

Ethics of health research priority setting

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Pecha Kucha presentation

Ecology of engagement. A model for prioritizing research in mental health

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Brief description of case study context

During the meeting of the Global Forum on Bioethics in Research (Canada 2021) it was determined that stigma can lead to discrimination and poor social integration of people with mental health problems. Recognizing the importance of strengthening relevant regional capacities, a seminar/workshop was held in Mexico City in February 2023. The purpose of the workshop was to identify, analyze and understand the Stigma-Discrimination Complex (SDC). The workshop highlighted the importance of linking family and community as a strategy to address SDC by developing new approaches and perspectives¹.

Community involvement has been seen as "inviting outsiders" into research² which implies that researchers decide who to involve and how to involve them in order to achieve their study objectives. Generally there is an imbalance of power that can affect the ability of certain groups to participate fully in research and thereby benefit from its results. There is a need to review models that offer a reciprocal perspective on participatory leadership, ensuring that there is true shared decision-making, rather than a merely tokenistic approach. The coordination among public, private and non-profit organizations actors makes it likely that resources are globally better allocated and decrease the problem of wasteful research.

Inclusion and fair processes

¿What are good models for sharing power with patients, caregivers, or community members in research priority setting exercises? ¿How can decision-makers remove power imbalances and inequalities that may hinder the full participation of certain groups in research and limit their benefits? ¿In the context of research priority setting, what would be effective approaches to address decision-making processes in a more inclusive and equitable manner?

The Founder and director of the Colectivo TLP Mexico and the + Info - stigma movement Iliana Romero, Psycho-educator, Communicator and companion (Peer Support, TEAM), diagnosed with Borderline Personality Disorder (BPD) and ADHD for 6 years with current remission of disabling symptoms, has commented that on multiple occasions, she refused to take part in clinical trials because she thinks that her participation should start in the planning phase of the research. She believes that people with lived experience or who have some kind of diagnosis are really the experts on the problem, the symptoms, and how the experience of the diagnosis is lived and perceived.

Iliana is the creator of the Psico Educación Online project that has educated more than 5000 people and has a social networking platform that has more than 4 million followers³.

Her work is based on ecological models, which propose an integrated perspective on engagement in the co-production of health⁴⁻⁵ and focuses on understanding, supporting and evaluating engagement relationships in health ecosystems. This approach called the Engagement Ecology Model may be suitable for conducting mental health research, looking for possible systemic effects of engagement on co-production, resilience, equity, sustainability, and uncertainty in the mental health ecosystem.

The Ecology of Engagement Model aims to i) build coherent engagement policies in the mental health ecosystem, and not just fragmented and short-lived engagement support strategies; ii) redefine engagement as a dynamic relationship embedded in evolving ecological systems, rather than framing engagement as a static "intervention" designed by researchers; iii) adopt a reciprocal typology of engagement relationships between individuals and groups, recognizing dynamic shifts in leadership between community members and researchers.

Conclusions and recommendations

A group of researchers from Colombia and Argentina, in collaboration with the Colectivo TLP Mexico, is preparing a mental health research protocol based on the Engagement Ecology Model proposed by the "Center of Excellence for Partnership with Patients and the Public" (CEPPP/Canada). Given the absence of documented previous experiences in Latin America with this specific model, this research presents itself as an opportunity to explore and evaluate the feasibility and effectiveness of the approach in a practical setting. Its objective will be to establish real priorities for mental health research, ensuring there is genuine shared decision-making and not just symbolic approaches. The Engagement Ecology Model is proposed as an effective mechanism for sharing power with patients, caregivers, or community members in research priority-setting exercises.

The Ecology of Engagement Model must include at least the following activities:

1. To form the research team with i) functional persons, diagnosed with some mental illness, who may belong to support groups, community organizations and mental health clinics; ii) caregivers iii) mental health researchers.
2. Training of the entire research team in methodological and ethical aspects, to ensure homogeneous and effective skills throughout the research process. It is intended that the whole team assumes influential decision-making roles, to generate balance in knowledge and power, seeking the co-production of research and the transformation of the mental health ecosystem.
3. Training in the Ecology of Engagement model. Through the partnership approach, we seek to achieve a "transformation from within", through collaborative leadership, experience sharing and partnership synergy. People with lived experience are the team members who are experts in the situation and living conditions; with the leadership of a principal investigator, the team directs the study model, forms of evaluation, or questions that help meet the research priorities.
4. Communicate the research results to the entire team through various means and social networks, involving study participants and the community at large. The guiding motto for this model is "We research together, learn together, and promote mental health".
5. Define the evaluation criteria for the study, focusing on synergy in the partnership, sustained collaborative efforts, and collective knowledge production. In this process, the Canadian framework for assessing public and patient involvement in research (CEPPP/Canada) will be considered⁶.

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