Navigating Research Ethics

Community Mental Health Drug and Alcohol Research Network Research Forum

SYDNEY MEDICAL SCHOOL

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VELiM

› Social scientist working in public health

› Sexual heath and drug health ~ Stigma ~ Marginalisation ~ Health care/health services

› Qualitative methods ~ creative methods ~ participatory methods

› Participation: from community (merely) consenting to engage to empowering community to engage as co-researchers

› Aboriginal and Torres Strait Islander communities (through ACCHS in Townsville, Redfern, Adelaide, GWS) – ICIHRP; REACCH

› LGBT communities (through ACON) – SWASH; ACON Board; ACON REC; LBQ health

› increase knowledge and understanding of what constitutes ethical research.

› strategies for improving the process to gain ethic approvals.

› how to address issues and dilemmas.

› Topics:

› Research ethics from start to finish

› Is AOD research special?

› Except as required by law – participant confidentiality

› Navigating research ethics committees

› Are researchers accountable to committees or communities?

› Nothing about us without us

› No research without service

The National Statement on Ethical Conduct in Human Research

› **Respect -** recognition of the intrinsic value of human beings

› **Respect -** due regard for the welfare, beliefs, perceptions, customs and cultural heritage, both individual and collective, of those involved in research.

› **Respect** - privacy, confidentiality and cultural sensitivities of participants and, where relevant, of their communities. Any specific agreements made with participants or community should be fulfilled.

› **Respect** - giving due scope to the capacity of human beings to make their own decisions (or where diminished empowering them where possible and providing for their protection as necessary)

› **Beneficence** - research benefits must justify any risks of harm or discomfort to participants

› **Beneficence** - design research to minimise the risks of harm or discomfort; clarify for participants potential benefits and risks; and be responsible for participant welfare

› **Merit** - research is justified by its contribution*; appropriate methods; grounded in literature; expertise

› **Integrity -** seeking knowledge and understanding; following recognised principles of research conduct; conducting research honestly; disseminating and communicating favourable and unfavourable results; contribute to public knowledge and understanding

› **Justice** - selection, exclusion and inclusion (and recruitment) of research participants is fair and accurately described; there is no unfair burden on particular groups; fair distribution of the benefits; no exploitation of participants

How should we conduct this research?

› What would AOD research with merit and integrity look like?

› What would respect for participants (and their communities) look like?[1]

› How can we design research to minimise risks? What are the risks?[2]

› How can we ensure there is no unfair burden?

› How can we ensure a fair distribution of benefits? What are the benefits?

› Procedural ethics AND ethics in process / micro ethics

Is AOD research special? More ethically fraught?

› NHMRC public consultation – 5/21 public submissions, special guidelines

› Stigmatised forms of behaviour

- Who is doing the research, who is collecting the data - are they equipped

- How will data be used, experiences represented?

› Consent

- Common perception is don't interview an intoxicated person

- ??lucid and intoxicated, intoxicated<->withdrawal, evidence re understanding

› Reimbursement for participation

- Common concern is coercion

- protectionist, unfair (respect autonomy, effort, risk), evidence that not coercive

› Legal risks to participants and researchers

› Research may discover illegal activity

- "inadvertently and unexpectedly"

- it had not "specifically intended to discover" but was likely to do so

- it "intended to study"

› Researchers must consider how discovery of illicit activity during research may create participant and researcher vulnerabilities

› "except as required by law" = **all** researchers have legal responsibilities and some (eg clinicians) have additional responsibilities

› Balance informed consent and giving undue weight to risk

› No clear guidance on the relevant legal obligations

› *Q: What role might your org have in protecting participants?*

› What is their role? What are their interests?

› Decisions must be supported by The National Statement ("show me")

› Advice:

  - Committees (and secretariats) are a valuable resource

  - Make friends, seek guidance early

  - Problem solve with them (rather than try to get around them)

  - Share successful applications and supporting documents

› Why should community orgs use them? Independent; Publication

› Non-HREC review – ACON

› *Q: Can community orgs do research without HREC approval?*

› Can *(good; meaningful; ethical)* research be conducted without some/full participation of people affected by the issue?

› What does community bring to research?

› Agenda setting - What issues do the community prioritise, value?

› What kind of participation? Who represents?

› What role do community orgs have?

› Developing research capacity in the community (meaningful; sustainable)

› Should community initiate and/or conduct research?

› **Q: Should community have a veto on research findings?**

Role	Quality of community participation in the research process			
	Compliant participation	Directed consultation	Mutual consultation	Empowering co-investigation
Professional researchers	Provide community with balanced information about the research aims and process. Recruit subjects according to the project's design. Researchers are in complete control of the research.	Consult with community members on researcher-identified tasks to take advantage of the community members' unique perspectives. Input limited to specific tasks. Researchers retain complete control over study.	Develop a longer-term partnership with community members that offers a holistic understanding of the project and its goals. Input no longer restricted to specific topics, concerns or tasks. Researchers retain control over study.	Develop egalitarian partnerships with community members that equalize the decision-making power between researchers and community members. Work collaboratively to make research decisions, including the goals, scope, design, and use of the research.
Community members	Voluntarily consent to participate as 'subjects'.	Provide advice on researcher-identified questions or task based on their own knowledge and experiences.	Develop a longer-term relationship in which community members engage in sustained communication with researchers about the project. Project is understood holistically, thus community input may directly shape any aspect of the study, including its purpose and applications.	Develop egalitarian partnerships with community members that equalize the decision-making power between researchers and community members. Remain engaged in research and take responsibility for making collaborative decisions about the research.
Promises made between researchers and community members	By researchers: We will inform you of how you will be involved in the research and about any potential harm that may come as a result of it. We will make public any results that are of sufficient academic interest.	By researchers: We will listen to you and acknowledge your concerns and inform you of how they influenced our research. We value your perspective and believe that it will improve the validity of our work.	By researchers: We value your perspective and will work with you throughout the process. We will listen to you and will integrate your concerns to the best of our ability into the research process.	By researchers and community members: We will look to each other for advice and expertise throughout the research process and will make joint decisions that reflect our shared goals and interests in the research project. Ownership of the study and its product(s) is shared.

Chung 2006

› What 'service' (provisions, benefits) does the community prioritise, value?

› Should service be to research participants or community?

› How can we ensure that research makes a difference to the community (and not just to a researcher's CV)

› **Q: What about no service without research? Or QI.. Is it research?**

› National Statement: "*What constitutes potential benefit and whether it justifies research <u>may sometimes require consultation with the relevant communities</u>*"

› Institutional HREC ask us to justify our plans, account for our actions, have the power to monitor us, can sanction us

› Some communities have a similar role mandated in National Statment[1] most do not… who represents?

› Feedback – an inadequate accountability mechanism?

› The National Statement
https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72_national_statement_march_2014_141126.pdf

› Guidance on legal obligations (NSW)
http://www.alfredresearch.org/ethics/policies/Research%20involving%20legal%20risks%20%28revis%20April%202012%29.pdf

› List of registered HREC https://www.nhmrc.gov.au/health-ethics/human-research-ethics-committees-hrecs/list-human-research-ethics-committees-registere

› The Ethics Application Repository http://tear.otago.ac.nz/

› Research Participation Continuum - Chung & Lounsbury (2006) The role of power, process, and relationships in participatory research for statewide HIV/AIDS programming, Social Science & Medicine: 63(8):2129-2140

› *Ethical Considerations in Quality Assurance and Evaluation Activities http://www.nhmrc.gov.au/guidelines/publications/e111*

› Ethical review of research in the disability services sector
http://asid.asn.au/article/view/21

› DAMEC research framework
http://www.damec.org.au/images/DAMEC_Research_Framework_2014_v7.pdf