Panel ABSTRACT

Panel 43: Co-produced Intersectional Justice and Trauma-informed ethnographic research methodologies: emancipation and inclusion possibilities and co-optation risks

Organizer: Carolina Borda, Xandra Miguel-Lorenzo

Abstract: In health research, 'co-producing research' involves people with lived experience in formulating research aims, objectives, data collection, analysis, and publication. This approach is similar to 'co-producing health services,' where service users design and deliver services in partnership with professionals (Boyle & Harris 2009:3). A main critique of co-production is tokenism, where involvement is superficial rather than meaningful. It differs from 'user-led research,' particularly in mental health, where service users and survivors develop research topics, decide on approaches, and conduct the research themselves (Faulkner & Nicholls, 2001:32).

This panel invites papers exploring the critical and emancipatory possibilities of ethnographic methodologies that enable user-led and co-produced research. Such research should be intersectional, considering multiple forms of discrimination, gender-sensitive, trauma-informed, collaborative, reciprocal, non-hierarchical, ethical, and inclusive of various learning needs and mediums of expression, such as photo voices, audios, artwork, and written material. Additionally, it examines the limits and risks of co-option, where the non-hierarchical, de-colonial, activist, transformative, and healing potential of co-production might be compromised.

The panel seeks insights into anthropologists' journeys in innovating research methodologies to enhance opportunities for research led by interlocutors. Contributions are invited on topics including the negotiation between research expert and facilitator roles, creation and adaptation of methodological tools, exploration of co-researchers' positionalities, empowerment, and power imbalances. It also looks at the impact on data analysis and theory development, the preparedness of institutional, funding, and grassroots structures, and reflections on failed projects that aimed to "give voice" to underrepresented groups but risked co-optation.

SESSION SCHEDULE

19.09.2025 | Slot 1 | 4-0-3

Elena Blanco de Tena-Dávila, Mercedes Serrano Miguel, Ángel Martínez Hernáez: The Guide to Collaborative Medication Management in mental health: an ethnographically co-produced empowerment-generating tool

Liam Gilchrist: Biomedical Discourses and Community-Institutional Power Relationships: An Ethnographic study of UK Community Based Participatory Research.

Xandra Miguel-Lorenzo, Thomas Osborn: Recovery College students' self-care practices awareness: from crisis prevention to routine.

Nel Vandekerckhove: "Are You Really in Pain?": Epistemic Injustice in Chronic Pain Patients and the Potential of Trauma-Informed Care Methods in Pain Research and Pain Medicine.

SESSION PAPERS

The Guide to Collaborative Medication Management in mental health: an ethnographically co-produced empowerment-generating tool

Elena Blanco de Tena-Dávila, Mercedes Serrano Miguel, Ángel Martínez Hernáez

The first pilot test in Europe of the Guide to Collaborative Medication Management (CMM) in mental health has been implemented in Barcelona (Spain) in 2024. The main objective of the CMM Guide is to promote the autonomy of people who have experienced mental suffering and who use psychotropic drugs, and to encourage the construction of care pacts and networks outside and within the clinical setting. It is an instrument for social justice that aims to contribute to the eradication of direct and symbolic violence suffered by psychiatrized people.

This tool is the result of a qualitative ethnographic research that took place between 2017 and 2020 in Barcelona, co-produced by researchers, people with lived experience, their families and colleagues, and mental health professionals. It arrived in Spain after the development of similar research in Canada (1990) and Brazil (2009) linked to the GAM initiative (Gestion Autonome de la Médication and Gestão Autônoma de Medicamentos, in the respective countries).

In our presentation, we will review the process of co-production and adaptation of the CMM Guide in the Spanish context. Subsequently, we will critically analyse the mixed research methodology implemented in the recent pilot project, highlighting its strengths and limitations, and we will present the main quantitative-qualitative results of this experience. All this will allow us to reflect on the potential of the CMM Guide as a tool for empowerment, social and epistemic justice, the production of horizontal accompaniment strategies, and critical thinking about rights and experiences related to mental health and suffering.

Biomedical Discourses and Community-Institutional Power Relationships: An Ethnographic study of UK Community Based Participatory Research.

Liam Gilchrist

The normalisation of co-production across UK medical research has redefined relationships between the public and researchers across UK Universities, The Third Sector and Healthcare Providers. Co-production is increasingly a requirement for funding in major UK medical research funders (MRC 2024), and is embedded within research governance structures (AMRC 2024). The increasing acceptance of co-production in medical environments creates new opportunities to practice research which empowers marginalised communities through 'Critical Consciousness' praxis (Freire 1970). However medical institutional contexts contain their own cultural norms and governance structures that shape power relationships between institutions and communities (Guta 2011).

One co-production approach which has increasingly been adopted by UK health research institutions as a way of reaching diverse communities is 'Community Based Participatory Research'(CBPR) (Thompson 2021). In CBPR, research decision-making is equitably shared between communities and researchers across design, practice and outcomes. The social justice principles of CBPR is a form of co-production with social justice principles and aims to empower communities who have been historically marginalised from knowledge production (Minkler & Wallerstein 2017).

This paper presents findings from an ethnographic PhD study exploring how biomedical discourses shape, and are shaped by community-institutional power relationships within CBPR partnerships. One ethnographic site is a University-Healthcare Provider CBPR partnership involving grassroots community support groups for people with chronic respiratory illness in economically deprived areas of central Scotland. The second site is a UK CBPR project with an African-Caribbean unit of identity, where students from the African-Caribbean Diaspora are co-creating arthritis research together with African-Caribbean communities.

Recovery College students' self-care practices awareness: from crisis prevention to routine.

Xandra Miguel-Lorenzo, Thomas Osborn

Since 2007, UK Recovery Colleges have advocated a recovery approach and trauma-informed care principles, complementing the psychiatric diagnostic medical model. This paper describes a novel co-produced research methodology based on Recovery Colleges' lesson plan principles (Miguel-Lorenzo, 2023) that is intersectional, trauma-informed, and recovery-focused. The study examines Recovery College students' understanding and use of self-care practices in view of the framework of a 'materiality of [self]care' (Buse et al. 2018), embodied practices that heal disruptions or threats to the

self as ‘restorative work’ (Buse et al. 2018:250). Consulted about the research topic and methodology, Recovery College students, together with a clinical workshop co-facilitator and the principal-investigator collected information about their self-care practices in accessible auto-ethnographic journals (including the context when used, money and time invested, emotions, and bodily sensations) over two weeks in between two co-produced workshops. In the first workshop, Recovery College students decided on using photos; discussed their understanding of self-care practices; and chose one-hour interview questions. In the second workshop research co-producers shared and demonstrated self-care practices. By bringing awareness to their everyday experiences, emotions, bodily sensations, and their relationships with objects, a materiality of care, and people- in ongoing processes of self-assemblage, vis-a-vis Trauma cultures (Maté & Maté, 2022), the study participants articulated how their mental health improved and was maintained. Trustworthiness among study participants resulted from tutor/students and mentor/principal-investigator long-term relationships. The principal investigator is an NHS Recovery College Senior Peer Recovery Tutor, accredited domestic violence advocate; justice and trauma-informed anthropologist (Winfield, 2022); and NIHR researcher.

“Are You Really in Pain?”: Epistemic Injustice in Chronic Pain Patients and the Potential of Trauma-Informed Care Methods in Pain Research and Pain Medicine.

Nel Vandekerckhove

Chronic pain patients frequently face dismissal and invalidation of their lived pain experiences. Particularly, those who are women, BIPOC, or with a disability, run a higher risk of being disbelieved in their pain experiences. Healthcare systems are known for their rigid epistemic hierarchies where clinical ‘objectivity’ trumps patients’ ‘subjective’ accounts, rendering patients’ pain experiences as untrustworthy. Healthcare providers generally view themselves as neutral and benevolent actors but may fail to recognize how systemic violence, such as sexism, racism, and ableism, affects diagnostic and treatment decisions. This suborn belief in the treatment room being an apolitical space perpetuates epistemic injustice whereby historically underserved patients are denied credibility and agency in articulating their pain.

This paper explores the potential of health approaches which aim to question and challenge epistemic power imbalances in clinical interactions. While trauma-informed care and user-centred practices are gaining traction in mental health services, their application is limited in pain research and pain medicine. Drawing on the Dutch healthcare context, this study examines how chronic pain patients are required to continuously narrate their pain across fragmented systems, often encountering ‘psychologization’ or outright dismissal of their pain experiences. Through an exploration of trauma-informed care methods, based on the SAMSHA principles, this paper investigates whether TIC can offer a viable framework to address epistemic injustice in pain medicine or whether more radical approaches are necessary to end the systemic injustice that has prevented historically underserved patients from having their voices heard and their chronic pain experiences believed.