

3 - 4 MAY 2018

# 2018 CONTROLLING THE HIV EPIDEMIC SUMMIT

## Strengthening Community Engagement in the AIDS Response

Laurel Sprague

Global Network of People Living with HIV (GNP+)

# Dr Patrick Welsh



Detroit Free Press, 13 October 1992



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Dr. Carol Chenoweth  
University of Michigan Medical Center



# Communities



Shine a light on the gap between promise and reality

# Commitments

- **Treatment**

- Universal Health Coverage (SDG 3)
- By 2030, end the epidemics of HIV, Tb, malaria and NTDs... (SDG 3.3)

- **Human Rights**

- Commit to targets for 2020...to eliminate HIV-related stigma and discrimination (2016 Political Declaration)

- **Funding**

- Ensure that at least 6 per cent of all global AIDS resources are allocated for **social enablers**, including advocacy, community and political mobilization, community monitoring...as well as **human rights programmes** such as law and policy reform and stigma and discrimination reduction (2016 Political Declaration)

# Promise: Treatment for all

- Adherence – by governments
  - Enough ARVs, in time, good quality
- Government funds need to be spent effectively
  - Communities as watchdogs (corruption and mismanagement) and advocates for improvements

# Treatment for all



Monitoring of procurement (prices, corruption) and monitoring of ARV formulary



# Treatment for all

## Stock-out Monitoring & Advocacy



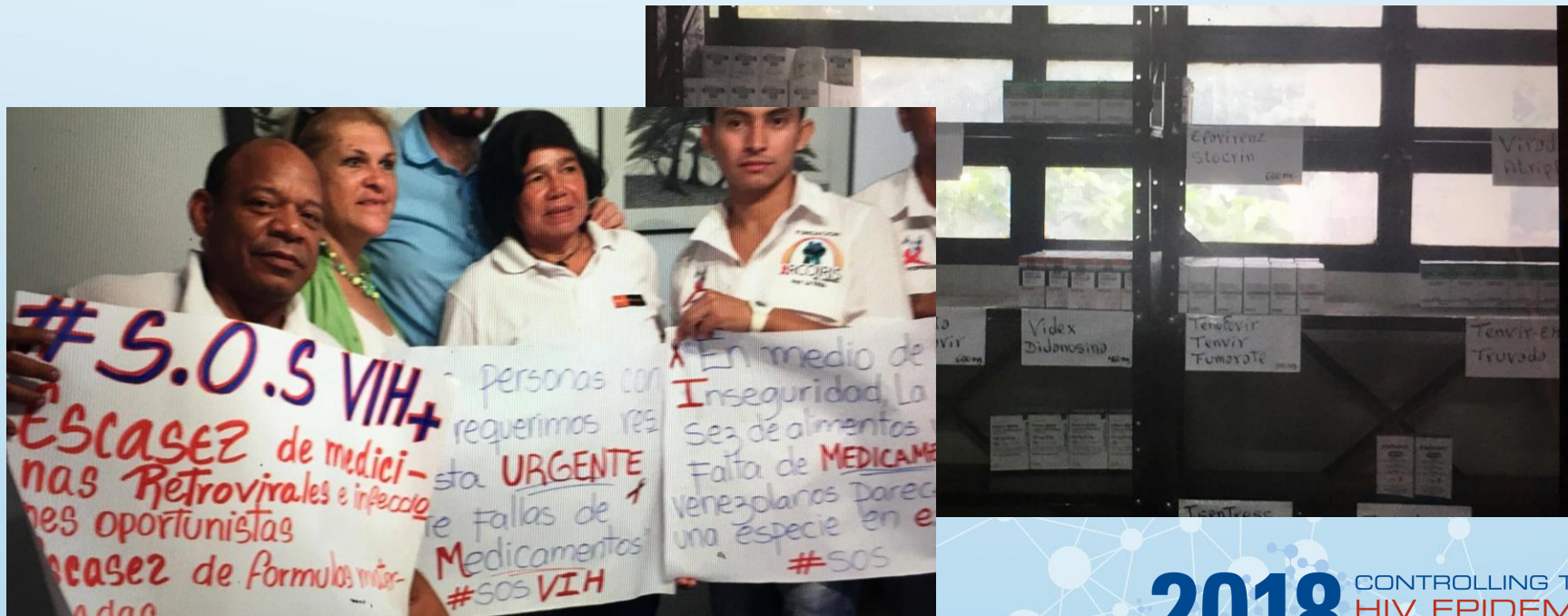
# Treatment for all

Advocacy for health  
system reform



# Treatment for all

## Emergency human rights response



# Treatment for all



Prices for ARV drugs significantly reduced from \$10,000 per patient/year in 2000 to \$100 per patient/year in 2016 for a basic WHO recommended treatment combination package.

India become '*pharmacy for developing world*' and remain as supplier for generic ARVs globally

Brazil, Thailand, Indonesia use compulsory licensing to produce ARVs for local demand.

# Treatment for all – where do we stand?

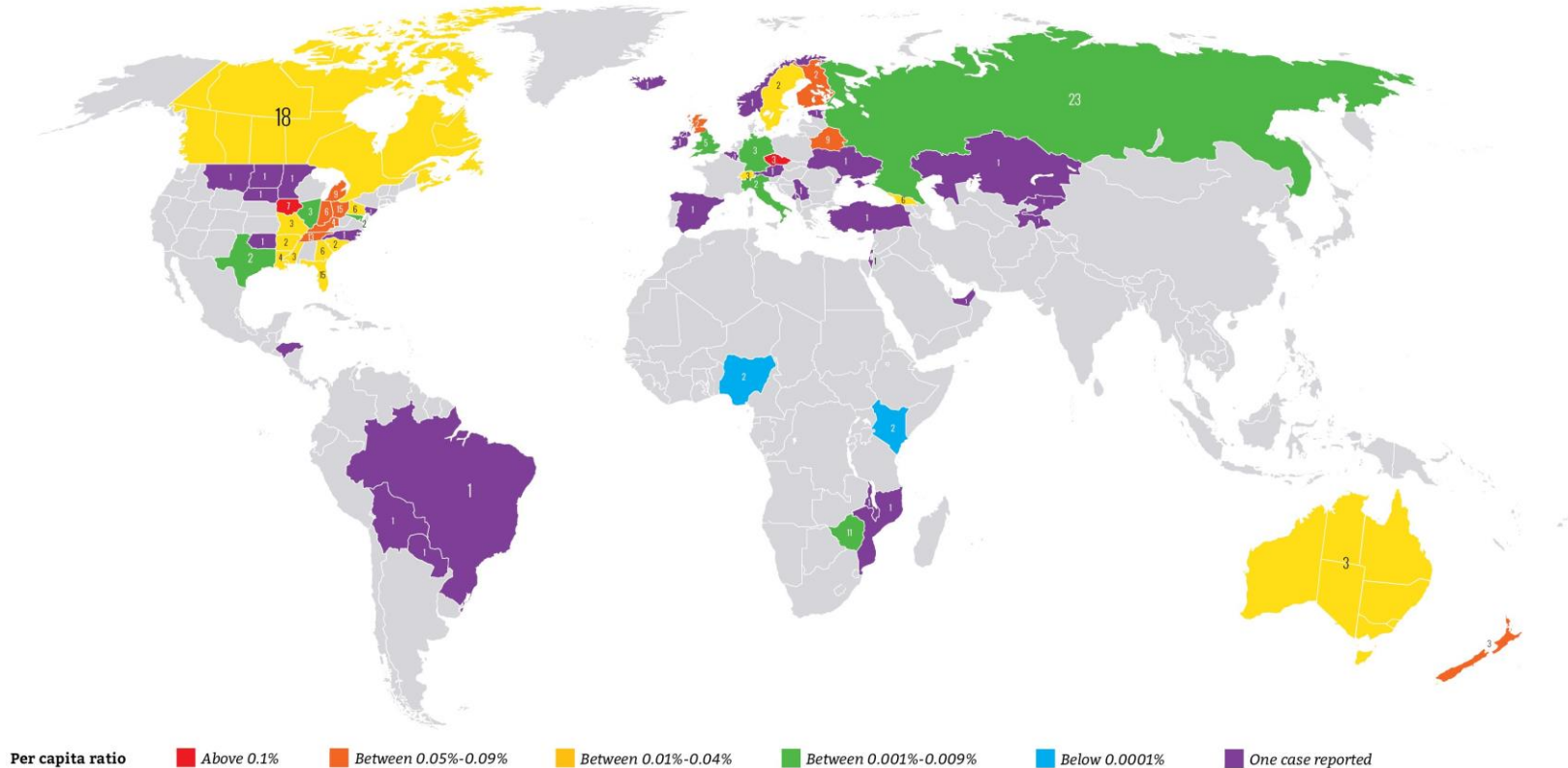
- Threat to treatment access with IP provisions under international trade agreements (FTAs, TPP, RCEP, etc.)
- Global treatment coverage is now 17 million, long way to go to reach 30 million by 2020 to meet UNAIDS 90-90-90 target.
- International support for AIDS response has changed significantly in particular in the funding landscape and shrinking space for community engagement.
- Legal barriers become threat for efforts towards organized marginalized communities.

# Promise: Protect Human Rights

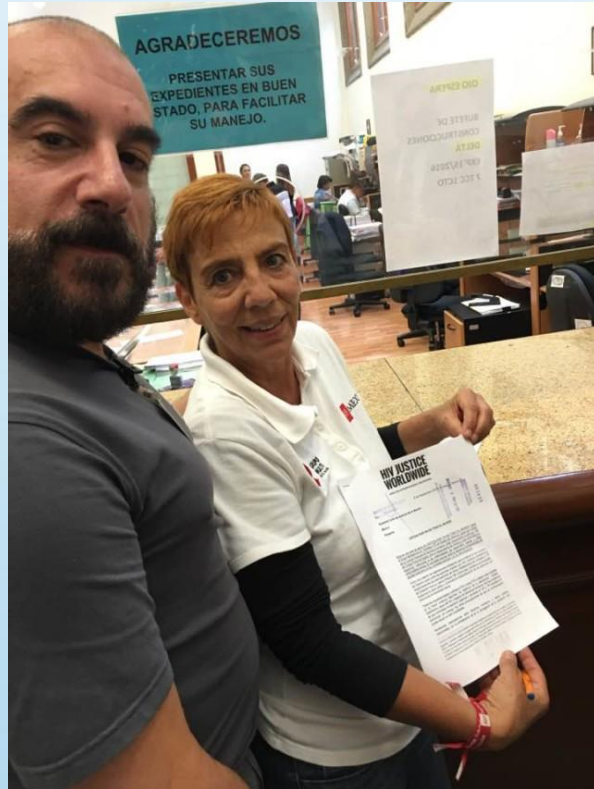


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# Where HIV-Related Prosecutions Have Been Reported (October 2015-September 2017)



# Protect Human Rights



**MEXICO: SUPREME COURT FINDS VERACRUZ LAW CRIMINALISING 'WILFUL TRANSMISSION' OF HIV AND STIS TO BE UNCONSTITUTIONAL**

May 1, 2018





# PLHIV Stigma Index



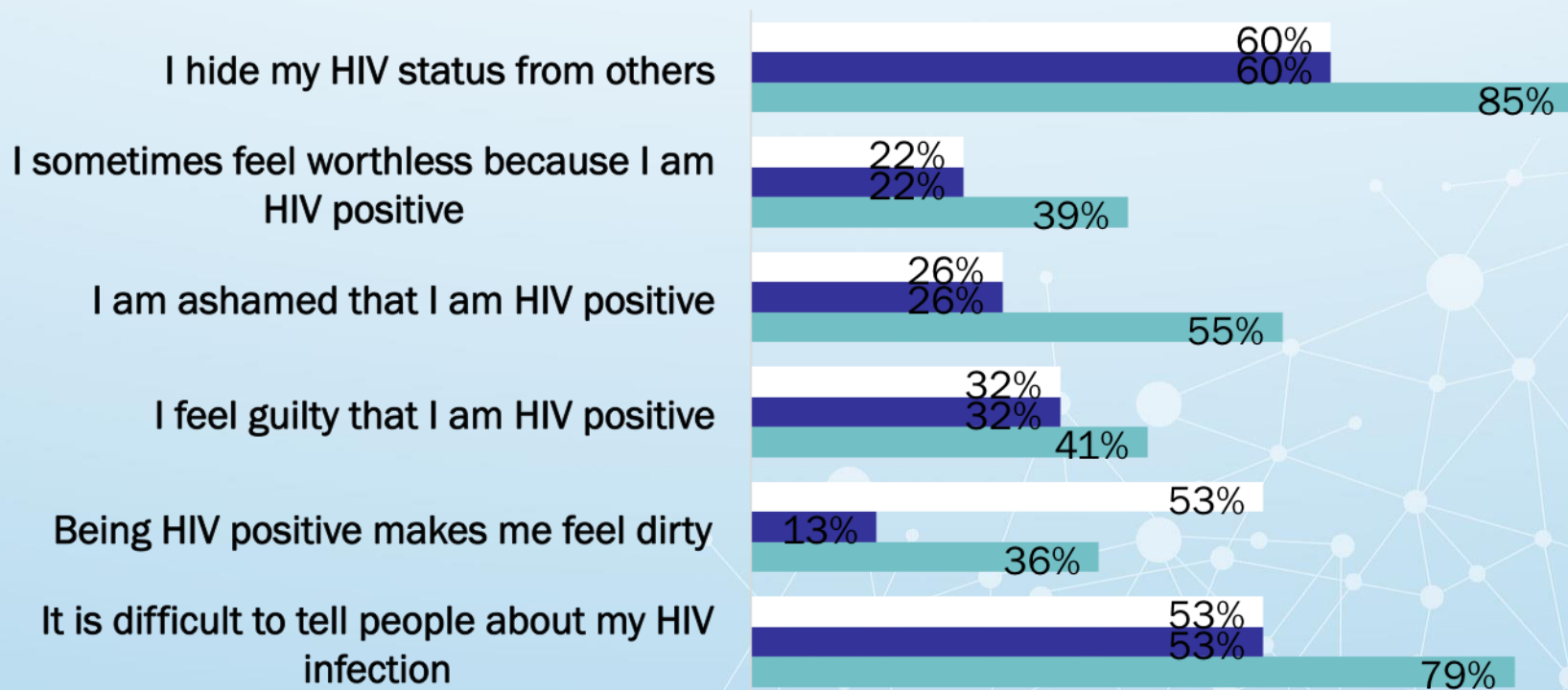
- Developed by IPPF, UNAIDS, GNP+, ICW; launched in 2008
  - Questionnaire-based methodology to quantify stigma and discrimination – implemented by PLHIV among PLHIV
  - Complements experiences of individuals with the collective diverse experiences of a community of PLHIV
- Provides for evidence-informed advocacy, policy reform, and service delivery

# PLHIV Stigma Index



- Builds capacity of PLHIV networks—GIPA principle in action
- As of October 2017:
  - >100,000 PLHIV interviewed from 90 countries in >50 languages
  - 2,000 PLHIV trained as interviewers
- PLHIV Stigma Index 2.0 launched in 2018
  - Current implementations in 16 countries in all regions

# High Rates of Internalized Stigma (2017)



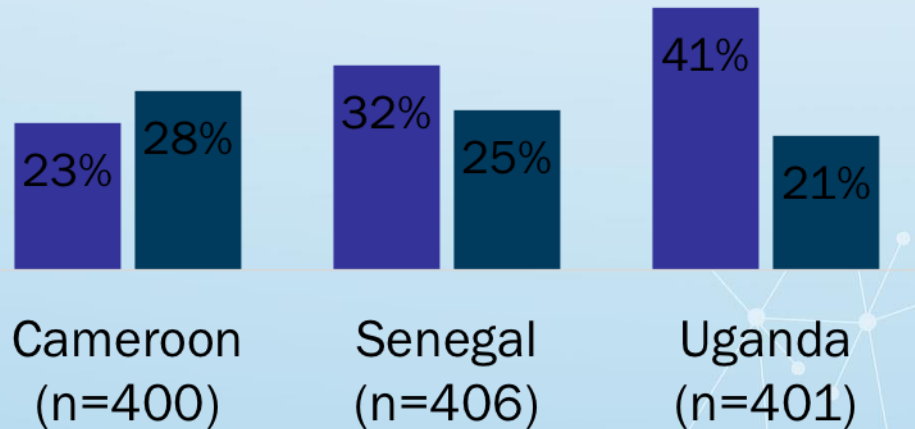
Uganda (n=401)

Senegal (n=406)

Cameroon (n=400)

# Stigma Affects HIV Care Cascade (2017)

- Hesitated to get tested due to fears
- Delayed entering care

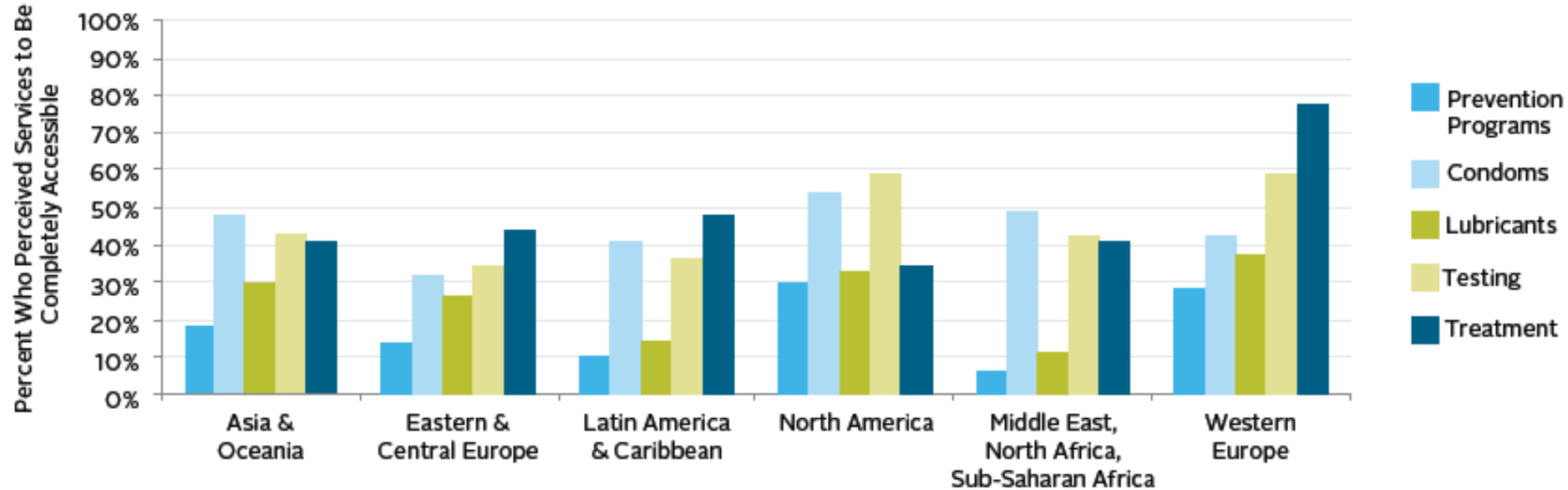


Delayed entering care because:

- *Not ready to deal with HIV infection (16–33%)*
- *Worried others would find out status (11–13%)*
- *Afraid health workers would treat me badly or disclose status without consent/had a bad experience with a health worker previously (4–11%)*

# Global Men's Health and Rights Survey

## HIV Service Access by Region



George Ayala, Sonya Arreola, Glenn-Milo Santos, Keletso Makofane, Ayden Scheim, Tri D. Do, Pato Hebert, Jack Beck, Patrick Wilson. Research funded by Bill and Melinda Gates Foundation, The Ministry for Foreign Affairs, the Netherlands

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# Funding the Community Response

## UNAIDS PROGRAMME COORDINATING BOARD

UNAIDS/PCB (39)/16.22  
Issue date: 11 November 2016

### THIRTY-NINTH MEETING

Date: 6-8 December 2016

Venue: Executive Board Room, WHO, Geneva

Agenda item 7

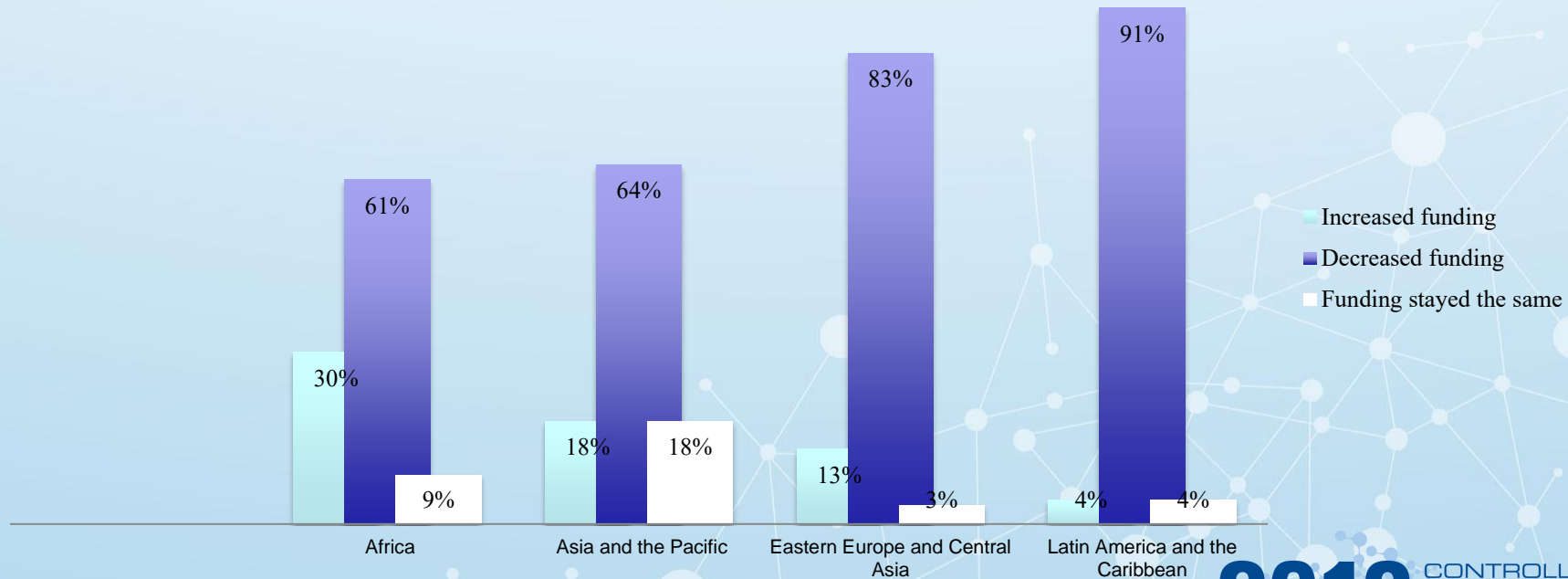
### Report by the NGO representative

**An unlikely ending: ending AIDS by 2030 without sustainable funding for the community-led response**

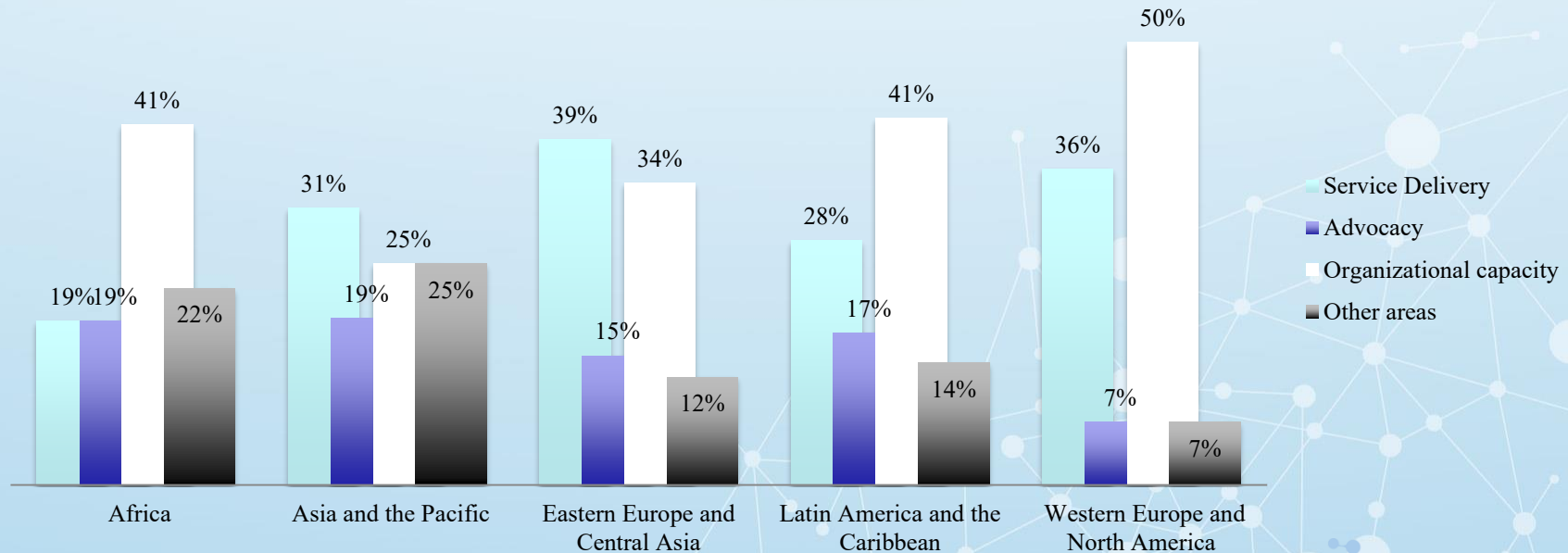


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# Have there been changes in the amounts of funding available from global donors?

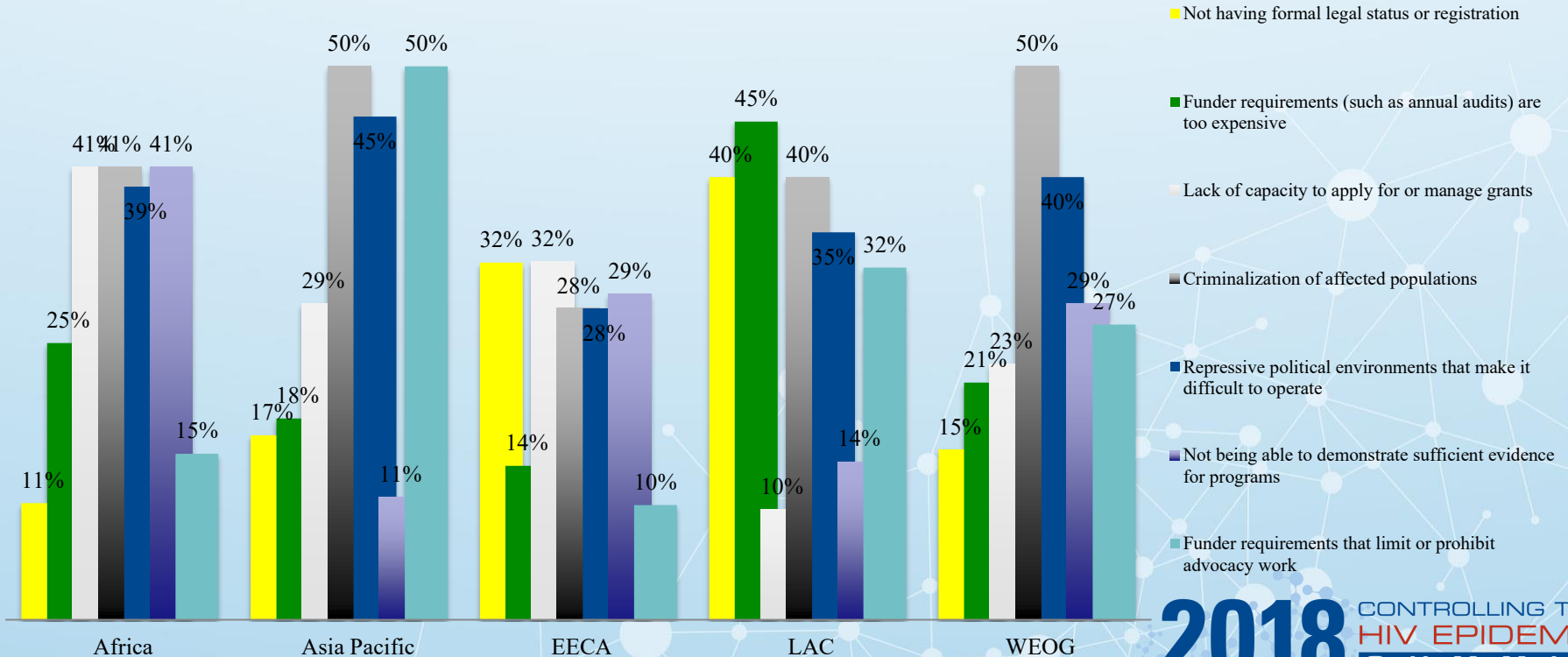


# What areas of your work (if any) have suffered the most from these cuts?





# Top Barriers to Funding the Community-led Response



# Strengthening Community Engagement

- Community-led research, monitoring, and advocacy need to be funded and recognized
- Legal barriers to organizing, especially for most marginalized populations, need to be removed
- Commitment to Zero Discrimination across sectors (laws, education, employment, health facilities, etc.) needs to be realized

# THANK YOU

To all of the people living with HIV and key populations worldwide who shared their experiences with stigma, discrimination, and activism. You made this presentation possible.



George Ayala (MSMGF) for the Men's Global Health and Rights survey data.

Alexandra Volgina and Omar Syarif at GNP+ for EECA and Asia Pacific Region photos and treatment advocacy information.

PLHIV Stigma Index International Partnership: **GNP+**, **ICW**, & **UNAIDS**; **Population Council/Project SOAR**; & **Laura Nyblade**, RTI/HP+ & **Stef Baral**, Johns Hopkins University for the People Living with HIV Stigma Index 2.0 data/charts

*The PLHIV Stigma Index 2.0 revisions and pilot projects were funded by **USAID** and **PEPFAR**.*

**HIV Justice Network/HIV Justice Global Consortium** for the HIV criminalisation global data/maps

*The HIV Justice Global Consortium, an alliance of PLHIV networks, human rights organizations, and HIV/AIDS legal networks is supported by the **Robert Carr civil society Network Fund**.*