase One Report. The following is a brief exploration of the available literature.

A number of papers explore consumer participation in mental health services. Even in that sector, where developments in consumer participation could be argued as most advanced, there are significant critiques aimed at policy and practice (Browne and Hemsley, 2008). For example, Stewart et al (2008) argue that mental health facilities have failed to implement consumer participation despite the lead provided by policy in this area. This supports the view of Happell and Roper (2007) that consumer participation needs to occur at different levels (advisory, consultation, collaboration and consumer led) to ensure that consumer participation is not tokenistic and, in turn, risks undermining consumer participation.

An area of importance identified in the literature is the influence of service staff on the success of consumer participation (Goodwin and Happell, 2007; Roper and Happell, 2007). While the literature identifies that the lack of a receptive culture, especially negative staff views of consumer participation, can produce significant barriers (Paterson et al, 2009), understanding the patterns and dynamics of staff attitudes (e.g. related to gender or professional experience) is important to better plan and support consumer participation (McCann et al, 2008). Besides the attitudinal culture in which consumer participation may be implemented, other aspects of the organisational context — such as bureaucratic processes, resources (human and material) and mechanisms to provide clear and timely feedback to consumers on consumer participation processes — have also been identified as important (Paterson et al, 2009).

❖ Chapter 3: Demonstration Projects

3.1 Selection of Jurisdictions

Although the TSU Project: Phases One and Two are national projects, the available resources for the projects did not allow either the first research phase or the demonstration project phase to be conducted in all states and territories. Given this situation, a process was developed to identify the states and territories that would be most suitable for the demonstration projects phase.

An assessment process was undertaken to identify those states and territories with the greatest capacity to support effective demonstration projects within the resources and timeframes set down for the project. As part of this process, each jurisdiction was assessed against a series of criteria which included:

- **Budget Feasibility and Logistics:** Whether the available resources for the TSU Project: Phase Two were adequate to support one or more demonstration projects in the particular state/territory;
- **Range of Treatment Services:** The scope and range of drug treatment services currently operating in the particular state/territory;
- **Existing Peak Bodies:** Whether the particular state/territory had an established AOD sector representative body and an active peer-based drug user organisation to provide support for and be involved in the demonstration project(s);
- **Policy Frameworks:** Whether the particular state/territory had existing policy frameworks to underpin consumer participation in drug treatment services.

A rating sheet was developed to assess each of the jurisdictions against the above criteria. Although all jurisdictions rated mid to high on some of the criteria, it was the jurisdictions with the highest ratings across all criterion that were ultimately selected as the TSU Project did not have sufficient resources to undertake the demonstration projects in all states/territories. This process identified the states of New South Wales, Victoria and Western Australia as the preferred jurisdictions for the TSU Project: Phase Two demonstration projects. While it was not the primary basis for selection, an additional benefit from the selection process was that the selected states coincided with the jurisdictions that participated in the TSU Project: Phase One, which would allow for greater correlation across the project phases.

3.2 Expressions of Interest Process and Selection of Sites

In order to select the successful services from the 'Expressions of Interest' (EOI) process, a series of selection criteria was developed to act as the essential or 'first cut' criteria for the agency applications.

These 'first cut' criteria included:

- **Type of service:** Government or non-government operation;
- **Treatment approach:** Pharmacotherapy, inpatient detoxification, residential rehabilitation;
- **Geographical area:** New South Wales, Victoria and Western Australia in metropolitan and regional areas;
- **Key local partnerships:** With state peer-based drug user organisations and AOD peak bodies;
- **Evidence of existing consumer participation:** Demonstrated activities within their service;
- **Willingness to participate in evaluation process:** Evidence that the service is willing to facilitate and participate in the process evaluation (e.g. discussion and agreement at a staff meeting);
- **Organisational policies:** Evidence of internal policies and procedures supporting consumer participation activities; and
- **Ability to meet logistics:** Including financial/accounting/timeframe requirements.

Once interested services met the above selection criteria, they would then be assessed against a set of question-based criteria specifically relating to their proposed consumer participation projects. As part of the EOI application process, each service was required to respond to the following criteria/questions:

- **Model of consumer participation:** Proposed consumer participation models should be of medium/high levels;
- **Sustainability of project:** The plan for the project is sustainable;
- **Education/training for staff/consumers:** Project plan includes appropriate education and training for staff and consumers;
- **Remuneration of consumers:** Participants will be paid for their contributions and involvement in the project;
- **Project outcomes:** Clarity and relevance of stated project outcomes and deliverables;
- **Performance indicators:** Clearly define impact and outcomes measures for the project;
- **Project timeframe:** Project can be completed in the required timeframe;
- **No adverse effects:** Strategies to ensure that there will be no adverse or negative implications for staff or consumers as a result of participation;
- **Consumer engagement:** Strategies to ensure the project will be developed and implemented in consultation with consumers; and
- **Feedback procedure:** A feedback procedure is included in the project design for consumers and staff.

Prior to the call for EOI being disseminated, an information pack was developed to assist interested services in the EOI application process. The information pack included:

- Covering letter explaining the project and the call for EOI;
- An application/EOI form;

- Information on how to submit an EOI;
- The definition and model of consumer participation document;
- Information on and practical examples of low-, medium- and high-level consumer participation activities in the context of drug treatment;
- A flyer on the local peer-based drug user organisation.

(Examples of some of the above documents from the EOI process have been provided at Appendix 3 to this report.)

The call for EOI (in the form of the information pack) was mailed directly to drug treatment services in the selected states of New South Wales, Victoria and Western Australia using the available list of services from the ANCD Mapping National Drug Treatment Capacity Report (ANCD, 2005) and directly through the jurisdictional health departments. AOD peak bodies in these states, such as NADA, VAADA and WANADA, also advertised the call for applications through their individual networks. In addition, notices were uploaded to national online forums such as 'ADCA Update', the 'AIVL E-list' and the AIVL web site.

Based on feedback received from a number of potentially interested services, AIVL agreed to extend the EOI process for a two-week period to allow busy drug treatment services to develop their applications and respond to the criteria effectively. The dissemination process outlined above for the initial EOI notification was repeated with an 'Extension to Expressions of Interest' notice.

In response to the extended call for EOI, the project received nine applications from interested drug treatment services from within New South Wales, Victoria and Western Australia. A short listing process was then undertaken jointly by AIVL and NCHSR and seven applications were chosen which were deemed to have met the required selection criteria.

An initial assessment of the quality of the applications in terms of the selection criteria was undertaken by the project staff at AIVL and NCHSR. This initial review was not a decision-making process and did not involve an assessment of the relative merits of the individual applications. It was a quality check designed only for the early identification of missing or lack of information. As part of this process, further clarifications and information was sought from all seven short-listed applicants to ensure that the information that was made available to the formal assessment panel was thorough and provided all the necessary information for a good decision-making and selection process.

Some of the additional clarifications sought from the prospective sites included clarification on project outcomes, performance indicators, age of participants, practical issues relating to participation in the process evaluation, payment of participants, and how the proposed consumer participation activities would increase existing levels of consumer participation in their service. Further information was also requested on issues such as the long-term sustainability of the project outcomes, access to education and training and existing local partnerships, particularly with the peer-based drug user organisation.

Once all further information was received from the applicants of the EOI process, the formal assessment panel was convened to consider all applications and make final recommendations to AIVL and DoHA on the selected demonstration sites. The membership of the three-person assessment panel was specified in the funding agreement between AIVL and DoHA and included;

- A representative from the ANCD;
- A representative from an AOD peak body (from a state or territory other than New South Wales, Victoria or Western Australia); and
- A representative from AIVL.

To ensure that the selection process was transparent, a rating sheet was developed to allow each panel member to numerically score each of the short-listed applicants on the totality of information provided in response to the EOI selection criteria outlined above. The information from each panel member was collated and the AIVL representative on the panel then convened individual teleconferences with each of the other panel members to address any clarifications and to finalise their selections.

A summary report was then developed for the DoHA outlining the EOI and selection process, and making a final recommendation on the five successful demonstration sites. These selections were then confirmed in writing by DoHA. One of the unsuccessful sites did submit a written query of the process adopted and the reasons why they were not successful. A written response to these questions was provided by AIVL and this was accepted by the applicant.

3.3 Establishment of Projects

Following the confirmation of the selected demonstration project sites by DoHA, AIVL worked with each site to develop and finalise a project contract and a detailed project plan based on information provided by the agencies in their proposals. As part of the project planning process with each site, a 'logical framework' or 'project logframe' was developed to help both the service and AIVL monitor the progress of the project and measure its outcomes. *(An example 'project logframe' has been provided at Appendix 4 to this report).*

The logframes listed specific activities in the project, their timelines, the process to be undertaken in completing the activity and verifiable outputs leading to specific project outcomes. These logframes have been used as the basis of progress reporting for the duration of the project and for the final reporting template used by each site at the completion of their projects.

Following the completion of the project establishment documentation above, AIVL liaised with each site to commence the project and, in particular, to ensure each site had a liaison person at the local peer-based drug user organisation (in the absence of an existing relationship). It was a requirement of all projects that they work collaboratively with the local peer-based drug user organisation, particularly in relation to negotiating with them to provide training for consumers and staff involved in the projects.

Once the projects and links with the local drug user organisation were established, AIVL stepped back from the selected sites to ensure that each project was genuinely 'owned' by the services, their staff, consumers and local partners. Although AIVL continued to undertake an overall monitoring role, this mostly consisted of making monthly contact with the selected sites to 'check-in' on the progress of the projects, seek written progress updates where possible, and to attempt to 'trouble-shoot' within extremely limited project resources and without compromising independence of the process evaluation stage of the project.

The very limited resources available for the five demonstration projects, coupled with the fact that

there is also very limited levels of consumer participation activity currently underway within the drug treatment sector in Australia, made it important that these small demonstration projects were, in reality, locally driven and openly evaluated. If we were to genuinely learn what is needed to create good-quality, meaningful and sustainable local consumer participation activity in drug treatment settings, it was essential that these projects be able to thrive or fail on their own merits rather than through an 'artificial' and ultimately unsustainable process of AIVL being overly interventionist in a project administration/management role.

The process evaluation stage of the demonstration projects and the results and findings of those evaluations are the focus of Chapters 4, 5 and 6 of this report.

❖ Chapter 4: Evaluation Aims and Method

4.1 Evaluation Aims

The research and evaluation component of the TSU Project: Phase Two aimed to evaluate the suitability and impact of consumer participation at the organisational level within various drug treatment settings, including pharmacotherapy, outpatient detoxification and residential rehabilitation programs.

The five services developed and implemented demonstration projects aimed at increasing levels of consumer participation at the organisational level. In-depth interviews were conducted with service providers and drug treatment consumers at each site prior to the pilot projects commencing and then again five to six months later. The two rounds of interviews were intended to provide the research team an opportunity to assess whether the pilot projects led to changes in the level and quality of consumer participation at the organisational level, improved service delivery and improved communication between staff and consumers.

While the evaluation is intended to be explorative and focus on processes rather than outcomes, a model was developed to assess the demonstration projects across the five sites based on the available literature, advice from the Project Advisory Committee (PAC) and was informed by the findings of the TSU Project: Stage One. The model was used to develop interview questions and to provide a framework through which data was interpreted.

The relative short timeframe of the projects makes it difficult to explore their medium- and long-term impacts and therefore the evaluation focuses primarily on readiness, implementation and short-term changes. Each demonstration project will be evaluated to determine the appropriateness and effectiveness of the consumer participation model, including:

- The suitability of the model across a range of treatment contexts;
- Identifying strengths and weaknesses of the model in a range of treatment contexts;
- Identifying methods to improve the manner in which the model is practiced or delivered;
- To evaluate the impact of the model of consumer participation in a range of treatment contexts;
- Determining changes in attitudes of consumers towards providers and vice versa;
- Determining changes in communication between consumers and providers;
- Determining changes in communication among consumers;
- Determining the extent of capacity building in relation to the consumer participation model for consumers and providers (knowledge, skills, confidence);

- Identifying other direct and indirect outcomes of the project as perceived by consumers and providers; and
- Estimating monetary and time costs of implementing the model.

The findings will be used to refine the model of consumer participation to ensure that it is a framework suitable for use in a diverse range of drug treatment settings. Further, the findings from this research will contribute to the development of consumer participation policies that can enhance service delivery and health outcomes.

4.2 Ethics

As this was a national project and involved government and non-government drug treatment services, a number of different human research ethics committees were responsible for reviewing and giving approval to the research component of the TSU Project: Phase Two. Ethical approval for the three non-government sites was granted by HREC of the University of New South Wales. The HREC of Melbourne Health granted approval for the government site in Victoria. South Eastern Sydney and Illawarra Area Health Service HREC-Northern Sector gave approval for the government site in New South Wales.

4.3 Developing the Interview Schedule

The primary method of data collection for the evaluation was in-depth interviews. An interview guide was drafted by the NCHSR research team in consultation with AIVL and the PAC. Additionally the content of the interview guide was shaped by the available literature on consumer participation and the model of consumer participation.

The interview guide was piloted with a project worker and consumer at NUAA in Newcastle, New South Wales. The primary purpose of the pilot interviews was to test the overall appropriateness of the content, structure and language of the guide and identify gaps or areas of interest that needed to be included. As a result of the pilot interviews, a number of new areas of investigation were added to the guide, including questions about power relations between staff and clients and the fit between clinical models of treatment and consumer participation.

The pilot interviews also identified some specific problems with language: For example, the consumer found the use of the word 'support' in the question 'What things do you think support consumer participation?' confusing, because in the drug treatment context support is usually associated with counselling and therapy. The consumer suggested that the guide needed to use everyday language: For example, 'What things do you think could make consumer participation easier?' These comments were used to refine the interview guide and ensure that the language used was accessible and meaningful to both service providers and consumers.

4.4 Capacity Building

The pilot interviews also provided an opportunity for the AIVL peer interviewer to gain some hands-on experience with in-depth interviewing prior to going into the field. The TSU Project: Phase Two aimed to develop the research literacy of the AIVL staff on the project to ensure that consumer participation was embedded in the research process. The AIVL project worker also attended a workshop on qualitative

research and in-depth interviewing conducted by experienced qualitative researchers at NCHSR. The workshop was specifically designed for peer interviewers and covered in-depth interview techniques as well as providing an overview of qualitative research.

The NCHSR researchers also gained significant knowledge from AIVL about working with drug users, the experiences of people in drug treatment and conducting research within drug treatment services. This type of intensive collaboration with affected communities is central to the research practice of the NCHSR and is endorsed through the NCHSR's statement on community engagement.

Data analysis processes also provided opportunity for AIVL staff to further develop their understanding of qualitative data management and analysis. The process for this is provided below.

4.5 Sample

Approximately 10 people were recruited and interviewed at each site at both baseline and evaluation data collection. In order to include the perspectives and experiences of a range of staff and clients, the research team actively targeted four groups within the drug treatment services:

- Key staff such as team leaders, nursing unit managers, executive officers, and staff members directly involved in consumer participation activities;
- Key consumers directly involved in consumer participation activities such as consumer representatives;
- Staff not directly involved in consumer participation activities; and
- Consumers not directly involved in consumer participation.

However, it should be noted that in many cases the baseline interviews did not include consumers or staff directly involved in consumer participation as the services did not have any consumer participation activities in place at baseline.

4.6 Recruitment

A key criterion of the selection process was the willingness of the services to facilitate and participate in the evaluation of the demonstration projects. While there was an expectation that key staff would facilitate the evaluation process, including assisting with recruitment, there was no expectation that individuals within each service, including key staff, should agree to be interviewed. Individual decisions to participate in the evaluation interviews were entirely voluntary. To ensure this was the case, different recruitment strategies were established for the four groups:

- Key staff were sent an invitation letter by the research team;
- Key staff were asked to approach key consumers and invite them to participate in an interview. Key consumers (e.g. consumer representatives) were integral to the implementation of the demonstration projects and therefore known to key staff. Key staff provided the key consumers with the contact details of the peer interviewer. Key consumers who were interested in doing the interview were able to contact the interviewer directly by phone or email, or on site when the research team visited each service;
- Key staff were asked to distribute an invitation letter to all service staff. Staff were invited to

contact the research team by phone or email or during site visits if they wished to participate in an interview;

- Consumers who use the service, but are not directly involved in consumer activities, were also aware of the project via flyers displayed in the service. These consumers were able to contact the peer interviewer by phone or email. Alternatively, consumers visited the service on days the peer interviewer was on site and arranged a mutually suitable time to conduct the interview. Consumers were paid AUD \$25 for their time and/or travel expenses.

We recruited separately for both baseline and evaluation data collection as we anticipated there would be changes in staff and consumers during the life of the demonstration projects, thus making it difficult for consumers and staff to participate in both rounds. Further, not all staff and consumers would have the time or desire to participate in both baseline and evaluation. While we expected there would be some people who chose to participate in both, this was not a prerequisite for participation in the study. We asked people who participated in baseline if they wished to be considered for evaluation interviews. If they were interested, we took their details and re-contacted them prior to the second wave of data collection to ascertain their availability and willingness to participate.

4.7 Interviews

Interviews were conducted by an experienced researcher from NCHSR and a peer interviewer from AIVL. The staff interviews were conducted by the NCHSR interviewer and the consumer interviews were conducted by the peer interviewer in collaboration with the researcher from NCHSR. Interviews were digitally recorded and transcribed verbatim. Transcripts were de-identified, removing personal names, names of health-care workers, health services and specific towns or suburbs.

4.8 Data Analysis and Evaluation Framework

The demonstration projects were evaluated using qualitative methods and drew on a realist evaluation framework (Pawson, et al., 2005). Realist evaluation is a relatively new evaluation framework that acknowledges that effective programs and interventions are dependent on context and implementation as well as on the type or form of program or intervention being used (McEvoy, 2003; Pawson et al. 2005). Realist evaluation explores more process-orientated questions about services in order to explain what works about a particular program and in a specific context. The rationale for using this approach was that it provided rich and detailed data about the development, implementation and impact of organisational consumer participation. The evaluation focused on the specific context of each service and project to explore what worked, how it worked, what did not work well and why. While the project includes a diverse range of drug services, including location and type of treatment, the evaluation did not aim to explicitly compare the sites. Rather, the evaluation of individual sites was used to gather data to refine the model of consumer participation and inform the development of consumer participation policies that can be used across a diverse range of drug treatment contexts.

Transcripts from baseline interviews were transcribed verbatim. Transcripts were checked for accuracy against recordings and then de-identified (names and other identifying information removed). For a variety of reasons, evaluation interviews were delayed in most of the settings. These delays required the data management and analysis processes to be modified to ensure the timely completion of the project. Where possible, evaluation interviews were transcribed verbatim. Where this was not possible,

a targeted transcription of the interviews was conducted. In these cases (typically interviews conducted with consumers), the AIVL worker listened to the recordings and selected sections of the interview to transcribe that were directly relevant to the evaluation analysis. For example, sections of the recording in which the participant described their own drug treatment journey and where there was no involvement in previous or current consumer participation processes were not transcribed.

Baseline interview data was analysed and the results presented in a draft report. The data was read closely by the NCHSR researcher and a number of themes were identified as relevant to the research questions. These themes (with supporting quotes) were examined in a workshop involving NCHSR and AIVL staff. Each aspect of the thematic analysis, that is the interpretations and meanings drawn from the interview data, was critically examined.

The themes identified from the baseline data were used to structure the analysis of the evaluation data. That is, data drawn from the four groups of participants were examined for patterns and shifts within each of these themes. A similar process occurred for the analysis of the evaluation data as for the baseline data. That is, NCHSR and AIVL staff examined each of the themes in a workshop format and critically examined the material drawn from interviews to exemplify the meanings made of the data. Following the approach to realist evaluation, the data was examined for findings within each drug treatment setting with attention paid to the specific local demands and resources, and for general patterns across the settings. To facilitate this, a summary was prepared of the progress and extent of achievements of the demonstration projects conducted in each site, including an analysis of the factors that facilitated or impeded the projects. This summary was drawn from both consumer and staff data.

Finally, a summary of the main findings was presented to the PAC along with a series of questions for review and discussion in a workshop format in order to inform the development of the key recommendations. A number of PAC members were unable to attend this final meeting and therefore an opportunity to provide written comments on the draft report and input into the key recommendations were offered to all members.

❖ Chapter 5: Evaluation Findings

This chapter presents the findings of the baseline and evaluation interviews conducted with staff and consumer participants in each of the five sites conducting demonstration consumer participation projects. Baseline interviews aimed to collect information about understandings of consumer participation and expectations of the demonstration project prior to the implementation of the demonstration projects. Evaluation interviews were conducted three to six months after the implementation of the demonstration projects and aimed to explore staff and consumers' experiences of the project, and to map changes in understandings or attitudes toward consumer participation. We will present the findings of the baseline interviews, then evaluation interviews, and then summarise key themes across both sets of findings. The table below provides a summary of the participants in baseline and evaluation interviews.

	Baseline		Evaluation	
	Males	Females	Males	Females
Key staff	6	3	5	2
Key consumer	3	5	2	4
General staff	11	13	10	7
General consumer	8	9	10	8

5.1 Baseline Findings

All sites were visited prior to commencement of their projects and interviews were conducted with staff and consumers. The baseline interviews were aimed at identifying current levels of consumer participation, understandings of consumer participation, interest in consumer participation, awareness of the project, expectations of the projects, training and capacity building needs, and perceived barriers to consumer participation. In addition, the baseline interviews were included to provide data to measure any changes as a result of the demonstration projects.

5.1.1 Awareness, Understanding and Interest in Consumer Participation

The term 'consumer participation' did not resonate with many service users — few had heard of the term. Service staff were more likely to have heard the term 'consumer participation', but only a few had any prior experience with consumer involvement in the drug treatment field.

While few treatment service users had heard of the term 'consumer participation', the majority of service users interviewed said it would be a positive shift if consumers had a voice within the treatment services they access, as the following examples suggest:

'It sounds like a good thing...yeah for sure. Because we're the ones that are using it so that makes sense.' (Male consumer)

'You need a service that is run by workers and what-not, but I really think the service would benefit more from people who are currently in that position ... consumer reps can be a sort of focal point between the guy that runs the service, like between the workers and the people who use the service. I also feel like we're a good resource to help the community understand services.' (Female consumer)

In one instance, and in response to an invitation from the service, the local drug user organisation had organised and delivered training workshops for both service staff and consumers around the theme of consumer participation. Here the notion of 'consumer representative' (as 'advocate') began taking hold:

'To give those a voice that don't feel they have one, and a place to voice it on that is like them... like they come to me instead of coming to a staff member, they can come to someone who's been there and done that, even if the staff member has been there and done that it's still a bit intimidating to people... it's to advocate for them.' (Consumer)

Indeed, as will be reiterated throughout the report, those services that involved their local drug user organisation as a means of improving knowledge, implementation and support vis-a-vis 'consumer participation', demonstrated consistently higher levels of understanding among their consumers than those services that did not. In the instance cited above, a key staff member later described the drug user organisation's involvement — including their assistance recruiting the consumer representative — as a highlight of the demonstration project, commending their 'highly professional' approach. As the following comment suggests, even the distribution of printed resources assisted consumers' awareness, not only of consumer participation but of their relevant user organisation:

'And I got a folder [of information from the drug user organisation] ... I've sort of gone back through the folder and had a bit of a look at it, and I sort of relate to what they're trying to do for people... So it was really good to sort of finally realise that there is an organisation that's trying to help people in getting their needs met.' (Consumer)

The majority of staff also supported the concept of consumer participation and believed it offered a range of potential benefits, for example:

'...So like it's one thing to give a service, but if it's actually not a service that is useful to consumers then it's futile. So therefore I see them [consumer representatives] as actually directing us to make sure that we are providing proper services...' (Staff member)

Some staff felt services would gain new and alternative ideas about the service from their consumers:

'You just get, you just get different views... the client views as opposed to what, you know, we can try and think that we would know how they are thinking or how they felt. See they can, they might come up with completely different ideas of how to better the service... To get just like stuff that we might not think of that they would think was good, or stuff that we do that actually irritates

them, they could bring it [to] our attention. I mean obviously we can't change everything but just new eyes.' (Staff member)

The majority of sites, while committed to consumer participation, did not currently have consumer participation at the organisational level. Further, most services and their staff had little engagement with the service users outside of clinical interactions. One community drug treatment service did have a drop-in centre where staff and other consumers could meet and talk. This service also offered programs for their consumers that were not explicitly treatment orientated, but included sport and art activities.

The residential rehabilitation service did offer many opportunities for staff and consumers to interact on a daily basis. The staff and managers of the residential rehabilitation service described their service as having a range of consumer activities. Indeed, unlike the other services, they considered that all aspects of their service were informed by a consumer perspective.

Treatment service consumers and staff were asked what skills and characteristics consumer representatives were likely to require. These included good communication skills and experience with drugs and treatment, and having a capacity to communicate with staff and consumers was regarded as central, as the following example illustrates:

'A good candidate... someone who is a good communicator. I don't mean written skills, I mean someone who can talk to people. Someone who... I guess it is a lot of the things we look for in our staff. Rather than employment qualifications, we're looking for people who get along with our client group - not everyone can - and can communicate effectively with us. And someone that's been around long enough to know what the issues are and have a bit of perspective on them.' (Staff member)

Other qualities highlighted included being non-judgmental, having determination, courage and confidence:

'Well, good people skills, communication skills and to be confident within themselves as well as having the inside knowledge of what's going on. And I think confidence is a big thing and the ability to articulate exactly what you mean.' (Female consumer)

The notion of confidence seemed particularly crucial, with consumers often interpreting their peers' 'bad', defensive or antagonistic behaviour within treatment settings as symptomatic of a lack of confidence. This interpretation of others' behaviour was not pejorative but rather proffered as further evidence of the [perceived] advantages of consumer participation — in this instance via a consumer representative:

'I think because the main thing I've noticed with people on methadone is the, you know, the 'scuse my language, but they're always like "oh these people are cunts, they don't listen, they're fuckin' dogs, you know, they don't let me get my dose, (even though I haven't been there for three days)". But you know, and I just think by giving them the confidence to come to somebody and talk, it may help them to have the confidence to improve their life as well.' (Consumer)

A significant number of consumers believed that other consumers were able to provide real-life experiences of drug use and treatment and were therefore likely to offer treatment services opportunities to enrich their programs and services in ways that would be beneficial to their consumers. It was common for consumers to compare knowledge derived from lived experience with drugs and drug treatment positively in comparison to knowledge developed through formal education and training:

'...some people that aren't in the scene wouldn't have a clue... Like you have new people coming straight out of school that have never bloody used the drugs. And like how are they going to be able to tell you anything... Whereas us on the other hand, we're in here and we know...' (Female consumer)

"...You wouldn't really want someone representing you that had to train to represent you because it comes back to the experience thing and they'd be learning out of a text book." (Male consumer)

The TSU Project: Phase Two aimed to develop organisational consumer participation; however it was not uncommon for staff and consumers to frame their project aspirations in terms of support and self-help and not in terms of organisational decision-making.

Knowledge of the TSU Project: Phase Two was minimal among staff and consumers. In most cases consumers had no prior knowledge of the demonstration projects before the interview and in no cases were consumers consulted or included in the development or writing of the project proposal.

This was also the experience of staff who were often only hearing about the project just prior to the interview or at the interview. In many cases, a manager or one or two staff interested in consumer participation had written the project proposal in isolation and not discussed it with other staff:

"... If you are not involved in the planning it can have the effect of resentment, because the people that often end up doing the groundwork are workers like myself. They're not the high level where you can have the ideas and the vision and all that. But the people who tend to have to run with it and implement it are the people that may, and do in some instances, have the least say." (Female staff member)

The model of consumer participation used in the TSU Project: Phase Two notes the importance of involving staff and consumers from the outset. While this may be ideal, very few of the sites had degrees of engagement with their consumers to make this practicable. The nascent state of consumer participation in the drug field will likely require staff or managers with a particular interest to play a central role in initiating consumer participation.

While failure to engage consumers from the outset may be able to be explained by low levels of existing engagement, it is less clear why some services did not seek to inform and engage their staff in the early stages of developing the projects. However the failure to include staff and consumers from early in a project may have ongoing negative impacts — as staff and consumers feel disengaged and imposed upon.

One site had actively involved staff from the outset and, although not all staff were interested, a number of staff chose to become actively involved in the project, working together to develop the proposal. While they did not expect to achieve a great deal in six months, they were committed to continuing to build consumer participation with a long-term aim of changing the service culture.

5.1.2 Stability

Among both staff and service users interviewed at baseline, the subject of 'stability' was interpreted exclusively as a question of consumers' suitability for roles as representatives or advocates. Both service users and staff proposed that consumers who took on roles as consumer representatives or advocates would need to be 'stable'. While the definition of 'stability' invariably reflected the service's treatment

ethos —typically ‘abstinence’ or ‘harm reduction’ — it was nonetheless used and understood as an attribution belonging to individuals.

What constituted an individual’s ‘stability’ thus varied between individuals and drug treatment services. Staff who worked in services that promoted harm reduction were, for example, more likely to frame stability in terms of reduced use or being on pharmacotherapy. Services or staff who were committed to abstinence as the goal of drug treatment tended to define ‘stable’ as relating to no longer using drugs or pharmacotherapy. During baseline interviews the range of views regarding stability was similar among both staff and consumers, including among those individuals identifying as current ‘users’. As one consumer remarked:

‘Well it depends on your lifestyle as to your commitment level.’ (Consumer)

5.1.3 Ex-drug Users

Staff and consumers were also asked what, if any, role they felt ex-users had to play in consumer participation. Many of the consumers felt that ex-users would bring valuable experience to the role and were therefore broadly supportive of their involvement. However, some consumers felt that ex-users eventually preferred to cut ties with the drug-using community and therefore could end up disconnected from current users and not really representative of their needs.

A number of staff at one service were negative about the inclusion of ex-users on the grounds that they often had strong preferences for abstinence-based and 12-step approaches to drug treatment and were opposed to harm reduction approaches. They were concerned that if ex-users were involved in consumer participation a diversity of views and needs would not be considered, in particular the voices of and the issues for consumers who continued to use drugs.

5.1.4 Capacity Building and Training

While some staff believed consumer representatives would need some training, others did not identify specific training or support needs. Staff tended to focus on support in dealing with other consumers, and very few staff identified the need for the management and staff to undergo training. The following example is fairly indicative of attitudes among staff:

What skills do you think will be needed to be developed among both staff and consumers?

‘Oh I don’t know, I think the skills are just... I think the skills are there, people [staff] just have to work their head around... yeah I think... I’m not... I don’t know about the consumers, although I think the skills are probably largely there anyway. A lot of people have done a lot of stuff with treatment programs and support groups and stuff.’ (Male staff member)

For some staff answering the same question, the issue of additional training was less important than attitudinal change:

‘I think it’s attitude. Yeah, I think because they... what the staff have been doing here, I think it’s sufficient for... like for how they do things.’ (Female staff member)

‘Maybe a bit more open just to try, see how it goes.’ (Male staff member)

5.1.5 The Role of Consumers in Organisational Decision-Making

Staff were asked whether they would be comfortable having consumer representatives on interview panels and staff development reviews. Initially, many staff expressed concern, particularly in relation to performance reviews, which is consistent with the findings from the TSU Project: Phase One. In this phase, however, few staff were completely opposed to the idea and a small number saw it as having a range of positive benefits:

What would you think about having a client or consumer involved in staff recruitment?

"I would be quite favourable. But it would depend on, I mean I just know from my experience there are some clients that wouldn't be in a position to make an informed decision. But there would be a couple that if they had some experience in the organisation, did some mentoring, they would certainly be valuable in that role." (Staff member)

When recruited to his current position, one senior staff member recalled positively the presence of a consumer on his interview panel some nine years ago, noting the strong message this had conveyed to him that he would be there to work not just for management but for the service users.

Nonetheless, such support for higher level consumer participation was not uniform, particularly around the issue of staff appraisals. One worker at another service was asked how she would feel about having consumers involved in staff performance reviews:

'Would I like them to review me? If it was current residents, it would definitely make me uncomfortable.' (Female staff member)

5.1.6 Expectations of the Projects

Staff and managers were consistently circumspect in their expectations regarding the possible short-term benefits of the demonstration program. Opinions varied more widely, however, with regards to its longer-term possibilities. The following examples illustrate the optimism and sense of possibility felt by some staff regarding the latter:

'... right across the board I think the benefit is that people [consumers] might well see that the service is theirs and that they have an ability to speak about what they need. And, of course, then the service gets feedback about things that you don't necessarily see yourself and the process of that, if it works successfully, is empowering.' (Male staff member)

'I would sort of hope is that, at the very least, what we would get is a better rapport or connection to the, you know, the consumer group, which gives us better insight into programming and the consumer group gets better programs.' (Male staff member)

Assessing consumer expectations at baseline was difficult, given the low levels of awareness among service users regarding consumer participation generally and the demonstration project specifically. The notable exception to this was the service where consumer representatives had already been recruited and were able to be interviewed at baseline. As the following example illustrates, initial expectations and aspirations were high:

'Well I believe that what'll achieve is, it'll achieve being able to break down communication barriers between the service providers and clients. It'll help by us having a voice and speaking up about issues. It'll help, hopefully to better the service, so that it's not so narrow-minded. It'll be able to be broader.' (Consumer)

Importantly, this optimism was coupled with a sophisticated and sensitive understanding of the role the consumer representative might conceivably play. As touched upon earlier (in the brief discussion of 'confidence'), the consumer representatives interviewed demonstrated an empathetic understanding of the institutional vulnerability of their peer population:

'To give those a voice that feel they have none, and a place to voice it on that is like them... like they come to me instead of coming to a staff member, they can come to someone who's been there and done that, even if the staff member has been there and done that it's still a bit intimidating to people... it's to advocate for them.' (Consumer)

5.1.7 Limitations and Risks

While many participants did not see any significant risks associated with consumer involvements, others did identify a range of potential risks:

'There is some risk that if people have had a negative experience then they are not going to be able to, in some situations, step back and be objective.' (Female staff member)

Other staff, particularly those supportive of the demonstration projects, expressed concerns about the 'institutionally' vulnerable and tenuous status of consumer participation. Their primary concerns were two-fold: Firstly, that should something go awry during the demonstrations then future support from higher management/external authorities for consumer participation would be withdrawn; and secondly, that the consumers themselves were particularly exposed and any such 'failures' could jeopardise consumers' investment in the project and the hard-won trust built up between service users and staff. Concerns were also identified by some staff regarding the potential negative repercussions for individual consumers who had assumed additional responsibilities during the projects; not merely in terms of possible project 'mishaps' but more generally in the advent of unintended consequences, such as those outlined below.

Some consumers were concerned that consumer representative roles could produce conflict and mistrust among users:

'Jealously and just spitefulness, and lies and power of people: "I want that job, I can do that job." All the bad side of the consumer could come out. But there would be a lot of good stuff too.' (Male consumer)

To some extent such fears were borne out during baseline interviews held at the service where consumer representatives had already been recruited:

'Sort of outcasting me because I'm a so-called worker. Some people were saying "she's a worker now"... It was weird. It was almost like going against the whole aim, in trying to keep it sort of, peers working with peers. A lot of them were seeing me as not a peer any more, one of them.' (Consumer)

It is important to acknowledge that for some staff the 'risks' identified with consumer participation were associated with what they believed to be a possible threat to their role as 'staff members'. Both the following examples cite staff speculating about the fears of their colleagues:

'... if they [staff] don't think it [consumer participation] is a good idea because may... maybe it's a power thing. They feel they... some staff feel there should be more power than clients...' (Female staff member)

'... it's quite intimidating to think that members of that client group are going to have access to us at a level where they're not on the other side of a counter.' (Male staff member)

5.1.8 Power and Consumer Participation

Participants were asked to consider the issue of power dynamics and its potential impact on achieving consumer participation. In some cases staff challenged the idea that there was an imbalance. For example, some staff in a residential therapeutic community cited the fact that people were voluntary and free to leave at any time as evidence of shared power. Some staff in other services were uncomfortable with the question as they felt it ignored the strong personal relationships they had with consumers.

Others were aware of this issue and sought to balance it through communication and being clear and honest with consumers. For example, alerting a consumer prior to mandatory reporting:

'Look, I suppose that the rules are set out fairly thoroughly and people are aware that there is a framework and there are guidelines, and there rules. And if they were really informed about that and aware of reporting requirements... I think if there is clarity from the beginning and people know that there are certain procedures that are implemented and have to be followed then it should be possible.' (Female staff member)

While some consumers were less certain that issues of trust and power could be readily overcome, at least one elected consumer representative reported this transformation:

'I mean, I've noticed with me, like I feel like I'm more — I'm like one of them [staff]... I've changed my way but my perspective of staff has changed a bit, but not for the bad, like I have a bit more respect for their position now. I know what I'm going to be doing.' (Consumer)

Perhaps the most apposite reflection on the merits of consumer participation vis-a-vis 'power' was the following made by a senior staff member:

'... right across the board I think the benefit is that people [consumers] might well see that the service is theirs and that they have an ability to speak about what they need... Then the service gets feedback about things that you [staff] don't necessarily see yourself and the process of that, if it works successfully, is empowering.' (Male staff member)

What is important here is the recognition that 'power' and 'empowerment' do not have to exist as phenomena that one 'side' or group possesses at the expense of another. That, in fact, the empowerment of consumers does not necessitate the disempowerment of staff but rather may contribute to the betterment of both groups in co-existence.

This is a central issue if consumer participation is to develop successfully in the drug treatment context and will therefore be explored further in the follow-up analysis and in the final report.

5.2 Evaluation Findings

Evaluation interviews were conducted with staff and consumers of the five participating sites in the months following the baseline interviews. The primary aim of these interviews was to explore and record the impact of the demonstration projects, from both consumer and staff perspectives. The following section details the findings under a number of organising themes: awareness, understanding, interest and valuing in consumer participation; stability; who is a consumer; sustainability; expectations – project, consumer representative; power and empowerment.

Prior to addressing the findings proper, it is worth briefly revisiting the breakdown by service type of the five participating agencies. A brief overview of each demonstration project has also been included. These overviews have been written using primarily data from the staff interviews augmented with that from consumer interviews. To ensure the independence of the evaluation and the confidentiality of participating services and service consumers, the names and identifying details of the services have been withheld.

Pharmacotherapy:

- A metropolitan, government-operated pharmacotherapy service:
The aim of the demonstration project was to recruit, train and notionally employ two services users as consumer representatives. The role of the consumer representative was envisaged to provide both support and advice to peers on the pharmacotherapy program, particularly those new to the service. As part of the recruitment process, the local drug user organisation was invited to run training and education sessions for both staff and consumers; subsequently the two representative positions were filled. It was at this juncture – just prior to the consumer representative’s deployment on ‘the floor’ – that the project stalled. The primary explanation offered subsequently by staff interviewees was the high turnover of staff, particularly the key contact staff member. The protracted delay that followed included the late remuneration of the two representatives. At the point of evaluation, the key contact had returned to the service and efforts were underway to revitalise the project and, most especially, the flagging enthusiasm of the consumer representatives.
- An inner-metropolitan, non-government, primary health-care service model:
Here the aim of the demonstration project was two-fold: Firstly, to garner feedback from consumers concerning the service’s recent move into new premises, especially the co-location of the needle syringe program with the primary health-care unit; and secondly, to organise a consumer-driven review of the existing ‘Client Rights and Responsibilities Charter’. A well-known, long-term service user was approached directly by key staff and appointed (discretely) as the consumer representative. A questionnaire was drafted by the project’s key staff member, with input from the local drug user organisation, and reviewed widely by staff. This instrument was then administered by the consumer representative to those consumers willing to participate. At the point of evaluation a short report had been tabled by the key staff member using de-identified material from the questionnaire. The second part of the project was yet to be completed.
- A regional, non-government, community-based service model:
There were three aims of the demonstration project: Appointing a consumer representative; reviewing policies and procedures; and running a series of regular focus groups with consumers. It is important to note, however, that the consumer consultant did not identify as having any current

drug treatment experience but did have other 'consumer' experience. At the point of evaluation, the service had only recently appointed the consumer consultant and the other outcomes had not been achieved. The manager of the drug and alcohol team, however, remained committed to the project and it was intended that the consumer consultant would continue reviewing policies and procedures and, with the help of a staff member, commence running the focus groups. At this juncture, concerns were noted regarding the apparent disengagement of both consumers and staff from the project. It was hoped that the appointment of the consumer consultant would begin to address at least the former.

Detoxification:

- An outer-metropolitan, government-operated, multi-disciplinary service model:

The principal aim of the demonstration project was to 'legitimise the voice of the consumer' via the establishment of a 'consumer participation council'. The 'amazing reluctance' to get involved, even among supportive staff, coupled with misunderstanding (even resistance) from other staff, resulted in little progress at the point of evaluation. The notion of a 'consumer council' was already a concession to those staff concerned about higher levels of consumer participation (such as the involvement of consumers in staff recruitment etc.). Nonetheless, the service director remained committed to the concept of consumer participation and a long-term goal of having a consumer representative on the payroll. In practical terms, a steering committee, comprising partner agencies (including the local drug user organisation), had been established and the terms of reference and job description for the 'lead' consumer councillor had been completed.

Residential rehabilitation:

- Based on a therapeutic community model:

The broad aim of the demonstration project was to better meet the needs of service consumers via increasing their levels of participation. At the point of evaluation, staff fed back three key achievements: Increased levels of consumer feedback sought (and received) across all stages of the program; the establishment of a 'formal' meeting held once a week between management and senior residents; and lastly, the establishment of a 'consumer reference group' that met fortnightly and was drafting a questionnaire regarding staff training needs. Staff of the therapeutic community reported very positively on the progress and outcomes of the demonstration project. This was commonly at odds with data from consumer interviews — a point of discussion addressed later in the report.

5.2.1 Awareness, Understanding, Interest and Valuing in Consumer Participation

Baseline interviews with service consumers noted a limited awareness of the term 'consumer participation'. The introduction of the demonstration projects made limited, if negligible, impact on general levels of consumer awareness — both in terms of their knowledge of the actual demonstration projects or the concept of consumer participation generally. The clear exception was in those instances where consumer representative positions had been created as part of the demonstration project and the consumers fulfilling these roles were able to be interviewed. Those services that engaged drug user organisations to deliver tailored education and training appeared to foster a better understanding of consumer participation among service users than those that did not.

As noted in the baseline findings, staff were more likely than consumers to be familiar with the term 'consumer participation', even if they had had no practical experience of consumer participation in a drug treatment setting. With regards to an awareness of the demonstration project itself, staff interviewed in the evaluation stage exhibited a range of understanding and interest. While individual staff differences — such as their employment status as casual or part-time — may be partially responsible for the disparity in levels of knowledge, a further explanation may lie with the developmental histories of the demonstration projects. In some instances, projects had been developed in relative isolation, with only a manager or several interested staff involved, and with little communication more broadly among staff. It is worth noting that the model of consumer participation promoted in the TSU Project: Phase Two shows the importance of involving staff and consumers from the outset. However, in practice, none of the services consulted or included consumers in the development or writing of the project proposals, or in later activities such as writing the position description of the consumer representative or, even when consumers were actively involved, reviewing and revising the project plan. While the lack of pre-existing consumer participation may have understandably precluded consumers from early involvement in projects, it is less clear why staff should also have had such limited engagement.

The general high level of support for the concept of consumer participation among staff noted at baseline remained so during the evaluation interviews. As both the following examples illustrate, for some staff the notion of consumer participation was a matter of principle:

'It is actually part of our organisational ethos that we're a community health centre so you can't call yourself "community" if you don't have community involvement.' (Male staff member)

'Our clients are the experts in their own lives and, you know, we've gotta listen to them... And it's not a matter of we're the experts sitting here on our high and lofty mountain looking down on people, you know. It's about people. And they're actually the experts in their own life. And if we don't work with them then we're, I feel, then we're not, we're not doing what we're supposed to do.' (Male staff member)

Nonetheless, staff support for consumer participation was neither uniform nor unproblematic. As one senior staff member explained, there was still an attitude of 'I don't like this', 'I don't want this' (male staff) among some staff. While another service manager noted that he anticipated some staff to 'white-ant' the demonstration process and had put in place contingency plans for strong staff opposition to the consumer participation project (male staff). The attitude of staff towards the demonstration project — specifically the notion of consumer participation — was an issue of concern for some of the staff interviewed. As one staff member explained, when introducing the concept of consumer participation, one must 'tread very carefully', particularly when dealing with a large cross-section of staff (male staff). Indeed, this same staff member went on to suggest that the greatest barrier to the project succeeding was 'us — the staff'. So while none of the staff interviewed actually expressed any opposition to the concept or implementation of consumer participation, they were nonetheless aware of antipathy among members of their team.

Levels of awareness and/or understanding of consumer participation remained universally low among consumers. Moreover, and more alarmingly, knowledge of their services' demonstration projects was equally poor. Consumer interviewees were frequently unfamiliar with the subject matter of their interview and commonly required prompting by staff prior to interview. The type of service, the state of project progress, and the particular consumers interviewed were all influential in shaping responses to

questions of interest and belief in consumer participation. The role of service type will be addressed in detail elsewhere in the report but, generally speaking, consumers of the residential rehabilitation and detoxification services appeared to exhibit relatively less belief in their capacity to participate — that, indeed, having input into the running of a service was typically considered a ‘staff job’. As with staff, the level of project progression clearly contributed to levels of awareness and understanding of consumer participation among service users.

There appeared to be a correlation between the extent of project progress and the level of awareness and knowledge demonstrated among consumers at interview. As noted earlier, this was also evident where drug user organisations had provided education and training sessions as part of the demonstration projects’ implementation. Finally, there was a clear relationship between levels of consumer understanding and their level of involvement (or otherwise) in the demonstration project. Unfortunately, interviews with ‘appropriate’ (i.e. involved) consumers could not always be arranged, suggesting a limited involvement of consumers in the demonstration project and/or a limited relationship between services and consumers.

Having remained unobserved or unremarked upon during baseline interviews but evident during evaluation, was varying degrees of consumer cynicism regarding staff motives for promoting consumer participation. Some service users indicated the involvement of consumers in service evaluations appeared tokenistic at times — that staff would seek out what consumers wanted but not put it into action. Some consumers were critical of what they considered to be bias in the manner in which consumers were recruited to provide service feedback, suggesting services’ attempts to tailor responses. The following examples are illustrative:

‘They are very picky in this place sometimes, like who they pull out... that’s a lot of what goes on here, it’s just fuckin’ feathering of the nest in the extreme.’ (Male consumer)

‘They are very careful about who gets to say what.’ (Male consumer)

‘They tend to, with things like this, they let certain people know... who would be good for it.’ (Male consumer)

What remained a strong theme during evaluation interviews, as during the baseline interviews, was a conviction among consumers in the value of ‘lived experience’. The latter was invariably coupled with and judged superior to what might be euphemistically termed ‘textbook learning’. The following are illustrative:

‘You can’t learn that stuff from a textbook.’ (Male consumer)

‘My experience tells me that only an addict knows an addict.’ (Male consumer)

This seems to suggest that while considerable skepticism, if not explicit cynicism, exists among consumers towards a service’s commitment to genuine consumer participation, there was nonetheless a privileging of consumers’ knowledge (as ‘lived experience’) over that of a textbook variety commonly attributed to staff.

5.2.2 Stability

Among both staff and consumers interviewed at baseline, the subject of ‘stability’ was interpreted

exclusively as a question of consumers' suitability for roles as representatives or advocates. While at baseline the definition of 'stability' was somewhat fluid — in so far as its definition changed across service type, invariably reflecting the service's treatment ethos (typically 'abstinence' or 'harm reduction') — it was nonetheless used and understood as an attribution belonging to individuals. During baseline interviews the range of views regarding stability was similar among both staff and consumers, including among those individuals identifying as current 'users'.

In evaluation interviews the term 'stability' was again employed to describe an individual's status, with a number of consumers stating that many consumers were simply too 'unstable' to assume responsibility within the organisation. However, what also became apparent during evaluation was the question of service stability: Was the service itself fit for duty? The lack of stability of staff and the concomitant lack of organisational memory was a predominant feature of evaluation interviews, particularly among service staff. All five participating sites experienced considerable delays and disruptions with their projects. One service's project that had initially exhibited promise was effectively left 'feel[ing] like a rudderless ship' in the aftermath of continual staff changes; or as the interviewees remarked:

'And I have to be perfectly honest here, it's not gone smoothly... We've had a succession of people being the prime mover and as people leave, [are]seconded, lose interest, that sort of thing... We've had many, many hands being, being the prime person.' (Male staff member)

'I think a handover would have saved us five months of stuffing around.' (Female staff member)

While there was divided opinion as to the need for a paid, dedicated staff position solely responsible for the promotion of consumer participation, there was universal support for the need for stability of key staff during the project, including — as a minimum — a designated and recognised 'contact person'. One service advocated having few staff directly involved in the demonstration:

'Easier to have less people, keep it simple.' (Male staff member)

Nonetheless, opportunities were afforded all staff to contribute. This same service emphasised the importance of having not only a 'stable' management team during the demonstration but a 'stable and experienced' staff, ideally one with a history of, and familiarity with, consumer participation.

The term 'core' was one commonly deployed by staff interviewees to describe service 'business' that was deemed essential as opposed to matters considered marginal or 'non-essential'. In at least one service the demonstration project was considered to have suffered because of its 'non-core' status. As one staff member explained:

'And I guess at times the, just the workload... in the whole centre meant that the consumer rep project wasn't getting the, the time and input that it required.' (Male staff member)

In this instance it was felt that the absence of 'core' status meant that while the 'lofty ambitions' of the demonstration was laudable, it was neither well-planned nor adequately resourced. Furthermore, it was stressed by this interviewee that this lack of attention to the project was compounded by other 'non-core' projects taken on by the service at the same time. This participant suggested that, in future, such projects be introduced one at a time, ensuring adequate resourcing, including a dedicated staff member to promote sufficient and sustained focus.

An analysis of the broader, public health and socio-economic context within which these individual

services operate, and within which the demonstrations were introduced, lie outside this report. Nonetheless, it is worth noting that several senior staff emphasised the pressures of a 'system' that placed ever greater demands on services and staff with little or no provision of additional resources; or, indeed, the role of 'decision makers' who are not always aware of the particular constraints operating within individual workplaces.

5.2.3 Who is a consumer?

Not unlike the concept of 'stability', the term 'consumer' was somewhat free-floating in its application, tending to reflect both individual and contextual variations. The term took on different meanings within different types of treatment. Many users of residential rehabilitation or detoxification services considered all ex-users to be 'consumers'. Alternatively, some consumers receiving opiate substitution therapy believed ex-users to be too far removed from the drug-using community and therefore unrepresentative of 'consumers'. In the context of consumer participation they believed such ex-users had the potential to do more harm than good as 'they think they are better than us' (consumer).

It was noted during interviews and visits to services that, in some instances, a high proportion of staff identified as past drug users. In one service, for example, it was reported that anecdotally up to 70% of staff were 'ex-users'. The vexing question of when a 'consumer' becomes an 'ex-user' remains an important, if unresolved, one. It is of central importance precisely because the TSU Project has been founded on a division between those who provide and those who consume services. Are, for example, some staff of the aforementioned service to be considered 'consumers' — and, by extension, others not?

In another service the team leader mooted possible concerns about staff 'allegiances' when discussing several young team members he identified as having their own drug- using histories. These staff were also considered by their team leader to be the most vocal and committed advocates of consumer participation. Such staff have invariably been employed on the basis of their professional qualifications and not as a result of their personal history, yet are sometimes still identified on the basis of the latter. This raises important conceptual and practical questions concerning self-other identity making: blurring what has been constructed as an absolute distinction between staff and consumer.

5.2.4 Who Should Represent Treatment Consumers?

One unexpected issue that arose in interviews with consumers in both residential rehabilitation and detoxification settings was the matter of discrimination between people within the same services. The TSU Project: Phase One excluded services (and, by extension, the consumers of those services) that provided treatment for alcohol use only. As the TSU Project: Phase Two was focused on evaluation of a series of demonstration projects in a realist framework, it was not feasible or appropriate to exclude consumers on the basis of whether they were being treated for alcohol or illicit drug use issues. A number of the services involved in the demonstration projects provided a 'mix' of services for both licit and illicit drug use issues and therefore projects were open to all service consumers. Although the majority of consumers interviewed at baseline and evaluation were illicit drug treatment consumers, others were accessing the service for either licit or a combination of licit and illicit drug use issues. For other services, such as pharmacotherapy, it should be noted that some consumers are managing issues associated with the use of multiple substances.

At baseline and evaluation a number of consumers talked of the differences between their own drug use and that of others, the primary differences being 'drug choice'. On separate occasions, service consumers receiving treatment for alcohol use expressed a very clear distinction between the use of alcohol and what they deemed as 'drug' use, which for them was illicit drug use only. In one instance a consumer stated he didn't like 'chemical users' for a number of reasons including negative perceptions of illicit drug users being nasty, selfish, untrustworthy, and unable to stick to the rules, such as bringing drugs into the service, unable to socialise with others, etc. Following these comments, the interviewer questioned how such views (that 'alcohol' users were perceived to be of a better calibre or more suitable for certain roles than those in treatment for illicit 'drug' use) might be managed in relation to consumer participation in a service that provides treatment for both alcohol and other drug dependence? In particular, could one person represent both groups if there were different needs for different consumers? The consumer stated in response that he thought it would be best for different groups of consumers (based on drug of choice) to be represented separately.

5.2.5 Sustainability

The question of sustainability, with regards to consumer participation, is a complex and multi-faceted one. What follows is necessarily only an overview of several key issues.

Higher/external management:

The role of higher management, such as area health services or executives of community health boards, were cited as crucial for both the short- and long-term success of consumer participation. Without their imprimatur, service provider participants considered current or future consumer initiatives were unlikely to be introduced or sustained. The presence of external structures required careful consideration and negotiation, along with a recognition of potential limitations. Policies such as those governing the payment of consumer representatives, mandatory police checks for employees, and the placement of volunteers were three examples cited. Conversely, the presence of supportive senior management acted as a facilitator, as the following example illustrates:

'... having a supportive management structure was really important — really important. And it gave us the confidence to do this.' (Male staff member)

Experience:

Feedback from evaluation interviews suggested that the small successes experienced during demonstration projects were instrumental in building the confidence and the belief to attempt further initiatives. The following description from a residential rehabilitation staff member captures the enthusiasm and momentum that can follow consumers' participation:

'It's magic really... just incredible seeing people's confidence build as they're given more and more responsibility. And they are actually stepping up to the mark.' (Female staff member)

The benefits of consumer participation were not limited to consumers but were also noted among service providers, particularly those who had previous positive experiences of consumer participation. Some staff with backgrounds in mental health brought with them valuable training and experience in consumer participation. For some staff these earlier experiences had proven formative in their ongoing approach to service provision and consumer work.

5.2.6 Expectations — Project, Consumer Representative

Given the low levels of awareness among consumers of either consumer participation as a concept or its application via the demonstration projects, it is difficult to comment generally on the expectations of consumers. Of those consumers who were interviewed at evaluation most had little to no expectations. A notable exception was among those consumers who became consumer representatives during the course of their service's demonstration project. Among this small cohort the expectations were high at baseline, as the following example illustrates:

'... what I'm hoping it will achieve is a common ground for staff and consumers to work out things, like you know, how do you put it in to words? It's like an even plane so everyone's on the same level, everyone's the same, like no-one's better than anyone, no-one's — even though this person works here and you're a consumer, you both got the same rights and you're both equal. You don't have to sit there, you know put your head down and think "Oh they're the staff I can't say anything what if they take my kids? What if they do this? What if they do that?" you know.'
(Consumer)

In this instance, despite a promising start — including the active utilisation of the local drug user organisation and a carefully crafted consumer representative selection process — the demonstration stalled at the point of real possibility. The reasons for this were varied — principally the high turnover of key staff — but one consequence for the consumer representatives was the service's protracted delay in remunerating them. This failure, itself a symptom of broader failures, understandably resulted in the diminished enthusiasm, motivation and trust of the two consumer representatives affected.

One senior staff member expressed his 'annoyance' at what he considered to be the lack of adequate support or resources made available to undertake the service's demonstration properly. This had resulted in what he saw as the 'unfair' treatment of consumer representatives — 'playing with people's emotions', their sense of self-worth and trust in the organisation:

'I'm thinking of one consumer rep in particular [who] was taken on board as a life-changing experience... to have responsibility, to have input, to be able to give back to a service...' (Male staff member)

Alongside the limited outcomes described above were also positive reports of some services' reinvigorated commitment to the principle and practice of consumer participation as a result of the demonstration project; of high expectations for the future. One staff member described what she believed to be the effect of the project:

'It's reinforced what we do but I think, more importantly, the "why" we do it. It's not just habitual. But it's made us revisit the, the rationale. It's been very, very useful; professional practice-wise it's been very useful.' (Female staff member)

The same optimism is also present in the staff member's description of consumers' participation:

'The absolute goodwill and enthusiasm, dedication and commitment from all the consumers... consumers have been the stars of this project.' (Male staff member)

Similarly, a senior staff member of another service suggested the outcome of the demonstration project had been to reinforce the value of consumer participation and the service's confidence in it, auguring well for its future development and expansion.

Finally, the position of consumer representative, introduced as the key constituent of several demonstration projects, warrants mention within this discussion of expectations. The position of consumer representative was challenging, if not also rewarding, for the individuals appointed. The position of consumer representative was subject to not only occasions of jealousy and mistrust from fellow service users, but burdened too by their inappropriate and sometimes onerous expectations. The risk for consumer representatives was exposure to a level and type of demand that was often unrealistic and inappropriate. As this consumer representative foresaw at baseline:

'[Service users] want [methadone takeaways] and they won't be able to get them because it's just government policy, and we can't change that, even as consumer reps. Even as staff they can't change that, so...' (Consumer)

It was as a result of such demands that services focused considerable attention on publicly clarifying the role of the consumer representative and enacting appropriate forms of support and supervision for the position. In several cases the latter involved ensuring external supervision was available from the local drug user organisation in addition to internal staff support.

5.2.7 Power and Empowerment

The themes of power and empowerment remain a defining issue if consumer participation is to be successfully developed in the drug treatment context. The following brief discussion of power and empowerment will focus on the position of consumer representative, drawing on comments and observations made in the course of the evaluation interviews. While obviously other expressions of power were at play during the demonstration projects, such as the higher management of area health authorities discussed earlier, these will be explored in a more general and in-depth exploration of power and empowerment canvassed later in the report.

The position of consumer representative provides an elucidating illustration of the complex and, at times, blurry nature of power and empowerment within the context of consumer participation in drug treatment. On one hand the consumer representative appears to occupy a position of increased power (and empowerment) relative to their peers. Indeed, it can be understood as a promotion, even attracting jealousy from others. On the other hand, what power can be said to accrue to the position of consumer representative is only so if permitted by staff; the reigns must be loosened by those ordinarily holding them. This 'letting go' of control was, in turn, described by one senior staff as a 'challenge' that was 'complex and layered'.

In one service, staff reported witnessing the personal empowerment (growth in confidence etc) that accompanied a consumer's appointment as a consumer representative, while within another service a staff member bemoaned the 'playing with people's emotions' (the 'disempowerment') that resulted when the consumer representative positions were not appropriately remunerated nor properly exercised. Paradoxically, the position of consumer representative can only be effective if the individual is still recognised as a 'peer' by the consumer group. Coming to be identified as 'one of them' (a staff member) effectively robs the position of credibility, and therefore power, among its constituents. (A hypothetical variation on this theme was mooted by interviewees and might be termed the 'yes man': effectively an overly compliant peer chosen by staff to act as a token consumer representative.) In both instances it seems that the 'voice' of the representative must remain identifiably 'ours' to consumers in order to remain authentic and empowered — as 'us' and not 'them'. Yet this in turn appears to draw

upon and reinforce the very dichotomy (of staff versus consumer) that consumer participation purports to challenge. Consumer participation may work best when these distinctions are appreciated in positive and collaborative terms.

5.3 Summary

Levels of awareness and understanding of consumer participation exhibited among service users across all five sites remained universally low throughout the project. A clear exception was apparent in those instances where consumer representative positions had been created as part of the demonstration project and the consumers fulfilling these roles were able to be interviewed. Importantly, the data suggests that most consumers did value the concept in principle once it had been adequately explained. Staff were generally more likely than consumers to be familiar with the term 'consumer participation' (albeit most without any professional experience) and broadly supportive of it. Aside from a minority of staff that remained consistently disinterested, opposition among staff appeared most vociferous when higher forms of consumer participation (such as staff recruitment or appraisals) were mooted.

The terms 'stability', 'ex-users', and even 'consumers', prompted a number of important conceptual and practical questions. The notion of 'stability', initially considered a 'positive' attribution of individuals, became a means to assess the suitability of services. The readiness of individuals to take on the responsibilities of consumer participation became a concern about the fitness of services to run the project. Not unlike 'stability', the terms 'ex-user' and 'consumer' have become normalised within the taxonomy of drug and alcohol practice and policy. However, like 'stability', these terms are neither neutral nor fixed: their meaning and application varied across treatment settings and between speakers, from senior staff to consumers. The fluidity (and power) of these terms need to be recognised in the context of this project where each carried considerable currency.

Expectations of the project remained low to non-existent among consumers due to universally poor levels of awareness. The exception, as noted above, was among those consumers interviewed who had been recruited as representatives. Staff were mixed in their aspirations for the long-term benefits of consumer participation. In the service where consumer representatives and staff had been the most vociferous in their initial expectations there was the most dejection, frustration and cynicism reported at evaluation (for reasons of project discontinuity, failed consumer representative remuneration etc). This 'failure' merely highlights the institutional vulnerability of consumer participation in its nascent stages and, most particularly, of those consumers who were drawn into the process in good faith only to be 'let down' by the very service which encouraged their involvement.

By way of explanation for the lack of progress with the demonstration project, several senior staff made explicit mention of their over-stretched, under-resourced service. It is also important to emphasise how services also consistently acknowledged they had underestimated the amount of work involved in implementing the demonstration projects. Here a parallel could be drawn between staff's baseline belief (in evidence across most services) that they did not require any specific training or education vis-a-vis consumer participation and services as a whole, being somewhat underprepared in their approach to the demonstration project. Careful consideration and planning needs to take place in future before services take on the complexities incumbent in consumer participation in this context.

❖ Chapter 6: Discussion

6.1 Scope of the Study

In 2005 AIVL commenced a peer-driven research study in collaboration with NCHSR to gain a better understanding of consumer participation in drug treatment services in Australia. This study resulted in the publication of the TSU Project: Phase One Final Report in April 2008. The project recommended a series of priority actions to support education and training, policy development, funding and leadership in relation to consumer participation in drug treatment services (AIVL, 2008 and Byrant et al, 2008).

The TSU Project: Phase One was a ground-breaking project within the Australian AOD treatment sector (Patterson et al., 2009 and Ottman et al., 2009). As the first national research study into consumer participation in drug treatment settings in Australia, the project identified a number of key findings. These findings included a very high level of support for consumer participation among both consumers and service providers; a lack of resources, skills and capacity to implement consumer participation in practice; and a number of significant barriers to consumer participation caused primarily by the culture and power dynamics in drug treatment services.

Of particular note was the fact that although the vast majority of stakeholders indicated a strong level of support for consumer participation in the planning and delivery of drug treatment services, many stakeholders did not feel confident when it came to translating this 'theoretical' support into practice at the level of everyday service delivery. In this regard, the TSU Project: Phase One Report highlighted the need:

- To raise awareness of the benefits of consumer participation; and
- To provide advice to services on how to implement consumer participation in practice (AIVL, 2008, p.15)

As a strategy to actively support drug treatment services to implement consumer participation in practice, in mid-2007 AIVL commenced the TSU Project: Phase Two — once again in collaboration with NCHSR. The aim of this project was to conduct and fully evaluate five consumer participation demonstration projects in drug treatment services across Australia. The key objectives of the TSU Project: Phase Two were to:

- Further refine and then apply the definition and model of consumer participation in drug treatment services developed in the TSU Project: Phase One; and
- Conduct an independent evaluation of the suitability and impact of the expanded model within the five selected demonstration sites.

By supporting and fully evaluating a series of consumer participation demonstration projects, the TSU Project: Phase Two was seeking to further explore some of the issues and barriers to consumer participation identified in the first phase of the project. In addition, the project aimed to document the potential benefits of involving consumers in drug treatment services and explore practical strategies for implementing effective consumer participation in treatment settings.

For consistency and to support comparisons across the two project phases, the five demonstration sites were selected from the same states as those who participated in the TSU Project: Phase One – New South Wales, Victoria and Western Australia. The demonstration projects included a range of metropolitan and regional, and government and non-government drug treatment services. The drug treatment approaches offered by the demonstration sites included:

- Pharmacotherapy;
- Inpatient Detoxification; and
- Residential Rehabilitation.

Below we will discuss the key findings of the project evaluations. In Chapter 7 we will propose implications drawn from these findings in relation to recommendations for policy and practice.

6.2 Key Themes Identified in the Project Evaluations

6.2.1 Defining Consumer Participation

Based on the issues and inconsistencies identified with the definition and model applied in the TSU Project: Phase One (see Chapter 2), the definition and model of consumer participation in the TSU Project: Phase Two Project were modified to better articulate some of the complexities surrounding meaningful consumer participation in the drug treatment context. The revision process included:

- Providing more detail on some of the unique issues associated with consumer participation in drug treatment settings;
- The development of a set of guiding principles for consumer participation in drug treatment services; and
- A reworking of the TSU Model of Consumer Participation to include the qualitative aspects of meaningful engagement, such as ensuring that all mid- to high-level participation activities by definition would incorporate empowerment and genuine decision-making roles for consumers.

As in the TSU Project: Phase One, the TSU Project: Phase Two applied the above definition of consumer participation in all aspects of the project including site selection process and in evaluating the demonstration projects. The main point of difference between the two phases was redefining some activities within the levels of participation framework and adding a narrative section to the model to give more context and background to the definition. It should also be noted that there are many other definitions and models of consumer participation in the health context, and the definition and model utilised and the findings and outcomes of the TSU Project: Phase Two should be viewed within the context of this specific definition and model of consumer participation.

Following the evaluation of the TSU Project: Phase Two demonstration projects, some further issues were highlighted in relation to the definition and model of consumer participation. In particular, it

seems it may be necessary to further modify the model to incorporate a 'pre-consumer participation' stage whereby services are encouraged and supported to conduct establishment activities. Despite the fact that the TSU Project: Phase Two was targeted at services who were already undertaking lower level consumer participation activities, such as consultation and information sharing with consumers, the project evaluations did not confirm this level of consumer participation across most of the services involved. Indeed, the majority of services involved experienced significant barriers to undertaking their planned projects due to resourcing and planning difficulties and a general lack of opportunities to engage with consumers outside of the clinical environment.

As it currently stands, the definition and model of consumer participation adopted in the TSU Project: Phase Two commences the process of consumer involvement at the point of 'low level' information sharing between staff and consumers. However, the demonstration projects have highlighted the need for an additional level or stage of engagement that is focused on:

- Establishing communication and trust between staff and consumers;
- Raising basic levels of awareness and understanding of consumer participation;
- Increasing support for consumer participation and its potential value and benefits;
- Building skills in project planning and implementation; and
- Providing practical training for staff and consumers on consumer participation.

The outcomes from the demonstration projects (outlined in detail below) strongly indicate that there is still a need to build basic supporting frameworks for consumer participation within drug treatment services before meaningful engagement between staff and consumers can commence. The recommendations arising from this project emphasise this preliminary stage and outline actions at a number of levels to prepare the AOD service for greater consumer participation

6.2.2 Awareness and Understanding of Consumer Participation

Not unlike the TSU Project: Phase One study findings (AIVL, 2008, p.15), awareness of consumer participation was still generally low among both staff and consumers in the TSU Project: Phase Two. While staff in the TSU Project: Phase Two were somewhat more likely to have an understanding of 'consumer participation' very few had direct experience with consumer participation in practice. A number of services stated the existence, or planned implementation of, 'Consumer Charter of Rights' and 'Consumer Rights and Responsibilities' as being a legitimate form of consumer participation. However, in interviews with consumers most were not aware of the development of these policy frameworks.

Similar to this was the lack of consumer input into the development, design, implementation and assessment of the TSU demonstration projects. Despite the original aims of the demonstration projects, this lack of input meant that in practice most of the projects would be characterised as low-level consumer participation according to the model applied in the project (see Chapter 2). Similarly, many service staff were not involved in project processes including application, development, planning and implementation stages. While it is recognised that in some instances this will have occurred due to genuine staffing and resourcing limitations, staff in some services commented that processes tended to be done by a select few within the services, leaving other staff unaware of the projects. Similar issues to those identified above have also been discussed in the literature on barriers to consumer participation in other health settings (Cleary et al, 2006; Fortune et al., 2007; Hassett et al., 2007; Schauer et al., 2007).

Interviews with general service consumers, typically at both baseline and evaluation stages, demonstrated that many lacked an understanding and awareness of consumer participation in both theory and practice. In many instances 'consumer participation' and 'consumer representation' had to be explained to interviewees from the outset of interviews in order to continue. The consumers who did have an awareness and knowledge of consumer participation were, for the most part, those who had participated directly in the TSU Project: Phase Two demonstration projects, usually as consumer representatives. There also appeared to be a greater level of understanding among those consumer representatives that had participated in consumer participation training provided by the local peer-based drug user organisations.

In some cases, the interviews also created confusion for some consumers as it became apparent that service staff had told consumers the interviews were about the services they attended (and not the consumer participation demonstration project). For the most part, this meant that those consumer participants believed that service 'evaluation' — not evaluation of the demonstration projects — was the premise of the interview. This highlights the low profile that the demonstration projects had within some services and concomitantly points to the lack of knowledge and awareness about consumer participation processes in general.

Tending to fall into two categories, there were a few consumers who had a good awareness of both consumer participation and representation, and then a much larger proportion of service consumers who lacked clear knowledge of consumer participation. The significant gaps between the two groups of consumers indicate differences in how the demonstration projects were communicated to various consumers, and also suggest the need for capacity building and training to improve communication, confidence and trust among both staff and consumers. Service consumers' awareness and comprehension of consumer participation, as well as their willingness to participate in the process, appeared to correlate with both project progress and with the degree and type of training provided by services. In particular, consumer confidence in the project seemed to increase among those services where some training had been provided by the local drug user organisation either alone or together with another local consumer advocacy group.

This suggests that future consumer participation projects could significantly benefit from a number of key actions including the utilisation of training for consumers and staff from the early stages of project planning. Further, such training should be conducted with both staff and consumers with the help of local drug user organisations and other appropriate advocacy groups. This training should include understanding consumer participation and identifying its value and benefits, different approaches/models of consumer participation, recognising the knowledge and skills that consumers possess, and how services and consumers can work together to support consumer involvement.

6.2.3 Support for Consumer Participation

As with the findings from the TSU Project: Phase One, staff showed overall support for consumer participation, albeit at generally low levels (AIVL, 2008, p.14). When asked, the most common examples of consumer participation activities that staff were aware of included: client satisfaction surveys, consumer councils or committees, and suggestion boxes. Very few staff interviewed indicated support for consumer participation at higher levels, such as service planning committees and staff recruitment panels. Reluctance to endorse consumer participation was especially high when it involved decisions that could have potential impacts on staff (i.e. work appraisals, recruitment, etc). This is also consistent with the finding from the TSU Project: Phase One (AIVL, 2008, p.57).

A small number of staff directly involved with consumer participation projects stated that some staff were opposed to the concept of consumer participation, which in some cases caused problems with the demonstration projects. One staff member was quoted as saying he believed 'white-anting' took place as well as an overall reluctance to take on board the project aims. The influence of service staff on the success of consumer participation and the significant barriers that negative staff attitudes can have on consumer participation outcomes is well documented in the literature in relation to drug treatment and other areas of health service delivery (Patterson et al., 2009, Goodwin and Happell, 2007: Roper and Happell, 2007). At both the baseline and evaluation interviews a number of staff stated they felt 'disengaged' with the projects and were being asked to carry responsibilities for projects that had been developed without their input or approval. Given that there are existing concerns within some services about some staff being opposed to the inclusion of consumer participation activities, services should place a high priority on ensuring all staff are engaged appropriately in the planning and development phases of consumer participation projects (Patterson et al., 2009). Staff should also be provided with appropriate training and support in consumer participation and project planning.

While both the TSU Project: Phase One and Phase Two findings reflected a very low understanding of consumer participation among service consumers, once the concept and practice of consumer participation was explained, consumers generally expressed a high level of support for consumer participation (AIVL, 2008, p.86). Further, 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). Given the absence of base-level knowledge of consumer participation among most consumers interviewed, the consumer interviewer explained consumer participation to consumers as being a form of advocacy, representation and participation in drug treatment. Some consumers misunderstood consumer participation to be more of an individualistic issue (i.e. what they could get for either the services or themselves, such as access to more take-away doses in pharmacotherapy programs and plasma televisions in residential rehabilitation services).

While improvements in service facilities are neither unrealistic nor unreasonable, consumer driven changes to clinical procedures and policies are more complex, particularly when governed by external authorities, such as area health services, government policy, etc. Nevertheless, this confusion highlights the importance of managing the expectations of consumers, particularly those expectations that are beyond the scope of the project, and that such management is an important part of consumer participation initiatives. The central importance of organisational context issues, including the full engagement of management and the establishment of mechanisms to manage the expectations of and provide timely feedback to consumers, has also been highlighted in a recent consumer involvement study in the United Kingdom drug system (Patterson et al., 2009).

A number of consumers interviewed did not see the value of either consumer participation or consumer representation. Instead, they maintained that the skills and experience required to undertake consumer participation and representation was more in the area of staff expertise and/or knowledge. This was due either to people thinking that they were not capable of making decisions regarding their own treatment (self-perceived deficits), or that staff were simply more capable of making these decisions on their behalf. While this could imply a good level of trust between those consumers and staff, it also highlights power and empowerment issues between staff and consumers in drug treatment settings.

It remains unclear whether such trust is a product of positive client-staff relations or, conversely, a reflection of high levels of disempowerment among consumers. It is acknowledged that some consumers do not wish to be involved in consumer participation, preferring instead to focus on their treatment and/or because they have other priorities and commitments (AIVL, 2008, p.62). However, the issues raised here highlight the important role of staff in empowering consumers to further consider and/or take up participation opportunities. These issues and others relating to power and empowerment will be discussed in more detail in section 6.5 below.

While the issue was identified earlier in relation to staff awareness of consumer participation, evaluation interviews with staff indicated that another reason for lack of support for consumer participation may have been attributable to a lack of inclusion in the planning of demonstration projects. Some staff (both those with direct involvement in the projects and more general staff) stated that projects had been commenced without their knowledge. As a result, some expressed a lack of ownership over the projects and described feeling resentful due to having no inclusion in the beginning yet being expected to undertake much of the groundwork for the projects. Staffing and resourcing limitations notwithstanding, such problems could be avoided in the future by ensuring all staff are informed of potential projects at the planning stages.

As noted elsewhere in this and the previous chapter, successful consumer participation requires considerable effort and commitment from the service, staff and consumers. Without an adequate understanding and appreciation among key stakeholders of the value and benefits of consumer participation, it is unlikely that the requisite level of commitment to support a successful project will follow. For this reason, future projects should utilise the experience and expertise of local drug user organisations to provide training to dispel negative misconceptions about consumer participation, including fear and misapprehension for both consumers and staff and to identify the positive impact that consumer participation can have on in the treatment context. Indeed, the National Treatment Agency in the United Kingdom has speculated that the unique expertise and experience of drug user groups may be central to achieving desired outcomes in relation to user involvement in drug treatment settings and, in any case, that users have the right to be involved (National Treatment Agency, 2002).

6.2.4 Valuing Consumer Participation

While staff in both the TSU Project: Phases One and Two interviews seemed to show support for consumer participation projects (AIVL, 2008, p.15), it is less clear whether there was an equivalent level of support for the 'value' of consumer participation. Some staff stated they believed it to be an essential need of their services (i.e. 'You can't call yourself a community service if you don't have community involvement'), however these opinions were not reflected across interviews with all staff. The evaluation data reflects a lack of a realistic appreciation of the level of work and the organisational infrastructure needed to implement their projects in line with the project plans submitted by services. Although some services appeared to commence and implement projects well in the early stages, in most cases there did not seem to be adequate contingency planning in relation to how they would respond to unforeseen problems and developments. For this reason, it was a combination of unrealistic expectations, inadequate project planning and support, and lack of contingency planning that resulted in the projects falling short of their planned outcomes. It remains arguable whether this lack of planning and, ultimately, progress represents a case of poor project planning or a more fundamental devaluing of consumer participation in this context. It is likely the answer to this question will differ across the services involved.

The above issues raise questions about the motivations of services in applying for the TSU Project demonstration project funding. Notwithstanding the low levels of funding available to support the demonstration projects, with the demonstration of consumer participation increasingly being included in service accreditation processes within the AOD sector, it is not unwarranted to ask whether services might apply for available funding for consumer participation projects with the main aim of meeting service accreditation requirements. This is particularly the case where meeting such requirements is increasingly linked to levels of funding and, therefore, staff and service opportunities. In this context it is not difficult to envisage a devaluing of genuine consumer participation policies and practices in favour of more perfunctory approach of 'ticking the boxes'.

Alternatively, the underperformance of the demonstration projects could also be interpreted as an issue of core versus non-core business. In this scenario any 'additional project' would suffer from a lack of attention and commitment because it was not designated as 'core' business and incorporated into position descriptions, business plans, etc. Once again, the level of funding AIVL was able to make available for the demonstration projects may have contributed to the relative deprioritising of the projects. The idea of consumer participation not being 'core' business was certainly raised in the evaluations by staff and some consumers.

Regardless of whether the demonstration projects seemed to suffer due to ulterior motives related to accreditation standards or an undervaluing or deprioritising of consumer participation, or some of both, the pathway to addressing the problem of project underperformance is essentially the same. Although the reasons why the projects did not achieve their full outcomes is very important (particularly the unique reasons for each service), it is also reasonable to state that the full value of consumer participation will not be recognised until it becomes a 'normal' or required practice within each service. In this regard, it is recommended that the core requirements and policy frameworks for drug treatment services are amended to support and embed active consumer participation at all levels of organisation. This process could start to foster a higher level of interest and participation from staff and perhaps counter negative staff attitudes. It could also serve as a precipitator for making more service resources available for consumer participation activities.

6.2.5 Who is a Consumer?

The determination of 'who is a consumer?' in relation to consumer participation is not an issue that can be surmised easily or universally agreed upon. While in lay terms it can be defined as someone who buys and/or consumes merchandise or services, in treatment settings there are many varied opinions as to where this begins and ends, and also what characteristics make a 'good' consumer representative. The study findings in both the TSU Project: Phases One and Two reflect that different treatment settings can influence a variety of beliefs among both staff and consumers in relation to 'who is a consumer'. In addition to this, there were also differences in opinions in relation to what constitutes a 'current user' and an 'ex-user', what roles past consumers can have in consumer participation, what constitutes 'stability' for consumers (often stated as a 'required' characteristic for being a consumer participant) and, finally, who should represent consumers in general. Each of these complex and multifaceted issues will be explored in turn below in the context of the findings of the demonstration projects.

6.2.6 Current Users and Ex-Users

Much like defining who is a consumer in the context of consumer participation, the question of what constitutes a 'current user' and an 'ex-user' varied greatly among and across those interviewed at

baseline and evaluation. Far from viewing this as a single continuum where a person is a 'current' or 'active' drug user then progresses to abstinence thereby becoming an 'ex-user', the concept of the 'current user' and the 'ex-user' had very different meanings for both staff and consumers across the different types of treatment services. For those in residential rehabilitation and detoxification facilities, 'ex-users' appeared to be those who had engaged in treatment and remained abstinent from drug use. Coupled with this sentiment was the opinion that ex-use (or abstinence) must be followed by a significant amount of time free from drug use. While acceptable 'times' of abstinence were not stated specifically by either staff or consumers, it seemed necessary for one to be 'drug free' for a significant period of time. Among certain service types and some staff and consumers, the presence of 'stability' in one's life was often indicated as being a good sign that someone was 'drug free'. The concept of stability and how it was perceived by both consumers and staff is discussed in detail in 6.4 below.

Within pharmacotherapy settings, distinguishing between 'current' and 'ex-users' was not as clear-cut as within residential rehabilitation services nor was it considered a necessary prerequisite in choosing 'good' consumer participants. Moreover, consumers held the view that people still on treatment (i.e. pharmacotherapies such as buprenorphine and methadone) were better suited to being consumer participants than those who were not. The main reason provided for this view was that people not currently in treatment were too far removed from the drug-using community and thus unable to accurately relate to those in current treatment. It is also worth noting that many consumers in these settings were of the opinion that staff who were 'ex-users' were much more effective in relating to service users needs than 'non-users' who they believed had gained their knowledge primarily through 'textbooks' as opposed to lived experiences.

While the question of when a current user becomes an ex-user remains a murky one, it is undoubtedly one of the most contested issues in relation to effective consumer representation. It may be that there is a call for different 'types' of consumer participants within different treatment settings. For example, people on pharmacotherapies representing others in the pharmacotherapy setting, and current and/or past consumers of residential rehabilitation and detoxification services representing those within their relevant settings.

Finally, a related issue that emerged during the baseline and evaluation interviews was that of the role of 'ex-user' staff member. As identified in the findings, a staff member at one service claimed that at least 70% of their current staff were ex-users. While this issue potentially raises questions about staff identity and allegiances, particularly on more 'sensitive' issues of service policy and practice, the more important issues in relation to consumer participation are those of relative role and power. While staff members in treatment services with personal drug use and/or treatment histories undoubtedly bring a different experience than staff without this background, it does not necessarily follow that staff with direct personal experiences can simply 'replace' the need for input from current treatment consumers. There are a number of reasons for this, including the fact that one could be a staff member who is an ex-user who has never been in treatment or in that type of treatment and therefore have little more to offer than other non-using staff. Perhaps more importantly, however, is the fact that being a staff member (even one with a 'past') is not the same as being a consumer of that or any other treatment service. Staff are appointed in a professional capacity. Their role and power within the service is very different to that of a current consumer. The other issue that is very important in relation to 'ex-users', particularly those on staff, is that of 'community connectedness', which is explored below in relation to 'past consumers'.

6.2.7 The Role of Past Consumers

In both the baseline and evaluation interviews for the TSU Project: Phase Two, the role of past consumers in treatment services was acknowledged as being important for consumer participation. Much like the issues 'who is a consumer?' and 'users versus ex-users', there were mixed opinions on what the role of past consumers should be, and who was more appropriate for consumer participation roles. Staff at both baseline and evaluation were reasonably consistent in their belief that, while past consumers should definitely have a role in consumer participation, the level and extent of this role was limited to what would be classed as 'low-level' consumer participation, that is non-decision making roles. Limiting the role of past consumers is also consistent with the view put by many staff in both baseline and evaluation interviews that it was not the role of consumers (presumably past or current, although this was not specified) to have significant input into service planning and delivery or general organisational decisions; least of all those processes that directly affect staff, such as staff appraisals.

Opinions on the role of consumers also differed greatly among consumers interviewed, though more so across different services and individuals, rather than over time (thoughts were fairly consistent across both baseline and evaluation interviews). Again comparable to the responses in the TSU Project: Phase One, some consumers were uncomfortable or reluctant with the idea of consumers having a role in their own treatment, believing that this could have negative repercussions for them with their service provision or that they were not knowledgeable enough or confident to represent consumers effectively (AIVL, 2008, p.62). Others held the belief that consumers should be entitled to have input into their treatment and were the most suited to 'knowing' what other consumers wanted and/or needed.

Although there could be disadvantages to involving past consumers in consumer representative roles, particularly the potential for them to be 'out of touch' with the issues or what is happening in services at that time, the advantage is that it could be a way to address the very real concern raised by consumers above about negative repercussions for their treatment. If you are not currently a consumer but someone with past consumer experience you may have a good understanding of the issues facing consumers without having anything 'to lose' by having to raise 'difficult' issues or criticisms of the service.

In many ways, whether this is a viable option or not will depend on the level of 'community connectedness' for each past consumer. If a past consumer continues to be part of local drug user and/or consumer treatment networks or has personal connections with people on treatment programs, their understanding of and capacity to represent the issues and needs of current consumers could be much greater. Alternatively, being removed from direct experience with treatment services over a long period of time or having only ever been involved in one type of treatment service may mean the individual is unable to adequately represent consumer issues regardless of whether they have ongoing connections or not.

The complexities of this issue are also reflected in the consumer data. In many instances, consumers at both baseline and evaluation held similar views about the importance of including past consumers in consumer participation. Consumers of residential rehabilitation services at baseline and evaluation were more likely to believe that past consumers were more suited to consumer participation due to their 'stability' (i.e. further removed from 'chaotic' lifestyles and more able to commit to involvement at this level). Likewise, consumers from detoxification facilities also believed 'stability' or being 'clean' (complete abstinence from drugs) was important for consumer participation — thus the emphasis of past consumers being more suitable.

Those from pharmacotherapy settings were a lot less likely to hold the belief that a consumer participant should be a past consumer; though some consumers did not seem completely opposed to this concept. There was a general support for keeping people within the service engaged (which implied current users and/or people on pharmacotherapies) in consumer participation as it was stated that people who were on treatment would have more of a personal and immediate understanding of other consumers' experience in treatment. For some in this setting 'past consumers' literally meant 'past' — that is, no longer a consumer and therefore not representative of current consumers and related issues.

While the comments above illustrate wide-ranging views among current treatment consumers on the role of consumer representatives and what constitutes consumer representation, it is clear that many believed 'current treatment consumers' had a valued and important role in consumer participation. The issue of 'stability' was raised either directly or implied through other terminology (such as the need to be 'able to fully commit to consumer participation'). To some extent, this implied that many people believed or assumed 'stability' to be a continuum on which consumers consistently 'improved' (i.e. more time passed equalled more stability). Much like 'who is a consumer?', the issues surrounding 'stability' are neither easily surmised nor clear-cut; this is also discussed in more detail throughout the following sections.

The central issue proposed here is that more than stability and ex-use or current use, 'connectivity' with the community represented should be the principal measurement or guidance that determines a person's suitability for consumer representation and participation. Connectedness to community or a person's acceptance within drug user/treatment consumer networks results in an awareness of the current and relevant issues and experiences for current treatment consumers. If people are too far removed from users and treatment consumer networks then they are not sufficiently 'connected' to represent these issues for consumers. This is an issue repeatedly discussed within the peer education literature — that the acceptance by the target group is the key characteristic of a peer (AIVL, 2006). The literature in relation to hepatitis C peer education and treatment support also highlights this concept with peers stating that their most trusted and credible source of information and support is through other peers and drug user organisations (Norman, J et al., 2008 and Richmond, J. 2010).

In the final analysis, it will be important to carefully weigh the pros and cons of considering the use of past consumers for representative roles as this could easily act as just another barrier to current consumers developing the confidence to represent and address their own issues and needs. Ultimately, if current consumers are expressing concerns about repercussions or their own capacities to take on representative roles, perhaps it is better for services to tackle the underlying causes of these reservations rather than seeking to avoid them by using non-consumers (such as family members or carers — no matter how well meaning), past consumers or even staff with past using or treatment experiences to undertake the role. In the end, the focus must be on what best meets the needs of current service consumers not whatever is easiest for the service and its staff.

6.2.8 Who Should Represent Consumers?

Although it was raised somewhat unexpectedly, the issue of a small minority of consumers that people in treatment for alcohol use were somehow a better-quality person or more suitable for undertaking consumer representative roles than those seeking treatment for illicit drug use issues is a matter that warrants further discussion. Setting aside the merits or otherwise of the views expressed, the issue highlighted by these comments is the importance of considering relationships between consumers. In planning for and conducting consumer participation, it is not just about the relationships between

staff and consumers or about the nature and structure of the service. Complex relationships among consumers within services and across services are also central to making consumer participation work.

The wide-ranging views expressed by both staff and consumers on critical issues such as identifying who has the 'right' to represent consumers, who would make the 'best' consumer representatives and inter-related issues of power and trust indicate the centrality and importance of diversity to consumer participation in this setting. In particular it indicates a need to ensure a 'valuing' of diversity and of the associated principles of self-determination and community connectedness. Attitudes and assumptions of staff in relation to both consumers and other staff, and the attitudes and assumptions of consumers towards both staff and other consumers, highlight a need to provide training and education to challenge negative stereotypes and dispel myths and poor attitudes before meaningful consumer participation can even begin.

However, the data shows that many of these attitudes and values are deeply held and are unlikely to be changed through training and education alone. Indeed, other areas of research have shown that changing entrenched negative attitudes, particularly those of health care professionals towards people who use or have used illicit drugs, needs more than training and education to achieve genuine change (Treloar, C and Hopwood, M., 2004). Consumer participation in the general health context has also shown that it is the creation of opportunities for staff and consumers to engage outside of the usual clinical environment — an environment that has often reinforced rather than challenged poor attitudes — that, over time, can help both staff and consumers to understand each other's values and skills (Alexander and Hicks, 1998). While we are not aware of research into strategies for changing negative perceptions and stereotypes held by consumers about other consumers, it is reasonable to assume that opportunities for further engagement and consultation could also assist consumers to better understand and appreciate each other's contributions.

Addressing a broad diversity of views in relation to 'who' should represent treatment consumers will also require the development of fair processes to allow different groups of consumers to form their own networks and identify representatives that they believe best represent their issues and needs. This includes ensuring that current service consumers are part of developing any criteria for consumer representative positions and/or proposals for consumer participation activities. This allows for self-determination and for consumers to be part of the defining processes by which their needs and issues will be addressed. There will be a need for flexibility, to refine approaches or make mistakes and start again. Opening genuine communication between staff and consumers about the characteristics of an effective consumer representative allows for the exploration of issues that, for the most part, did not seem to be discussed in the demonstration projects.

This apparent lack of focus on some of the more formal aspects of consumer representation and participation within the projects has resulted in a situation where this report is unable to do more than raise a range of extremely important yet highly complex and inter-related issues in relation to consumer identity and representation in drug treatment settings. For example, the distinctions raised above in relation to alcohol treatment consumers versus consumers of illicit drug treatment services raises the possibility of consumers being inappropriately represented 'within' a single service or 'across' services. This could occur by people who use or have used different drugs to some or even most of the consumers in a particular service or cluster of services being selected to represent 'all' consumers, and perhaps lacking the requisite knowledge and/or experiences to understand and articulate what others want/need for their own treatment.

The data also raises the possibility of current consumers being represented by people who are possibly too far removed from (or not at all connected to) the issues of relevance (i.e. non-drug users or ex-drug users representing current treatment consumers). Finally, the issue of staff with past using or treatment experience being a 'substitute' for current consumer representatives was also raised by the data. It is unfortunate that the important issues raised by the concept of 'staff consumer representatives' — including that of self-identity, role definition, professional boundaries and power — were not sufficiently explored by any of the projects. It is arguable that these issues were beyond the scope of this project but, equally, the fact that they were raised within the context of projects on consumer participation does potentially bring them within the project's scope.

So what then can be said about the above issues and what they mean for 'appropriate' consumer representation? For the reasons already outlined above, 'connectedness' to one's network or community is probably the most powerful asset a consumer representative can possess. Community connectedness is also likely to be the most effective way to address the complex representative issues raised across the evaluation data. Taking this approach avoids getting caught in either circular or dead-end discussions about who is a consumer, when does someone become an ex-user, can past consumers represent current consumers, does drug of choice matter, etc. Ultimately, by reviewing one's connectedness to people currently using and in drug treatment, a consumer representative can assess and, importantly, be assessed as to whether they can effectively represent the issues and needs of a particular group of treatment consumers. The necessity of this two-step process of not only self-identifying as a peer or consumer but being identified and accepted by others as their peer or fellow consumer is well documented in the available literature (AIVL, 2006). It also goes some way towards addressing many of the issues and questions outlined above from the data.

Treatment consumers have the right to be represented by people who have a genuine interest in and commitment to consumer participation and the skills needed to represent and advocate for the relevant consumers. However, this can only occur in practice when consumers are genuinely supported to implement or be part of fair processes that are inclusive, consultative and designed to meet the actual rather than perceived issues and needs of treatment consumers. This includes supporting consumers to drive processes to elect consumer representatives by seeking the support of local drug user organisations in training and ensuring processes to allow consumer representatives to consult with other service consumers. It also means ensuring that consumers have genuine input into the decisions made and activities undertaken. Consumer representatives identified, selected, trained, supported and managed by staff and services alone may result in a form of consumer participation that is considered easier for the staff and service concerned, but it is unlikely to result in meaningful consumer participation or in an 'appropriate' consumer representative.

6.3 Type of Treatment Service

The type of treatment service and its influence or impact ran through almost every issue and theme in regards to consumer participation. Among the different service types there were very different ideas on who consumers are and should be from both the consumer and staff perspective. Some of the reasons for this situation related to the different models of care, treatment environments and service philosophies among each of the services. For example, within residential rehabilitation, abstinence was the end ambition or goal. Similarly, in detoxification facilities, short-term medication was offered with

abstinence presumed afterwards. In pharmacotherapy settings, however, the underlying premise of treatment is one of harm reduction that does not necessarily assume or exclude total cessation of or abstinence from illicit/licit drug use.

6.3.1 Pharmacotherapy Services

At baseline and evaluation the pharmacotherapy services were the ones that had taken steps to engage drug user organisations in the training for their demonstration projects. It appeared they were more accepting of the role of drug user organisations, in general, and the principles underpinning them. This apparent acceptance most likely related to the fact that these services and the drug user organisations shared a support for the philosophy and practice of harm reduction; unlike other services where promoting harm reduction (and therefore the potential of continued drug use — illicit or licit) would conflict with organisation's core values. It is also the case that these services had some degree of existing relationship with their local drug user organisation, which is likely to have created a platform upon which to base involvement in the consumer participation demonstration projects.

Overall, the consumer participation projects in pharmacotherapy services involved consumers to a greater degree and were also more supportive of consumer participation in general. Consumers interviewed from these services generally exhibited a higher knowledge of consumer participation, more direct involvement in service projects, and showed confidence (more so at baseline than at evaluation) in their ability to represent other consumers within the service. The findings also suggest that there was a direct correlation between the degree of project progress and training provided by the local drug user organisations.

In some instances, both baseline and evaluation interviewees stated that they were content to allow staff to speak and/or act on their behalf as they believed that staff not only knew what was best for them but had their best interests at heart and were far more likely than consumers to do an effective job of representing consumer needs and issues. While this apparent level of trust could on the one hand be a sign of the quality of the relationship between staff and consumers, on the other it could be a sign of almost total consumer disempowerment or at least resignation. It was not clear through interviews how this situation had been allowed to develop. For example, it was unclear whether it had come about through 'empathetic' staff actively speaking on behalf of consumers, thereby removing the need for consumers to speak or take action on their own behalf, or whether consumers had actively given up their right to speak or take action — or a combination of both. It is also possible that a situation like this could develop if staff did not have the confidence in consumers to represent themselves effectively, were concerned about consumer 'vulnerability' and/or if staff did not believe consumers would be interested in taking part in consumer participation activities — a view also supported in the findings of the TSU Project: Phase One (AIVL, 2008, p. 14).

Whatever circumstances have given rise to this situation, it is one that needs to be redressed in the best interests of both consumers and staff. The very nature of pharmacotherapy services can militate against the empowerment of consumers and towards the formation of highly dependent relationships. There is strong evidence that many pharmacotherapy consumers will experience multiple treatment episodes across many years (ANCD, 2009). In this regard, it is important that staff do not enable or facilitate (even inadvertently) consumers taking a passive role in relation to advocating for and representing their treatment needs and issues. If, as the evidence suggests, consumers are likely to be spending long periods of time in treatment and moving between treatment services, they need to be supported to develop the skills and confidence to respond effectively to a variety of treatment contexts. Regardless

of whether consumers express the view that they are happy with the service and do not need to have avenues to represent their needs and issues, staff should initiate steps to empower consumers and support them to make their own independent decisions and develop their confidence to represent themselves effectively.

As mentioned above, pharmacotherapy service settings by their very nature have consumers who are highly dependent on the medication they are prescribed. While consumers may have a willingness to engage in consumer participation, some, indeed many, may be acutely aware of risking losing access to take-away doses and even their place in a treatment program itself by saying and/or doing something that is perceived by staff or the service as 'wrong' (i.e. being critical of services or staff or being labelled as a 'trouble-maker'). Whether this is a real or perceived fear of consumers, it is still a fear that may inhibit consumer involvement. Such fears were also confirmed in the responses from consumers in the TSU Project: Phase One (AIVL, 2008, pp.54-56). However, there are many practical steps that can be taken by staff and services to address such concerns or at least to reduce the likelihood of them resulting in consumers choosing not to participate. For example, providing opportunities for consumer participation away from clinical interactions (such as a separate room for consumers to meet privately) will support more confidentiality and allow interaction to take place away from the immediate clinical environment.

6.3.2 Residential Rehabilitation Services

Some staff interviewed from residential rehabilitation services believed that the environment and setting of their services were by nature conducive to consumer participation. The shared living environment and duties (such as cleaning and cooking, etc.) meant that consumers participated in service programs and had input and contribution into how they 'lived'. Many staff argued that the very nature of therapeutic community-based residential rehabilitation fosters almost constant consumer participation. While it is possible to identify processes and activities to support this case, it is also possible to point to factors that might question whether it is appropriate to label all activities within the residential rehabilitation context 'consumer participation'. This theme was also explored in the TSU Project: Phase One where describing ongoing involvement in practical operational issues (such as work schedules, menu planning and cleaning) as 'consumer participation' was questioned. While it was recognised that such activity could be useful in building a foundation for future consumer participation, the absence of 'choice' (in that consumer involvement in practical operational tasks is not optional but a compulsory part of one's therapy) led to a questioning of whether certain activities should really be characterised as consumer participation in their own right.

At both baseline and evaluation the residential rehabilitation service was less likely to engage the local drug user organisations in their consumer participation project than the pharmacotherapy projects. Despite the fact that AIVL directly facilitated connections between the service and the local drug user organisation, neither the service nor the drug user organisation actively pursued this relationship beyond these initial meetings. Further work needs to be done to better understand why neither party attempted to continue the dialogue and whether this related to a lack of resourcing, philosophical differences or other factors. The evaluation of the demonstration projects has shown the important value of involving drug user organisations in consumer participation initiatives and resolving potential barriers to collaboration.

In the residential rehabilitation project, communication between staff members about the project appeared to breakdown with some staff not knowing what 'project' had been done, or who was

managing the project. Likewise, communication between staff and consumers was also limited. Many consumers were not aware that the demonstration project was being run, with most consumers stating in interviews that they were told they were participating in a 'service evaluation' rather than an evaluation of the consumer participation demonstration project. At baseline and evaluation, consumers in the residential rehabilitation site were also less likely than pharmacotherapy consumers to believe they were capable or suitable to be consumer representatives. Many stated they would prefer staff to make these decisions or, at the very least, have long-term residents (people who had been there longer) as consumer representatives. While there were some opportunities for 'senior' or long-term residents to participate in certain aspects of service decision-making and planning, similar opportunities for new or younger residents were not particularly evident.

As identified in relation to the pharmacotherapy services above, regardless of whether consumers express that they are happy with a service and do not need to have avenues to represent their needs and issues, it is important that staff initiate steps to empower consumers. This should include supporting consumers to make their own independent decisions, and to develop their confidence to represent themselves effectively. The fact that the majority of consumers interviewed at evaluation were not aware of the consumer participation demonstration project serves to underline the urgency of this issue. In therapeutic community-based residential rehabilitation services, in particular, there also needs to be discussion about the nature of consumer participation in this environment and whether it can really be claimed, as it currently is, that compulsory participation by residents in the 'day-to-day running' of the service (such as cooking, cleaning, etc.) equates with meaningful consumer participation as defined in other areas of health service delivery. It is recognised that levels and models of consumer participation vary between service types and even between different residential rehabilitation services. In this regard there is a need for a better articulation of the models of consumer participation being adopted in various treatment contexts and the rationale underpinning these approaches.

6.3.3 Detoxification/Withdrawal Services

As with the other treatment settings, consumers from the detoxification service also showed an initial lack of knowledge of consumer participation. After the concept was explained, many still expressed less interest in participating in consumer participation and less enthusiasm for the general concept. Most were more willing to let staff make treatment or service decisions on their behalf, and also tended to state that if there were to be consumer representatives they should be 'ex-users' or 'stable'.

Similar to the other projects, the demonstration project at the detoxification service also experienced difficulty in meeting stated project goals and outcomes, and did not engage the local drug user organisation in their project. A significant issue in interviews with both consumers and staff was that of how to maintain consistency in consumer participation when consumers are only based at services for a relatively short period of time (on average one week) and are also very likely to be quite ill for a large proportion of this time. Given these circumstances alone, it would be very difficult to have meaningful engagement, training and an ongoing presence at services. For future reference it would be advantageous to examine ways in which these obstacles may be overcome. In particular, this is one service environment where the concept of accessing 'past consumers' of the service may have some application.

It should also be noted that detoxification services are also environments where fixed concepts such as 'current user', 'ex-user' could be problematic and act as barriers to consumer participation. The main reason for this is that consumers access detoxification services for many reasons, including for court

references, wishing to take a temporary break from licit or illicit drug use, wishing to detox from only one substance while continuing to use others, as an entry requirement for a residential program, while waiting for a place on a pharmacotherapy service, etc. This diversity also means that strict definitions of current or ex-user are unlikely to resonate with current or past consumers of detoxification services and could act as significant barriers to a group that is already difficult to engage in consumer participation.

6.4 The Concept of 'Stability'

6.4.1 'Stability' and Consumer Representation

The concept of 'stability' was raised by both consumers and staff at baseline and evaluation. Those who raised this as an issue appeared to place a good deal of importance on 'stability' and many seemed to regard it as being a critical factor for successful consumer participation in drug treatment settings. However, finding a working definition of 'stability' that took into account the diversity of opinion on this issue was very difficult. While there were some common themes and characteristics consistently referred to in the evaluation interviews as being the hallmarks of 'stability' for a consumer representative, there were also some fundamental philosophical differences in the views expressed on this issue.

For some staff and consumers, 'stability' specifically related to a state of being, such that the person — the consumer representative — is considered 'stable' in relation to their current drug-using patterns. For others, it was a much broader concept that included current drug use patterns but also seemed to include other lifestyle issues and attitudes, such as having a stable place to live, being employed, taking care of their children, and having a 'commitment' to what they are doing.

Among consumers, the concept also seemed to vary depending on the type or types of services they had experienced in the past or were currently utilising. Consumers from residential rehabilitation services held a common view that 'stability' meant total abstinence from drug use of any kind for a specified period of time. Whereas consumers from pharmacotherapy services were more likely to view 'stability' as including drug use patterns but not necessarily requiring total abstinence to be 'stable'. In many ways this dichotomy is not surprising, as for the most part it reflects the overarching therapeutic approach or philosophy of the respective services.

Staff also invested in the concept of 'stability' as a valued attribute for potential consumer representatives. As with the consumers, there was no real consensus among staff about this term and how it should be applied in the context consumer participation. There is some evidence in the evaluation that the concept of 'stability' was applied (albeit in an ad hoc manner) by some of the project sites when consumer representatives were selected. The high level of importance placed on this concept of stability was highlighted in one project where the selection of a consumer representative was significantly delayed due to concerns on behalf of the service that the person needed to be 'stable'. The service concerned claimed that despite an extensive recruitment process they were unable to attract or indentify a suitable current treatment consumer for the position. However, at evaluation at least one current consumer from that service stated they were and remained very interested in the position but were not informed or encouraged to apply when the position was advertised.

Given the potential for this issue to have a significant impact on consumer participation opportunities, there is a need for further discussion about the utility and relevance of this concept for consumer participation in drug treatment settings. In particular, there needs to be discussion about how 'stability' is defined and characterised; how stability is determined, and who should judge the 'stability' of an

individual consumer; and how 'stability' is managed over time in the context of a project or ongoing paid position. These questions will need to be identified and addressed in discussions with both staff and consumers before this concept can be usefully applied in this setting — or, indeed, abandoned.

The concept of 'stability' is already well-utilised in clinical practice in the illicit drugs treatment sector as its corollary, 'chaotic'. In this context, too, the concept has been the subject of much deliberation and debate. One of the main applications of this concept has been for clinicians to determine eligibility for take-away or unsupervised doses of opioid pharmacotherapies such as methadone and buprenorphine. Victoria is one of the jurisdictions that has developed a tool to assist clinicians in decision-making in relation to stability and eligibility for take-aways. Although this tool is considered useful in the context of clinical practice, its complexity and the individualised nature of the advice provided both serve to highlight the difficulties associated with attempting to use this concept in a systematic manner in consumer participation (Victorian Department of Human Services, 2006).

The concept of 'stability' and associated beliefs and assumptions about the levels of consumer interest in consumer participation was highlighted in the TSU Project: Phase One. Of interest was the fact that both staff and consumers held strong beliefs, largely based on generalisations about stability and capability, that most consumers would not be interested in consumer participation (AIVL 2008, pp. 86-87). These generalisations did not hold up when individual consumers were interviewed, but it did raise important questions about how assumptions, beliefs and generalisations among staff and consumers can act as a barrier to consumer engagement and involvement.

As a highly marginalised group in the community, beliefs about the capacities, skills and interests of illicit drug treatment consumers can often be driven by discriminatory attitudes and stereotypes. As highlighted in the policy audit for the TSU Project: Phase One, in areas of health service delivery to marginalised communities (such as drug users, people with mental health issues, etc), the relationship between attitudes and consumer participation is circular. In fact, in mental health, negative attitudes held by service providers have been shown to act as a barrier to genuine consumer participation (Mental Health Council of Australia, 2000).

Entrenched and internalised stereotypes about the capacities of other drug treatment consumers often drive consumer comments about the role of 'stability' in consumer participation. This is evidenced by comments from consumers in the TSU Project: Phase Two that suggest the 'stability' and, therefore, the 'suitability' of particular consumers to act as a consumer representative is associated with the type of treatment they are accessing. For example, as explored above, some consumers expressed the view that people who were in treatment for alcohol-related problems would make better consumer representatives than potentially less 'stable' opioid pharmacotherapy consumers.

Problems with the concept of 'stability' as a static measure for suitability and effectiveness are also highlighted by comments from consumers who are new to consumer participation. Consumers referred to how their capacity and interest in being involved in the demonstration projects changed over time with changes in their personal circumstances and growing awareness of the value of consumer participation. These comments show the need for flexibility and openness when considering and selecting consumers to act as representatives. Assessing people against a 'one-size-fits-all' concept of stability at a single point in time could not only result in a service overlooking an effective consumer representative but does not allow for change in people's lives.

As found in the TSU Project: Phase One, the most effective consumer participation is based not on assumptions, judgments or beliefs about person's capacity, interest or stability, but on open

communication and accessible pathways for engagement. Consumers of drug treatment services are a diverse population with different needs and a variety of skills and experiences to offer. Services need to ensure they have a range of engagement points and different types and levels of participation to suit the diverse needs of their consumers. This also means resourcing for consumer participation as core business rather than an added extra on the workload of an already over-stretched staff member. It means creating the physical spaces to allow engagement with consumers outside of one-on-one clinical interactions where concepts such as 'stability' take on very different meanings and can often act as a barrier to genuine communication. Finally, it also means providing opportunities for consumers to consult each other and build the skills necessary for effective consumer participation.

6.4.2 Being 'Fit' for Service

One of the more interesting developments that emerged across the two evaluation points was a shift in the focus of comments about the concept of 'stability'. In baseline interviews many staff focused on a perceived need for consumers to be 'stable' if they were to be effective consumer representatives. By evaluation however, this focus on the 'stability' of consumers had effectively dropped out of the data to be replaced with more of a focus on whether the service itself had the level of stability required to effectively involve consumers. This shift seemed to indicate a growing awareness among staff and services of the level of commitment and systems required across the entire organisation to effectively carry out consumer participation projects. In short, there seemed to be a shift away from whether the consumers were 'fit' to be consumer representatives to more of a focus on whether the services themselves are 'fit for service' — 'fit to conduct consumer participation projects'.

While this shift was not evident in all services, those projects that experienced difficulties certainly reflected this change of view. For example, comments by staff in evaluation indicate this growing level of awareness included comments on the lack of stability in staffing, lack of stability in organisational memory, projects passing through many hands, financial systems unable to cope with the requirement to pay consumer representatives in a timely fashion and a lack of appropriate record keeping for the projects.

Indeed, the difficulties encountered by one service in paying the promised reimbursement to consumer representatives placed this person in a highly vulnerable position if they chose to take issue with the service. Previous research has documented how clients of drug treatment services (particularly pharmacotherapy) perceive that their access to treatment is fragile and that staff can be punitive in their response to client distress or dissatisfaction (Treloar, Fraser, Valentine, 2007). It is conceivable that there may have been negative implications for the consumer representative if they had become upset or visibly distressed at the failing of the drug treatment service to meet its obligations.

This concept of services and systems being 'fit for duty' has also been examined in the area of HIV treatment adherence among injecting drug users in a development context. This work highlights that while much of the focus has been on the ability of the individual to adhere to treatment regimens, there has been little focus on the capacity of the treatment systems themselves to provide accessible and integrated treatment services that are responsive to patient needs. In his work on this issue, Wolfe states:

Labelling active drug users as socially untrustworthy or unproductive, health systems can create a series of paradoxes that ensure confirmation of these stereotypes (Wolfe, 2007).

One of the main implications of this reframing of 'stability' to be, in the first instance, about services being 'fit for duty' rather than commencing with a focus on whether consumers are 'fit to be consumer representatives', is that it offers services an opportunity to reflect and consider what they need to create an environment of engagement. This capacity assessment needs to occur before services consider undertaking consumer participation projects and should include:

- Training and capacity building for management and staff;
- Adequate resourcing for consumer participation activities;
- Commitment at all levels of the service to involving and valuing consumers; and
- Engagement with local drug user organisations.

Finally, the fact that this issue has been canvassed should not be read as a criticism of those services who applied to undertake the demonstration projects or as an attempt to characterise the projects as failures. In many ways, these services have displayed significant courage in taking on the challenge of consumer participation under the scrutiny of national evaluation. However, the above comments are aimed at encouraging critical reflection on a significant shift that occurred across a number of projects with the genuine hope that this experience can be used to improve consumer participation processes and outcomes in the future.

6.5 Power and Empowerment

Issues of power and empowerment ran throughout most issues and themes of consumer participation in the TSU Project: Phase Two. This issue was most evident in consumer interviews (at both baseline and evaluation) which showed a fundamental lack of understanding in regards to both the concept and practice of consumer participation. After an explanation of consumer participation was given by the interviewers, consumers expressed their support. However, in many cases, the consumers lacked confidence in their ability to participate in treatment decisions. While in some cases this lack of confidence related to the individual's life experiences and treatment journey, in other cases it was clear that a sense of confidence in relation to participation was linked to feelings of powerlessness.

Staff interviewed at both baseline and evaluation were significantly less likely to believe that there was an imbalance of power within their services, with many failing to recognise the potential power dynamics and the impact of this on consumer participation. Examples put forward for perceived equal power ranged from 'consumers being able to leave services whenever they chose', therefore being in 'voluntary stay' with regard to the residential rehabilitation service, to many pharmacotherapy service staff believing that the 'close relationships' formed with consumers enabled more of an equal relationship between the staff and consumers. When power differentials were acknowledged there was a divide as to whether or not these could be challenged. Some stated communication and honesty as the key to fostering equal relationships and overcoming these challenges, but others were less confident that power differences could be overcome — implying trust, power and empowerment were too entrenched in services to be changed overnight — or even at all.

As mentioned above, while many staff (and to a lesser extent consumers) did not acknowledge great differences in power standings between staff and consumers, there were many examples where this was evident. A fundamental reality of pharmacotherapy treatment that could not be ignored when considering the impact of power on consumer participation is the issue of physical dependence. Within pharmacotherapy settings, consumers are heavily reliant on the medications provided to them by

services. This factor alone does not lend itself to feelings of equality with staff by consumers, and there is the inherent threat that taking part in consumer participation could 'cost' someone access to their medication or other provisions that services provide such as take-away doses. Even within residential rehabilitation and detoxification facilities there are still similar constraints — speaking honestly about service deficits will not be looked upon favorably and could result in privileges (such as recreational time) being withdrawn and even removal from the service. While some services disagreed that this would happen, often consumers past experiences of stigma, discrimination and poor treatment meant that perceptions, not simply reality, could have a powerful effect on people's decisions to become involved in consumer participation, or not.

Many consumers seemed to be resigned to considering that changes to the way services ran would be out of their hands. Changes at the policy level were seen as too distant from the consumer experience or to input via a consumer participation process. In many interviews (at baseline and evaluation) the power imbalances were simply accepted by consumers as standard and even necessary, with many consumers believing and stating that staff knew what was better for them. In some instances staff were seen as 'peers' due to the knowledge of them being 'ex-users'. In addition to earlier discussions about 'who is a consumer' and when does someone become an 'ex-user', this issue raises another potential barrier to consumer participation. For example, if consumers consider staff (that they know to be 'ex-users') as their peers, then can these staff also reasonably represent them as consumers? Even if they are peers, first and foremost they are staff and this fact raises important questions about the potential crossing of professional boundaries and confusion of roles (i.e. can you be at once a consumer and a staff member, particularly in relation to consumer participation?). This question may be answered in the positive if you are working in a drug user organisation, but a drug treatment service is a very different context which it is argued fundamentally changes the power relationships and prevents such dual roles. This issue has also been explored in the section above on the role of staff who are ex-users and/or treatment consumers.

The staff interviews at evaluation also indicated that they witnessed the personal empowerment of those in the consumer representative role across the course of their projects. Paradoxically, the position of consumer representative can only be effective (powerful) if the individual is still recognised as a 'peer' by the client group. Being identified as 'one of them' (a staff member) effectively robs the position of credibility and, therefore, power among its constituents. A hypothetical variation on this theme was mooted by interviewees and might be termed the 'yes man': effectively an overly compliant peer chosen by staff to act as a token consumer representative. In both instances it seems that the 'voice' of the representative must remain identifiably 'ours' to consumers in order to remain authentic and empowered — as 'us' and not 'them'. Yet this in turn appears to draw upon and reinforce the very dichotomy (of staff versus client) that consumer participation purports to challenge.

The issue above brings into question the empowerment of consumers. As mentioned previously, many consumers were quite willing to let staff make decisions regarding services and treatment. This implies that services may not be doing enough to empower their consumers to make these decisions. Indeed, some staff in evaluation acknowledged power as a central issue in developing consumer participation and indicated that they found the consumer participation project challenging, as it required them to 'let go' of control. While power and empowerment issues in treatment services cannot be addressed easily, or quickly, it is suggested that it could be more effective if large-scale changes were made within organisation structures. Changes to current practices and policies — such as core requirements to train (utilising drug user organisations) staff and consumers, and engage service consumers in meaningful levels of consumer participation — would go a long way to actualising consumer participation as a

valid and highly worthwhile practice. Should this not be feasible then further research and project evaluations would be beneficial, at the very least to contribute to the limited research currently available on consumer participation and consumer representation in drug treatment settings.

6.6 AIVL Reflections on Demonstration Projects as Project Administrator

One of the significant distinctions between the TSU Project: Phase One and Phase Two is the fact that Phase Two focused on the implementation and evaluation of a series of demonstration projects whereas Phase One was a research project to map issues and attitudes in relation to consumer participation. The focus on implementing demonstration projects changed the nature of AIVL's role in the TSU Project: Phase Two from that of research investigator to project administrator. In contrast to the discussion points above, which specifically relate to the findings of the formal evaluation process, the comments below are a series of observations and reflections on project administration and working with the demonstration sites from AIVL's perspective. While these issues are not documented from an objective standpoint, they nevertheless contain important lessons for the future of consumer participation in drug treatment settings and therefore have been accorded an appropriate level of consideration in this report. In a number of places, the issues outlined below also have strong thematic connections with the findings from the baseline and evaluation interviews discussed above, and together this data forms an overall and realistic picture of the benefits and challenges of consumer participation in drug treatment settings. However, it should be noted that AIVL accepts the project sites may have a different and equally valid experience of the issues outlined below.

6.6.1 Involvement and Role of Drug User Organisations

One of the more disappointing outcomes from the demonstration projects was the overall lack of genuine involvement and collaboration between the project sites and the relevant local drug user organisation. This is not to state that there was no involvement or relationship between these key stakeholders, but it is worth noting that when reviewing the project as a whole, no project site really made the most of this valuable resource, and the engagement that did occur with drug user organisations was sporadic. The reasons for this lack of engagement seem to mirror many of the barriers and challenges to involvement experienced by individual treatment consumers including structural and communication barriers.

Concerns about how structural and communication problems can act as barriers to consumer participation both for individual consumers and drug user organisations was identified in the TSU Project: Phase One. The National Consultation with Consumer Organisations in the TSU Project: Phase One highlighted the need to develop 'pathways to support more positive and constructive communication' between consumer organisations and services. They stated that such pathways could act as a strategy to address entrenched attitudes, identify and remove structural barriers and increase meaningful participation (AIVL, 2008, pp.73-74).

Taking this into consideration, all project sites in the TSU Project: Phase Two were required in the EOI process to address how they would work with the relevant drug user organisation in their state or territory. All project sites were able, in a theoretical sense, to outline how they would encourage such involvement. Subsequently, the requirement to engage with the local drug user organisation was also written into the service agreements with each project. The question that arises then is why was the engagement with drug user organisations so limited across the projects? Of the five demonstration

projects only three sites (one in each of the three states engaged in the projects) had any contact with the local drug user organisation, and the engagement in one of those three sites amounted to only two meetings, initiated by AIVL, between the service and the local drug user organisation.

The reasons for the lack of user organisation involvement among the project sites that had little or no contact are likely to be explained with reference to existing roles and relationships between drug treatment service providers and service consumers. The TSU Project: Phase One highlighted the strong belief among many service providers that it was not 'the place' of consumers to have a role in decision-making with regard to service planning and delivery (AIVL, 2008, p.87). Similar sentiments were also expressed by service providers in the TSU Project: Phase Two. This attitude has also been highlighted in other studies relating to the culture of drug treatment services and how certain types of service culture can act to close off consumer roles and opportunities for service provider and consumer engagement (Treloar and Holt, 2006).

In this context, it is possible to envisage how such attitudes could be extended to relationships with drug user organisations and act as a very real barrier to engagement. If services do not support consumers taking a role in decision-making in relation to service planning and delivery, it follows that proactively seeking a relationship with the local drug user organisation may not be a priority for those service providers. It is possible this reluctance would be further underlined by the fact that the 'consumer relationship' in this case is even more likely than with individual consumers to result in consumer organisations asking for involvement in decision-making roles within the service. On the other hand, it is also possible that the problem of the consumer participation projects not being considered 'core business' by any of the services meant that there was not one staff member following up on contacts and liaison with the local drug user organisations and it therefore simply 'slipped through the cracks'. Either way, it highlights a problem with valuing the role and contribution consumers can bring to their services.

However, as outlined above, a number of project sites did include a reasonable degree of engagement with the local drug user organisation in their consumer participation projects. Of interest is the fact that both of these project sites had existing working relationships with the local drug user organisation. Indeed, one of the sites had already commenced discussions about another potential consumer participation project in partnership with the local drug user organisation prior to applying for the TSU demonstration project. From the evaluation data both the consumers and the staff in these services also seemed to have a greater level of awareness and understanding of consumer participation in the drug treatment context. This outcome is supported by available literature in the area of mental health and consumer participation which highlights the importance of 'practical experience' in changing attitudes towards the value or benefits of consumer participation, particularly in relation to consumers having a role in decision-making (Northern Area Mental Health Service, 2003).

While these sites were able to utilise existing relationships with their local drug user organisations as a platform for further engagement, it is noteworthy that even in these projects the involvement of the drug user organisations was not consistently sustained across the projects. The reasons behind this include the chronic turnover of staff in one service, which made ongoing involvement and stability of the relationship impossible, and a lack of resourcing in the drug user organisations which severely reduced their interest in and capacity to participate in a meaningful way in the project. While the negative impact of staff turnover is addressed elsewhere in this section, the lack of adequate resources to support the involvement of drug user organisations in the demonstration projects was a significant problem.

In addition to agreeing to involve drug user organisations in their demonstration projects, services also agreed to ensure that some of the available project funding would be used to resource drug user organisations for the roles they were asked to undertake within the projects. As outlined above, the majority of services did not engage the local drug user organisation in a meaningful way and therefore resourcing this role did not arise. However, a lack of resourcing did affect at least one of the projects and this example highlighted the importance of ensuring adequate resourcing for drug user organisations if they are expected to support the development of consumer participation in treatment services.

This is consistent with the findings in the TSU Project: Phase One which identified the lack of resourcing for consumer participation work as one of the 'main reasons why they struggle to effectively coordinate consumer participation efforts across the drug treatment sector' (AIVL, 2008, pp.89-90). Although the service involved did offer some resourcing for delivery of training for consumer representatives, the overall level of project funding meant that the service was not able to offer the level of resourcing needed to cover the 'real' cost to the drug user organisation of designing and delivering the training. At the heart of this problem is the fact that the vast majority of drug user organisations do not receive 'core capacity' funding for consumer participation work and this makes it very difficult for these organisations to prioritise participation in projects conducted by individual treatment services. In this regard, what can appear to be a lack of interest in participating from drug user organisations can in fact be a lack of ability to participate due to resourcing limitations.

In the end, regardless of the reasons, all five demonstration projects suffered from a lack of sustainable involvement from the local drug user organisation. The significant role that consumer organisations have played in increasing access to and uptake of health services and improving health outcomes for Australians is well documented (Consumer Focus Collaboration, 2001). A consistent theme across the TSU Projects: Phases One and Two is an ongoing reluctance to involve drug user organisations in consumer participation activities within the drug treatment sector.

This is further compounded by side discussions about which consumers drug user organisations can or do represent, and how to address the needs of those consumers who are not thought to be represented by such organisations. However, it is up to drug user organisations to decide who they purport to represent. Whether this is accepted by others or not is a separate matter, but it does not change the way that drug user organisations view themselves or those they seek to represent. Too often it seems that discussions about the diversity of treatment consumers are used to avoid taking action on the central issue — that with proper resourcing, existing drug user organisations would have the capacity (and view themselves) as the appropriate entities to represent treatment consumers with illicit drug dependencies. The apparent absence of a group to represent alcohol treatment consumers does not diminish this fact. It is time to move away from continual and unproductive discussions about the 'absences' and 'gaps' in drug user organisations to an acknowledgement of their role and value. In short, it is time to acknowledge and make use of what is there rather than focusing on what isn't.

While there were some exceptions, the majority of treatment services involved in the TSU Project: Phase Two chose to conduct their consumer participation projects without the meaningful involvement of local drug user organisations. This was the case despite:

- All projects experiencing problems with accessing and engaging their service consumers;
- At least two services experiencing problems recruiting suitable consumers to take up paid consumer representative positions; and
- A number of services complaining about a lack of resources and skills among existing staff to support consumer representation and the project generally.

The above issues are significant as they are all issues that could be successfully addressed by establishing and adequately resourcing an effective working relationship with the local drug user organisation.

This outcome reflects an increasingly urgent need to build greater awareness, understanding and, most importantly, acceptance among services and funding bodies of the role that drug user organisations can and must play in building consumer participation in drug treatment settings. Ultimately however, this will require a change in the culture of treatment services to allow consumers and, by extension, their representative organisations to take an active role. Other areas of health service delivery have managed to bridge this gap with very positive results for both service providers and service consumers (NAMHS, 2003). In this regard, it is positive that at least three services mentioned in evaluation that the experience of other sectors in consumer participation, particularly mental health, could provide useful lessons for the drug treatment area. That said, addressing the issues and concerns outlined above will require transformation at the level of both policy and practice.

Finally, it should be noted that transforming the relationship between drug treatment services and drug user organisations will require good faith, trust and commitment from all parties. The TSU Project: Phase Two evaluation data reveals that meaningful collaborations between treatment services and drug user organisations not only results in a greater awareness of the potential benefits of consumer participation for all involved, including consumers, but also has a positive effect on how consumers view the work and role of drug user organisations. Some consumers expressed the view that involvement in the consumer participation project at their service not only raised their awareness of their local drug user organisation, but also provided a 'way into' the drug user organisation as they could now see the tangible benefits of being involved.

While the demonstration projects funded for the TSU Project: Phase Two did not necessarily achieve the level of project outcomes specified in the original project plans and logframes, overall the project has begun the process of identifying both the barriers and incentives to consumer participation projects in this setting. With both treatment services and drug user organisations having a good deal to gain from collaboration in this area, the future of consumer participation in drug treatment services will rely on the development of effective working relationships between these two key stakeholders. Despite some existing relationships, by and large this work still needs to be undertaken.

6.6.2 EOI Process, Project Plans and Implementation

The TSU Project: Phase Two was unique in that it focused on the implementation and subsequent evaluation of five consumer participation demonstration projects in a range of drug treatment settings. The process for selecting the demonstration sites involved an advertising and EOI process followed by an assessment and selection process. This backdrop to the projects is important largely because it goes to the heart of some of the issues experienced by AIVL as the project administrators.

The evaluation data reflects an inconsistency across all projects in relation to the agreed project plans and logframes compared to the actual outcomes and achievements of the projects. While AIVL received a good level of interest from drug treatment services when the advertising and EOI process was conducted (and found services to be co-operative and enthusiastic when negotiating and finalising the project plans), it subsequently experienced a range of complications with the projects from a project administration viewpoint.

High staff turnover in key project positions caused long delays to one project and, from a project administration perspective, this appeared to be further complicated by the lack of an adequate handover

to new staff. This not only caused further project delays but also resulted in confusion and misinformation among consumer participants in relation to project activities and arrangements. The impact of this situation can be seen in the evaluation data which reflects a 'change of heart' from consumers between baseline and evaluation data collection as their initial enthusiasm and commitment to the project wanes due to a drop in project momentum and confusion and delays in agreed consumer payments.

While the service acted to address the staff vacancies as quickly as possible, these types of problems are part of the reality of conducting consumer participation projects within large treatment services. Consumer participation activities are unlikely to be well-resourced or even resourced at all within most treatment services. Inevitably, staff will move on to new opportunities creating vacancies not only in their primary position but in the 'associated' roles they carry, such as consumer participation projects. In the end, the root of the problem may be associated, once again, with the overall lack of adequate resourcing and philosophical support for consumer participation activities within treatment services rather than what appears to be the problem on the 'surface' — that is staff vacancies.

The funding for the demonstration projects as a whole was insufficient and meant that projects were only provided with a 'contribution' towards project costs from AIVL. As the project administrators, AIVL was restricted in the funding that could be provided to services by the amount of overall funding received for the TSU Project: Phase Two. AIVL was clear at the EOI stage that the funding available for demonstration projects was a 'contribution towards project costs'. However, in offering this contribution there was an expectation that services would already have or would be in the process of establishing their own investment in consumer participation as an essential rather than 'optional' aspect of a quality treatment framework. Indeed, all of the services selected for the TSU Project: Phase Two identified in their EOI that they had already made some level of commitment to consumer participation within their service model.

A significant part of the rationale for this approach was that the TSU Project: Phase One found that engagement in lower level consumer participation activities (according to the definition and model adopted for the project) was relatively commonplace among drug treatment services (AIVL, 2008, p.84). Therefore, it was agreed that the TSU Project: Phase Two would focus on services that were ready to move beyond lower level participation activities. On this basis, the TSU Project: Phase Two assumed a level of existing investment in consumer participation and presented services with an opportunity to 'start-up' higher level activities or 'value-add' to their existing consumer participation activities. It would not, however, provide the basis for large-scale projects that were commencing from 'day one'. The concept of providing extra funding to support services to 'start-up' consumer participation activities was also strongly identified in the TSU Project: Phase One Report (AIVL, 2008, p.89).

It is interesting to note that comments from services in the evaluation data continued to identify the need for 'start-up' resources to build support and commitment for consumer participation before being able to embed it as a standard practice within the organisation. Given that all of the services were provided with funding as part of their participation in the TSU Project: Phase Two to value-add to existing and 'start-up' higher level activities, it must be asked whether resourcing problems are the only barrier to embedding consumer participation in drug treatment settings. Perhaps it is possible that although a lack of resourcing is a significant part of the problem, it is not the total picture. For example, are there problems at the policy or structural level that are preventing meaningful consumer participation being put into practice in the drug treatment context despite a level of resourcing being made available?

In evaluation some services identified the importance of flexibility in project administration as a very important factor in allowing under-resourced treatment services to adapt projects as needed and in response to client needs. While AIVL agrees with this principle and did attempt to provide a flexible environment for project implementation, concerns emerged across most projects in relation to the seeming lack of involvement of consumers in project planning and a lack of response to progress reporting requirements. Despite requests for update reports to allow AIVL as project administrator to provide targeted support and trouble-shooting for projects, only one of the five projects provided any of these reports.

AIVL had attempted to keep the progress reporting for the projects to a minimum — requiring only a brief update on progress after the first month and one at another point across the six-month projects. In addition, as AIVL was aware of the negative impact onerous reporting requirements could have on the small-scale projects, the request to provide progress reports was not included in the logframes as a formal project outcome but rather as a more informal agreement with each of the project sites. The AIVL Project Officer contacted the sites as appropriate, based on their commencement date and relative progress, to seek brief, written progress reports. While sites were willing to provide a verbal update of progress, only one site complied with the request for the written updates.

Given the numerous comments in evaluation relating to services being under-resourced and understaffed, it is possible that projects found it difficult to justify and/or prioritise progress reporting for a relatively small amount of funding. The negative impact that unnecessary reporting can have on project outcomes and the need to ensure reporting does not place a disproportionate burden on small projects and organisations has been well documented in numerous studies within the health sector (New South Wales Council of Social Services, 2009). In this regard, it is a legitimate concern for services implementing small-scale consumer participation projects. Nonetheless, if this was a problem it needed to be raised with AIVL and addressed through a renegotiation of appropriate milestones rather than by neglecting or refusing to report.

The lack of regular progress reporting meant that in a project where there were five different sites across three states, AIVL was effectively locked out of the support role it could have provided to services in the implementation of their projects. AIVL's budget, too, was extremely limited and without funds to regularly visit the projects, and in the absence of written progress reports, a 'disconnect' developed between the projects and AIVL as the administrators. While AIVL accepts responsibility for its part in creating this breakdown in ongoing communications, it also needs to be acknowledged that the project sites did not make active attempts to contact AIVL and address this situation.

Verbal reports were useful when provided but this relied on the ability of the AIVL Project Officer to reach relevant contact people at each of the sites within a reasonable timeframe. As the AIVL Project Officer was a part-time position and services are busy and under-resourced, this was often difficult. Verbal reports also increased the chance of important issues being lost in translation or overlooked as they were communicated from the project site to the AIVL Project Officer, and then onto other AIVL staff and staff from the NCHSR. When this issue is coupled with the general lack of engagement with local drug user organisations identified above, the result was an unfortunate dismissal of a good deal of expertise and support in relation to consumer participation that could have been provided by AIVL and its members.

In addition to the concerns about reporting, the evaluation data raises questions in the majority of cases about the level of consumer involvement in the development of the project plans at any stage

of the process. Statements by services admitting a lack of genuine involvement of consumers when planning their projects and referring to consumers as typically being engaged at the 'rubber stamping stage', raise concerns about the quality of some of the projects conducted. It is accepted that consumer participation in drug treatment settings can mean it takes time for understanding, relationships and trust to be established. In this context it can be difficult to find consumers who are interested and willing to act as consumer representatives. However, what is less clear is why the opportunity to revise project plans with genuine consumer input was not taken up after the project commenced and once a number of key consumers were involved?

Evaluation data from both consumers and staff reflected an absence of consumer involvement in key project activities, particularly those in the mid- to high-level range involving decision-making roles such as having input into the job descriptions for consumer representative positions. This resulted in many consumers having very limited knowledge of the project, and many framing the project outcomes more in terms of individualised self-help and support rather than as active involvement in service planning and decision-making. In some services, this view was reinforced by the belief of some staff that there are certain roles that are 'staff only' and 'inappropriate' for consumer involvement. The view that there are certain roles that are 'inappropriate' for consumer involvement was also a theme expressed by some services in the findings from the TSU Project: Phase One (AIVL, 2008, pp 57-60).

While it is acknowledged that in all health-care settings there are roles and responsibilities that are appropriately restricted to trained professionals, the roles being referred to in relation to these projects do not fall into this category. They are roles and responsibilities that many other areas of health service delivery have designated as not only appropriate to be undertaken by consumer representatives but frequently result in better outcomes for both consumers and services when undertaken by or with consumers (Norman, J et al., 2008). These roles include input into project plans, consumer representative position descriptions, service planning committees, staff training sessions, service policies and staff recruitment, etc.

In addition to the lack of consumer involvement, in many cases the projects had also been developed without the input of the majority of staff. Evidence of this lack of staff involvement was highlighted in the evaluation process and is discussed further in Section 6.6.3 below. In some cases, services did not have effective strategies for encouraging and supporting communication among staff. This suggests that many of the services were not well-placed to embark on medium-level consumer participation despite indications to the contrary in the initial project proposals. Developing clear and effective ways to communicate with staff and consumers within services is likely to be central to successful consumer participation and, therefore, 'pre-consumer participation activities' aimed at developing engagement and communication strategies among consumers and staff should be first priorities.

It should also be noted that all services involved in the TSU Project: Phase Two had at least one key staff member who was committed to and interested in consumer participation within the service. By and large it was these staff members who drove the EOI process and took responsibility for developing the project plans, negotiating the logframes and liaising with AIVL and other staff within their service. Despite the best intentions of a few enthusiastic staff in the services involved, much of the activity being labelled as 'consumer participation' over the course of the evaluation was shown to be largely staff-driven project activity designed primarily to meet accreditation standards, internal evaluation needs and externally imposed performance measures. Some projects had more genuine consumer involvement than others but no project had a strong sense of consumer ownership or being truly 'consumer-driven'.

The lack of consumer ownership over the activities and outcomes of the majority of the TSU Project: Phase Two demonstration projects is highlighted by the lack of awareness and understanding among consumers identified in Section 6.2 above. A few understood the purpose of the evaluation process but most did not and thought that the evaluation was an evaluation of the service, not of the consumer participation projects. Outside of a very small number of consumers who were employed in paid consumer representative roles, the majority of consumers interviewed had little or no knowledge of the consumer participation projects overall, let alone any involvement in developing the project activities and outcomes.

This situation highlights the level of training and capacity building that is needed among staff and consumers but, importantly, also among senior management and funding bodies in relation to consumer participation. Such training could support an understanding of consumer participation as a fundamental activity in its own right — with its own benefits and value — not just as a way to meet service accreditation and/or funding outcomes and deliverables. The need to reposition or shift the mind-set about consumer participation as being an 'optional extra' or done as a 'favour' to consumers was another underlining theme identified by AIVL and backed up by the evaluation data. In some of the services there appeared to be a lack of fundamental support and engagement in the project from senior management resulting in a general deprioritising of the project. This was reflected in comments from staff about a lack of support for consumer participation as 'core business' within the service, staff writing project plans in isolation, and little or no evidence of action taken by management in relation to 'white-anting' or outright refusals to participate in the projects by other staff.

Consumers interviewed in evaluation also identified this important issue. Consumer representatives involved in one project with high levels of staff turnover recalled the project as feeling 'rudderless' at times due to the overall lack of organisational investment in the project. These comments indicate a belief that the negative impact of staff turnover during a consumer participation project could be minimised, providing there is a strong commitment from senior management to ensure consumers feel supported and valued while new staff are recruited. Consumers also highlighted the potential for even enthusiastic consumers to gradually lose interest if there appeared to be little progress within the project. This is a major concern given that both consumers and staff identified the difficulties associated with getting consumers interested and involved in ongoing consumer participation roles as opposed to participating in one-off surveys or informal discussions.

These experiences are contrasted with the comments from consumers involved in one of the projects with a good level of senior management and organisational support. In this project, consumers identified the importance of staff support and feeling trust and commitment at a service or organisational level. As identified in 6.6.1 above, drug user organisations could play an important role in building an understanding of the potential benefits and value to the service of consumer participation. Interestingly, the above project where consumers identified a high level of staff and management support was one of the demonstration projects that involved the local drug user organisation in the development of the consumer training for the project.

From the vantage point as Project Administrators, AIVL strongly identified the need for organisational change and capacity building in relation to consumer participation for most services. Very few staff at baseline identified the need for management or staff training in this area, however there was some shift in this view at evaluation. This shift supports the view articulated in the TSU Project: Phase One

and consumer participation projects in other areas of health service delivery that an understanding and valuing of consumer participation often only comes after services have had some practical experience of engaging with consumers (AIVL, 2008, p.25 and NRCCPH, 2004).

In some cases, the existence of consumer charters of rights and responsibilities and/or quality frameworks requiring consumer participation were seen as sufficient evidence of organisational commitment to consumer involvement. Others, however, recognised the need for cultural change within their services before such policy frameworks would result in the meaningful involvement of consumers. The TSU Project: Phase One also showed that the mere existence of policies identifying the need for consumer participation did not necessarily result in a valuing of consumer participation by the service in a practical sense (AIVL, 2008. pp.85-86).

6.6.3 Evaluation Process

As the Project Administrators, one of AIVL's roles was to organise the logistics for the evaluation process. This involved contacting the demonstration sites to arrange two rounds of data collection — at baseline and then at evaluation towards the completion of the project timeframe. The data collection methodology is outlined in full in Chapter 4 of this report. A number of issues were highlighted during the process of coordinating the data collection which, although largely administrative in nature, have implications for the larger themes explored in other parts of this section.

Despite the fact that each of the project sites had designated and agreed project contact staff, at the time of organising the baseline and evaluation data collections AIVL experienced difficulties in making contact with these staff in a number of the sites. As identified above, the TSU Project: Phase Two had limited resources and for this reason AIVL aimed to provide a degree of flexibility for the project sites in relation to the timing of their data collection. However, there were important ethical obligations guiding both AIVL and the NCHSR to ensure that all data collection was conducted in accordance with strict ethical guidelines for evaluations of this type.

While two project sites met all evaluation requirements and responded in a timely fashion to all AIVL requests to schedule data collection points, unfortunately AIVL experienced moderate to significant delays in the three other project sites. It should be noted that one project site in Victoria experienced unforeseen delays to their project associated with the Victorian bushfires, which also affected scheduling for the second data collection point. However, this project site still worked effectively with AIVL to schedule all data collection points in a timely manner. Despite this, delays in contacting and therefore scheduling the evaluation points at the three other services ultimately caused irreparable damage to the overall timeframe for the TSU Project: Phase Two and resulted in AIVL having to seek a variation to contract to extend the project and deliverables. Some of the delays and problems included the inability to make contact with project staff via email or telephone for more than four weeks; scheduling data collection points to have them cancelled on the day AIVL and NCHSR staff were due to travel; and ongoing delays to scheduling of data collection points due to constant turnover of project staff.

In addition to the above problems, a number of concerns also surfaced once AIVL and NCHSR staff arrived at the project sites for the scheduled data collection. At all but one project site, staff at reception or other first points of contact did not seem to be aware of the project or know who the relevant contact person was for the project. Further, the majority of staff at two project sites also seemed to have little or no awareness of the scheduled evaluation. These occurrences raise a number of questions about

the consistency and quality of the projects in these sites, including why were so few staff aware of the projects, and what were the implications for the ongoing progress of the project if the single responsible staff member needed to take leave or resign from their position?

These questions were somewhat answered by the fact that the project experienced a high level of staff turnover, with at least three different project staff. In evaluation, consumers involved in this project expressed highly divergent views about their involvement in — and the quality of the project between — baseline and evaluation data collection. At baseline consumers were enthusiastic, committed and expressed a sense of empowerment about the possibilities of the project. In evaluation, the consumers were difficult to locate for interview and those who did come forward expressed disappointment with how the project had been managed, the lack of continuity and the fact that commitments made to consumers about payment and work had not been honoured.

At baseline and evaluation, five consumers were interviewed from each of the demonstration project sites. The project sites were asked to provide five consumers, preferably all directly involved in the project, for interview by the evaluators. Of concern was the fact that all project sites seemed to have difficulty in finding five consumers for the evaluation interviews who had been directly involved in the consumer participation projects. Although most of the project sites were able to provide one consumer, often a paid consumer representative, to interview specifically about the demonstration project, no site was able to provide five or even a majority of consumers who had been involved in the project. Of the consumers who were interviewed, a majority at all project sites seemed to have little or no knowledge of the project.

While these issues have also been explored above, they require some further comment as they do have implications for the quality of evaluation. The evaluations took longer than expected due to having to return to one site for follow-up interviews and having to take extra time to explain the focus of the evaluation to consumers. This would no doubt have been different if consumers who were directly involved in the projects could have been interviewed. Although the reasons for not being able to provide relevant consumers for the evaluation interviews varied from site to site, the major reasons included that the project had not yet properly commenced or interviews with appropriate consumers could not be arranged as services had found it very difficult to access and involve consumers in the projects. While not seeking to make 'excuses', one of the project sites also highlighted the difficulties associated with recruiting consumers to be involved in ongoing consumer participation projects as opposed to one-off surveys and focus groups.

From AIVL's perspective as Project Administrator these concerns also linked to the issue outlined above in relation to consumer involvement and ownership of the demonstration projects. While AIVL fully acknowledges the barriers to conducting consumer participation projects in drug treatment settings, the difficulties in accessing informed consumers for the evaluation interviews at the very least raise questions about the priority given to these projects by the services involved and the quality of the engagement that occurred.

Finally, it should be noted that both AIVL and the NCHSR also experienced staff turnovers during the TSU Project: Phase Two. While staff changes during time- and resource-limited projects always create logistical and strategic challenges, in both cases replacement staff were located, briefed and in place with little or no impact on the overall timeframe and with no significant break in contact with demonstration project sites. The major negative impact of the AIVL staff changes on the overall project

was that email updates to the PAC and monitoring calls to the project sites were less frequent than planned. While this was not ideal, it did not affect the implementation of the demonstration projects and both face-to-face PAC meetings were held at the planned project points — at project commencement and at draft final report stage.

6.6.4 Expectations of the Project

Following on from the issues raised above about the degree of ownership over the projects by services and consumers, this final section explores a range of issues in relation to project expectations. One of the key issues for AIVL as the Project Administrators was the degree to which the demonstration sites took responsibility for their projects and their outcomes at evaluation. As noted above, demonstration sites were selected based on an EOI and independent selection process. The interest in conducting the consumer participation projects was more than twice the amount that could be funded within the project budget. The result was that AIVL had to unfortunately reject numerous EOIs from enthusiastic and highly regarded drug treatment services as only five projects could be selected.

This background context is very relevant as a number of concerns have emerged across the project, in many but not all project sites, about the need to improve:

- The level of senior management commitment to consumer participation;
- The overall culture and environment in drug treatment services to better support consumer participation; and
- The degree of involvement and therefore ownership of consumers in consumer participation projects in drug treatment settings.

Despite applying to conduct the project and putting considerable effort into developing project plans and negotiating the project logframes, AIVL did not experience the same level of commitment from a majority of the projects in the project implementation phase. At certain points in the project implementation, AIVL was forced to reiterate to two of the sites that the demonstration projects were not 'AIVL' projects but their projects. It seemed at these two sites, at least, there was an expectation that after being selected to conduct their project, AIVL would work with them directly on the implementation phase. Not only was this inappropriate as AIVL is a national organisation, but also because AIVL would be playing a strong role in the evaluation of the projects through the consumer interviews. It was this separation of roles that was behind the rationale to require all project sites to work in collaboration with their local drug user organisations. Such arrangements would have established sustainable, locally relevant relationships between consumers, consumer organisations and drug treatment services.

AIVL also had to manage and modify its expectations of the project outcomes during the course of the demonstration projects. As already outlined above, all of the sites selected were required to demonstrate their existing commitments to low-level consumer participation activities and their interest in utilising the TSU Project: Phase Two to build on and expand these activities. The services not only offered different types of treatment services but they also had different levels of experience and development in relation to consumer participation and involvement. From the project plans submitted and the baseline interviews it was clear that some services had a higher level of senior management support for their project, existing relationships with local drug user organisations, and more established communication channels with their consumers.

In this context it was surprising that none of the projects seemed able in evaluation to fully demonstrate that they had achieved all or even most of their original project outcomes. Why was it that even those services that seemed to have some of the key indicators for successful consumer participation in place at project commencement were still unable to translate this advantage into clear and tangible project outcomes? Certainly, staff in some services claimed to have achieved significant results from their projects with staff from one service remarking on the fact that one client was so committed to the consumer participation project that they extended their stay in the service to continue their involvement. Regardless of this situation, this was not one of their project outcomes and for this service, and all the other project sites, consumers across the board did not verify the degree of activity and outcomes that key staff outlined in evaluation interviews.

AIVL acknowledges that there may be differences in the way that staff and consumers both perceive and articulate project outcomes. It is also acknowledged that not all consumers interviewed at the evaluation stage contradicted the statements and views of service staff. However, the difficulty is that the differences greatly out-number the similarities and they are significant and point to fundamental problems with communication between consumers and services. These communication barriers seem to be heavily associated with the existing roles and relationships between service providers and consumers. It seems that even where there is willingness to explore these roles, the TSU Project: Phase Two demonstration projects were not able to break through these barriers despite the best of intentions. This is supported by many comments made by both parties in evaluation, with staff acknowledging entrenched attitudes and power differences, and consumers expressing hope for a breakdown of these barriers and differences. Once again, these same issues and hopes were also articulated in the findings of the TSU Project: Phase One (AIVL, 2008, pp. 87-89)

Where does this leave the ideal of consumer participation in drug treatment settings? Is it impossible to genuinely involve consumers of drug treatment services — regardless of the service type — in the decisions about their service and their treatment? Are the treatment service models incapable of coping with the openness required for such engagement to work? Although it could be argued that some, even many, of the conclusions drawn about the demonstration projects in the TSU Project: Phase Two could indicate that consumer participation in illicit drug treatment services is not possible, this conclusion seems wholly unsatisfactory.

While all the services were committed to their demonstration projects, in practice many struggled to implement their projects and have not achieved the outcomes that they or AIVL had hoped would be achieved. However, it is important to acknowledge that these services have, for the first time, opened themselves to what it might take to make consumer participation in this context a reality. It is promising that the project sites identified in evaluation that they had underestimated the demands on the organisation, particularly at the 'higher levels' and that they needed to do further work on developing strategies for engaging consumers outside of the therapeutic or clinical environment. It is also important that a number of the services stated they were surprised and encouraged by the positive feedback and enthusiasm of consumers and that this gave them encouragement to keep moving forward.

This was the first national project to conduct a series of demonstration projects to support consumer participation in drug treatment settings. Many problems and barriers have been uncovered. We cannot pretend these barriers and problems are not present simply because we wish it so or because it might upset some services, staff or consumers. However, it is possible to take these challenges and commit to

the process of dismantling and addressing them one by one if necessary. Some of them are significant challenges for the drug treatment sector. Changing the culture of drug treatment services to open up communication and trust between staff and consumers will not be easy, but any steps in that direction will open the possibility of consumers having a stronger voice in the future. Some services are already making steps in this direction, but the need to continue the steps towards consumer participation in drug treatment services is probably articulated best by a consumer from one of the demonstration projects, who said:

'I think what I'm hoping it will achieve is a common ground for staff and consumers to work out things, like you know, how do you put it into words? It's like an even plane so everyone's on the same, like no-one's better than anyone, no-one's — even though this person works here and you're a consumer, you both got the same rights and you're both equal. You don't have to sit there, you know put your head down and think "oh they're the staff, I can't say anything what if they take my kids? What if they do this? What if they do that?" You know...'

❖ Chapter 7: Recommendations

The key findings from the five consumer participation demonstration projects have been used to identify five priority areas to act as an overarching framework for the recommendations and actions that follow. Although the key findings have been drawn from the specific issues and outcomes identified by the staff and consumers of the services involved in the demonstration projects, the key recommendations and actions take a broader 'services and systems' approach. In this regard, we have not sought to make recommendations that would be of relevance and benefit to the services involved in the demonstration projects alone. Instead, we have focused on the overarching themes and lessons learnt from the projects and have attempted to interpret these in a way that supports the further development and sustainability of consumer participation in all drug treatment settings. It should also be noted that while the recommendations have been clustered as appropriate under one of the five priority areas, there is significant interconnectedness across the areas and recommendations — these linkages have been identified as appropriate. While some of the recommendations and associated actions specify the need for resourcing, it should be taken as read that all of the recommended actions will require appropriate resourcing if they are to be implemented.

Priority Area 1: Increasing awareness and understanding of consumer participation

- **Training for staff of drug treatment services:**

Recommendation:

The development of a new consumer participation module within the Certificate IV in Alcohol and Other Drugs (AOD).

Action:

AIVL to approach the National Centre in Education and Training on Addiction (NCETA) and the Drug Strategy Branch, Department of Health and Ageing (DoHA) to identify opportunities and pathways for the resourcing, development and implementation of the above module.

- **Training for consumers of drug treatment services:**

Recommendation:

The development of a national consumer participation in drug treatment training program and plan to support the delivery of consumer training at the local level.

Actions:

AIVL to approach the Drug Strategy Branch, DoHA to identify opportunities and pathways for the resourcing development and delivery of the above training program.

Should suitable resources be identified, the program would need to be developed and delivered in partnership with AIVL member organisations, other relevant advocacy groups and local consumer health forums.

- **Ongoing awareness raising in relation to consumer participation:**

Recommendation:

The development of a national communications strategy to address the lack of general awareness and understanding of both the concept and practice of consumer participation within the AOD sector and among drug treatment consumers.

Actions:

AIVL to seek placement of articles and editorial comment on the issue of consumer participation in key national AOD sector publications including, but not limited to, Of Substance, ANEX Bulletin, DANA Newsletter, etc.

AIVL and its member organisations to include articles and discussions on consumer participation and rights in drug user magazines, and provide articles for publications that target treatment consumers produced by other relevant organisations and services.

AIVL to seek a symposium or workshop at the Australasian Professional Society for Alcohol and Other Drugs (APSAD) Conference, which will focus on the definition of consumer participation in drug treatment settings, the value and benefits of consumer participation in this context, and practical strategies for developing and implementing consumer participation.

Priority Area 2: Making consumer participation ‘core business’ for drug treatment services

- **Developing the policy framework to support consumer participation:**

Recommendation:

The development of a national advocacy strategy to promote the need for a policy framework at the national and state/territory levels to provide leadership and underpin support for consumer participation in drug treatment settings.

Actions:

AIVL to develop a brief consumer participation advocacy paper to be disseminated to, and as appropriate used to inform meetings with, the drug policy units of federal and state/territory governments and other government and non-government drug policy and consumer health bodies including the Inter-Governmental Committee on Drugs (IGCD), Australian National Council on Drugs (ANCD), Drug Policy Modelling Program (DPMP), national and state/territory consumer health forums, etc.

AIVL and its member organisations to advocate for the inclusion of principles and outcome indicators to support consumer participation in drug treatment settings in national and state/territory drug strategies and other relevant policy documents.

- **Funding and resourcing consumer participation in drug treatment settings:**

Recommendation:

Federal and state/territory governments to take a leadership role in supporting drug treatment services to incorporate consumer participation into service planning and delivery.

Actions:

Governments should incorporate minimum consumer participation requirements (based on the AIVL Model of Consumer Participation) into performance and funding agreements for drug treatment services.

*(** It should be noted that responsibility for the above action will be with the federal or state/territory health departments, or a combination of the two, depending on the outcomes of national health system reforms currently underway. Based on the outcome of these reforms, this recommendation should be undertaken by the government entity(ies) with primary responsibility for funding government and non-government drug treatment services in the future.)*

Drug treatment services should be appropriately resourced to support and conduct consumer participation in drug treatment settings.

Should the above minimum requirements for consumer participation be incorporated into funding and performance agreements, AIVL and its member organisations should be resourced to provide expertise, partnership and support for drug treatment services in meeting such requirements.

AIVL will seek endorsement and support from the Chapter of Addictions Medicine, the Australasian Therapeutic Communities Association (ATCA), APSAD and other relevant bodies in relation to the above role and in being a recognised source of expertise and support on consumer participation in drug treatment settings.

AIVL will seek to work in partnership with other national and local consumer advocacy organisations as appropriate.

Priority Area 3: Developing a stronger theoretical basis for consumer participation in drug treatment settings

• **Revising the AIVL definition and model of consumer participation in drug treatment settings:**

Recommendation:

To conduct a deeper analysis of the AIVL Definition and Model of Consumer Participation, including an exploration of definitions of 'who is a consumer', the concept of 'stability', 'who should represent consumers' and the significance of 'service type' for consumer participation.

Actions:

The NCHSR and AIVL to produce at least two peer-reviewed papers drawing on the findings and analysis of the TSU Project: Phase Two demonstration projects to further explore the definitions and issues identified above.

AIVL and the NCHSR to incorporate the ideas and thinking in the above peer-reviewed articles into the AIVL Definition and Model of Consumer Participation.

In addition to the above, AIVL and the NCHSR will incorporate a new section into the AIVL Definition and Model of Consumer Participation.

on 'who should represent treatment consumers' including:

- i. the concept of self-determination in relation to representation for different 'types' of treatment consumers;

- ii. appropriate consultative mechanisms to support the role of consumer representatives; and
- iii. the role of 'past treatment consumers' in the context of consumer participation in inpatient detoxification treatment settings and explore the potential value of other models of consumer participation in acute clinical care settings for application in the detoxification context.

Priority Area 4: Acknowledging and understanding power and empowerment in the drug treatment context

- **Managing dynamics and relationships between staff and consumers:**

Recommendation:

To provide opportunities for staff and consumers to discuss how power and empowerment operates within the drug treatment context and develop positive strategies for acknowledging and managing these dynamics.

Actions:

AIVL to ensure issues of power and empowerment are addressed within the training for staff and consumers outlined in Priority Area 1.

Senior management of drug treatment services to encourage regular reviews of service systems and practices to remove barriers to consumer participation.

- **Managing dynamics and relationships between consumer representatives and other treatment consumers:**

Recommendation:

To empower consumers to take a leadership role in consumer participation activities in order to support the development of consultative consumer participation structures and processes.

Actions:

Drug treatment services should work with consumers to define the role of consumer representative positions and to develop consumer participation structures that support ongoing consultation between consumer representatives and other service consumers.

Consumer participation training for drug treatment consumers should be open to all treatment consumers, not simply consumer representatives.

Priority Area 5: Engaging drug user organisations in consumer participation

Recommendation:

To support the greater involvement of drug user organisations in consumer participation in drug treatment settings.

Actions:

Training for services on working with drug user organisations should be included in funding and performance agreements for drug treatment services (also see Priority Area 2 for further actions on funding and performance agreements).

Drug user organisations should be appropriately supported and resourced to participate in consumer participation initiatives in drug treatment settings.

Appendix 1

TSU: Phase Two Promotional Flyer



IMPROVING CONSUMER PARTICIPATION IN DRUG TREATMENT AGENCIES

The 'Treatment Service Users Project' is an exciting and pioneering project funded by the Australian Commonwealth Department of Health & Ageing, Drug Strategy Branch.

It will be implemented by AIVL (The Australian Injecting & Illicit Drug Users League), a peak national consumer

representative organisation, in collaboration with NCHSR (The National Centre in HIV Social Research).

The project has already completed its first phase. Phase 1 found that consumer participation has a highly beneficial role to play in the planning & delivery of high quality drug treatment services

Phase 1 also found that while there were currently only relatively low levels of consumer participation across drug treatment services in Australia there was, widespread support for moving to higher levels of consumer participation.

What does the project plan to achieve in this phase?

Phase 2 of the project will involve the development and evaluation of 5 consumer participation projects in 5 different drug treatment services. The projects will be located in 3 Australian States, within various drug treatment settings; including pharmacotherapy, detoxification and rehabilitation programs. A model of consumer participation derived from available literature and findings from Phase 1 will be used to evaluate the demonstration projects. Phase 1 of the project found that there is a significant amount of low level participation occurring in Australia, for example feedback sessions and suggestion boxes. While these consumer participation activities are valuable, Phase 2 will focus on the development and evaluation of projects where consumers are more actively involved in decision making processes, for example staff recruitment, policy working groups and membership of management committees. Phase 1 also identified obstacles in implementing consumer participation such as lack of funds and appropriate expertise. Phase 2 of the project will respond to these obstacles via specific actions, including providing resources to the selected drug treatment agencies so that they have the capacity to develop consumer participation activities, tailored to suit the individual needs of each service.

The demonstration projects will provide insights and data that will be used to develop a national model of consumer participation for drug treatment services. Towards the end of the project all the project partners and key stakeholders will be brought together at a national workshop where the findings from the demonstration projects will be disseminated and discussed and used to develop a nationally agreed definition of consumer participation. The findings of phase 2 will also lead to the development of policy that supports consumer participation and increases the capacity amongst drug treatment service providers and consumers to undertake consumer participation effectively.

Who will be involved?

This project is a great opportunity for the AOD sector to work together. AIVL and the NCHSR have forged an exciting partnership bringing together a balance of consumer experience and research expertise.

The project will also look to bring together a range of key stakeholders including:

- AOD peak bodies
- State/Territory and Commonwealth AOD government departments
- Consumer Representative Organisations
- Drug treatment service providers
- Drug treatment service users (consumers)

An advisory committee has been formed to provide overall advice on the development and implementation of the project and comprises of representatives from key stakeholders and project partner agencies.

How will this project be implemented?

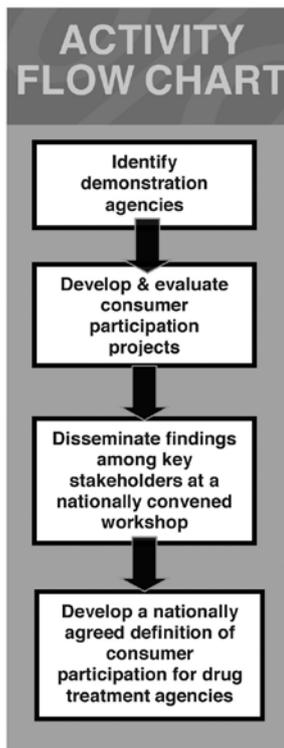
The project will be implemented through the following process:

- Through a call for expressions of interest, from drug treatment agencies across 3 Australian states, NSW, Victoria and Western Australia.
- These agencies will have the opportunity to apply for funds to assist them develop a demonstration

consumer participation project.

- AIVL will provide assistance to the agencies to develop their applications.
- A total of 5 agencies will be selected as project partners across the 3 states.
- The demonstration projects will then be evaluated by the NCHSR & AIVL

A national workshop will then be convened involving all key stakeholders to discuss the findings from the demonstration projects and develop a nationally agreed definition on consumer participation in drug treatment services.



Project Outputs

At the end of Phase 2 the project will look to achieve specific outputs such as:

- The development, implementation and evaluation of a suitable model of consumer participation in a range of drug treatment settings.
- Policy development.
- A national workshop bringing together all key stakeholders.
- A nationally agreed statement or definition of consumer participation in drug treatment services.

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

Better Health Outcomes for Australians
1994 Commonwealth Dept. of Human Services & Health.

What impact will this project have?

Considering the fact that only low levels of consumer participation exist among drug treatment agencies, the project at selected sites will seek to:

- Increase skills and capacity amongst service providers and consumers in relation to consumer participation.
- Increase consumer participation among drug treatment agencies.
- Develop policy at the local level which supports the sector and stakeholders in undertaking consumer participation.
- Improve consumer satisfaction and quality of service delivery.
- Strengthen partnerships among key stakeholders to progress consumer participation in the drug treatment sector.

How can you be kept informed about this project?

The TSU project is committed to keeping all stakeholders informed about the project's progress. Regular project updates will be accessible through:

- AOD sector publications such as 'Of Substance' from ANCD and "ADCA News" and AIVL e-list.
- State/territory Drug User Organisation newsletters and state/territory AOD Peak body newsletters.

Or you can contact the TSU Project Worker

John Francis, Tel: (03) 93291500, Email: johnf@aivl.org.au

AIVL: Level 1/112-116 Sydney Building, Alinga St, Canberra, ACT 2600, T: 02 6279 1600, www.aivl.org.au
NCHSR: Level 2, Webster Building, UNSW, Sydney, NSW 2052, T: 02 9385 6776, www.nchsr.arts.unsw.edu.au

Appendix 2

List of TSU Advisory Committee Members

Ms Annie Madden	Executive Officer, Australian Injecting and Illicit Drug Users League (AIVL) – Chairperson
Professor Carla Treloar	Deputy Director, National Centre in HIV Social Research (NCHSR)
Mr Jake Rance	Research Associate, National Centre in HIV Social Research (NCHSR)
Dr Jeanne Ellard	Research Associate, National Centre in HIV Social Research (NCHSR)
Ms Tamara Speed	Treatments and Policy Manager, Australian Injecting and Illicit Drug Users League (AIVL)
Mr John Francis	TSU Project Worker, Australian Injecting and Illicit Drug Users League (AIVL) <i>August 2007 – May 2009</i>
Ms Laura Liebelt	TSU Project Officer, Australian Injecting and Illicit Drug Users League (AIVL) <i>June – November 2009</i>
Ms Karen Price	Director, Research, International and Policy Section, Drug Strategy Branch, Australian Government Department of Health and Ageing (DoHA) <i>July – December 2007</i>
Mr Patrick Smith	Assistant Director, Research, International and Policy Section, Drug Strategy Branch, Australian Government Department of Health and Ageing (DoHA) <i>July 2007 – April 2009</i>
Ms Collette Coleman	Diversion and Treatment Section, Drug Strategy Branch, Australian Government Department of Health and Ageing (DoHA) <i>January 2008 – April 2009</i>
Ms Robyn Davies	Assistant Director, Treatment and Indigenous Programs Section, Drug Strategy Branch, Australian Government Department of Health and Ageing (DoHA) <i>May – October 2009</i>
Ms Tracey Andrews	Acting Director, Treatment and Indigenous Programs Section, Drug Strategy Branch, Australian Government Department of Health and Ageing (DoHA) <i>November 2009 – March 2010</i>
Ms Sue Brownbill	Consumer Representative
Ms Sarah Lord	Consumer Representative
Prof Jason White	Director, Drug and Alcohol Services of South Australia (DASSA)
Mr David Clements	Executive Officer, Alcohol, Tobacco and Others Drugs Council of Tasmania <i>January 2008 – November 2009</i>
Ms Helene Delaney	Director, Alcohol and Other Drug Policy Unit, ACT Health
Mr Chris Shipway	Director, Drug and Alcohol Services, NSW Health and Inter-Governmental Committee on Drugs (IGCD) representative
Mr Garth Popple	Member, Australian National Council on Drugs (ANCD)

❖ Appendix 3

Demonstration Projects: Expressions of Interest



Att: <enter service>

Dear Sir/Madam,

AIVL's Treatment Service Users (TSU) Project is a pioneering project which is being implemented in collaboration with The National Centre in HIV Social Research and it focuses on consumer participation in drug treatment agencies. The project is funded by the Commonwealth Dept. of Health and Ageing.

The Treatment Service Users (TSU) project has now entered its second phase. During this phase, 5 demonstration consumer participation projects across 3 Australian states/territories, NSW, VIC and WA will be implemented. A small grant ranging \$5,000 - \$9,000 will be available to agencies interested in implementing these projects. Since AIVL works closely with state/territory Drug User organisations, interested agencies will be required to work in collaboration with them in developing the projects and implementing them. The demonstration projects will then be evaluated and the findings disseminated within the sector. After this, we will bring together all key stakeholders in a nationally convened workshop and develop a nationally agreed framework for consumer participation in drug treatment agencies.

In this regard we are offering your organization an opportunity to apply for a grant between \$5,000 and \$9,000 to develop and implement a demonstration consumer participation project. Added to this your organization will also get a fully funded evaluation of the project which will be conducted by AIVL and the National Centre in HIV Social Research.

In order to help you apply for this grant we have enclosed the following documents;

1. An application form to address criteria for expressions of interest.
2. A guide to help you develop a consumer participation project.
3. A document broadly defining consumer participation.
4. A flyer on your local drug user organization.

The last date for receiving completed applications will be 4th April 2008, and applications must be mailed to;

AIVL – TSU Project Phase 2
PO Box 12720 A' Beckett Street
VIC 8006

Or emailed to: johnf@aivl.org.au

You may also contact John Francis the TSU Project Officer at email: johnf@aivl.org.au or tel: 03-93291500 for any assistance in completing and submitting your applications. We look forward to your response and thank you for your interest in the TSU Project.

Yours Sincerely,

Tamara Speed

AIVL Program Manager, AIVL Treatment Service Users Project

ABN: 20 467 449 392
GPO Box 1552
Canberra ACT 2601

Level 2, Sydney Building
112-116 Alinga Street
Canberra ACT 2601

Telephone: (02) 6279 1600
Fax: (02) 6279 1610
www.aivl.org.au



THE TREATMENT SERVICE USERS PROJECT- PHASE 2

Criteria for Expressions of Interest

1. Criteria for agencies to apply

(Organizations interested in applying for a grant should meet the following criteria and provide the information that has been requested in this document).

1. The organisation should be registered as a;
 - **Government**
 - **Non-Government**

2. The organisation should provide one or more of the following drug treatment services;
 - **Detoxification**
 - **Residential rehabilitation**
 - **Pharmacotherapy**

3. The location of the treatment service of the organization should be;
 - **Metropolitan**
 - **Regional**

4. The organisation should have partnerships/alliances with the state drug user organizations and the state AOD peak body.

Briefly describe your partnerships/alliances with; (Please mention specific activities you have been engaged in and projects you have collaborated in)

Your state drug user organizations;

Appendix 3 — Demonstration Projects: Expressions of Interest cont...

Your state AOD peak body.

5. Briefly describe any consumer participation activities your organisation is currently implementing or has implemented in the past;

6. Describe any organizational policies supporting consumer participation that may exist in your organisation;

Appendix 3 — Demonstration Projects: Expressions of Interest cont...

8. **The education/training component of your project – How will you provide training for your staff and consumers to prepare them for undertaking a consumer participation activity? (You need to collaborate with your local state/territory drug user organisation in developing this component)**

9. **A plan for remunerating your consumers for participating.**

10. **Ensuring there is no adverse effect as a result of participation for staff/consumers.**

11. **How will the project be developed in consultation with your consumers?**

12. **A feedback procedure for your consumers/staff.**

Please send this completed form back to;
AIVL – TSU Project
PO Box 12720
A' Beckett Street
VIC 8006

Or

Email;
johnf@aivl.org.au

Appendix 3 — Demonstration Projects: Expressions of Interest cont...

Model of Consumer Participation in Drug Treatment Services

The purpose of this document is to provide a framework for conceptualising and implementing consumer participation in drug treatment services. While there is a role for consumer participation at a number of levels (individual, local, State, and National), the focus here is in developing and implementing consumer participation at the organisational level of drug treatment services and not in relation to individual treatment plans. The examples of consumer participation provided in this document are not exhaustive and nor are they intended to be prescriptive, but rather to provide a guide for developing and implementing consumer participation in drug treatment services.

Treatment service users are not a single identifiable group or community and therefore individual consumers and consumer groups will want different degrees and forms of consumer involvement (Greater London Authority, 2005). Likewise different drug treatment services will have different needs and capacities and this will influence the types and levels of consumer participation that are appropriate for an individual service to conduct.

This model was developed with reference to available literature on consumer participation, findings from Treatment Service Users Project, Phase 1 and through consultation with the members of Treatment Service Users Project, Phase 2 Project Advisory Committee.

Definition of Consumer Participation

'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).

Consumer participation models typically incorporate varying degrees of involvement in service planning and delivery, ranging from the sharing of information and opinions about services to engaging in shared problem solving and joint decision-making (National Resource Centre for Consumer Participation, 2002).

Definition of Consumer in the Drug Treatment Context

In the context of drug treatment services, consumers can be defined as treatment service users, including current and past users of services and people who are contemplating treatment (New South Wales Health, 2005:3).

Steps to Developing and Implementing Consumer Participation Activities in Drug treatment Services

Drug treatment services need to establish where the organisation is before developing a new consumer participation initiative as it may be difficult to develop and implement consumer participation at the level of shared decision making if the organisation does not already have a range of low

Appendix 3 — Demonstration Projects: Expressions of Interest cont...

level consumer participation activities in place such as mechanisms for feedback, information sharing and recognition and commitment to consumer participation in vision statement (Greater London Authority, 2005). Consumers and service providers will need to identify what if any forms of consumer participation already exist within the service. Identifying existing levels of consumer participation will assist the service in determining what level of consumer participation is most appropriate in the current environment. For example if a drug treatment service wanted to involve consumers at the higher shared decision-making level the service needs to be able to answer yes to these two questions.

1. Does the organisation currently have mechanisms for keeping service users routinely informed about service developments?
2. Does the organisation have mechanisms for getting feedback from service users?

Answering no to these questions does not mean the service is not ready for consumer participation per se. However it does mean the service will need to implement some strategies for sharing information and getting consumer feedback as a first step in the process of implementing and developing meaningful consumer participation. In addition to ensuring there are mechanisms for information and opinion sharing treatment service users and providers should explore the following questions:

- In what ways would consumers like to participate in the service?
- What kind of skills will be required?
- What are different levels and possibilities for participation within the service?
- How will the contributions of consumers in terms of time and expertise be supported?
- How will staff be encouraged and supported to engage with new practices of consumer participation?

Services will need to identify the skills already available and the skills that it will be necessary to build.

Training and skills development will be important for consumers, staff and management. For example a consumer may need training around meeting procedures and business planning in order to participate in an effective way on a management committee. Staff and management may need training in approaches to communication and information sharing in order to build their capacity to work in a collaborative way with consumers (Greater London Authority, 2005).

Core Guiding Principles for consumer participation in drug treatment services:

Appendix 3 — Demonstration Projects: Expressions of Interest cont...

- Service providers need to acknowledge the benefits of consumer participation and the right of consumers to have input into how services and programs are run.
- 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.
- The form and purposes of consumer participation need to be able to evolve over time
- There needs to be appropriate training available for staff and consumers
- Together consumers and providers need to create a non-threatening environment for both staff and consumers
- Processes need to be established whereby both positive and negative feedback can be conveyed to staff
- A budget needs to be established to fund consumer participation activities, including financial remuneration for consumer representatives. Remuneration has both a material and symbolic value.
- Mechanisms need to be developed to ensure that consumer participation does not have adverse effects for the consumers involved
- Commitment and capacity for trust and mutual understanding needs to be established and maintained
- Acknowledgment that consumer participation might involve organisational change, including managers and staff being willing to relinquish decision-making power in order to achieve shared of decision-making.
- Consumer participation activities should be evaluated, reviewed and where necessary adapted to ensure consumer participation activities remain responsive to the needs of consumers.

The typology of consumer participation below was used in the *Treatment Service Users Project Phase 1*. The diagram recognises varying degrees of consumer involvement, from 'low degree' information provision and consultation to 'high degree' involvement such as shared decision-making between consumers and providers (following Arnstein's (1969) ladder of citizen participation). The model provides examples of consumer activities associated with each degree of consumer participation, ranging from 'low' level information provision and consultation, to 'mid' degree involvement of consumers in non decision-making activities, to 'high' degree shared decision-making (Australian Injecting and Illicit Drug Users League (AIVL), 2007)

Appendix 3 — Demonstration Projects: Expressions of Interest cont...

Degree of consumer involvement	Type of participation	Example of Activity
HIGH	Activities in which consumers share in decision-making	<p>Consumer representatives involved in service planning committees – the service has had a consumer representative as a member of any committee that plans or makes decisions about services or programs.</p> <p>Consumer representatives attend staff meetings – the service has had a consumer representative regularly attend staff meetings.</p> <p>Consumer representative involved in staff recruitment – the service has had a consumer representative involved in the recruitment process for new staff at the service e.g. a consumer representative contributed interview questions or was a member of an interview panel.</p> <p>Consumer representative involved in staff performance appraisal – the service has had a consumer representative involved in assessing staff job performance e.g. consumer representatives meet with the nursing unit manager to give feedback on staff performance.</p>
MID	Activities in which consumers have non-decision-making roles	<p>Consumer involvement in resource development – consumers involved in writing or reviewing written materials such as brochures, fact sheets, newsletters, magazines or educational resources.</p> <p>Consumers involved in staff training – consumers involved in determining the content of in-service training that is directly relevant to consumers and their treatment.</p>

Appendix 3 — Demonstration Projects: Expressions of Interest cont...

<p>LOW</p>	<p>Activities that promote and support consumer involvement</p>	<p>Consumers are supported to conduct their own group activities – a service has ways to help consumers facilitate and run their own support groups (e.g. fitness groups, mums' and dads' groups) such as providing space, training or transport</p> <p>Service displays user group publications - Consumer forum – the service displays or makes available in other ways the publications of drug user organisations (e.g. NUAA, VIVAIDS, WASUA).</p>
<p>LOW</p>	<p>Activities concerned with providing information to or receiving information from consumers</p>	<p>Consumer councils – committees or groups of consumers whose role it is to advise the service about how services and programs are run.</p> <p>Forums – open meetings held in which consumers could express their views about how services or programs are run.</p> <p>Surveys – surveys that specifically asked consumers for their opinions about how programs and services could be improved.</p> <p>Suggestion box – the service provides a box where consumers can leave written comments regarding their views about how service or programs are run and suggestions for changes and improvements.</p> <p>Complaints process –the service has put in place a process for consumers to register their complaints about the delivery of the service</p> <p>Produce resources for consumers that include information about service planning – 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.</p>

Appendix 3 — Demonstration Projects: Expressions of Interest cont...

	<p><i>Consumer participation built in to values and policies of service</i></p>	<p>Consumer participation incorporated into vision or mission statement; Consumer charter of rights – a document is produced outlining client/patient rights, responsibilities and expected levels of service.</p>
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These levels represent a range of opportunities for consumer participation. In practice participation does not occur in all of these areas, in all services, or for all consumers all of the time. Opportunities to develop and implement consumer participation are greatly affected by context, environment and the attitudes of those who provide the services and the desires and needs of individual consumers. (Australian Injecting and Illicit Drug Users League (AIVL). 2007:23-24). Furthermore while shared decision-making is a marker of high level consumer participation it should be noted that information-sharing and the inclusion of consumer participation in the values and policies of services, for example a consumer charter of rights are not insignificant. In many cases these lower level activities will provide the basis for the development and implementation of other higher-level forms of consumer participation.

References:

Australian Injecting and Illicit Drug Users League (AIVL). 2007. *Treatment Service Users Project: Final Report*, Canberra Australia.

Commonwealth Department of Health and Aged Care. 1998. *Consumer Focus Collaboration*, Commonwealth of Australia, Canberra.

Greater London Authority. 2005. *Lessons Learned: Some approaches, tools and good practice for improving drug user involvement*, Greater London Authority, London.

New South Wales Health. 2005. *Consumer Participation in NSW Drug and Alcohol Services-Guide*. Department of Health, NSW, Sydney.

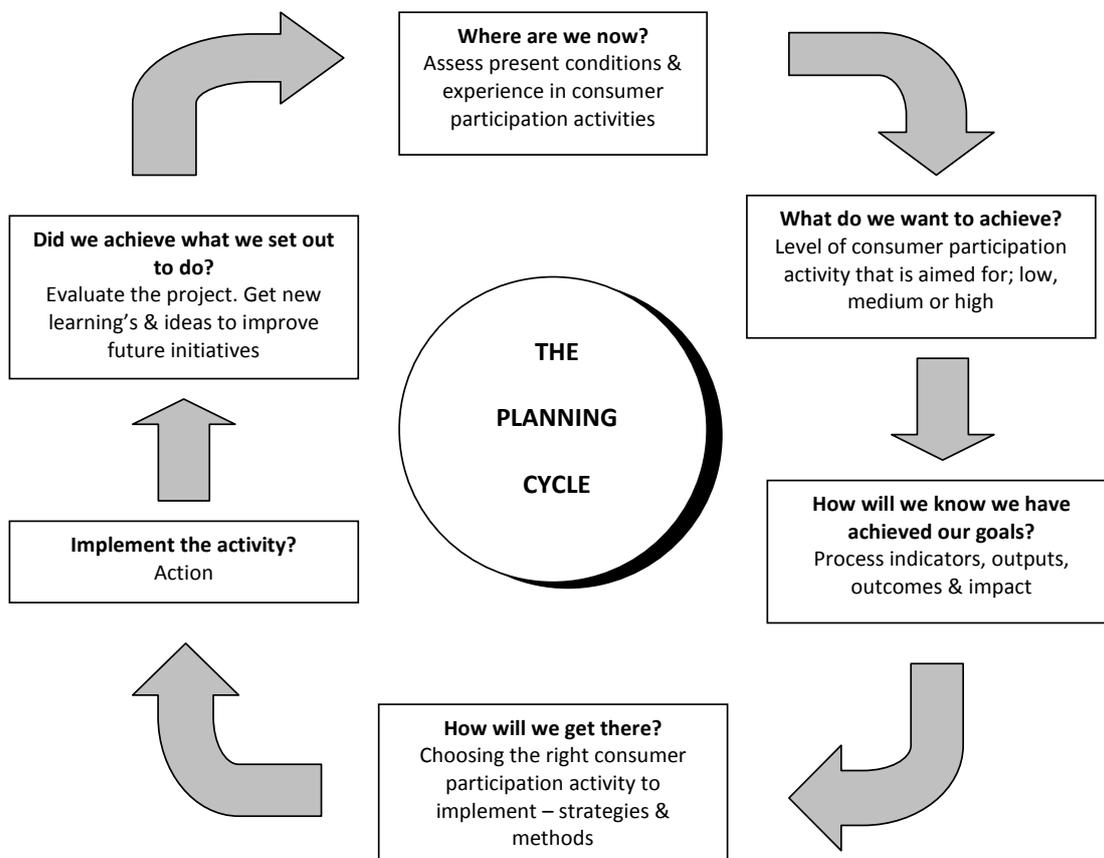
A GUIDE TO DEVELOPING & IMPLEMENTING A CONSUMER PARTICIPATION PROJECT FOR PHASE 2 OF THE TREATMENT SERVICE USERS PROJECT

STAGE 1 : Planning for implementing a consumer participation activity

Introduction

Planning for consumer participation is no different from planning for other activities. Planning should always aim to be a collaborative exercise between consumers and service providers and it is important that the planning process be informed by consumer experience.

Important: those involved in the planning exercise should seek advice from your state/territory drug user organization.



Appendix 3 — Demonstration Projects: Expressions of Interest cont...

STAGE 2 : Developing a consumer participation project

Agencies should look to address the following components while developing their consumer participation projects.

- Your objectives.
- The participants you wish to involve.
- The consumer participation activity you have chosen for implementation.
- Timelines
- Budget and personnel required.
- How the project will be documented so you can promote your efforts and share lessons learned.
- The key partners that you need to involve in the project other than your service consumers.

(Having the above information available will assist you in better addressing the expressions of interest criteria).

STAGE 2 : Choosing a suitable consumer participation activity

Phase 2 of the Treatment Service User's Project requires agencies to implement mid to high levels of consumer participation activities. The activities on the following pages have been provided as examples to help you develop your own consumer participation project. Please note these are only examples to assist you with ideas – there are many other types of consumer participation projects you may wish to consider for your project.

CONSUMER PARTICIPATION ACTIVITIES

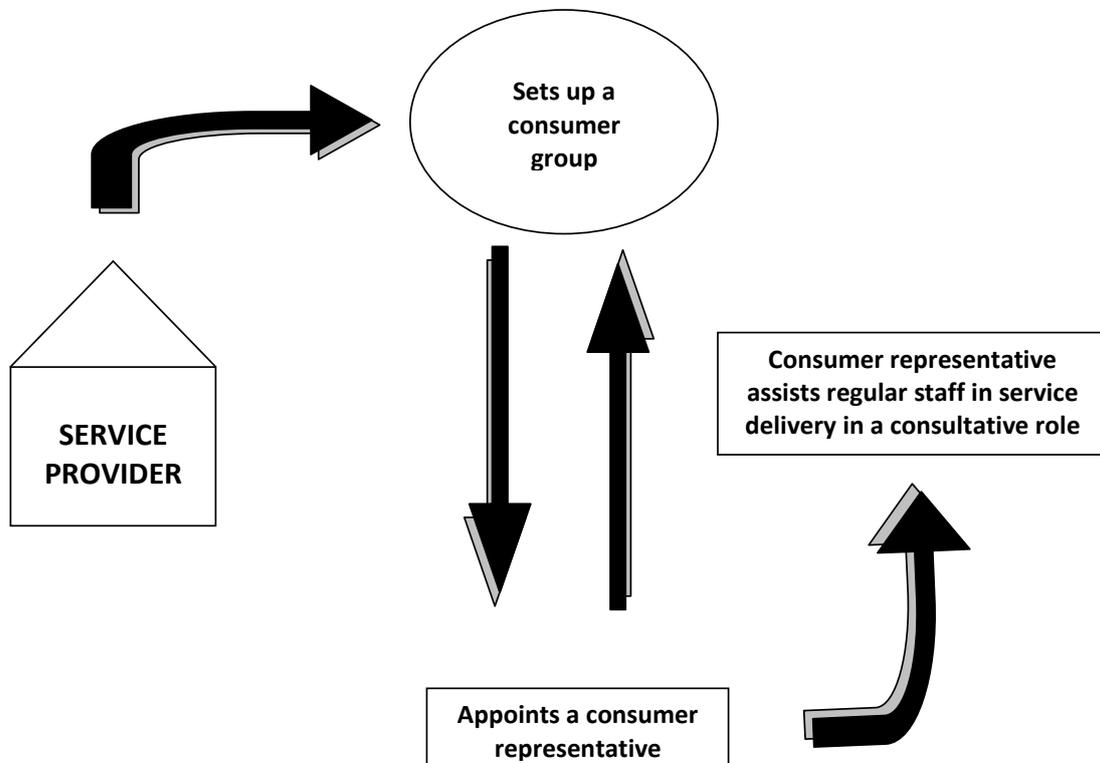
1. Participation in direct service delivery

In this activity a consumer group would elect a representative who would assist regular staff in the direct delivery of services. This representative would help staff better understand the needs of consumers and act as a liaison between the staff and the consumers. The consumer representative would be present during actual service delivery and would act more in a consultative role than that of an actual worker.

Some examples of specific activities the consumer representative could be involved in are:

- As a pharmacotherapy support worker for a pharmacotherapy service – Supporting pharmacotherapy prescribing services in better meeting client needs.
- A support worker in a detoxification service – Supporting clients undergoing withdrawals in a detoxification service.
- In residential rehabilitation service – Assisting in the structuring and developing of daily client activities.

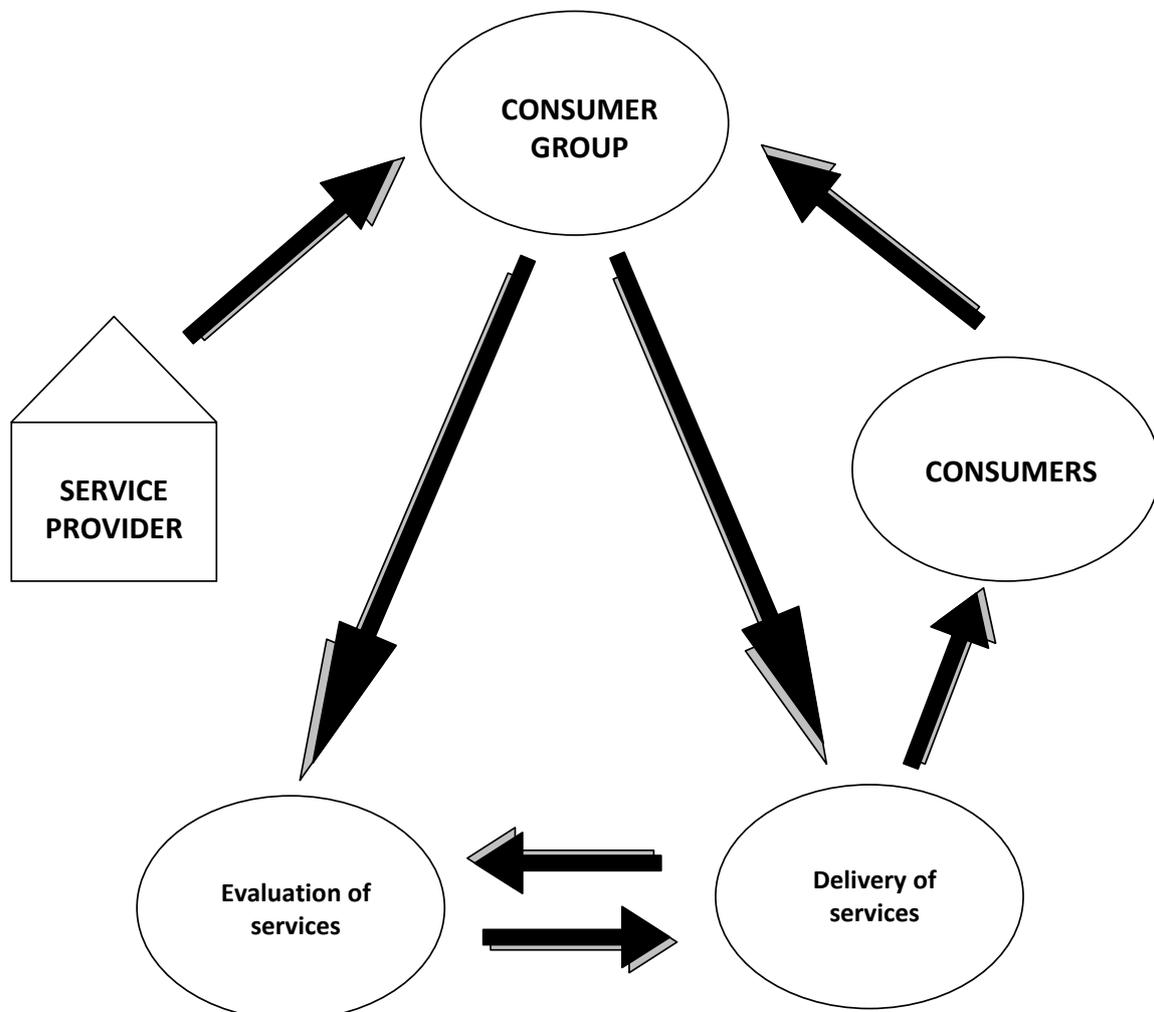
The consumer group should keep in regular periodic contact with their representative, providing direction and inputs.



Appendix 3 — Demonstration Projects: Expressions of Interest cont...

2. Participation in the planning of service delivery and evaluation

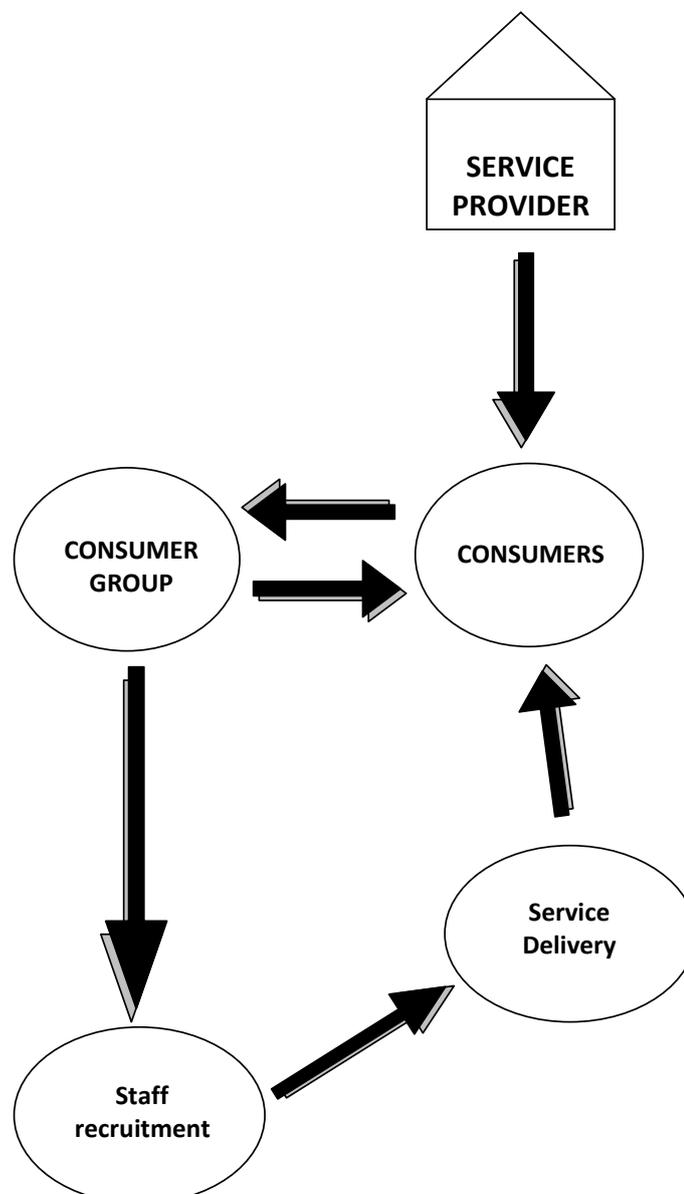
In this activity the service provider establishes a consultative consumer group, members of which are appointed by the consumers of the treatment service. This group then acts as an expert committee providing insight and direction to the service provider on the delivery and evaluation of the service.



Appendix 3 — Demonstration Projects: Expressions of Interest cont...

3. Participation in staff recruitment

In this activity consumers actively participate in the recruitment of staff. Consumers elect their representatives who as a consumer group, then become part of an interview panel for the recruitment of a position that is directly involved with service planning and/or delivery. They are involved in the development of the position description, recruitment tools and also the actual interview process.

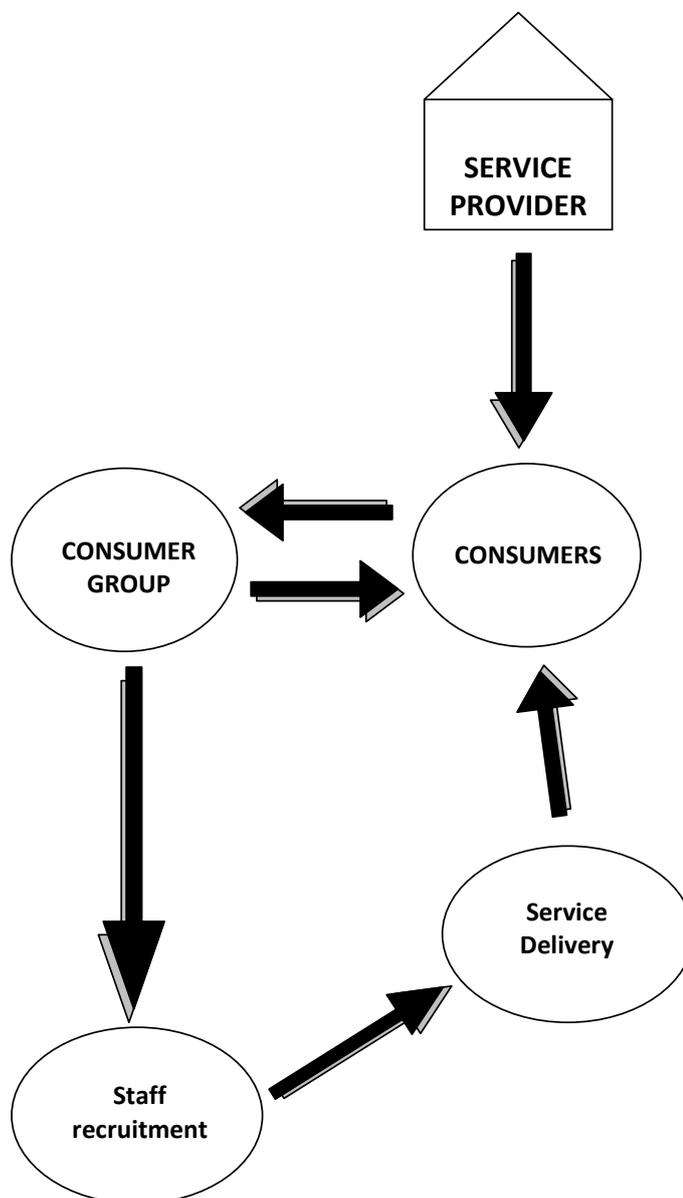


Appendix 3 — Demonstration Projects: Expressions of Interest cont...

4. Participation in staff training

In this activity consumers actively participate in the training of staff. Consumers elect their representatives who as a consumer group, then;

- Organize training for the consumer representative on consumer participation (which might be provided by the local user organisation).
- Work with local drug user organizations to develop a training session for staff of the service on issues and needs of service consumers and/or attitudes and values which could then be delivered as part of a larger training program and evaluated.



Appendix 4

Demonstration Projects: Logframe

PROJECT LOGFRAME - EXAMPLE

PROPOSED ACTIVITIES	PROCESS INDICATORS	OUTPUTS	OUTCOMES	PROJECT TIME FRAME
Engage a client who accesses the pharmacotherapy service, to work with other clients, an external consultant facilitator and key staff of the service to advise the service on ways to improve the pharmacotherapy program.	<p>Development of a plan that will document a 'typical' experience of the service with a view to developing an 'ideal' experience.</p> <p>Feedback gathered from clients before and after the service changes.</p> <p>Involvement of consumer representative/s in the work of the Programs Services and Quality Committee and the Community Liaison and Participation Committee including communications with the board of management.</p> <p>Development of a consumer representative system including a process to support feedback from and consultation with the pharmacotherapy service user population.</p> <p>Development and implementation of training and orientation process and manual for consumer representatives of the service.</p> <p>Re-development of an in-house charter of service user rights and responsibilities.</p> <p>Development of measures of service quality that can be integrated into service evaluation and reporting systems. <i>(Note: This is a longer-term goal and progress towards this will be measured across the timeframe for the TSU Project.)</i></p>	<p>A plan documenting the experience of service users.</p> <p>A report outlining feedback from clients before and after service changes.</p> <p>Documentation from meetings of the PS&Q Committee and CL&P Committee including meeting minutes.</p> <p>A policy outlining the service consumer representative system.</p> <p>A training and orientation manual for consumer representatives.</p> <p>A charter of service user rights and responsibilities.</p> <p>A report on progress made towards the development of quality service measures and program evaluation and reporting systems.</p>	<p>A greater engagement of consumers in relation to policy and service delivery issues which will inform service thinking and will ensure that the service becomes even more responsive to the needs of pharmacotherapy consumers.</p>	6 Months
Provide education/training for consumers and staff undertaking consumer participation activities.	<p>Development of a close working relationship between the peer workers at the local drug user organisation, consumer participants and service staff to ensure that consumer participants receive adequate training and ongoing support and mentoring. <i>(Note: The Manager and Team Leaders of the service would also be directly involved for Support and Supervision.)</i></p>	<p>A report documenting the working relationship between the local drug user organisation, consumer representative and service staff and the systems for providing ongoing support, supervision and mentoring for consumer representatives.</p>	<p>An increased capacity among consumers and staff to support effective consumer participation activities.</p>	
Provide remuneration for consumers participating in the project.	<p>Provision of a "sitting fee" to consumer representatives to cover time spent and any related expenses e.g.: travel. <i>(Note: this includes clients involved in focus groups)</i></p>	<p>A policy and process for payment of sitting fees and other relevant expenses to consumer representatives.</p>	<p>Consumers remunerated for participation and valued for their expertise.</p>	

❖ Appendix 5

Interview Guide

While the interviews were conducted in a conversational style, they included a number of central thematic questions relating to consumer participation and the demonstration projects:

Round One:

- knowledge and understanding of consumer participation (consumers and providers)
- extent of current consumer participation activities (consumers and providers)
- level of awareness of the demonstration project
- involvement in the development of the demonstration project
- level of interest in consumer participation
- perceived barriers to consumer participation
- ways in which consumers would like to be involved in the service (consumers)
- ways in which service providers would like consumer to be involved (providers)
- perceptions of what is needed in terms of funding, skills building to achieve increased consumer participation (consumers and providers)
- level of personal interest in consumer participation (consumers and providers)

Round Two:

- The extent of changes in consumer satisfaction with service quality and delivery (consumers)
- changes in attitudes of consumers towards providers and vice versa (consumers and providers)
- changes in communication between consumers and providers (consumers and providers)
- changes in communication among consumers (consumers)
- the extent of capacity building in relation to the consumer participation model for consumers and providers (knowledge, skills, confidence) (consumers and providers)
- direct and indirect outcomes of the project as perceived by consumers and providers (consumers and providers)
- estimating monetary and time costs of implementing the model (consumers and providers).
- strengths and weaknesses of model (consumers and providers)
- attitudes (consumer and providers)
- ongoing barriers (consumers and providers)

Appendix 6

Consent Forms for Provider Participants

Approval No (08073)

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For staff in drug treatment services (round two data collection)

Treatment Service Users Project Phase 2 (TSU2)

Participant Selection and purpose of the study

You are invited to participate in a research study into the suitability and impact of consumer participation in drug treatment services. The drug treatment service where you work has been selected through an expression of interest process to conduct a demonstration consumer participation project. The project is being conducted as a partnership between the National Centre in HIV Social Research and The Australian Injecting & Illicit Drug Users League (AIVL). We hope to learn from this study what model of consumer participation will be most suitable for the drug treatment sector, the strengths and weaknesses of the demonstration project, the impact of consumer participation demonstration project on service delivery, communication between providers and consumers and on health outcomes for consumers. Ultimately, we hope to use the findings of this study to develop a nationally agreed definition of consumer participation that can be used to guide consumer participation across the drug treatment sector. You were selected as a possible participant in this study because you are a staff member at one of the drug treatment services that is conducting a demonstration consumer participation project and you indicated that you might be interested in participating.

Procedures

If you decide to participate in this research, we will ask you to take part in either a discussion group with other staff and/or an interview, of one to one and half hours in length, at a time and place convenient to yourself. It will however be your choice as to whether you participate in an interview and/or a focus group. The study will have two data collection rounds, one at the beginning of the demonstration project and one at its completion. This information and consent form is for round two data collection. If you participated in round one you are also eligible to participate in this second round of data collection. However you do not need to have participated in round one in order to take part in round 2.

We would like to digitally audio-record your voice during the research so we do not miss any important points. If you feel uncomfortable about that, you can ask at any time for the tape recorder to be turned off.

During the focus groups and interviews we will discuss the impact of the demonstration projects on staff and consumers, service delivery, communication between consumers and providers, attitudes to consumer participation, the suitability of the chosen model of consumer participation, changes in health and treatment outcomes and changes in skills and capacity amongst consumers and service providers in relation to consumer participation. We will also ask you a few questions about your background so we can describe who participated in the research.

Appendix 6 —Consent Forms for Provider Participants cont...

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued) **For staff in drug treatment services (round two data collection)**

Treatment Service Users Project Phase 2 (TSU2)
THE UNIVERSITY OF NEW SOUTH WALES

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. If you give us your permission by signing this document, we plan to publish the most important results in academic journals, an evaluation report published by the Australian Injecting & Illicit Drug Users League, community-based magazines and online at

www.aivl.org.au and <http://nchsr.arts.unsw.edu.au>. A number of measures will be put in place to ensure participant confidentiality. Following the interview or discussion group all your contact details will be removed from our records. Following transcription of the interview your real name will be replaced with a pseudonym (or nickname). In addition, all other details you mention that might identify you or others will be changed (e.g. the name of your workplace, friends, colleagues, drug treatment services and venues attended). The digital audio recordings will be destroyed as soon as they are transcribed and the de-identified transcripts will be kept in a locked filing cabinet to which only the researchers will have access. In any publication, information will be provided in such a way that you cannot be identified.

Complaints

Complaints 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 investigated promptly and you will be informed of the outcome.

Feedback to participants

A plain language summary of results will be available on the AIVL www.aivl.org.au and NCHSR <http://nchsr.arts.unsw.edu.au> websites at the completion of the evaluation process and distributed to participating services. Upon completion of the project, data will be analysed and an evaluation report written. The findings will also be published in academic articles for peer-review. The results will also be presented at conferences. An overview of the demonstration projects will be written up and the findings of the evaluation will be discussed at a nationally convened workshop hosted by AIVL.

Your consent

Your decision whether or not to participate will not prejudice your future relations with The University of New South Wales or your health service provider. 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 now, please feel free to ask the researcher. If you have any additional questions later, please contact Dr. Jeanne Ellard on (02) 9385 6406, or email j.ellard@unsw.edu.au.

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

Appendix 6 —Consent Forms for Provider Participants cont...

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)
For consumers in drug treatment services (round two data collection)

Treatment Service Users Project Phase 2 (TSU2)

THE UNIVERSITY OF NEW SOUTH WALES

You are making a decision whether or not to participate. Your signature indicates that, having read the information provided above, you have decided to participate.

.....
Signature of Research Participant

.....
Signature of Witness

.....
(Please PRINT name)

.....
(Please PRINT NAME)

.....
Date

.....
Nature of Witness

Appendix 6 —Consent Forms for Provider Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

Treatment Service Users Project Phase 2 (TSU2)

REVOCAION OF CONSENT

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.

.....
Signature

.....
Date

.....
Please PRINT Name

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

Appendix 6 —Consent Forms for Provider Participants cont...

Approval No (08073)

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For staff in drug treatment services (round one data collection)

Treatment Service Users Project Phase 2 (TSU2)

Participant Selection and purpose of the study

You are invited to participate in a research study into the suitability and impact of consumer participation in drug treatment services. The drug treatment service where you work has been selected through an expression of interest process to conduct a demonstration consumer participation project. The project is being conducted as a partnership between the National Centre in HIV Social Research and The Australian Injecting & Illicit Drug Users League (AIVL). We hope to learn from this study what model of consumer participation will be most suitable for the drug treatment sector, the impact of consumer participation on service delivery, communication between providers and consumers and on health outcomes for consumers. Ultimately, we hope to use the findings of this study to develop a nationally agreed definition of consumer participation that can be used to guide consumer participation across the drug treatment sector. You were selected as a possible participant in this study because you are a staff member at one of the drug treatment services that is conducting a demonstration consumer participation project and you indicated that you might be interested in participating.

Procedures

If you decide to participate in this research, we will ask you to take part in either a discussion group with other staff and/or an interview, of one to one and half hours in length, at a time and place convenient to yourself. It will however be your choice as to whether you participate in an interview and/or a focus group. The study will have two data collection rounds, one at the beginning of the demonstration project and one at its completion. This information and consent form is for round one data collection. Agreement to participate in this first round of data collection will not mean who are required to take part in the second round of data collection. If however you are interested in being considered for the second round of data collection please provide your contact details on the form provided on page 5 of this document. The peer interviewer will re-contact you a few weeks prior to the round two data collection to check your availability and interest.

We would like to digitally audio-record your voice during the research so we do not miss any important points. If you feel uncomfortable about that, you can ask at any time for the tape recorder to be turned off.

During the focus groups and interviews we will discuss the role of consumers in service delivery, levels of communication between consumers and providers, awareness of existing consumer participation activities and attitudes to consumer participation. We will also ask you a few questions about your background so we can describe who participated in the research.

Appendix 6 —Consent Forms for Provider Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued) **(For staff in drug treatment services round one data collection)**

Treatment Service Users Project Phase 2 (TSU2)

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. If you give us your permission by signing this document, we plan to publish the most important results in academic journals, an evaluation report published by the Australian Injecting & Illicit Drug Users League, community-based magazines and online at www.aivl.org.au and <http://nchsr.arts.unsw.edu.au>. A number of measures will be put in place to ensure participant confidentiality. Following the interview or focus group all your contact details will be removed from our records, except if you agree to be re-contacted in relation to the second round of data collection. If you agree to be recontacted your details will be removed either when you decline to participate in the second round or after round two data collection. Following transcription of the interview your real name will be replaced with a pseudonym (or nickname). In addition, all other details you mention that might identify you or others will be changed (e.g. the name of your workplace, friends, colleagues, drug treatment services and venues attended). The digital audio recordings will be destroyed as soon as they are transcribed and the de-identified transcripts will be kept in a locked filing cabinet to which only the researchers will have access. In any publication, information will be provided in such a way that you cannot be identified.

Complaints

Complaints 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 investigated promptly and you will be informed of the outcome.

Feedback to participants

A plain language summary of results will be available on the AIVL www.aivl.org.au and NCHSR <http://nchsr.arts.unsw.edu.au> websites at the completion of the evaluation process and distributed to participating services. Upon completion of the project, data will be analysed and an evaluation report written. The findings will also be published in academic articles for peer-review. The results will also be presented at conferences. An overview of the demonstration projects will be written up and the findings of the evaluation will be discussed at a nationally convened workshop hosted by AIVL.

Your consent

Your decision whether or not to participate will not prejudice your future relations with The University of New South Wales or your health service provider. 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 now, please feel free to ask the researcher. If you have any additional questions later, please contact Dr. Jeanne Ellard on (02) 9385 6406, or email j.ellard@unsw.edu.au.

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

Appendix 6 —Consent Forms for Provider Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)
(For staff in drug treatment services round one data collection)

Treatment Service Users Project Phase 2 (TSU2)

You are making a decision whether or not to participate. Your signature indicates that, having read the information provided above, you have decided to participate.

.....
Signature of Research Participant

.....
Signature of Witness

.....
(Please PRINT name)

.....
(Please PRINT NAME)

.....
Date

.....
Nature of Witness

Appendix 6 —Consent Forms for Provider Participants cont...

Treatment Service Users Project Phase 2 (TSU2)

REVOCAION OF CONSENT

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.

.....
Signature

.....
Date

.....
Please PRINT Name

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

Appendix 6 —Consent Forms for Provider Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)
(For staff in drug treatment services round one data collection)

Treatment Service Users Project Phase 2 (TSU2)

If you would like to be contacted about participating in round 2 data collection please fill out this form.

Name (which can be just a first name)

Contact details:

Email:

Phone:

(H) _____

(W) _____

Please be assured that we will exercise discretion in making contact with you. We will not mention anything about the study or the name of the Centre to any person other than you who may answer the phone in either your home or workplace. If there is a specific time of day you would prefer us to call please let us know.

Thank you for your interest
Dr Jeanne Ellard
National Centre in HIV Social Research
j.ellard@unsw.edu.au
(02) 9385 6406

Appendix 7

Consent Forms for Consumer Participants

Approval No: UNSW (08073)

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM **For consumers in drug treatment services (round one data collection)**

Treatment Service Users Project Phase 2 (TSU2)

Participant Selection and purpose of the study

You are invited to participate in a research study into the suitability and impact of consumer participation in drug treatment services. The drug treatment service where you work has been selected through an expression of interest process to conduct a demonstration consumer participation project. The project is being conducted as a partnership between the National Centre in HIV Social Research and The Australian Injecting & Illicit Drug Users League (AIVL). We hope to learn from this study what model of consumer participation will be most suitable for the drug treatment sector, the impact of consumer participation on service delivery, communication between providers and consumers and on health outcomes for consumers. Ultimately, we hope to use the findings of this study to develop a nationally agreed definition of consumer participation that can be used to guide consumer participation across the drug treatment sector. You were selected as a possible participant in this study because you are a consumer at one of the drug treatment services that is conducting a demonstration consumer participation project and you indicated that you might be interested in participating.

Procedures

If you decide to participate in this research, we will ask you to take part in either a discussion group with other consumers and/or an interview, of one to one and half hours in length, at a time and place convenient to you. It will however be your choice as to whether you participate in an interview and/or a focus group. The study will have two data collection rounds, one at the beginning of the demonstration project and one at its completion. This information and consent form is for round one data collection. Agreement to participate in this first round of data collection will not mean who are required to take part in the second round of data collection. If you are interested in being considered for the second round of data collection please provide your contact details on the form provided on page 5 of this document. The peer interviewer will re-contact you a few weeks prior to the round two data collection to check your availability and continuing interest.

We would like to digitally audio-record your voice during the research so we do not miss any important points. If you feel uncomfortable about that, you can ask at any time for the tape recorder to be turned off.

During the focus groups and interviews we will discuss consumer satisfaction with service delivery, levels of communication between consumers and providers, awareness of existing consumer participation activities and attitudes to consumer participation. We will also ask you a few questions about your background so we can describe who participated in the research.

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)

(For consumers in drug treatment services round one data collection)

Treatment Service Users Project Phase 2 (TSU2)

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. If you give us your permission by signing this document, we plan to publish the most important results in academic journals, an evaluation report published by the Australian Injecting & Illicit Drug Users League, community-based magazines and online at www.aivl.org.au and <http://nchsr.arts.unsw.edu.au>. A number of measures will be put in place to ensure participant confidentiality. Following the interview or discussion group all your contact details will be removed from our records, except if you agree to be re-contacted in relation to the second round of data collection. If you agree to be recontacted your details will be removed either when you decline to participate in the second round or after round two data collection. Following transcription of the interview your real name will be replaced with a pseudonym (or nickname). In addition, all other details you mention that might identify you or others will be changed (e.g. the name of your workplace, friends, colleagues, drug treatment services and venues attended). The digital audio recordings will be destroyed as soon as they are transcribed and the de-identified transcripts will be kept in a locked filing cabinet to which only the researchers will have access. In any publication, information will be provided in such a way that you cannot be identified.

Recompense to participants

In recognition of your contribution to this study and the effort you made to attend this interview or focus group, we will recompense you with AUD twenty-five dollars for travel expenses.

Complaints

Complaints 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 investigated promptly and you will be informed of the outcome.

Feedback to participants

A plain language summary of results will be available on the AIVL www.aivl.org.au and NCHSR <http://nchsr.arts.unsw.edu.au> websites at the completion of the evaluation process and distributed to participating services. Upon completion of the project, data will be analysed and an evaluation report written. The findings will also be published in academic articles for peer-review. The results will also be presented at conferences. An overview of the demonstration projects will be written up and the findings of the evaluation will be discussed at a nationally convened workshop hosted by AIVL.

Your consent

Your decision whether or not to participate will not prejudice your future relations with The University of New South Wales or your health service provider. 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 now, please feel free to ask the researcher. If you have any additional questions later, please contact Dr. Jeanne Ellard on (02) 9385 6406, or email j.ellard@unsw.edu.au.

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

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)
(For consumers in drug treatment services round one data collection)

Treatment Service Users Project Phase 2 (TSU2)

You are making a decision whether or not to participate. Your signature indicates that, having read the information provided above, you have decided to participate.

.....
Signature of Research Participant

.....
Signature of Witness

.....
(Please PRINT name)

.....
(Please PRINT NAME)

.....
Date

.....
Nature of Witness

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

Treatment Service Users Project Phase 2 (TSU2)

REVOCAION OF CONSENT

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.

.....
Signature

.....
Date

.....
Please PRINT Name

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

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)
(For consumers in drug treatment services round one data collection)

Treatment Service Users Project Phase 2 (TSU2)

If you would like to be contacted about participating in round 2 data collection please fill out this form.

Name (which can be just a first name)

Contact details:

Email:

Phone:

(H) _____

(W) _____

Please be assured that we will exercise discretion in making contact with you. We will not mention anything about the study or the name of the Centre to any person other than you who may answer the phone in either your home or workplace. If there is a specific time of day you would prefer us to call please let us know.

Thank you for your interest
Dr Jeanne Ellard
National Centre in HIV Social Research
j.ellard@unsw.edu.au
(02) 9385 6406

Appendix 7 —Consent Forms for Consumer Participants cont...

Approval No (08073)

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM **For consumers in drug treatment services (round two data collection)**

Treatment Service Users Project Phase 2 (TSU2)

Participant Selection and purpose of the study

You are invited to participate in a research study into the suitability and impact of consumer participation in drug treatment services. The drug treatment service where you work has been selected through an expression of interest process to conduct a demonstration consumer participation project. The project is being conducted as a partnership between the National Centre in HIV Social Research and The Australian Injecting & Illicit Drug Users League (AIVL). We hope to learn from this study what model of consumer participation will be most suitable for the drug treatment sector, the strengths and weaknesses of the demonstration project, the impact of consumer participation demonstration project on service delivery, communication between providers and consumers and on health outcomes for consumers. Ultimately, we hope to use the findings of this study to develop a nationally agreed definition of consumer participation that can be used to guide consumer participation across the drug treatment sector. You were selected as a possible participant in this study because you are a consumer at one of the drug treatment services that is conducting a demonstration consumer participation project and you indicated that you might be interested in participating.

Procedures

If you decide to participate in this research, we will ask you to take part in either a discussion group with other consumers and/or an interview, of one to one and half hours in length, at a time and place convenient to you. It will however be your choice as to whether you participate in an interview and/or a focus group. The study will have two data collection rounds, one at the beginning of the demonstration project and one at its completion. This information and consent form is for round two data collection. If you participated in round one you are also eligible to participate in this second round of data collection. However you do not need to have participated in round one in order to take part in round 2.

We would like to digitally audio-record your voice during the research so we do not miss any important points. If you feel uncomfortable about that, you can ask at any time for the tape recorder to be turned off.

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued) **(For consumers in drug treatment services round two data collection)**

Treatment Service Users Project Phase 2 (TSU2)

During the focus groups and interviews we will discuss the impact of the demonstration projects on staff and consumers, service delivery, communication between consumers and providers, attitudes to consumer participation, the suitability of the chosen model of consumer participation, changes in health and treatment outcomes and changes in skills and capacity amongst consumers and service providers in relation to consumer participation. We will also ask you a few questions about your background so we can describe who participated in the research.

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. If you give us your permission by signing this document, we plan to publish the most important results in academic journals, an evaluation report published by the Australian Injecting & Illicit Drug Users League, community-based magazines and online at www.aivl.org.au and <http://nchsr.arts.unsw.edu.au>. A number of measures will be put in place to ensure participant confidentiality. Following the interview or discussion group all your contact details will be removed from our records. Following transcription of the interview your real name will be replaced with a pseudonym (or nickname). In addition, all other details you mention that might identify you or others will be changed (e.g. the name of your workplace, friends, colleagues, drug treatment services and venues attended). The digital audio recordings will be destroyed as soon as they are transcribed and the de-identified transcripts will be kept in a locked filing cabinet to which only the researchers will have access. In any publication, information will be provided in such a way that you cannot be identified.

Recompense to participants

In recognition of your contribution to this study and the effort you made to attend this interview or focus group, we will recompense you with AUD twenty-five dollars for travel expenses.

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Appendix 7 —Consent Forms for Consumer Participants cont...

Feedback to participants

A plain language summary of results will be available on the AIVL www.aivl.org.au and NCHSR <http://nchsr.arts.unsw.edu.au> websites at the completion of the evaluation process and distributed to participating services. Upon completion of the project, data will be analysed and an evaluation report written. The findings will also be published in academic articles for peer-review. The results will also be presented at conferences. An overview of the demonstration projects will be written up and the findings of the evaluation will be discussed at a nationally convened workshop hosted by AIVL.

Your consent

Your decision whether or not to participate will not prejudice your future relations with The University of New South Wales or your health service provider. 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 now, please feel free to ask the researcher. If you have any additional questions later, please contact Dr. Jeanne Ellard on (02) 9385 6406, or email j.ellard@unsw.edu.au .

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

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)
(For consumers in drug treatment services round two data collection)

Treatment Service Users Project Phase 2 (TSU2)

You are making a decision whether or not to participate. Your signature indicates that, having read the information provided above, you have decided to participate.

.....
Signature of Research Participant

.....
Signature of Witness

.....
(Please PRINT name)

.....
(Please PRINT NAME)

.....
Date

.....
Nature of Witness

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

Treatment Service Users Project Phase 2 (TSU2)

REVOCAION OF CONSENT

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.

.....
Signature

.....
Date

.....
Please PRINT Name

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

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Relevant Contacts

AIVL

Australian Injecting and Illicit Drug Users League (AIVL)

Level 2, Sydney Building

112—116 Alinga Street

Canberra ACT 2601 Australia

Telephone: (02) 6279 1600

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NCHSR

National Centre in HIV Social Research

Level 2, Webster Building

University of New South Wales

Sydney NSW 2052 Australia

Telephone: (02) 9385 6776

Facsimile: (02) 9385 6455

Email: nchsr@unsw.edu.au

Website: www.nchsr.arts.unsw.edu.au

AIVL Member Organisations

NUAA

NSW Users & AIDS Association
345 Crown St
Surry Hills NSW 2010
Telephone: (02) 8354 7300
Facsimile: (02) 8354 7350
Email: admin@nuaa.org.au
Website: www.nuaa.org.au

CAHMA

Canberra Alliance for Harm Minimisation and Advocacy
c/- AIVL
Telephone: (02) 6279 1600
Facsimile: (02) 6279 1610
Email: cahma@aivl.org.au

Harm Reduction Victoria (formerly VIVAIDS)

128 Peel Street
North Melbourne VIC 3051
Telephone: (03) 9419 3633
Facsimile: (03) 9329 1501
Email: admin@viv aids.org.au

SAVIVE

SA Voice of IV Education
64 Fullarton Rd
Norwood SA 5067
Telephone: (08) 8334 1699
Facsimile: (08) 8363 1046
Email: manager@savive.org.au

WASUA

WA Substance Users Association
519 Murray St
West Perth WA 6000
Telephone: (08) 9321 2877
Facsimile: (08) 9321 4377
Email: info@wasua.com.au

QUIHN and QUIVAA

Queensland Injectors Health Network
and Queensland Intravenous AIDS Association
Brisbane Headquarters
89–101 Gipps St
Fortitude Valley QLD 4006
Telephone: (07) 3620 8111
Facsimile: (07) 3854 1070
Email: hqmb1@quihn.org.au
Website: www.quihn.org.au

TASCAHRD

Tasmanian Council on AIDS, Hepatitis & Related Diseases
c/- Harm Reduction Coordinator
319 Liverpool St
Hobart TAS 7000
Telephone: (03) 6234 1242
Facsimile: (03) 6234 1630
Email: mail@tascahrd.org.au
Website: www.tascahrd.org.au

