Strengthen a radical national movement.

Share current work on principles of self-representation in harm reduction, HIV/AIDS and substance use research, policy and programming.

Develop guidelines for meaningful participation of people who use(d) illicit drugs in the development of drug policy, harm reduction and HIV/AIDS policy, services, and research.

Hosted by Society of Living Illicit Drug Users (SOLID) and community leaders from Street College

In collaboration with Canadian Association of People Who Use Drugs (CAPUD), Centre for Addictions Research of BC, AIDS Vancouver Island

Funded by Canadian Institutes of Health Research
With funding acknowledgement to
Introduction

Peer-run organizations of people who use drugs are an important voice representing peers and addressing issues of concern to people who use drugs. Peer-run organizations are committed to improving the health, safety and well-being of people who use drugs by advocating for improvements in health services, policies and research. On October 16 and 17, 2013, a national meeting of peer-run organizations of people who use drugs was held in Victoria, BC. At the meeting, there were over 40 people from across Canada, including representatives from 14 independent peer-run organizations, peer representatives from BC Health Authorities and supporters from ally organizations (See Appendix A).

The meeting was organized by a national steering committee composed of representatives from peer-run organizations across Canada. The national steering committee met monthly for a year preceding the conference. The two-day meeting was planned and hosted by SOLID (Society of Living Illicit Drug Users) in collaboration with the national steering committee, with support from AIDS Vancouver Island (AVI), the Canadian HIV/AIDS Legal Network, the Canadian Harm Reduction Network, Centre for Addictions Research of BC (CARBC), the Canadian Drug Policy Coalition (CDPC), and the Vancouver Island Public Interest Research Group (VIPIRG).

Funding for the conference was obtained from Canadian Institutes of Health Research through an application for a Meeting, Planning and Dissemination Grant. Additional funds were received from several BC health authorities to support the attendance of additional peer representatives.

Purpose of the National Meeting

The purpose of the meeting was for peer-run organizations of people who use drugs to build a collective voice and influence decisions that affect people who use drugs. (The agenda for the two-day meeting is attached as Appendix B).

This report outlines:

- Who are we?
- What are the issues?
- What are we doing?
- What needs to be done nationally?
- How should we be involved?
- What next?

Who Are We?

Peer-run organizations of people who use drugs in Canada

In Canada, there are at least 14 independent peer-run organizations of people who use drugs (see Appendix A). A survey of peer-run organizations was conducted prior to the two-day meeting to provide an overview of peer-run organizations in Canada. Representatives from each organization were invited to complete a short survey online or by telephone about the structure, priorities, goals, collaborations with other peer-run organizations, facilitators, and barriers faced by their organization. Ten of the 14 independent peer-run organizations completed the survey. A full report of the findings of the survey will
be reported elsewhere. In addition, each of the 14 organizations provided an introduction to their organization as part of a cross-country check-in on the first day of the meeting.

The history of peer-run organizations of people who use drugs is one of both success and struggle. One of the earliest peer-run organizations in Canada was Vancouver Area Network of Drug Users (VANDU), established in 1997. Since 1997, at least 13 more independent peer-run organizations have been established. There are provincial organizations in Alberta (AAWEAR – Alberta Addicts Who Educate and Advocate Responsibly), Manitoba (MANDU – Manitoba Network of Drug Users), and Quebec (AQPSUD - L’Association Québécoise pour la promotion de la santé des personnes utilisatrices de drogues). Each of these provincial organizations has a number of regional or local organizations under their umbrella. There are six local or regional organizations, including DUAL (Drug Users Advocacy League, Ottawa), Métà d’Âme (Association of People who use Opiates, Quebec), SOLID (Society of Living Illicit Drug Users, Victoria, BC), REDUN (Rural Empowered Drug User Network, Nelson and Grand Forks, BC), TDUU (Toronto Drug Users Union, Toronto) and VANDU (Vancouver Area Network of Drug Users). VANDU has established and supported the development of at least four independent groups: BCAPOM (British Columbia Association of People on Methadone), WAHRS (Western Aboriginal Harm Reduction Society), SNAP (Salome/Naomi Association of Patients), and BC/Yukon Association of Drug War Survivors, as well as emerging groups including EIDGE (Eastside Illicit Drinkers Group for Education). CAPUD (Canadian Association of People Who Use Drugs) is the national organization of people who use drugs and was established informally in 2010, partially with the support of the Canadian HIV/AIDS Legal Network, and formally incorporated (in BC) in 2011. Two of the 14 peer-run organizations are focused specifically on concerns of people with methadone, and one group is a peer-run organization for indigenous peoples. All groups are concerned with responding to regional issues of concern to people who use drugs and advocating to improve the health, safety and well-being of people who use drugs.

All ten of the organizations that responded to the survey indicated that members are people with past or current drug use. Four organizations permit allies (people defined as supporters of peer-run organizations who do not identify as having past or current experience with drug use) to be members, vote, and hold positions as a board member. Four of the ten organizations identified having staff members. The most common organizational goals and activities are identified in the table below.

<table>
<thead>
<tr>
<th>Organizational Goals</th>
<th>Main Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Advocacy (10)</td>
<td>• Peer outreach (8)</td>
</tr>
<tr>
<td>• Education (10)</td>
<td>• Provision of needle exchange services (6)</td>
</tr>
<tr>
<td>• Peer support/peer-run services/gender specific services (10)</td>
<td>• Advocacy, including community education, meetings and peer support (6)</td>
</tr>
<tr>
<td>• Policy/research (10)</td>
<td></td>
</tr>
<tr>
<td>• Health promotion (9)</td>
<td></td>
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</table>

At least seven of the participating organizations are involved in research. While research was identified as part of their activities, only one group identified it as an organizational priority. Research priorities primarily focused on the importance of either building capacity for peer research or research related to peer support.

Funding for peer-run organizations comes from a range of sources including health authorities, public health, federal government and research funding. All of the peer-run organizations stressed that they are
committed to work and advocacy on behalf of people who use drugs, and that has resulted in a wide range of activities and action despite limited or lack of funding. The conditions identified by peer-run organizations that support effective work include

- Opportunities for advocacy (8),
- Participation in community committees, networks or coalitions (8),
- Adequate funding (7),
- Physical space or location (5),
- Leadership capacity (6), and
- Support of allies (6).

What Are the Issues?

**Key issues for people who use drugs in Canada**
Across the country, people who use drugs and peer-run organizations highlighted multiple issues that impact the health, safety and well-being of people who use drugs. Chief among these were:

- Lack of access to affordable housing
- Stigma and discrimination when accessing housing and healthcare services
- Police harassment, criminalization and the need for drug policy reform
- Lack of harm reduction services, particularly in rural areas

What Are We Doing?

**Current actions being undertaken by peer-run organizations of people who use drugs**
Peer-run organizations of people who use drugs are involved in many aspects of service provision, education, community organizing, advocacy and community participation in order to improve the health and quality of life for all people who use drugs. The activities of the 14 peer-run organizations are diverse and highlight the way in which peer-run organizations respond to relevant and important issues that affect the lives of people who use drugs. Activities included advocating for improved health and harm reduction services for people who use drugs (e.g., take-home naloxone, needle exchange, supervised injection and methadone services), supporting peers, building peer capacity and empowerment among peers, peer organizing, providing a voice for peers to improve policy and practice related to harm reduction and conditions such as housing and income, peer and healthcare provider education, working to end criminalization, and peer delivery of harm reduction services.

What Needs to Be Done?

**Strategies for building a radical national movement**

“This conference is a real moment for all of us to live up to some of this. We need to come out of here with some kind of strategy. It would be a shame if we didn’t do that.”

As a group, we readily met this challenge, and seven potential strategies for building a radical social movement were identified:
1. Advocate for and strengthen social inclusion in conferences and Canadian Drug Policy Coalition
2. Endorse and support harm reduction as a fourth pillar in Canadian drug policy
3. Share expertise, success and strategies to support each other in local initiatives
4. Obtain support from others to increase local and national response to issues
5. Strengthen national networks (CAPUD) and regional coalitions of people who use drugs
6. Continue national teleconferences of people who use drugs
7. Prepare for the next election

How Should We Be Involved?

Principles for participation and self-representation

Participation and social inclusion of people who use drugs is the foundation for taking action to improve the health, safety and well-being of all people who use drugs.

Why is greater involvement needed?

- There is strength and greater impact in numbers
- To empower and involve all groups of people who use drugs
- To uphold the human rights of people who use drugs

In Canada, principles to guide participation and self-representation have been developed by CAPUD (Nothing About Us Without Us), AQPSUD (Guidelines for the Inclusion of People Who Use Drugs), and VANDU (Manifesto, Guiding Principles for Research). A key area for further development of the principles is the need to incorporate and acknowledge cultural differences into the principles (e.g., Aboriginal peoples and people on methadone were specifically identified). Also, there is a need for Aboriginal representation on CAPUD.

Important areas for meaningful participation and social inclusion are:

- Hiring and training of peer workers as part of health and social programming
- Involvement in policy development and planning of services that impact people who use drugs
- Hiring and training of peer researchers
- Early involvement in the development and implementation of research

At the meeting, there was agreement that, while there are well developed and useful principles for guiding social inclusion of people who use drugs, meaningful participation is not yet a reality. There was agreement that there is an urgent need for making meaningful participation a reality, and that a number of obstacles need to be addressed.

1 http://capud.org/?page_id=23
4 http://capud.org/?page_id=23
What are the obstacles to meaningful participation?

- Tokenism and lack of representation are still common
- Inconsistent representation of people who use drugs in policy across the country
- People who use drugs are not always aware of the principles of inclusion
- Funding is a huge barrier, particularly lack of funding for peer organizations
- Peer-run organizations have yet to be established in many areas of the country

What can be done to enhance meaningful participation?

- Need to post Nothing About Us Without Us manifesto in agencies everywhere
- Involvement of people who use drugs in the design and delivery of research is critical
- Need enhanced research training and development for peers
- Service agencies need to be supportive but not dominate
- Need funding and support for establishment of peer-run organizations
- Need to be treated with respect in all partnerships with service agencies and governments
- Need to take national action to inform our peers and the public about the role of peers, human rights and harm reduction
- Allies can provide advice, but it is critical that people who use drugs own decision-making and action

What Next?

The following Motions were passed at the national meeting:

**Motion 1**

Whereas drug users are the most affected by the drug and oppressive drug laws, and
Whereas drug users have unique insights into what reforms will actually contribute to the health, dignity and self-determination for people who use drugs,

Be it resolved that non-drug-user policy organizations, advocacy organizations and research institutions should provide political, financial and logistical support to drug users and drug user organizations to participate and provide leadership at the local, national and international levels.

To adopt the principles of “Nothing About Us Without Us” as the guiding principles for CAPUD.

*Motion passed unanimously*

**Motion 2**

CAPUD to send a letter of protest to the Federal Minister of Health, Rona Ambrose, protesting her decision to exclude some drugs (i.e., heroin) from the Special Access Program. This letter should contain a description of impact of the Minister’s decision on people. CAPUD should try to get the letter

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5 This manifesto was developed as part of the “Nothing About Us Without Us” project and published with the report and accompanying booklet (2005). In conjunction with the later international version of the report published in 2008, an updated version of the manifesto was developed, available here: [http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=846](http://www.aidslaw.ca/publications/publicationsdocEN.php?ref=846).

published in newspapers in French and English across Canada. The letter should also emphasize that bureaucrats and politicians should not be making decisions that negatively affect people’s health.

Motion passed unanimously

Additional Motions
Following the October national meeting in Victoria, a plan for bi-monthly teleconferences was established. Organizations take turns hosting, and the costs of the teleconferences would be shared between CDPC, Canadian HIV/AIDS Legal Network and CARBC. The first one was held in November 2013. The following additional motions were approved by the national group:

Motion 3
To consider that CAPUD takes part in International Drug Users Remembrance Day on July 21 each year.

Motion passed unanimously

Motion 4
To support the creation of a National Harm Reduction Awareness Day. This is important because, among the four pillars drug strategy (harm reduction, prevention, treatment, enforcement), harm reduction has been the least supported, and it is important because it involves housing and other important social supports.

Motion passed unanimously

Motion 5
To support discussions about shifting the Alberta Harm Reduction Conference (every two years) into a national conference.

Motion passed unanimously

Motion 6
CAPUD endorses Housing First as a model that incorporates the principles of harm reduction.

Motion passed unanimously

Conclusions
Peer-run organizations have shared goals of advocating on behalf of their peers and are committed to strengthening policy, services, research and practice to improve conditions for people who use drugs in society. While the funding capacity is often limited, peer-run organizations have been established throughout Canada since 1997 and have become an important voice in the promotion of health, safety and well-being of people who use drugs.

This report outlines who we are, the issues for people who use drugs, and strategies for peer organizing and enhancing the meaningful participation of people who use drugs in programs, services, research, policy and practice. We will continue to share common issues and to develop national strategies that will improve conditions for people who use drugs across Canada. We urge people who are developing policy, programs and services and undertaking research to recognize, engage and collaborate with peer-run organizations and use these strategies for the betterment of society and people who use illicit drugs.
## Appendix A

**Peer-Run Organizations of People Who Use Drugs in Canada**

<table>
<thead>
<tr>
<th>Organization</th>
<th>Description</th>
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<tbody>
<tr>
<td>AAWEAR</td>
<td>Alberta Addicts Who Advocate and Educate Responsibly</td>
</tr>
<tr>
<td>AQPSUD</td>
<td>l’Association Québécoise pour la promotion de la santé des personnes utilisatrices de drogues</td>
</tr>
<tr>
<td>BCAPOM</td>
<td>BC Association of People on Methadone</td>
</tr>
<tr>
<td>BCYADWS</td>
<td>BC/Yukon Association of Drug War Survivors</td>
</tr>
<tr>
<td>CAPUD</td>
<td>Canadian Association of People Who Use Drugs</td>
</tr>
<tr>
<td>DUAL</td>
<td>Drug Users Advocacy League (Ottawa)</td>
</tr>
<tr>
<td>MANDU</td>
<td>Manitoba Drug Users</td>
</tr>
<tr>
<td>Méta d’Âme</td>
<td>Association of People Using Opiates in Quebec</td>
</tr>
<tr>
<td>REDUN</td>
<td>Rural Empowered Drug Users Network (Nelson and Grand Forks, BC)</td>
</tr>
<tr>
<td>SOLID</td>
<td>Society of Living Illicit Drug Users (Victoria, BC)</td>
</tr>
<tr>
<td>TDUU</td>
<td>Toronto Drug Users Union</td>
</tr>
<tr>
<td>UNDUN</td>
<td>Unified Network of Drug Users Nationally</td>
</tr>
<tr>
<td>VANDU</td>
<td>Vancouver Area Network of Drug Users</td>
</tr>
<tr>
<td>WAHRS</td>
<td>Western Aboriginal Harm Reduction Society</td>
</tr>
</tbody>
</table>

**Ally Organizations**

<table>
<thead>
<tr>
<th>Organization</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AVI</td>
<td>AIDS Vancouver Island</td>
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<tr>
<td>CAS</td>
<td>Canadian AIDS Society</td>
</tr>
<tr>
<td>CARBC</td>
<td>Centre for Addictions Research of BC</td>
</tr>
<tr>
<td>CDPC</td>
<td>Canadian Drug Policy Coalition</td>
</tr>
<tr>
<td>CHRA</td>
<td>Canadian Harm Reduction Association (representative not able to attend)</td>
</tr>
<tr>
<td></td>
<td>Canadian HIV/AIDS Legal Network (representative not able to attend)</td>
</tr>
<tr>
<td>VIPIRG</td>
<td>Vancouver Island Public Interest Research Group</td>
</tr>
</tbody>
</table>
Appendix B: National Meeting Agenda

COLLECTIVE VOICES/EFFECTING CHANGE

National Meeting of Organizations of People Who Use Drugs

Oct 15  Coffee House - Welcome
6pm – 9pm Orientation to Victoria (Services and Contacts)

Oct 16  Autonomous Organizing
9:00 Registration, Coffee, Breakfast
9:45 Territory Acknowledgement
10:00 Introduction to Victoria Steering Committee and Meeting Agenda
10:30 Cross-Country Check-In (Reps present on issues they face and work they're doing)
11:00 15-minute break
11:15 Cross-Country Check-In (cont’d)
12:00 Lunch
1:00 Building a Radical National Movement
1:45 15-minute break
2:00 Building a Radical National Movement (cont’d)
3:00 End of Day One

CAPUD Meeting and Membership Drive
6pm – 9pm Food and Discussion (open to all people who use(d) illicit drugs)

Oct 17  Developing Guidelines for Meaningful Participation
9:00 Coffee, Breakfast
10:00 Existing Principles of Participation and Self-Representation
   CAPUD “Nothing About Us Without Us”
   VANDU “VANDU Manifesto / 5 Principles for Working with Researchers”
   AQPSUD “Meaningful Engagement”
   DUAL “Harm Reduction at Work”
11:00 15-minute break
11:15 Common Challenges and Priorities (small group discussion)
   • What parts of existing principles are being acted on, and what aren’t?
   • Does anything need to be added to principles?
12:30 Lunch
1:30 Strategies for Future Work
   • If guidelines are needed, discuss authorship, ownership, and publication.
   • Continue to build national networks and movements.
2:30 End of National Meeting