Community engagement in HIV research: Lessons learned from four studies

Andrew D. Eaton & John W. McCullagh

Contact: andrew.eaton@utoronto.ca

Article preprint: https://bit.ly/2VIAylI

FACTOR-INWENTASH
FACULTY OF SOCIAL WORK
UNIVERSITY OF TORONTO

ONTARIO
HIV TREATMENT
NETWORK

the CTN
CIHR Canadian
HIV Trials Network

le Réseau
Réseau canadien
pour les essais VIH des IRSC

Background

Community engagement – frequently referred to as *community-based participatory research (CBPR)* – is now a requirement for many funding streams of health and social science research in Canada, especially in HIV research.

- CBPR may improve a study's relevance and sensitivity to a population, impact of findings, and community capacity-building

- This approach also acknowledges the longstanding history of people living with HIV leading and contributing to their own health, wellbeing, and socio-political-legal climate

However, research continues to be conducted and published with varying levels of community engagement and there is a lack of literature detailing pragmatic possibilities to engage peers in exploratory and intervention-based research.

- Existing literature on CBR focuses largely on principles and guidelines, or on CBR implementation in a single study

This paper synthesizes strengths and weaknesses of four studies conducted by the authors and discusses lessons lessons learned for future endeavours

Four Studies

1. Magnetic Couples – a pilot psychoeducational support group:
   https://www.tandfonline.com/eprint/QCP2M9SPXNMD8HGWQIPG/full?target=10.1080/01609513.2017.1369922

2. HIV-Associated Neurocognitive Disorder (HAND) & Social Work:
   https://www.tandfonline.com/eprint/6FP5PR9TNHJJBXTQR82T/full?target=10.1080/00981389.2017.1339759

3. ART of Conversation – a pilot, personalized peer intervention:
   https://bmjopen.bmj.com/content/9/3/e026674.full

4. HAND Group Therapy – a pilot randomized, controlled trial:
   https://bmjopen.bmj.com/content/9/10/e033183 &
   https://www.researchsquare.com/article/rs-21835/v1

Community engagement across four studies				
Engagement type	Magnetic couples	HAND & social work	ART of conversation	HAND RCT
Concept development	X	X	X	X
Questionnaire development	X	X	X	X
Intervention design	X	N/A	X	X
Data collection		X	X	X
Data analysis	X	X	X	X
Dissemination	X	X	X	X

Types of Community Engagement

Concept Development – client engagement sessions, community-based research team meetings, and needs assessment questionnaires

Questionnaire Development - developing and modifying standardized measures and determining relevant and sensitive demographic and qualitative questions

Intervention Design – developing a new intervention, choosing potentially promising interventions and adapting them for a specific context, or recruiting participants and engaging in a participatory process to design the intervention as it is being received

Data Collection – peer-conducted surveys, focus groups, and interviews

Data Analysis – coding and group consensus on emerging themes

Dissemination – presentation and publication

Bolstering Strengths, Mitigating Challenges

Training and Supervision
https://www.tandfonline.com/eprint/HMPZHCDYDFBEQMJDT9DN/full?target=10.1080/14767333.2018.1462143 and https://academic.oup.com/swr/article-abstract/43/3/195/5550914?redirectedFrom=fulltext

Choice and Variety
Considering different types of engagement on a study, from full involvement at all stages to completion of a single task, and distinct roles for peer researchers and peer interventionists

Motivation
https://journals.sagepub.com/doi/full/10.1177/1476750318811913?journalCode=arja

In Conclusion
Developing a supportive work environment of thoughtful training and supervision alongside choice and variety and consideration of motivations beyond compensation are the key takeaways for successful community engagement in this context.