

# CONSUMER-LED RESEARCH

What is happening at the Seclusion  
Review that makes a difference?: a  
consumer led study

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# Beyond Representation



- ✦ Proposing the research in the first place
- ✦ Developing the proposal as a funding application
- ✦ Networking supportive partnerships (ANU, ACTMHCN, VMIAC)
- ✦ Publicising the Research at forums and conferences

# The Seclusion and Restraint Review

- ✦ Canb. Hosp. Psychiatric Services Unit, Weekly review of seclusions, code blacks and near misses
- ✦ Data to drive change
- ✦ Story telling of consumers' lived experience gave permission for sharing subjective experiences
- ✦ Clinicians share – bleeding the boundaries of professional and personal identities
- ✦ Trust, empathy, willingness to engage with staff and consumers at a personal level

# Social mechanisms that changed rates of Seclusion

- ✦ Developing and adapting Seclusion Review form – seeking social data
- ✦ Creating new tools – Coping and Safety Tool, C and ST and “How to use the C and ST”
- ✦ Early Support and Intervention Team
- ✦ helped create early engagement, relationship and empathic responses



# History: The where and why

- ✦ UK – move from “best interests” model to “expressed need”
- ✦ USA - Beacon project adopted across Australia
- ✦ Seclusion & Restraint seen as a failure of care
- ✦ Consumer Representatives in leadership roles at various levels in ACT Health
- ✦ High value of consumer voice enabled consumer-led research
- ✦ Catalyst for increased social inclusion, reduced seclusion and restraint

# Changes and innovations

- ✦ Breaking the rules:
- ✦ Instead of “leaving lived experience at the door” reps began to tell their own stories to support consumers’ views and experiences at the Review
- ✦ Holding the space for discomfort and vulnerability; the “rubbing points”

# Research mirrors SRRM Processes

- ✦ Subjective experiences – Real people, real voices
- ✦ Consumer participation in CRG and SRRM
- ✦ Story-telling takes private experience safely into public domain within ethical practices
- ✦ Relationship – respect, trust, empathy
- ✦ Collaboration – commitment to work together to achieve intentions

# Research methodology



- ✦ Consumer Reference Group consulted at three points
- ✦ Definitional Ceremony (from Narrative Research)
- ✦ Collaborative Biography – enables individual voices within dis-identified collective accounts
- ✦ Repeated consultations with research collaborators during analysis and reporting stages.



# What Now?



- ✦ The “What’s happening?” report is available at <http://www.actmhcn.org.au/> publications tab  
Consumer- led Research tab
- ✦ Mental Health Policy Unit have made funds available for the submission of a journal article and presentation at the Nat. Seclusion and Restraint Forum later this year
- ✦ Presentation at “Care without Coercion” Conference, Inside Out Associates in October 2012