

CMHDARN Ethics Forum



Nicola Hancock

GOT
ETHICS?

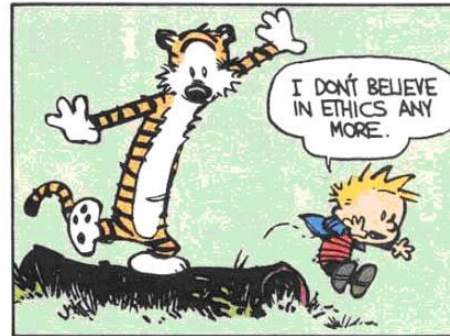
- › 20 years mental health practice (government & CMO)
- › Academia 10 years
 - Research:
 - Co-production/collaborative methodologies
 - Mental health recovery (and recovery oriented practice)
 - Understanding
 - Measurement



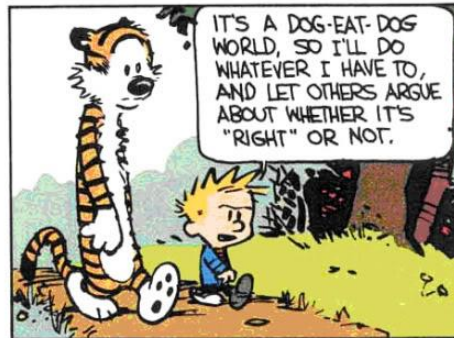
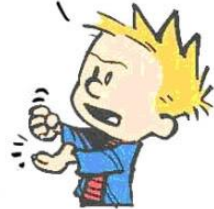
Why BOTHER with ethics?

calvin
and
hobbes

by WATKINSON



GET WHAT YOU CAN WHILE THE GETTING'S GOOD - THAT'S WHAT I SAY! MIGHT MAKES RIGHT! THE WINNERS WRITE THE HISTORY BOOKS!



To help:

- › protect the welfare, rights, dignity and safety of research participants
 - › protect researchers' rights to conduct legitimate investigation
 - › protect the organisation's reputation for research conducted and sponsored by it
 - › minimise the potential for claims of negligence made against any individual researchers and the organisation
-

Why bother?

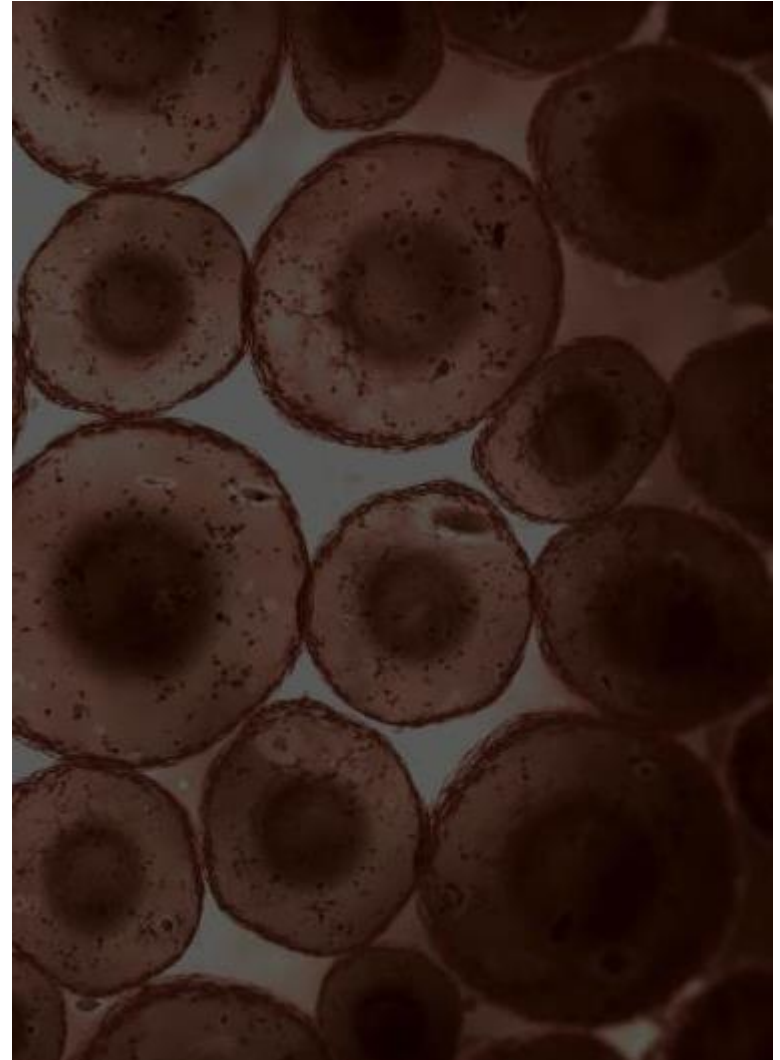
- › And to PUBLISH (share publically) the results....
 - Why does that matter?
 - Is it ethical to conduct research and not disseminate results?

**Innovations of
this
sector are under
reported & thus
under-valued**



Helps with quality of the plan

- › Peer review process of checking and confirming the quality and integrity of what you are planning
 - Respect
 - Merit
 - Moral (beneficence)
 - Justice





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HELPS Planning your Research



Do I **NEED** human research ethics approval?

- › if in MHDAO services, if at a University (staff or student), and if you want to publish your work – YES
- Administering questionnaires/surveys;
- Conducting interviews or focus groups;
- Investigating or observing human behaviour;
- Routine testing/assessing of human participants;
- Any experimentation or data collection involving human beings;
- Even secondary analysis of pre-existing data requires approval.



Special considerations?

To do research with people who:

- have a mental illness
- have a cognitive impairment
- are children
- are your patients or clients

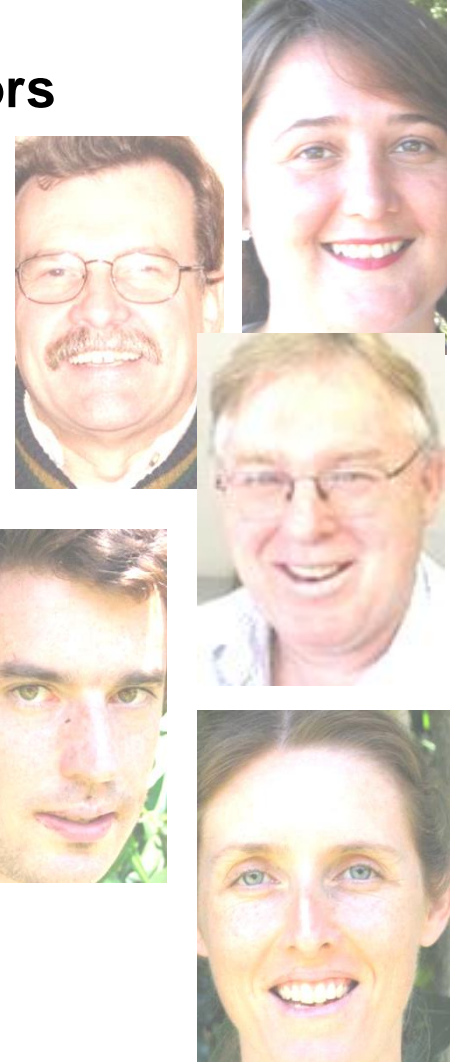
WHY?



Some of my examples...

Partnering with consumers as research collaborators

What do you think the ethical challenges were?

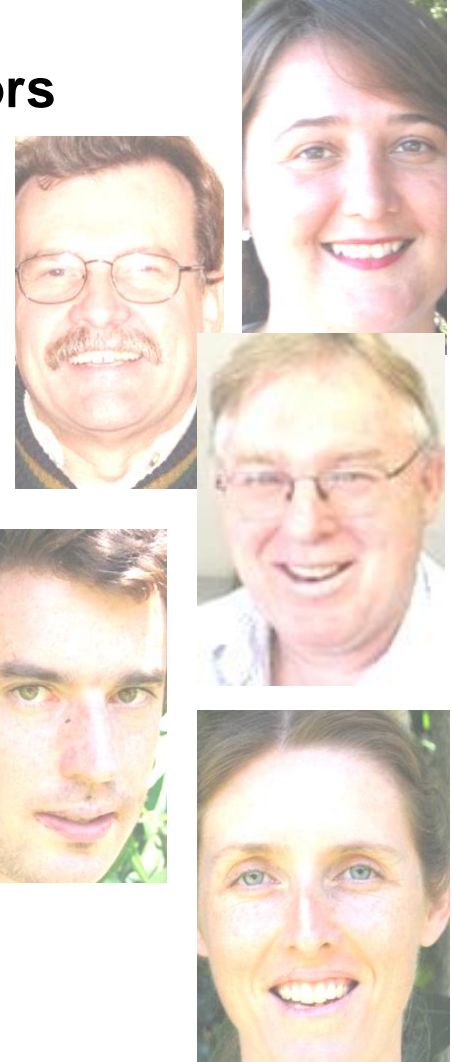


Some of my examples...

Partnering with consumers as research collaborators

Ethics committee questioned ...

- 1. their capacity to cope (risk to them)
- 2. their capacity to maintain confidentiality/respect privacy
- 3. their capacity collect quality data
- 4. whether their relationship with potential participants would overly 'influence' whether people would participate (voluntary nature)



Some of my examples...

Partnering with consumers as research collaborators

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My support and supervision

Training
(consumer researchers)

(and educating the committee)

And detail selection process...

Skills/attributes and not acutely unwell



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This would not have been possible without

Community Ment Health J
DOI 10.1007/s10597-012-9533-y

ORIGINAL PAPER

Measuring the Later Stages of the Recovery Journey: Insights Gained from Clubhouse Members

Nicola Hancock · Anita Bundy · Anne Honey ·
Stephanie Helich · Sally Tamsett

Received: 5 July 2011 / Accepted: 12 July 2012
© Springer Science+Business Media, LLC 2012

Abstract The Recovery Assessment Scale (RAS) is a frequently used measure of recovery from mental illness

Introduction

KEY WORDS

- disability evaluation

Improving Measurement Properties of the Recovery Assessment Scale With Rasch Analysis

ONLINE ONLY

Nicola Hancock, Anita Bundy, Anne Honey, Geoffrey James,
Sally Tamsett

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Demystifying Research

Training Modules designed to empower
mental health consumers to
engage more fully in research



A collaborative project developed in partnership between:
The University of Sydney; Schizophrenia Fellowship of NSW Inc.; Pioneer Clubhouse
(Consumer Research Team); Queensland Centre for Mental Health Research
Funded by: Australian Rotary Health Research Fund

Australian Occupational Therapy
Journal

Occupational
Therapy Australia

Australian Occupational Therapy Journal (2012) 59, 218–224

doi: 10.1111/j.1440-1630.2012.01011.x

Research Article

Participation of mental health consumers in research: Training addressed and reliability assessed

Nicola Hancock,¹ Anita Bundy,¹ Sally Tamsett² and Mark McMahon²

¹Faculty of Health Sciences, University of Sydney, Lidcombe, NSW, Australia and ²Pioneer Clubhouse, Balgowlah, NSW, Australia



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A free & useful resource

Demystifying Research

Training Modules designed to empower
mental health consumers to
engage more fully in research



A collaborative project developed in partnership between:
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<http://hdl.handle.net/2123/9318>



Level of Risk?

Masters student: Interviewing mothers living with mental illness about experiences of and adapting to child removal

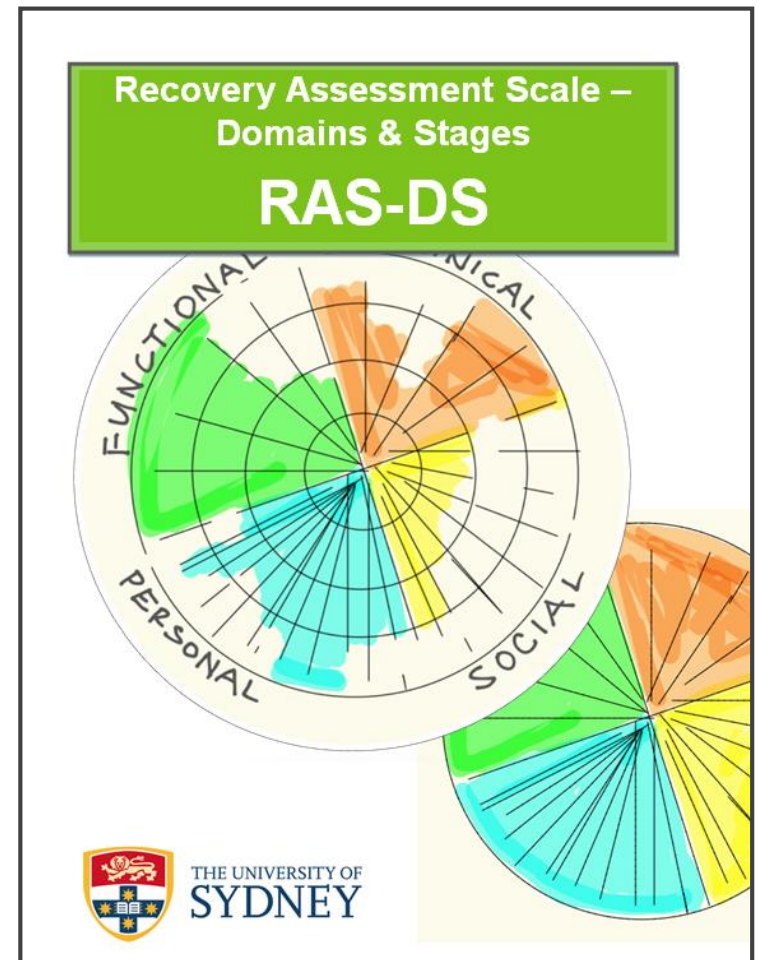
Honours student: interviews with mothers living with mental illness who were identified by support worker as successfully managing parenting – barriers and strategies they use to overcome

What do you think the ethical challenges were?

How do they differ?

RAS-DS (Recovery Assessment Scale – Domains & Stages)

- › Examining how useful consumers and staff found it
 - Consumer & staff pairs (3 CMO/NGOs)
 - Complete, discussion, survey for each
 - Who needed to consent?
 - What were the ethical considerations?





you at the moment. Circle only one number for each statement and do not skip any items.

FUNCTIONAL RECOVERY				
	Definitely UNTRUE	Partly untrue	Partly true	Definitely TRUE
It is important to have fun	1	2	3	4
It is important to have healthy habits	1	2	3	4
I do things that are meaningful to me	1	2	3	4
I continue to have new interests	1	2	3	4
I do things that are valuable and helpful to others	1	2	3	4
I do things that give me a feeling of great pleasure	1	2	3	4
PERSONAL RECOVERY				
	Definitely UNTRUE	Partly untrue	Partly true	Definitely TRUE
I can handle it if I get sick again	1	2	3	4
I can help myself become better	1	2	3	4
I have the desire to succeed	1	2	3	4
I have goals in life that I want to reach	1	2	3	4
I believe that I can reach my current personal goals	1	2	3	4
I can handle what happens in my life	1	2	3	4
I like myself	1	2	3	4
I have a purpose in life	1	2	3	4
If people really knew me they would like me	1	2	3	4
If I keep trying, I will continue to get better	1	2	3	4
I have an idea of who I want to become	1	2	3	4
Something good will eventually happen	1	2	3	4
I am the person most responsible for my own improvement	1	2	3	4
I am hopeful about my own future	1	2	3	4

I ask for help, when I need it	1	2	3	4
I know what helps me get better	1	2	3	4
I can learn from my mistakes	1	2	3	4
CLINICAL RECOVERY				
	UNTRUE	A bit TRUE	Mostly TRUE	Comple TRUE
I can identify the early warning signs of becoming sick	1	2	3	4
I have my own plan for how to stay or become well	1	2	3	4
There are things that I can do that help me deal with unwanted symptoms	1	2	3	4
I know that there are mental health services that help me	1	2	3	4
Although my symptoms may get worse, I know I can handle it	1	2	3	4
My symptoms interfere less and less with my life	1	2	3	4
My symptoms seem to be a problem for shorter periods of time each time they occur	1	2	3	4
SOCIAL RECOVERY				
	UNTRUE	A bit TRUE	Mostly TRUE	Comple TRUE
I have people that I can count on	1	2	3	4
Even when I don't believe in myself, other people do	1	2	3	4
It is important to have a variety of friends	1	2	3	4
I have friends who have also experienced mental illness	1	2	3	4
I have friends without mental illness	1	2	3	4
I have friends that can depend on me	1	2	3	4
I feel OK about my family situation	1	2	3	4

- › De-identified data from 5 PIR programs – to evaluate the measurement strength of the instrument
 - ? Need participant (consumer) consent?
 - Who did need to consent?
 - ? Any ethical risks/considerations?

Other thoughts/questions...

- › Reimbursement – coercive or respectful?
- › Power relationship between researcher/gate keeper & potential participants (staff/service users...)
- › Breaking confidentiality.... ever?
- › > risk permitted if > benefit
 - Weighing it up...and minimising risk as much as possible





Addressing risks

- › Consider nature, likelihood and severity of risk
 - › Take action to MINIMISE risk
 - › Ensure benefits OUTWEIGH risks
 - › Plan how you will MANAGE any risk.
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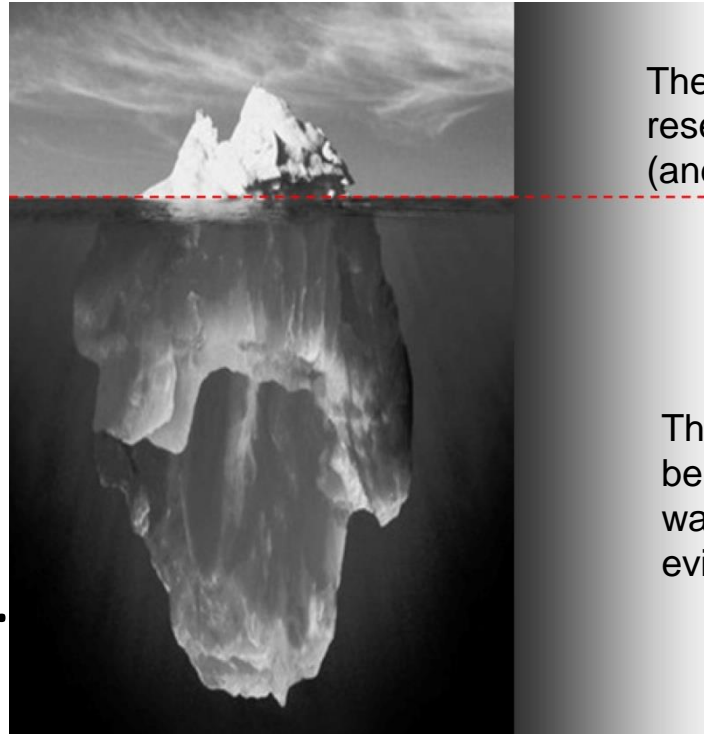
THANK YOU

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The CMO sector
research already done
(and published)

The research waiting to
be done (the innovations
waiting to be
evidenced)!