CMHDARN RESEARCH FORUM: *Sharing our learning*

5TH MARCH 2013

NOTES FROM DISCUSSIONS

> **FORUM OUTCOMES**
> 1. *To have an opportunity to exchange knowledge gained through your research projects.*
> 2. *To increase your knowledge and understanding of research processes.*
> 3. *Provide a networking opportunity for recipients of CMHDARN Research Seeding Grants.*

Session 1: Sharing our learning

What is one thing which has surprised you about the work you are doing through this project, and why it has been a surprise?

SUMMARY Surprises

1. Interest and support for project
2. Some of the results and or process have already had an impact on our organisation's activities
3. Developing a relationship with academic researcher has been successful, and happened more quickly than we thought
4. Internal resistance to the research project and related data collection was not expected.
5. Data collection- how much data we collect over the years, but how little of it might be useful; how you seek information will impact hugely on what responses you get- by not judging consumers you will illicit much more information.
6. Unexpected events, and the impact they can have on your plans- losing relevant and key staff; losing funding;
7. Discovering gaps - in published literature, and in service delivery
8. Willingness of consumers to be involved in the projects

Session 2: Consumer engagement and participation

Deb talked about the area of consumer participation and explained that we are hoping and expecting more active involvement of consumers in your research projects, not just including them as sources of data. Deb suggested people look at the presentations and notes on the CMHDARN website, both in Resources and in the materials from the August 2012 forum on Consumer participation and representation, or the December 2012 forum on Ethics in research.

Handout- Are we recovery oriented? An Australian encounter of learning from people with lived experiences

Key issues identified in discussions: Detail

- Consumers actually provide a lot of information about themselves in groups- with an approach of recognising steps- *'how did you do that?'*
- Ideas of where consumer engagement starts and stops- has implications for ethics
- Informed consent - is a dilemma- often given at a time of crisis
- What about paying people- how does that impact on research… Suggestion- you pay people up front when they arrive, they then have the choice to leave. If they stay, then you know they want to be there.
- What if your primary group of people you are working with are not 'consumers'? ie. They are carers or parents of people affected by MH/DA?
  -They are your service's key 'consumer or service user
  - Ilse referred to 'Critical reference group'- ask yourself, who are the intended beneficiaries of the service and research?
- Issue of language discussed

Session 3: Interactive discussion and exercise

1. Partnerships and collaboration
    Conversation around partnering with universities, and concern that the university agenda may override CMO priorities. Suggested that this is important to sort out early on in the piece- Outcomes should be negotiated upfront, being clear about what you can and can't do. Important to remember that CMOs have important data and access to people for researchers- that you should go to the table with a sense of strength, that the relationship is two way. Reminder about assertiveness in relation to ownership and acknowledgement of project
    Resource: develop or find a simple list of points to cover in initial discussions

2. How to identify and evaluate funding opportunities
    Deb referred people to the CMHDARN website for opportunities. Also suggested that people may wish to look more broadly to Trusts and Foundations as possibilities. Everyone was reminded also that it is possible to do good research with a small amount of money, and that you can grow this research on the basis of the smaller project.
    BUPA; Rotary; ARC, NHNRC, Pharmaceutical companies (although there may be ethical issues arise)

3. How to narrow down the research proposal in terms of methodologies and target groups?
    Don't be too ambitious. Take small steps. Do what you do well- it is better to do something small well than the opposite.

4. Navigating ethics
    Referred to the materials and resources on the CMHDARN website

5. What other options can be considered as an outcome of the research project?
    Concern if the research project outcomes demonstrated that the issue was not a good one, or was flawed etc. Suggested this is still exploratory research and that the results could be used to inform the research proposal anyway- about how to address the issue better.

Suggestions/ Resources

CMHDARN Website
Consumer forum resources
http://www.cmhdaresearchnetwork.com.au/research-resources/publications-and-resources/

Past research forums
http://www.cmhdaresearchnetwork.com.au/research-network-activities/research-forums/past-research-forums/

Schizophrenia Fellowship/ USydney- Consumer training resource
Training Modules designed to empower mental health consumers to engage more fully in research
Download or view HTML and PDF files

Institute of Psychiatry- Consumer advocacy training
http://www.nswiop.nsw.edu.au/index.php?option=com_content&view=category&layout=blog&id=85&Itemid=88

Consumers Health Forum Australia
https://www.chf.org.au/pdfs/rep/rep-1012-futuredirections-Feb13.pdf

Yoland Wadsworth 3rd edition 2011 Everyday Evaluation on the Run Allen & Unwin

End of project reports and outcomes

There will be two documents required

1. End of Project report- which will be an overall project report, addressing the entire project. This will be the place to try to capture the experiential and cultural issues about what the project has meant for the organisation/s, the unexpected outcomes, both positive and negative. This will also include a financial acquittal statement. *Deb will send out this proforma in the future*
2. Research Proposal- this will generally follow the proforma which was previously distributed in late 2012.
 - This will largely be a generic document which can be adapted to suit a particular funding source. However, if someone is applying for a particular grant and know which one it is, they may choose to submit this proposal as it can also be adaptable.
 - With respect to detail regarding ethics approvals- where these are to obtained beforehand, then a clear strategy and outline should be included- identifying the key consumer issues, and proposals for addressing these.