

Community involvement in prevention trials

Gus Cairns

Policy Working Group, European AIDS Treatment Group: www.eatg.org

Editor, *HIV Treatment Update, Preventing HIV* and www.aidsmap.com

Why involve the community?

- Trial acceptability/design
- Researching your population
- Community networking/testing
- Disseminating and communicating results

Who are “the community”?

- Activists
- Service users
- People at risk
- People not at-risk but affected
- Academics
- Healthcare providers (formal and informal)
- Local providers
- Local politicians/leaders
- Most of these categories overlap

What may happen if you don't...

- Cambodia tenofovir PrEP trial protest, Bangkok AIDS Conference, 2004
- “The issues raised by activists, academics, and the research community highlight the poor communication between stakeholders and the need for mutual understanding of values.”
- (Mills, BMJ, 02.09.05)
- May have delayed PrEP research for several years



ormation

What can happen if you don't (2)



- “Secret lover” (Makhwapheni) campaign, Swaziland
- USAID-funded national campaign targeting concurrent relationships: “Secret Lovers Kill”
- Led to public protest by National Association of People Living with HIV who felt it stigmatised them as “makhwapheni”
- Tagline changed to “Hey, HIV is Everywhere”
- Much more ambiguous result: debate raised in national media

The community does *not* speak with one voice...

- ...and shouldn't be expected to
- New York "It's never just HIV" video
- Reactions amongst activists ranged from praise to condemnation
- 'Consulting the community' is not rubber-stamping
- It may involve receiving diametrically opposed opinions



Trial acceptability/design

- Community needs to be actively involved in prevention trial design
- Likely acceptability of method
- A way of avoiding obvious pitfalls and assumptions
- Ethics check
- May know more than researchers about e.g. behavioural prevention methods
- Example: current e-group and community discussion meetings concerning proposed UK PrEP study

Researching your population

- Social anthropology: Who needs our intervention? Who do we target? Who are our supporters? Who will spread the word for us?
- Example: iPrEx trial community research : **“Finding the Community in ‘Community Consultation’”** (Goicochea et al CROI 2006, #898)
 - Identified 7 groups
 - Academics/political campaigners
 - Activists – CAB [NB a CAB does not = ‘the community’]
 - Fellow prevention researchers
 - TV and TG
 - Feminine-identifying gay men (deschavados)
 - Masculine-identifying gay men (buses)
 - Male sex workers
- Each group may have different concerns, knowledge, level of awareness and need

Community networking/testing

- Once you've written your protocol/have your funding, will need community to further spread the word/recruit/publicise
- Example: TRT-5 community meetings re French Ipergay PrEP RCT
- First round involved 12 meetings in 10 main French cities targeting HIV-negative gay people + HIV and LGBT orgs.
- >300 attended, 50 unaffiliated to orgs
- Second round of meetings happening
- Issue: is there such a thing as “the HIV-negative community”?



Disseminating and communicating results

- Examples: work of Global Campaign for Microbicides in convening community meetings to explain results of microbicide trials
- Small- and large-media awareness: talking to gay press etc
- Issue: tension between advocacy/keeping interest in the issue vs. raising premature expectations

This one was commissioned by a community NGO...

- ‘The community’ doesn’t always get it right
- “AIDS is a mass murderer” campaign
- Commissioned by Regenbogen, German community HIV/AIDS prevention organisation
- Condemned as stigmatising by other NGOs
- Raising awareness – or stigma?

