

# The Power of Community Generated Data

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# Breaking with Business as Usual

Conducting Population Size Estimates (PSE) in MSM, Trans and Sex Workers in the Small Island Context of the Eastern Caribbean to Yield Reliable Results.

# Caribbean Vulnerable Communities Coalition

- Founded in 2004, by renowned Caribbean human rights activist the late Dr. Robert Carr
- Largest indigenous regional coalition of civil society leaders, actors and organisations, grouping over 60 CBOs working with marginalised populations especially vulnerable to HIV/AIDS.
- Provides a platform for policy dialogue, and coordinated responses that address vulnerability, human rights (HR), and sexual health.
- Supports local and regional KP activists and their organisations at the forefront of efforts to:
  - ✓ Improve outcomes along the continuum of care,
  - ✓ Advance the rights of marginalised groups in the region by challenging discriminatory laws and exposing HR violations.

# Traditional Model of Collaboration

Traditionally research partnerships between CBOs & research institutions have been based on single arrangement:

*Research institutions:* develop research protocol & direct data collection and analysis

*CBOs:* provide access to target populations

- However, strong rationale for CBOs to rethink how they approach strategic information & research collaborations.
- New trends & pressures have impacted both NGOs & academic institutions.
- Increasingly, NGOs are expected to demonstrate the impact of their interventions, & develop an evidence base for their work.
- At the same time, academics are being asked to demonstrate the usefulness & wider impact of their research on real world issues & policy.
- These demands favour an environment of research partnerships between different actors to produce research that is both high quality and actionable.

# Breaking with Business as Usual

- However, in reality, there are many questions that still need to be addressed.
- About what each actor brings, what role each will play and how the collaboration will work in practice.
- These include different priorities, schedules and capacity; hierarchies of knowledge and uneven power relations.
- Ignoring these differences can obstruct ways of working and limit the transformative potential of such partnerships.

# The Robert CARR Centre Action Research Resources

- The creation of a specialised research unit within CVC provides a critical space to address & negotiate the differences between the assumptions & different knowledge that partners bring to the table.
- It provides an opportunity for CVC to create new kinds of research processes and outputs.
- It draws on the CVC's presence on the ground, as a coalition with member organisations throughout the region within CVC, and on building research expertise in local members, who have gained trust and access to key population groups on the ground.

# Win-Win

- Joint partnerships contribute research knowledge and credibility, and a long term, reflective lens that CVC's activism and advocacy can sometimes lack.
- The partnerships foster mutual capacity building
- Typically this has been a one way street where academic institutions from the North strengthen CS from the South
- Our experience is that academia also benefit greatly from the field experience offered by CVC.
- Eg. USF was able to validate and revise theoretical/modelling approaches to MI based on real case studies in the DR
- Eg. UAB strengthened the relevance and content of its Global Health curriculum through field internships placements at CVC

# Case study:

## Partnering to Conduct PSE in the OECS

- PSE are invaluable to guide programming and resource allocation to ensure that dedicated funds and interventions adequately cover the populations in need of HIV prevention, treatment and care services.
- Traditionally PSE have proved difficult to conduct in small country contexts, and the results obtained have frequently been questioned by community groups.
- Insufficient attention has been given to adapting the established PSE estimate approach, developed in places like San Francisco, to country contexts where the overall number of key populations are very much smaller.
- This has led to studies in regions like the Eastern Caribbean or the Pacific Islands being abandoned, or the results not being published or used.



# Case Study in Democartizing data.

- CVC's overall approach in the OECS was based on tested and established PSE methods,
- However, critical adaptations and variations were made by CVC to address the small Island context of the OECS where KP behaviours are criminalised
- Understanding what modifications were made and why, and the impact they had in the results obtained makes for a good case study in the importance of Democartizing data.

# Results

- Greater sample sizes achieved when compared to earlier attempts to conduct PSE data in the Eastern Caribbean.
- New sub-groups of MSM, trans women and sex workers, previously unknown or poorly characterised, made visible.
- Larger and more accurate size estimates generated for each of the population groups in the 6 countries.
- Additional buy-in of study results by Community-based organisations doing front-line work with Key Populations in the OECS
- Substantial cost savings achieved that allowed for reprogramming of PSE funds to other areas.
- Capacity of local organizations built, community systems strengthened and regard for CBOs by local authorities enhanced as added value of the study's approach.

# Conclusions

- Key populations in the Caribbean face pervasive and persistent health and justice issues and should be entitled to excellent research.
- However, too often they have been subjected to extractive, irrelevant, and exploitative research – and when seeking out data often find inferior quality products and services available to them.
- CVC has a responsibility to ensure that community groups are properly engaged in research processes and provided with strategic information products that reflect the principles of accuracy, relevance, rigour, accessibility, and usefulness.



Thank You