

# Community engagement

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TasP Summit, 18<sup>th</sup> September 2014

# Definition of “community”

- **community-led structures** and mechanisms used by communities through which **community members** and **community-based organizations** and **groups** interact, coordinate and deliver their **responses** to **needs affecting their communities**
  - a critical component of an overall and complex system that aims to protect and promote health and human rights
- **community response** - the collective of **community-led activities** in response to HIV

# Levels of engagement

- Advocacy, campaigning, policy change
- Community-based research
- Community-based service delivery
  - community engagement in quality of care

# Advocacy, campaigning, lobbying

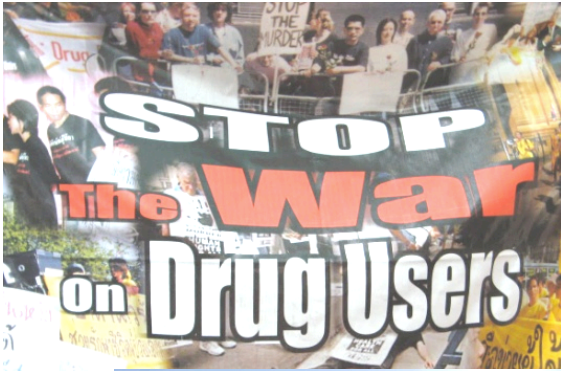


Strengthening Community Response to HIV Treatment & Prevention



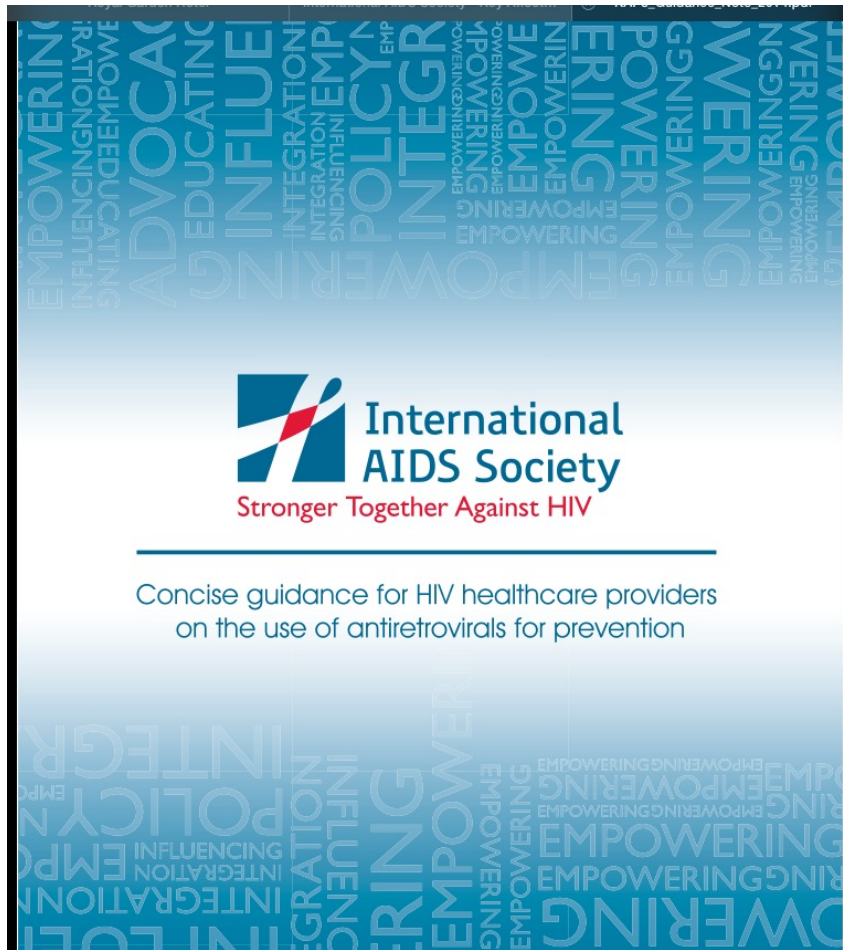


# Repression endangers the fight against HIV



- Access to quality treatment of a person who use drugs/sex workers/ migrants/ prisoners/ transgender
- A second class citizen treatment when accessing care
- Coerced testing
- Laws of no confidentiality for those with a communicable disease
- Criminalisation of behaviour (drug use and sex work)
- Criminalisation of HIV transmission

# Concise guidance for HIV healthcare providers on the use of ART for prevention



- Core principle 1:
  - Being honest and open and acting with integrity.
  - Listening to, and responding to, your client's concerns and preferences.
  - Providing clear information in a way they can understand.
  - Never abusing, coercing, discriminating, judging, pathologising or punishing.
  - Working in partnership with them and respecting their right to make their own decisions about HIV testing, treatment and/or care.

# Community-based research



- At July 2014 the total number of PLHIV who have been interviewed by the PLHIV Stigma index is **44,027** this number is rising...
- The Stigma Index has been implemented in **50 countries**

## • Key populations interviewed globally to date

- People who use drugs 5866
- Men who have sex with men 3852
- Prisoners 1576
- Migrants 1329
- Sex Workers 1297
- Transgender 671
- Indigenous 652
- Internally displaced persons 479
- Refugees 189



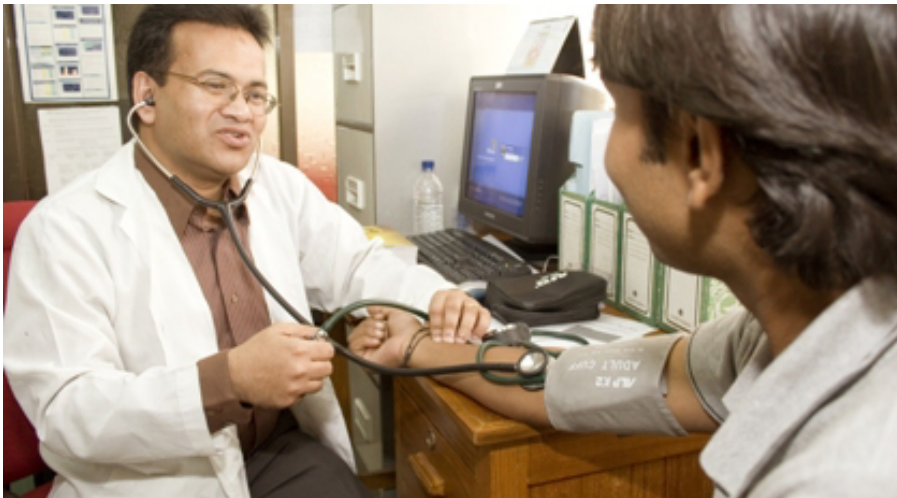
- Regional analysis of Stigma and Discrimination
- Thematic analysis and action: workplace policies , in faith settings, barriers to testing and uptake of services
- ‘Key’ Population priorities and knowledge about specific stigma faced by key populations
- Concrete actions connected with HIV programming:
  - Country advocacy
  - Development of people-centred services

# Community-based research

- **Putting Trans\* issues at the centre of research**  
(*Siluetas X, Ecuador and Gender DynamiX, South Africa*)
  - the first trans-specific health and human rights study in Ecuador
  - analyze factors that may influence HIV transmission among trans women
- Research led by people living with HIV **changes access to treatment**  
(*APN+, Asia-Pacific region*)
- Sex Workers lead research resulting in **better practice** (NSWP, *Global*)
  - best practices to guide sex worker programming
- Understanding MSM risk to **better meet needs** (*Checkpoint LX, Lisbon*)
- **Rights-based approach to Treatment as Prevention, Maximizing ART for Better Health Prevention and Zero New HIV Infections (MaxART)**

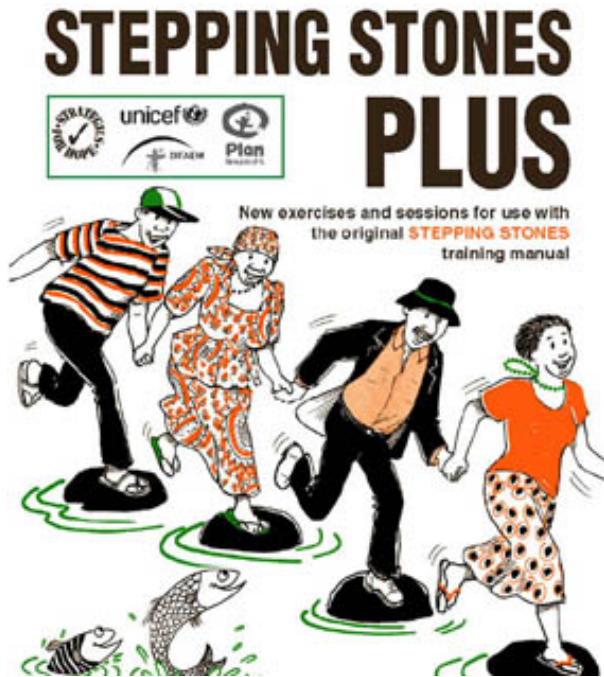


# Community-based service delivery





# Tackling gender norms through training



- **gender transformative** community-training programme
  - for HIV vulnerable communities living in low-income countries
  - thirteen 3-hour sessions and 3 peer group meetings
- **systematic review** (2012) that looked at eight reports from seven studies
- study sample- 14,630
- Angola, Ethiopia, Fiji, Gambia, India, South Africa, Tanzania and Uganda
- people who had participated in *Stepping Stones* **were less likely to acquire HSV-2** (Herpes Simplex Virus)
- trends of **increased condom use** (seen in findings from two of the eight countries).

# Health literacy

is a major component of **democratization** of the healthcare system.

- ART
- Adverse events
- Pipeline
- Health systems
- Quality



Being:

- Your own **advocate**
- **Proactive**



# Let's change the way we test globally

- Community-based testing performed by non-medical trained testers
- Rapid test as a diagnostic tool also in clinics

**CHANGE OF LEGISLATION NEEDED!**

# Traditional “comprehensive” model

- Comprehensiveness is determined by the length of clinics specialists’ roster



Drug dependence, poverty (need to struggle to get living), stigma, fear of the system, low self-efficacy, depression...

Healthcare system

Infectious diseases specialist

Pulmonologist

Gastroenterologist

Endocrinologist

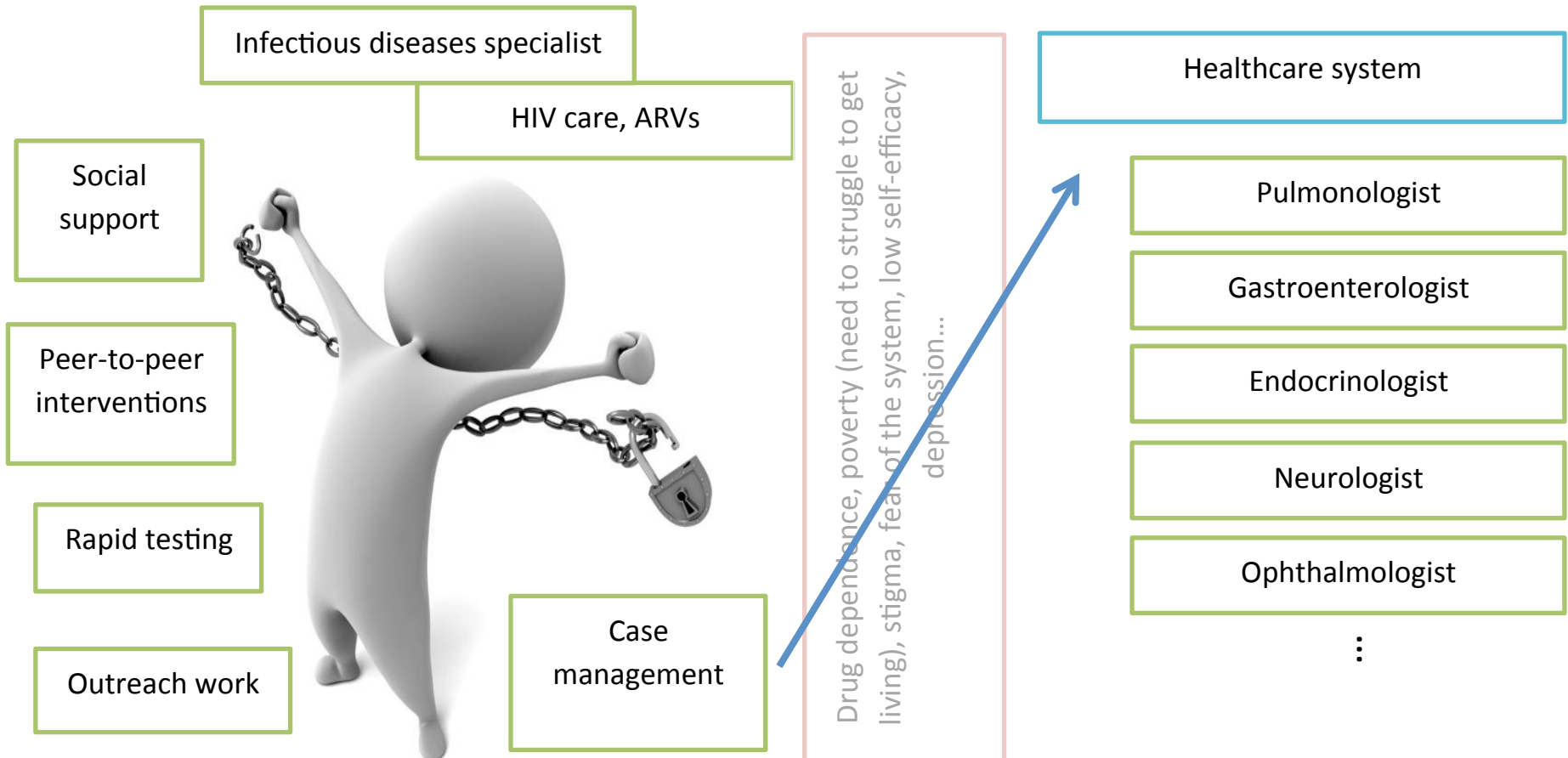
Neurologist

Ophthalmologist

⋮

# People-centered comprehensive care

- Comprehensiveness determined by patients' most significant demands. The most needed services, including infectious disease doctor and ARVs are provided in one place. Other services provided via referral system and active case management.





# Linda Clinic: a community-based response to a gap in HIV-care in Narva, Estonia



Before..(2011)



After...(2013)

# Linda Clinic Services

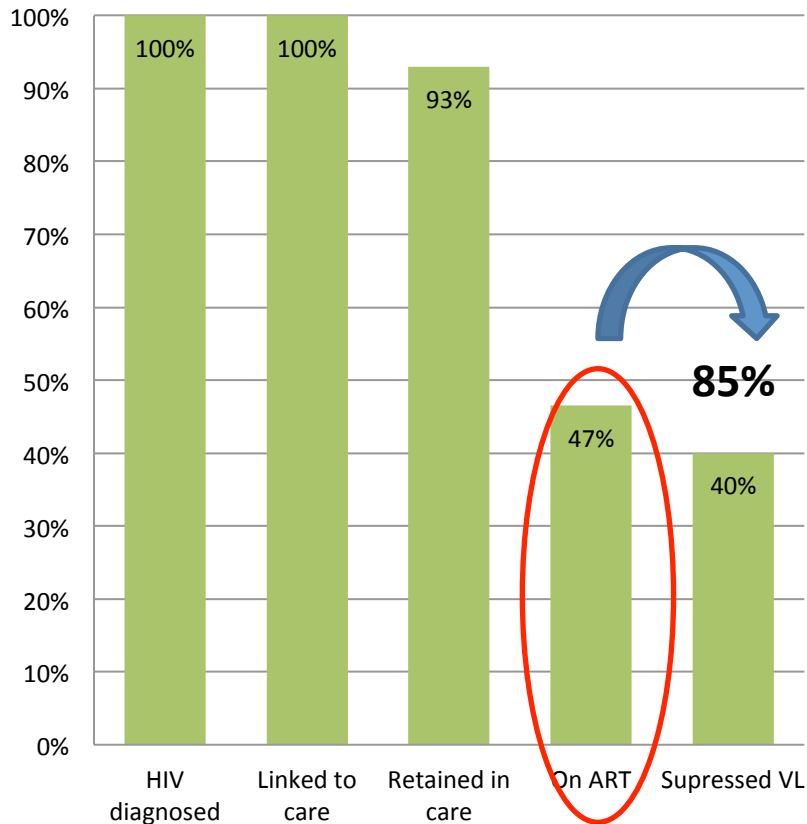


- **Testing services**
- **Medical Services**
  - Provided by MD and a nurse, referred to another specialist if needed (guided by Social worker)
- **Psychosocial support**
  - Regular support group leading by a psychologist and Individual counseling
  - Individual social counseling and social support (debt counseling, social public services, benefits, drafting CV and job search, obtaining a residence permit, communication with Department of Child Protection, support with social housing)
  - Children's psychological hour
  - Group work aimed at holistic health improvement, spiritual and personal development
  - Sports, cultural and educational activities for children and parents
  - Food packages for families in difficult financial situation and clothing for adults and children
  - Counseling of specialist by phone or e-mail

# Linda Clinic cascade



Linda clinic cascade



- 123 patients
- 100 % of patients have been tested for CD4 cells count
- 100% of patients have been examined as required by EACS
- Zero deaths
- 20% of eligible are not on ART

PATIENT=



# Paradigm shift for 21<sup>st</sup> century

- 20th Century – the patient/citizen in relation to professional knowledge is hierarchical/paternalistic
- 21st Century – need to “fully engage” the public as co-producers of health (collaborative partnership)

*Prof. Jane Wills, South Bank University London, UK*



**Language- a way to change the  
perception**

*Respect*

# Shake-hands campaign



## Quality of people's relationships with HIV care providers and retention in care

- Being treated with dignity and respect
- Being involved in decisions about care
- Feeling listened to
- Having information explained in a way that could be understood
- Feeling known as a person

*Flickinger et al, J Acquir Immune Defic Syndr, 2013*

# Retention in care

Participants who gave the highest ratings to their care providers:

- in terms of being treated with dignity and respect (p = 0.015)
- always having things explained in an understandable way (p = 0.073)
- careful listening (p = 0.008)

were 7, 7 and 6% more likely to keep their appointments than people who gave less than optimal ratings in these domains.

*Flickinger et al, J Acquir Immune Defic Syndr, 2013*

# Retention in care

- Appointment adherence could be enhanced by **optimizing the quality of relationships, so that patients feel known and respected as persons by their providers**
- Specific provider communication behaviors, such as **listening and carefully explaining**, could make a difference in retaining their patients in care
- Evidence-based interventions to improve **providers' communications** could be tailored to target skills with known links to patient behaviors and outcomes

*Flickinger et al, J Acquir Immune Defic Syndr, 2013*



# Improving retention in care

- Enhanced Personal Contact With HIV Patients Improves Retention in Primary Care
- Better outcomes in both the EC and EC+skills arms
  - (visit constancy: RRs=1.22 (1.09-1.36) and 1.22 (1.09-1.36)
  - visit adherence: RR=1.08 (1.05-1.11) and 1.06 (1.02-1.09), all  $p$ s<0.01)
- Additional intervention elements may be needed for patients reporting illicit drug use or who have unmet needs

# *Investing in Communities Achieves Results* *(2013, World Bank)*

- Aim:
  - report HIV and AIDS results achieved at the community level
  - identify areas where investments can achieve greater results
  - discuss critical policy and programmatic issues
- Kenya, Lesotho, Nigeria, Senegal, South Africa, Zimbabwe, India, Burkina Faso
- RCT, longitudinal, qualitative, desk reviews

## Key findings- behavioral change

- There is strong associative evidence that **empowerment (power within)** of groups at high risk of infections, such as female sex workers (FSWs) and men who have sex with men (MSM), can lead to behavioral changes
- The effects of the community response on behaviors are weaker in Burkina Faso, Kenya, and Nigeria.
- The **intensity** of community mobilization matters
- **Participation in community groups** and **frequent discussion of HIV- and AIDS related issues** are two important characteristics of effective community activities
- A poor match between **needs** and **CBO activities** contributes to lower impact

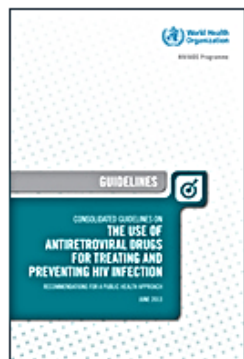
## Key findings- use of HIV-related services

- Community response can increase the demand for health services in the context of a concentrated HIV epidemic among groups at high risk of infection
- Community response can **increase the demand for services**
- **Broad community member and leader involvement** can increase the demand for services and overcome the adverse effects of stigma
- **Dedicated support** from community peer members is effective
- **Peer adherence** support combined with **nutrition** can increase the timeliness of scheduled hospital visits for ART

## Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection

Recommendations for a public health approach

June 2013



The 2013 *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* provide new guidance on the diagnosis of human immunodeficiency virus (HIV) infection, the care of people living with HIV and the use of antiretroviral (ARV) drugs for treating and preventing HIV infection.

# WHO 2013 Consolidated ARV Guidelines March 2014 Supplement 2014 HIV Prevention, Diagnostic, Treatment and Care for Key Populations

## March 2014 supplement to the 2013 consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection

Recommendations for a public health approach

Authors:

WHO



### Publication details

Number of pages: 128

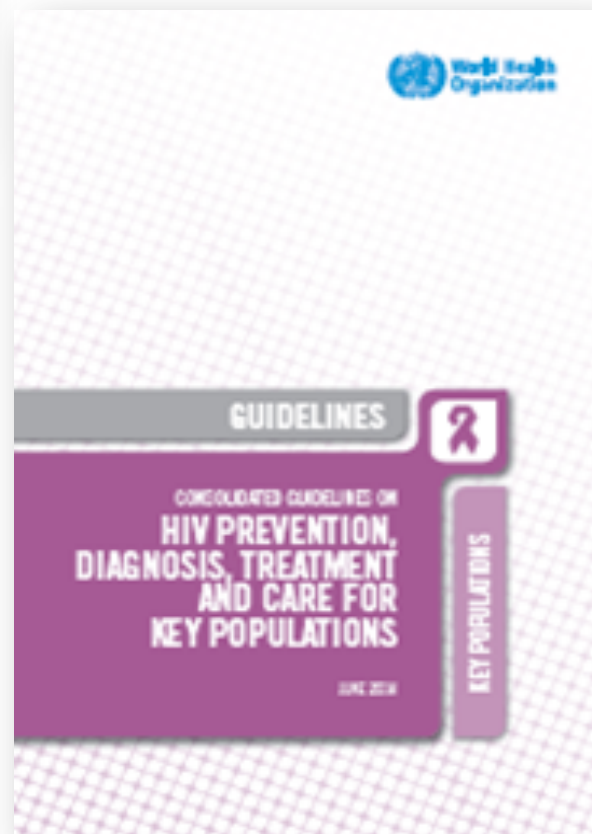
Publication date: March 2014

Languages: English

ISBN: 978 92 4 150683 0

### Downloads

- [March 2014 supplement to the 2013 consolidated ARV guidelines](#)





## Clinically relevant

- **Earlier initiation of ART** (CD4 count  $\leq 500$  cells/mm<sup>3</sup>) for adults & adolescents
- **Immediate ART for children below 5 years**
- **More potent regimens for children < 3 years** (LPV/r)
- **Immediate & lifelong ART for all pregnant and breastfeeding women** (Option B/B+)
- **Simplified, less toxic 1<sup>st</sup>-line regimens (TDF/XTC/EFV)**

## Operationally relevant

- Use of **Fixed Dose Combinations (FDCs)**
- Improved patient monitoring with **increased use of viral load**
- Recommend **task shifting, decentralization, and integration**
- **Community based testing and ARV delivery**



# Driving the HIV response

A community guide to the WHO 2013 Consolidated  
Guidelines on the Use of Antiretroviral Drugs for  
Treating and Preventing HIV Infection

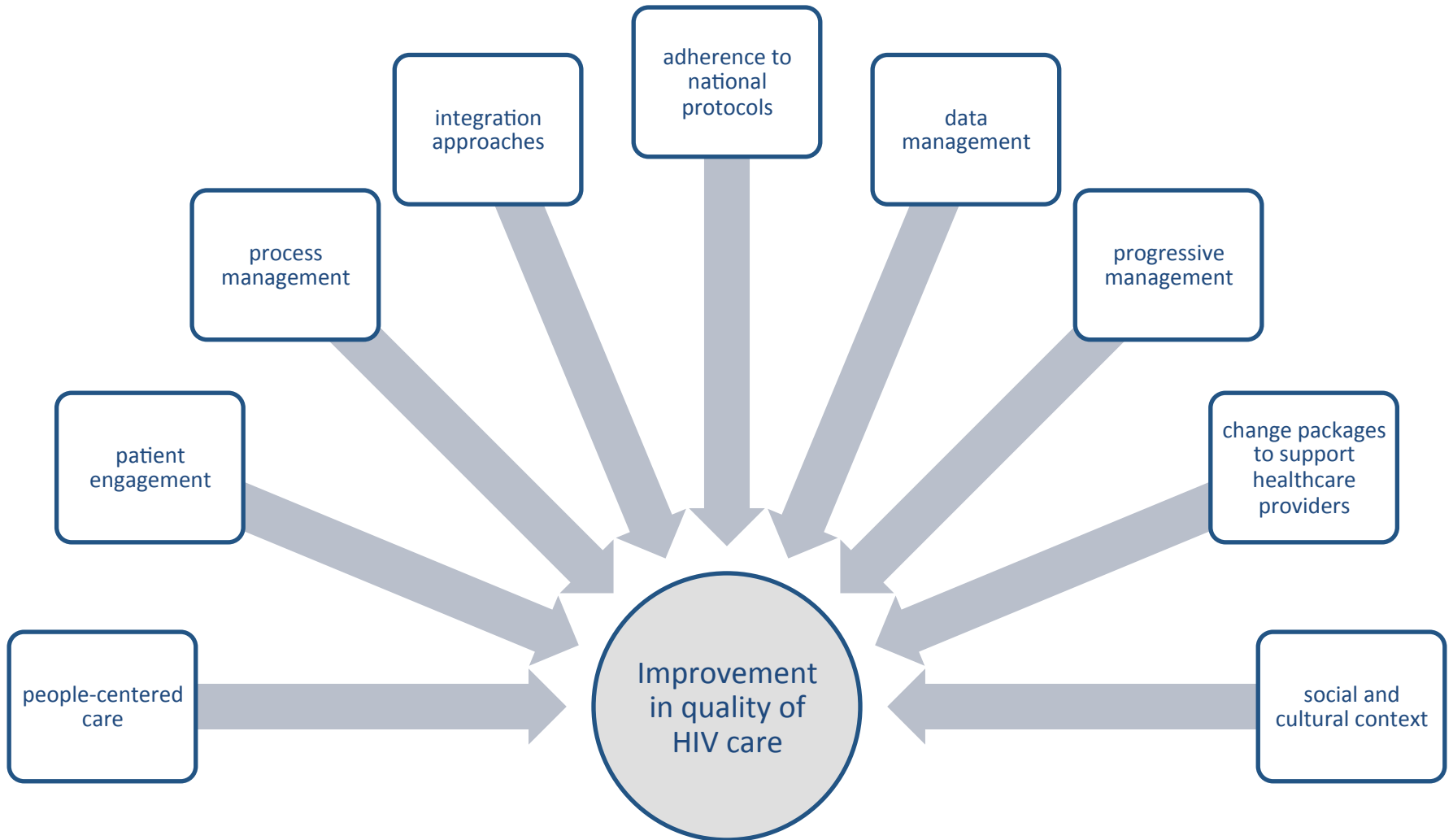




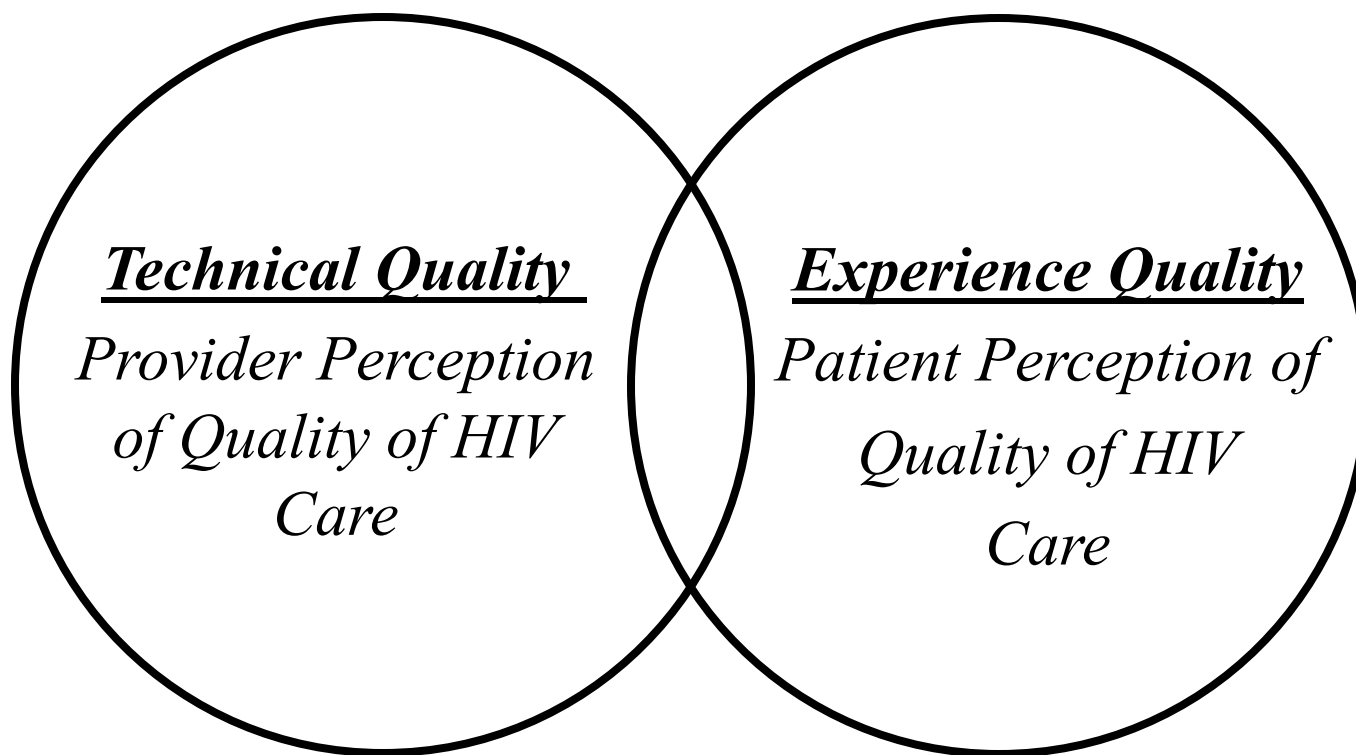
# Community engagement in quality of care

# Strengthening quality of HIV clinical services

## Scoping consultation



# Dimensions of Quality



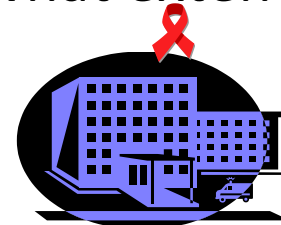
*Leonard Berry, Texas A&M University, IHI conference 2001*

# Consumer Involvement in QM

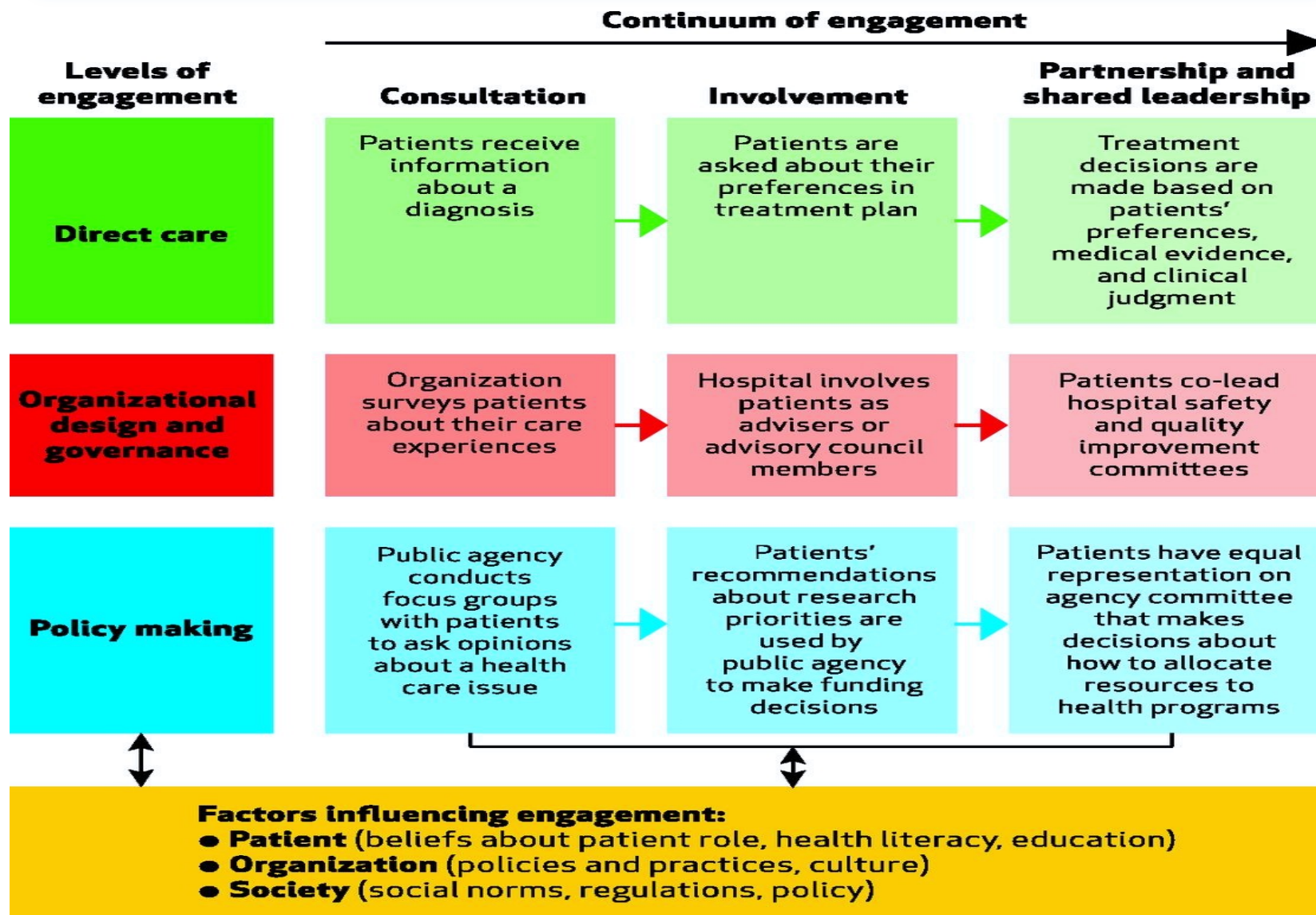
- Quality improvement (QI) models used in health care were created for the automotive industry



- Critical dimension of QI is:
  - **determining consumer needs**
  - **developing products and services that meet and/or exceed customer expectations**
- Adapted for use in health care settings, although many medical disciplines are still grappling with how and to what extent they should involve consumers



# A Multidimensional Framework For Patient And Family Engagement In Healthcare



Carman K L et al. Health Aff 2013;32:223-231

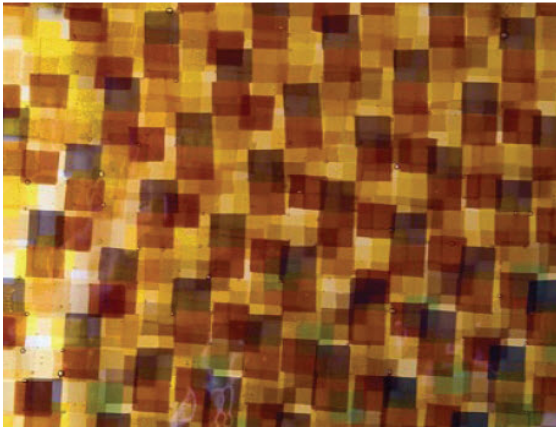
HealthAffairs

# Other Consumer Capacity Building Resources

## A Guide to Consumer Involvement

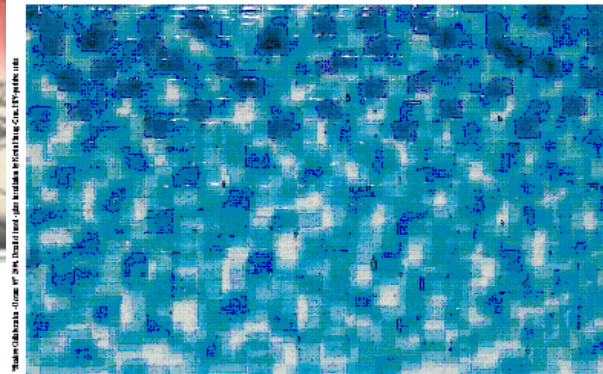
Improving the Quality of Ambulatory HIV Programs

New York State Department of Health AIDS Institute  
Health Resources and Services Administration HIV/AIDS Bureau



## Patient Satisfaction Survey for HIV Ambulatory Care

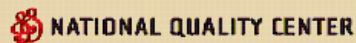
New York State Department of Health  
AIDS Institute



## Making Sure Your HIV Care is the Best It Can Be

A Consumer Quality of Care Training Workshop

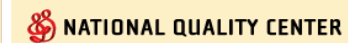
New York State Department of Health AIDS Institute  
Health Resources and Services Administration HIV/AIDS Bureau



## Making Sure HIV Patient Self-Management Works

A Training Workshop for HIV Care Providers  
Curriculum Guide for Workshop Facilitators

New York State Department of Health AIDS Institute  
Health Resources and Services Administration HIV/AIDS Bureau









# THANK YOU!

Special thanks to:

Julian Hows

Damir Bismukhametov

Alexander Chuykov

Chris Mallouris

Daniel Tietz

Bruce Agins

Meg Doherty

AHF Europe/AHF team

GNP+ team

and all my friends in fight for the well being of people who live with HIV and might be affected by HIV