THE INVOLVEMENT OF DRUG USER ORGANISATIONS IN AUSTRALIAN DRUGS POLICY

~ A RESEARCH REPORT FROM AIVL’S ‘TRACKMARKS’ PROJECT ~

AUSTRALIAN INJECTING & ILLICIT DRUG USERS LEAGUE (AIVL)

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

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

Executive Officer
Australian Injecting and Illicit Drug Users League
GPO Box 1552
Canberra ACT 2601

Telephone: +61 2 6279 1600
Facsimile: +61 2 6279 1610
Email: info@aivl.org.au
Website: www.aivl.org.au

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Australian Injecting & Illicit Drug Users League (AIVL)
- Dayle Stubbs
- Wayne Capper
- Annie Madden

Social Research and Evaluation Pty Ltd
- David McDonald

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AIVL wishes to acknowledge the contribution made by the DPMP and Social Research and Evaluation Pty Ltd to this research, and to the ‘TrackMarks’ Project overall. This work was undertaken in the interests of furthering collaboration with drug user organisations and promoting new research in which drug users and drug user organisations drive the research process. It was also undertaken as a ‘first’ in Australian drugs policy – tracing the not insignificant contribution of drug user organisations in Australian drugs policy and in the field of “illicit drugs” more broadly. TrackMarks is, in a sense, a celebration of the history of Australian drug user organising – from the loose networks that have formed with high ideals and best intentions, yet have fallen due to lack of funding or other supports, to the well established incorporated organisations that exist, with government funding support to one degree or another, but essentially as independent fully fledged organisations.

AIVL would also like to acknowledge the support of the state and territory peer-based drug user organisations in undertaking this research project. This after all, is their history too.

Finally, AIVL would like to acknowledge the importance of individual people who use illicit drugs (PWUID) and drug treatment consumer advocates and representatives. The value of their role and contribution to Australian drugs policy activity should not, indeed cannot, be underestimated.

This report is available electronically on the AIVL website at: www.aivl.org.au/trackmarks
Objectives of AIVL

The Australian Injecting and Illicit Drug Users League (AIVL) is the national peak organisation for the state and territory drug user organisations and represents issues of national significance for people who use illicit drugs and people on opioid pharmacotherapies.

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

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

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

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

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

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

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

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>ACON</td>
<td>AIDS Council of NSW</td>
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<tr>
<td>ACTIV League</td>
<td>ACT Intravenous League</td>
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<tr>
<td>AIVL</td>
<td>Australian Injecting &amp; Illicit Drug Users League</td>
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<tr>
<td>ANPUD</td>
<td>Asian Network of People who Use Drugs</td>
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<tr>
<td>CAHMA</td>
<td>Canberra Alliance for Harm Minimisation &amp; Advocacy</td>
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<tr>
<td>CIN</td>
<td>Canberra Injectors’ Network</td>
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<td>DPMP</td>
<td>Drug Policy Modelling Program</td>
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<td>DUO</td>
<td>drug user organisation</td>
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<tr>
<td>HR Vic</td>
<td>Harm Reduction Victoria (formerly VIVAIDS)</td>
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<tr>
<td>INPUD</td>
<td>International Network of People who Use Drugs</td>
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<tr>
<td>MIPUD</td>
<td>Meaningful Involvement of People who Use Drugs</td>
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<tr>
<td>NAP</td>
<td>Network Against Prohibition</td>
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<tr>
<td>NUAA</td>
<td>NSW Users &amp; AIDS Association</td>
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<tr>
<td>PHAAT</td>
<td>Pharmacotherapy Advocacy and Action Team</td>
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<tr>
<td>PWUID</td>
<td>People Who Use Illicit Drugs</td>
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<tr>
<td>QuIHN Ltd</td>
<td>Queensland Injectors Health Network</td>
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<tr>
<td>QuIVAA Inc</td>
<td>Queensland Intravenous AIDS Association</td>
</tr>
<tr>
<td>SAVIVE</td>
<td>SA Voice for IV Education</td>
</tr>
<tr>
<td>SCIIVAA</td>
<td>Sunshine Coast Injectors’ Voice &amp; Action Association</td>
</tr>
<tr>
<td>TasCAHRD</td>
<td>Tasmanian Council on AIDS, Hepatitis and Related Diseases</td>
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<tr>
<td>TTAG</td>
<td>Thai AIDS Treatment Action Group</td>
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<tr>
<td>TUF</td>
<td>Territory Users Forum</td>
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<tr>
<td>VIVAIDS</td>
<td>Victorian Intravenous &amp; AIDS Association</td>
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<tr>
<td>WASUA</td>
<td>Western Australian Substance Users Association</td>
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<td>YSAS</td>
<td>Youth Substance Abuse Service</td>
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Introduction

During 2007, the Australian Injecting & Illicit Drug Users League (AIVL) and the Drug Policy Modelling Program (DPMP) began a dialogue about ‘consumer participation’ in drugs policy and the contribution of drug user organisations to the formulation and implementation of drug policy in Australia. As this was happening, there was a growing international call for the inclusion of affected communities and the meaningful involvement of people who use illicit drugs in all facets of drugs policy and practice. In an Australian context, people who use drugs had been demanding a voice since the 1980s:

“The advent of HIV and the discovery of AIDS in the early 1980s meant that, in Australia, there was a radical rethinking of the concept of the Australian User. The Australian User was revealed as someone who could be educated, who lived in communities of like-minded individuals, who could play a role in Government policy, who could be profitably consulted and who could be employed through the state. Australia is the only developed country to have avoided the so-called second wave of HIV infection. This is a result of a policy which allowed drug users to play a role in preventing the transmission of HIV infection. It was the result of policy that allowed drug users to become human again.” ¹

The above statement was made in 1992 and since that time, people who use illicit drugs (PWUID) and their representative organisations in Australia (AIVL and its state/territory member organisations) have continued to actively promote the health and human rights of people who use/have used illicit drugs, and their right to participate in the processes, policies and practices that affect them. Drug user organisations (DUOs) have been at the forefront of ensuring the voices of drug users are heard, and their needs addressed in health, social and legal contexts.

Many of the most visible activities drug user organisations have undertaken have been highly proximate to drug use in a harm reduction/public health context (e.g. peer education and blood borne virus prevention, hepatitis C treatment, drug treatment issues, participation in research, and the development and dissemination of health promotion resources). Activities with more of a policy focus have been largely under-recognised, despite the breadth and depth of such activity. This policy activity has included drafting position papers, preparing written submissions in response to draft policies and national strategies, participating on policy advisory committees, making presentations to parliamentary and other inquiries, advocacy and representation, etc.

In recent years, policy related advocacy and representation has become an increasingly important aspect of AIVL’s work, despite the fact that the organisation is largely funded for activities relating to communicable diseases, rather than for engagement in drug-related policy activity. The increased policy workload reflects, in part perhaps, the acknowledgement in recent phases of Australia’s National

Drug Strategy, and some of the state/territory drug strategies, that the meaningful engagement of people who use illicit drugs (including consumers of drug treatment service agencies) is essential if illicit drugs policies are to be effective in achieving their goals.2

Internationally, acknowledging the importance of the meaningful involvement of people who use drugs (MIPUD) in developing effective, evidence-based drug policy in a range of areas including HIV, hepatitis C, drug treatment, harm reduction, etc has become increasingly important. The Goa Declaration which was published in early 2008 by the Asian Network of People Who Use Drugs (ANPUD) refers to the need “to empower drug using communities to advocate and protect their rights and to facilitate meaningful participation in decision making on the issues that affect their lives”.3 The ground-breaking international report titled: “Nothing About Us Without Us: Greater, Meaningful Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative” took this idea even further by making the point that involving people who use drugs in the issues that affect their lives is not only the ‘right’ and ‘ethical thing to do’ but is ‘in the best interests of society as a whole because it is an inextricable part of ensuring effective responses to illicit drugs’.4

Despite the rhetoric of partnership and consumer participation in the 2004–2009 National Drug Strategy, however, and unlike the most recent Third National Hepatitis C Strategy (for example), where AIVL was a member of that strategy’s writing group, no affected community participation in the latest National Drug Strategy (2010–2015) is formally endorsed beyond the capacity to make written submissions and comment. It should also be noted that AIVL and its member organisations remain significantly under-resourced to undertake the considerable workload in relation to working within various government strategies, including:

- National & State/Territory Drug Strategies;
- National & State/Territory HIV/AIDS Strategies
- National and State/Territory Hepatitis C Strategies;
- National Hepatitis B Strategy;
- National Aboriginal & Torres Strait Islander Complimentary BBV&STI Strategy;
- National Aboriginal & Torres Strait Islander Complimentary Drugs Strategy;
- National Illicit Drugs Strategy;
- National Heroin Overdose Strategy;
- National Mental Health Strategy; and
- National Homelessness Strategy.5

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5 More detailed information about the breadth of AIVL’s work on a range of government strategies will soon be available on the TrackMarks website: www.aivl.org.au/trackmarks.
Recognising the vital role of consumer participation in drugs policy, and the resourcing issues DUOs face in undertaking such policy-related activities, the Drug Policy Modelling Program (DPMP) provided funding in 2008 for AIVL to undertake a project that would document its contributions to Australian drugs policy. Called ‘TrackMarks’, an online archive was compiled to trace the history of DUOs and to highlight their drug policy-related activities in Australia over a 20 year period. TrackMarks is an ambitious ground-breaking, consumer-led project. Focused on documenting the history of drug user organising in Australia and the contribution that PWUID and DUOs have made to Australian drug policy, TrackMarks seeks to provide an insight into the enormous amount of work AIVL and its state/territory members have undertaken in the interests of contributing to better drugs policy. The project features an online historical archive and timeline, along with several key drug policy issues outlined in detail. A broad range of resources have been collated, including historical materials, short video interviews with key activists and other stakeholders, plus a selection of submissions and letters to government and parliamentary processes. Nowhere before in Australia has all of this information been brought together and made accessible in one location. In addition to this large volume of work, TrackMarks also involved a national research consultation with people involved with DUOs, exploring their experiences with drug policy activities and processes. The results of this consultation are presented here in this report, which will be included on the TrackMarks website, due to be launched in 2013 and will be accessible via www.aivl.org.au/trackmarks.

The DPMP’s interest in AIVL’s TrackMarks project stems from its commitment to “create valuable new drug policy insights, ideas and interventions that will allow Australia to respond with alacrity and success to illicit drug use ...using a comprehensive approach that includes ...harm reduction.” The DPMP’s support of a consumer-led project on drugs policy, and the involvement of DUOs in policy processes and activities, clearly demonstrates this commitment, along with a commitment to engage “affected communities” wherever and whenever possible.

Linking the work of other DPMP researchers to AIVL’s TrackMarks project, it can be useful to view drug user organisations’ involvement in drug policy activity through the lenses of (a) sound governance and (b) Integration and Implementation Sciences (I2S). In terms of sound governance, DPMP researchers have explored the following eight principles for good governance in Australian illicit drugs policy:

- participation;
- consensus-orientation;
- accountability;
- transparency;
- responsiveness;
- equity and inclusiveness;
- effectiveness and efficiency; and
- following the rule of law.

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The principle of ‘participation’ is described thus:

‘No one sector of government can address the drugs issue alone. There should be opportunities for all jurisdictions, sectors and groups affected by drugs to participate either directly or through representation. Processes should be carefully constructed so as to not exclude groups or citizens with limited access.’

This picks up the language used in the previous National Drug Strategy: Australia’s Integrated Framework 2004–2009 where it was argued that ‘The success of Australia’s drug policy is based on four features, [one of which is] the promotion of partnerships between health, law enforcement and education agencies, affected communities, business and industry in tackling drug-related harm’. Whilst this may have been so in the past, the latest National Drug Strategy makes no such mention of either consumers or affected communities in relation to the continuation of the ‘partnership’ concept, despite the aforementioned “success” of this approach in previous strategies. This is both disappointing and, somewhat frustratingly, confusing, as the latest National Drug Strategy makes several oblique references to actions which by definition must include consumer participation, without actually naming them; and it only belatedly acknowledges ‘consumer involvement’ in relation to treatment service delivery and governance.

Integration and Implementation Sciences (I2S) is a discipline which covers four domains:

- fresh thinking on intractable problems;
- integration of disciplinary and stakeholder knowledge;
- understanding and management of ignorance and uncertainty; and
- the provision of research support for decision-making and practice change.

Developing principles and practical strategies for improving the meaningful engagement of DUOs in drug policy activity falls within the domain of the ‘integration of disciplinary and stakeholder knowledge’, since people who use illicit drugs, and their representative organisations, are clearly key stakeholders in drug policy, even if this has not been adequately acknowledged in all key government strategies and policy documents in the past. Further, in some quarters at least, PWUID are increasingly being seen and recognised as health consumers, with rights to participate in the decisions which affect their lives. This, alone, provides the backdrop against which participation in drugs policy activity might take place.

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7 Ibid. p. 3.
Consumer Participation

Throughout Australia, there has been substantial progress in the health consumer movement. It is, for example, now commonplace to have consumers involved at a range of levels in health services – in their development, implementation, research and evaluation. The shift towards involving consumers in the planning and delivery of health services emerged from a much broader set of social reform movements of the last 50 years, such as the women's and civil rights movements. These movements have the concept of human rights as a central feature and argue that each individual is entitled to, amongst other things, self-determination. The idea of entitlement to determine the nature of one's own health care has been taken up and incorporated into health consumer movements in Australia. Concerned initially with improving the individual experiences of receiving medical treatment, the health consumer movement in Australia now has a broader reach to include issues of health care policy and planning, service planning and delivery and research and evaluation. The concept of rights has been fundamental to this movement and is used to lobby on behalf of, and validate the views of, health consumers. These rights include the right to satisfaction of basic needs, the right to safety, and the right to be informed, the right to choose and to be heard the right to redress, the right to be educated about services, and the right to a healthy environment.

Within consumer movements, the notion of consumer participation has developed significantly in Australia with the backing of a considerable body of academic and policy-oriented literature. Here, consumer participation is broadly defined as ‘the process of involving health consumers in decision making about health service planning, policy development, setting priorities and quality issues in the delivery of health services’. In more ideological terms it can also be defined as ‘more sharing, not only of information and opinion, but also of decision making power. Real participation means joint problem-solving, joint decision-making, joint responsibility.’

Many benefits and successful outcomes from consumer participation in health services have been documented, with the consumer movement successfully gaining representation on government advisory bodies and committees. Consumer groups routinely make submissions to government inquiries into health care and consumer representatives appear before parliamentary committees and meet regularly with parliamentarians. For over 10 years now there have been positions for health consumers on numerous Australian government and ministerial committees, including the National Health and Medical Research Council, the Australian Health Minister's Advisory Council, Ministerial Advisory Committees on AIDS and Hepatitis, and the Australian Institute of Health and Welfare. Consumer involvement in service planning and delivery has also developed at the local service level.

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12 See, for example, Consumers Health Forum of Australia 2004, Guidelines for consumer representatives, Consumers Health Forum of Australia, Manuka, ACT and National Health and Medical Research Council & Consumers Health Forum of Australia 2002, Statement on consumer and community participation in health and medical research, NHMRC, Canberra.
13 See, for example, Consumers Health Forum: www.chf.org.au
in various health service settings, including mental health services and government area health services.18

A ‘consumer-oriented’ movement for people who use or have used illicit drugs has developed in parallel to the broader health consumer movement. In the mid to late 1980s, largely in response to the emergence of the global HIV/AIDS epidemic, peer-based drug user organisations were being established in Australia. Over the past several years now a number of local peer-based drug user organisations have gained funding for dedicated drug treatment consumer representative positions and/or projects within their organisations. These have enhanced the capacity of peer-based DUOs to represent consumers of treatment services. However, the development of a strong consumer movement for people who use or have used illicit drugs is challenging, largely because of the comparative marginalisation, stigma and discrimination they experience and the illegal status of their drug use. And yet, no matter how challenging it remains, the value of consumer participation cannot, or should not, be underestimated. This was made clear by an Australian Government funded Consumer Focus Collaboration Project in 2001, which concluded (in part):

- effective consumer participation uses methods that facilitate participation by those traditionally marginalised by health services; and
- active involvement of consumers at all levels of the development, implementation and evaluation of health strategies and programs is integral to their success.19

Despite the strong history of the general health consumers’ movement within Australia and the existence of the ongoing work of peer-based drug user organisations, encouraging the greater and more meaningful involvement of people who use drugs in health services (such as drug treatment settings) remains extremely challenging. Although a small number of drug user organisations have managed to secure funding for dedicated drug treatment consumer representative positions and/or projects, for the most part this work remains under-resourced and under-valued. At the national level, over the past seven years now, AIVL has been attempting to bring further attention and understanding to the role and benefits of consumer participation in drug treatment settings.

Two major AIVL initiatives recently carried out in this area were the Treatment Service Users (TSU) Project Phase One and Phase Two, which were conducted between 2005 and 2010. The TSU Project Phase One was a peer-driven social research initiative undertaken in collaboration with the National Centre in HIV Social Research (NCHSR) which involved a mixed method survey of over 60 drug treatment service providers and approximately 180 treatment service users. This project revealed a significant level of overall support for the concept of consumer participation in drug treatment settings among both service providers and consumers but major gaps in the levels of communication and engagement necessary to support meaningful involvement of consumers were also plainly evident. The project also found many services were already engaged in low level consumer participation activities but supporting the greater involvement of consumers in roles that involved decision making was met with significant resistance from service providers.20


Following the publication of the final report for the TSU Project Phase One in 2008, AIVL was successful in gaining further funding to undertake a second phase of the TSU Project, aimed at further investigating some of the key findings from the first phase. The Phase Two project involved a further collaboration between AIVL and the NCHSR to commission and evaluate a series of consumer participation demonstration projects in a variety of drug treatment settings. Despite achieving a range of positive outcomes, all of the demonstration projects struggled to achieve their stated aims and objectives. While at baseline both services and consumers identified the capacity and skills of consumers as potentially being one of the main barriers to meaningful consumer participation, at final evaluation, the emphasis became focused on whether the service itself was ‘fit’ and prepared for genuinely meaningful engagement with their consumers. This finding also has relevance for the present TrackMarks study.

In the context of AIVL’s two Treatment Service Users Projects, it can, perhaps, be seen as a logical next step for AIVL to move from research about the meaningful engagement of drug users in drug treatment service settings, to examining their meaningful engagement in drug policy activity more generally. Undertaking a national consultation with key stakeholders within the national and state/territory drug user organisations, the TrackMarks project research sought to:

1. examine drug user/consumer contributions to Australian drug policy, including expectations versus experience;
2. document past and existing practice, including both good and poor practice examples; and
3. identify what constitutes meaningful engagement and the benefits such engagement might bring to policy formation.

It is AIVL’s belief, along with the support of the DPMP, that the aim of increasing our understanding of the meaningful engagement of consumers with policy activity and to document how both the amount and quality of this can be improved, can ultimately lead to better policy outcomes in the long term.

In addition, the results from this national research consultation, have contributed to the following outcomes of the broader aims of the TrackMarks project overall:

1. development of a set of ‘key principles’ for supporting meaningful engagement with drug user organisations and people who use drugs in drug policy development;
2. development of an on-line ‘Meaningful Engagement Kit’ to include a copy of this report and a ‘Key Principles & Checklist’ for drug user involvement in drug policy activity; and
3. development of an on-line interactive timeline and archive to document the history of drug user involvement in Australian drug policy, including a number of major advocacy campaigns and achievements.

The national consultation research undertaken for the TrackMarks project has built on existing knowledge including understandings from the social sciences about the nature of policy and how policy changes, the nature of participation including consumer participation, and how policy can be impacted upon through the meaningful engagement of advocates and others.

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The nature of policy influence

As the concept of ‘policy’ lies at the heart of the project, defining ‘policy’ is an important boundary-setting activity. For the purposes of this study, ‘policy’ is defined as:

’a statement of government intent, and its implementation through the use of policy instruments’.\(^{22}\)

Although this report is focused on government policy, it is important to note that other organisations (eg corporations and community organisations) develop and implement policies. A particular strength of the above definition is that it captures both what governments state that they are planning to do or achieve, and the actual implementation processes and their outcomes. It is also worth noting that failing to take action in addressing an issue reflects policy as much as implementing a particular program does.

Underlying AIVL’s interest in drug user organisations’ engagement with policy activity is the desire to influence drug policy in such a way as to enhance both the well-being of people who use illicit drugs, as well as meeting the needs and expectations of the broader community at large. This raises the question: what do we know about the processes through which policy is made? Without an understanding of this, AIVL’s capacity to influence policy activity is limited.\(^{23}\) Many models of policy influence exist in the social science literature, four of the most prominent being:

• the rational/comprehensive model;
• the incrementalism model;
• the multiple streams model; and
• the advocacy coalitions model.\(^{24}\)

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\(^{22}\) Althaus, C, Bridgman, P & Davis, G 2007, *The Australian policy handbook*, 4th edn, Allen & Unwin, Crows Nest, N.S.W., p. 246. We acknowledge that many other definitions exist, but have assessed this one as being especially useful for the purposes of this study.

\(^{23}\) In this paper we largely refer to ‘policy activity’ not ‘policy making’. This is because policy making, i.e. the decision phase, is just one of a number of stages or types of policy activity. See McDonald, D, Bammer, G & Breen, G. 2005, *Australian illicit drugs policy: mapping structures and processes*, Drug Policy Modelling Project Monograph Series no. 4, Turning Point Alcohol and Drug Centre, Fitzroy, Vic., p. 5.

\(^{24}\) Other models include: the systems model; the stages heuristic; the bounded rationality model; and institutional rational choice frameworks. It is beyond the scope of this report to detail all possible models. See, however, Howlett, M, Ramesh, M & Perl, A 2009, *Studying public policy: policy cycles and policy subsystems*, 3rd edn, Oxford University Press, Toronto.
The rational/comprehensive model assumes that policy decisions are made rationally with the aim of maximising social gain, and on the basis that all required information is available and considered. There is a common belief in the community that this is how policy decisions are made, that policy decision-making is scientifically evidence-based and objective. Such an approach, though, would effectively need to operate within a climate of political bi-partisanship, which is rarely, if ever the case in an Australian context. The reality is, “policy is developed in a fluid environment, and is subject to competing vested and political interests”.25 This, we suggest, is certainly the case for Australian illicit drugs policy.

The incrementalism model argues that people engaged in policy activity build on their existing information, particularly their knowledge of what worked (or failed) in the past. Policy activity in the Australian context would appear to in part follow this model, rather than one that is based on seeking out and attending carefully to new information and opportunities.26 Again, however, we would suggest that the many arguments surrounding the ‘failure’ of prohibition in relation to the “War on Drugs” rhetoric might point to the incrementalism model to be only partially endorsed at best and not a true reflection of how policy decisions (in particular) are made.

The multiple streams model suggests that problems get on the agenda and solutions are found when three ‘streams’ combine: namely the politics stream, the policy stream and the problem stream. This combining creates ‘windows of opportunity’. Opportunities may exist for drug user organisations to identify when those windows are opening, and to use the resulting opportunities to improve or at least influence a policy debate.

The advocacy coalitions model draws attention to the various policy communities that operate within particular policy domains and to the power that advocacy groups can exercise. This last model reflects, in part, the policy space in which AIVL has been able to work effectively on a range of drug policy issues, the Disability Discrimination Amendment Bill (2003) being one in particular that saw positive results.27

In addition to models of policy influence, models of research influence are also important to policy activity. In terms of how DUOs might exercise influence on drug policy, for example, three major models of research influence can be considered. These are:

- the engineering model;
- the enlightenment model; and
- the engagement model.28

27 A detailed description of this particular policy issue will soon be available on the TrackMarks website, www.aivl.org.au/trackmarks or by contacting AIVL directly at: info@aivl.org.au
The engineering model (also called the pipeline model) is a rational one through which it is assumed that information is gathered, communicated to people engaged in policy activity and used by them directly (that is, instrumentally) to produce new and better policy. This fits with the rational/comprehensive model of policy influence. The enlightenment model is one which draws attention to how information can be generated through research, experience or other means and communicated to the society broadly. People engaged in policy activity, as members of the community at large, will absorb this information, perhaps unconsciously, incorporate it into their knowledge bank and use it in their policy activity, perhaps without even knowing its source. The engagement model, in contrast, draws attention to how policy can be influenced by the various actors working through structures and using explicit processes for communicating information and insights. This model in particular has much to offer in terms of how consumers, through DUOs or individual participation, can engage with the people charged with developing policy within government.

As the findings of this report will highlight, however, we believe that all three models of research influence (the engineering, engagement and enlightenment approaches) have, in some contexts, failed in any comprehensive sense to deliver policies that adequately reflect the needs and potential contributions of DUOs and PWUID. This means that more effective engagement is required, and a prerequisite for that is deeper understanding of the principles that underlie meaningful engagement, and then the practical means to enhance its effectiveness. Whilst understanding the principles that underlie meaningful engagement is essential, it is not enough on its own. A much deeper commitment from governments and other stakeholders (including DUOs and individual people who use illicit drugs) to the engagement process, and to the real value that DUOs can bring to policy activity is also required. In this sense, we believe the TrackMarks project and this report should be seen as a first step in that process.
Methodology

The broad methodology of the national consultation was developed by the chief investigator, David McDonald, under the direction of AIVL and a Project Advisory Committee.

The research objectives were:

1. To document the contributions of drug user organisations, and people who use illicit drugs, to the development of drug policy in Australia over the last 20 years;
2. To identify key principles that underlie the meaningful engagement of people who use illicit drugs and peer-based drug user organisations in drug policy activity; and
3. To identify barriers and facilitators of meaningful engagement, such that people whose role it is to develop drugs policy, primarily in government agencies, are able to make more informed policy decisions.

The study incorporated a mixed methods embedded design in which quantitative data were embedded in a predominantly qualitative design. The mixing occurred at the design, data analysis and interpretation levels.29

An online survey30 was designed to be undertaken by key informants, predominantly those from peer-based drug user organisations and others knowledgeable about such organisations. In addition to the survey, a small number of one-to-one interviews were anticipated to expand on issues identified through the survey. The interviews, however, did not go ahead in the end as the chief investigator determined that the data captured in the survey’s narrative components allowed for the level and depth of analysis the interviews would have covered and that the interviews were therefore not essential in the final analysis.

A survey instrument was developed and went live, using SurveyMonkey, in May 2009. The survey was promoted principally via AIVL’s E-List, a restricted electronic mail discussion list only open to people who use drugs and people working in drug user organisations. Other approaches included direct emails to relevant people, and follow-up telephone calls. This was a successful recruitment strategy. By the survey close-off date, 129 online responses had been received. Of these, over 30 respondents provided detailed information on their experiences of participating in drug policy processes and

30 A copy of the survey instrument is in Appendix 3.
activities. The other respondents skipped these narrative-type questions but still provided useful responses to the multiple-response questions.

The level of response was pleasing as the 30-plus detailed responses lend themselves to qualitative analysis, whereas the full 129 responses are sufficient to indicate both the breadth of views among people in peer-based drug user organisations, as well as clustering of views. Furthermore, the information that respondents provided about themselves indicated that they came from a wide range of organisations, such that the recruitment strategy was considered successful.

**Ethics approval**

The ANU Science/Medicine Delegated Ethics Research Committee approved the research on 12 March 2009, protocol number 2009/057.

**Respondents**

Responses were received from all States and Territories although there was only 1 from the Northern Territory and 5 from Tasmania. 18 came from the ACT, reflecting the fact that both national and ACT drug user organisations are located there. Table 1 provides details.

**Table 1  Respondents' State/Territory of residence**

<table>
<thead>
<tr>
<th>In which State or territory do you live?</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>25.6%</td>
<td>33</td>
</tr>
<tr>
<td>Vic</td>
<td>23.3%</td>
<td>30</td>
</tr>
<tr>
<td>Qld</td>
<td>11.6%</td>
<td>15</td>
</tr>
<tr>
<td>WA</td>
<td>11.6%</td>
<td>15</td>
</tr>
<tr>
<td>SA</td>
<td>9.3%</td>
<td>12</td>
</tr>
<tr>
<td>Tas</td>
<td>3.9%</td>
<td>5</td>
</tr>
<tr>
<td>NT</td>
<td>0.8%</td>
<td>1</td>
</tr>
<tr>
<td>ACT</td>
<td>14.0%</td>
<td>18</td>
</tr>
</tbody>
</table>

answered question 129

skipped question 0
In addition to the 30 detailed narrative responses, 20 respondents indicated their willingness to engage in a follow-up interview, a pleasing number which indicates the widespread support for the project among people involved in drug user organisations and other stakeholders.

Participants were asked to identify the name of any drug user organisation in which they were currently working on either a paid or voluntary basis. It should be noted that whilst the survey instrument did not strictly define a drug user organisation as being ‘peer-based’ there was an implicit expectation that AIVL and its state/territory member organisations would be widely represented. The results are in Table 2 below.

Table 2  Drug user organisations in which respondents were currently working (on a paid or voluntary basis)

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>NUAA</td>
<td>10</td>
</tr>
<tr>
<td>AIVL</td>
<td>9</td>
</tr>
<tr>
<td>SAVIVE</td>
<td>6</td>
</tr>
<tr>
<td>CAHMA</td>
<td>5</td>
</tr>
<tr>
<td>Harm Reduction Victoria</td>
<td>5</td>
</tr>
<tr>
<td>QuHNN Ltd &amp;/or QuIVAA Inc</td>
<td>4</td>
</tr>
<tr>
<td>WASUA</td>
<td>3</td>
</tr>
<tr>
<td>PHAAT</td>
<td>2</td>
</tr>
<tr>
<td>Palmerston Association</td>
<td>1</td>
</tr>
<tr>
<td>TasCAHRD</td>
<td>1</td>
</tr>
<tr>
<td>Territory Users’ Forum (TUF)</td>
<td>1</td>
</tr>
<tr>
<td>The Connection</td>
<td>1</td>
</tr>
</tbody>
</table>

Of the responses to this question, it should be noted that Palmerston Association is an alcohol and other drug (AOD) service, rather than a peer-based DUO, and PHAAT is an ACT peer-based pharmacotherapy consumer group which is facilitated by CAHMA.

Participants were then asked which drug user organisation(s) they had been involved with at any time, past or present (Table 3). The relatively large numbers for AIVL, NUAA, VIVAIDS/Harm Reduction Victoria, SAVIVE, WASUA and CAHMA reflect the longevity of these organisations, their size, range of activities, and capacity to attract funding for the employment of staff and for service delivery. The list also highlights the breadth and depth of respondents’ experience in drug user organisations.
### Table 3  Drug user organisation involvement at any time, past or present (multiple responses permitted)

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIVL</td>
<td>27</td>
</tr>
<tr>
<td>NUAA</td>
<td>26</td>
</tr>
<tr>
<td>VIVAIDS/Harm Reduction Victoria</td>
<td>23</td>
</tr>
<tr>
<td>SAVIVE</td>
<td>14</td>
</tr>
<tr>
<td>WASUA</td>
<td>13</td>
</tr>
<tr>
<td>CAHMA</td>
<td>12</td>
</tr>
<tr>
<td>QuiHN Ltd &amp;/or QuIVAA Inc.</td>
<td>8</td>
</tr>
<tr>
<td>ACTIV League</td>
<td>5</td>
</tr>
<tr>
<td>SA Users Group</td>
<td>4</td>
</tr>
<tr>
<td>CIN</td>
<td>3</td>
</tr>
<tr>
<td>Gold Coast Users Group (GAIN)</td>
<td>3</td>
</tr>
<tr>
<td>Territory Users' Forum (TUF)</td>
<td>3</td>
</tr>
<tr>
<td>INPUD</td>
<td>2</td>
</tr>
<tr>
<td>Tasmanian Users Health Support League (TUHSL)</td>
<td>2</td>
</tr>
<tr>
<td>INPUD Asia</td>
<td>1</td>
</tr>
<tr>
<td>Network Against Prohibition (NAP)</td>
<td>1</td>
</tr>
<tr>
<td>PHAAT</td>
<td>1</td>
</tr>
<tr>
<td>SCIVVA</td>
<td>1</td>
</tr>
<tr>
<td>TasCAHRD</td>
<td>1</td>
</tr>
<tr>
<td>Tasmanian Users Forum (TUF)</td>
<td>1</td>
</tr>
<tr>
<td>TTAG</td>
<td>1</td>
</tr>
<tr>
<td>WA Users Group</td>
<td>1</td>
</tr>
</tbody>
</table>

As in the responses in Table 2, responses to this question included organisations that are not peer-based DUOs, but are organisations that either provide services to PWUID or have worked in partnership with DUOs and individual drug users in drugs research (eg Burnet Institute). Those organisations, with number of responses in brackets, are:

- Palmerston Association (1)
- ACON (2)
- YSAS (1)
- Turning Point (1)
- Burnet Institute (1)
- “disease control at the Health Department” (1)
Further, TTAG, INPUD and INPUD Asia (now ANPUD) are international networks of drug users, and PHAAT, as previously mentioned, is a peer-based pharmacotherapy consumer group which is facilitated by CAHMA.
Experiences of drug user organisations with drug policy processes

Thirty-four respondents provided detailed information on their experiences with Australian drugs policy-related activities. A wide range of activities were mentioned, revealing the extent of the efforts undertaken in peer-based DUOs to engage with policy-making processes and policy-related activities. In a survey format, it can be difficult to bring out the full extent of the work that DUOs have done (and continue to do) in the policy sphere. Much of it remains untold, and so the survey responses highlighted here provide only a glimpse into that work. Survey respondents’ experiences, as shared in the survey, are summarised in this section as:

• aspects of policy the respondents have tried to create or influence;
• methods used;
• outcomes of these efforts; and
• the facilitating and impeding factors PWUID and DUOs face in actually influencing drug policy activity.

What aspects of policy activity have been addressed?

From responses to this part of the survey, it is clear that people involved with drug user organisations have been engaged in a wide range of activities – attempting to create, influence or change aspects of drugs-related policy. Responses can be thought of as being clustered around several key issues or themes, such as:

• drug treatment – and in particular opioid pharmacotherapy treatments such as methadone maintenance treatment (MMT) and buprenorphine;
• hepatitis C – especially policies in relation to prevention, diagnosis and treatment;
• discrimination, stigma and drug law reform; and
• harm reduction – including peer education and access to sterile injecting equipment.

Clustering in this way, however tempting it is for research, often does not adequately capture the extensive range of issues DUOs attempt to confront, nor does it capture the extent of the issues PWUID often encounter as an enduring reality of their lived experiences. It is particularly salient to remember that many of the issues for those working in peer-based DUOs are often personal issues of people’s everyday lived experiences, and not merely an abstraction or research curiosity, something that ‘policy’ sometimes feels like for those from affected communities when they participate on various policy bodies, working groups or reference committees. Below, therefore, is a more detailed list of the specific responses given to the question regarding which aspects of policy respondents had tried to create or influence.
What methods have been used to influence policy?

In seeking to influence or create policy, a wide range of methods were reported. While some of these can be seen as DUOs operating from the outside (e.g. media advocacy and writing letters to editors of newspapers) there are other examples of more direct engagement with people responsible for developing policy proposals, and for making policy decisions. Examples of the latter include dialogue with policy officers and parliamentarians, operating from the inside as members of policy advisory committees, undertaking research both in their own right and in partnership with national research centres and other bodies, making submissions to parliamentary enquiries, etc.

Also significant have been community organising and direct action, developing and using networks and coalitions of organisations, information development and dissemination, and providing supports to individual drug users so that they can better contribute to policy processes.

Referring back to the engineering, enlightenment and engagement models of research influence discussed earlier, all three categories have being employed to one degree or another. The question is whether such models can be seen to have been consistently and effectively utilised. For example, the engineering or pipeline model is illustrated by members of DUOs presenting evidence about an issue to policy makers. The enlightenment model is illustrated by organisations seeking to influence broad public opinion through letter writing campaigns, and opinion editorial pieces in newspapers for example. The engagement model is realised through processes of dialogue with decision-makers and their policy advisors, usually via participation in committees and advisory body structures.
However, as will be shown below, the degree to which these models have been successfully adopted is somewhat open to conjecture.

The methods reported by respondents are presented in detail below.

- Researching, documenting and presenting evidence
- Consulting with consumers, providing information to consumers
- Consumer forums
- Eliciting feedback from stakeholders on policy issues under consideration
- Sitting on committees
- Dialogue and lobbying parliamentarians
- Dialogue and lobbying other AOD and community organisations
- Dialogue and lobbying policy advisers
- Lobbying the community through, e.g., placing articles in community newsletters and letters to editors
- Seizing opportunities to correct misinformation
- Community organising
- Direct action including public demonstrations
- Advocacy generally
- Assisting researchers
- Networking
- Information resource development
- Insisting on drug user organisations representation in services
- Making presentations at national conferences
- Developing policy position papers and discussion papers
- Developing and participating in coalitions of community organisations
- Developing form letters and circulating for use by PWUID and like-minded agencies
- Developing coalitions with other advocacy groups
- Developing submissions to parliamentary enquiries
- Providing briefing notes to people in other organisations who are developing submissions to parliamentary enquiries
- Implementing and evaluating government trials (e.g., retractable needles and syringes)

**What have been the outcomes of applying these methods?**

The work of drug user organisations and their members in seeking to influence policy have, to some extent, had mixed results. Most respondents had no difficulty identifying a range of positive effects in relation to their efforts, and these are summarised below.

Results are diverse, reflecting, as highlighted earlier, the range of work DUOs undertake under the broad term ‘policy’. Some are highly tangible, such as attaining government funding for DUOs, or influencing decisions by governments not to implement a particular planned policy. As one respondent noted, in reference to the planned introduction of a Disability Discrimination Amendment Bill,31 “we successfully lobbied that the legislative change did not come into being”. Others may be seen to have had more of a process focus, such as the acceptance by committees of enquiry for policy positions put forward by DUOs for the acceptance of consumer representatives as full members of

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31 As mentioned elsewhere, this particular policy issue will be covered in detail on the TrackMarks website, which will be available to access from: www.aivl.org.au/trackmarks.
policy advisory committees: “the establishment of two consumer positions on a methadone advisory group; .... a ‘user’ member of a planning group for an NSP nurse and NSP services at an NGO outlet.” Yet other outcomes have been more diffuse, such as perceived positive attitudinal changes on the part of some sectors of the community, and on decision makers and their policy advisers: “definitely, through word of mouth and advocacy you sometimes see information open eyes and minds.”

The range of outcomes identified by respondents includes:

- Re-establishing priority research on the agenda
- Professionals’ understanding of the issues has increased
- A positive shift in attitudes
- Some policy advisors have become far more enlightened
- Government funding of drug user organisations
- Reduction in BBV transmission
- Drug user organisations are members of policy advisory committees
- Inclusion of harm reduction interventions in AusAID’s programs
- Revised, improved treatment guidelines
- Increased flexibility in opioid pharmacotherapy dispensing practices
- Cessation of discriminatory practices at a drug treatment service
- Reports of enquiries that have accepted drug user organisations’ proposals
- New and improved policies on police attendance at overdoses
- Users are now more organised and demanding of their rights
- Contributing to community debate about prison NSPs
- Commonwealth withdrew planned discriminatory legislation
- Cessation of the trial of retractable needles and syringes
- Strengthening of drug user organisations; increased effectiveness and efficiency

Whilst a majority of respondents reported at least some positive outcomes they have witnessed, some respondents were less sure about the success of their own attempts (and DUOs’ attempts more broadly) to influence policy outcomes. This is drawn out further in later sections of this report, on facilitators and barriers to meaningful involvement of DUOs in drugs policy. In measuring the success of any particular instance of policy activity or participation, it is important to note the role of expectations. One respondent who discussed a range of methods used to attempt legislative change for drug law reform reported that, despite positive findings and recommendations for the changes, “the State Government of Victoria did not enact the recommendations”. There may well have been no real expectation of success, if success were to be measured solely in terms of whether the Victorian Government introduced the proposed legislative change. In this sense, it can be difficult to classify some policy activity against outcomes alone. Another respondent reported “some minor improvements but [they are] not systemic” in relation to their efforts to provide support for prisoners and people exiting prisons. Yet another respondent reported feeling completely ineffectual, where “no changes were made... as a result of [our] activities”. Another commented that whilst he/she had not personally been responsible for any outcomes, “over the years I have seen many changes, good and bad”.32

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32 These feelings about one’s own impact or effectiveness can be quite common. In the recent DPMP Evaluation, DPMP researchers were more critical of themselves than external commentators. It may well be that other stakeholders involved in the particular policy activity had a more positive perception about the role and contribution of the drug user organisation/drug user representative than they themselves did.
Outcomes reported in this way are a reminder of the challenges facing DUOs and others who seek to influence policy in a domain such as drug policy which is characterised by powerful stakeholders, strongly held opinions and deeply vested interests. And yet despite the challenges, there is clear evidence that much has, in fact, been achieved, particularly if we think in terms of change occurring incrementally over time. There is however, from AIVL’s perspective, a need to do better, through building meaningful engagement and dialogue between the parties, such that drug policy itself can ‘do better’ in terms of achieving its stated aims but without doing so at the expense of the health and human rights of people who use illicit drugs. This is an important principle of the ‘Track Marks’ project.

Setting out responses to survey questions can make it difficult to fully appreciate the degree to which drug users and drug user organisations have contributed to drug policy activity. The extent to which DUOs experience successful (or otherwise) outcomes, can perhaps best be demonstrated with two examples taken from the survey. In addition to the examples provided here in this report, the soon to be released TrackMarks website will provide detailed information on seven policy/advocacy issues in which DUOs have played an important role.33

Example 1: ACT review of pharmacotherapy guidelines

A number of consumer representatives sit on the ACT’s Opioid Treatments Advisory Committee (OTAC). Staff from CAHMA and The Connection (AIVL’s ACT member organisation) participate, along with two consumers from the community. These are chosen by CAHMA’s peer-support group PHAAT (Pharmacotherapy Advocacy Action Team). During 2009/2010 the ACT undertook a review of its pharmacotherapy guidelines. The consumer representatives argued for greater flexibility, more respect to be shown for consumers within treatment settings and better mechanisms for dispute resolution. The methods used to influence change in this policy area included: consumer consultations to identify priority issues; regular PHAAT meetings to strategise; research into national guidelines and other policy documents; and representation of the issues at OTAC meetings. According to this respondent, the ACT Guidelines have been “substantially improved” as a result.

Example 2: Police attendance at ambulance overdose attendance

A number of methods were used to change the practices of police attending ambulance overdose events in South Australia and arresting others present for various offences, including supply, possession and use of a prohibited substance. The local DUO, SAVIVE, undertook extensive negotiations and liaison with police on this issue, and in the face of denials that police were attending ambulance overdose visits, a local drug user was prepared to come forward and report how he was arrested and charged when he called an ambulance for a friend who had overdosed. The case went to court and subsequent media coverage led to a high level meeting between SAVIVE and both government and police representatives. As a result of this action, police standing orders in SA were changed such that police would only attend an overdose if specifically requested by ambulance officers. Furthermore, they would not seek or use any evidence of minor drug or other offences at the scene of an overdose.

33 The policy-related activities highlighted on the TrackMarks website are: heroin trials; consumer participation in government strategies; the Disability Discrimination Amendment Bill; consumer participation in research; opioid maintenance treatments; and retractable needles and syringes.
What factors facilitate Drug User Organisations in influencing policy?

There was a variety of factors identified as facilitators of the drug policy changes that occurred wholly or partially through the work of DUOs. Some of these facilitating factors were created by the organisations themselves, while others have more diffuse origins. An example of the former is long-term work to establish and maintain networks between DUOs and other, like-minded organisations with which concerted action can be taken when a particular policy issue is on the agenda. The community coalition to address the then Howard Government’s Disability Discrimination Amendment Bill 2003 (DDAB) is a good example of this. The DDAB sought to allow discrimination against people on the grounds of ‘drug addiction’. Had this bill been passed through both houses of Parliament it would have opened the door for individuals and organisations to withhold services such as housing, health care, education, employment and other social services to an already heavily marginalised group in the community.

After an intensive 6 month campaign, and in the face of growing public, political and media condemnation, the Federal Government abandoned its proposed Amendment. The proposed Bill was never put to the vote in the Senate but rather quietly slipped from the Government’s agenda. In one respondent’s view, this was “true grassroots action” successful because “through partnership, providing information for others to use, engaging the [drug] using community and encouraging [direct] involvement also raised the profile of the DUO.” For this respondent, the strength of the community coalition, driven by the DUO, helped the DUO gain credibility with parliamentarians who opened the door for future consultation and dialogue. In this instance, being instrumental in a widely supported and ultimately successful campaign has been a facilitating factor when it comes to DUOs being able to influence drugs-related policy.

An example of factors with more diffuse origins might be thought of as what was reported to be an increasing proportion of people in clinical, research and policy management areas demonstrating more open, progressive attitudes towards drug use and the people who use illicit drugs, largely as a result of positive exposures to people from DUOs within various policy settings. This viewpoint is evident in comments such as: “getting a seat on the task force [and] putting a human face to drug users; being able to meet them at their own game, attend meetings and go to conferences to get our community involved”, as one respondent put it. This sentiment was echoed several times, where the power of ‘presence’ could indeed be seen as facilitating, as was the opportunity to partner in research opportunities. Several respondents referred to the ability to “challenge stereotypes” about PWUID; and how “increased awareness by policy makers that ‘user representation’ delivers better results” was also a facilitating factor. However, as will be discussed in the next section on impeding factors, these same people – clinicians, researchers and policy advisors/decision makers – are also often seen to hinder a DUO’s ability to influence drugs policy.

Issues internal to DUOs have also been highlighted as important facilitators of successful influence on policy activity participation. These include adequate funding and resourcing such as “designated policy positions” in DUOs; but also opportunities to acknowledge, build and support a range of capacities throughout organisations, and also to include “both consumer org reps and independent reps on committees”. This can be seen as strengthening DUOs, building on past successes and ensuring inclusion of PWUID outside established DUOs. Another aspect of strengthening DUOs is the need to “learn from mistakes made by others”.

34 The story of this particular campaign will be available on the TrackMarks website at www.aivl.org.au/trackmarks.
The list below, which summarises the considered views of respondents about the facilitating factors of DUO policy influence, is much more linked to quiet, yet intensive, behind-the-scenes work in policy domains rather than the more public activities mentioned to date, such as community organising and direct action, although these have also been shown to have been effective for some issues. It needs to be remembered though that the levels of stigma and discrimination PWUID experience and the risks associated with ‘coming out’ publicly as someone who uses drugs (usually a pre-requisite to represent on behalf of others, for community organising and direct action) has meant DUOs have needed to tread very carefully and use such approaches with more care than other organisations who represent groups who are viewed as more palatable and deserving of more sympathy in the wider community. This is why, perhaps, facilitating factors can often appear more prominent in those quieter activities.

Specific factors that facilitate DUO policy influence were identified as:

- Availability of relevant information to the policy area
- Participation by the people affected
- Keeping consumers informed about policy activity
- Willingness of other organisations and key individuals to collaborate in creating change
- Availability of established networks with people in policy advisory positions
- An existing ethos of ‘walking the talk’
- Drug users being willing and able to stand up and speak out in public
- A demonstrated ethic of team work
- Pre-existing knowledge of structures and networks that can be used
- Membership on policy advisory committees
- Pre-existing personal networks
- An ethic of being articulate and assertive in fighting for issues identified by consumers
- Funded DUOs
- Track record of DUOs as advocates
- Increasing proportions of clinicians and policy staff who have more modern, open perceptions of drug users and drug treatment
- Past history of activism from respected drug user organisation leaders
- Development of trust between DUOs and mainstream services through the activities of drug user representatives
- Pre-existing partnerships
- A more enabling environment for DUOs
- Increased awareness by policy makers that user representation delivers better results and provides an important perspectives on potential difficulties
- Learning from previous experience by the same or another organisations
- Evidence that drug user organisations can operate in an effective and efficient manner to achieve worthwhile goals

The above list of facilitating factors forms the basis of what could be developed into a ‘checklist’ for those wishing to engage DUOs and PWUID more meaningfully in drug policy activity, as well as for those drug users who would like to be so engaged.
What factors impede Drug User Organisations from influencing policy?

Although respondents were generally positive about the achievements of drug user organisations in influencing policy, and were able to provide examples of where this had occurred, they were also able to identify many impediments to success in this area. As with the facilitating factors, some of these are internal to the DUOs themselves, such as a lack of policy experience of members and staff, an over-reliance on peer knowledge and ill-conceived campaigns. A “lack of feedback from other state user orgs has sometimes made it difficult to proceed” was cited by one respondent as an internal impediment, as was DUOs’ own internal structures that can “impede” staff in their capacity to work in a fast moving, rapidly changing environment, and to make decisions about policy responses: “by the time they [DUO internal processes] have processed the request the issue has moved on”. This can mean that the number of people who are empowered (by their organisation’s own internal policies) to make decisions severely restricts the capacity of people to participate in the timeframes allowed.

Most impediments cited, however, were factors external to DUOs. The most common and prominent examples of these relate to the attitudes of the public and key powerful individuals who, perhaps fuelled by the media, perpetuate stereotypical views of people who use illicit drugs. As respondents commented: “in my experience, drug user representation is threatened by the attitudes of those in powerful positions... some have had a bad experience with users and wrongly assume this is the case with all users”; “many are just biased and take the moral view on drug use”; “negative attitudes to drug users fed by the media”. General discrimination in the community is also cited, along with stigma and marginalisation.

Limited and/or restricted funding often made it difficult for DUOs to participate in meaningful ways, as did short turn-around times for responses to requests for information, for example. One respondent found the limitation of small budgets hindered the ability “to provide [the] necessary support for DUOs elsewhere to participate more alongside AIVL”. Several respondents directly named the “overarching and prevailing policy of prohibition” as perhaps the single biggest impediment, for whilst ever certain drug use remained illegal it would always be difficult for drug users to participate fully, particularly in fora that can often include law enforcement officials, or their pharmacotherapy providers as a number of governmental committees do. Dealing with vested interests, lack of openness and transparency in the policy structures and processes, were also cited as impeding factors.

Further impediments identified are summarised below:

- Lack of communication between DUOs
- Challenges in reaching consensus on policies where highly divergent, value-based differences exist among participants
- Negative, inaccurate, sensationalist media about drugs and drug users
- Complacency
- Conservative politics
- Reluctance of people who use illicit drugs to speak out in public
- Lack of understanding of the potential contributions of DUOs
- Inflexible contractual obligations between DUOs and funding bodies, including limitations on advocacy activity
• Inadequate resourcing of DUOs
• Prior negative experiences in engaging with DUOs on the part of some key people in treatment and policy areas
• Negative attitudes towards people who use illicit drugs in the community generally; discrimination
• Inadequately thought out direct action campaigns resulting in problematic backlash
• Certain characteristics of some people who use illicit drugs that make it difficult for them to develop and maintain effective DUOs (eg lack of confidence)
• Entrenched systemic marginalisation of, and condescension toward, drug users by some professional elites
• Highly risk-aversive politicians and their advisors
• Over-reliance on peer knowledge leading to insufficient collaboration and co-operation with other services
• DUOs’ internal organisational processes can waste time and energy
• Neglecting to seed and support satellite grass roots drug user groups based around specific local issues
• Micro-management by funding bodies
• Challenges in accessing high level decision-making committees and having users’ voices heard there
• The low level of political and bureaucratic interest in improved drug policies
• The limited policy backgrounds of many workers inside DUOs
• Prohibition
Drug user organisations’ participation in Australian drugs policy

In addition to identifying particular types of policy activity PWUID and DUOs have been engaged in, respondents were invited to assess the quality of that engagement. These particular experiences and perceptions are summarised under the following headings:

- Current levels of participation: using a ‘ladder of participation’;
- Current levels of participation: issues identified;
- Benefits of meaningful engagement; and
- Perceptions about future engagement

**Current levels of participation: A ‘ladder of participation’**

Using a hierarchy of seven levels of participation, or ‘ladder’, respondents were asked to select the step on the ladder that best summarised their overall view of the current situation. Seven response options were available to choose from, ranging from ‘none’ at one end to ‘have control’ at the other. The opportunity to add open-ended comments was also provided.

A number of ‘ladders of participation’, however named, are available in literature. The earliest and for many years most cited was that produced by Sherry Arnstein some decades ago. The approach was developed further in the field of community organisation by Brager & Specht, and in the field of youth development by Hart. For the purposes of this study, however, it was considered appropriate to use a formulation derived from the broad area of governance.

The ‘ladder of participation’ used in the survey was based on the statement of principles of multi-stakeholder participation documented in what is known as ‘The MSP Book’, (where ‘MSP’ stands for multi-stakeholder processes (or participation). Its title *Multi-stakeholder processes for governance and sustainability: beyond deadlock and conflict*, reveals its emphasis on the utility of meaningful

stakeholder engagement as a tool for enhancing the quality of governance. This has further been picked up in the latest National Drug Strategy, in which governance is to include “partnerships and consumer participation”.39

Thirty two responses were provided to this question and the results of where respondents believe DUOs sit in this particular hierarchy are provided in Table 5, over the page. 21 of those answering this question provided comments. In summary most respondents rate current DUO engagement at the mid-point of being able to ‘advise’ on policy making processes, or somewhere below this:

• 46.9% believed DUOs currently ‘advise’ on drug policy, where advice was defined as ‘Policy body presents a draft policy and invites questions. Prepared to modify the policy only if absolutely necessary’. This sits in the middle of the ‘ladder’;
• 25% believed DUOs ‘are consulted’;
• 9.4% said they ‘receive information’; and
• another 9.4% believed DUOs are not involved in policy-making processes, neither by initiating, developing, evaluating nor revising drug policies;

Moving up the hierarchy from ‘advise’:

• 6.3% said DUOs ‘plan jointly’;
• and 3.1% (1 respondent) said DUOs ‘have policy delegated’, such that the DUO community is presented with a policy defined by the policy body and is asked to ‘make a series of decisions which can be embodied in a policy that the policy body can accept’.
• The highest ‘rung’ on the ladder, that of ‘have control’ received no responses.

Table 4  Where DUOs currently sit in a hierarchy of participation levels – a ladder of participation

<table>
<thead>
<tr>
<th>Level Description</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>None: Users and user organisations not involved in initiating, developing, evaluating or revising drug policies in Australia.</td>
<td>9.4%</td>
<td>3</td>
</tr>
<tr>
<td>Receive information: Policy body creates a policy and announces it. Users and user organisations provide information only. Compliance is expected.</td>
<td>9.4%</td>
<td>3</td>
</tr>
<tr>
<td>Are consulted: Policy body tries to promote a draft policy. Seeks to develop support to facilitate acceptance or give sufficient sanction to the policy so administrative compliance can be expected.</td>
<td>25.0%</td>
<td>8</td>
</tr>
<tr>
<td>Advise: Policy body presents a draft policy and invites questions. Prepared to modify the policy only if absolutely necessary.</td>
<td>46.9%</td>
<td>15</td>
</tr>
<tr>
<td>Plan jointly: Policy body presents draft policy subject to change and open to change from those affected. Expects to change the draft policy at least slightly and perhaps more subsequently.</td>
<td>6.3%</td>
<td>2</td>
</tr>
<tr>
<td>Have delegated: Policy body identifies and presents a policy problem to the drug user community (users and user organisations). Defines the limits and asks user community/organisations to make a series of decisions, which can be embodied in a policy that it can accept.</td>
<td>3.1%</td>
<td>1</td>
</tr>
<tr>
<td>Have control: Policy body asks users and user organisations to identify the policy problem and to make all the key decisions on goals.</td>
<td>0.0%</td>
<td>0</td>
</tr>
</tbody>
</table>
Current levels of participation: Issues identified

The majority of responses (23) reflected a view that drug users and drug user organisations are engaged in drug policy activity at the level of consultation and advice. This indicates that there is a clear perception that some mid-level engagement does happen. However, the additional comments provided by 21 respondents illuminate the degree to which people do not feel properly or meaningfully engaged at these levels, and the degree to which barriers to meaningful engagement currently exist for drug user participation in that activity. In the context of engaging with affected communities, where the meaningful involvement of people who use drugs is increasingly (in the international sphere at least) being acknowledged and included at both a policy and program implementation level, the research here picks up some of the tensions that exist in making participation meaningful.

From the open-ended responses provided, a small number of broad, but overlapping, themes relating to meaningful engagement emerged. Overall, the extent to which people believed meaningful engagement occurred (particularly in relation to whether drug user organisations were ‘consulted’ or ‘advised’) was often felt to be dependent on a number of factors that could vary from time to time, from jurisdiction to jurisdiction, from policy to policy, and even from individual to individual. The themes identified in the responses to this question are categorised as issues concerned with:

1. **Tokenism.** A level of cynicism was expressed by a number of respondents about the degree to which drug user involvement in policy processes is a genuine attempt at engagement, with a number commenting that participation often feels tokenistic and that (some) policy makers are not interested in the views of drug users. Several responses referred to “box ticking”, “window dressing” “we are mostly there so they can say consultation occurred”. The perception of tokenism extends to beliefs about a lack of genuine process commitment on the part of policy makers, evidenced by such things as: lack of understanding or appreciation of peer-based organisations and their limitations, particularly regarding resourcing and capacity issues; and unrealistic timeframes that make genuine or meaningful participation extremely difficult.

2. **Power.** A number of respondents believed that power imbalances hampered the level of contribution that drug users and drug user organisations are able to make. This is quite closely linked to beliefs about tokenism, and respondents commented that gaining any concessions was often very difficult and usually based on government fear rather than any genuine desire to arrive at the best possible policy outcome. It was also felt that external political agendas often drive drugs policy. According to one respondent, “unfortunately, it seems that most drug policies are either influenced more by political concerns than by drug user organisations and drug users at this stage”. Or, as another respondent commented,

   “[the] current situation in NSW [is] grim. Policy makers/power centres [are] largely disinterested in users (sic) views. Especially NSW Health, Corrective Services and DoCS. Dominance of ‘evidence based research/practice’, entrenched networks of influence, and fetishization of technical expertise, among other things, leave users outside”.

This comment points to the way in which drug users can feel disempowered by the very language, and relationships, that ‘others’ at the policy table exhibit. In terms of more meaningful engagement, it would seem that at least some of these power differentials stem from the diverse, and even divergent, environments various policy activity participants inhabit.
3. **Ownership**: “after all it is about drug users”. This and several other comments indicated that for more meaningful participation in policy processes to occur, a greater sense of ownership needed to be developed, particularly given the power imbalances drug users feel they find themselves in. This is underpinned by a rights-based philosophy of ‘by us for us’ or ‘nothing about us without us’, which is also explicitly borne out elsewhere in the research and at the international policy level. The need for drug users themselves to own their own behaviour and to examine what they contribute (both positively and negatively) to policy processes was mentioned, as was the need to challenge “negative stereotypes”, and to build greater “coherence and cohesion among user communities”.

Taking the three ‘themes’ above, of tokenism, power and ownership, it is important to note the variation in the ‘quality’ of particular policy activity engagements between different types of policy activity. People were concerned to note the gap between genuine and tokenistic participation, and also the difference in the quality of participation when DUOs are adequately resourced for the role and can properly train and support people to be effective consumer representatives.

Interestingly, only one respondent noted the importance of moving up the ladder of participation, and how it was important for PWUID to be a positive part of the processes that might see that happen. Comments about “the lack of regard some government staff have for drug users” which is reciprocated, “addressing the perpetuation of negative stereotypes, addressing the “near universal victim mentality” and “defensive” behaviour” of some drug users are a sobering reminder that more meaningful engagement needs to be addressed both internally (by DUOs) and externally. It is worth remembering, too, that attitudes are, or can be, a by-product of the ways in which drug users are routinely treated by a system in which a ‘lack of respect’ is an expected norm.

**Benefits of meaningful engagement**

Respondents were given the opportunity to outline the benefits that might flow from more meaningful engagement of PWUID in drug policy activity. Twenty Nine respondents provided answers to this question. Overwhelmingly, respondents believed that better, ie ‘more informed’ and ‘effective’ policy would result from such engagement. Some believed that it is ‘absolutely crucial to have users and their organisations involved’ because without such engagement no ‘realistic perspective’ can be achieved. One respondent candidly and simply stated that “meaningful engagement means policy itself has the chance to be meaningful”.

Some respondents referred to the ‘humanisation’ of drug users, and the potential for stigma and discrimination to be addressed through more meaningful policy engagement. This notion of community development and capacity building was also raised in the context of ‘nothing about us without us’. A number of the responses to this question can be linked back to notions of ownership and power (but more specifically empowerment) raised by respondents in relation to how PWUID are currently engaged in drug policy activity.

**Perceptions about future engagement**

“My hope is more involvement, and to some extent I have seen this in certain cases. I think funding (or lack thereof) will determine some levels of engagement, [and] I also think changes with public opinions (i.e. discriminations and stigma) will enable more meaningful engagement.”
When it comes to the likelihood of future meaningful engagement of PWUID and DUOs in drug policy, some mixed feelings were expressed by respondents. Whilst many expressed hope that more involvement was possible, others felt less optimistic about the future when it comes to meaningful engagement. Whilst one respondent felt “the current Labor government has 0 interest” in illicit drugs generally, another expressed a view as to why less involvement would be the result.

“Sadly, less involvement. Co-option of [the] ‘brightest and best’ by the ‘Establishment, ie working within the institutions requires compromise and distance from [the] social experience of marginalised users (Labour led governments are very adept at this!); ageing and death of cohort of 70’s/80’s activists – loss of collective memory and experiences; generational drug use experience [and] cultural differences among users (‘old school’ heroin users contrasted with Gen Y stimulant users for example) [are] hard to reconcile.

Largely, for many, future engagement was seen as an area of major uncertainty, and highly contingent on unpredictable political factors, in particular factors outside the control of PWUID and their representative organisations.

“Political situations determine this [the level of engagement], so it’s difficult to predict. It could go either way depending on the situation, either politically or based on the issues. I would like to think that it will get better, and I think some things will not go too far backwards if there is a history of drug user involvement ..... losing that would require justification, but I don’t know if meaningful involvement will become more common, and I’d be surprised if it happened on a large scale any time soon.”

In terms of future engagement, even amongst those more hopeful about future engagement, there was a repeated concern that DUOs face less support and need to fight for their very survival in political climates not necessarily conducive or supportive of the rights of PWUID to participate directly in issues that affect them. These concerns emerged not only when asked whether people believed there would be more or less engagement, but in the last open ended question for respondents to add any other comments. Of the 14 responses, respondents offered thoughtful comments regarding the need for all stakeholders, including drug user organisations themselves, to be more open to reflection on issues of meaningful engagement, and to avoid falling into a ‘victim mentality’ that had at times hampered the process and how people felt about participating in policy activity.
Key principles of meaningful engagement in drug policy activity

In determining a set of key principles to underpin the more meaningful engagement of PWUID and DUOs in drugs policy activity, survey participants were first invited to provide their own ideas of what such principles might be. The aim of this question was to determine what drug users believe should underlie and guide future DUO involvement in drug policy activity, in order to improve policy overall. This was then followed by a list of principles underlying stakeholder participation taken from another field, and respondents were asked to rate each one in order of importance. This list was taken from the same ‘MSP’ book as the ladder of participation, and respondents were asked to rate them on a five-point Likert scale of ‘very important’, ‘important’, ‘neither important nor unimportant’, ‘unimportant’, or ‘very unimportant’. Overall, there was only a limited spread of responses, with most respondents indicating that the principles listed were very important or important.

Survey respondents’ own ideas about the key principles of meaningful engagement are interesting, particularly when compared with the list from the MSP book. From responses to this question, four broad themes stood out. Importantly, these issues were not adequately reflected in the list of principles provided. The four issues respondents felt most important for meaningful engagement were:

1. The principle of engagement between diverse stakeholders was most prominent. Respondents emphasised the fact that members of communities affected by drug policies should be involved in the development of those policies. Closely linked to this were comments about the importance of, and need for a breadth of consultation and involvement: it should not be simply a narrow elite which represents others’ viewpoints.

2. The second most prominent comment was the need to have the knowledge and expertise of drug users and drug user organisations acknowledged and actively harnessed as part of policy activity. This reflects perceptions that the value of the contributions DUOs and PWUID make is denigrated as subjugated knowledge, rather than recognised in the spirit in which DUOs are often asked to participate in policy activity, as consumers with valuable inputs.

3. The need for a range of supports to be available to drug users and drug user organisations to facilitate meaningful participation was also prominent. These supports include money (funding), training for people engaging in policy processes, mentoring (a strategy that can be linked to

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training), the provision of sufficient time to prepare for engagement activities, and written guidelines covering patterns of engagement. These are issues that have been well advanced in the health consumer participation movement but far less so in drug policy. These are the same support needs arising out of AIVL’s Treatment Service Users Project Phase Two.

4. The fourth particularly prominent principle requiring attention, in the views of respondents, was the need for open communication between the various stakeholders. Components of open communication include the willingness of people to compromise, and transparency in policy activity.

A number of other useful points received attention, but not as strongly as the four listed above, as follows:

5. Engagement needs to be genuine, not tokenistic.
6. People and agencies who propose new or revised policies should give adequate time for drug user organisations to respond to them properly.
7. People in policy positions should show respect for individual drug users and for their organisations.
8. It is important to acknowledge the diversity of people who use illicit drugs and not stereotype them. This reflects, in part, the changing patterns of drug use in the Australian community and the demographics of the drug using population.
9. It is also important that people in government agencies acknowledge that drug user organisations have a responsibility to their constituents, to act as a powerful advocates. This may mean that it will not always be possible to reach consensus or agreement on contentious issues or to expect drug user representatives to compromise their position, even if this risks them being characterised as ‘difficult’ and ‘unrealistic’, or, worse still, providing an excuse not to include a drug user representative in future.
10. It is important that the representatives of drug user organisations behave in a professional manner when representing their community in policy forums.
11. It is important to maintain focus on achieving positive outcomes from the meaningful engagement with policy as, after all, this should be its goal.
12. Processes of meaningful engagement between drug user organisations and the policy agencies should commence from the beginning of the policy process, rather than part way through it.
13. Other matters mentioned included:
   a. the need to focus on human rights;
   b. the importance of accountability;
   c. acknowledging that some people expose themselves to personal risk when they publicly identify as drug users and seek to engage in policy activity;
   d. the challenges of fulfilling a representative role and, linked to this, the need for guidelines on how to be an effective and responsible representative.

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42 AIVL 2011 Treatment Service Users Project, Phase Two, Final Report, AIVL: Canberra, Australia.
These are valuable contributions provided by the survey respondents. They will be taken into account, in conjunction with the highest rated principles derived from the multi-stakeholder processes book and other sources, to produce a new set of principles underlying meaningful engagement of people who use drugs.

Thirty one (31) respondents completed the principles checklist. The principle which received a ‘very important’ rating from the highest number of respondents (24 of the 31) was ‘participation and engagement, engaging all the key stakeholders’. A further 6 respondents rated this as ‘important’. This was closely followed, in frequency of rating as ‘very important’, by the principle of inclusiveness, an allied concept. Effectiveness and transparency had the next highest level of support.

One of the principles given a relatively low level of support was the ‘strengthening of institutions’. This probably reflects participants finding it difficult to associate that concept with meaningful engagement in drug policy. Nonetheless, it does remain an important issue and one which perhaps could be explored through means other than this type of survey.

<table>
<thead>
<tr>
<th>Principle</th>
<th>Very important</th>
<th>Important</th>
<th>Neither important nor unimportant</th>
<th>Unimportant</th>
<th>Very unimportant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accountability</td>
<td>61.3% (19)</td>
<td>32.3% (10)</td>
<td>6.5% (2)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Effectiveness</td>
<td>71.0% (22)</td>
<td>29.0% (9)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Equity</td>
<td>67.7% (21)</td>
<td>29.0% (9)</td>
<td>3.2% (1)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Flexibility</td>
<td>35.5% (11)</td>
<td>64.5% (20)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Good governance</td>
<td>41.9% (13)</td>
<td>51.6% (16)</td>
<td>6.5% (2)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Inclusiveness</td>
<td>77.4% (24)</td>
<td>19.4% (6)</td>
<td>3.2% (1)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Learning</td>
<td>63.3% (19)</td>
<td>33.3% (10)</td>
<td>3.3% (1)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Legitimacy</td>
<td>56.7% (17)</td>
<td>43.3% (13)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Ownership</td>
<td>69.0% (20)</td>
<td>20.7% (6)</td>
<td>10.3% (3)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Participation and engagement, engaging all key stakeholders</td>
<td>80.0% (24)</td>
<td>20.0% (6)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Partnership/co-operative management</td>
<td>69.0% (20)</td>
<td>27.6% (8)</td>
<td>3.4% (1)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Societal gains</td>
<td>43.3% (13)</td>
<td>36.7% (11)</td>
<td>16.7% (5)</td>
<td>0.0% (0)</td>
<td>3.3% (1)</td>
</tr>
<tr>
<td>Strengthening of institutions</td>
<td>33.3% (10)</td>
<td>36.7% (11)</td>
<td>26.7% (8)</td>
<td>3.3% (1)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Transparency</td>
<td>70.0% (21)</td>
<td>26.7% (8)</td>
<td>3.3% (1)</td>
<td>0.0% (0)</td>
<td>0.0% (0)</td>
</tr>
<tr>
<td>Voices not votes</td>
<td>51.7% (15)</td>
<td>31.0% (9)</td>
<td>13.8% (4)</td>
<td>0.0% (0)</td>
<td>3.4% (1)</td>
</tr>
</tbody>
</table>
Findings and implications for future engagement

Summary of Findings and Key Principles for Future Engagement

The “TrackMarks” national consultation was a research project with a primary focus on the meaningful engagement of people who use illicit drugs (PWUIDs) through peer-based drug user organisations (DUOs) in the policy process. Broadly summarised, the major aims of this study were:

a) to document the contributions of DUOs and PWUIDs to the development of drug policy in Australia;
b) to identify the principles underpinning meaningful engagement with DUOs and PWUIDs in the drug policy process; and
c) to improve our understanding of how knowledge transfer and synthesisation occurs between key stakeholders engaged in developing illicit drugs policy – in this case DUOs and government agencies.

In documenting what is already occurring in relation to drug user involvement in the Australian drug policy process, AIVL was seeking to increase understanding about what constitutes ‘meaningful engagement’ and utilise this to ensure more and better quality policy outcomes in the long term.

The research built on existing knowledge from within the social sciences on policy development processes, the nature of policy change and how policy can be impacted upon through the meaningful engagement of advocates. The study also drew upon a range of models in relation to policy influence and research influence to assist in better understanding the processes through which policy is made.

Models or Methods of Policy Influence:

In the area of policy influence the main models investigated in relation to the way that Australian drug policy activity currently occurs were the rational/comprehensive model and the incrementalism model. The report argues that rather than using a rational/comprehensive approach whereby policy decisions are made rationally based on all available information, the current Australian illicit drug policy approach attempts to reflect more of an incremental model of building on existing information including knowledge of what worked or failed in the past (the failure of the “war on drug users” notwithstanding). The operation of the incrementalism approach was reflected across a range of the responses from the survey participants which highlighted that much of the policy change they had experienced as user advocates were ‘small steps’ that build upon or sought to improve existing policy rather than large-scale reform or wholesale change based on newly available evidence.
Models of policy influence identified within the policy and advocacy work of the DUOs were the *multiple streams* model and the *advocacy coalitions* model. The *multiple streams* model suggests that problems get on to the government agenda when the streams of politics, policy and problems come together to create ‘windows of opportunity’ to find solutions. Responses from survey participants highlighted times when DUOs had clearly identified a window of opportunity and used that opportunity to create policy change such as addressing the issue of police attendance at overdoses and the establishment and expansion of NSPs in Australia.

The *advocacy coalitions* model was identified as a major policy approach adopted by DUOs whereby policy communities or coalitions have been used to create a more powerful advocacy voice in particular policy domains including in the area of disability discrimination and retractable needles and syringes. On both of these issues DUOs initiated and participated in broad coalitions of advocacy groups and other stakeholders in an effort to disrupt an intended course of policy action on behalf of the government. It must be stated however that advocacy coalitions are far more difficult prospects for DUOs to take part in. The illegal status of drug use and the great personal risk drug users face in publicly advocating as a ‘representative’ makes it more difficult to adopt this approach, except in certain circumstances.

In addition to the above, there were three main models of research influence (in particular the methods DUOs have used to influence drug policy through the generation and communication of information) that were identified in the survey responses including: the *engineering* model; the *enlightenment* model and the *engagement* model. The *engineering* (or pipeline) model in which information is gathered and communicated to people engaged in a policy activity and used by them to produce new and better policy was illustrated by the work DUOs had done to present evidence on a particular issue to policy makers. Examples of this approach in survey responses included the process of researching, documenting and presenting evidence through the development of policy position or discussion papers, submissions to parliamentary enquiries and participation in research and evaluations. Further evidence of DUO involvement in policy work of this nature is also documented through the seven policy areas within the broader TrackMarks website.

The *enlightenment* model which involves strategies to generate and communicate information on a policy issue to society broadly was identified in the research as a strategy that was increasingly being adopted by DUOs to advocate for policy change. In particular this model was illustrated by organisations seeking to influence broad public opinion through letter writing campaigns, opinion editorial pieces in the press, direct action including public demonstrations, letters to the editor and media interviews for example. Finally, the *engagement* model which seeks to influence policy change through a process of dialogue with policy makers and advisory structures was identified in the consultation process as one of the main ways DUOs were currently involved in policy activity. A significant number of the methods of policy influence identified by respondents included strategies under the *engagement* model such as participating in committees and government advisory structures, dialogue with and lobbying policy advisors and parliamentarians and making presentations at policy forums and conferences. Once again, this is further supported in the work of DUOs documented in the policy areas of the TrackMarks website clearly showing the enlightenment and engagement models in action.
Outcomes from Models/Methods Adopted

Although the results were diverse, on the whole there were a broad range of positive outcomes identified by respondents as a result of the involvement of DUOs in drug policy activity. Some of the perceived outcomes were quite tangible or measurable, such as the government withdrawing planned amendments to current legislation in the area of disability discrimination, the cessation of a trial of retractable syringes and increased flexibility in opioid pharmacotherapy dispensing practices. Other outcomes identified were far more ‘process oriented’ such as gaining new opportunities for consumer or DUO representation on advisory bodies or strengthened advocacy capacity within DUOs. Quite a few respondents identified outcomes that were more diffuse in nature as they spoke to perceptions about how greater engagement had improved attitudes towards both drug users and DUOs among service providers, health professionals, policy advisors and the broader community. Taken together, these outcomes are important indicators of both the value of drug user involvement in drug policy and the potential benefits of greater and more meaningful engagement in the future.

In being asked to identify factors that facilitate or impede policy change, survey participants identified a range of internal and external factors on both sides of ledger. In relation to facilitating factors respondents highlighted the importance of adequate resourcing for DUOs to support their capacity to mentor and support effective consumer representatives. This type of stable and professional environment was seen as essential for DUOs to be able to demonstrate their capacity to operate in an effective and efficient manner, to establish and maintain critical networks with other organisations and to been seen and accepted as leaders in consumer advocacy. More ‘external’ factors included ensuring an enabling environment for DUOs, willingness from other organisations to work in collaboration and awareness by policy makers of the value of drug user representation in creating effective drug policy outcomes.

Perhaps not surprisingly, a large number of potential impediments to DUO involvement in drug policy were also identified by respondents. Many of these responses were directed toward the problems associated with:

- entrenched attitudes and values of the general public and key powerful individuals towards drug users;
- the difficulty of achieving consensus where there are highly divergent, value-based differences between committee members;
- the highly risk-adverse nature of many politicians and governments; and
- the general lack of understanding about the value of DUOs.

More ‘internalised’ impediments for DUOs were also identified in relation to inadequate funding for policy activity, an over-reliance on peer-knowledge and experience potentially leading to insufficient openness to collaborations, the ‘costs’ associated with drug users having to ‘come out’ to be a drug user representative and the limited number of people with policy backgrounds in DUOs. Overall, it was considered extremely important not to under-estimate the potential impact of such barriers in an area where entrenched views, strong emotions and vested interests can make it extremely difficult for DUOs to not only influence policy but even attain a ‘place at the table’.
The Quality of Engagement

A number of experiences and perceptions were assessed in order to identify what respondents felt about the ‘quality’ of DUO engagement in drug policy as opposed to whether they had been engaged at all, or methods used to achieve that engagement. In the first instance respondents were asked to assess their experience against a seven level ‘ladder of participation’ ranging from ‘none’ through to ‘have control’. In response to the ladder the majority of participants described the involvement of DUOs in current policy processes as ‘advisory’ in nature. This level of engagement describes the type of work most often undertaken by DUOs, and can include invitations to comment on draft policies, participate in advisory committees and, more rarely, be part of a writing group to actually draft the policy. At least one respondent felt that responding to an invitation to comment on a draft policy can feel like a “waste of time — they won’t change it anyway”, and “they’re just ticking boxes… they rarely give you enough time to make comments”. These perceptions highlight the frustration some respondents expressed when trying to engage in an advisory capacity, which is also drawn out in responses about impeding factors to meaningful engagement.

Although the ‘advisory’ role represents the ‘half-way’ point on the ladder of participation, it should be noted that the vast majority of other responses fell below this mid-way point on the ladder. For example, a significant number of the remaining respondents to this question nominated ‘are consulted’ as being an accurate description of the overall quality of their participation in drug policy processes however, other remaining respondents identified ‘receive information’ and ‘none’ (meaning they are not involved in drug policy processes at all) as reflecting their involvement. It is instructive that very few (only 3 of 32 respondents) identified a level higher than ‘advisory’ on the ladder to describe the quality of their engagement in drug policy such as ‘plan jointly’ and in one case, that DUOs ‘have delegated’. No respondents claimed to ‘have control’ in terms of engagement in the drug policy process which although hardly surprising given the general picture presented across the survey by respondents, it does speak to the need for government agencies to examine the level of participation currently open to DUOs in the drug policy process with the view to improving the ‘meaningfulness’ of this involvement.

In particular, AIVL believes there is a need to further investigate the degree to which people feel meaningfully engaged and to identify the barriers to improving the quality of current DUO involvement. When asked, respondents were able to identify a number of specific barriers to meaningful engagement in the policy process including tokenism versus genuine engagement, power imbalances and a general lack of a sense of ownership over processes which, after all are about the lives of people who use illicit drugs – that is the very people that DUOs represent. There was a clear sense of cynicism about whether governments are really interested in the views of DUOs or whether many policy activities are more focused on ‘box-ticking’ and being able to say that DUOs and/or PWUIDs have ‘been consulted’ on a given policy issue. Linked to this sense of tokenism was a belief that DUOs don’t have any real power in the process and that despite seeking their input, drug policy in particular was more likely to be driven by short-term political imperatives. Both of these issues underline a need to review approaches to drug policy development, evaluation and implementation in favour of a shift towards an approach based on a recognition of human rights, respect for the contribution of DUOs and a genuine implementation of the principle of ‘nothing about us without us’.

Without such a re-evaluation and re-orientation of current approaches to policy engagement with DUOs, some respondents felt that negative perceptions about the value of the contribution of DUOs (from the perspective of government agencies) and of the intentions and motivations of government
agencies (from the perspective of DUOs) were likely to continue. Responses to questions about the benefits of meaningful engagement however, suggest that a genuine commitment to improve the quality of the engagement with DUOs could result in important and positive outcomes for all stakeholders in the drug policy process. Many respondents were able to identify a significant range of benefits from the more meaningful engagement of DUOs including more informed, realistic and effective policy. The rationale behind such beliefs from the drug user perspective is that more ‘meaningful engagement’ must result in more ‘meaningful policy’. This would indeed represent a win-win in many instances, the need for compromise (identified in the survey) and realistic expectations notwithstanding.

Some respondents identified the potential for positive outcomes well beyond the potential for simply better and more meaningful policy if government agencies were to genuinely commit to the issue of ‘meaningful engagement’ with DUOs. The possibility of ‘humanising’ drug users, challenging negative and harmful stereotypes and reducing stigma and discrimination against people who use illicit drugs were identified as some of the potential benefits of more meaningful engagement. Whether the commitment necessary to achieve such benefits would materialise through the drug policy process in the future was a matter that elicited divergent views from respondents.

While some respondents held out hope for more involvement in the future, others were less optimistic, citing the unpredictable nature of the political environment as an ongoing barrier to meaningful participation in the drug policy process for DUOs and PWUID. It is telling that respondents were divided on the likelihood of greater and more meaningful involvement in the future with many uncertain about whether DUOs themselves would survive at all in the current political environment let alone having any real sense of confidence in DUOs being supported to be a more active and equal partner in policy activity. Despite this sense of uncertainty, respondents were able to identify a number of key principles that, if adopted would lead to greater meaningful involvement of DUOs and PWUID in the future.

**Recommendations – Key Principles for Future Meaningful Engagement**

The survey participants’ responses on the issue of meaningful engagement of drug user organisations and people who use drugs in policy activity offer much for stakeholders to contemplate and take forward into future engagement in the quest for better drugs policy. Throughout this report, respondents have raised a number of ideas, suggestions and recommendations around which their engagement with drugs policy could be made more meaningful. These have been distilled and synthesised into the following ten key principles, as identified by the respondents, as most important for the future of meaningful engagement for drug user organisations and people who use drugs in Australian drugs policy activity:

1. The importance of engaging with a broad range of communities affected by drug policies – not just a narrow elite. This includes recognising the diversity of people who use illicit drugs, and acknowledging and responding to changing drug use patterns within the Australian community as appropriate;

2. The need to acknowledge the expertise of DUOs and PWUID – this expertise should be given the equal respect, recognition and priority within policy processes as other forms of expertise or experience are afforded;

3. The need to properly support DUOs and PWUID to participate in a meaningful way in drug policy activity – this includes proper resourcing (such as inviting a minimum of two consumer
representatives to sit on policy advisory bodies), and funding, training, support and mentoring for drug user representatives engaged in these processes, along with sufficient time to respond and understand different patterns of engagement;

4. The need for open communication among stakeholders including a genuine willingness to compromise and act transparently in policy activity;

5. The need for commitment to genuine engagement rather than tokenistic representation of DUOs and PWUID in drug policy activity;

6. The need to recognise that DUOs are under-resourced for the policy and advocacy roles they are expected to undertake and therefore a need to be provided with adequate time to respond properly to new and revised policies that affect the lives of those they represent;

7. Those engaged in policy activity need to understand and accept that DUOs often have to represent complex issues, with a responsibility to act as powerful advocates on behalf of their constituents, without being characterised as ‘difficult’ or unwilling to compromise, or seen as unrealistic about political imperatives. Unwillingness to accept the above should never be used as a reason to exclude DUOs from policy activity; rather, it should be acknowledged as a reality of the process and something to be worked through;

8. DUO representatives need to commit to acting in a professional manner when representing their community in policy forums but there is also a need to recognise the personal nature of consumer representation: drug user representatives often expose themselves to personal risk to publicly identify as a drug user seeking to engage in policy activity; this is an extremely challenging role and there should be recognition of the work involved for DUOs in developing and supporting effective and responsible drug user representatives;

9. The processes of meaningful engagement between DUOs and other policy stakeholders should commence from the beginning of the policy process rather than part way through it;

10. Human rights should underpin drug policy and the meaningful engagement of PWUID in policy processes and activity.

The above principles should be seen as a ‘starting point’ for more meaningful dialogue between the various policy stakeholders. The growth of the involvement of affected communities, both here and internationally points to the need for effectively resourced, trained and supported consumer representatives in policy activity. This small, but important national consultation research has unearthed a wealth of qualitative detail about what meaningful engagement of people who use drugs in policy activity might look like. It is up to the appropriate stakeholders to take these findings forward and bring them to fruition as we continue to seek to improve the engagement of PWUID in all areas of policy in which they have a stake. AIVL will seek to do this through its TrackMarks website – www.aivl.org.au/trackmarks and its continued advocacy and representative work in the Australian drug policy context.
Appendices

Appendix 1: Project Advisory Committee Members

Laura Bondeson – Consumer Representative, Western Australia
Sue Brownbill – AIVL President – 2009/10 – South Australia
Paul (Ringo) Gill – Consumer Representative – Western Australia
Jenny Kelsall – A/g Executive Director, Harm Reduction Victoria (formerly VIVAIDS)
Peter Lucas – Consumer Representative – Tasmania
Susan McGuckin – NSW Users & AIDS Association (NUAA)
Kerri Shying – AIVL Vice President
### Appendix 2: AIVL and Its Member Organisations

<table>
<thead>
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<th>State</th>
<th>Organisation</th>
<th>Abbreviation</th>
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<td>National</td>
<td>Australian Injecting &amp; Illicit Drug Users League</td>
<td>AIVL</td>
</tr>
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<td>ACT</td>
<td>Canberra Alliance for Harm Minimisation &amp; Advocacy</td>
<td>CAHMA</td>
</tr>
<tr>
<td>VIC</td>
<td>Harm Reduction Victoria (formerly Victorian Intravenous &amp; AIDS Association VIVAIDS)</td>
<td>HRVic</td>
</tr>
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<td>New South Wales Users and AIDS Association</td>
<td>NUAA</td>
</tr>
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<td>Queensland Intravenous AIDS Association</td>
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<td>SA Voice for IV Education</td>
<td>SAVIVE</td>
</tr>
<tr>
<td>WA</td>
<td>Western Australian Substance Users Association</td>
<td>WASUA</td>
</tr>
</tbody>
</table>

* AIVL currently does not have a member organisation in Tasmania.
Appendix 2: Survey Instrument

Welcome from Annie Madden, AIVL’s Executive Officer

1. Introduction and survey information

AIVL sponsored research to identify the key principles that underlie meaningful contributions of drug user organisations to the development of drugs policy in Australia

The project

AIVL is undertaking a research project to identify the key principles that underlie meaningful contributions of drug user organisations to the development of illicit drugs policy in Australia. It is called ‘Track Marks’. This survey is part of the project’s research component. The lead researcher is David McDonald from the National Centre for Epidemiology and Population Health at The Australian National University. Wayne Capper from AIVL (the Australian Injecting and Illicit Drug Users’ League) is the Coinvestigator.

The project aims to document the contributions of drug user organisations to the development of drug policy in Australia over the last 20 years, and to identify the key principles that underlie their meaningful engagement in drug policy activity.

Why are we carrying out this research?

The aim of this project is to improve understanding of the contributions of drug user organisations to the development of drug policy in Australia over the last 20 years. The key product of this research will be a report that will be presented to AIVL that describes the contributions of these organisations to drug policy development and that draws out from these descriptions the principles that underlie the meaningful engagement of drug user organisations in drug policy activity. This statement of principles will be used by AIVL and its member organisations, as well as by people in government, to improve the engagement between both groups of stakeholders and to facilitate mutually respectful collaborative work in drug policy development.

What does the research involve?

We have invited you to contribute to this study by completing a web-based questionnaire. It will take you about 20 minutes to complete. This will involve answering questions about your experience of and perceptions about Drug User Organisations’ contributions to the development of drug policy. Completion of the web-based questionnaire is, of course, completely voluntary.

The results of this study will be communicated to AIVL by means of a written report and AIVL will publish the report on its website.

It is likely that the project report will identify some participants by name and organisation. In these cases, prior to publication the draft text will be sent to those who provided the information for checking and provision of written approval to publish. Furthermore, the results of the study may be published in academic journals. The same approval process will be used in these cases, as well.

AIVL will provide you with access to the results of the research once they are published.

Are there any risks if I participate?

No. We are not seeking any information in the questionnaire that is particularly sensitive or confidential.
Further information
If you have any questions or complaints about the study please feel free to contact its Chief Investigator:

David McDonald, Visiting Fellow, National Centre for Epidemiology and Population Health, The Australian National University, Canberra ACT 0200
phone (02) 6238 3706;
fax (02) 9475 4274;
email david.mcdonald@socialresearch.com.au

If you have concerns regarding the way the research was conducted you can also contact The Australian National University Human Research Ethics Committee:

Human Ethics Officer, Ethics Office
Lower Ground Floor, Chancellry 10B
The Australian National University, Canberra ACT 0200
Ph (02) 6125 7945;
Email: Human.Ethics.Officer@anu.edu.au

Privacy Information

‘Track Marks’: Drug User Organisations and Australian drug policy

2. Information about yourself

Please provide some information about yourself by responding to the following brief questions.

1. In which State or Territory do you live?*

2. If currently working in a Drug User Organisation on a paid or voluntary basis, which Drug User Organisation is it?

3. Which Drug User Organisation(s) have you involved with at any time, past or present?

4. (Optional) What is your name and contact details please?

* □ NSW □ Vic □ Qld □ WA □ SA □ Tas □ NT □ ACT
3. Your experiences in influencing drug policy activity

We would now like you to tell us about your experiences in influencing, or trying to influence, drug policy in Australia. This could be activities undertaken at any level: the national level, the State/Territory level, the local government level or the community level.

Please describe any current or past activities in which you or your organisation have attempted to engage with drugs policy activity, that is, attempted to create or influence drugs policy.

You can describe more than one example. We will provide a new page for each policy activity.

1. What aspect of policy are you or were you trying to create or influence? Please describe it.

2. What method or methods are you or were you using? (For example, researching the issues, dialogue with policy advisors or policymakers, lobbying, community organising, direct action, etc.)

3. Have you seen any results from this? For example, was the policy process or policy contents actually influenced, for the better or worse, by your own involvement, or by Drug User Organisation involvement? If you have observed any results, please describe them.

4. How did your/your organisation's activities help to create the results that you have described?

5. What factors are helping, or have helped, to produce the desired results, that is, drug users and/or their organisations actually influencing drugs policy?

6. What factors are impeding, or have impeded, the production of the desired results, that is, drug users and/or their organisations actually influencing drugs policy?

7. Is there anything else that you would like to say about this example of drug user and/or Drug User Organisation engagement with the drug policy process?

8. Would you like to provide another example of drug users’ and/or Drug User Organisations’ involvement in drug policy development?*

* ☐ Yes ☐ No
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7. Is there anything else that you would like to say about this example of drug user and/or Drug User Organisation engagement with the drug policy process?
8. A ladder of participation

1. Here is 'a ladder of participation', a hierarchy of levels of participation. Thinking about the degree to which drug users and Drug User Organisations engage with the drug policy-making processes, please select the step on the ladder that best summarises your overall view on the current situation.

☐ None: Users and user organisations not involved in initiating, developing, evaluating or revising drug policies in Australia.

Receive information: Policy body creates a policy and announces it. Users and user organisations provided information only. Compliance is expected.

☐ Are consulted: Policy body tries to promote a draft policy. Seeks to develop support to facilitate acceptance or give sufficient sanction to the policy so administrative compliance can be expected.

☐ Advise: Policy body presents a draft policy and invites questions. Prepared to modify the policy only if absolutely necessary.

☐ Plan jointly: Policy body presents draft policy subject to change and open to change from those affected. Expects to change the draft policy at least slightly and perhaps more subsequently.

☐ Have delegated: Policy body identifies and presents a policy problem to the drug user community (users and user organisations), defines the limits and asks the user community/organisations to make a series of decisions, which can be embodied in a policy that it can accept.

☐ Have control: Policy body asks users and user organisations to identify the policy problem and to make all the key decisions on goals and means. Willing to help the user community at each step to accomplish goals.

☐ Do you have any comments on this?
9. Participation in drug policy activity

1. What do you see as the real or potential benefits of drug users and Drug User Organisations being meaningfully engaged in the policy-making process?

2. Can you think of any key principles that should underlie and guide user involvement in policy-making processes?
10. Participation in drug policy activity: principles checklist

1. Here is one list of principles underlying stakeholder participation, drawn from another field. Please rate each one in terms of importance for drug user engagement in drug policy activity.

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<td>Participation and engagement, engaging all the key stakeholders</td>
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</tbody>
</table>
11. Concluding comments

1. What do you see as the future of Drug User Organisations’ engagement with drug policy activity in Australia?
   Do you foresee greater or less involvement as time goes by?
   What might determine how this evolves?

2. Is there anything you would like to add?

3. Thank you so much for contributing to AIVL’s research into the involvement of drug users and their organisations in drug policy in Australia.
   We would like to hold one-on-one interviews with some survey participants to go into more detail on some of the comments provided. If you are willing to participate in this way, will you please provide your name, phone number and email address in the following text box. (AIVL regrets that we may not have the resources to contact everyone who offers to engage in a follow-up discussion with our research team.)

Thanks once again for your participation in this survey. Your contribution is very much appreciated. Later in the year AIVL will publish a report on the findings of the research project into Drug User Organisations’ engagement with Australian drug policy. When it is available it will be placed on AIVL’s web site: www.aivl.org.au.

Please click ‘Done’ to finish and exit the survey.
References


McDonald, D, Bammer, G & Breen, G 2005, *Australian illicit drugs policy: mapping structures and processes*, Drug Policy Modelling Project Monograph Series no. 4, Turning Point Alcohol and Drug Centre, Fitzroy, Vic.


THE INVOLVEMENT OF DRUG USER ORGANISATIONS IN AUSTRALIAN DRUGS POLICY

~ A RESEARCH REPORT FROM AIVL'S 'TRACKMARKS' PROJECT ~

AUSTRALIAN INJECTING AND ILLICIT DRUG USERS LEAGUE

MARCH 2012