

Guideline to Consumer Participation in NSW Drug and Alcohol Services

Summary This Guideline aims to provide drug and alcohol treatment services in NSW with tools to engage consumers and / or carers. The purpose of Consumer Participation is to improve consumers' health care through patient-centred service delivery. The strategies suggested are evidence-based and guided by policy directives on best practice.

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Author branch Centre for Alcohol and Other Drugs

Branch contact (02) 9424 5938

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GUIDE TO CONSUMER PARTICIPATION IN NSW DRUG AND ALCOHOL SERVICES

PURPOSE

The purpose of this Guideline is to provide drug and alcohol treatment services in NSW with tools to engage consumers and / or carers. Consumer Participation is designed to improve consumers' health care through patient-centred service delivery. The Guideline suggests several strategies that are evidence-based and guided by policy directives on best practice.

The needs of drug and alcohol consumer groups vary from other consumer types. Therefore activities designed to increase the participation of these consumers in individual treatment plans, as well as in meetings and Committees, requires well-designed plans that consult with consumers from the very beginning of the planning stage.

KEY PRINCIPLES

Access - The right to receive health care.

Safety - The right to safe and high quality care.

Respect - The right to be treated with respect, dignity and consideration.

Communication - The right to be informed about services, treatment and options in a clear and open way

Participation - The right to be included in decisions and choices about healthcare

Privacy - The right to privacy and confidentiality

USE OF THE GUIDELINE

The Guideline can be used by services to assist them in meeting accreditation standards under the *National Safety and Quality in Health Care (NSQHC) Standards*. These Standards stipulate that consumers and / or carers should be involved in governance and quality improvement processes. The specific methods that services can choose to meet these Standards range from suggestion boxes and meetings of consumers to volunteer or paid Consumer Representatives or Advocates involved in Consumer Advisory Groups or on Boards and Committees.

The Guideline can also be used to develop strategies to increase consumer and / or carer participation and patient-centred care at all levels of the Health system. This encompasses individual services through to organisation or systems levels for increased consumer representation and involvement in strategic directions and policies.

REVISION HISTORY

Version	Approved by	Amendment notes
April 2015 (GL2015_006)	Deputy Secretary, Systems Purchasing and Performance	Amendments since the GL2005_075 include new case studies and types of consumer participation.
December 2005 (GL2005_075)	Deputy General, Systems Purchasing and Performance	New guideline

ATTACHMENTS

1. Guideline to Consumer Participation in NSW Drug and Alcohol Services - Procedures

GUIDE TO

**CONSUMER
PARTICIPATION IN
NSW DRUG AND
ALCOHOL SERVICES**



Health

NSW MINISTRY OF HEALTH

73 Miller Street

NORTH SYDNEY NSW 2060

Tel. (02) 9391 9000

Fax. (02) 9391 9101

TTY. (02) 9391 9900

www.health.nsw.gov.au

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Introduction

The NSW Health system has a vision to improve timely access to quality health care by putting patients back at the centre of every decisionⁱ. Consultation with the local community, including patients and carers, is a necessary step in achieving this goal.

This Guide aims to provide drug and alcohol treatment services in NSW with tools to engage consumers and/or carers. The purpose of consumer participation is to improve consumers' health care through patient-centred service delivery. The strategies suggested are evidence-based and guided by policy directives on best practice.

The Guide can be used by services to assist them in meeting accreditation standards under the *National Safety and Quality in Health Care (NSQHC) Standards*ⁱⁱ. These Standards stipulate that consumers and/or carers should be involved in governance and quality improvement processes. The specific methods that services can choose to meet these Standards range from suggestion boxes and meetings of consumers to volunteer or paid Consumer Representatives or Advocates involved in Consumer Advisory Groups or on Boards and Committees.

The Guide can also be used to develop strategies to increase consumer and/or carer participation and patient-centred care at all levels of the NSW Health system. This encompasses individual services through to organisation or systems levels for increased consumer representation and involvement in strategic directions and policies.

The needs of drug and alcohol consumer groups vary from other consumer types. Therefore, activities designed to increase the participation of these consumers in individual treatment plans, as well as in meetings and Committees, requires well-designed plans that consult with consumers from the very beginning of the planning stage.

The experiences and learnings from several consumer participation initiatives in NSW across different treatment types have been incorporated into this updated Guide. The updates provide current links to resources, suggested policies to include in plans, and specific suggestions for consumer and/or carer participation initiatives.

Policy context

INTERNATIONAL POLICY CONTEXT

There are varying degrees of consumer and/or carer participation and involvement in health systems governance and drug and alcohol services in the international literature. Within Organisation for Economic Cooperation and Development (OECD) member countries, consumer participation is increasingly seen as an important component of service quality relating to the appropriateness and suitability of health services. In the United Kingdom, for example, there is mandated consumer involvement in health system governance, including drug and alcohol services.

NSW AND AUSTRALIAN POLICY CONTEXT

The principles outlined in this Guide align with the National Safety and Quality Health Care Standards of partnering with consumers and consumer involvement in governance. These standards are mandatory for all NSW Health services, including drug and alcohol services.

More information on tools to assist with meeting accreditation requirements for standards for partnering with consumers and consumers involved in governance is available in the Relevant Policies section.

*NSW 2021: A plan to make NSW Number One*ⁱⁱⁱ, the NSW Government's strategic business plan, outlines the goal of giving communities and health care providers a strong voice in improved patient care; patients and their carers must be at the heart of decision making to ensure timely access to quality health care. Patients must also have an opportunity to provide feedback on their experiences if we are to continuously improve the delivery of health services and learn from mistakes. Strong collaborations will promote more choice and quality in services. The NSW government will increase opportunities for people to participate in the way governments make decisions, including ways for people to have a real say and be involved in localised decision making. By devolving decision making as close as possible to the people and places affected by decisions, people are able to

take more control over their choices and opportunities and shape their own futures.

The purpose of the *NSW State Health Plan: Towards 2027*^{iv} is to deliver an integrated system of care that will empower patients to be partners in their care. This will be achieved by improving feedback processes and supporting consumers and carers to navigate the health system.

Consumer participation in their health care, and the right to comment on care and have their concerns addressed, are integral rights outlined in the NSW Health Policy Directive PD2011_022 *Your Rights and Responsibilities*^v. This document outlines the tenet that the NSW Health system “has a clear mandate for involving communities in the planning and delivery of health care across NSW”. Individuals who would like to become involved can contact the Community Participation Office in their Local Health District to find out more.

NSW Health is also committed to consumer and/or carer participation from Culturally and Linguistically Diverse (CALD) communities. The NSW Health policy document *Policy and Implementation Plan for Healthy Culturally Diverse Communities 2012- 2016*^{vi} outlines the commitment that, “People from culturally, religiously and linguistically diverse backgrounds will have an opportunity to contribute to decisions about health services that affect them.”

Equally, NSW Health is committed to participation from children and young people and/or their carers. Based on the United Nations *Convention on the Rights of the Child*^{vii}, the *Charter on the Rights of Children and Young People in Healthcare Services in Australia*^{viii} outlines the rights of children and young people to participate in their care, including the right to express their views and participate in decision making.

RESEARCH

Research relating to the improvement of patient care as a result of consumer and carer participation in health care decisions is well established.^{ix} Specific research on consumer

participation in drug and alcohol treatment and services is emerging.^X The research shows that although there are challenges inherent in involving consumers in both their individual treatment and in service provision decisions, there are many rewards that stem from the tailoring of treatment and services to meet consumer needs.

PRINCIPLES OF CONSUMER PARTICIPATION

The principles of consumer participation in drug and alcohol treatment are drawn from the NSW Health Policy Directive PD2011_022 *Your Rights and Responsibilities*:

- Access** – The right to receive health care.
- Safety** – The right to safe and high quality care.

Respect – The right to be treated with respect, dignity and consideration.

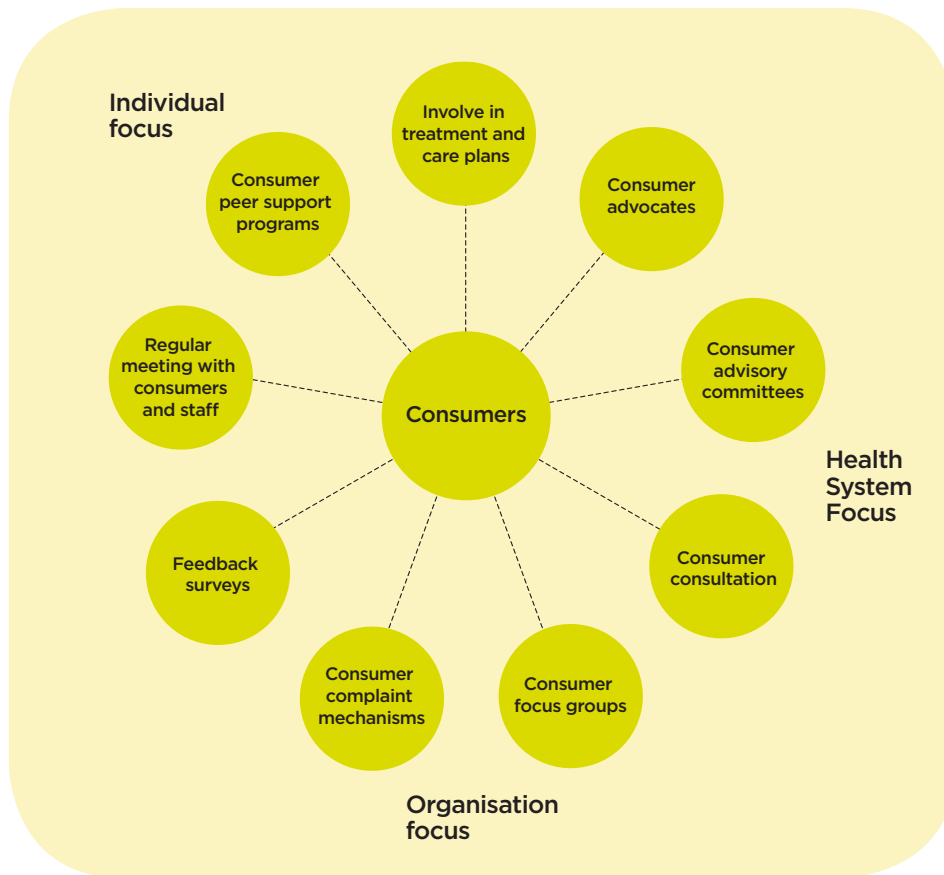
Communication – The right to be informed about services, treatment and options in a clear and open way.

Participation – The right to be included in decisions and choices about health care.

Privacy – The right to privacy and confidentiality.

The core steps for consumer participation and the types of consumer participation are underpinned by these principles. There is a specific focus in this Guide on increasing consumer participation in decisions and choices about health care, and increasing the safety and quality of care through increased communication between consumers and services at an individual and group level.

MODEL FOR CONSUMER PARTICIPATION



This model outlines tools for consumer participation that can be implemented at different levels of the health system. Some of the tools may be appropriate across the health system, organisation and individual level. Some of the tools, such as involving individuals in their own treatment and care plans, fall more naturally under the

Individual Focus heading. The Tools for Consumer Participation section below expands on these different strategies.

STRATEGIES FOR CONSUMER PARTICIPATION AN ORGANISATION LEVEL

The following steps are recommended for ensuring good consumer and/or carer participation outcomes:

Services should consider the development of a 'Drug and Alcohol Consumer and Carer Participation Plan', which identifies benefits and outcomes of consumer engagement and participation. Ideally, this plan should identify models, strategies, outcomes, available resources, partners, and linkages with clinical and service delivery governance, and take into account the issues identified below.

ACKNOWLEDGE THE RISK OF COMMENCING CONSUMER PARTICIPATION INITIATIVES AND PLAN TO DEVELOP SYSTEMS TO SUPPORT CONSUMERS AND STAFF

Systems should be put in place to ensure ongoing support of consumer participation projects and consumer representatives. Being mindful of consumers' health and need for support and feedback can help to reduce the risks of consumer's disengaging with the service, of conflict arising between consumers or consumers and staff, or deteriorating health outcomes from poorly planned or resourced initiatives. Well-planned and supported consumer participation initiatives can result in many improvements in consumer's engagement in treatment.

Key issues to consider when planning include:

INVOLVE CONSUMERS AND/OR CARERS AND STAFF FROM THE BEGINNING OF THE PLANNING FOR CONSUMER PARTICIPATION

Consumers, carers and staff have a wealth of experience that can be drawn on to plan consumer participation and involvement.

TRAIN CONSUMERS TO UNDERTAKE CONSUMER PARTICIPATION INITIATIVES

Training may be required to build consumers' confidence and skills to participate. See Consumer Participation Resources) for examples of training options.

ENSURE STAFF ARE SUPPORTED TO COMMENCE CONSUMER PARTICIPATION INITIATIVES

For example, ensure that there is visible leadership and support from Managers and Senior Managers.

ENSURE THAT LINKS ARE EXPLORED BETWEEN CONSUMER PARTICIPATION IN MENTAL HEALTH SERVICES AND DRUG AND ALCOHOL SERVICES

Many Local Health District (LHD) mental health services have staff working as Consumer Representatives/Advocates and peer support staff in mental health services. Consulting with and engaging these people in service design and delivery can assist in identifying pitfalls and problems when planning services.

REVIEW POLICIES TO ENSURE THAT THE NECESSARY INTERNAL WRITTEN GUIDELINES ARE IN PLACE

Additional policies and resources may also need to be developed that:

- Clearly define how information gathered will be used.
- Clarify or add responsibilities for consumer participation to position descriptions.
- Include consumer participation in any strategic and operations plans.
- Provide information about any financial or other incentives to consumers to encourage their participation and to recognise the time and experience of consumers.
- Acknowledge consumer input into any policies or documents developed.
- Acknowledge consumer input into any conference papers or publications that have involved consumers.
- Develop consumer feedback mechanisms.
- Review the codes of conduct for staff and consumers involved.
- Support consumer participation, including staff time and the provision of a budget for incentives to promote participation.
- Promote access to technology for the purposes of aiding consultation and engagement.

ALIGN CONSUMER PARTICIPATION AND ENGAGEMENT STRATEGIES TO YOUR HEALTH SERVICES QUALITY ASSURANCE PROCESSES

Ensuring that your regular quality assurance activities actively include consumer engagement and participation strategies outlined by local and national quality assurance frameworks.

Tools for consumer participation

Different tools may be appropriate at different levels of the drug and alcohol system, at a systems, organisation or individual level. There may be a crossover for some of the strategies. Not all services or organisations will set up all of these processes, but different services and organisations can choose to use some of these tools as a guide to establish their own consumer and/or carer participation programs.

INVOLVE CURRENT SERVICE USERS IN INDIVIDUAL TREATMENT AND CARE PLANS

Treatment agreements are common practice within drug and alcohol services. It is important that users of services are offered multiple opportunities to ensure that they understand and commit to such agreements.^{xi} For example, consumers are commonly required to sign treatment agreements at the commencement of treatment. For those commencing detoxification or pharmacotherapy services, this is sometimes a time when consumers are unwell, experiencing high levels of chaos in their lives, and may be less able to make informed decisions. Treatment agreements need to be revisited with consumers regularly to optimise their understanding and ensure informed consent. Partnering with consumers in determining treatment goals assists in promoting self-determination in consumers.

Global Care Plans are being introduced across public health services in NSW as part of the rollout of Electronic Medical Records in the Community Health Outpatient Care project. These Global Care Plans are undertaken in partnership between the consumer and the clinician, and reviewed regularly. The Community Health and Outpatient Care (CHOC) Program is a state-wide program that will deliver an Integrated Clinical System (ICS) into community health and outpatient care clinical services such as drug and alcohol. Benefits to consumers include: Improved monitoring and discussions over health outcomes and goals; Potential to reduce the number of tests clients may need to undertake due to easy access of previous test results undertaken; Improved co-ordination

between health services over consumer care and ongoing needs.

The NSW Health Charter outlined in the *Your Health Rights and Responsibilities* Policy Directive (PD2011_022) mandates that consumers be involved in treatment decisions. For drug and alcohol services, this could in practice mean routinely involving consumers in all decisions about their treatment, and giving consumers access to treatment files, such as assessment reports and file notes. Partnering with consumers over goals and discharge planning and reviews are best practice examples.

INVOLVE CONSUMER REPRESENTATIVES/CONSUMER ADVOCATES

Consumer Representatives/Consumer Advocates can be involved in different levels of the health system. The function of the role will vary according to the purpose and level of the role. Representatives and Advocates are people who can advocate and argue for consumer-identified issues, and any related issues, through clinical and service governance processes.

Consumers in these roles can provide input on policies, governance, strategic directions, and quality improvement, as well as facilitate consumer participation activities such as consumer involvement in policy revisions, revision of induction guides for new consumers, newsletters, training, referrals, and peer support. They can also provide referrals to counsellors, caseworkers, legal or other services, and act as a liaison between consumers and staff.

CASE STUDY: CONSUMER PARTICIPATION (CHANGE) PROJECT

The NSW Ministry of Health funded the NSW Users and AIDS Association (NUAA) to undertake the Consumer Participation (CHANGE) project over two years. Three drug treatment sites were chosen as pilot sites for the two-year project: Two opioid treatment sites and one residential treatment of opioid dependence site. A range of service

modalities and locations were selected in order to learn as much as possible during the pilot period. The Centre for Social Research in Health at the University of New South Wales evaluated the project.

A project worker was employed by NUAA to recruit and train consumers, to train staff and to provide ongoing support and training to each site. Consultation workshops were undertaken during the initial training with consumers and staff to develop consumer participation initiatives that they believed most suited their service. The ongoing refresher training was provided to consumers in particular and included meeting skills; setting agendas; taking minutes; writing; editing and printing a newsletter; staffing an information desk; keeping a journal of consumer participation; training in advocacy; and training in non-violent conflict resolution.

In one service, a policy review group involving consumers and staff formed after a suggestion was made to make service policies more transparent. Meetings were held over successive weeks and consumer participants were involved in learning about policy and why particular policy exists. The policies were rewritten in an accessible, attractive format in Plain English. Consumer participants also passed on policy information to other consumers. This initiative had both a consumer participation process and outcome. The resulting booklet was professionally laid out and printed for the group. In another service, an initiative that focused on reviewing the induction process and rewriting the induction booklet was undertaken.

CHANGE desks were set up at two of the sites and were staffed by volunteer CHANGE consumers. These provided a focal point for meetings and for passing on information about the project itself. For instance, the policy review group were able to pass on feedback and consult with other consumers in this space.

In all the pilot sites, staff partnered with consumers to actively review suggestion box comments, and provide feedback to consumers through posters and meetings.

Consumers perceived that open and two-way communication in consumer participation initiatives improved relationships between staff and consumers. It also demonstrated the commitment on both sides to establish a partnership.

CASE STUDY: SOUTH EAST SYDNEY LOCAL HEALTH DISTRICT (SESLHD) CONSUMER PARTICIPATION PROJECT

SESLHD Drug and Alcohol Services (DAS) has developed and implemented a Consumer Participation Framework in consultation with key stakeholders, including consumers, to ensure that SESLHD DAS continues to be responsive to patient, carer and consumer input and needs.

SESLHD DAS employ three part-time consumer worker positions to support consumer needs; facilitate effective communication between consumers and the service; and to ensure consumer participation occurs on an individual, system and strategic level. The project commenced in 2013 and will be evaluated over a two-year period.

CONSUMER ADVISORY COMMITTEES

Consumer Advisory Committees can be useful at the service, district, and state-wide level for increasing consumer involvement. Education and training for consumers to engage and participate is essential. Consumers participating in committees should be assigned another committee member to act in a mentor role, to ensure that the consumer has understood the content, any acronyms and historical information, and to generally support the consumer's participation.

The Terms of Reference need to clearly define the role of the Committee, the role of the representatives, what the parameters are, what the Committee can do, and what will be outside of its scope. The Terms should also outline how members will be recruited and what resources will be provided to support the committee; for example, training, secretariat, sitting fees, transport, and access to computers and a printer.

CASE STUDY: SOUTH PACIFIC PRIVATE HOSPITAL

South Pacific Private Hospital caters to people with drug or alcohol addictions or mood disorders. Best practice consumer participation strategies have been in place for over ten years. Committee members are paid a sitting fee on the Consumers and Carers Committee. The consumers and carers vote on the Chair. Recruitment occurs through the quarterly alumni newsletter. The Committee conducts interviews of interested people.

A business plan for the year is worked out with the

Committee, with four or five key objectives for the year and individuals are responsible for actions arising. The business plan, along with formal agendas, assists the Committee to stay focused and achieve objectives. The Manager participates in the Committee. The Manager formally presents minutes of the meetings and recommendations from the Committee to the Board.

The Committee has designed a consumer feedback survey that they administer to recent alumni via telephone. An exit survey is also conducted for all consumers leaving the service with results from both surveys being formally presented to the Board by the Manager.

CASE STUDY: CONSUMER ENGAGEMENT MODEL – COMMITTEE OF NEPEAN BLUE MOUNTAINS LOCAL HEALTH DISTRICT (LHD) AND NEPEAN BLUE MOUNTAINS MEDICARE LOCAL

The Nepean Blue Mountains LHD and Nepean Blue Mountains Medicare Local made a decision at Board level to join together to develop and implement a joint Consumer Engagement Strategy. A Joint Interim Health Consumer Committee was formed with a focus on all health areas and the Committee has been working with the Drug and Alcohol team to ensure adequate consumer representation is achieved. The Committee formulated and conducted consumer consultation forums and focus groups in four different Local Government Areas of the Local Health District. The Committee Chairperson is supporting the roll out of the community engagement strategy and participates in online and offline community forums outlining the model and how it works. The volunteer Consumer Representatives are reimbursed for their travel and expenses. A range of Consumer Working Groups have been established. For more information see: www.nbmdl.com.au/CommunityForums

CONSULT WITH POTENTIAL SERVICE USERS TO IMPROVE ACCESS

Best practice examples of tailoring services to meet unmet needs in the community involve developing strategies to consult beyond the current client base to elicit the views of potential users of the service.

Advantages of consulting with potential service users are:

- Finding out about the factors that prevent people from accessing available services.
- Finding out about any gaps in services.
- Finding out about the appropriateness of services, particularly for specific population groups.
- Finding out ways to increase service appropriateness and access.
- Learning about any unmet needs in the local community.

One option for finding out about unmet needs is to send anonymous surveys to people who have made an appointment, given contact details and agreed that they could be contacted, but who do not show up for their first appointment.^{xii}

This method does not address the issues of people who do not make appointments. Community outreach may be another method to determine unmet needs. Consulting with specific communities can assist with collecting information on unmet needs and with tailoring services.

CASE STUDY: INCREASING ENGAGEMENT WITH CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) CONSUMERS – DRUG AND ALCOHOL MULTICULTURAL EDUCATION CENTRE (DAMEC) SYDNEY

DAMEC conducts outreach with specific language groups through community forum and online forums, as well as through contact with community groups, community and religious leaders, and Non Government Organisations (NGOs) such as the NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS); the NSW Refugee Health Service; and the Trans Cultural Mental Health Centre (TCMHC).

DAMEC uses bi-lingual counsellors. Outreach services are often conducted in Vietnamese or Arabic. These outreach and networking activities raise the profile of the service and make it more likely that consumers or their families will self-refer to the service. It also provides an opportunity for potential consumers of treatment and their families to provide feedback on what types of services are needed or the accessibility of services.

REVIEW COMPLAINTS MECHANISMS

Complaints are just one form of consumer feedback. It is part of NSW Health's Policy Directive PD 2011_021 *Patient's Rights and Responsibilities* that consumers have the ability to comment about any aspect of their treatment. Issues to consider for drug and alcohol services are:

- Is the process for making a complaint routinely provided to consumers and widely promoted in public access areas?
- Is information about making a complaint user-friendly?
- Is the grievance procedure explained to new consumers?
- Is there feedback provided to consumers about patterns of complaints and their responses?

For consumers of NSW pharmacotherapy services there is a separate complaints mechanism that can be utilised – the Opioid Treatment Line^{xiii} (OTL), which has been established to collect information and report to NSW Health about complaints or concerns regarding opioid treatment. Consumers should be aware of this mechanism and the most appropriate way to utilise it.

FOCUS GROUPS

Focus groups bring small numbers of people together to discuss specific issues. They can be used for current and potential service users or for consumers. Some things to consider when using focus groups are:

- Anonymity and confidentiality
- Experience of facilitator
- Incentives
- Gender mix and/or or mix of CALD, Aboriginal, GLBT or other group representation as appropriate. Separate focus groups may yield richer results for some consumers.

CONSUMER FEEDBACK SURVEYS

It is important to design surveys in partnership with consumers and provide timely and effective feedback to consumers on the results of the surveys and any changes implemented as a result (through meetings, posters or newsletters).

There are a number of options for implementing consumer evaluation of services, for example:

- Paper-based surveys to be filled in on exit or posted to consumer's homes after exit.

- Online surveys on applications such as Survey Monkey and/or in computers in reception areas. (Note that such options are not possible in a custodial setting where consumers do not have Internet access.)
- Telephone surveys of consumers after exit.
- Hand-held devices fixed in services, such as Patient Experience Trackers (PET) (see the Case Study: Hunter New England LHD PET).
- Development of a voluntary consumer survey to be available to the client at the closure of the service request.

The involvement of consumers in the evaluation of survey results, as well as in the development of questions, is one way to ensure consumer involvement in quality improvement processes.

Telephone follow-ups with consumers may not result in a high number of responses. Suggested strategies for overcoming this barrier include:

- Providing consumers with contact phone numbers as part of their exit documentation, with an explanation that they will be contacted within a certain time frame as a follow-up if they do not contact the service first (see Case Study: Aboriginal Consumer Engagement, Hunter New England Local Health District (LHD) .
- Calling should be done from phones that do not show up as blocked/number withheld.
- Having Consumer Representatives call to administer the survey, having first sought permission from consumers on exit of the service (see South Pacific Private Hospital Case Study).

CASE STUDY: HUNTER NEW ENGLAND LOCAL HEALTH DISTRICT (LHD) PATIENT EXPERIENCE TRACKER (PET)

Hunter New England LHD uses hand-held devices (fixed to the wall or fittings) for consumer feedback. A third-party organisation is paid for the devices and collating of responses into reports back to the LHD. The initial five questions were developed in consultation with a Consumer Representative who ran focus groups with consumers on five draft questions.

The PET was trialled over three months in the drug and alcohol services in Hunter New England. Consumers were encouraged by staff to use the electronic devices every time that they were in the service. The reports from the surveys were sent regularly to the LHD. Consumer issues at different

times of the day were revealed. The results were used for quality improvement purposes.

Results: At the end of the trial, staff and consumers were consulted about the questions and the process. This feedback informed the revised questions. NUAA were consulted about these questions. Feedback on the trial was that it was effective in quality improvement and well received by staff and consumers so long as the purpose of the surveys was explained. The number of devices and time limit of the use of the device in each service was adjusted as a result of the feedback.

REGULAR MEETINGS BETWEEN CONSUMERS, STAFF AND SERVICE MANAGERS

Regular meetings between consumers and service providers can improve communication in services. Training consumers in running meetings and conflict resolution strategies can help to empower consumers. Implementing formal feedback mechanisms between consumers and staff through the presentation of concerns of consumers in minutes or resolutions to management, and feedback from management to consumers in formal replies to consumer meetings, can also increase the communication between staff and consumers.

A less formal means of gathering feedback can be obtained through the hosting of informal events, such as barbecues for clients/consumers, with the intention of gathering feedback on services.

NGO CASE STUDY: TRIPLE CARE FARM

Triple Care Farm is a residential program run by Mission Australia for young people (aged 16-24) experiencing homelessness, substance abuse, mental illness, or acute behavioural problems. Consumer participation has been embedded in the program development and review for many years.

Consumers prefer to be called students in this service. Complaints and compliments posters and forms are available. The Manager of the service conducts a thematic assessment of the complaints and compliments and then uses it to inform service planning and staff appraisals. If ongoing issues are raised in the complaints these are raised in the quarterly Student Forums.

Students are involved in reviews of policies and programs through Consumer Forums. A weekly Student Council is also held. A staff member is present who trains the students in holding formal meetings. The meeting elects two Consumer Representatives who present the minutes and the concerns of the meeting the following business day to the Manager. The Manager then types up an action list and provides feedback to the students on what can and cannot be changed as a result of their concerns, with the reasons being given for particular policies.

EX CONSUMERS OF SERVICES CAN PROVIDE SUPPORT AND ROLE MODELS

Some NGOs invite ex-consumers of services back to give talks to consumers in order to provide support and role models to current consumers. Ex-consumers can also provide feedback to service providers on their experiences with the service without the fear of repercussions.

NGO CASE STUDY: KAMIRA DRUG AND ALCOHOL REHABILITATION FACILITY FOR WOMEN

Best practice consumer participation strategies have been in place for many years in this service. Consumers participate in groups to evaluate the service. Evaluation groups are held every five weeks on different parts of the program and every week in the activities of that week. Program planning days also occur every quarter, which involve reviewing all jobs, rules, group topics, and timetables, as well as planning for gardening and other extra curricular activities.

Once a year recently graduated consumers are invited back to reflect back upon their experiences of Kamira and to provide vital input. Graduated consumers are invited to come back and run a morning group and stay for lunch. They talk about their experiences and provide hope for current consumers, as well as provide feedback on the service.

Areas for consideration for specific drug and alcohol services

DETOXIFICATION SERVICES

It can prove difficult to attract consumer involvement in governance within detoxification services owing to the treatment processes and possibly complex health issues. These consumers may benefit from other forms of consumer representation instead, such as ex-consumers serving as Consumer Representatives or on Advisory Committees. Other forms of engaging consumers in detoxification services (for example, focus groups run by an ex-consumer) may be effective. Forms, surveys or feedback on services at the time of exiting services, or sent to consumers at home at a later date, may also be effective in eliciting feedback.

DRUG AND ALCOHOL COUNSELLING SERVICES

Counselling services may also have difficulty attracting Consumer Representatives or consumer involvement in the governance of the service. Ex-consumers, or representatives from consumer or support organisations, may be more successfully recruited into governance structures.

Other ways to engage consumers may include innovative approaches, such as community based forums to consult consumers, potential consumers, and their families and partners.

Anonymous consumer surveys, including exit surveys, are another option for counselling services, as is consumer feedback session rating tools which are completed whilst the consumer is with the clinical, allows for both the manager and the clinician to track progress. Whipple and colleagues (2003) found clients of therapists who had access to outcome and alliance information were less likely to deteriorate, more likely to stay longer, and twice as likely to achieve a clinically significant change.^{xiv} Some service in the Illawarra Shoalhaven LHD use the session rating tools.

REHABILITATION SERVICES

Rehabilitation services may benefit from consumer feedback days run off-site with peer facilitators. There may be a reluctance of consumers to criticise staff. However, several rehabilitation services have successful consumer participation initiatives in place. These include analyses of suggestion boxes with feedback to consumers, feedback to staff, and staff appraisals, and consumer meetings with rotating volunteers giving formal minutes and feedback to service managers with formal feedback then given back to consumers. Advisory Committees of ex-consumers and carers is another option, as are exit surveys and phone surveys of recent graduates conducted by Consumer Representatives.

OPIOID TREATMENT CLINICS

Some consumers may be concerned that access to feedback or continued access to treatment may be affected by consumers speaking out. Strategies for overcoming this include meetings of consumers, with feedback mechanisms to staff, and Consumer Representatives recruited from another service or an ex-consumer. (See also the CHANGE case study.)

PERINATAL AND FAMILY DRUG HEALTH SERVICES

These services are likely to have similar issues in recruiting Consumer Representatives and participants in focus groups as drug and alcohol counselling services. A best practice example of community involvement from a related health initiative is the Aboriginal Reference Groups set up for the Aboriginal Maternal Infant Health Services, which provide guidance on the program and have a high level of community and consumer engagement.

Consumer participation resources

RESOURCES AND STRATEGIES FOR CONSUMERS WITH SPECIFIC NEEDS

Youth participation

Youth participation is a key principle of the *Youth Health Better Practice Framework*, which was designed to assist services in reviewing, planning and evaluating organisational processes related to youth health-related programming. It includes young people's active involvement in developing, implementing, reviewing, and evaluating services and programs. When young people can express their opinions it provides an important source of feedback about how to make services more youth friendly.

The *Youth Health Better Practice Framework Factsheets*^{xv} suggests services should use existing policies on youth participation as a starting point, in addition to consulting with young people. Be clear on why you want young people to participate, negotiating both parties' roles and expectations. Explain to young people the specific ways in which their input will influence your service.

The *Youth Health Better Practice Framework checklist*^{xvi} within the *NSW Youth Health Policy 2011-2016: Healthy bodies, healthy minds, vibrant futures*^{xvii} asks services the following questions with the aim of improving their youth participation mechanisms:

- Does your service have policies and procedures in place that outline how young people's participation and decision-making can be used in program development, implementation, review and evaluation?
- Does your service regularly review and revise its youth participation mechanism in consultation with young people?
- Does your service provide opportunities for increasing young people's confidence, knowledge and skills in using participation mechanisms?
- Does your service have specific ways in which it acknowledges and values young people's input and contributions?

- Does your service ensure that its youth representatives reflect the diversity of young people's views and needs?

The NSW Commission for Children and Young People^{xviii} has a series of resources including:

- *Citizen Me!* - Helps organisations, including government departments, meaningfully and effectively involve children and young people in their decision-making <http://www.kids.nsw.gov.au/Publications---resources/Participation-resources/Citizen-me-/Citizen-me->
- *TAKING PARTicipation seriously* - Provides practical advice about how to involve children and young people in activities, events and decision-making about issues that affect their lives <http://www.kids.nsw.gov.au/Publications---resources/Participation-resources/Taking-PARTicipation-seriously>

Other resources include:

- Centre for Multicultural Youth Issues (2005). *Considering consulting? A guide to meaningful consultation with young people from refugee and migrant backgrounds* <http://www.cmy.net.au/sites/default/files/publication-documents/Considering%20Consulting%20good%20practice%20guide%202009.pdf>
- Multicultural Disability Advocacy Organisation <http://www.mdaa.org.au/>

Culturally and linguistically diverse (CALD) consumers

Engaging CALD consumers has its own set of requirements, including language needs of consumers and cultural sensitivity. The following strategies are recommended:

- Employ bilingual staff where possible.
- Conduct outreach to specific cultural groups.
- Develop programs in conjunction with CALD communities to target specific communities.
- Provide a list of culturally specific resources and organisations.

- Provide pamphlets and information sheets in a variety of languages. There may be grants available through LHD's Multicultural Health Services to translate resources. Translations of health resources can also be paid for through the NSW Multicultural Health Communications Service <http://www.mhcs.health.nsw.gov.au/mhcs/services/translation/translation.asp>
- Make contact with Multicultural Health Services, CALD organisations and refugee organisations to increase referrals and knowledge sharing, e.g. NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS), <http://www.startts.org.au>; NSW Refugee Health Service; and, if available, the Transcultural Mental Health Centre <http://www.dhi.health.nsw.gov.au/tmhc/default.aspx>
- Provide interpreting services through the local Healthcare Interpreter Services in LHDs where available.
- Use the Telephone Interpreter Service (TIS) 131450 for consumers who need interpreters. On-site interpreters can be booked online http://www.immi.gov.au/living-in-australia/help-with-english/help_with_translating. Non-profit, non-government, community-based organisations for case work and emergency services, where the organisation does not receive funding to provide these services, can apply for exemptions from the fee for telephone interpreters. General Practitioners, Specialists and Pharmacists can also register for free interpreting services <https://www.tisnational.gov.au/> Train workers in CALD cultural competencies.

CONSUMERS WITH A DISABILITY

- Contact the Deaf Society for translators for deaf consumers and/or carers. They are available either on site or through video conferencing. Deaf Society of NSW can also be contacted <http://deafsocietynsw.org.au>. The Deaf Society also offers a service to translate resources such as web-based resources into AUSLAN.
- Make contact with groups for people with a disability such as the Disability Council of New South Wales <http://www.disabilitycouncil.nsw.gov.au>. People with a Disability - advocacy group <http://www.pwd.org.au>. Chronic Illness Alliance - peak advocacy group <http://www.chronicillness.org.au/index.php/ab-out-us>

ABORIGINAL CONSUMER ENGAGEMENT

The harmful use of alcohol and other drugs can be seen as a result of the disadvantage experienced by many Aboriginal people. Aboriginal people are 1.4 times more likely than non-Aboriginal people to abstain from drinking alcohol, but a greater percentage of Aboriginal people who do drink consume alcohol at levels that pose both short-term and long-term risks for their health than non-Aboriginal people. Beyond engaging consumers and developing patient-centred care, an opportunity exists to enhance how the needs of Aboriginal people are met.

Any approach taken needs to be flexible and acknowledge diversity amongst Aboriginal people, community and settings. Aboriginal culture and communities are diverse, comprising many different nations, tribes and groups living in NSW. Exercising a 'one size fits all' approach will not work and services need to tailor their ways of working and communicating to meet the needs of the individuals and communities concerned.

NSW ABORIGINAL HEALTH IMPACT STATEMENT (AHIS) AND GUIDELINES

The NSW AHIS and Guidelines ensures the needs and interests of Aboriginal people are embedded into the development, implementation and evaluation of all NSW Health initiatives. Therefore, an AHIS should be completed wherever possible. For more information, see: <http://www.health.nsw.gov.au/aboriginal/Pages/impact-statement-guideline.aspx>

NSW ABORIGINAL HEALTH PLAN (AHP) 2013-2023

Consumer participation methods for Aboriginal consumers should align with the guidelines of the NSW AHP, which identified six strategic directions to drive the changes needed in the health system to improve Aboriginal health. They are:

1. Building trust through local partnerships.
2. Building the evidence and implementing what works.
3. Ensuring integrated planning and service delivery.
4. Strengthening the Aboriginal workforce.
5. Ensuring culturally safe work environments and health services.
6. Strengthening performance monitoring, management and accountability.

For more information on the NSW AHP see: http://www0.health.nsw.gov.au/policies/pd/2012/PD2012_066.html

The following strategies can also help increase Aboriginal consumer engagement:

- Consult with an Aboriginal organisation, Aboriginal Liaison Officer or Aboriginal Medical Health Service.
- Contact the Chief Executives of the local Aboriginal Medical Service and ask permission to talk to the men's group or women's group being run through the service.
- If possible, employ Aboriginal workers in identified positions.
- Train workers in Aboriginal cultural competency.
- Aboriginal staff should conduct follow-ups with Aboriginal consumers.

Case study: Aboriginal consumer engagement, Hunter New England Local Health District (LHD)

Hunter New England LHD has a specific Aboriginal drug and alcohol team and, overall in the LHD, 12 Aboriginal staff in working in drug and alcohol services. There is an Aboriginal staff forum held three times a year. An Aboriginal staff member attends the first meeting or session in mainstream services with a non-Aboriginal staff member and Aboriginal consumer. Informal training in Aboriginal cultural competency is provided.

Outreach and education is conducted with schools as well as Aboriginal men and women's groups. Focus groups are conducted with Aboriginal consumers over specific issues, such as their experience of consumer surveys and feedback mechanisms such as the Patient Experience Tracker (PET) (see the Hunter New England LHD PET Case Study).

Aboriginal staff conduct follow-ups with Aboriginal consumers. They place their business cards and service pamphlets into discharge folders and tell the consumer that they will call in a week.

GAY, LESBIAN, BISEXUAL AND TRANSGENDER (GLBT) ENGAGEMENT

The following strategies can help increase engagement with GLBT populations:

- Train staff in GLBT cultural competency.
- Run specific programs or groups for GLBT people.
- Make contact with the AIDS Council of NSW (ACON) or the National LGBTI Health Alliance for resources and referral suggestions.

GENERAL RESOURCES

There are many generic resources available to assist health services with consumer participation endeavours. Some useful general consumer and/or carer participation examples are as follows:

Consumer and Community Engagement Framework (February 2012), Health Consumers Queensland (2012), <http://www.health.qld.gov.au/hcq/publications/consumer-engagement.pdf>

Developing a consumer and community engagement strategy: a toolkit for Hospital and Health Services (2012), Health Consumers Queensland, <http://www.health.qld.gov.au/hcq/publications/hcq-toolkit.pdf>

Engaging Healthcare Users: A Framework for Healthy Individuals and Communities (2012), American Hospitals Association, http://www.aha.org/research/cor/content/engaging_health_care_users.pdf

The following report describes current citizen and patient engagement in healthcare decision-making in Belgium. It develops possible alternate models for public involvement in the health system. The report also assesses the acceptability of its recommendations to stakeholders.

Models for citizen and patient involvement in health care policy: Part 1: Exploration of their feasibility and acceptability (January 2013), The Belgian Health Care Knowledge Centre, https://kce.fgov.be/sites/default/files/page_documents/KCE_195C_citizen_and_patient_participation.pdf

DRUG AND ALCOHOL SPECIFIC RESOURCES

Australian resources that are specific to drug and alcohol consumers include:

Straight From the Source: A Practical Guide to Consumer Participation in the Victorian Alcohol and Other Drug Sector (2010), Self Help Addiction Resource Centre

<http://sharc.org.au/wp-content/uploads/2014/04/APSU-Straight-From-the-Source-Manual.pdf>

The Self Help Addiciton Resource Centre - Training Resources for Alcohol and Other Drug (AOD) Services in Victoria is a project funded by the Federal Department of Health, Substance Misuse Service Delivery Grant Fund. The website contains a number of consumer resources

<http://sharc.org.au/consumer-participation/>

Voices on Choices: Working Towards Consumer Participation in the Drug and Alcohol Sector (2010), Anglicare Tasmania, http://www.anglicare-tas.org.au/docs/research/Voices_on_choices_-_working_towards_consumer-led_alcohol_and_drug_treatment.pdf

Treatment Service User's Project, Final Report, Phase 2 (2011), Australian Injecting and Illicit Drug Users League (AIVL), [http://www.health.gov.au/internet/main/publishing.nsf/Content/554CF99A8009BF97CA257BF0001E7552/\\$File/tsuall.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/554CF99A8009BF97CA257BF0001E7552/$File/tsuall.pdf)

NSW Users and AIDS Association (NUAA) have developed a resource, *If I knew then what I know now: A user's guide to pharmacotherapy*, as a guide for potential or new consumers of opioid treatment services. The information contained in the resource was collated from many community consultations held by NUAA with its members. For more information phone NUAA on (02) 8354 7300 or 1800 644 413 or email nuaa@nuaa.org.au.

NADA has developed a Consumer Participation Workplace Audit Tool to support their members. The tool is available publicly here:

http://www.nada.org.au/media/60213/nada_consumer_participation_workplace_audit_tool_sept14.pdf

NADA have developed a Consumer Participation Consent Form to support organisations engage with consumers about the level of participation they are interested in when entering an AOD service. Both of these resources, and more, are available on the *Consumer Participation* page on the NADA website. <http://www.nada.org.au/nada-focus-areas/consumerparticipation/>

CONSUMER POLICIES

The report *Nothing About Us Without Us: Greater, Meaningful Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative*, produced by the Canadian HIV/AIDS Legal Network, International HIV/AIDS Alliance and Open Society Institute, provides the following suggestions:^{xix}

- Do invite several consumers. Don't invite just one of us.
- If possible, do invite a user's group to select representatives (or have an expression of interest or other process so that selection is transparent and fair) and don't always handpick the same consumers that you know and are comfortable with.
- Do invite consumers who are current consumers of a treatment service. Don't only invite former users — it is OK to invite them and they have lots to offer, but they are not the same as I am, and I have a perspective that is valuable and needs to be heard as well.
- Do provide a cash payment for our participation—contrary to most people who attend government meetings, we are not paid to attend by our jobs, but still need to look after our needs.
- Do come to our city or region, if possible. Don't ask us to come and meet you where you are.
- Do guarantee confidentiality. Don't identify what a particular consumer said in proceedings of the meeting.
- Do listen to consumer's answers and take them seriously. Don't just ask the question because it is politically correct to ask us.
- Do ask us what we need. Don't be afraid to ask.
- Do acknowledge that you may have needs too, and that unfamiliarity may make you uncomfortable. Don't assume that I am the problem and the only one who needs to learn.

- Do assign us a support person or provide training (if you ask us to be on a committee or board, not just a one-time event). Don't run your committee or board meetings without acknowledging that it may be the first time for us to be on a committee or board.
- Do consider training for you and the other committee or board members specific to the issue of consumer involvement and ask a consumer to participate.
- Do provide support if we are travelling to cities that we are unfamiliar with.

TRAINING ORGANISATIONS

Training for consumers and staff is available through external agencies. Please contact the following organisations for information about current costs and availability.

Consumers Health Forum of Australia provides generic one-hour online training module, *Guidelines for Consumer Representatives*: <http://ourhealth.org.au/consumer-rep-support/online-training-and-education#guidelines>

Health Consumers NSW runs courses for Consumer Workers and for staff involved in consumer participation. <http://hcnsw.org.au/consumer-representation/training>

Other Registered Training Organisations (RTO's), such as the NSW Institute of Psychiatry (NSWIOP), offer consumer advocate training for mental health consumers, but the criteria for inclusion is a lived experience of a mental illness. Consumer Advocacy courses are available and courses tailored specifically to drug and alcohol consumers can potentially be developed. Contact NSWIOP for more information: (02) 9840 3833; institute@nswiop.nsw.edu.au; www.nswiop.nsw.edu.au

NSW Users and AIDS Association (NUAA) (nuaa.org.au) are not a Registered Training Organisation at this time, but may be available to train consumers and staff in consumer participation. The costs would need to be negotiated with NUAA. Contact NUAA on (02) 8354 7300 or 1800 644 413 or email nuaa@nuaa.org.au

The Public Interest Advocacy Centre runs advocacy workshops for mental health consumers, as well as general advocacy skills that can be customised for particular groups. Costs for customised courses are sliding for Non-government or government organisations. Courses can be delivered in regional NSW but costs of travel will be added. See: <http://www.piac.asn.au/training/customised-training/customised-training>

RELEVANT POLICIES AND TOOLS

These policies are directed to LHDs but some of these may be of assistance to NGO's as well:

National Safety and Quality Health Care Standards (NSQHS). Suggested strategies for meeting these Standards are contained in the *Partnering with Consumers Safety and Quality Improvement Guide*:

http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2_Oct_2012_WEB.pdf

The Queensland Government (2012) has developed *Audit tools for National Safety and Quality Health Service*. Standard 2 (Partnering with Consumers) may assist services or units to plan for accreditation against the national standards: <http://www.health.qld.gov.au/psu/safetyandquality/nsqhss-audit-tools.asp>

The Network of Alcohol and Other Drug Agencies (NADA) has developed a resource tool with the Australian Council on Health Care Standards (ACHS) to assist services to improve consumer participation practices that will contribute to meeting accreditation standards in this area: *ACHS Equip 5: Quality Improvement Resource Tool for Non Government Drug and Alcohol Organisations*. http://www.nada.org.au/media/41192/nada_achs_equip5_resourcetool_april2013.pdf

NSW HEALTH POLICIES

For policy on the formation of committees and sitting fees, see Governance PD2007_089: http://www0.health.nsw.gov.au/policies/pd/2007/pdf/PD2007_089.pdf

For policies on the Codes of Conduct for NSW Health employees (volunteer or paid) see Governance PD2012_018: http://www0.health.nsw.gov.au/policies/pd/2012/pdf/PD2012_018.pdf

Other policies necessary for training such as Occupational Health and Safety Policy and Workers Compensation and Injury Management Policy: http://www0.health.nsw.gov.au/policies/PD/2005/PD2005_360.html

Mandatory reporting on child protection issues:

NSW Health Frontline Procedures for the Protection of Children and Young People:

<http://www0.health.nsw.gov.au/policy/hsp/child-protection/procedures/frontlineprocedures.pdf>
Aboriginal cultural competency. See Governance PD2011_069, *Respecting the Difference: An Aboriginal Cultural Competency Framework for NSW Health*: http://www0.health.nsw.gov.au/policies/pd/2011/pdf/PD2011_069.pdf

NSW Department of Health, 2010, *NSW Youth Health Policy 2011-2016: Healthy bodies, healthy minds, vibrant futures*. NSW Department of Health, North Sydney: http://www0.health.nsw.gov.au/policies/pd/2010/PD2010_073.html

Resources

The tools and strategies recommended in this Guide are based on best practice recommendations. Service planning should take into account consumer feedback from these methods, as well as work closely with the LHD and utilise the District consumer processes and structure where possible. Consumer advisory committees should be established but require capacity building and support to ensure sustainability.

Means of implementing strategies within existing resources may need to be explored in resource-constrained environments. Cost-neutral strategies can be a starting point. Low-cost improvements could be made in client surveys, client focus group methods and, where appropriate, engaging the client more in decision-making. For example, Illawarra Shoalhaven LHD has limited resources available to implement higher cost strategies and therefore focuses on real time consumer feedback and strategies that can improve service accessibility and visibility and treatment outcomes.

Changing internal culture to include consumer participation can also be a slow process and thus realistic timeframes need to be put in place. The support of all levels of management is needed to ensure that realistic priorities and timeframes are established.

RESOURCES FOR CONSUMERS IN CUSTODIAL/DETENTION SETTINGS

In custodial/detention settings, consumers don't have access to communications technology and therefore cannot participate in online surveys such as Survey Monkey. Most are also limited in their movement, often only able to access resources in their immediate location.

There are also high levels of literacy problems; hence resources need to be in simple language and pictures.

The Network's Connections Program, which supports adult correctional patients with drug and alcohol issues by linking them into community-based health and welfare service providers post release, routinely has consumer feedback incorporated into the patient journey.

The Forensic Hospital (see: <http://www.justicehealth.nsw.gov.au/about-us/forensic-health/the-forensic-hospital>) does not conduct drug and alcohol specific consumer participation programs. Drug and Alcohol is represented by NUAA on the Justice Health and Forensic Mental Health Network Community Reference Group.^{xx}

Justice Health and Forensic Mental Health Network undertakes regular patient experience surveys, which aim to assess the perceptions of the NSW custodial population on healthcare services and their access to these services whilst incarcerated. The suggested strategies in this Guide align with the rehabilitation and recovery framework for forensic mental health.

RESOURCES FOR CONSUMERS IN RURAL/REMOTE SETTINGS

There are complications involved in implementing some strategies in a rural/remote environment where there may be a lack of necessary resources to maintain and sustain programs if clients are asked to be advocates. Getting consumers to participate can be difficult and advocates would need payment to be motivated, including travel and accommodation expenses should they be required to travel. There have also been complaints that when consumers pay out of their own pockets the process of invoicing and getting refunded takes too long.

Other less resource intensive consumer participation strategies could be explored in these settings.

List of abbreviations

ACON	AIDS Council of Australia
AHIS	Aboriginal Health Impact Statement
AHP	NSW Aboriginal Health Plan
AUSLAN	Australian Sign Language
CALD	Culturally and Linguistically Diverse
DAMEC	Drug and Alcohol Multicultural Education Centre
FTE	Full Time Employment
GLBT	Gay, Lesbian, Bisexual and Transgender
LHD	Local Health District
NGO	Non Government Organisation
NSQHC	National Safety and Quality in Health Care
NSW	New South Wales
NSWIOP	NSW Institute of Psychiatry
NUAA	NSW Users and AIDS Association
OECD	Organisation for Economic Cooperation and Development
OTL	Opioid Treatment Line
PET	Patient Experience Trackers
RTO	Registered Training Organisation
SESLHD DAS	South Eastern Sydney Local Health District Drug and Alcohol Services
STARTTS	NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors
TCMHC	Trans Cultural Mental Health Centre
TIS	Telephone Interpreter Service

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