Lessons Learnt from Transgender Women’s participation in the HIV Bio-Behavioural Surveys (BBS) South Africa

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BACKGROUND

• South Africa currently implementing the first ever BBS for transgender women (TGW) supported by CDC

• Rationale for the study:
  – Globally, TGW have been shown to be at high risk for HIV infection.
  – Little information regarding the specific HIV vulnerabilities of TGW.

• An important exploratory one in order to fill this information gap.
STUDY SETTING

• This study will be conducted:
  – The Cape Town Metropolitan area, located in the Western Cape Province,
  – Johannesburg metropolitan area in the Gauteng province,
  – Buffalo City Metro Municipality located in the Eastern Cape province of South Africa.

• The rationale for conducting the study within the aforementioned cities and metros is because of the existence of organisations working with trans women.
  – Gender Dynamix
  – SHE Feminist Collective in East London
  – Sex Workers’ Advocacy and Education Taskforce (SWEAT)
  – Access Chapter 2 (AC2)
METHODOLOGY

Seed is purposively selected (no recruiter)

Seed recruits 3 individuals: “Wave 1” of recruitment chain

Each of the 3 recruits from Wave 1 becomes a recruiter. Each new recruiter then recruits up to 3 more recruits: “Wave 2” of recruitment chain

Sampling continues until the desired sample size has been achieved
OVERALL OBJECTIVES OF THE STUDY

• To identify the social, structural, economic and cultural factors that are related to HIV infection in TGW
• To understand individual behaviours and practices related to HIV in TGW
• To determine the percentage of TGW who are HIV positive in the three study cities
• To conduct a size estimation of TGW in the Cape Metropolitan area, the Johannesburg metropolitan area in, Gauteng as well as in East London (which will also include King Williamstown, Bisho and Mdantsane) based on “Wisdom of the Crowds” methodology.
A NOTE OF CAUTION...

To our knowledge, there has not been a BBS targeting Transgender women in Southern Africa!!!
LAYING A FOUNDATION...

• Involvement of TGW themselves has been instrumental to this process;

• One of the co-investigators self identify as a TGW and this had significant implications for community mobilisation; and data collection;

• Each of the different sites employ TGW as part of the study team(s)

• An advisory committee comprising of TGAW, CDC staff, HSRC staff and other researchers was established
Asking the right questions is key to finding the right answers

B1. What is your current gender identity?

1. Male
2. Female
3. Trans male/Trans man
4. Trans female/Trans woman
5. Genderqueer/Gender non-conforming
6. Different identity (please specify): ________________

B2. What sex were you assigned at birth, meaning on your original birth certificate?

1. Male
2. Female
LESSONS LEARNT SO FAR...

• The survey has to be led by TGW
  – Involvement of TGW in the conceptualisation, throughout survey implementation and dissemination of research findings

• Formative research is essential before and during implementation of the BBS
  – Establishment of not only social connections with TGW but also identified HIV prevention services and civil society organisations providing services for TGW.
  – It is important for the successful implementation of the survey to collaborate with not only civil society organisations but also with healthcare services working with TGW.
LESSONS LEARNT CONT...

• Formative research also important:
  – To identify TGW who are considered champions and well respected in the community of TGW.
  – Identification of specific demographic groups within the study locations from which seeds should be chosen to ensure a sample representative of TGW at risk of HIV.

• Interview sites for our study were established in locations that are accessible to TGW.

• Accessibility was defined in terms of:
  – (i) Easy to find and affordable to get to (i.e. close to public transport);

• Incentives which are integral to RDS were considered insufficient to compensate for travel costs particularly for those participants who came from afar.
CONCLUSION

• Even though recruitment was slow, it is too early to say that RDS does not work for TGW;
• Additional methods to respond to the research question(s) e.g. modified versions of different methods;
• Methods should consider additional benefits for TGW’s participation in research such as referral to gender affirming care, legal gender recognition and other services
  – Most NB lesson learnt from BBS: Meaningful collaboration of TGW in the entire process