It’s Time for Community-Based Participatory Research in Neuroethics

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Unidirectional Engagement

Data Collection
- Usually one or a few interactions with participants – e.g., interviews, surveys

Data Analysis
- Coding and analyzing interviews transcripts, aggregating survey results

Scholarly Product for Dissemination
- Publication in a peer reviewed journal
"Helicopter Science"

- Context influences study design and research questions
- Participation in dissemination of results
- Partners in research, protocol design, fundraising, data ownership

Level of Community Engagement

- CBPR

From Study Participant...
- No influence on research design
- Opinions actively solicited through pre & post data collection
- Leverages study results & partnerships to promote social change

...to Research Partner

(Balazs & Morello-Frosch 2013)
Community-Based Participatory Research (CBPR)

- Engage communities throughout the research process

- Promote equitable partnerships between communities and academic researchers (i.e., bidirectional, power sharing)

- Collaborative engagement; Cyclical rather than linear relationship

- Co-learning and co-production

(Balazs & Morello-Frosch 2013; Wallerstein et al 2020)
Participatory Dialogue

### World Café Approach

- Set the context
- Create hospitable space
- Explore questions that matter
- Encourage everyone’s contributions
- Cross-pollinate and connect diverse perspectives
- Listen together for patterns, insights, and deeper questions
- Share collective discoveries

![Diagram](image)
Why CBPR?

• Equity and inclusion
• Long-term relationship building
  • Dialogue and trust
  • Iterative feedback
  • Accountability
• Epistemic diversity
• Mutual Benefit

… diversify engagement practices in neuroethics
Thank you!

Questions

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## Participatory Data Analysis

### Phase 1
- Evaluator analyzes data and organizes preliminary findings in the form of data placemats

### Phase 2
- Evaluator facilitates a data interpretation meeting in which stakeholders verbalize the story being told in their own words

### Phase 3
- Evaluator conducts additional analysis (if needed) and produces a final deliverable