



THE UNIVERSITY OF
NEW SOUTH WALES
SYDNEY · 2052 · AUSTRALIA

Sharing Care

Dissemination Report of the Illicit Drug Shared Care Project

**Centre for General Practice Integration Studies
University of New South Wales**

2002

Funded by the Commonwealth Department of Health and Aged Care

Acknowledgements

The Illicit Drug Shared Care Project was implemented and supported through the contributions of a number of people:

Ms Susie Purcell, Project Manager
 Professor Mark Harris, Chief Investigator
 Mr Gawaine Powell Davies, Director, Centre for General Practice Integration Studies UNSW

Members of the project working team:

Ms Paula Cahill, Project Officer, Mid-Western/Central West NSW
 Ms Gayle Stannard, Project Officer, South West Sydney

Members of the steering committee:

Ms Wendy Backhaus	Mid Western Area Health Service
Ms Nicky Bath	Australian Injecting and Illicit Drug Users League (AIVL)
Ms Liane Beatie	Fairfield Division of General Practice
Ms Lyn Chapman	Central West Division of General Practice
Dr Elizabeth Comino	UNSW Centre for Health Equity Training Research and Evaluation (CHETRE)
Dr Jan Copeland	National Drug and Alcohol Research Centre (NDARC)
Ms Lyn Hill	Commonwealth Department of Health and Ageing
Ms Didi Killen	Mid-Western Area Health Service
Dr Shield Knowlden	Department of General Practice Fairfield Hospital and UNSW
Mr James Mabbut	Public Health Unit, South Western Sydney Area Health Service
Ms Victoria Nesire	Drug and Alcohol, South Western Sydney Area Health Service
Professor Ian Webster	Emeritus Professor University of NSW
Professor Nicholas Zwar	Department of General Practice Fairfield Hospital and UNSW

The Literature review was conducted by Ms Jonine Penrose-Wall
 The Dissemination report was prepared by Ms Linda Kurti.

In addition – thanks to the following people:

Ms Etty Matalon in the provision of education workshops for the project
 Mr Terry Bishop for support from the Fairfield Division of General Practice
 All of the service users, service providers and GPs who participated in the project.

ISBN:

© School of Public Health and Community Medicine, University of New South Wales.

For further copies see: <http://www.commed.unsw.edu.au/cgpis>

Table of contents

	<u>Page</u>
1. Introduction	4
2. Key lessons learned	5
3. What is shared care?	6
4. Initiating shared care	9
4.1 Exploring evidence and needs	9
4.2 Assessing the context	10
4.2.1 South West Sydney	10
4.2.2 Mid-Western/Central West NSW	11
4.3 Engaging stakeholders	11
4.3.1 Creating ownership and gaining consensus	11
4.3.2 Consultation processes	13
4.4 Lessons learned	15
5. Implementing shared care	18
5.1 Setting up and maintaining mechanisms for shared care	18
5.1.1 South West Sydney	19
5.1.2 Mid-Western/Central West NSW	20
5.2 Treatment interventions	21
5.3 Lessons learned	21
6. Evaluating shared care	23
6.1 Assessing outcomes and satisfaction	23
6.1.1 Provider survey	23
6.1.2 Client survey	23
6.2 Monitoring and improving program	24
6.3 Lessons learned	24
7. Elements of successful shared care	26
Appendices	27
Appendix 1: Sample memorandum of understanding	28
Appendix 2: Sample information sheets	29
Appendix 3: Consumer questionnaire	31
Appendix 4: Charter of Rights and Responsibilities	37
Appendix 5: Sample pathways for shared care	38
References	40

1. Introduction

The Illicit Drug Shared Care Project (the Project) was funded by the Commonwealth Department of Health and Ageing to develop and trial a model for developing shared care treatment programs for people with illicit drug problems. The model included general practitioners (GPs), drug and alcohol workers and other service providers. The model, and the local treatment programs, were to be trialed and evaluated in an urban and rural area (South West Sydney and Central/Mid Western NSW) with the results to be disseminated nationally.

Management groups were established in the two areas including the Divisions of General Practice (the Divisions), drug and alcohol services, other primary care providers (such as community health, indigenous health, pharmacists), and consumer and community organisations. The partners in the Project formalised their relationship through memoranda of understanding and formed a steering committee for the Project. The management groups provided an important focal point for resolving issues such as gaps in services or service availability and procedures for accessing services by GPs.

The Project objectives were to:

- ◆ conduct a comprehensive review of Australian and overseas literature on shared care models, identifying examples of shared care relevant to illicit drug treatment management;
- ◆ develop models for sharing care between different groups of primary care providers and different situations (eg urban and rural) with people using illicit drugs, based on the best available evidence;
- ◆ identify the most appropriate models to be trialed following consultation with key stakeholders;
- ◆ conduct trials of shared care in two areas involving a number of professional groups including GPs, nurses, health and welfare workers, police, Aboriginal health workers and specialist drug and alcohol workers;
- ◆ evaluate the trials in terms of their impact on organisational structures and collaboration, communication, patient/client satisfaction and outcomes of care, and costs;
- ◆ identify best models of shared care based on these trial projects; and
- ◆ disseminate the results to maximise uptake of the model.

This dissemination report has been prepared to assist in the development of shared care programs between GPs, Divisions, and other groups involved with providing care to people using illicit drugs. The information, and lessons learned, which are provided in this report will be of interest to people who are thinking about improving ways of sharing care across services.

The full report of the trial is available from the Centre for General Practice Integration Studies. The literature review and discussion paper prepared for this Project can be found at: http://www.commed.unsw.edu.au/cgpis/publicat/pub_illicitdrug.htm

2. Key lessons learned

The Project showed that there is scope for better sharing of care between providers even where highly structured shared care is difficult to achieve. The results of this study suggest that the process of consultation and engagement with all the stakeholders is of great importance in the development of shared care with people who use illicit drugs.

1. Engagement needs to occur at all levels, including senior management, to clarify not only key roles but also the human resources, training and time required to develop shared care.

2. Local advisory groups are a key structure to develop and oversee the implementation of shared care processes.

It takes time to develop shared care processes, which are dependent upon the quality of relationships, communication and trust between service providers as well as between service providers and clients. Sharing care also requires flexibility and responsiveness to local situations as they develop in order to provide for clients' changing needs. It is important that the partners recognise that a lengthy period of time may be needed to develop the systems, policies and procedures necessary to ensure seamless care.

3. Sufficient time needs to be devoted to the development of shared care programs and the systems and supports required to make them work.

Consultation with consumers is especially important. This can be difficult at the local level where there may not be organisations or structures to facilitate this. Consumers were supportive of the development of shared care. However, they were concerned to protect their rights and treatment options especially in rural areas where significant financial and distance barriers to accessing GP services exist.

4. Consumer consultation questionnaires and a charter of rights and responsibilities (see Appendix 4) should be considered as part of the development of any shared care program.

The treatment options provided by GPs in this trial included general health care, assessment, provision of community detoxification, brief interventions, pharmacotherapies, relapse prevention and referral. The most important constraint in the development of the trial was the availability of specialised drug and alcohol services with which GPs could share care. Shared care referral and consultation pathways cannot work where services are in short supply or absent.

5. A multidisciplinary approach is required which provides a menu of treatment options, depending on client needs and local service availability.

Building on existing programs and activities, such as methadone maintenance treatment services and activities under the Enhanced Primary Care Program (EPC), was a successful strategy in both urban and rural areas. The EPC activities provided a model for GPs to engage in multidisciplinary care planning as well as an opportunity for Divisions to help build the capacity of practices to work with people who use illicit drugs.

6. Shared care programs should build on existing drug and alcohol shared care programs and other initiatives such as the EPC.

Although providers' needs did differ, most GPs, drug and alcohol providers and other providers expressed the need for some further education and information about various aspects of illicit drug use and treatment options. Despite the considerable problems experienced with staff shortages and other demands on drug and alcohol services during the time of this Project, most providers felt that their knowledge and skills had improved, as had access to support and quality of care. Most felt that their clients had achieved improved outcomes as a result of the Project.

7. Education and training for all health providers are critical components of any shared care program.

3. What is shared care?

Shared care is a structured system for achieving integration of care across multiple autonomous providers and services, including GPs and specialist services. Shared care involves¹:

- ◆ systems to create linkages between services or organisations;
- ◆ common goals, objectives and guidelines;
- ◆ information and communication systems;
- ◆ education and quality assurance; and
- ◆ care planning.

Models of shared care, relevant for informing the Project, were identified in the literature review. The literature however strongly suggests that 'there is no single model' for shared care. While these previous experiences are important in determining the shared care treatment programs, they have also highlighted the need to explore the factors required for the local process of developing shared care programs.

Within this Project, the models piloted in the rural and urban areas were based on a common set of principles derived from the literature and from discussions among the management group:

1. The aim is to reduce harm and improve social functioning and health. Abstinence should be seen as only one possible outcome.
2. Guidelines for treatment and other interventions need to be based on evidence where this is available.
3. Care should be comprehensive, and tailored to address individual as well as population needs, addressing problems associated with specific drugs of dependence as well as co-morbidity.
4. A shared care program should address the effects on social relationships and on children and other family members as well as on other aspects of drug users' health and wellbeing.

The development of shared care in this Project was based on information from the literature, from the experiences of participating services and the consultations. A three-stage process for developing mechanisms for sharing care informed the Project and is outlined below.

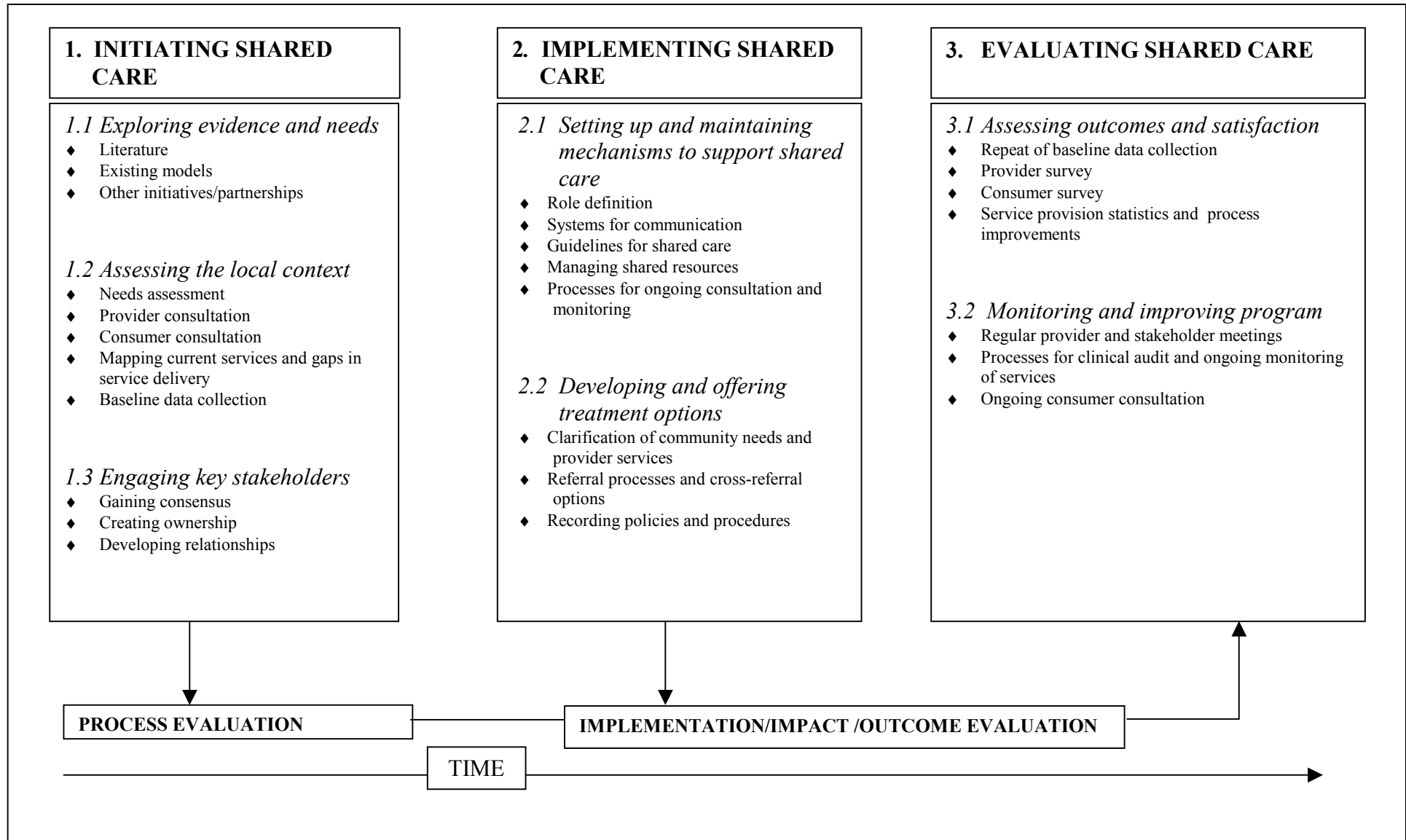
1. Development:
 - ◆ assessing the local context;
 - ◆ exploring evidence and needs;
 - ◆ conducting consultations with service users and service providers; and
 - ◆ setting priorities

2. Implementation:
 - ◆ ensuring a multilevel approach at the level of the region/area, service and individual provider and client;
 - ◆ establishing what resources are available and maximising existing resources;
 - ◆ developing strategies to facilitate access and pathways to care from both primary care and specialist services that are acceptable to clients;
 - ◆ setting up systems to support shared care;
 - ◆ determining the treatment programs and implementing these with service users; and
 - ◆ involving liaison officers who provide a crucial link and resource for the development of programs.

3. Monitoring and quality improvement:
 - ◆ conducting satisfaction questionnaires with service users and service providers;
 - ◆ ensuring sustainability through continuing capacity building and education initiatives; and
 - ◆ enhancing services and service providers' ability to absorb change.

Based on the experiences of the Project, the suggested model for developing shared care is shown on page 8. This is a modified version of the process used within the Project itself. The diagram shows the main steps to create the communication and collaboration necessary for sharing care. This three-stage model is used as a framework for the remainder of the report.

A Model for Developing Shared Care



4. Initiating shared care

1. **Initiating shared care:**
 - exploring evidence and needs
 - assessing the local context
 - engaging key stakeholders
2. Implementing shared care:
 - setting up and maintaining mechanisms to support shared care
 - developing and offering treatment options
3. Evaluating shared care:
 - Assessing outcomes and user and provider satisfaction
 - Monitoring and improving program

4.1 Exploring evidence and needs

The first stage of developing a shared care program requires the collection of information, including evidence about successful shared care programs, based on published literature and evaluation reports, and local information about services and community needs. This is the *evidence* necessary to build a successful program without having to reinvent the wheel. A shared care program is also informed by the *experience* of all those participating, as to what has been tried before and what particular needs should be addressed.

The literature review which was completed as part of this Project is available on line at: http://www.commed.unsw.edu.au/cgpis/publicat/pub_illicitdrug.htm. The existing literature will also provide information on what other shared care models and initiatives have been developed, and what has been learned from them¹.

Consultation and a needs assessment are key activities in developing effective shared care programs specific to local areas. Crucial information might include such things as current levels of service provision, projected service uptake figures, demographics and specific drug use, support services such as language and translation services, satisfaction of users and providers with current services, assessment of perceived unmet needs, and levels of communication and integration across services².

There are a number of Commonwealth and state policies which influence the development of local alcohol and other drug services. A summary of national and New South Wales programs is included in the main report of this Project, available at www.commed.unsw.edu.au/cgpis.

¹ Some additional resources include:

- a. General Practitioner Drug and Alcohol Project report 1994-2000, Central Coast of NSW Shared Care Program.
- b. Shared Care: Specialist Alcohol and Drug Services and GPs working together, Turning Point Alcohol and Other Drug Centre Inc (2000), Victoria NSW.
- c. National Drug and Alcohol Resource Centre (NDARC): <http://ndarc.med.unsw.edu.au/ndarc.nsf>
- d. National Drug Strategy – Commonwealth Department of Health and Ageing website: www.nationaldrugstrategy.gov.au/

² Some resources for consultation and needs assessments include the following:

- a. Mazza & Russell, (2000). 'Dissemination and Implementation of Guidelines in General Practice'. Melbourne: Royal Australian College of General Practitioners.
- b. 'Consultation and participation – what do we mean? Community Consultation and Participation Resource Kit', which can be found on the New South Wales Health website at: <http://www.asnsw.health.nsw.gov.au/public-health/crcp/hib/publications/toc.html>
- c. Edwards, C., Roche, A., Gill, A., Polkinghorne, H., Evershed, K., Mant, A. (1996) *General Practitioner Drug and Alcohol Needs Assessment*. Gosford: Central Coast Area Health Service.

The National Illicit Drug Strategy's demand reduction initiatives target five identified key priority areas.³ Development and implementation of these initiatives is occurring in consultation with the Australian National Council on Drugs (<http://www.ancd.org.au>), State and Territory Governments, non-government organisations and the community sector⁴.

4.2 Assessing the local context

The rural and urban models of care which were trialled in this Project were strongly influenced by the characteristics of the areas in which they were developed and the services operating in these regions. The Project team sought profiles of these areas through the needs assessment and the consultations, including geography, demographics, client groups, services, and issues affecting service provision. Summaries of the profiles of South West Sydney and Central West NSW are given below.

4.2.1 South West Sydney

South Western Sydney Area Health Service (SWSAHS) covers the local government areas of Bankstown, Fairfield, Liverpool, Campbelltown, Camden and Wingecarribe. The population is projected to grow by nearly 110,000 people (or 15%) from 731,615 in 1996 to 840,680 in 2006. The area has a diverse and multicultural population. A high proportion (28.4%) of the population was born overseas, compared to 17.8% for the rest of NSW. Some Local Government Areas have even higher rates, with 53% of people living in the Fairfield Local Government Area born overseas. More than a third (37.5%) of the population speak a language other than English at home. One quarter of Sydney's Aboriginal population lives in South Western Sydney (SWSAHS Website: <http://www.swsahs.nsw.gov.au/main.asp>).

People living in South Western Sydney have more social disadvantage than other areas in NSW. For example, unemployment, sole parent households, people living in public housing and the number of people receiving welfare are high in South Western Sydney.

The Division of Population Health of the SWSAHS includes the Drug and Alcohol Directorate, Department of General Practice and the Public Health Unit. The Drug and Alcohol Directorate has overall responsibility to the Area Board for prevention, treatment, support and rehabilitation for drug and alcohol concerns. The medical staff provide a 24 hour consultancy to all the hospitals and health services in the South West of Sydney. Public methadone programs (involving approximately 700 people in 2001) are supervised through public methadone units. GPs are involved in methadone and buprenorphine treatment

³ See <http://www.health.gov.au/pubhlth/strateg/drugs/illicit/index.htm> The five key priority areas are:

- treatment of users of illicit drugs, including identification of best practice;
- prevention of illicit drug use;
- training and skills development for front line workers who come into contact with people who use drugs or at risk groups;
- monitoring and evaluation, including data collection; and
- research.

⁴ Other sources of information regarding existing initiatives include:

- a. the NSW Health Drug Programs Bureau (<http://www.health.nsw.gov.au/public-health/dpb/about.htm>);
- b. the Australian Drug Foundation (www.adf.org.au);
- c. the Alcohol and Other Drugs Council of Australia (<http://www.adca.org.au>),
- d. local drug & alcohol providers, and
- e. consumer organisations (<http://www.aivl.org.au/default.htm>).

programs on a shared care basis. The area Drug and Alcohol Service runs regular education and training programs for GPs and pharmacists in methadone and buprenorphine treatment options. The General Practice/Pharmacy Liaison Officers (GPPOs) visit and support GPs and pharmacists. Drug Health staff also manage detox on an outpatient and in-patient basis. Education/training programs are conducted for GPs in other areas of drug and alcohol treatment and GPs are supported in a 'shared care' approach in the provision of community detox services. SWSAHS runs a detox unit on the campus of the Fairfield Health service which can provide for 20 in-patients in detox and runs a community detox program.

4.2.2 Mid-Western/Central West NSW

The Mid-Western Area Health Service (MWAHS) covers a diverse geographic area of 59,835 square kilometres stretching from the foot of the Blue Mountains to plains country around Lake Cargelligo. The population of 171,366 residents (1997 Australian Bureau of Statistics) is projected to increase to 184,000 by 2011.

There are projected changes in the structure of the population due to ageing and net outward migration. Much of the region is socio-economically disadvantaged, and this is associated with poorer levels of health in some communities, for example excess mortality and hospitalisation due to injury, digestive disease and respiratory disease. The 3.1% of the Area Health Service's population who are of Aboriginal or Torres Strait Islander origin have a significantly greater burden of ill health, with higher excess mortality, higher rates of hospitalisation and problems with accessing and using health services (MWAHS website: <http://www.mwahs.nsw.gov.au/>).

Alcohol and other drug (A&OD) services in the region are limited and experience difficulties attracting and retaining appropriately qualified staff. The region operates a methadone program, a generalist A&OD service based in community health centres and a MERIT (Magistrates Early Referral Into Treatment) program. The MWAHS A&OD workforce across the 24 communities in the region totals 43 FTE workers, including area program staff. The region also has two non-government treatment services – Weigelli in Cowra, a residential rehabilitation program for the Aboriginal and Torres Strait Islander community and Lyndon, which provides an illicit drug detoxification & living skills program in Orange with a long term residential rehabilitation program in Canowinder. The Area Health Service operates a methadone program in seven towns with approximately 304 clients enrolled.

There are many gaps in service delivery and this also impacts on the ability of clients to access a continuum of care. The lack of detoxification services in the region is particularly significant, especially for alcohol and benzodiazepine dependent people. There are no purpose built A&OD treatment facilities, no A&OD medical specialists in most areas and only a temporarily funded 0.6 FTE Clinical Specialist for the whole MWAHS. Nursing staff report high stress levels in managing these problems. Training and support is made difficult due to distance, travel time and lack of backfill. This impacts significantly on the quality of care.

4.3 Engaging key stakeholders

The consultation showed that engaging key stakeholders was critical for gaining support for the Project and ensuring that it met local needs.

4.3.1 Creating ownership and gaining consensus

The Illicit Drug Shared Care Project was coordinated by a project manager based at the University of New South Wales in the Centre for General Practice Integration Studies. Two project officers were recruited for the local level— one in the rural area of Central West NSW (Mid-Western NSW) and one in the urban area of South West Sydney, NSW. Consortium members formed a steering committee for the Project, with local advisory committees being formed in each of the areas where the trials were carried out.

Memoranda of understanding (MOU) were signed by the participating Divisions, Area Health Services and the University of New South Wales (see sample MOU in Appendix 1). These were important for maintaining commitment for the duration of the Project, in spite of changes in staff and service management, and reassured frontline workers that the Project had management support.

A project plan was developed incorporating a consultation phase, project implementation phase and an evaluation, writing and dissemination phase. The project proposal was submitted and approved by the three relevant ethics committees – the University of New South Wales, South West Sydney Area Health Service and Mid-Western Area Health Service. As part of the ethics process, information forms about the Project were developed for both service providers and participating clients (see Appendix 2 for sample information sheet). Signed consent forms were required from all clients before their inclusion in the Project. The ethics approval also specified that any client or service provider could remove themselves from the trial at any time, and required that participants be over the age of 18.

The Project was initially introduced to service providers and organisations in each area through a discussion paper which was distributed as part of the consultation process (available at www.commed.unsw.edu.au/cgpis/publicat/pub_illicitdrug.htm). This was followed by targeted forums and introductory workshops. Information and fax back forms were mailed or faxed to GPs and other providers and project staff subsequently visited those who expressed interest.

Project officers initially contacted clinicians who provided alcohol and other drug treatments in SWSAHS or Central West NSW and were thought to be interested in the area of illicit drug shared care. Further candidates were then recruited primarily through snowball techniques. In all, 201 service providers were approached either personally or through letters introducing the Project and inviting them to participate, with a facsimile form to indicate their level of interest. Those interested were followed up with phone calls and then visited by the local project officers.

Different strategies were used for reaching service providers in each of the two areas. In South West Sydney, after initial consultation with service providers and consumers a letter was sent to GPs, drug and alcohol services, Aboriginal health services and pharmacists in the area outlining the Project and inviting providers to express their interest in participating. Contact lists were provided by area drug and alcohol GP liaison officers and the Fairfield Division of General Practice.

In the Central West the first stage of recruitment involved an assessment of information and resources gathered during the Division's earlier drug and alcohol project. Service maps were developed that included information about GP methadone prescribers, GPs with an interest in alcohol and other drugs, drug and alcohol services (government and non-government), needle

and syringe programs and sexual health services. Community Drug Action Teams meetings, Mental Health services, probation and parole/corrections health, dosing pharmacies and other community based support groups were also informed about the Project.

Involving drug and alcohol service providers in GP education activities worked well. However high staff turnover in the drug and alcohol sector resulted in an ongoing process of introducing and involving new drug and alcohol workers. It required a continuous effort to maintain the partnerships between GPs and other service providers.

Strategies that were found to be effective for engaging stakeholders included:

- ◆ mapping the services available in the community, using existing manuals of services as a starting point;
- ◆ attending meetings in each area, including the Community Drug Action Team (CDAT) meetings;
- ◆ promoting the idea of shared care and the various opportunities for shared care treatment at workshops and introductory meetings;
- ◆ mailing out information and following up with phone calls and practice visits; and
- ◆ using local GPs who were providing services for illicit drug users as a role model and resource for other GPs and as well advisers on methods of dissemination.

Although a number of rural GPs initially expressed interest, many found it difficult to find time to complete the pre-trial questionnaire and be officially 'recruited' to the Project. However where GPs with positive experiences of illicit drug shared care were willing to share their experiences with other GPs in workshops and meetings this helped overcome concerns about involvement with shared care. Drug and alcohol GPPOs were also very effective in supporting recruitment.

Barriers to GP recruitment included the following.

- ◆ Some GPs were reluctant to become involved because of concerns that illicit drug using patients might disrupt their practices⁵.
- ◆ Some busy GPs were hard to access (and were in some cases 'protected' by reception staff). In some practices busy support staff were also limited in the amount of support they could give the GP.
- ◆ Some GPs, having reached the number of methadone patients that they could reasonably manage, felt pressured by the expectation that they should increase the number of methadone patients on their caseload.

A variety of strategies were needed to match the needs of different groups and different areas, although an understanding of services available in the area was always a crucial starting point. Personal approaches were also important, particularly with GPs, and project officers took the time to talk about any difficulties and concerns.

⁵ An interview with one general practitioner revealed that this practice had ceased providing treatment to illicit drug using patients. The practice decision was based on the difficulties experienced with the behaviour, levels of intoxication and states of withdrawal of heroin using patients. This had caused problems for other patients, the doctors and practice staff.

4.3.2 Consultation processes

Extensive consultations were carried out at national, state and local levels for the Project. The consultations involved service providers and their organisations, policy makers, consumer organisations, and consumers of illicit drug treatment services residing in SWSAHS and MWAHS.

4.3.1.1 National consultation

The aim of the national and state consultations was to get advice from a wide range of stakeholders and service providers and to make sure that the trial would be relevant to as wide a range of settings as possible. A discussion paper was developed in consultation with the steering committee and reviewed by the Department of Health and Ageing. The final version of the paper was distributed to key stakeholders who were asked to complete a questionnaire providing feedback on the paper. The discussion paper was then distributed to numerous workers and organisations at a national, state and local level.

Respondents identified the following as particularly important if service providers were to provide effective shared care:

- education and training of service providers;
- inclusion of families and significant others in treatment provision; and
- ensuring that adequate support structures were available for consumers and service providers.

They also identified factors which needed to be addressed at the local or organisational level. These included:

- local consumer input;
- liaising with other projects;
- financial incentives for service providers;
- pharmacist involvement;
- planning for sustainability; and
- using a range of different methods for disseminating the results of the project.

In addition, there were some areas that were not included in the discussion paper but were considered important. These were:

- reviewing education and training needs;
- involving Family Drug Support;
- using support structures to assist collaboration (eg. GP Liaison Officers);
- consumer input (perhaps through a consultation questionnaire);
- education on use of the EPC Medicare Benefit Schedule items; and
- linking in with local service development to ensure sustainability.

These issues were incorporated into the project plan and included where possible in the development of the local shared care treatment programs.

4.3.1.2 Local consultation

The aim of local consultations was to ensure that the Project was locally appropriate and to begin to engage those who might take part in the trial. These consultations used the discussion paper, and service providers were invited to fill out the pre-trial questionnaire, 58 of which were completed.

The consultations were conducted through the following activities:

- Using the Local Advisory Group as a forum for discussing the Project. This involved representatives from the Area Health Services, Aboriginal Health, GPs, a Pharmacist, Police, Drug and Alcohol treatment providers, the Divisions of General Practice, Community Health and local government.
- Informal discussions with D&A service providers regarding local illicit drug trends, service gaps and opportunities for expansion of shared care.
- Interagency or discipline meetings. These were a good way to access services, and also provided an opportunity for groups to fill in the pre-trial questionnaire. Additional cannabis information sessions were arranged at agencies and the project officer asked them to complete the discussion paper when they did the evaluation.
- Drug and Alcohol Forums. These provided an opportunity to share information, network, build partnerships and consult with drug and alcohol service providers further regarding illicit drug shared care.
- The Project provided a series of articles published in the Fairfield Division of General Practice newsletter. These articles included information about service providers in the Fairfield area, referral criteria, hours of operation and contact details⁶.

Issues raised in these consultations were also taken into account in developing the local shared care programs.

4.3.1.3 Consumer consultations

The aim of the consumer consultations was to find out what consumers wanted from shared care, and to engage them as active participants in the project.

Research has shown that there are general benefits from involving consumers through consultation processes. These benefits include:

- better needs identification and planning, leading to higher quality services and products;
- better quality assurance;
- a higher profile of health services in the community, with health professionals being seen as more approachable;
- broader support for health service activities;
- greater credibility when lobbying government; and
- a greater voice for consumers, leading to a greater sense of influence over health services they use and enhanced self-esteem².

A consumer consultation questionnaire was developed in consultation with user organisations (Appendix 3), including the Australian Injecting and Illicit Drug Users League (AIVL) and NSW Users AIDS Association (NUAA). The consumer consultation questionnaire was circulated to members of user organisations and to people who use illicit drugs for comment and pre-testing. The questionnaire was then administered on location at drug and alcohol services in both local areas, primarily by the local project officers.

⁶ This strategy did not occur in the Central West. However some information was distributed to GPs.

4.4 Lessons learned

The consultations contributed useful ideas for developing the shared care program and helped create relationships with important groups. The process of consultation also enabled the project committee, which was itself multi-disciplinary, to review its ideas and develop a consensus about the direction that shared care should take.

A number of important lessons were learned from these consultations.

Effective communication between GPs, drug and alcohol service providers, health sector managers, and area drug and alcohol services was influenced by service boundaries. In South Western Sydney in particular, as there were several Divisions whose boundaries fell into the SWSAHS, it would have been of benefit to have other Divisions of General Practice (in addition to Fairfield Division which was participating in the Project) involved in the SWSAHS trial. In both rural and urban areas, there was a need for regular area drug and alcohol meetings where shared care issues could be discussed.

There were advantages in recruiting and educating GPs and drug and alcohol workers for shared care at the same time. This facilitated cross-disciplinary discussion and communication as well as providing training for participants.

There were a number of barriers to participation in the Project. One of the community health drug and alcohol teams did not participate, making it difficult to provide shared care for clients or engage GPs in that sector, and one of the SWSAHS Drugs in Pregnancy services stated that they did not have contact with GPs. Changes to drug treatment services in Fairfield restricted the opportunity to engage some service providers. It was also difficult to involve this service in some aspects of shared care as drug and alcohol counselling positions were not filled at the time of the project. In both the rural and urban areas, many GPs remained reluctant to provide services to people who use illicit drugs.

Factors which would help sustain the effectiveness of future projects include:

- the establishment of permanent General Practice Pharmacy Liaison Officers (GPPLLO) positions to assist with care plans and keep referral information updated; and
- regular ongoing meetings between service providers.

The consumer/service user consultation was particularly valuable, although the challenge of meeting with the consumer group made it perhaps the hardest part of the consultations to carry out.

Some respondents whose first language was not English experienced difficulties with participating in the consultation process. It would have been desirable to use interpreters, but unfortunately this was not practical in this study.

Other research projects operating at the same time provided financial inducements to consumers to participate. This made it more difficult to engage consumers in this consultation, where there were no financial benefits.

Service users wanted to be respected, know their rights and responsibilities and have an active role in selecting treatment options and setting their own goals. Most consumers were at least

moderately satisfied with their general medical and drug and alcohol care and desired a greater role for GPs in their drug and alcohol management as long as this did not restrict access to drug and alcohol services. Confidentiality was an important issue in relation to all providers largely because of the stigma associated with illicit drug use. However most consumers accepted that, with appropriate safeguards, providers needed to communicate with each other.

The process of consulting consumers led to the development of a Charter of Users Rights and Responsibilities (Appendix 4). The Charter was developed in collaboration with and has been endorsed by both the New South Wales Users AIDS Association (NUAA) and the Australian Injecting and Illicit Drug Users League (AIVL). The goal of the charter is to provide a standard set of principles to which both service providers and service users agree to adhere. It is a mechanism for ensuring the rights and responsibilities of both service users and service providers are respected and protected. The charter is being promoted to services and recommended for incorporation into service delivery mechanisms. The charter is also a reminder to service providers of the importance of service user consultation in all aspects of treatment and service development and that sharing care involves all service providers and service users as equal partners.

5. Implementing shared care

1. Initiating shared care:
 - exploring evidence and needs
 - assessing the local context
 - engaging key stakeholders
2. **Implementing shared care:**
 - **setting up and maintaining mechanisms to support shared care**
 - **developing and offering treatment options**
3. Evaluating shared care:
 - Assessing outcomes and user and provider satisfaction
 - Monitoring and improving program

5.1 Setting up and maintaining mechanisms

Following the initial assessment and scoping of the initiation phase, the implementation phase requires the *establishment* of mechanisms which allow different services to work together to share care, and the *development* of effective treatment options for service users. Important elements for this phase include:

- facilitating links between GPs, pharmacists and drug and alcohol services (for example through the GPPLO positions);
- identifying and disseminating guidelines;
- establishing protocols for referral and consultation between primary care and drug and alcohol services;
- training primary care providers and drug and alcohol workers;
- developing ways to support practices (practice visits etc);
- establishing systems for consultation (eg telephone advice, referral);
- care planning involving GPs and drug and alcohol services; and
- involving GP practice staff and practice nurses.

Central to the success of all these activities is the commitment of management to the process of shared care, and the ownership of those who are actually delivering services. In both rural and urban areas, commitment and ownership were obtained through continuous consultation and involvement in decision-making processes.

The development of the treatment models for the shared care trials were informed by existing literature, evidence, the experiences of other services in their attempts to establish shared care treatment, and by the consultation process. The importance of the local context became increasingly evident during the consultation. Issues such as the availability, culture and priorities of the organisations involved (especially the Divisions of General Practice and the drug and alcohol services) were critical to the establishment of the model as well as its sustainability.

The structures and systems for shared care were particularly important. In each locality there were management groups for the implementation of the shared care program that included the Divisions of General Practice, the drug and alcohol services, other primary care providers (such as community health, Aboriginal health, pharmacists) consumer and community organisations. These provided an important forum for resolving issues such as gaps in services or service availability and procedures for accessing services by GPs.

The program encouraged multi-disciplinary treatment, with service users being able to get different parts of their care from a range of service providers, with the range of services

depending on the availability and the capacity of different services. However this was restricted to health services: despite consultations and attempts at engagement, it proved difficult to involve other sectors in the trial.

The sharing of care was supported in a variety of ways.

GP/Pharmacy Liaison Officers

The liaison officers played an important role in supporting shared care for participants in the trial.

Guidelines

Where possible evidence based guidelines and protocols were used. This was most formalised for community detoxification and pharmacotherapies (eg NSW Health guidelines for detoxification and The NSW Methadone Maintenance Treatment Clinical Practice Guidelines).

Care plans

GPs were encouraged to develop care plans for clients within the program. The EPC Program includes payments to GPs for developing care plans or arranging case conferences for clients with complex multidisciplinary health care needs³. These provided an important tool for role clarification and communication.

Monitoring and quality improvement

As a part of the trial, the treatment options provided to service users and the outcomes of that care were monitored for feedback to individual providers.

Specific details regarding the ways in which the Project was developed in South West Sydney and Central West are given below.

5.1.1 South West Sydney

An Illicit Drug Shared Care Information Manual was developed by a small working group from the SWS local advisory group for the Project, including the project manager and the local project officer. All service providers who had expressed interest in the project were invited to attend an introductory evening at which the manual was launched.

A working group from the local advisory group developed flow charts of pathways through treatment for clients presenting through a GP or a drug and alcohol service. The GP flow charts outlined the options or steps for establishing shared care with a client who presented at their surgery. The flow chart for drug and alcohol workers outlined when and how to involve a GP in illicit drug treatment (Appendix 5). These treatment options included the use of EPC items to help establish shared care through care plans and case conferences with other service providers.

The treatment options in South West Sydney predominantly involved pharmacotherapy treatment options for people dependent on heroin, cannabis treatment interventions and community detoxification. They were initially developed around a 'single point of access' telephone number for drug treatment services, which had recently been funded as a recommendation from the NSW Drug Summit (1999). This was intended to provide a single contact point for people experiencing problems associated with their illicit drug use which would channel clients into appropriate treatment services. However, difficulties with

establishing this service (for example the phone service was not available at the expected date⁷ and there were staff shortages in out-patient counselling services) meant that other mechanisms for shared care had to be encouraged, for example the use of the EPC items.

GPs were offered education sessions to increase their knowledge of other services to which they could refer patients with illicit drug concerns. These were organised by the Project in collaboration with area drug and alcohol services and the Fairfield Division. Education and training for service providers was an important part of setting up the program, both for recruiting providers to the program and for increasing their skills in providing treatment to people with illicit drug problems. Where possible the training sessions included a range of service providers, both GPs and other providers such as drug and alcohol workers.

Education/training workshops for drug and alcohol workers on conducting the Brief Treatment Outcome Measure (BTOM) interviews were also organised by the Project. Those who attended the workshop were provided with further information about the Project and invited to complete the pre-trial questionnaire. Relevant information regarding Enhanced Primary Care items were incorporated into the education workshops. The Project also assisted in other education activities convened by SWSAHS and agency visits for GPs arranged by the Fairfield Division.

5.1.2 Mid-Western/Central West NSW

The Project recognised that practice nurses and other staff played an important role in helping people with illicit drug problems to access treatment. The role of practice nurses and other staff was frequently mentioned in the consumer consultations, and their involvement in shared care is supported by Commonwealth Government initiatives, including the EPC items and the Rural Practice Nurse Incentives.

One widespread concern identified through the consultations was the extent of cannabis use in the Central West and the lack of treatment services, provider knowledge and skill for addressing this with clients. In response, five cannabis brief intervention workshops were held in Lithgow, Bathurst and Orange. They were facilitated by a clinical psychologist and consultant with the National Drug and Alcohol Research Centre (NDARC) and attended by 42 service providers including GPs, drug and alcohol workers and other health providers such as mental health workers, probation and parole officers and supported accommodation workers.

Brief Treatment Outcome Measure (BTOM) education/training workshops were also conducted, primarily with alcohol and other drug workers. Additional support for workers to complete the BTOM with their clients was negotiated with the area health service.

Although the Project was a pilot program, it was recognised from the start that shared care would only be sustainable if it was integrated into mainstream services. The project officer therefore participated in strategic planning and submission development for A&OD services wherever possible.

⁷ This central telephone point of contact is now operational and functioning smoothly.

5.2 Treatment interventions

The treatment models for shared care used in this Project were based on evidence from the literature, the experiences of other services which had attempted to establish shared care and on the outcomes of the consultations. During the consultations it became increasingly evident that the local context would have a considerable impact on the model. The capacity, culture and priorities of the organisations involved (especially the Divisions and drug and alcohol services) had to be taken into account if the model was to be successful and sustainable.

Initial discussions regarding the treatment options most suitable for sharing care focused particularly on pharmacotherapies. There were already several GPs in each area who were accredited methadone prescribers and were working in shared care arrangements, which provided a starting point for increasing pharmacotherapeutic interventions among other GPs. The consultations also suggested to the steering committee that the real need was for a shared care pathway that would provide multiple options for managing all illicit drugs.

As the trial evolved, the range of treatment interventions included:

- general health care including screening for blood borne viruses, immunisation and care for inter-current illnesses and providing care for families and children;
- identification and assessments of illicit drug use;
- providing community detoxification from illicit substances;
- pharmacotherapy options for managing opiate dependence, especially methadone and buprenorphine;
- brief interventions for cannabis dependence;
- relapse prevention; and
- referral to drug and alcohol services, and residential services.

The sharing of care was organised in a variety of ways. Some service users were referred from drug and alcohol services to GPs for shared care. (This particularly applied to people who were well stabilised on methadone maintenance programs). Some service users were identified by a service provider as being already engaged in informal shared arrangements. The program made it possible to formalise this and to define the communication and care planning processes more clearly. Some GPs and pharmacists who were providing drug and alcohol interventions received consultation support from the drug and alcohol service.

5.3 Lessons learned

The biggest challenge facing the implementation of the shared care interventions in both areas was the availability of drug and alcohol services as they attempted to respond to staff pressures operating during the study. This affected the support they were able to offer GPs and the viability of the referral and communication pathways developed.

The lessons from the client recruitment process included the following:

- ◆ Relying on methadone clinics as a source of participants limited the scope of issues being managed, the range of appropriate interventions and to some extent the opportunities for GP involvement.
- ◆ Where participants were recruited through general practice this allowed a wider range of other treatment options to be considered.

- ◆ Clients who identified problems with cannabis use often used other drugs as well. This meant that it might have been inappropriate for the GP to provide a cannabis brief intervention. Where such clients were recruited, GPs often experienced problems referring to drug and alcohol services for non-pharmacotherapy treatments because they were unavailable at the time of the trial. Since the completion of the Project, these services are more readily available and some of the staff positions which had been vacant have been filled.

Although it required significant effort to engage with GPs this was not an insurmountable problem. GPs and the other primary care providers were prepared to share care according to the flexible models developed. A large number of GPs did engage in the education workshops, were interested in learning new skills and their evaluations were generally positive. However they did require support and the ability to refer patients who they could not treat. Unfortunately this was not always available.

Other barriers that GPs experienced included limited access to ongoing education because of high workloads especially in the rural area, and lack of practice support to manage new procedures especially in the urban area.

On the positive side the support from Division EPC coordinators and the drug and alcohol GPPLOs was critical to the implementation of the model of care. The EPC activities provided a model for multidisciplinary care and capacity building.

6. Evaluating shared care

1. Initiating shared care:
 - exploring evidence and needs
 - assessing the local context
 - engaging key stakeholders
2. Implementing shared care:
 - setting up and maintaining mechanisms to support shared care
 - developing and offering treatment options
3. **Evaluating shared care:**
 - **Assessing outcomes and user and provider satisfaction**
 - **Monitoring and improving program**

6.1 Assessing outcomes and satisfaction

Once the mechanisms for sharing care have been established, and the treatment options have been developed and made available, ongoing processes for *evaluation* and *continual improvement* should be created. In this Project evaluation was carried out using a service provider survey, a client satisfaction survey and the Brief Treatment Outcomes Measure (BTOM). A detailed report of the evaluation of the Project is contained in the full report of the trials, available at www.commed.unsw.edu.au/cgpis.

6.1.1 Service provider survey

Service provider pre-trial and follow-up questionnaires were developed by building on needs assessment questionnaires used in previous studies, both in the area of alcohol and other drugs and in other areas of health care research involving GPs. They were piloted within both local areas. Seventy-six of the original 104 service providers completed the follow-up questionnaire. Of these, 41 were from South Western Sydney and 35 from Central West NSW. Thirty-six were drug and alcohol workers, 23 were GPs, 2 were Aboriginal health workers; there was 1 pharmacist, 1 corrections health officer, and 13 other service providers (primarily mental health providers). Of the 28 who did not complete the final survey, most had moved onto other services or positions and were no longer participating in the Project. Only two service providers said they did not have time to complete the follow-up survey.

The pre-trial questionnaires were conducted by the local project officers and the follow-up service provider questionnaires were conducted by the SWS local project officer and a casual project worker employed in Central West NSW. For the follow-up process, the project workers contacted service providers who had completed the pre-trial questionnaire and who were participating in the shared care project. Once contact had been made, a time was scheduled to complete the questionnaire either face to face or over the phone. A few questionnaires were left with service providers for self-completion and later returned.

Although the trial period was only three months, over 50% of GPs felt that their quality of care had improved, and a third of providers, both GPs and drug and alcohol workers, felt that access to education, ability to involve clients in decision-making, and understanding of drug use had improved.

6.1.2 Client evaluations

The client evaluations aimed to determine what effect the trial had on the satisfaction, service use and health status of service users at baseline and follow up. Sixty-three clients were

recruited to the Project, of whom 42 completed baseline BTOM questionnaires, 20 completed the follow-up BTOMs and 22 clients completed the satisfaction survey.

Clients were followed up through the service providers who initially recruited them to the Project. Local project officers contacted the services who were providing treatment for participating clients at three months from baseline. Where clients were unable to be contacted, project officers attempted to locate clients through the contact details they provided upon completing the baseline BTOMs.

The client satisfaction questionnaires were completed face to face with clients who had been in treatment for three months. Attempts were made to complete the satisfaction questionnaires when clients completed their follow-up brief treatment outcome measure questionnaire. In some instances, this was not possible. As some clients completed their follow-up BTOM with a service provider from their treatment service, the project officer needed to contact the client separately to complete the satisfaction questionnaire. It was not appropriate for service providers of the services involved in care to complete the satisfaction questionnaires with clients, as this would have affected the reliability of the questionnaires. It was necessary for some questionnaires to be completed with clients over the phone.

Clients reported high levels of satisfaction, and felt that their care under the new shared care arrangements was better than it had been previously. Comments such as this were common: *“This time was no comparison as the previous 18 months was of no benefit – this episode was good.”* Another wrote that *“I go to several people who got the same information and are consistent”*, while one person added *“shared care made it a lot easier. Previously they didn’t know that you were supposed to be there.”*

6.2 Monitoring and improving program

A majority of the providers who were surveyed indicated that they would continue to be involved in shared care. The “normalisation” of shared care for illicit drug users can be supported through the roles of the GPPOs and through incorporating shared care principles into the Divisions’ drug and alcohol and EPC programs.

Feeding back the findings of the evaluation to all participants in the Project has helped to inform further development of drug and alcohol services in both areas. It is envisaged that this process will continue to occur even though the formal Project itself is completed. The incorporation of shared care issues and protocols into strategic planning documents and shared care project plans at the local areas will further assist with the sustainability of sharing care at local levels.

6.3 Lessons learned

There was support for the concept of shared care from both clients and providers at baseline and follow up.

Urban service providers indicated that they needed more professional support but still felt more satisfied with the services they provided compared with their rural counterparts. This could relate to the particular nature of the location and services offered in South West Sydney.

These services were already working to some extent in shared care arrangements, which could explain the higher level of satisfaction than in Central West where providers had fewer shared care arrangements for illicit drug users in place prior to the Project.

Rural providers identified more barriers to sharing care than their urban counterparts. The lack of GPs who bulk bill is perceived to be an important barrier to access to shared care in the rural area.

The majority of providers felt that there had been some improvement in access and quality of care over the period although their ability to involve clients in decisions about treatment was largely unchanged. The greatest improvement regarded expressed concerns about disruptions to general practice by drug using clients. This suggests that the program had been successful in addressing these concerns.

Difficulties were encountered when attempting to follow-up clients.

One mechanism for meeting up with clients to complete the follow-up questionnaires was to make times to meet with clients during their appointments with their service providers. However this proved difficult when appointments were missed as it was difficult for project officers to keep rescheduling and presenting at every appointment made by clients.

It was expected that follow-up methods would be easier for clients on methadone maintenance treatment programs, but this did not prove to be the case. Most methadone services in SWSAHS had been introducing and/or implementing the BTOMs as standard practice, so that project officers were able to gain copies of those BTOMs completed as part of treatment with these services, with client consent. However problems arose when clients dropped out of treatment or started and stopped treatment on a number of occasions during the three month period – which meant it was not possible to obtain accurate follow-up BTOM data. The stopping and starting of treatment during the course of the Project was the main reason for the inability to follow-up clients on the methadone program within the short time frame of the trial.

Many clients were not able to be contacted. Some of the reasons included such communications reasons as the telephone being disconnected or the parents of the clients being suspicious of telephone calls (for confidentiality reasons the project officers could not provide information to the parents). Other reasons included the client declining to participate further in the trial, dropping out of treatment without notice, or going to prison. In addition, increased law enforcement programs at the time of the trial may have made many clients or their families unwilling to respond to telephone follow up.

7. Elements of successful shared care

What are the crucial elements in sharing care between providers for users of illicit drugs?

Some of the most important lessons learned from this project are the following:

- ◆ MOUs are helpful in providing a framework for relationships, but could be improved by including agreements at each level of the services, and by being reviewed regularly.
- ◆ There is a need for realistic support and acceptance that managing complex conditions takes time; within this Project 18 months was insufficient to establish and ensure that pathways and opportunities were sharing care were functioning smoothly within two area health services, particularly when one area was going through a major transition period.
- ◆ Establishing models for sharing care takes time and requires understanding between service providers.
- ◆ Consultation with consumers is especially important, but not easy to implement.
- ◆ Sharing care in a relatively informal way across services is a more attainable outcome than a very formal 'shared care' arrangement; in the long term it is cooperative service development and provision that is likely to make the most difference.

Some of the elements which were important in developing and refining the shared care program were:

- Service mapping to identify appropriate and inclusive participation;
- Strategies to attract engagement and involvement of stakeholders;
- Strategies to facilitate access and pathways to care from both primary care and specialist services that are acceptable to clients;
- Mechanisms to monitor and improve quality of care;
- Identification of clear benefits for providers, services and clients;
- A multilevel approach at the level of the region/area, service and individual provider and client;
- Identification of competing programs and priorities for all providers;
- Liaison officers to provide a crucial link and resource for the development of programs; and
- Opportunities for reflection and critical evaluation.

Some pointers to those intending to establish or improve shared care arrangements include the following:

- ◆ Know the local services very well and engage them early.
- ◆ Include multi-disciplinary teams, genuine partnerships, and high level communication and information exchange systems as foundations for shared care.
- ◆ Monitor and feed back the client's perspectives on the process to maintain and improve the services provided.
- ◆ Personalise the education/training needs of the various sectors and locations.
- ◆ Develop processes for sharing care which are most responsive to local needs, including the placement of and communication between services.

Appendices

1. Sample memorandum of understanding
2. Sample information sheet
3. Consumer questionnaire
4. Charter of Rights and Responsibilities
5. Sample pathways for shared care

Appendix 1

MEMORANDUM OF UNDERSTANDING BETWEEN:

1. University of NSW
2. Division of General Practice
3. Area Health Service

The parties aim to work in collaboration to develop and pilot a model of shared care for illicit drug users, building on existing collaborative projects and activities between the Area Health Service and the Division of General Practice.

The project will be managed by a joint committee comprising representation from all the parties with input from other stakeholders.

The **University of NSW** will coordinate the overall project, providing professional input and funding to support the development of materials and provision of a local project officer on site for 12 months to implement and collect evaluation data on the pilot study. UNSW will provide reports and feedback to both the Area Health Service and the Division of General Practice.

The **Division of General Practice** will facilitate and support the involvement to general practitioners in the conduct of the pilot. This may involve communicating with GPs through the divisions usual means as well as working with the University of NSW to develop the model and organise local education and support systems for GPs. The Division will provide appropriate information for planning and evaluation of the trial.

The **Area Health Service** will provide appropriate support and services to underpin shared care by GPs and other primary care providers involved in illicit drug shared care in accord with local service availability and models of care. This will include contributing to training and education for GPs in illicit drug shared care. The Service will provide appropriate information for planning and evaluation of the trial.

Signed

On Behalf of UNSW

On Behalf of the
Division of General Practice

On Behalf of the
Area Health Service

Appendix 2

Illicit Drug Shared Care Project

Sample Information Sheet for Health Care Providers

The Illicit Drug Shared Care project is a study to improve the health care of people presenting to services with concerns about their illicit drug use. The aim of the study is to improve the coordination of health care between general practitioners, specialist drug and alcohol workers and other relevant professionals. This will enable timely delivery of health care for people using illicit drugs, improve management of physical and mental health issues and address social support networks, housing, legal assistance and education and training.

Patients/clients will be approached for recruitment to the study upon their presentation to General Practitioners and Drug and Alcohol Services. If you agree to participate you will be asked to participate in a coordinated shared care arrangement with appropriate patients/clients and other health professionals. The treatment interventions included in this study are outlined in the project information folder.

Your participation is important and will help to inform the development of treatment services for people who use illicit drugs. Service providers and patients/clients participating in the Illicit Drug Shared Care project will be voluntary. All of the information that you provide is confidential and will not be used for any purpose other than that of the study. You might be required to conduct a questionnaire at the beginning of treatment, at three monthly intervals and at the completion of treatment. This will comprise of the Brief Treatment Outcome Measure (BTOM) developed by the National Drug and Alcohol Research Centre (NDARC). Any service provider conducting the BTOM will be provided training on the questionnaire interview.

A project officer will contact patients/clients in three and six months to complete a short telephone administered questionnaire about how their health care is going and how they feel about this care. The study will last for 6 months. You have a right not to participate in, or to subsequently withdraw from the study. Any decision not to participate will not affect your current or future relationships with any institution cooperating in this study.

If you would like any more information please contact the following:

NAME AND ADDRESSES OF LOCAL CONTACTS

Illicit Drug Shared Care Project

Sample Information Sheet for Consumers

Your doctor/health care professional is participating in a study to improve the health care of people with concerns about their illicit drug use. The aim of the study is to improve the coordination of health care between doctors, specialist drug and alcohol workers and other relevant professionals.

Patients/clients will be asked if they want to participate by their General Practitioners (doctors) and Drug and Alcohol Service workers. If you agree to participate you will be assigned to receive coordinated shared care with your doctor and other health professionals and complete a brief treatment questionnaire. Your primary health care professional will continue to be the main person treating you. A project officer will contact you in three and six months to complete a short telephone questionnaire about how your health care is progressing and how you feel about this care. The study will last for 6 months.

Your participation is important and will help us develop better services for the future. Participation in the Illicit Drug Shared Care project is entirely voluntary. All of the information that you provide for this project will be kept confidential except, as in standard treatment arrangements, where there are legal reasons for limiting confidentiality (e.g. if child abuse or a serious criminal offence is involved). Your health care professional can explain these limits to confidentiality in more detail.

You have a right not to participate in the study, or to withdraw from it at anytime, and this will not affect your treatment or your relationship with your doctor, or any other person treating you.

If you would like any more information please do not hesitate to ask your doctor or contact any of the following:

NAME AND ADDRESSES OF LOCAL CONTACTS

Appendix 3



WOULD YOU LIKE TO
HAVE YOUR SAY ON
LOCAL DRUG
TREATMENT?

If you have answered **yes**, then welcome to the ‘SHARED CARE OF ILLICT DRUG TREATMENT PROGRAMS’. These programs will involve illicit drug users, General Practitioners (GPs), Drug and Alcohol Services, Needle and Syringe Programs (NSP), Pharmacists, Aboriginal Health workers and other primary health care providers

What is it?

This project believes that drug users have the right to access good services as easily as possible and to be provided with quality care. Research is showing us that:

- most people who experience problems with illicit drug use present to GPs before going to Drug and Alcohol services.
- many drug services have waiting lists and some drug users prefer to access drug treatment from a GP.
- many GPs do not feel able to work with drug users unless they can get support from Drug and Alcohol services

This project is trying to tackle these issues by bringing together a variety of services to work together to provide you with quality drug treatment and support for any other needs that you may have.

Who’s involved?

This project wants to improve the care received by illicit drug users who visit GPs.

- New South Wales Users AIDS Association, (NUAA) your State based Drug User Organisation
- Australian Intravenous League, (AIVL) your national Drug User Organisation
- Local doctors and alcohol and drug services

However, you are the experts and know what the treatment in your area is currently like and how this project can be best run to improve your lives.

What can you do?

At the moment, the programs are in their initial stages and it is really important that YOU get a say in how they develop. The survey does not collect any information that identifies you personally.

Have a think about what is important for you in your drug treatment programs. What works well for you and what bits would you like to change? This questionnaire should take no longer than 5-10 minutes to complete.

If you have any further questions about this project please contact:

(Names of local contacts)

Thank you for your assistance.

SECTION 1
Service location

a) What town do you live in?

b) What town do you get your Drug and Alcohol Treatment from?

c) What town is your doctor in?

d) Drug of concern

SECTION 2
TREATMENT

What treatments have you received?

	From your doctor	From your D&A service
Counselling		
Assessment		
Residential detoxification		
Home detoxification		
Residential rehabilitation		
Methadone		
Naltrexone		
Campral		
Pain management		
Vaccinations (hep a & b)		
General health checks		
Sexual health checks		
HIV testing		
Hepatitis tests		
Blood borne virus treatment		
Safer injecting/using information		
Your children's health checks		
Other		

What treatment services would you like to receive:

	From your doctor	From your D&A service
Counselling		
Assessment		
Residential detoxification		
Home detoxification		
Residential rehabilitation		
Methadone		
Naltrexone		
Campral		
Pain management		
Vaccinations (hep a & b)		
General health checks		
Sexual health checks		
HIV testing		

Hepatitis tests		
Blood borne virus treatment		
Safer injecting/using information		
Your children’s health checks		
Other		

What is important to you when receiving treatment:

	From your GP	From your D&A service
Being treated with respect		
Treatment is flexible and matches life needs		
Being given a range of options – such as detoxifying at home, knowing all of the medication that is available, programs that are available		
Knowing your rights and responsibilities		
To be able to set my own goals		
To have input into my treatment program		
To be able to get accurate information		
To be able to change my program to meet my needs		
Comments		

SECTION 2
Treatment provided by doctors/General Practitioners

a) Do you see the same GP for your drug treatment as for your general health issues? Yes / No

Comments:

b) How important is confidentiality to you from your DOCTOR?

Very important Important Average Not very important Unsure
 1 2 3 4 5

Comments:

c) How satisfied have you been with the treatments you have received from your GP (please rate on a scale from ‘1’ being great to ‘5’ being terrible)

Excellent Above Average Average Below Average Terrible
 1 2 3 4 5

Comments:

f) How important is having a mechanism for complaints about your doctor?

Crucial	Very important	Average	Not very important	Unsure
1	2	3	4	5

Comments:

SECTION 3
Drug Services (Clinics, Detox and Counselling)

a) How important is confidentiality to you from your DRUG TREATMENT SERVICE

Very important	Important	Unsure	Not very important	Not at all important
1	2	3	4	5

Why:

b) Have you accessed a specialist D&A worker for treatment in the past 2 years? Yes / No

Why/why not:

d) How satisfied have you been with the treatments you have received from your D&A service? Have you found them:

Excellent	Above average	Average	Below average	Terrible
1	2	3	4	5

Comments:

g) How important is having a mechanism for complaints about your D&A service?

Very important	Important	Average	Not very important	Unsure
1	2	3	4	5

Comments:

SECTION 4
Pharmacists

a) Do you have adequate access to pharmacies? Yes / No

Comments:

a) What other services you would like to access at a pharmacy?

Please list:

c) What of the following is important to you when you are receiving treatment from a pharmacy:

	To be trusted		To be able to get accurate information
	To be treated like every other customer		To dose at flexible times
	To be able to access injecting equipment		Knowing your rights and responsibilities
	Confidentiality		Having a mechanism for complaints

Comments:

SECTION 5
Communication Between Services

a) Do your health care providers exchange information about your care? Yes / No

Comments:

b) How satisfied are you with the level of communication between health care providers?

Comments:

c) How could it be improved?

Comments:

d) Are there some organisations/agencies that you would not like your GP to communicate with?

Comments:

e) Would you be happy for your health care providers to discuss your treatment in order to better meet your needs - with your signed consent?

Comments:

SECTION 6
Your comments

Please add any other points that you think have not been included in the questions. Your views are really important

Appendix 4

CHARTER OF DRUG USERS RIGHTS & RESPONSIBILITIES IN SHARED CARE

This charter has been developed in consultation with drug users across Australia and has been approved and endorsed by both the New South Wales Users Aids Association, (NUAA) and the Australian Intravenous League, (AIVL). It aims to protect and promote the rights and responsibilities of illicit drug users within drug treatment services. It is acknowledged that many service providers do not meet the standards that are outlined in this charter. This charter is providing guidelines for services to at least be working towards achieving.

You are responsible for:

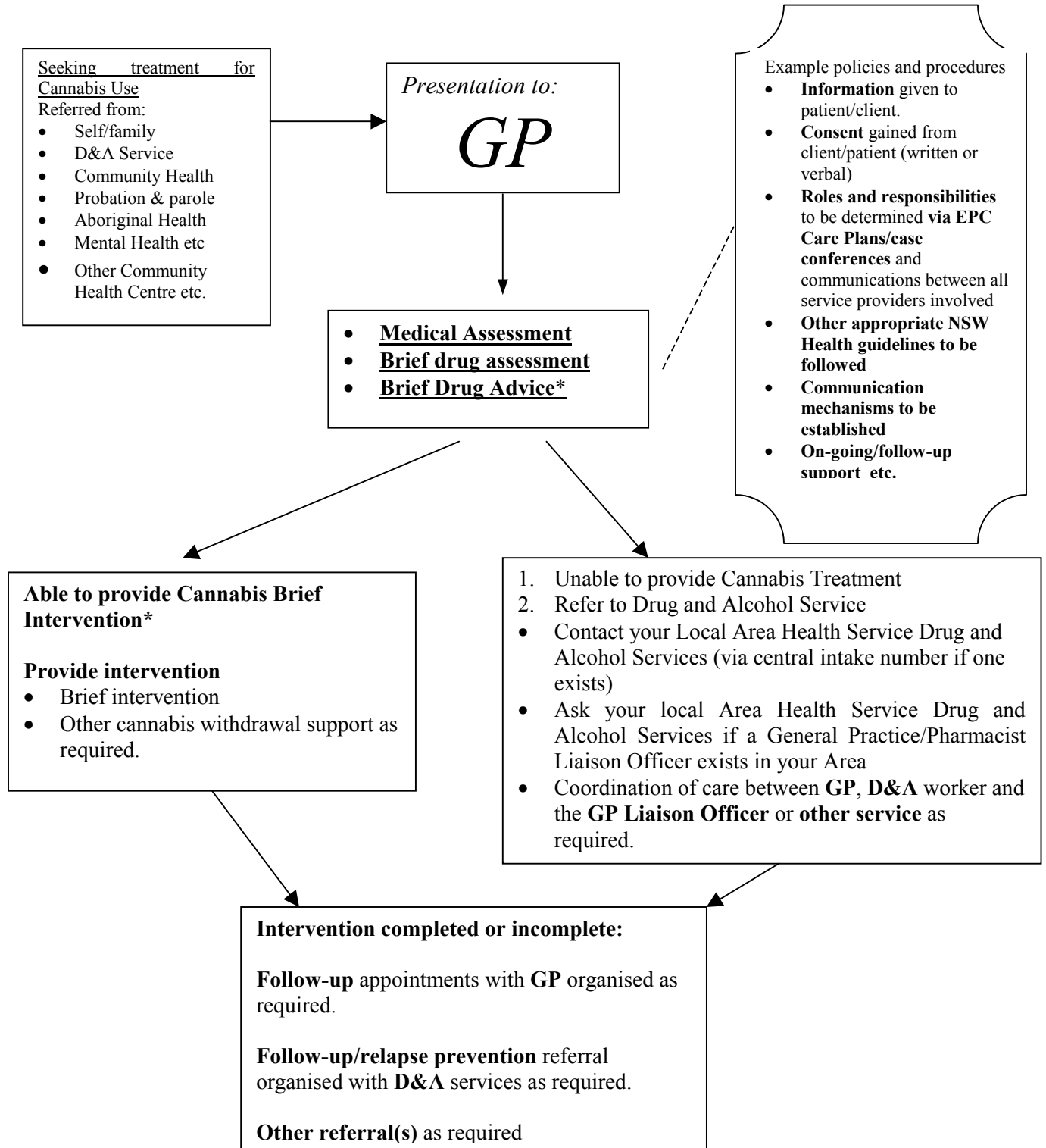
- Being an active and accountable partner in your treatment program
- Being on time for your appointments and letting your providers know if you can't make it or you are going to be late
- Letting your treatment providers know how your treatment program is going
- Making sure that your behaviour at your appointments does not compromise either your own or your peers treatment program
- Safely storing your medication from access to other people, especially around children
- Using your medication in the way it has been prescribed
- Being courteous towards your treatment providers
- Discussing the rights and responsibilities of this charter with your peers
- Discussing with your providers any house rules that need to be respected. Where you disagree with any house rules, you have the responsibility to raise this with your treatment provider and attempt to resolve them. It is your responsibility to inform your local drug user group of any unfair treatment and seek additional support

You have the right to:

- Be treated with respect at each of your appointments and when visiting your pharmacist
- Have input and control into the development of your treatment program and be presented with the fullest range of treatment options that are available so that you are able to make an informed choice as to what is best for you
- Ask for the qualifications and expertise of all the providers that are part of your treatment program
- Ask for and be given a copy of the treatment providers confidentiality policy
- Make a complaint and know that if you make a complaint that this will not negatively impact on your treatment program in any way
- Take a peer advocate, friend or family member with you to any of your appointments
- Refuse to take part in research and trials
- Where possible to be able to negotiate your appointments
- Make alternative dosing arrangements to accommodate work or travel, if this is within legal guidelines and that you give reasonable notice
- Know that your treatment providers will respect your confidentiality and will not discuss your treatment with other providers outside of the service unless they have your informed written consent
- Refuse pathology/urine tests that do not meet your own individual needs and are not a legal requirement of your treatment program
- Access pharmacies at mutually agreed times and be treated like all other pharmacy customers
- Request and have access to your file and all documentation related to your treatment
- Access appropriate pain management

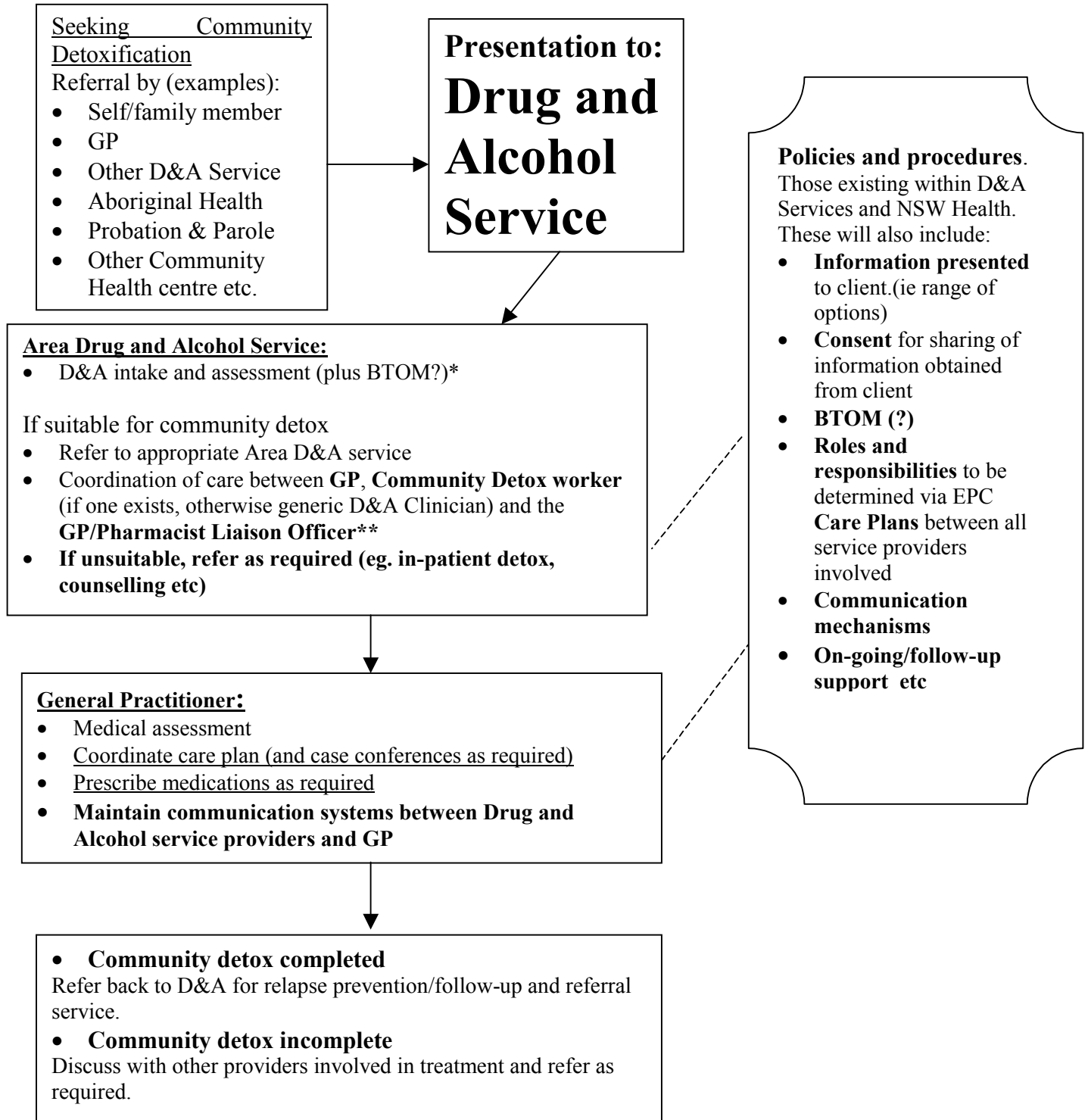
You can contact NUAA, your local Drug User Organisation on **1800 644 413**

Cannabis Treatment Program Model for Shared Care for GENERAL PRACTITIONERS



* This will depend on your knowledge, experience and training in providing Cannabis Brief Interventions (this Project recommended using the Quitting Cannabis NDARC manual). Copies of this manual are available from the National Drug and Alcohol Research Centre (NDARC).

Community Detoxification Treatment Program Model for Shared Care for DRUG AND ALCOHOL SERVICES (D&A)



* The BTOM is the Brief treatment Outcome Measure developed by NDARC and Drug Program Bureau, NSW Health. This might be an option for use to measure the health outcomes of clients

** A Shared Care Referral List could be located within area drug and alcohol services and with the GP/Pharmacist Liaison Officers (where they exist). It could contain details of GPs and other service providers participating in shared care treatment provisions.

References

- ¹ Hampson, JR, Roberts RI, Morgan DA. Shared care: a review of the literature. *Family Practice* 1996; 13:264-279.
- ² Illawarra Area Health Service (1997). A guide for working with consumers. Wollongong 1997:6. Cited in Consultation and participation – what do we mean? Community Consultation and Participation Resource Kit'. NSW Health website http://www.health.nsw.gov.au/publichealth/crcp/hib/publications/section_01.pdf
- ³ Royal Australian College of General Practitioners (2000) Enhanced Primary Care: Standards and guidelines for the Enhanced Primary Care Medicare Benefits Schedule items. Commonwealth of Australia 2000 ISBN 0 642 44673 3