The Quest for Dignity, Equity and Rights for HIV-Affected Communities

Anna Zakowicz
AHF Europe
Adherence 2016
HIV continuum of care
16 countries in Europe and Central Asia

European Union (EU) and European Economic Area (EEA) countries included – Austria, Bulgaria, Denmark, France, Germany, Luxemburg, Netherlands, Romania, Spain, Sweden and the UK; Non-EEA countries included - Armenia, Azerbaijan, Georgia and Serbia, ECDC, 2014
### Regional targets for new HIV infections (15+)

<table>
<thead>
<tr>
<th>Region</th>
<th>People acquiring HIV, 2010</th>
<th>2020 target</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>2,000,000</td>
<td>500,000</td>
</tr>
<tr>
<td>Asia and the Pacific</td>
<td>280,000</td>
<td>88,000</td>
</tr>
<tr>
<td>Eastern Europe and Central Asia</td>
<td>120,000</td>
<td>44,000</td>
</tr>
<tr>
<td>Eastern and Southern Africa</td>
<td>990,000</td>
<td>210,000</td>
</tr>
<tr>
<td>Latin America and the Caribbean</td>
<td>98,000</td>
<td>40,000</td>
</tr>
<tr>
<td>Middle East and North Africa</td>
<td>19,000</td>
<td>6,200</td>
</tr>
<tr>
<td>Western and Central Africa</td>
<td>360,000</td>
<td>67,000</td>
</tr>
<tr>
<td>Western and Central Europe and North America</td>
<td>86,000</td>
<td>53,000</td>
</tr>
</tbody>
</table>

*UN Secretary General Report, April 2016*
### Regional targets for treatment coverage (15+)

<table>
<thead>
<tr>
<th>Region</th>
<th>People on treatment, 2014</th>
<th>2020 target</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>14,100,000</td>
<td>27,900,000</td>
</tr>
<tr>
<td>Asia and the Pacific</td>
<td>1,700,000</td>
<td>4,100,000</td>
</tr>
<tr>
<td>Eastern Europe and Central Asia</td>
<td>270,000</td>
<td>1,400,000</td>
</tr>
<tr>
<td>Eastern and Southern Africa</td>
<td>8,500,000</td>
<td>14,100,000</td>
</tr>
<tr>
<td>Latin America and the Caribbean</td>
<td>890,000</td>
<td>1,600,000</td>
</tr>
<tr>
<td>Middle East and North Africa</td>
<td>30,000</td>
<td>210,000</td>
</tr>
<tr>
<td>Western and Central Africa</td>
<td>1,500,000</td>
<td>4,500,000</td>
</tr>
<tr>
<td>Western and Central Europe and North America</td>
<td>810,000-1,500,000</td>
<td>2,000,000</td>
</tr>
</tbody>
</table>

*UN Secretary General Report, April 2016*
UN Secretary General Report, April 2016

- a call for a dramatic pullout of international funding from Upper-Middle Income Countries
- The report acknowledges that domestic investment “nearly tripled” in 8 years, between 2006 and 2014.
- In the next 5 years
  - Low Income countries will increase domestic funding for the response from $200 million to $900 million per year — a 450% increase
  - Lower-Middle Income countries will increase domestic funding for the response from $700 million to $3.7 billion per year — a 530% increase. (analysis Health GAP)
Prosecutions for HIV non-disclosure, potential or perceived exposure and/or unintentional transmission

Russia (at least 115)
United States (at least 104)
Belarus (at least 20)
Canada (at least 17)
France (at least 7)
United Kingdom (at least 6)
Italy (at least 6)
Australia (at least 5)
Germany (at least 5)

Advancing HIV Justice 2, E. Bernard, S, Cameron, April 2016.
Gilead gets patent for Hepatitis C drug Sovaldi in India

• The decision is a major blow to the access to drug movement.
• There has been excessive pressure building up on the Indian government to dilute the independent functioning of the patent office to ensure that patent claims are granted far more easily to U.S. firms.

Leena Menghaney, South Asia head of MSF
The Hindu, 10 May 2016
“I used to think that the top environmental problems were biodiversity loss, ecosystem collapse and climate change.

I thought that with 30 years of good science we could address those problems.

But I was wrong. The top environmental problems are selfishness, greed and apathy…

... and to deal with those we need spiritual and cultural transformation

- and we scientists don’t know how to do that.”

James Gustave Speth
HIV in Narva

2,056 registered HIV cases in Narva
3% of population

960 HIV+ at Narva Hospital

499 on ART in Narva Hospital

HIV treatment cascade, Estonia

HIV treatment cascade, Narva

*(TAI HIV in Estonia progress report 2015)*
Linda Clinic:
a community based response to bridge the HIV care gap in Narva

Before..(2011)  

After... (2013)
Patient statistics

- Current clients: 211
- 33% of them use drugs
- 157 people on ART (74%)
- 129 people on treatment >6 mths
- 73 people VL supressed (57%)
- Since January 2016 – 432 social/peer counselling sessions
Challenges

- Estonian **national HIV strategy** which ended in 2015 has yet to be renewed
  - Rapid testing strategy
- **Need de-medicalization of testing** in order to reach high-risk groups
- **Shortage of qualifies medical workforce** in the region-infection diseases doctor
- **Pensions reform** in Estonia from July 2016
- **Lack of accurate data** on key affected populations to tailor programs
- Patient consent form- MoH requires any patients who defaults on treatment for **pay for treatment** upon re-initiation
PATIENT INFORMATION AND CONSENT FORM

I (the patient)_____________________________________, personal identification code:___________________________,

1. ☐ understand that I require ARV treatment;

2. ☐ assure that I have been informed, in a way that is comprehensible to me, of my health status, treatment possibilities, the nature and expediency of the treatment prescribed to me, and the side effects and possible consequences of the treatment that may affect my way of life from this point forward;

3. ☐ assure that I will take the drugs agreed upon in the treatment regime consistently and diligently;

4. ☐ agree to personally come get the drugs from the treatment facility once a month; in exceptional cases (e.g. prolonged absence from Estonia, mobility difficulties) and with a written agreement describing the exceptional case, I may agree upon an alternative way of receiving the drugs;

5. ☐ am aware that the drugs are free of charge to me as long as I follow the treatment regime as required; keeping to the treatment regime is evaluated by the doctor and, if necessary, by the treatment council, who is entitled to stop providing drugs if the training regime is repeatedly violated against; in that case, continuing the treatment is possible only by purchasing the drugs against payment from a pharmacy by prescription. YES    NO

Annex 4 to Directive No. 200 of the Minister of Health and Labour of 23rd December 2015 “Amendments to Directive No. 129 of the Minister of Health and Labour of 7th September 2015 “Reception, storing, and dispensing of antiretroviral drugs and vaccines, and corresponding accounting and reporting activities with the Health Board””

Annex 7 to Directive No. 129 of the Minister of Health and Labour of 7th September 2015 “Reception, storing, and dispensing of antiretroviral drugs and vaccines, and corresponding accounting and reporting activities with the Health Board”
Other burning issues

- Implementation of WHO treatment and testing guidelines
- Health workforce and task shifting
- Integration and co-location of services
- Decentralization
- Data management
- HIV/TB
- Health care in prisons
- ChemSex
- Progressive management
Paradigm shift for 21st 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
The workshop has the following goals:

- Present the concepts and provide examples of user-driven care in practice.
- Describe how to improve patient experiences and outcomes by implementing user-driven care.
- Reflect on and devise opportunities for participants in implementing user-driven care in their programmes.
- Identify the roles of individual participants to move forward in developing collective synergies in implementing user-driven care together.
- Identify any potential opportunities or challenges in implementing user-driven care.
Healthcare Stories Project

Strategies to Capture the Patient Experience

Abigail Baim-Lance
AI Consultant & PI

Dan Tietz
Manager of Consumer Affairs

Hazel Lever
Program Assistant
Healthcare Stories Project

Overview

• 3-part poster campaign to promote consumer-oriented experience-based activities:

  – Activity 1: “What words would you use?” – Word Cloud Poster
    • Awareness raising about consumer experiences of ‘quality’
    • Launch Date: April 2014

  – Activity 2: “How’s your visit going?” – Visit Mapping Poster
    • Using QI to Gather/Interpret Consumer Experiences during Healthcare Visits
    • Launch Date: December 2014

  – Activity 3: “What roles do we play?” – Mapping Roles Poster
    • Developing the Concept of “Co-Production” or producing clinic activities collaboratively between Patients and Providers
    • Launch Date: Spring 2015
Health Care Stories Project
Activity 1 (Word Cloud)

What words would you use?

These are the words HIV+ patients used to share their experiences and ideas about quality healthcare. Take part in the Healthcare Stories Project. Hearing from patients makes a difference.

www.hlvguidelines.org/hcsp
This is what quality health care means at The Harlem Family Center.

These are the themes in our health care stories.

What words would you use to describe quality care?

Evergreen Medical Group
"We Treat You Better"
Activity 2: Visit Experience Mapping

- **Healthcare User Visit Experience Mapping**
  A method that asks users to offer reactions to the elements of their healthcare visit

- **Touch points**
  Deeply felt moments, positive or negative, in healthcare delivery

- **Benefits of Activity 2:**
  Gain relevant information about the service delivery process
  Identify services that critically shape user experiences of “quality of care”
  Fully engage healthcare users in QI processes
Activity 3: Co-Production working together mapping (under development)

What is Co-Production?

Concept that everyone - from providers to policy makers to healthcare users - involved in healthcare mutually contributes to the delivery system
Areas of Co-Production

• **co-planners/designers**: consultation and advisory roles

• **co-delivery**: formally or informally taking an active role in service delivery
  - peer navigators, self-defined responsibilities, also simply making/missing visits

• **co-assessment**: evaluators or guidance on evaluation metrics
Respect
Thank you!