

Is it a bird? Is it a plane?

Exploring the impact of research on community responses to HIV



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Outline

- ▶ Introduce the What's in it for Me? Project
- ▶ Reflections on the impact of research on community responses to HIV

What's In it for Me?

- ▶ Workshop series, developed and implemented in 2011

Framing questions:

What does it mean to be an informed research participant?

What kinds of communities are created through research practice?



Curriculum Development

- ▶ Held 4 focus groups with people living with HIV
 - ▶ 27 people participated (10 women, 17 men)
- ▶ 1 focus group with service providers
- ▶ 8 consultations with research-involved people (Community-based researchers: academics, research assistants, research facilitators, research coordinators)

Workshop Series

- ▶ 7 week series
- ▶ Closed group
 - ▶ Participants: 14 total, 10 completed series
- ▶ Invited speakers
- ▶ Informal conversation

Key Issues

- ▶ All the focus group participants had experiences of no follow-up
- ▶ Lots of questions about how information moves through the research process

Overview of Workshop Series

#1 - Research and my story: What do I know?

#2 – Where does my information go?

Consent & confidentiality

#3 - Where does my information go?

Ethics, disclosure & legal implications

#4 - What happened to my story?

#5 - Why do I keep getting asked the same questions?

#6 - Your power as a participant!

#7 - Research on my terms!



**When is a research project just
a research project?**

Reasons to participate

There's a benefit

- ▶ Honorarium
- ▶ Treatment/support
- ▶ Lived experience is valued
- ▶ Education
 - ▶ Curiosity/interest in topic
 - ▶ Learn something new, learn about other's experiences
- ▶ Social Engagement
 - ▶ Opportunity to meet new people, share a meal
 - ▶ Relationship with the person who recruited you
- ▶ **Social justice issue/opportunity to support HIV community (social change work)**



Research Program

Research vs. Program

- ▶ Research project ends (not ongoing – less money for KTE)
- ▶ Facilitators/interviewers lack skills to create a safe and supportive environment
- ▶ Knowledge acquisition is prioritized over support or engagement
 - ▶ Questions are triggering, boring, intrusive, or poorly explained

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