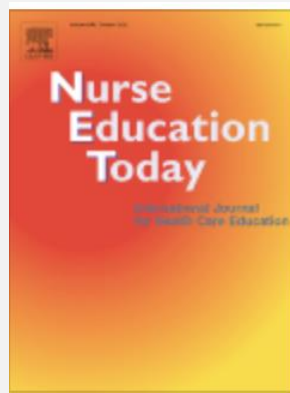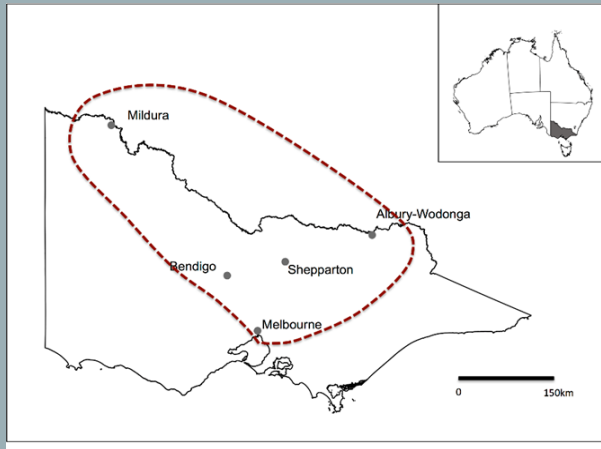# PARTICIPATORY ACTION RESEARCH: BEYOND DATA CHUNKS TO ACTION, CHANGE, AND IMPACT

Professor Emerita Amanda Kenny RN, Midwife, BN, Grad Cert Higher Ed, Post Grad Dip Mid, MN, PhD

La Trobe University, Dja Dja Wurrung country, Bendigo, Australia

Editor in Chief Nurse Education Today

a.kenny@latrobe.edu.au

LA TROBE UNIVERSITY

Nurse Education Today

I acknowledge that I live, work, and play on the traditional lands of the Dja Dja Wurrung people. As traditional custodians of the land, I acknowledge their connection to land, water, and community and pay respect to Elders past and present
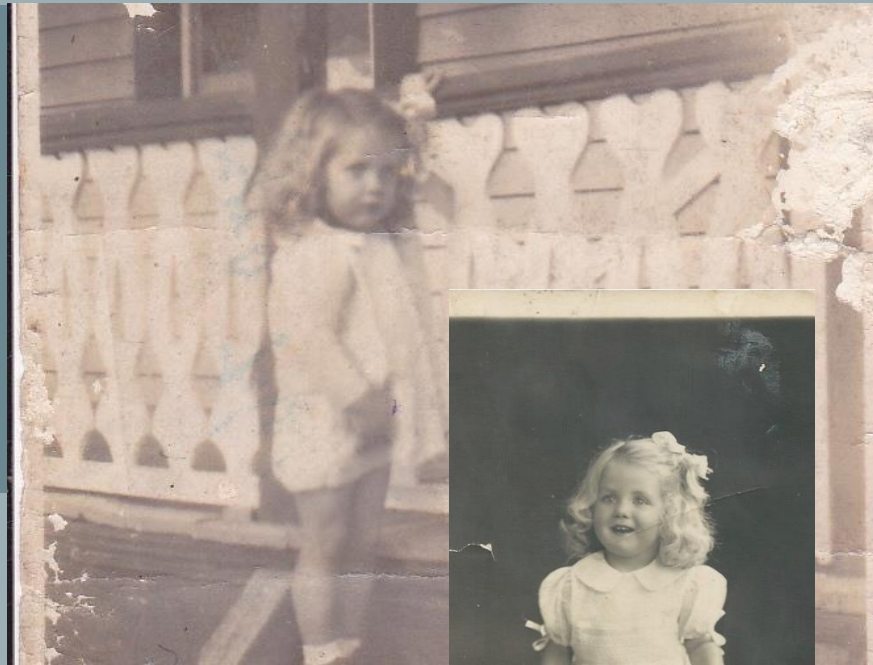
MY PLAN

My early influences

Theoretical underpinnings of participatory research

Key features

Case studies - reflect my health background

Final tips, takeaways, and questions

~WIFE~

Henrietta Harriet
(nee Haywood)
Born: c 1824

The power of individual and community action

MY EARLY INFLUENCES

The interdisciplinary approach to philosophy and social science from the Institute for Social Research in Frankfurt -1923 – the Frankfurt School – Horkmeier, Adorno, Marcuse, Benjamin – 2nd wave Habermas

- The importance of historical and social context to understand social phenomena.

- Focus on power and domination – how power operates in society and how it shapes social realities. How institutions and practices reinforce or challenge power structures and perpetuate inequality.

- Social conditions and history shape an individual's experiences and societal structures.

- Emancipation – the potential for social change – how can social structures be transformed to give individuals and societies greater equality?

- Interdisciplinary approach – insights from a multitude of disciplines – to comprehensively analyse social phenomenon, make sense of it, and address inequities.

Jürgen Habermas (1929)

- Theory of Communicative Action – human communication oriented to mutual understanding and consensus.

- Public Sphere – spaces where individuals come together to debate free from control. Democratic deliberation and formation of public opinion.

- Rational discourse – despite complexity, consensus and understanding can be achieved through communicative action.

Freire, P. (2000). *Pedagogy of the oppressed*. Continuum; Habermas, J. (1984); *The theory of communicative action*. Beacon Press; Habermas, J. (1992). *The structural transformation of the public sphere*. Polity Press; Held, D. (1980). *Introduction to critical theory: Horkheimer to Habermas*. University of California Press.
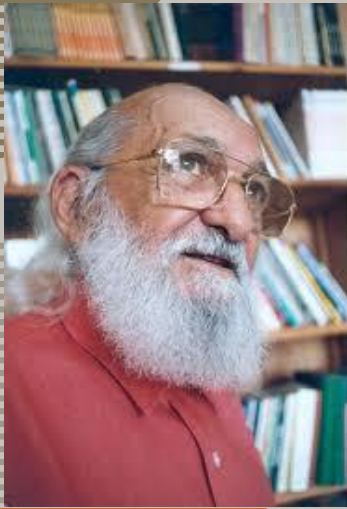
- Paolo Freire (1921-1997) Traditional education reflects and reinforces existing power structures.

- In oppressive systems – education serves to control and subjugate marginalized groups.

- "Attempting to liberate the oppressed without their reflective participation in the act of liberation is to treat them as objects that must be saved from a burning building."

Freire, P. (2000). *Pedagogy of the oppressed.* Continuum (again, a very simplistic overview)

Paradigms, theory, methodology, and methods - the value of philosophy and social science.
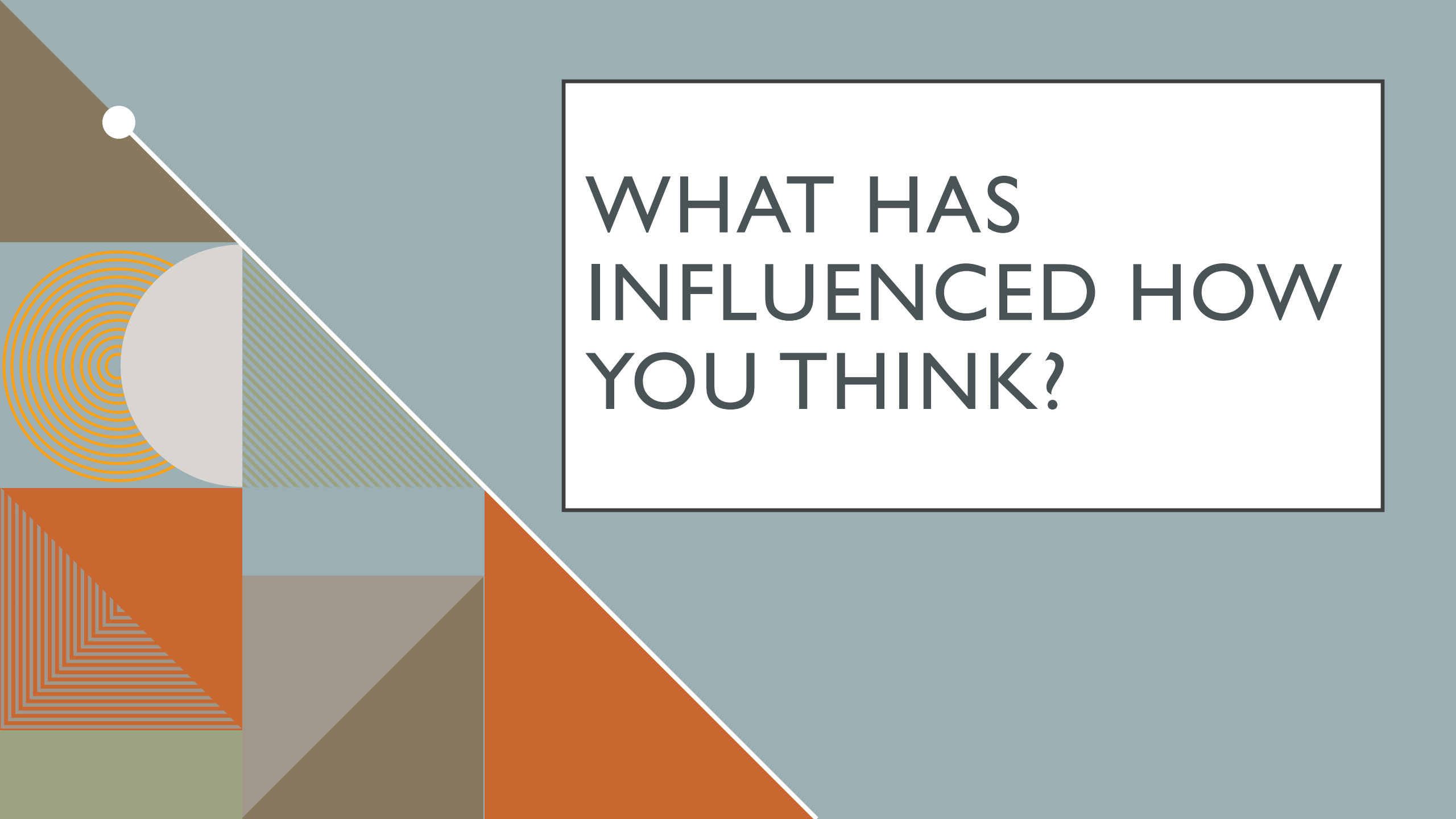
Personally, and professionally, I am a pragmatist heavily influenced by critical theory - critical paradigm
What is practical rather than ideals
Evaluate theory in terms of the practical applicability – so what, why does it matter, who cares?
Reality is socially constructed, ever-changing, and influenced by societal power relations.

- Critical theory – e.g., Jürgen Habermas, Paulo Freire
  - Empowerment and social justice
- Participatory theory – e.g., Kurt Lewin, Paolo Freire
  - Involving people impacted by research in the research, valuing lived experience
- Action Research – e.g., Kurt Lewin
  - Cyclic process of planning, action, reflection
- Pragmatism – e.g., John Dewey
  - Focus on real-world problem solving and action
- Transformative Learning Theory – e.g., Jack Mezirow
  - Perspective change through critical reflection and dialogue

… and others

WHAT HAS INFLUENCED HOW YOU THINK?

PRINCIPLES OF PARTICIPATORY ACTION RESEARCH – DEMOCRATIC PARTICIPATION, COLLABORATION, EMPOWERMENT, ACTION, CHANGE

1. Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology & Community Health, 60*(10), 854–857. https://doi.org/10.1136/jech.2004.028662
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3. Cornish, F., Breton, N., & Moreno-Tabarez, U. (2023). Participatory action research. *Nature Reviews Methods Primers, 3*, 34. https://doi.org/10.1038/s43586-023-00214-1
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Authority of lived experience – experiential knowledge of social systems and structures - the right to drive social change. Respecting local and individual knowledge, traditions, and practice.

Collaboration and partnership– harnessing diverse expertise, engaging in critical dialogue. Researchers and citizens working together as equal partners – shared knowledge, expertise, and decision-making. Inclusion of diverse voices.

Strong focus on ethical practice – more equitable research process, respect, transparency around goals and outcomes.

PRINCIPLES OF PARTICIPATORY ACTION RESEARCH – DEMOCRATIC PARTICIPATION, COLLABORATION, EMPOWERMENT, ACTION, CHANGE

Action focused - addressing issues and creating change. Not just about generating data and knowledge.

Knowledge in action – new learning and knowledge is generated from the experience of making change. Empowering all participants by building skills and capability.

Transformation – The process is as important as the outcomes, reflective practice, ensuring research is responsive to needs, actions are adapted as learning is shared.

Wicked problems and troubling questions – what are yours?

Power.
Social conditions and history shapes experiences.

Interdisciplinary.
Communicative action.
Valuing lived experience.
Collaboration and partnerships.
Ethical practice.

Action focused outcome.
Transformation.
Change.
Process as important as the outcome.
Emancipation – empowerment.

DIFFERENCES BETWEEN ACTION RESEARCH AND PARTICIPATORY ACTION RESEARCH
(But I think a fine line)

	Action Research	Participatory Action Research
Participant involvement	Participants not always engaged in all phases – decision making	Participants actively engaged in all aspects
Focus	Focus can be on a problem or practice improvement within a specific context	Collaborative problem solving, empowerment and social change
Power	Often more focused on researcher	Emphasis on equal power relationships
Process	Cycling process of planning, action, reflection	Iterative, flexible, and adaptive – continuous collaboration
Outcomes	Often focused on a single problem	Often extends beyond single problems - social empowerment, capacity building, and systemic change

THE MEANING OF RECOVERY IN A REGIONAL MENTAL HEALTH SERVICE

Problem – While consumer participation is evident in international mental health policy, meaningful integration in services is lacking

Aim - To engage stakeholders of a public mental health service to explore the way that recovery-oriented care was understood, enacted, supported, and sustained at a service delivery level.

1. What does recovery and recovery-oriented care mean to people with experience of low prevalence disorder and psychosocial disability who use and work in a public mental health service?

2. How integrated is consumer participation in developing recovery-oriented clinical mental health services and culture for people with low prevalence disorders and enduring mental illness?

3. How can consumer participation strategies support the ongoing development of recovery-oriented clinical mental health practice for people with enduring mental health problems?

THE MEANING OF RECOVERY IN A REGIONAL MENTAL HEALTH SERVICE

- One year study
- Advertised widely within a large public health service and advocacy groups.
- The PAR group was the forum for developing, testing, and refining ideas about strengthening a recovery - oriented service model.
- Four mental health clinicians, six mental health consumers, and one carer.
- Group met monthly over one year.

Sharing experiences, reflection, challenging diverse views, a framework for reflection between workshops, group reflection at each workshop
What do we do now? What would we like to do differently? What we have learnt? How has this changed us? Where to now?

A diversity of methods used including art, drama, digital storytelling – decided through group consensus.

Uncovered a propensity for defensive reasoning.

Challenged cultural norms.

Insights from the ways recovery was understood from different perspectives.

Ongoing conflict about consumer participation – understanding that a person can have a diagnosis of a low prevalence disorder but at the same time have enormous expertise.

Although participants had long - term relationships with a service – absence of focus on long - term needs including self – management.

Staff workshops across the service.
"Recovery conversations" program conducted by mental health consumers – the inclusion of lived experience perspectives was extremely challenging for staff.
Art exhibitions.
Digital storytelling presented to the community.
Developed a play that was presented in numerous forums.

SHARING KNOWLEDGE: COMMUNITY PARTICIPATION STRATEGIES FOR IMPROVING RURAL HEALTH

Problem – Poor rural health outcomes, need to better understand the magnitude and root causes. Need to prioritise and develop strategies to address.

Aim – to develop strategies to improve the health and well - being of people living within a large Australian catchment.

1. To explore the role of community stakeholders in informing and enacting healthcare in rural communities.
2. To determine whether a participatory action research method could be used to engage a range of stakeholders in health planning.
3. To establish the priorities that rural communities set for themselves given a range of data, information and research evidence.
4. To implement activities associated with community priorities, utilising co-design and co-production strategies, and consider longer - term sustainability of initiatives.
5. To explore whether the participatory processes used aligned with stakeholder expectations at the micro, meso, and macro levels.
6. To develop a sustainable model for ongoing community participation useful for health services in designing healthcare options for rural communities.

SHARING KNOWLEDGE: COMMUNITY PARTICIPATION STRATEGIES FOR IMPROVING RURAL HEALTH

- Three-year study
- A project governance committee – the researchers, CEO of the health service, Director from the Board of the health service, three community representatives – met three times a year to review progress and outcomes
- Advertised widely for a diverse group to form the participatory action research (PAR) group (newspapers, community groups, newsletters (bi-monthly) – 26 members
- The PAR group guided broader community interaction and communication and was the forum for developing, testing, and refining ideas

Presentation of relevant health data including cost data.	Presentation of an expert including health consumers.	4-6 participants in each group – what they had heard, their experience and that of their community.

Reflecting on progress so far, sharing knowledge and ideas about the focus, identifying key issues, and priorities for action

Further research by community members, gathering of researcher data, development of themes and topics for the next meeting – individual interviews, photovoice, focus groups etc.

SHARING KNOWLEDGE: COMMUNITY PARTICIPATION STRATEGIES FOR IMPROVING RURAL HEALTH

- Action needed to be focused and evidence based – massive community input.

- Major mental health forum including one on amphetamine use – 500 people attended.
- Developed major community gardens – intergenerational socialisation and distribution of health information.
- Aged care expos with presentations – massive community attendance.
- The installation of age-friendly gymnasium equipment in community spaces.
- Granny Skills movement - facilitating programs in local schools to support aged care clients and community members to teach students skills - facilitating intergenerational and interaction.
- Secondary school captain led workshops about issues affecting teenagers, including body image and the pressures on young people to be "perfect".
- Photovoice project to engage marginalised young people in conversations about health and wellbeing.

SHARING KNOWLEDGE: COMMUNITY PARTICIPATION STRATEGIES FOR IMPROVING RURAL HEALTH

- Action needed to be focused and evidence - based – massive community input.

- Breast cancer support services.

- Seasons of Wellness program – health literacy program - social connection, aim to build community capacity to drive change. A forum for community feedback used as a basis for future community consultation.

- Reinforcement of the role of healthy spaces in the community - "therapeutic landscapes".

- Development of "landscapes of care" understanding the social impact of care provision beyond health service walls.

FINAL TIPS AND TAKEAWAYS
What I have learnt.

Focus on PARTICIPATION, ACTION, CHANGE

- Prioritize actions that address the identified issues and benefit the community/individuals.

- Develop and implement practical solutions based on research findings.

- Takes a long time and requires enormous flexibility and patience to build strong relationship

- The flexibility needed can make ethics applications challenging.

- Ongoing ethical considerations critical.

- Mutual learning between researchers and participants.

- Diverse voices, including marginalised or underrepresented people.

- Fabulous facilitators, boundary spanners, and champions.

- Engaging often to understand perspectives.

- Clear, relevant goals and objectives but be prepared to pivot.

- Regularly reflect on the process and outcomes with participants to assess progress and make necessary adjustments.

- Equitable participation in decision-making processes.

- Balancing momentum with what can be realistically achieved.

- Engaging a multitude of methods - focus groups, digital storytelling, photovoice, workshops, art exhibitions, citizen juries, surveys, postcards.

- Methods to fit the context and preferences of participants.

- Evidence is important and not dumbing information down – the public does understand complex information.

- Being prepared for outcomes that people and organisations don't want.

- Resourcing is critical - Spaces, food etc., does matter.

- Methodical recording of the research process, data, decisions, and outcomes - Writing up can be challenging – so much data.

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QUESTIONS?
THANK YOU
Especially to AQHUN organisers

Professor Amanda Kenny

a.kenny@latrobe.edu.au