

Transforming the Research Enterprise

A World Cafe on How People with Lived(-ing) Experience
as Researchers Can Redefine Harm Reduction Research

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Overview

GOAL: Foster dialogue on disrupting conventional research structures and prioritizing community-led solutions



People with Living (-ed) Experience as Researchers (PLER)



The Participatory Landscape



Word Cafe - small group discussions



Creating an international community of practice

DISRUPTING THE RESEARCH ENTERPRISE



Lived(-ing) experience can't be taught

Communities are experts in their own culture and needs; research that lacks context can miss the target.

The research enterprise has a bad history

Tokenization, exploitation, stigmatization, and misrepresentation has been paired with inequitable benefit.

The researched can be the researchers

There is a consistent call for PWUD-led research, though the desire for ethical and community-engaged research is not new.

Systemic issues reinforce power differentials

An infrastructure that supports building research capacity, trust, respect, and an organic research priorities is needed.

Research can be a tool for empowerment and change

Research driven by lived(-ing) experience has the potential to produce timely, relevant insight on essential issues.

PEOPLE WITH LIVED(-ING) EXPERIENCE AS RESEARCHERS

Who

The PLER Board includes partners from drug user unions and harm reduction organizations across the United States who are receiving fair compensation for their subject matter expertise to define research priorities, develop a sustainable (and ultimately standalone) infrastructure, and leading research.

Where does this live?

American Institutes for Research and the National Harm Reduction Coalition have served in the "backbone" role to provide institutional legitimacy, capacity building resources, and research leadership opportunities. The role of the backbone was designed to evolve over time.

What

PLER prioritizes work and partners that meet certain expectations, such as providing opportunities for leadership, authentic engagement throughout, and impact on priority topics.

Why is this different?

While the pursuit of empowering research is not new, PLER emphasizes research in which people with living experience are not just participating but **they are in the driver's seat**.

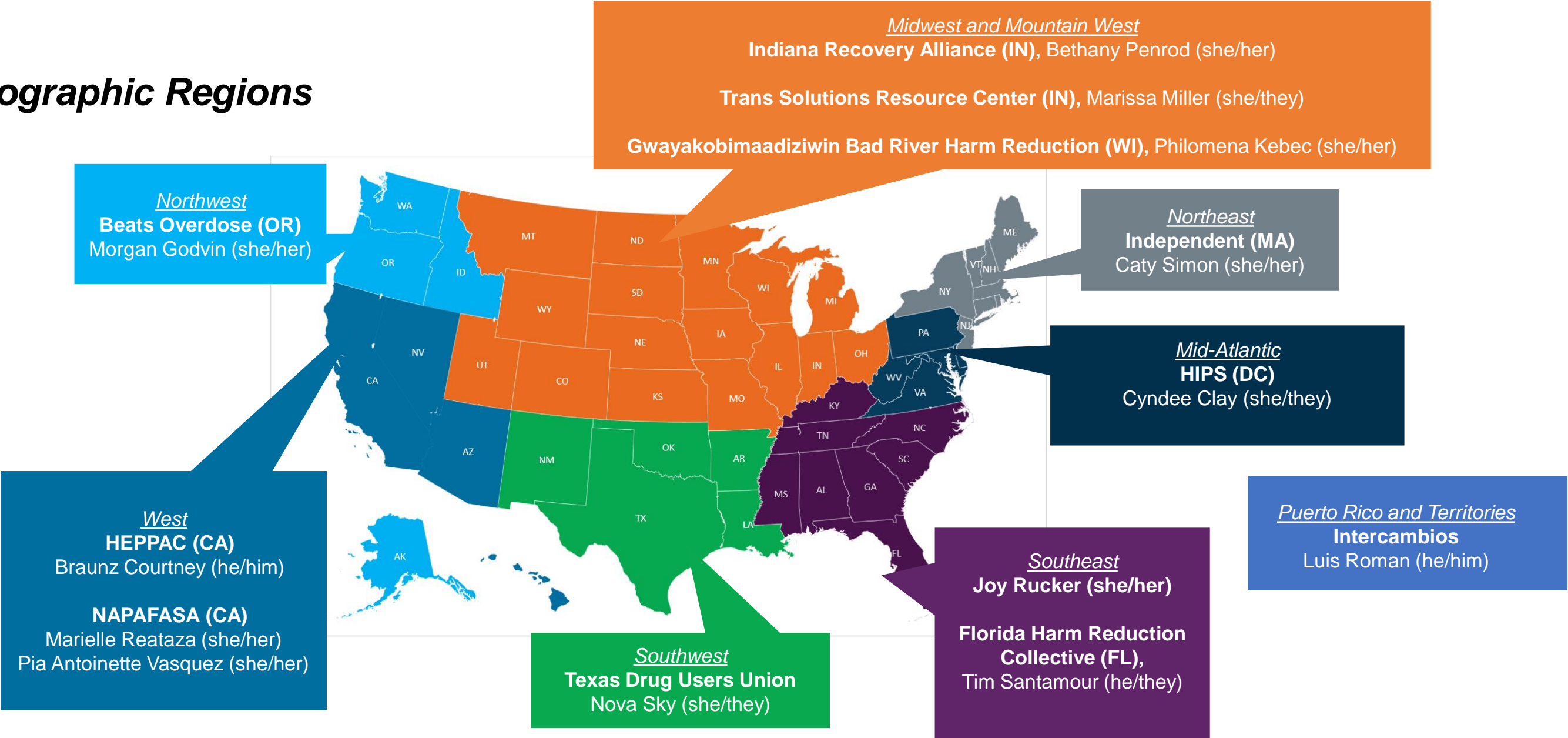
When

The full board meets monthly to strengthen infrastructure, engage in collaborative decision-making, and support sustainability. Work groups meet ad hoc. Compensation is provided quarterly for invoiced hours.

How is this sustainable?

Funding strategies include grants and fee-for-service agreements through the backbone organizations, with a transition to a solidarity economy.

Geographic Regions



Structure

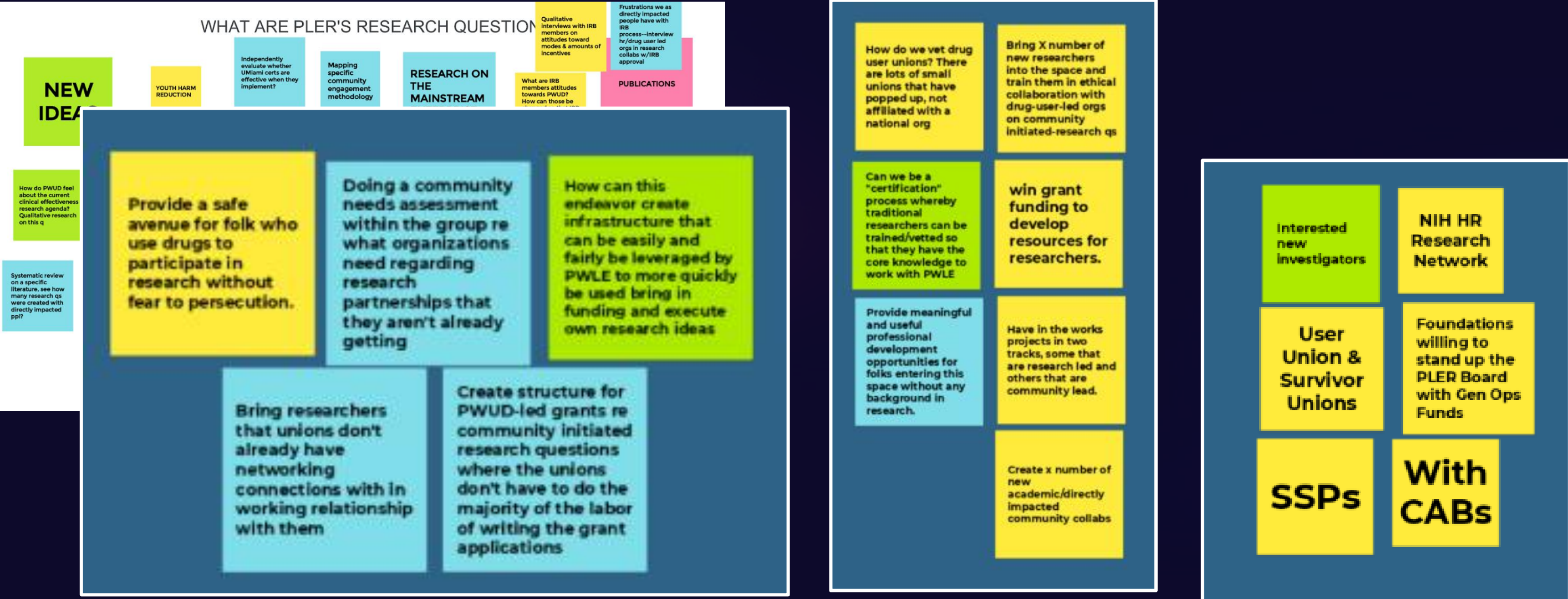


Workgroup Leads

1. Communications, Outreach, and Materials (COM) Workgroup
2. Funding and Research Agenda Setting Workgroup
3. Infrastructure Workgroup



Early PLER Conversations



Example Activities

Attend meetings

Workgroup meetings and tasks

Review, annotate, and respond to materials and emails

Research-related trainings (e.g., CITI, MAAPPS, PCORI)

Respond to Infrastructure surveys

Serving as an ambassador for PLER (e.g., webinars and presentations)

Conference prep

PLER-associated business development

Research funding opportunities

Researching potential members to serve on Board

Support other members

Consulting Meeting

MAAPPS

Measurements for Accountability to All People in Policy Solutions (MAAPPS) recognizes that

- Structural and social conditions facilitate or restrict health
- Intersecting risks amplify the consequences for drug use to create disparities in health outcomes



MAAPPS: Three Phases



PHASE I: Recognize

Engage in a meaning-making process to co-interpret the findings of an **environmental scan** of relevant outcomes and implementation contexts



PHASE II: Connect/Rebuild

Identify shared value space and develop holistic measures of success at a **multisectoral convening**

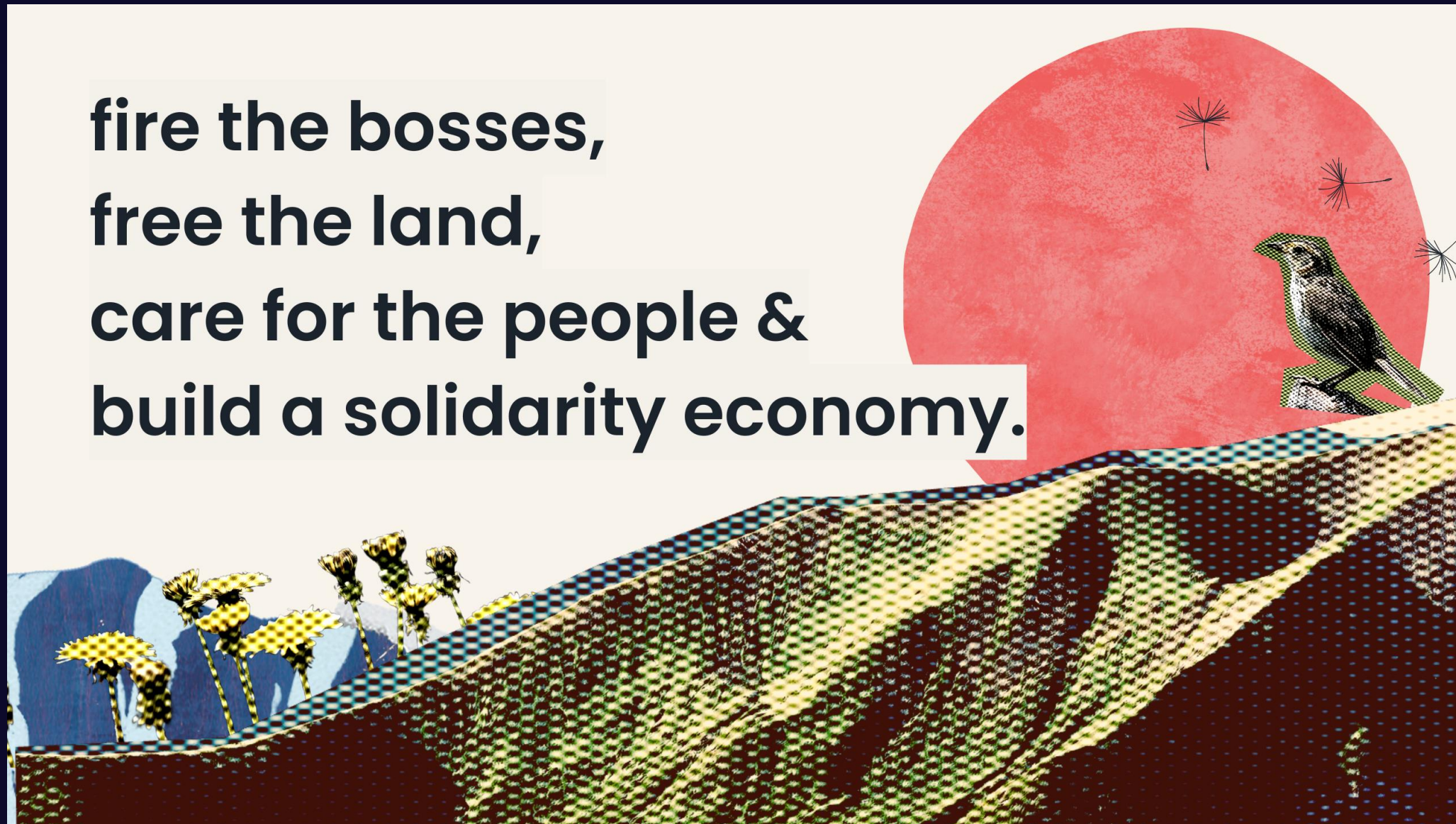


PHASE III: Transform

Apply the measures of success to help state **align spending to promote restorative justice**

PLER PHASE II: SOLIDARITY ECONOMY

**fire the bosses,
free the land,
care for the people &
build a solidarity economy.**



Graphic Source: The New Economy Coalition, <https://neweconomy.net/solidaritycircle/>

Models Across Diverse Communities and Settings

Key Features	Community Sets Agenda	Equal Partnership	Action/ Social Change	Iterative Cycles	Empowerment	Challenges Power	Centers Marginalized Voices	Health/ Public Health	Education	Rural/ Development
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- Community-Driven Research
- Participatory Action Research (PAR)
- Community-Based Participatory Research (CBPR)
- Action Research
- Community Science
- Participatory Evaluation
- Decolonizing Methodologies
- Emancipatory Research
- Educational Action Research
- Participatory Health Research (PHR)
- Participatory Rural Appraisal (PRA)
- Dialogue and Deliberation
- Concept Mapping



Models Across Diverse Communities and Settings



Vancouver Area
Network of Drug
Users (VANDU)



The International
Network of
People who Use
Drugs (INPUD)



Harm Reduction
Australia, Australian
Injecting and Illicit Drug
Users League (AIVL)



Drug Policy And
Research Board
(DPRAB)



Western Aboriginal
Harm Reduction
Network

Indigenous Futures
Institute



Canadian
Association of
People Who Use
Drugs (CAPUD)

DIALOGUE



World Cafe

1. Institutional Barriers - Tim
2. Funding - Amanda
3. Data Sovereignty - Philomena
4. Power Dynamics - Mike
5. Research Resources - Anthony



<https://bit.ly/PLER-HR25>

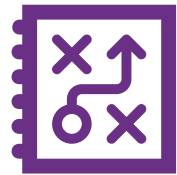


Joining an International Community of Practice



1. How can different research systems and **funding systems** most efficiently work together?
2. How can we ensure that the expertise of community researchers is given **measurable value**?
3. How can we create an **international manifesto** of community-led/community driven research?
4. How do we create a **standardized model** of what we can reasonably expect from academic/institutional researchers partners?
5. How can we **leverage information and training** to create a common language among directly impacted community researchers?
6. How can we disseminate lessons learned so people don't have to repeat each other's mistakes?
7. How can we, on the international level, ensure follow up to the community and **continued engagement** after discrete research projects?

Conclusions



What actionable strategies for equitable and sustainable collaborations can you take with you?









How might you disrupt conventional research structures and prioritize community-led solutions?



What are the next steps for an international community of practice?

THANK YOU!



Name	
	Global Community Driven Reserch Initiatives 
	HR25 SLIDES - PLER 04282025.pdf 
	HR25 World Cafe Discussion 

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