

Evidence, action and self-determination

Realizing the potential of social and behavioural HIV research to mobilize and engage communities for health and wellbeing



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PHA Empowerment and Engagement: Benefits, Challenges and Costs

November 18, 2013 – 10:45 am



OHTN 2013
RESEARCH
CONFERENCE

NOVEMBER 17-19, 2013

CHANGING THE COURSE OF THE
HIV PREVENTION, ENGAGEMENT AND
TREATMENT CASCADE

Outline

1. Challenge

- evidence
- community-based research
- power

2. Opportunity

- producing knowledge to enable social transformation

How knowledge is produced

- Research and the infrastructure that supports research activity
- Experience (personal and professional)
- Interacting and communicating with others
- Education and mentoring
- Modelling/demonstrating practices and behaviours

Self- determination

Theory

- Attaining control over the social determinants; sense of control over one's life
 - (a) the WHO definition of health promotion outlined in Raphael, D. (2000). The question of evidence in health promotion. *Health Promotion International* 15(4), 355-367],
 - (b) Nelson, G., Prilleltensky, I., MacGillivray, H. (2001). Building value-based partnerships: toward solidarity with oppressed groups. *Am J of Community Psychology* 29(5), 649-677

Practice

- Working with individuals and communities to enable them to take an active role in determining, planning and directing their health, care and wellbeing
- Valuing the rights of individuals to make informed choices that include, but are not limited to: sex, sexuality, reproduction, health care, substance use and treatment
[AIDS Committee of Toronto (2010). *Resilience! Together we are stronger*. Strategic Plan 2010-2015. ACT]

Whose knowledge?

“The San (Bushmen) in the Kalahari know of a succulent plant (*hoodia gordonia*) that relieves hunger pangs and allows them to carry on during a hunting expedition The South African Council of Scientific and Industrial Research (CSIR) identified the active constituent of *hoodia* and was in the process of patenting it and making a deal with two foreign pharmaceutical companies ... to develop an appetite suppressant drug ... without informing or consulting the San When the story appeared in the media, public pressure helped force the CSIR to negotiate with the San. Ultimately, an agreement was reached ... the San will receive a modest share of royalties on sales of the drug.”

Lor, PJ and Britz, J. (2006). Knowledge production from an African perspective: international information flows and intellectual property. *International Information and Library Review* 37(2), 61-76.

Community engagement – a poor relation to “science”

... it seems curious that we invest millions of dollars in product development, clinical training, design and building of facilities, etc., but often leave vital processes of community engagement largely to trial and error Rigorous qualitative research methods ... and ethnographic investigations could provide an empirical basis for theory-based interventions and social marketing strategies to support successful fieldwork ... and best practices in engagement with local communities.

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Acknowledgements

Jessica Cattaneo (ACT) tolerated my ramblings about knowledge production, and ACCHO's Research Committee allowed me to digress.

One love!

