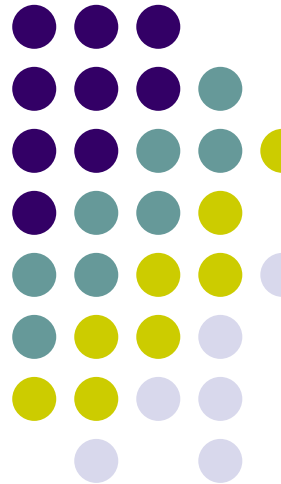


AUSTRALIAN INJECTING & ILLICIT DRUG USERS LEAGUE (AIVL)

ETHICAL ISSUES IN
RESEARCH INVOLVING
PEOPLE WHO USE
ILLICIT DRUGS



OVERVIEW



- Process used to develop the “*AIVL National Statement on Ethical Issues for Research Involving Injecting/Illicit Drug Users*”;
- Some of the key issues covered in the *AIVL National Statement*;
- AIVL’s role in research involving injecting/illicit drug users and peer-driven research.

PROCESS USED TO DEVELOP AIVL NATIONAL STATEMENT



- Developed by AIVL as part of National Hepatitis C Policy Program funded by Hepatitis C Section of DoHA in 2002/3;
- Built on guidelines originally developed by NUAA in 1997;
- AIVL undertook a comprehensive consultation process involving all key stakeholders;

PROCESS USED TO DEVELOP AIVL NATIONAL STATEMENT



- Started out developing a set of national ethical guidelines;
- Following consultation decided to develop a national statement from the ‘drug user perspective’;
- With the main aim of promoting discussion and encouraging further action on ethical issues in IDU research;

PROCESS USED TO DEVELOP AIVL NATIONAL STATEMENT



- Need national leadership from both MACASHH and ANCD to develop a set of national ethical guidelines;
- The involvement of MACASHH and ANCD would give the guidelines ‘authority’ and could support a consensus approach;
- More chance of guidelines being promoted through the AHEC framework for formal NHMRC recognition.

KEY ISSUES COVERED IN AIVL STATEMENT



AIVL Statement covers three key areas:

- Research Ethics Committees;
- Consumer Participation in Research;
- Ethical Issues in Conducting Research.

RESEARCH ETHICS COMMITTEES



- Consumer Involvement in Ethics Committees;
- Legal Issues in IDU Research;
- Free and Informed Consent;
- Peer-Driven Research and Ethics Committees.

CONSUMER INVOLVEMENT IN ETHICS COMMITTEES



- Ethics Committees have a central role to play in the area of ethics and IDU research;
- Main issue that needs to be addressed is the incorporation of IDU perspectives into decision making;
- Problems with the current approach to “consumer representation” on Ethics Committees.

LEGAL ISSUES IN IDU RESEARCH



- Research into illegal behaviours raises some complex legal and ethical issues;
- Data collected on illegal behaviours does not have legally protected status from police searches or court orders;
- Raises issues about the welfare and rights of participants (direct harm through incrimination);

LEGAL ISSUES IN IDU RESEARCH



- Needs to be seen in context though;
- Likelihood of authorities seeking access to research material is relatively small;
- Need to be aware of implications however;
- Eg. it is not ethical to provide participants with absolute assurances of confidentiality;

LEGAL ISSUES IN IDU RESEARCH



- Criminal or legal liability of researchers is far more complex in the area of peer research;
- Standard concepts of “complicity” and “aiding and abetting” can be far less clear;
- Peer researchers have experienced police surveillance, confiscation of data and materials, search warrants, threats, etc.

FREE AND INFORMED CONSENT



- Need to protect identity and confidentiality of participants can conflict with Ethics Committee requirements;
- Signed consent not necessarily the best way to proceed for IDU;
- Additional options for securing informed consent need to be continued to be developed (eg. taping verbal consent)

FREE AND INFORMED CONSENT



- Peers are the key to improving the informed consent process;
- Peers are more comfortable with each other and know when someone is uncomfortable or doesn't understand the process;
- Researchers need to work in partnership with drug users and their organisations to resolve concerns in relation to gaining free and informed consent from IDU.

Peer-Driven Research and Ethics Committees



- No clear guidance on how peer-based NGOs should proceed in relation to ethics approval;
- AIVL has experienced numerous barriers in initiating and conducting peer-driven research due to existing ethics approval processes;
- Lack of clarity about requirements for NGOs;
- Difficulties in accessing information about the ethics approval process;

Peer-Driven Research and Ethics Committees



- Very onerous process;
- Getting senior-level support for peer-driven projects can be difficult;
- Need to demonstrate long track record in research is unrealistic for many peer-based organisations;
- Lack of expertise and understanding on some Ethics Committees in relation to IDU peer-driven research;

Peer-Driven Research and Ethics Committees



- IDU experience was view as a 'disadvantage';
- No recognition that peer-driven research projects may need a more flexible approach to ethics approval;
- Lack of training and support to assist peer-based NGOs to develop the necessary skills.

CONSUMER PARTICIPATION IN RESEARCH



- Consumer Participation and Consultation;
- Principles for Participation and Involvement.

PRINCIPLES FOR PARTICIPATION AND INVOLVMENT



- Collaboration and Partnership;
- Consumer Participation;
- Consumer Consultation;
- Supporting Consumer Research;
- Supporting Consumer Researchers

PRINCIPLES FOR PARTICIPATION AND INVOLVMENT



- Recognition of Consumer Expertise;
- Resourcing to Support Consumer Participation;
- Communicating with Consumers;
- Respecting Consumer Rights;
- Informing Consumers;
- Training for Consumers.

ETHICAL ISSUES IN CONDUCTING RESEARCH



- Planning and Conducting Research;
- Storing, Managing and Analysing Data;
- Dissemination of Research Findings;
- Uses of Research Data.

AIVL'S ROLE IN RESEARCH



- Currently involved in numerous research projects in hep C, HIV and drug use issues (steering cttees, associate investigators and partnerships);
- Currently on the Scientific Advisory Committee for the NCHSR at UNSW;
- Have carried out peer-driven research projects in Safe Disposal, Methamphetamine Injecting and Hep C Risk and Young Women IDU and Hepatitis C.

AIVL'S ROLE IN RESEARCH



- Involved in three-way partnership on Barriers and Incentives to Drug Treatment research project (incl. resourcing for involvement and participation);
- About to commence new peer-driven research project into the Consumer Advocacy Needs of Drug Treatment Service Users;
- Continuing to lobby for national ethical guidelines.