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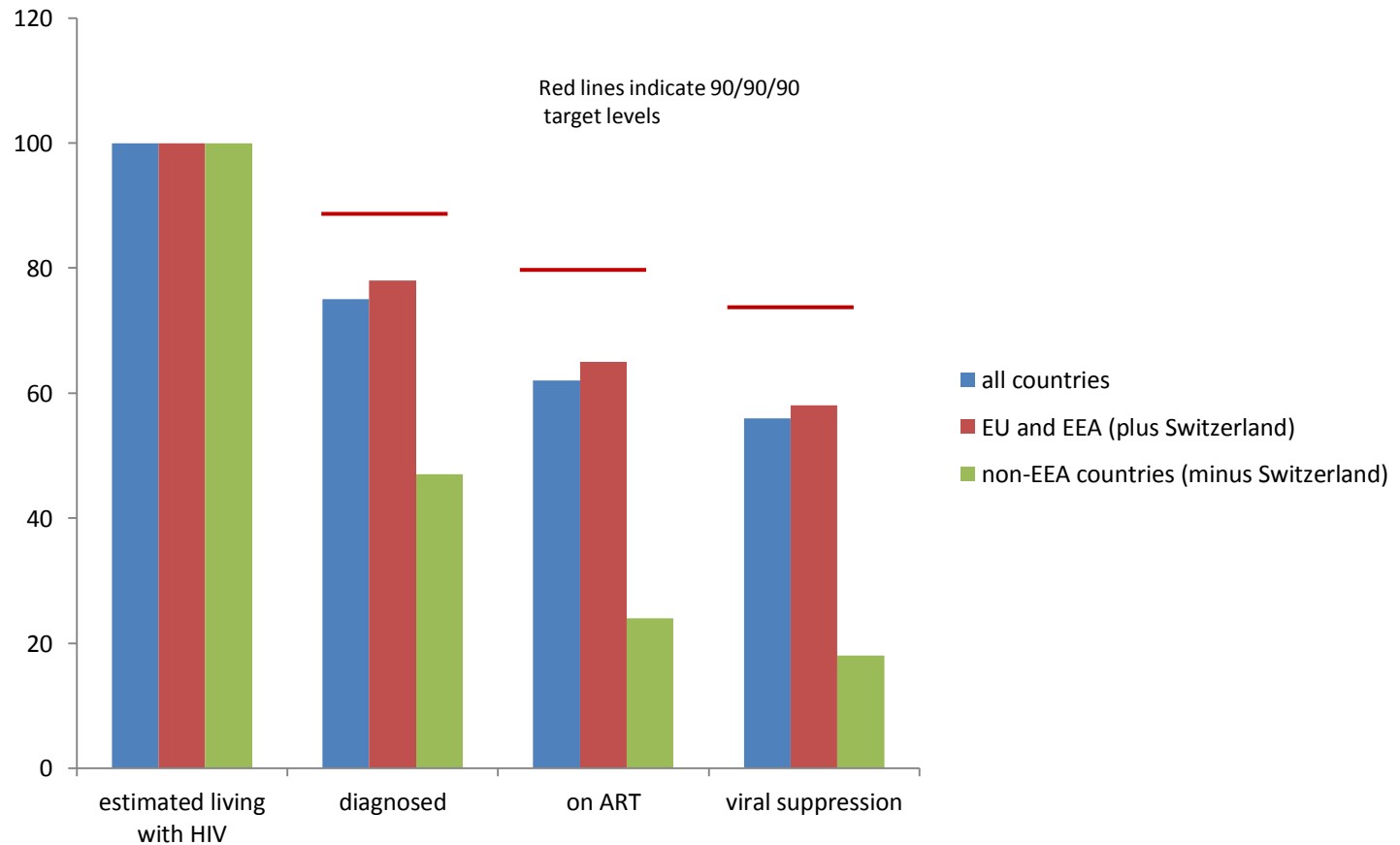
Anna Zakowicz

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+)

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

*UN Secretary General Report, April 2016*

Regional targets for treatment coverage (15+)

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

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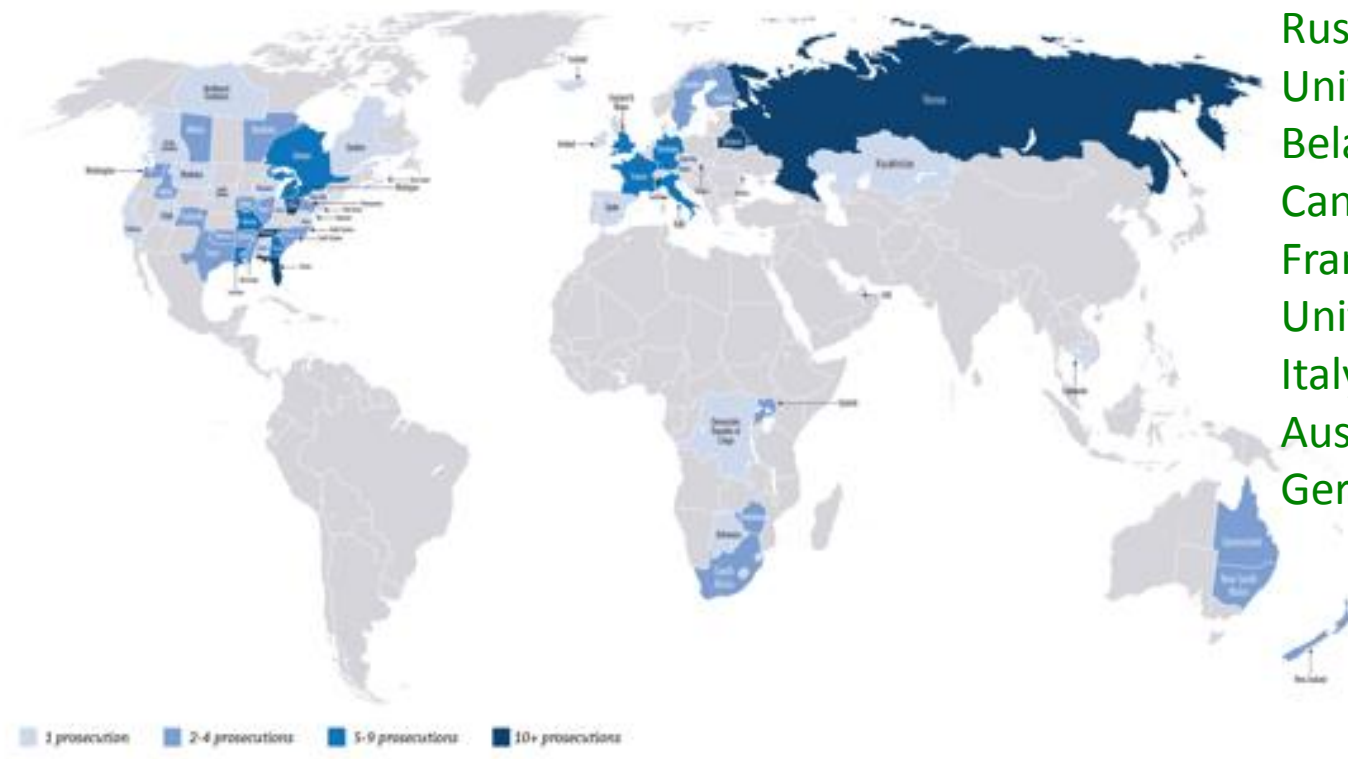
Russia (at least 115)
United States (at least 104)
Belarus (at least 20)
Canada (at least 17)
France (at least 7)
United Kingdom (at least 6)
Italy (at least 6)
Australia (at least 5)
Germany (at least 5)

1 prosecution   2-4 prosecutions   5-9 prosecutions   10+ prosecutions

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*

AHF EUROPE

LINDA KLIINIK AHF·EHPV

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-positive: 100%
- HIV-diagnosed: 87%
- Linked to HIV care: 59%
- Retained in care: 33%
- On ART: 29%
- Suppressed VL: 19%

HIV treatment cascade, Narva

- HIV-positive: 100%
- HIV-diagnosed: 89%
- Linked to HIV care: 47%
- Retained in care: 29%
- On ART: 20%
- Suppressed VL: 10%
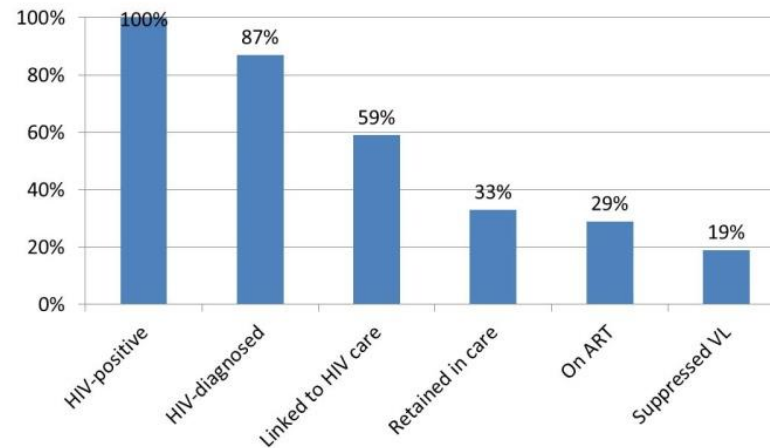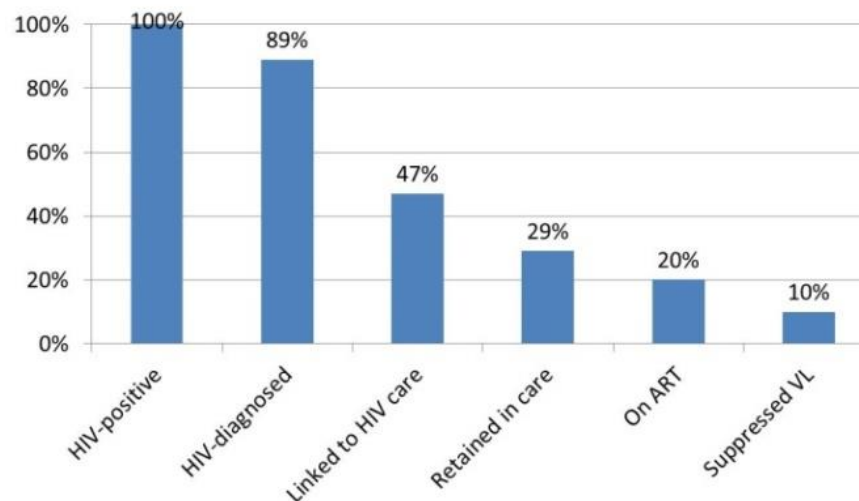
*(TAI HIV in Estonia progress report 2015)

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

LINDA KLIINIK

LINDA KLIINIK
AHF · EHPV

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-infectionus 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
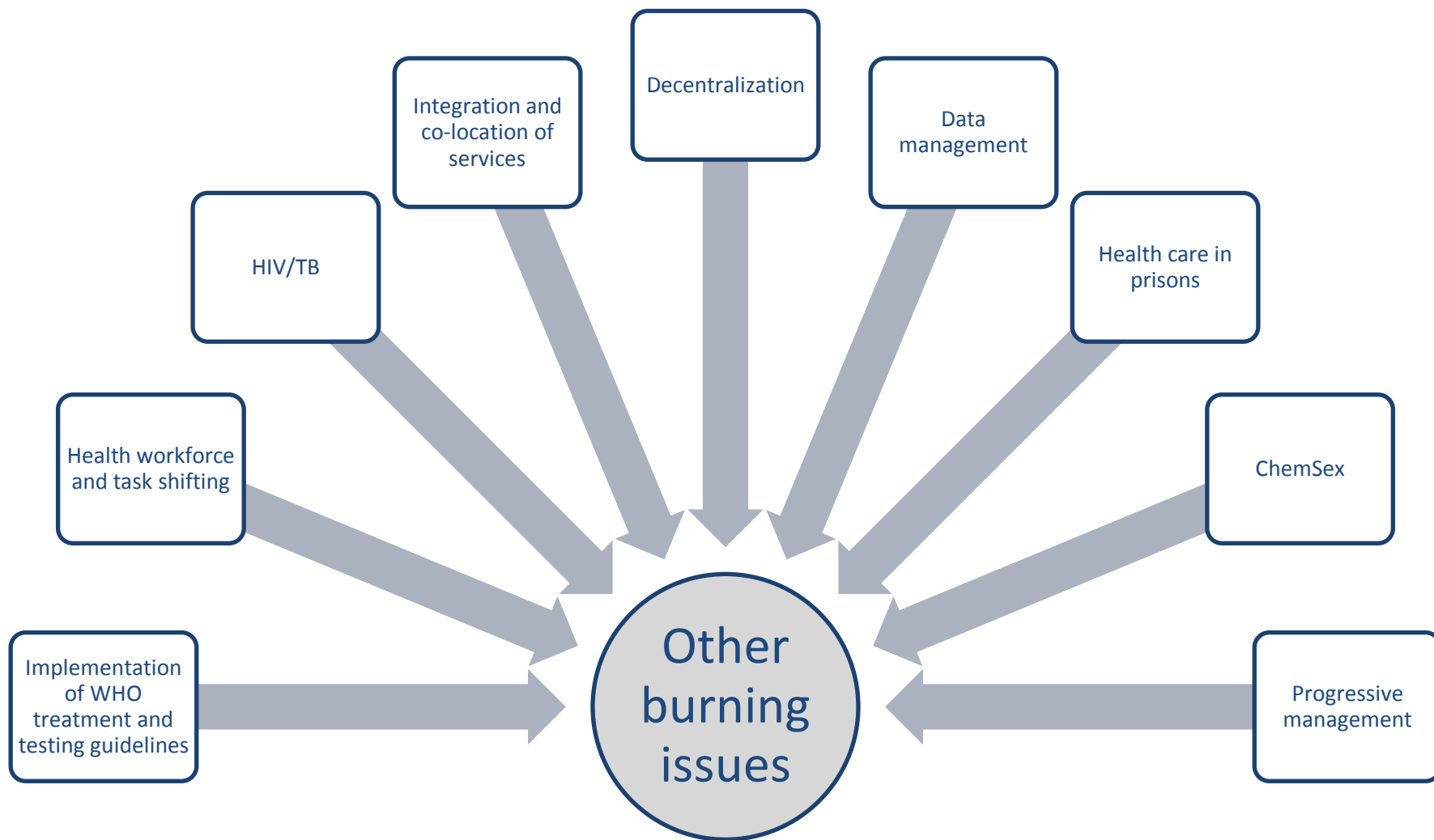
PATIENT INFORMATION AND CONSENT FORM

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

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

Workshop on User-driven Care
Tallinn, 12 November 2015

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

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)*

THIS IS WHAT QUALITY HEALTH CARE MEANS AT THE HARLEM FAMILY CENTER

THESE ARE THE THEMES IN OUR HEALTH CARE STORIES

Community Healthcare Network
Consumer Lens Project
Capturing Users Experience of Quality Care

What words would you use to describe **quality care**?

Evergreen Medical Group
"We Treat You Better"

Patients of EMG were asked to describe quality healthcare. These are the words patients used to describe care at EMG. (Part of Healthcare Stories Project, NYS DOH AI)

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

Healthcare Stories Project: Evergreen Medical Group
Facility-Level Word Cloud Poster and Ideal Patient Visit Map

Patients of EMG were asked to describe quality healthcare. These are the words patients used to describe care at EMG. (Part of Healthcare Stories Project, NYS DOH AI)

PRIMARY CARE: MODEL VISIT #1

BEFORE VISIT
staff sounds happy and friendly on telephone.

When possible, always answer the phone. Try not to let clients reach voicemail.

AT CHECK-IN
staff has good attitude, and creates a welcoming environment.

Make sure that all clients in the waiting room have checked in.

During NURSES/VITALS
staff listens, answers questions, and makes client feel at ease.

Communicate with clients and front-desk staff about wait times.

IN THE WAITING ROOM
keep clients informed.

During busy times, communicate with clients about their waiting times.

THE EXAM ROOM
is clean and well-appointed.

Check the exam rooms to make sure they are comfortable for clients.

SUPPORT & SPECIALTY SERVICES
staff is knowledgeable about internal and external programming.

Follow up with clients about their care plans (referrals, retention, and adherence).

AT CHECK-OUT
staff is friendly, happy, compassionate.

Follow up with clients about their upcoming and missed appointments.

LAB WORK
is fast and accurate, causing little to no pain/damage during tests.

Be patient with clients. Be sensitive to the fact that this is only one component of their visit.

EMG patients provided feedback to determine the ideal patient visit. Their responses helped us develop the Model Visit poster series. Part of Healthcare Stories Project, NYS DOH AI.

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

LOVE

Thank you!