

**"TRANSFORMING PARTICIPATION:  
UNRAVELING THE  
STIGMA-DISCRIMINATION COMPLEX  
WITH THE ECOLOGY OF ENGAGEMENT  
MODEL."**

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**SEMINAR-WORKSHOP**  
**STIGMA-DISCRIMINATION COMPLEX (SDC) AND ETHICAL**  
**IMPLICATIONS OF THE LANGUAGE USED IN RESEARCH ON MENTAL**  
**DISORDERS: OPPORTUNITIES AND CHALLENGES**

**MARCH 2 AND 3, 2023**



**Collaborative Strategy**

**Equity and social integration**

**Mental health research**



# DIMENSIONS ETHICS

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**COMMUNITY  
INVOLVEMENT  
IN RESEARCH**

**EQUITABLE  
APPROACH**

**DIVERSITY OF  
EXPERIENCES**

**ETHICAL RESULTS  
SOCIALY  
JUST**



**OMITTED OR NOT DONE**



OOPS!



*How to  
recognize it?*



*Justice and Equity*

**FAIR RESEARCH RESULTS**

# NEW RESEARCH MODELS?

## DECISION MAKING...

- GENUINE?
- OR MERELY SYMBOLIC?



## PEOPLE WITH LIVED EXPERIENCE

Is my experience as a person diagnosed with ADHD and BPD important?

Because?

For who?

And our needs?

What happens before, during and after?



**"Data collection and analysis"**

What does it mean?  
Do we understand it in the same way?

**"Results of the investigation"**

How are they communicated to the community people involved?

# **ECOLOGY OF ENGAGEMENT MODEL**

**ADDRESS ETHICAL  
CHALLENGES  
AND ENSURE  
EQUITABLE  
PARTICIPATION**

**FORM  
COLLABORATIVE  
RESEARCH AND  
PLANNING TEAMS**

**SEEK TO BALANCE  
POWER AND  
KNOWLEDGE**



# **ECOLOGY OF ENGAGEMENT MODEL**

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## **GOALS:**

- 1. Build coherent participation policies in the mental health ecosystem.**
- 2. Redefining engagement as a dynamic relationship embedded in evolutionary systems.**
- 3. Adopt a reciprocal typology of committed relationships.**

# RESEARCH PROTOCOL 2024-2025

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 Jackeline Bravo - Colombia

 Paola Buedo - Argentina

 Colectivo TLP México





Centre of Excellence on Partnership  
with Patients and the Public

## DEFINITION OF <<PATIENT ENGAGEMENT>> FROM THE CANADIAN INSTITUTE OF HEALTH RESEARCH (2019)

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**“Patient engagement in research is an approach that involves meaningful and active collaboration in governance, setting priorities, conducting research and translating knowledge.**

**Depending on the context, patient participation may also involve individuals providing the collective voice of specific affected communities.”**

Source: <https://ceppp.ca/en/resources/learning-together-evaluation-framework-for-patient-and-public-engagement-ppe-in-research/>



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# **EMERGING ETHICAL CHALLENGES:**

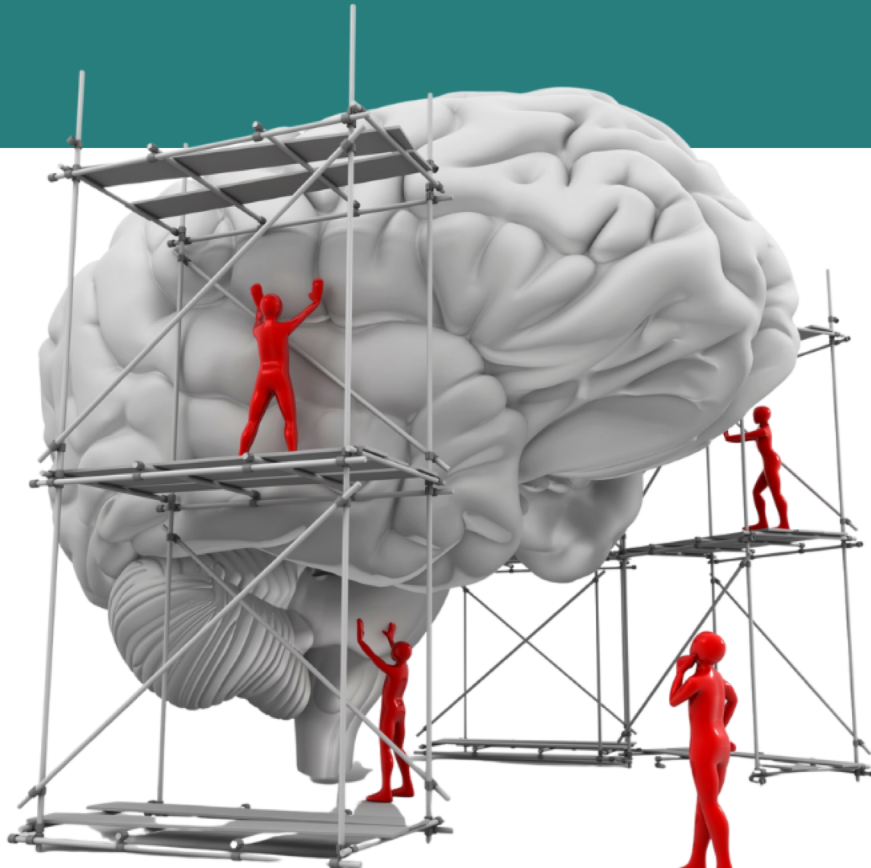
- **The recognition of stigma and its impact on discrimination against people with mental health problems.**
- **The need to reconsider community involvement in research, highlighting power imbalances.**
- **The importance of addressing the Stigma-Discrimination Complex (SED) as an ethical problem.**

## **SOME CONCERNS:**

- **Can this model be considered a comprehensive approach to addressing CED?**
- **Does it allow us to build coherent and adaptive participation policies in the mental health ecosystem?**
- **Do the relationships of engagement established by the model allow us to recognize the dynamic changes in leadership between the community and researchers, balancing knowledge and power?**
- **Does the model ensure equitable and meaningful representation of diverse voices and experiences in research?**

**We seek not only to address, but to unravel  
and redefine our approach to stigma,  
to the Stigma-Discrimination Complex and  
unequal community participation.**

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**THANK YOU SO  
MUCH!**