

The CQUIN Learning Network

The Science & Practice of Scale Up

Engaging Clients and Communities on Community Advisory Boards: Lessons from MaxART

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Presentation Outline



- Background of SWANNEPHA
- Mandate of SWANNEPHA
- Role of Civil Society [SWANNEPHA]
- Promoting Greater Involvement [MaxART Experience]
- Formation of the Community Advisory Board [CAB]
- Role of the CAB in the study
- Key Lessons Learnt

SWANNEPHA Background

- Registered Non Governmental Organization under section 21 of the company registration
- Founded in 2004 by SASO, Women Together, Swapol and 44 support groups
- Supported by NERCHA, SIPAA and UNAIDS and Ministry of Health
- Secretariat opened in March 2005

Mandate of SWANNEPHA

- Advocate for greater and meaningful involvement in the HIV response [GIPA]
- Capacity building of membership
- Advocate for the rights of PLHIV in terms of treatment access
- Promote adherence to treatment
- Reduction of stigma and discrimination
- Lobbying and advocacy for policy change

Role of Civil Society: SWANNEPHA

- Advocate for bottom-up approach to service delivery
- Promote community engagement in decision making
- Form and map support groups of PLHIV in Swaziland
- Form and monitor Community ART Groups
- Conduct treatment education
- Conduct stigma reduction campaigns



For Better Health
and Zero New
HIV Infections

EARLY ACCESS TO ART FOR ALL

Implementation

CLINICAL MENTORING



Supporting health care
workers with Early ART

COMMUNITY MOBILISATION



Creating demand for HIV
treatment services

COMMUNICATIONS STRATEGY



Effective messaging
for Early ART

Research

CLINICAL DATA



Analysing health
outcomes

SOCIAL SCIENCE



Analysing social and
cultural processes

ECONOMIC EVALUATION



Measuring
cost-effectiveness

INCIDENCE MODELING



Predicting HIV
incidence



COMMUNITY ADVISORY BOARD

Acting as a link between communities
and research team

1 Goal Better health and zero new HIV infections in Swaziland

Promoting Greater Involvement of PLHIV

- Designing and conceptualizing the project together with the Global Network of People living with HIV [GNP+]
 - To ensure meaningful participation and ownership during study implementation
 - To ensure that the voice of PLHIV is respected and all their concerns are addressed so that the study yields the desired results.
- SWANNEPHA was brought on board to be part of the study consortium
 - SWANNEPHA was the secretariat of the Community Advisory Board (CAB) which is designed to address all concerns of the study participants and health care workers
 - The CAB met quarterly to review and discuss all the issues raised and make recommendations to the study team and/or the Ministry of Health.

Establishment of the Community Advisory Board

- Identification of key community actors. *i.e.*, traditional leaders, religious leaders, MSM, CSW, youth, women's groups, rural health motivators, PLHIV, community police, academia, community expert clients etc.
- Invitation letters were sent out to the community actors to nominate someone who will represent that cadre in the community advisory board [CAB].
- Letters of acceptance and confidentiality forms were sent to the nominated candidate for signing.
- The CAB and research team jointly developed the Terms of Reference [TORs]
- A training of the CAB on human rights, interpersonal communication skills and ethics was conducted to equip CAB members with skills necessary to carry out their work.

Role of the CAB

- To protect the community interest by ensuring that the voices of the community and study participants are heard and addressed.
- To serve as the link between the study team, facilities, MOH and the community.
- To ensure that the study contributes to improved treatment outcomes for PLHIV.
- To ensure that all aspects of the study are conducted in accordance with ethical and human rights standards.
- To ensure that adequate information about the study is disseminated to increase community understanding of why it is being implemented and how it may benefit them.
- To make and share recommendations based on feedback from study participants and the community, CAB community visits, and facility visits
 - forwarded to the Ministry of Health and consortium members.

Key Lessons Learnt

- The introduction of the CAB to the community leadership made its work much easier when interacting with communities and made our demand creation and mobilization easy and impactful.
- Addressing the concerns and challenges of the service recipients bridged the gap between health care workers and clients.
- Community members feel taken care of when they are given attention and their issues addressed.
- Having the CAB as an oversight body during the whole project implementation made it possible for the Ministry to quickly identify some gaps and address them timeously.
- The CAB was continuously providing feedback to the study team and the Ministry of Health and to the community.
- The CAB structure has been an efficient feedback mechanism during the project implementation.