# Community Engagement and Advocacy

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Expanding HIV prevention options, especially for women

#### Presentation outline

- Defining community
- When to involve community
- Various models for community engagement
- Involving networks of PLHIV



### Who is the community?

Health care providers

Industry and product developers

**Funders** 

Researchers and scientists

Implementers especially NACs

Clinical trial staff and CABs

**Target populations** 



#### When to involve community

• For new prevention technologies, who to involve and when depends on your advocacy message



## ..... a shifting agenda

#### Loci for microbicide advocacy in the past decade

- 1. Supporting the idea that a microbicide could work
- 2. Financing for research on microbicides
- 3. Ethical development of the much needed product
- 4. Thinking about access for NPTs- regulators perspectives matter most as we dream of licensure
- 5. Regional perspectives matter during and after the trial
- 6. Advocacy for financing introduction and WHO is on the fore



## Facets of community engagement







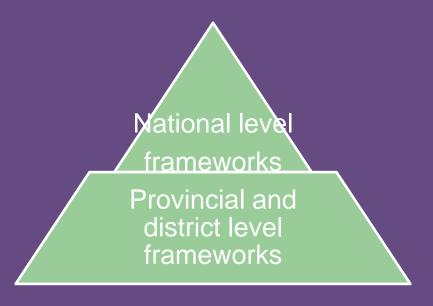
### 1. Learning end user perspectives

- Perspective in effective advocacy strategies ...does it apply to products fulfilling a public health
  - Determines what kind of product; and its augmentation;
- Who else should we be talking to ?
  - Funders
  - Scientists( both academic and product developers
  - Regulators
  - Governments

And when do we start including the conversation with all these stakeholders?



### 2. In the Policy Agenda



Grassroots level organizations



### .....Policy agenda

#### Technical assistance where needed

- HIV vaccine prevention plans- examples from AAVP IAVI and AVAC.
- Technical input into draft policies engaging parliamentarians and forums such as NEPAD to identify champions for microbicides.
- IAVI and GCM working with the champions for HIV prevention and GAF including the microbicide language in the SA NSP.
- Universal access AU statement and NPTs



## 3. Supporting the research process

Community engagement has been a recognized phenomenon over the years. Why?

- Need more support for research
- Demand creation from communities
- Broader prevention dialogue

<u>Understanding communities is essential in driving a relevant research agenda</u>



### 4. During the research process

- Updating communities on key research process issues, results and implications (MMCI and COP projects at GCM)
- Creating platforms for dialogue that will enrich the research process CAB members
- Closing the feedback loop from the community



## 5. Dialogue on access





## 6. Demand creation: The process (AIDA model)

• Attention: Identifying an underserved market segment; and through the process of involving them in research, they are aware that there is a product that is coming up.

 Interest: By making communities interested in identifying and solving their own problems around HIV, they will see probiotics as part of the solution "not for us without us".



#### Demand creation: AIDA model

Desire: Managing expectations important as communities start demanding a product.

 Action: need assured supply through manufacturing capability, provider logistics and end user reality consideration



## Challenge..... product doesn't exist yet!

- Service delivery priorities
- Urge for "visible action" like advocacy for existing options sounds more appealing
- Priority setting
- Capacity strengthening needs for the organizations

entextual issues cant be ignored...

## What do women say? Does it matter

At the rate infections are occurring, anything above 30% will do for me.

27 Year old female in a community training in Durban, November 2009

Hata wewe huwezi taka bidhaa ambayo imeanguka mtihani, imepata chini ya 50% (Even you would not like a product that has failed the exam). The woman equated efficacy to school exams whose pass mark is 50%.

30 year old in a film screening session in Nairobi, December, 2008

I would like the microbicide to be at least 60% effective. Even male circumcision which is being offered to men is 60% effective.

participant, training on new woman-initiated prevention options, Kisumu, May 2009

## Funds and leadership needed



#### Women leaders needed

Anything about us, without us, is not for us!







#### Conclusion

Why are you in this field....always remember

- We need to be working together with networks of PLHIV to make this work…
- Resources are not infinite but through creative thinking and effective stakeholder engagement we can increase the size of the pie



#### Vienna...Save the Date

Satellite to discuss CAPRISA Results Using Antiretrovirals to Prevent HIV: Implications of the outcome of the CAPRISA 004 tenofovir-gel microbicide trial

DATE: Tuesday, 20 July 2010, 6.30pm-8.30pm

An official satellite of XVII International AIDS Conference, Vienna, Austria, Messe Wien Exhibition & Congress Center -Mini Room 10

(Please note: a boxed meal will be served from 6:15pm for delegates attending the satellite)



# Thank you Dr. Samu Dube



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