



*I am able to tell my story, so that my voice can be heard*

Towards developing a model for community-led research in the first HIV prevalence study conducted with transgender women (TGW) in South Africa

Cloete, A.<sup>1</sup>; Van der Merwe, L.<sup>2</sup>; Skinner, D.<sup>1</sup>; Naidoo, D.<sup>1</sup>

<sup>1</sup>Social Aspects of Public Health, (SAPH) research programme, the Human Sciences Research Council (HSRC);<sup>2</sup>Social, Health & Empowerment (S.H.E.) Feminist Collective of Transgender Women of Africa;  
AIDS IMPACT Conference, London, the United Kingdom (UK) 29 July 2019 – 01 August 2019

# South African context and policy



- 1996 South African Constitution
- **ACT 49** The “Alteration of Sex Description and Sex Status Act, 2003 (Act No. 49 of 2003)” makes provision for transgender people to align their bodies to their gender identity without necessarily requiring gender-conforming surgery
- South African National LGBTI HIV Plan

# South African context and policy

- TGW face pervasive stigma and discrimination (gendered cultural practices and social vulnerability put TGW at risk for violence)
- TGW's engagement in HIV prevention, treatment and care is complicated because of experiences of stigmatization in the healthcare sector

# South African context and policy

- TGW in health research poses a particular challenge
- Stigma and mistrust towards the scientific community were reported by TGW as barriers to participation in a study conducted on factors influencing participation of TGW in HIV vaccine trials (Andrasik et al., 2014 & Owen-Smith et al., 2016)
- It is against this background that we grounded our survey in the community participatory approach.

# Project Setting

- This study was conducted:
  - The **Cape Town metro - municipality**, located in the Western Cape Province,
  - **Johannesburg metro - municipality** 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 metros is because of the existence of organisations working with TGW



# Botshelo Ba Trans Study



- *Botshelo* from Sesotho means life, love and happiness
- From project inception, the BBS was developed through community participation

# Project Approach

## Building rapport and meaningful connections with TGW

- Engaged in several activities fostered **trust** and **collaboration** between the research team and TGW
- **First** establishment of a Steering Advisory committee
  - “Influencers” and activists in the transgender movement of South Africa.
  - TGW recruited from trans-inclusive NGOs and were either involved in the sex worker movement or engaged in HIV prevention for key populations, including TGW.

# Project Approach



- **Second:** Members of the research team were engaged in several events organized by S.H.E. and GDX.



- “Hanging-out” in clubs and other informal events



# Project Approach



Peace and love: Dame Zsa Zsa does more than perform. She is an activist for transgender people's rights. Photo: Madelene Cronje

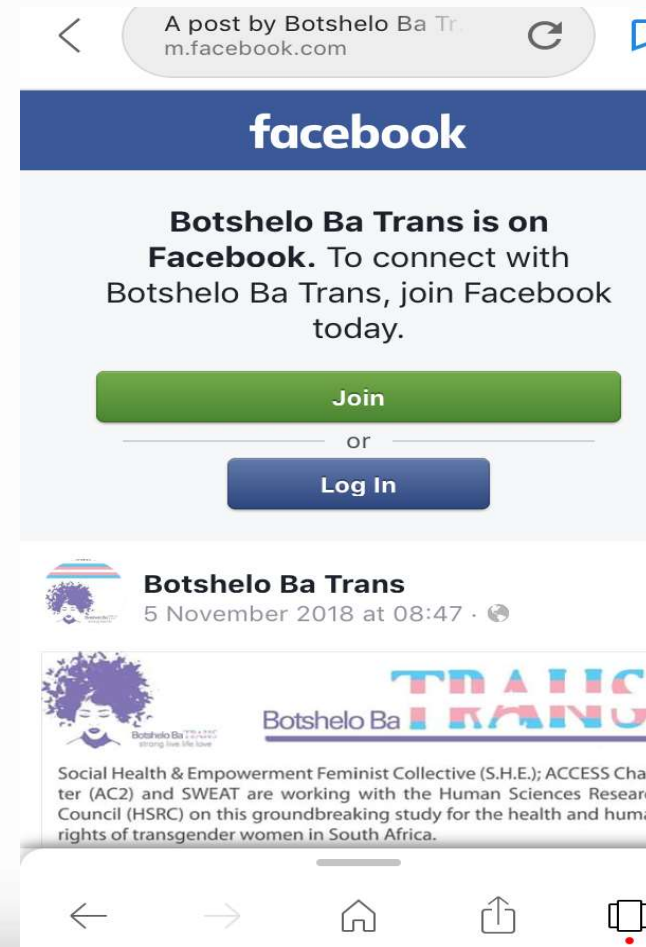
Johann  
hairdre  
der-var  
known  
more f  
the 196  
wrote  
in the  
2016. I  
the cou  
Africa,  
attenti  
queer p  
Town r  
Along  
Bruno  
ading a  
which  
clampd  
ning of  
moveme  
a vital p  
Since  
fracture  
der line  
women  
drag cor  
Zsa Zs  
these di  
drag qu  
woman  
culture  
what it's  
She re  
at Miss  
held at  
Blue. At  
Daveyto  
woman

how she expresses herself in drag

In her life off stage, the dame aims to create change through study and policy. "I'm currently working for the Human Sciences Research Council on a transgender project. This is the first of its kind in the country, and we look forward to this study being able to help enlighten everyone, most importantly the heterosexual people, on the risks and issues which we as the transgender community face on a daily basis."

Zsa Zsa started the Trans Power Care Centre in the hope of making providing transgender people with services, education on transgender issues for the public, families, friends and support groups, as well as shelters for homeless transgender people and HIV counselling. She says

Not limited to physical places and events but also occurred through social media platforms such as Facebook and WhatsApp.



# Project Approach

- **TGW as part of the research team**
  - One of the co-investigators on the study self-identify as a transgender woman
  - Several members of the research team were transgender women.
- **Establishing ownership of the study amongst TGW**
  - Engaged TGW concerning the selection of a name for the study; eligibility criteria; survey instrument etc.

# Project Approach

- **Transgender women as cultural insiders**
  - Having an ‘insider’ perspective facilitated recruitment of TGW in each of the three metros.
  - TGW who were employed in the study harnessed their connections with other TGW through social networking.
  - TGW who are considered veterans in the movement managed to mobilize juniors and new advocates
  - The importance of reaching and maintaining good relationships with these gatekeepers cannot be undermined.

# Project Approach



– Relied on cultural events in the TGW community, e.g. in Buffalo City Metro:

– Annual Miss Trans Diva beauty pageant

– The annual Queer Pride in Cape Town



# Lessons learnt

- Methods should consider additional benefits for TGW's participation in research such as referral to gender affirming care, legal gender recognition and other services

# Conclusion

- From protocol/conceptual phase development phase through implementation and dissemination of research, the involvement of TGW themselves has been instrumental to the successful implementation of the BBS.

# Funders



This research has been supported mainly by PEPFAR through Centres for Disease Control and Prevention (CDC)

Funding Opportunity Number: CDC-RFA-GH11-1151-A

- Catalog of Federal Domestic Assistance Number: 93.067
  - Entitled
- “HIV Prevention Services, Capacity Building Assistance And Evaluation Activities For High-Risk, Underserved Populations In The Republic Of South Africa Under The President’s Emergency Plan For AIDS Relief (PEPFAR)”

CDC for their consistent support of research in South Africa and for this study in particular.

**Helen Savva (Technical Advisor)**

# Acknowledgements

- The TGW who consented to take part in this study.
  - Without their voluntary participation, this study would not have been possible
- Civil society organisations



- Last, but by no means least: Fieldwork teams in each of the three study locations, HSRC staff and project administrators



**THANK YOU FOR YOUR ATTENTION!**

