CMHDARN FORUM: ETHICS IN RESEARCH December 4^{th,} 2012

Issues arising from morning presentations and discussions

These notes supplement the notes provided by presenters. For references or resources, please see the box at the end of document.

CONSUMERS - Ethical dilemmas/ practice issues

- How does someone (consumer) say 'no' to you as a researcher or say 'I don't like you' if they are a consumer of your service
- Social justice- how do you choose your priorities in who gets your attention in deciding on research
- Should we prioritise those who do least well in society? Any *inclusio*n leads to *exclusion*
- Trying for the situation where the good and the right coincide
- The more we set the research agenda without consumer input, the less ethical it is- who decides what- the notion of colonisation applies to research
- Failing ethically if we don't incorporate the agency of consumers. Competence is part of professional integrity
- Power partnerships- need to share power with consumers- must find different ways of valuing different skills and knowledge- power is tipped towards those who are experts by training
- Good ethical practice is good research - Ethics and techniques can't really be separated- can good technique but bad ethics mean good research?? Not really
- How much ethical review is required- most things in our organisation are research. You then ask the question- when does an ethical review have to take place?
- Different levels of ethical review

Ethical approval/ advisory committees
- Institutional frameworks are supposed to be there to address ethics, but sometimes more about legal protection
- Sometimes more about legal protection and risk management than serious consideration of ethics
- Important for people to be trained if they are sitting on ethics committees
- Question of what goes to Ethics Approval committees vs other assessments (e.g. research vs evaluation)
- Role- liaising or advocacy with government on research issues
- All Quality Improvement (QI) activity with or about people requires ethical consideration

Tools
- Checklist before you start- is your research actually needed- has someone already done this work? Assessment for risk level

AUDIENCE QUESTIONS/ COMMENTS
1. What training and preparation is available for consumers to be involved in ethics approval committees?
- Politics of increasing committees
- Ongoing professional support required
- Monash University has on- line courses
- Good to train people to be ready when vacancies occur

- St James Ethics centre also does training around Ethics issues, and in 2013 will be commencing specific training on being a member of an Ethics committee

2. What about consumers who come along to an organisation for a service- they didn't come along to be involved in research?
- Recruitment of consumers for research can be very difficult.
- How do consumers say no, realistically
- Co-coercion and consent overlap
- Need to show how people can say no- and important to record this as part of data and research
- At what point do we involve consumers – should be prior to delivering questionnaire

3. Do committees do a good job in looking at research?
- There is an adversarial situation between researchers and committees
- Training of undergraduates needs to be improved

Follow up issue: *Advocacy regarding MH language (NHMRC vs ATSI)*

Pre lunch session: ETHICS IN PRACTICE

Phillip Wright
- St James does ethics education, and has a service called Ethi- call where you can ring in and get support for an issue
- History of MH research is that it hasn't been done well
- Conflict between researcher and the ethics committee- maybe time to embrace a new model?
- Clinical case presentations- seen by clinicians as 'own material' but not seen as research. Essentially it is research data- used at conferences, articles etc, but often without consent
- Dilemmas arise- requirements from funding bodies- for efficacy and for evidence based practice (EBP)
    o Who goes back to the consumers- those who have provided service or have an existing relationship?
- Relationship provides the basis for gathering valuable data- raises consent issues
- Research- harm- if you exclude people it has impacts on outcomes- not telling the whole story

Consent/ informed consent
- can be very tricky
- power differential
- who makes the call regarding intervention when someone's health is threatened
- What do you do when things go wrong? - need complaints management- with process developed before things go wrong.

KAREN FISHER
- Excluding people can mean no voice
- Dissemination and sharing of results- must be in a form that consumers can use and distribute
- Need clear guidelines as to what to do when things do go wrong
- Need permission to be in place to conduct research

SHARON FALLEIRO
- Important to separate research governance from ethical review
- Discuss your research idea with colleagues early on
- Key documents

- o National Ethical Approval form (NEAF)
- o Research proposal
- o Survey instruments
- Make sure your documents & forms are detailed and consistent
- Address consent issues- how/ ongoing / guardians?

AUDIENCE QUESTIONS/ COMMENTS
1. Payment to participants?
- Tendency to use reimbursement via vouchers rather than cash
- Recognition of time- adjustment- issue of capacity, mobility, etc

2. Be careful that instruments are strengths based where possible- that they' re not going to cause unnecessary harm or anxiety

3. Concern that there is an assumption that people with lived experience of MH need to be treated 'carefully'- deficit based

AFTERNOON SESSION: Organisational Approach to Ethics Approvals- PANEL

John Williams Cancer Council
Issues regarding ethics approval committees- if you are registered as a HREC, there are specific guidelines regarding structure and operations
- Quorum- representatives from each group required can be a hindrance to operations
- Harmonisation of Multi-Centre Ethical Review (HoMER)
- Knockbacks- re-submits are possible

Sally Cowling Uniting Care Burnside (UCB)
- Wanted a systematic approach to evaluation approaches, needed to talk to academics
- Wanted to build a research culture- Research Advisory Group
- Research process was guided by NMHRC guidelines
- Because of size of organisation and range of operations, needed expertise across many different disciplines
- Pragmatic challenges
- Sometimes you need to refer to others with higher level of expertise
- Strategic research agendas
- 2013, UCB is moving to model of Research Advisory committee-
- Want to get translation into practice better

Alan Brotherton ACON
ACON's ethical approval committee- 2 staff, 6 external

Tim Broady Carers NSW
- Research is a rising issue in the organisation- Tim's role is fairly new
- Ethical culture increasing
- Strategy- external researchers contact CNSW for support
- Internal discussions occurred, now wanting to formalise process
- No ethics committee, but developing strategy
- Partnerships- formalising with University of Wollongong, and hope to access the uni's HRE committee

AUDIENCE QUESTIONS & ISSUES

1. Do you review applications which have already been reviewed & approved by other committees?
2. Resources needed for organisation?
   o ACON- done within position descriptions of 2 staff. Also has a separate service evaluation review team which doesn't have explicit ethics process
3. Uniting Care Burnside- decided to document their programs- looking at minimum data set and outcomes framework. They will be releasing a book on this soon.

ACRONYMS- LNR - Low and Negligible Risk Research (LNR Application Form)

ETHICS IN RESEARCH FORUM: WORKSHOP

1. **What do you think of having a community sector ethics approval committee?**
   Important that there is a process
   CS is supported through ethics- some structure
   Requires diversity (including smaller organisations)
   Capturing the broader consumer voice
   Accreditation??
   Practicalities- size, membership, resources, funding??
   Current barriers- cost; need to understand range of NGO processes
   How do we define community?
   Expertise/ relevancy
   Not single committee- you wouldn't get all the expertise
   Expanding employment opportunities for unemployed academics

2. **What do you think it should look like- e.g. should it cover the whole NSW NGO sector, or should it be particular to one sector or two (e.g. drug and alcohol and/ or mental health? Should each organisation be left to develop its own processes?**

   ➢ *Ideas*
   Regional pilot project in a region D&A & MH- parallel to LHD
   Tools to be made available- Guidelines/ checklists / Flowcharts

   Different objectives in different sectors
   Cover the whole- seek external expertise for particular sectors
   Structural issues (different org't departments)
   Concern re DA/MH issues being put to the side
   Divided views
   In principle a good idea   - state based? Would this body complicate the system more? Would it just be a proxy for a risk management process?
   Advisory committees might be better
   Supervision/ control issues
   Research the research

3. **What are the pros and cons of these different approaches?**
   Get grass roots research worked, lead agent, increase standards, accountability
   Currently risk averse process rather than values based
   Issue- consumer voice through CS/MH/AOD
   Analysis of previous research

   PROS- Accessible expertise for poor NGOs, External- independent, Fresh eyes- constructive criticism

Benefits- central point to share information/ high quality of research

CONS- may not understand value for NGO, resources- support secretariat? Reporting and control of ethics body; implies endorsement
Power imbalance of smaller orgs- could be seen as a barrier

4. **Who should take responsibility for developing such a model?**
   NADA/MHCC
   Ethical codes not supporting the consumer voice- current guidelines need to change
   A collaboration approach- ensuring the consumer voice is contributed
   A lot more discussion needed to get to development mode
   How do you represent the voices that don't get heard?
   Committee membership agreed but who should drive the process???
   Broader independent community platform funded by gov't (but independent) including stakeholders from NGOs as well as experts- lawyers, academics, lived experience

5. **How many of the organisations represented at your table have in place an existing ethics approval process of some sort?**
   A small number of agencies represented had an existing process in place at most tables.

➢ **Recommended Websites/ resources**

Australian Health Ethics Committee (AHEC)
http://www.nhmrc.gov.au/about/committees-nhmrc/australian-health-ethics-committee-ahec

Monash University courses
http://artsonline.monash.edu.au/bioethics/

St James Ethics www.ethics.org.au/
Ethi-call 1800672303

Harmonisation of Multi-Centre Ethical Review (HoMER)
http://www.nhmrc.gov.au/health-ethics/national-approach-single-ethical-review