

DR. KATHERINE GILL  
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NETWORK

CULTIVATING RESEARCH  
INTEGRITY: INVOLVING  
CONSUMERS IN A REAL AND  
MEANINGFUL WAY

 CMHDARN Research Forum, Turning Ideas into  
Action (2017)

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WHY, WHAT, HOW & WHEN

**No Engagement:**  
- Inform or  
Educate - *Doing*  
to People

**Tokenism:** Doing  
for People  
Consultation -  
asking for  
people's views

**Co-Production:**  
Doing with  
People in an  
Equal Partnership

**Consumer Led -**  
Directed and run  
by consumers for  
Consumers



CONSUMER ENGAGEMENT

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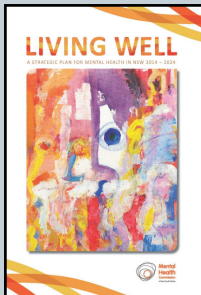
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WHY?



**8.SUPPORTING REFORM**  
8.5 Research and knowledge exchange

**Actions**  
**8.5.1**  
The NSW Mental Health Commission will  
establish a research co-ordination unit to  
oversee the implementation of the Research  
Framework for Mental Health in NSW.

**8.5.2**  
Establish a model for developing and  
supporting consumer researchers that takes  
the principles of recovery into account.

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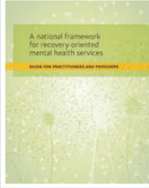
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**CONSUMER INVOLVEMENT ALIGNS WITH RECOVERY PRINCIPLES**

- *National Framework for Recovery Orientated Practice (2013) – Domain 4 and 5: Acknowledging, valuing and learning from people’s lived experience in workforce development and planning and Supporting Social Inclusion*
- *4B: Provide opportunities for research and evaluation conducted by peers and people in recovery, and incorporate findings into quality improvement initiatives and ongoing organisational change.*



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**WHY? Consumer Involvement**

**‘Nothing about us, without us’**

- **National Health and Medical Research Council and the Consumer Health Forum of Australia: Statement on Consumer and Community Involvement in Health and Medical Research. [Sep 2016]**
- **Vision:** Consumers, community members, researchers and research organisations *working in partnerships*, to improve the health and well-being of all Australians through health and medical research.
- **Values:** Shared understanding, respect and commitment

*‘Consumers and the community offer **unique and valuable insights** as research is framed, conducted and translated, helping to **ensure research quality and relevance**’*

**ETHICALLY RESPONSIBLE**

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**WHY? Consumer Involvement**

- The Australian Code for the **Responsible Conduct of Research** (2007), the primary guidance for institutions and researchers in responsible research practices, states: *Appropriate consumer involvement in research should be encouraged and facilitated by research institutions and researchers.* - 1 Refer: [www.nhmrc.gov.au/guidelines-publications/r39](http://www.nhmrc.gov.au/guidelines-publications/r39)
- NHMRC encourages researchers to consider the benefits of actively involving consumers in their proposed research, when they apply to NHMRC for research funding. - Refer: [www.nhmrc.gov.au/book/nhmrc-funding-rules-2016](http://www.nhmrc.gov.au/book/nhmrc-funding-rules-2016)



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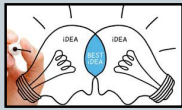
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### STATEMENT ON CONSUMER INVOLVEMENT IN RESEARCH

- RESEARCH INSTITUTIONS SHOULD:
  - Have a policy on consumer involvement in research
  - Define the roles consumers will play in research
  - *Involve consumers in all stages of the research*
  - Build capacity of consumers and researchers through training, mentoring and support
  - Ensure consumer time and expertise is valued and appropriately remunerated



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### WHAT? CONSUMER Leadership in Research

#### CO-PRODUCTION & CONSUMER-LED

- *“Co-Production is the relationship where citizens and professionals share power to plan and deliver services together, recognising that both parties have vital contribution to make in order to improve the quality of life for people and community”*
- **EQUAL AND RECIPROCAL RELATIONSHIP**
- **WORKING TOGETHER**
- **PARTNERSHIP**

- **CO-PRODUCTION IS NOT**
  1. **User Involvement**
  2. **Engagement**
  3. **Consultation**
  4. **Volunteering**

Consumer Led Research: Planned, directed and executed by consumers. Professionals may still be involved but the balance of power remains with the consumer.

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### BENEFITS OF CONSUMER INVOLVEMENT

- Consumer Researchers can better related to participants
  - IMPROVED RELEVANCE
- IMPROVED PUBLIC CONFIDENCE IN RESEARCH
  - IMPROVED ACCOUNTABILITY
  - IMPROVED QUALITY
- INCREASED OPPORTUNITIES
  - IMPROVED OUTCOMES
  - DECREASED COSTS
  - MORE EFFECTIVE SERVICES
- MORE EFFECTIVE TRANSLATION

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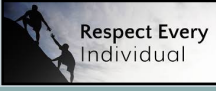
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### HOW? - Implementation Issues

- To enable meaningful consumer involvement:
  - Start planning early
  - Consider HR issues, processes, recruitment strategies, payments, confidentiality, accommodations, organisational support [top down]
  - Reach out to a diverse range of consumers, as appropriate – target strategies (who, how)
  - COMMUNICATE: Treat people with courtesy, respect and integrity
  - Keep everyone informed and in the loop
  - Use accessible, inclusive language
  - BE INCLUSIVE
  - Don't make assumptions - ask



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### HOW? Barriers to Meaningful Participation

- Tokenism
- Poor Attitudes
- Power Imbalances
- Feeling Powerless
- Disempowering language
- Feelings of Isolation / Siloed
- Strong Organisational Cultures
- Lack of Communication – uncertainty
- Poor role descriptions and HR processes
- Managing illness while contributing
- Lack of training, supervision & support
- Lack of access to resources – treated differently
- Consumers brought in too late in the project



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### HOW – WHAT ROLES

- Creating Clarity
  - Consider skills, required training, expertise required for each step / role
  - Consumer reference groups
  - Consumer researchers – not a lack of trained researchers but a lack of opportunities for consumer researchers
- Avoiding Stigma and Discrimination Now and in the Future
- Creating Safety
- Putting lived experience on an equal footing as academic experience – mutual respect for research design, implementation and skill-sets.

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## HOW – Collaboration

### CONSUMER INVOLVEMENT

- Valuing the consumer experiential knowledge base
- Equal and reciprocal relationships
- Equality in representation
- Challenging the hierarchy of power
- Engaging consumers as leaders or partners in research
- Addressing misperceptions, stigma, discrimination and negative assumptions
- Teamwork – no 'them' & 'us'
- Recognition, acknowledging input & contribution

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## WHEN? FROM START TO FINISH

- DECIDING WHAT TO RESEARCH
- DEFINING THE RESEARCH QUESTION
- DECIDING THE METHODOLOGY
- RECRUITING PARTICIPANTS
- DATA COLLECTION
- DATA ANALYSIS
- KNOWLEDGE TRANSLATION
- DISSEMINATION – co-authors

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## Feedback

### VALUING CONSUMER EXPERTISE

Participants in Research – 'subjects' – *Researched About* – Often freely give time, expertise, advice, input, experience, with no recognition, remuneration, and receive no feedback on outputs.

- Value the time and expertise of participants
- Develop plain language summaries for participants and community
- Make available any publications for participants

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### Challenges for Consumer Researchers

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Breaking Down Barriers and Stigma for the Consumer Workforce

- Similar challenges that a peer workforce might face e.g. need for a flexible and supportive environment
- Demands of work and/or work environment impacting on physical and/or mental health
- Potential for relapse, and implications of needing time out from research/work
- Barriers to disclosure, impact of disclosure
- Stigma, invalidation, discrimination
- Exclusion
- Access to resources
- Funding for research/conferences etc.

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### Challenges for Professionals / Organisations

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Challenging Tokenism

- ✓ Creating inclusion, being flexible, adaptive & responsive
- ✓ Taking on board the advice and expertise of the lived experience
- ✓ Changing the language and nature of the interactions
- ✓ Breaking down power differentials to work in equal partnership with consumers
- ✓ Recognising that all opinions, perspectives & ideas have equal weight and are all respectfully considered
- ✓ Co-Production is a different way of working and can be a challenge for the system
- ✓ Requires a redefining of the way "experts" view "service users"
- ✓ Requires a shift in the organisational structure and culture

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### Challenges for Professionals / Researchers

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***"I saw that the clinician is not always the person with all the answers, instead clinicians need to be creative and open minded... co-production opens up new possibilities, it's a real challenge for the system...to be comfortable with not knowing all the answers, to be doing 'with' instead of doing 'to'...so empowering for the consumer... it is how services need to be moving."***

***"I had to develop new ways of interacting and listening, I had to be open-minded and take a step back ...It is such a different way of doing things and can be a bit destabilising..."***

Gill, K. (2014).

Recovery Colleges: Co-Production in Action: The value of the lived experience in "Learning and Growth for Mental Health"  
Gill, K. (2014).

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### LANGUAGE is not NEUTRAL

- Disempowering language – power deferential, invalidating, discriminating
  - Peer / Consumer
  - LIVED EXPERIENCE EXERTS
  - EXPERTS BY EXPERIENCE
- Consider the impact of disempowering language

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### ADDRESSING THE ISSUES

**Working Together for a Common Goal**

**ADEQUATE INFORMATION:** - Clear statements, purpose, process, roles, responsibilities, goals and deliverables

**SAFETY:** Open, respectful communication, transparency

**CO-CREATION:** Everyone involved in decision making, with equal weight

**OPEN MINDSET:** - Open to learning from the lived experience, everyone has something useful to contribute

**BUILDING RELATIONSHIPS –** Respect, trust, validation, working as a team

**PEER SUPPORT:** Debriefing, learning from each other

**LEARNING FROM EACH OTHER:** We all have something to share and learn

**PROJECT MANAGEMENT:** Co-production brings change and uncertainty, it can be innovative and working with a diverse groups of people can lead to disagreements – discuss differences with honesty, kindness, open communication and respect

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### QUESTIONS

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**REFERENCES**

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