

The Good, the Bad and the Ugly of Lived Experience Research: What are Some Things to Consider in this Work?

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Acknowledgment of Country

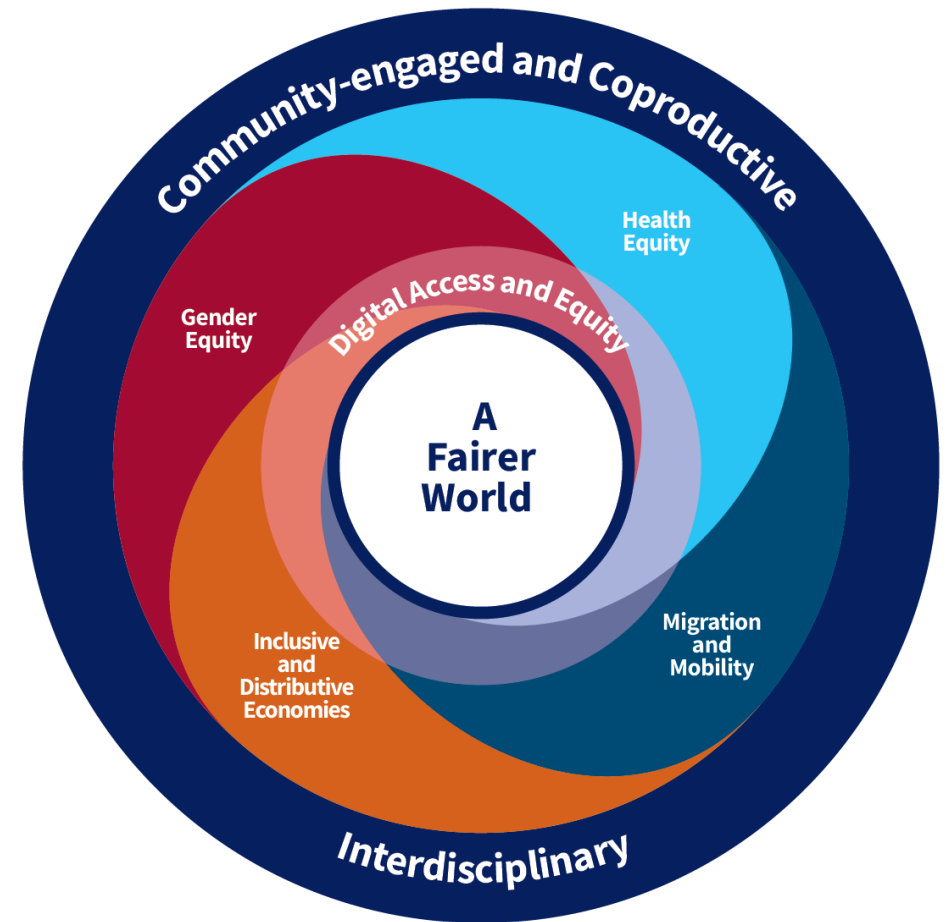


Melbourne Social Equity Institute

Achieving fairer societies through research that makes a difference



- Established 2012
- Funded by Chancellery Research and Enterprise, part of Interdisciplinary portfolio
- Administratively located within a host faculty
- Remit: support interdisciplinary research on social equity issues
- Part of a family of interdisciplinary institutes – Biodiversity, Disability and Energy
- Community engaged and coproductive research has becoming increasingly central



Researcher Positionality



- Migrant cis-woman of colour, able-bodied
- She/her pronouns
- Engagement practitioner and self-identified nerd 🤓
- Research undertaken through Master of Public Health research capstone
- Research project embedded within my work at the Melbourne Social Equity Institute, University of Melbourne



Edwards, C., Block, K., & Vaughan, C. (2026). The Need for an Interpersonal and Institutional Ethic of Care when Working Alongside Lived Experience Researchers: “For me there’s no lived, it’s always living.” *International Journal of Qualitative Methods*, 25. doi.org/10.1177/16094069261417902

From the Participatory ‘Turn’ to the Participatory ‘Zeitgeist’

- Participation become the ‘**norm**’, the new “**zeitgeist**” (Palmer et al., 2019, p. 247)
- Value of **lived experience leadership** highlighted in Victorian Royal Commissions
- Patient and consumer engagement in healthcare, as well as peer workforce in mental health, a **growing field**
- “**Co-biquity**” is reshaping our approach to research, policy and service design (Williams et al., 2020)
- Research impact agenda – community engaged research is one potential pathway to research impact
- Draws upon a long history – the “**radical roots**” - of lived experience leadership (Cataldo et al., 2021)



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Participatory Research



- **Values-based**, philosophical approach underpinned by a **social constructivist paradigm** (Liamputtong, 2020).
- Arose through grassroots organising to **reject the stigmatising impacts** of much research on people experiencing marginalisation (Cornwall & Jewkes, 1995).
- Heavily influenced by the work of **Paolo Freire** (b.1921-d.1997)
- Doing research **with**, **for** and **by** people with lived experience, **not on** or **to** them.
- Encompasses traditions such as Participatory Action Research (PAR), Community-Based Participatory Research and Inclusive Research.
- Social justice agenda – **shift / share power and decision-making** (Freire, 1970; Lenette et al., 2019; Minkler, 2004)

Lived Experience Researchers



- A.K.A. **peer researchers, co-researchers, consumer researchers** etc.
- **Lay people**, recruited for their lived expertise (e.g. disability, mental health, victim-survivors of family violence, refugee-background, current/formerly incarcerated people, people from low socio-economic backgrounds etc.)
- **Rooted in participatory research practices.**
- Engaged in **health and social equity research** (Bell et al., 2021b; Doyle et al., 2022; Fiolet et al., 2024; Goodson & Phillimore, 2012; Warr et al., 2017).

*“Rigorous peer research...can initiate **long-term, equitable, emancipatory** research collaborations in which the **researched become researchers**”
(Bell, Aggleton, & Gibson, 2021b, p. 16, my emphasis).*

“Promises and Pitfalls” of Working with Lived Experience Researchers



Benefits - enhanced **relevance**, **greater access** to participants, increased **richness** of data, more **nuanced** insights, **enhanced validity** of findings, and increased **impact** (Damon et al., 2017; Doyle et al., 2022; Warr et al., 2011; Webb et al., 2022).

Criticisms - methodological limitations and **potential lack of rigour** (Bell et al., 2021; Richardson, 2014).

Challenges - **ethical** challenges (Warr et al., 2011), **exploitative** practices (Damon et al., 2017), the **risk of re-traumatisation**/vicarious trauma (Fiolet et al., 2024; Kelly et al., 2020) and a **lack of institutional support** (Raynor, 2019). It can be both **time-consuming** and **emotionally laborious** (Lenette et al. 2019).

Research Gaps



- Existing literature focuses on the benefits, challenges and risks of LE research **for university-based researchers.**
- Less has been written about the **experiences of LE researchers themselves**, their motivations to be involved, or the long-term or sustained impacts of their participation (Fiolet et al., 2024; Ross et al., 2023).
- LE researchers work within a research ecosystem; there is a **need to understand how the different levels influence and impact the experience of LE researchers across the social ecological model.**



Research Questions

- What are the **motivations, expectations, and aspirations** of former or current UoM LE researchers and how might these be met?
- What **institutional supports** are required to embed **ethical, empowering, and equitable** LE research practices at UoM?



An Ethic of Care



- Feminist moral theory
- Critique of traditional, male-centric philosophies (i.e. unemotional, objective)
- Values relationality, interdependence, compassion, responsibility, competence, responsiveness, trust and reciprocity

“The ethic of care guides us in acting carefully...and highlights the costs of carelessness...of not paying attention, not listening, being absent rather than present, not responding with integrity and respect.” (Gilligan, 2014, p. 103)

- Interpersonal and institutional ethic of care if required for this work

Methods

RESEARCH STUDY

SEEKING PEER RESEARCHERS

PEER RESEARCHERS ALSO KNOWN AS COMMUNITY RESEARCHERS, LIVED EXPERIENCE RESEARCHERS, CO-RESEARCHERS ETC.

Have you been, or are you currently:

- Aged 18+
- Formally or informally employed by the University of Melbourne as a community-based, peer researcher.
- Had significant involvement in recruitment, data collection, analysis and/or writing up findings.

We are interested in hearing about the experiences of those who have been involved as peer researchers on University of Melbourne research projects. We are keen to hear about positive, negative and neutral experiences and about your motivations, aspirations and expectations of being a peer researcher at the University of Melbourne. Interested and eligible participants will be invited to participate in a 60-minute interview. Participants will be compensated \$45 for their time.

For more information about the study, contact
Charlene Edwards at
chedwards@student.unimelb.edu.au.

This project has human research ethics approval from the University of Melbourne Project ID: 29406.



- **Qualitative** research study, ethics approval.
- Inclusion criteria: **Former or current** LE researchers that have worked on one or more UoM project(s).
- Purposive sampling and phased recruitment through networks to ensure maximum variation.
- **5 in-person and 11 Zoom semi-structured interviews lasting between 35-60 minutes.**
- Reimbursed in line with MSEI's Equitable Compensation Guidelines.
- Pseudonyms assigned to protect anonymity.
- Inductive, reflexive thematic approach to analysis (Braun et al., 2019).
- Ethical challenges, inc. my role at the MSEI.

Participant Demographics



AGE		GENDER		RACIAL IDENTITY/ ETHNICITY		EDUCATIONAL LEVEL*	
18-24	2	Male	2	White	10	High School (incomplete)	1
25-34	3	Female	12	Southern European	2	High School	1
35-44	2	Trans/non-binary	2	Eastern European	1	Undergraduate	6
45-54	5	Prefer not to say	-	Black	2	Postgraduate	6
55-64	4	Not listed	-	South Asian	1	PhD	2

*Education Level includes current and completed.

Participants' Lived Expertise

Victim-survivors of
family/domestic/
sexual violence



Carers of children
with mental health
issues.

Young carers of
family members
with mental health
issues.

Alcohol and other
drug addictions,
mental ill-health &
suicidal ideation

Psychosocial
disabilities



Racialised young person

Migrant and refugee
background

6 participated in one
research project
3 are involved ongoing on
a LE panel
3 have ongoing work as
LE researchers
2 now have substantive
positions at UoM
1 is a LE PhD candidate.

Findings



Six themes emerged from the study:

1. LE researchers are motivated to create change
2. LE research can be both rewarding and taxing
3. Trust must be earned, nurtured and reciprocated
4. Power sharing is less important than responsible leadership
5. LE research is a methodology NOT a 'fashion'
6. An institutional ethic of care is critical

Motivated to Create Change



- Challenge injustices
- Improve systems and conditions for future generations
- Give voice to their communities, especially if they felt underrepresented
- Gain new skills

“Being involved...is my way of contributing and trying to make use of my experience...What has it all been for if not? You have to try to turn the negative into a positive.” (Rachel)

Rewarding and Taxing



- Profound, validating, sparking satisfaction and joy
- Life-altering, formative experiences:

“I gained a love of writing that I’d never had...my love of learning increased significantly...I wouldn’t have applied for the Masters had I not done that project. It’s been pretty darn significant for me.” (Alison)

- Therapeutic benefits:

“Fundamental to keeping me well.” (Cameron)

“There is a therapeutic benefit along the lines of post traumatic growth. It almost helps you process it by talking through it, you re-live it but in a safe space.” (Nat)

Rewarding and Taxing



- Risk of retraumatisation:

“Having experienced similar experiences of abuse or neglect or pain - leaving an interview and trying to bring yourself back to ‘everything’s OK’ is not easy. (Helena)

- Burden of responsibility, emotional toll, guilt and powerlessness:

“I’ve already felt myself burning out...you don’t have the capacity to be able to speak up, so you don’t say anything and that does take a toll. You know it’s going to affect your community. [I feel] powerless, and guilty as well. Guilty for the fact that I can’t speak up but I know I don’t have the power to.” (Jesse)

Trust: Earned, Nurtured and Reciprocated



- Academics must embody an ethic of care
- Nurturing positive group dynamics: ***“moving at the speed of trust” (Felicity)***
- Academics need create safe spaces to build skills and confidence:

***“They skilled us up...It was always OK...
to potentially stuff up or not do it perfectly.” (Angelika)***

- Academics need to demonstrate their trust in the LE Researchers – provide opportunities for them to shine
- Academics built trust through sharing their own LE:

“To be vulnerable with each other...[was] a really important thing” (Cameron)

Responsible Leadership



- Personal characteristics: “curious”, “people person”, and “**lack ego**”
- Skilled in participatory research and trauma-informed supervision
- Share benefits of research equitably
- Create a culture of care and safety
- Appreciate the complexities of LE researchers’ lives

“In the case of my family and my experience, there's no lived, it's always living.” (Hannah)

LE Research is NOT a “Fashion”



- Some LE researchers described misuse of LE in research as “**tokenistic**”, “**tickbox**” and “**flavour of the month**”
- Academics sometimes look for short cuts
- **Harmful and disempowering**
- Poor implementation: time-poor academics, or a lack of ideological commitment / epistemic incompatibility

“Wow, they’re talking about [participatory research] but not actually doing it.” (Sharmila)

An Institutional Ethic of Care



- Institutional ethic of care for both university and LE researchers (Baker et al. 2023). It **“highlights the costs of carelessness”** (Gilligan, 2014, p. 103)
- LE researchers recognised academics were battling systems not well suited to participatory research (Raynor, 2019).
- Suggested that UoM needs to provide more **centralised supports** for both University-based and LE researchers (e.g. training, professional development, accreditation, Community of Practice, LE supervision).

“If the University wants happy co-researchers than it needs to think about a happy workplace for everybody” (Steph)

The Good,

- Securely employed
- LE centered & valued
- Felt like a core team member

“They were always very insistent that I was a core researcher...I got a lot of reassurance from them which was really lovely.”



Felicity

the Bad,

- Precariously employed
- LE essential but he didn't always feel valued as a person
- Felt unsupported at times

“I learned to really lower my expectations.”



Cameron

the Ugly

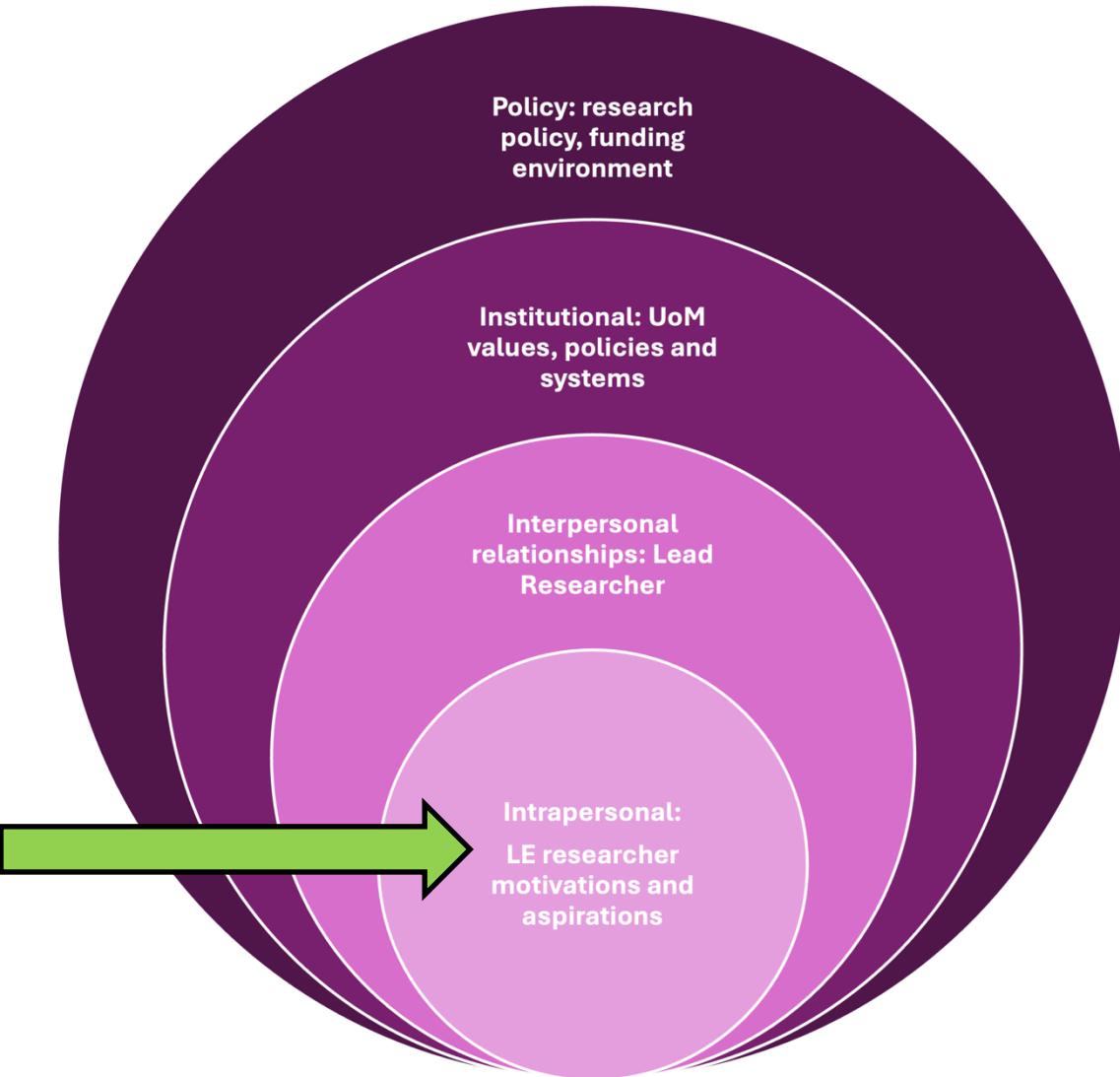
- Under-employed
- LE under-valued
- Felt exploited

“That's the frustration...realising I'm only part of the project to get grant funding.”



Jesse

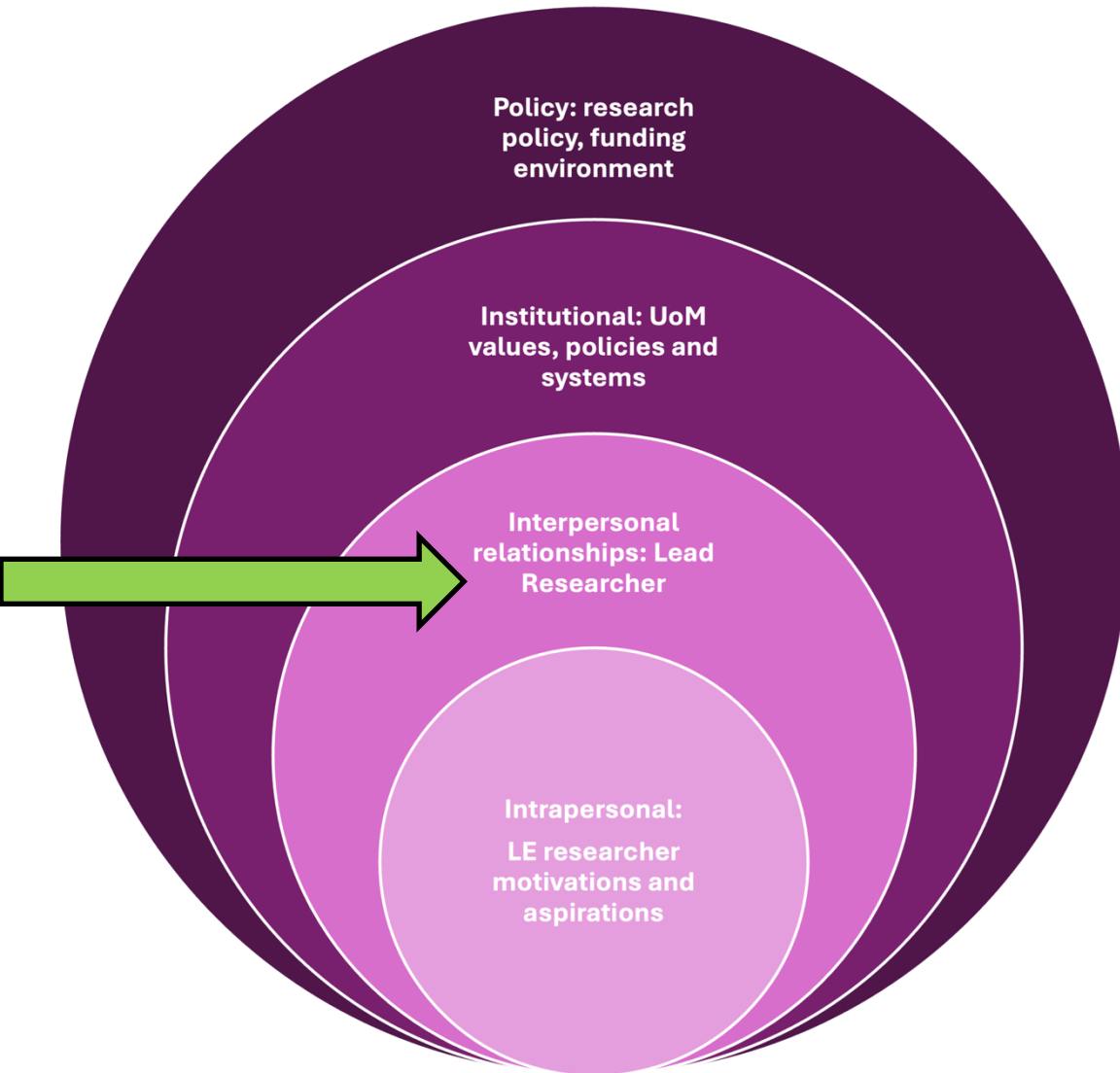
Discussion



Social Ecological Model for Lived Experience Research

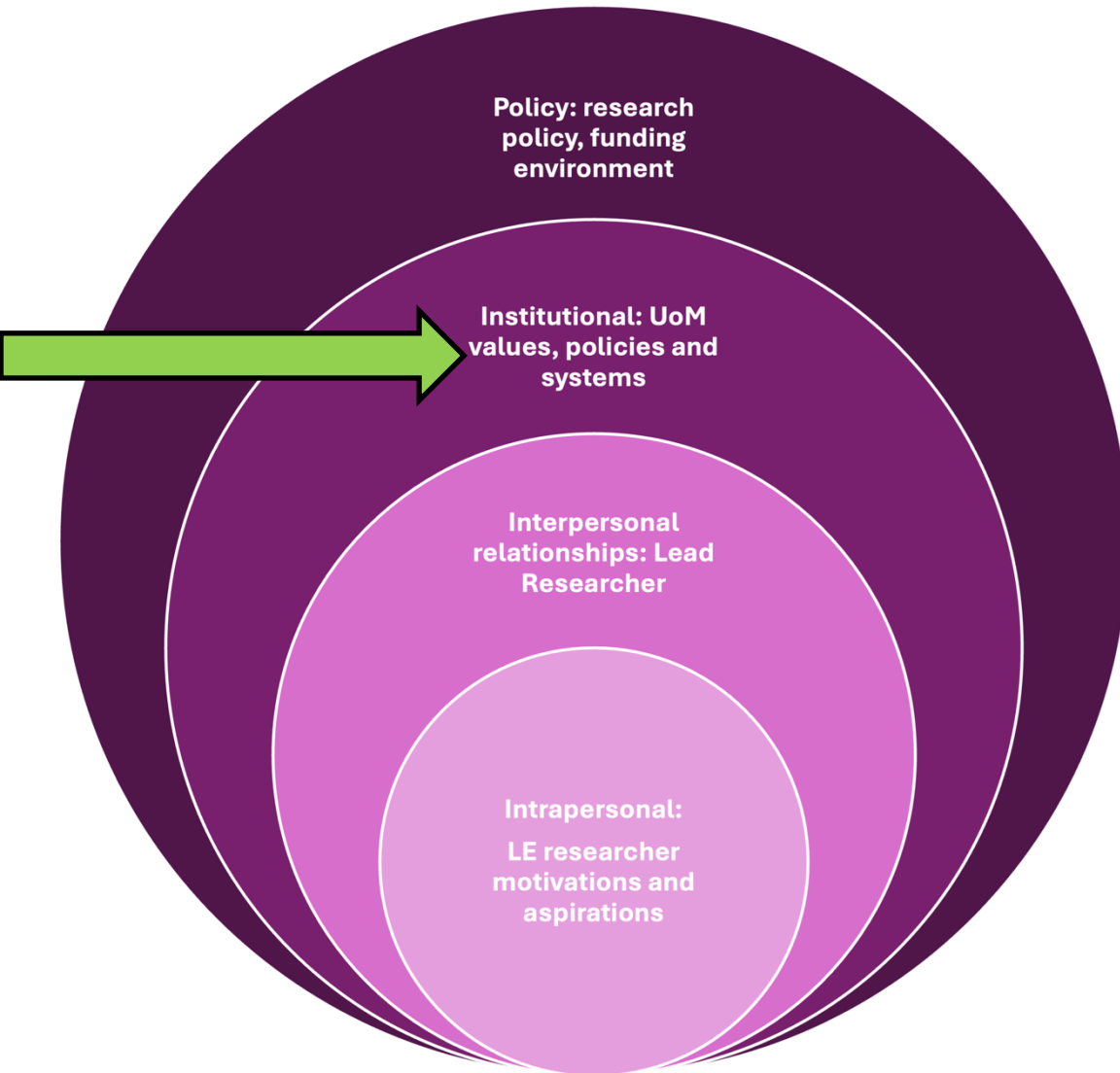
- LE researchers are motivated to create social change.
- LE must be appropriately utilised, otherwise harmful.
- “Trickery of opportunity” when “exploitation is disguised as opportunities” (Tynan & Bishop, 2019).
- Imposter syndrome.
- Usually on short-term, part-time contracts.
- Little opportunity to acquire a qualification through LE work.

Discussion



- Academics are pivotal to LE researchers' wellbeing.
- Academics must ensure they have the skills to lead projects that involve LE.
- Inadequate/inaccessible systems place a burden on academics, who act as 'buffers' and absorb pressures and mental/emotional load.
- Can take a toll and may result in downward pressure on LE researchers.

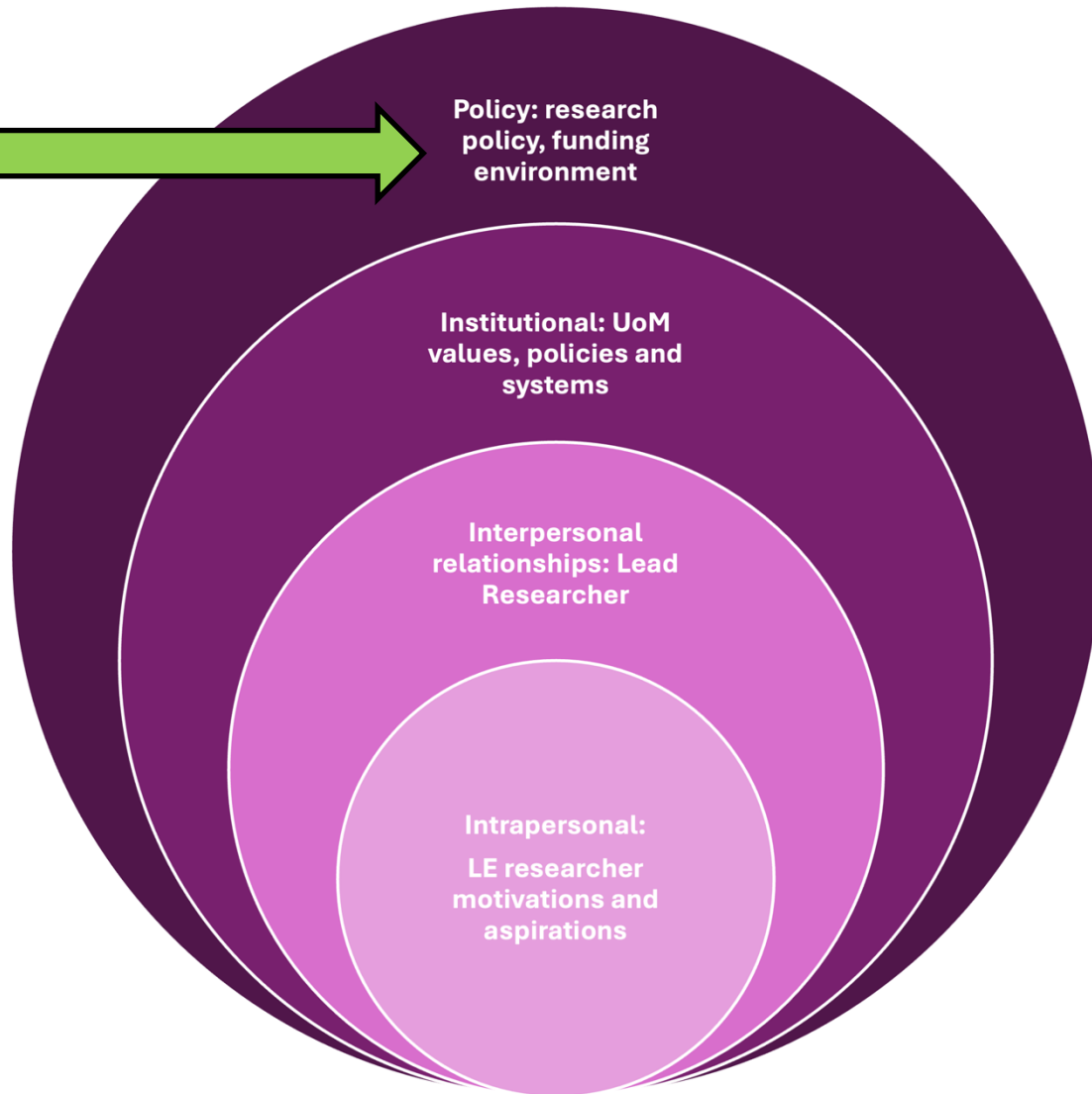
Discussion



The UoM should adopt an institutional ethics of care towards university-based and LE researchers by:

- Recognise designated LE researcher positions as an emerging category of employee
- Training and development opportunities
- Acknowledge that participatory research does not fit traditional metrics (and highly gendered)

Discussion



Social Ecological Model for Lived Experience Research

- Funders must go beyond supporting ‘tick box’ inclusion.
- Should require evidence of well-planned and co-designed research with LE researchers.
- Ensure project plans and budgets evidence how and with what resources LE researchers will be trained and supported.
- Must recognise the need for flexibility in timelines.

Strengths and Limitations



- Potential selection bias within the sample
 - Highly educated sample – not reaching the people most marginalised
 - Not generalisable beyond the University of Melbourne
 - Lacked participants from Indigenous communities
 - Not participatory!!
-
- Timely study
 - Good alignment with my work at the MSEI

Final Thoughts



Photo by [Shalev Cohen](#) on [Unsplash](#)

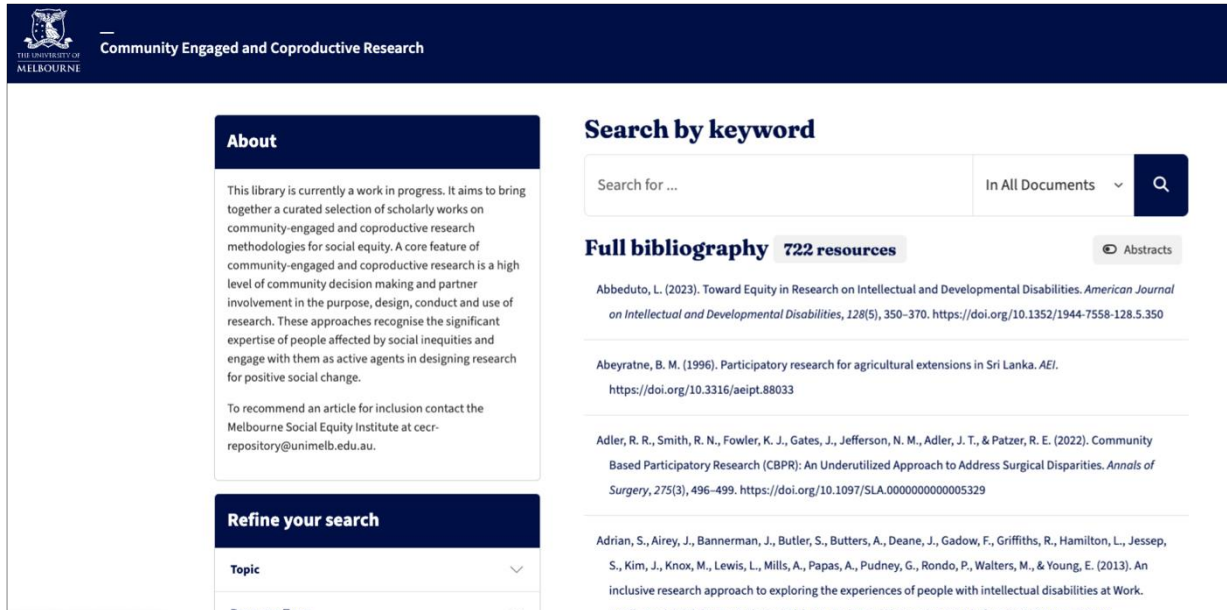
- Requires time (moving at the speed of trust), commitment, energy and there is a significant amount of emotional labour.
- Not always suitable: research isn't "magical just because it is participatory" (Lenette et al., 2019, p. 175)
- "Joys and risks of balancing together on a trampoline" (Liamputtong & Rumbold, 2008, p.10)
- Truly participatory research can be a "soft messy process" (O'Neill, 2013, p. 762)
- Honour the radical roots when working alongside lived expertise.

Acknowledgements



- Professor Karen Block and Professor Cathy Vaughan
- The 16 participants who shared their experiences and perspectives so honestly and openly with me.
- My colleagues at the Melbourne Social Equity Institute and those part of the broader MSEI community.

Resources



Community Engaged and
Coproductive Research Repository
coproductive.unimelb.edu.au

Join the:

- MSEI Community Engaged Research Network
- Lived and Living Experience Researcher Network

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Thank you! Questions?

Keep in touch!

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