# Community-based participatory research for quality assurance

Daniela Rojas Castro, PhD Coalition PLUS France



#### SEPTEMBER 8-11, 2019 | BARBICAN CENTRE

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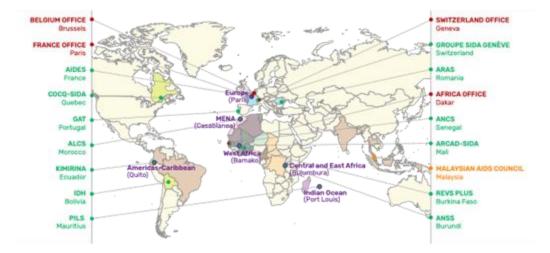


IN PARTNERSHIP WITH



### **Coalition PLUS**





- 13 members
- 100 partners
- 40 countries

International network of community NGOs to fight HIV / AIDS and viral hepatitis.

#### Our mission:

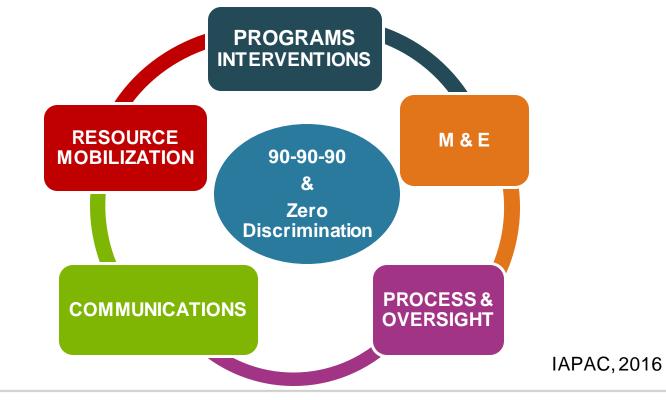
Contribute to the elimination of HIV/AIDS and viral hepatitis, in accordance with the objectives set by the international community.



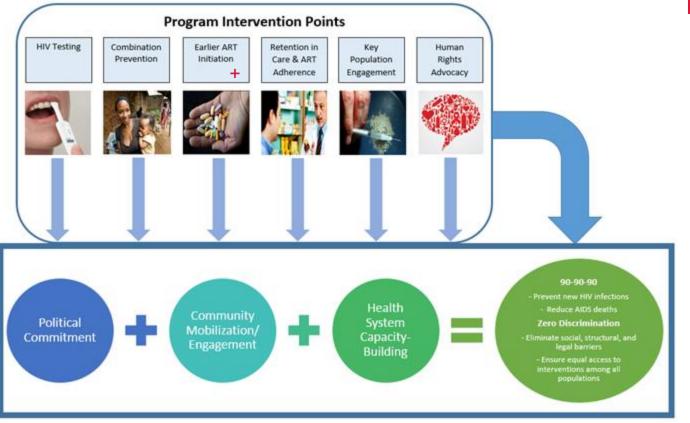
## FAST TRACK CITIES: THE FRAMEWORK



#### IMPLEMENTATION PLAN







IAPAC, 2016



## **COMMUNITY-BASED** PARTICIPATORY RESEARCH

# Community-based research is not...

#### Low-cost research (no rigor, not publishable)

Interventional or action research

The evaluation of associative programs

**Social Sciences** 

Research without researchers

Research using communities to fulfill an obligation without real community engagement

## Community-based research is...

A balanced partnership between researchers and community actors who do research together guided by the needs of the groups concerned and aimed at social transformation

Principal to "do with" and not "to do for"

Mobilisation of concerned groups who express their needs Problems identified in the field by community agents

Takes into account "lay" knowledge

Responds to the same methodological requirements as any other scientific research

#### **Community-based research - A double goal**



#### Science:

To contribute to the advance of knowledge, by offering access to new information and to a variety of analyses.

#### **Social Transformation:**

To strengthen community and transform results into action in the form of practical fields interventions.

Community-based research

Advocacy



Social Transformation

Do we **really** need more research and especially community-based participatory research!?



Today we have the right data, right tools, and right leadership to end the HIV epidemic.

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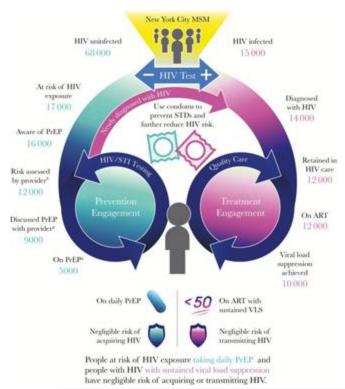






#### **BEFORE**, DURING AND AFTER THE "90-90-90" WE NEED COMMUNITY-BASED RESEARCH FOR REACHING THE "10-19-27"

#### Before the 90-90-90 Respond to people's needs



- Integrating key populations in a sexual health pathway
- Provision of culturally adapted sexual health services (ex. peer-led PrEP counseling: ANRS-Prevenir)

NDON

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Status-Neutral Approach to HIV (Myers et al. 2018)

#### Before the 90-90-90 Data are political



Davis SLM et al. Journal of the International AIDS Society 2017, 20:21386 http://www.jasociety.org/index.php/jas/article/view/21386 | http://dx.doi.org/10.7448/IAS.20.1.21386



#### Short report

#### Punitive laws, key population size estimates, and Global AIDS Response Progress Reports: an ecological study of 154 countries

Sara LM Davis<sup>18</sup>, William C Goedel<sup>2</sup>, John Emerson<sup>1</sup> and Brooke Skartvedt Guven<sup>3</sup>

<sup>1</sup>Corresponding author: Sara L.M. Davis, Center for Human Rights and Global Justice, New York University School of Law, 40 Washington Square South, New York, NY 10012, Tel: 1-212-992-6188. (vld387@nyu.edu)

**Conclusions:** Criminalization of same-sex sexuality is associated with implausibly low or absent MSM size estimates. Low size estimates may contribute to official denial of the existence of MSM; to failure to adequately address their needs; and to inflated HIV service coverage reports that paint a false picture of success. To enable and measure progress in the HIV response, UN agencies should lead a collaborative process to systematically, independently and rigorously gather data on laws and their enforcement.

### First 90 People know their HIV status



- Most difficult step to achieve among majority of countries.
- Need to develop interventions targeted to populations not successfully reached by health centers.
- Exemple: Hermetic Paris (France) -



### **HERMETIC - Paris**





Mathematical modeling to identify the "hidden epidemic" in France: migrant men (heterosexuals and MSM) from sub-Saharan Africa living outside Paris.

How can we improve our capacity to reach individuals from sub-Saharan Africa?

Literature, brainstorming and discussions led the decision to experiment a new approach to HIV testing: door-to-door.



### **HERMETIC - Paris**



Cité des Franc-Moisins à Saint-Denis



### **HERMETIC - Paris**



- 739 door-to-door contacts: 290 with people born in SSA (143 men et 147 women)= 39,2%
- 142 rapid tests with SSA born people at the van and 43 at home.
- More native Sub-Saharan African people were reached than in classical interventions.
- Fewer MSM were reached than in a classical interventions.
- This intervention reached people who reported a less frequent use of condoms during the last sexual act than in classical interventions.

### Second 90 PLHIV are on treatment



- Barriers still exist to accessing health care, especially for key populations facing stigma and discrimination.
- Need to identify and overcome specific barriers in local context.
- Example: TB-Check Bucharest (Romania) -



### **TB-CHECK - Bucharest**



- 1339 PWID diagnosed HIV-positive (2007-2017) (CNLAS, 2017), with an important increase in TB cases among this population.
- Implementation of a study to understand the underlying reasons for this refusing treatment (December 2017-March 2018) through the project "Treatment for all, now!" funded by the Global Fund, Romanian Angel Appeal Foundation.
- Mix-methods approach (N=116)



#### **TB-CHECK - Bucharest**



- Rewarded referrals were the most efficient method to successfully link PWID to TB services.
- Emotional status and physical appearance of PWID are major barriers to linkage to care.
- Adapted schedule and less restrictive conditions could increase PWID's attendance to TB dispensaries, in addition to peer support and information.
- Need to develop an integrated approach within medical, social and community-based services: one patient, one place, all needed services.

### Third **90** PLHIV are undetectable



- Achieving viral suppression is dependent on regular medical follow-up and treatment adherence.
- Need to set up interventions that address treatment adherence issues.
- Example: therapeutic education among PLHIV -Cochabamba (Bolivia)



# Therapeutic education among PLHIV - Cochabamba



#### **Objectives**:

- To evaluate the effectiveness of therapeutic education program (TEP) with regards to antiretroviral treatment adherence.
- Compare the percentage of patients with an undetectable viral load among those who participated in the TEP and those who did not.
- Determine the factors associated with treatment adherence in
  both study groups 2019 I SEPTEMBER 8-11, 2019 I BARBICAN CENTRE

# Therapeutic education among PLHIV - Cochabamba



- Among those in the TEP, 95% achieved an undetectable viral load at the last follow-up session (versus 68% of those not participating in the TEP).
- The percentage of PLHIV with an undetectable viral load between the first and the second follow-up session increased by 45% among participants in the TEP (versus 31%).
- Among those in the TEP, men achieved a higher percentage of undetectable viral load (50% compared to 33% among women).

#### After the 90-90-90 Fight against STIGMA

#### THE LANCET

#### Refusal to provide health care to people with HIV in France

Refusals to provide care to people with HIV have been reported in the USA,<sup>1</sup> the UK,<sup>2</sup> and elsewhere in Europe,<sup>3</sup> but their frequency remains poorly documented. In 2015, the French parliament examined a law that includes an article on non-discrimination in access to health care and the possibility of doing



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ALCS

### A final word



**Community-based research...** 

• Can better identify people's needs.

Nothing

Without

About

Us

Us

- Can improve the pertinence and quality of data.
- Can help better understand local epidemic(s).
- Puts into place sustainable solutions that can have a strong(er) impact thanks to community engagement.
- Mobilises concerned communities.
- Addresses the needs of the 10%-19%-27% who are in the margins of society and of traditional health care services.
- Let's work more and better together!





@drojascastro

drojascastro@coalitionplus.org

For more information on community-based research at Coalition PLUS (EN, FR, ES):

http://www.coalitionplus.org/brochure-recherche-communautaire-vih/