GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

EUROPEAN HIV NURSING CONFERENCE

19-20 October 2014 • Barcelona, Spain

PEOPLE LIVING WITH HIV ARE...

Remember the early 80's?

PEOPLE LIVING WITH HIV ARE...

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

Health Literacy and Stigma

Julian Hows

Monday 20th October 14.00- 14.45

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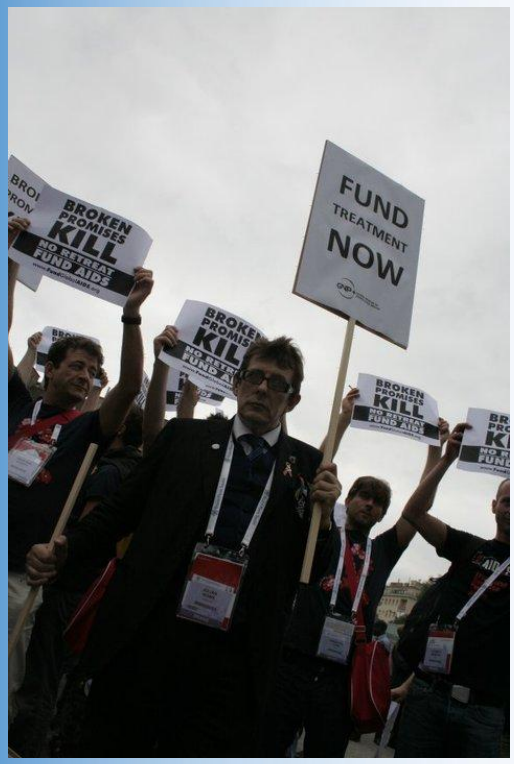
Overview of presentation

- Brief introduction to Me and to GNP+
- PLHIV related Stigma from PLHIV led research: the PLHIV Stigma Index
- what we we know
- what we think we know of ways to adress the issues
- and how we might move forward – together !

PEOPLE LIVING WITH HIV ARE…

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV



About me …

- Involved in the HIV response since 1983
- Worked with groups from Mexico to Moldova, Philippines to Poland, as well as in the UK
- My role at GNP+ is to enable, facilitate support the voices of others
- Living with HIV for more than 20 years

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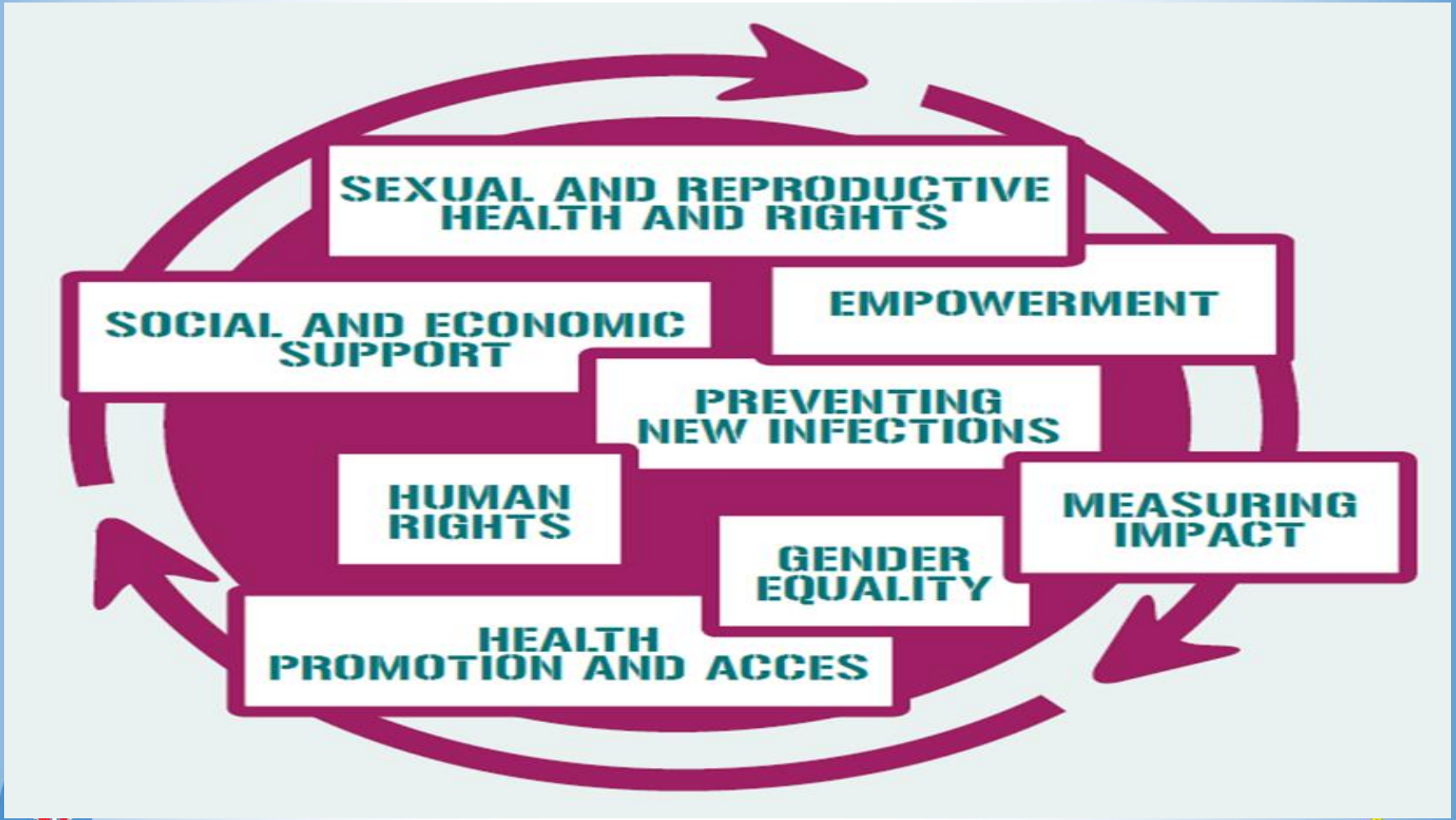
Overview of GNP+

- Advocacy for improvement in quality of life of PLHIV
- Programmes on SRHR, Human Rights, Empowerment
- Evidence-informed advocacy
- Consultative processes

All within an overarching context of a Positive Health, Dignity and Prevention to inform a Global Advocacy Agenda that can be utilized by (and is informed by) the local context

Positive, health , dignity and Prevention



Why involve PLHIV ?

- We believe the involvement of people living with HIV in all aspects of prevention, care, and treatment – including design, implementation, and monitoring – is critical to ensuring the success of these programs.

In other words…

Barriers to access of services

Stigma and Discrimination:

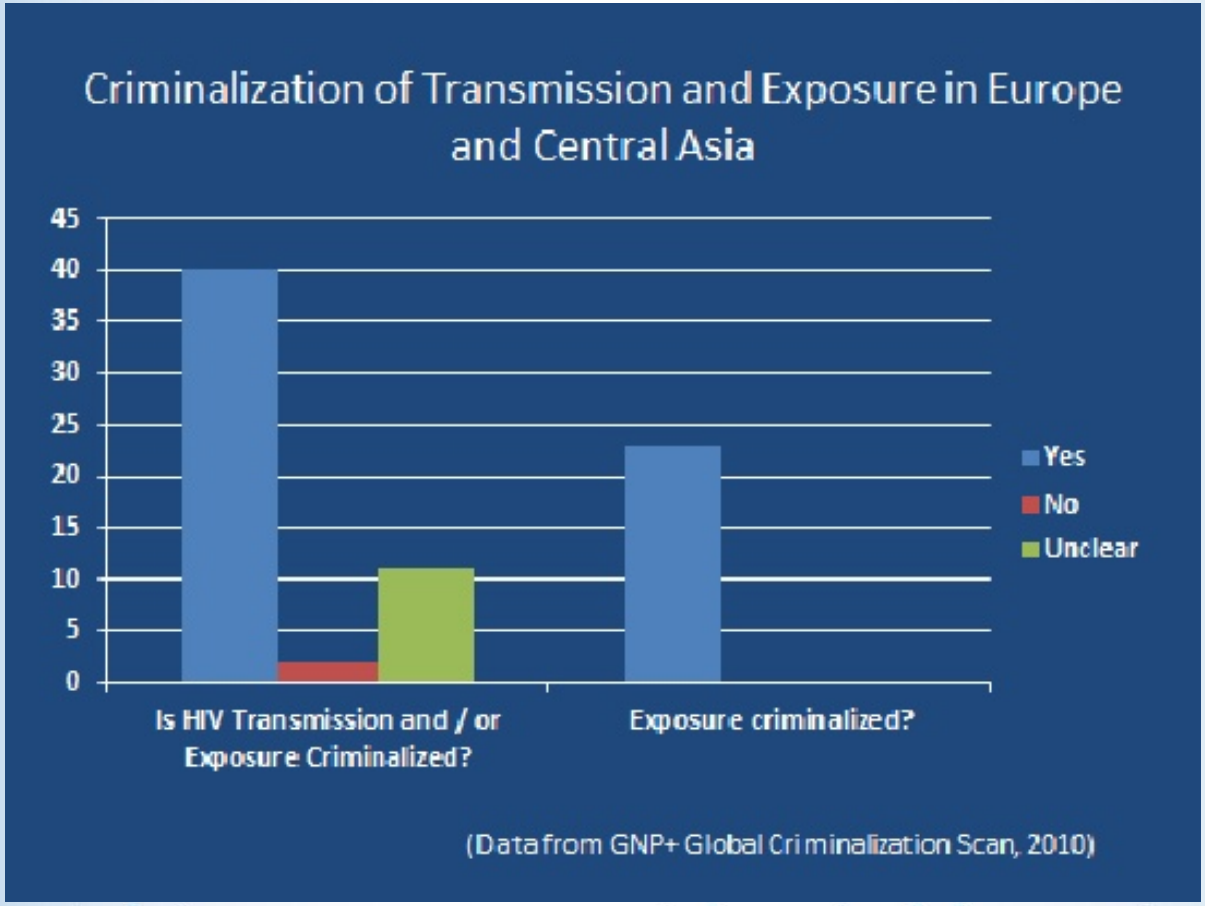
Stigma and discrimination are associated with lower uptake of preventive services, testing and counselling; reduced and delayed disclosure.....postponing or rejecting care, and seeking healthcare services outside one's community for fear of breach of confidentiality (Ogden and Nyblade, 2005; UNAIDS, 2007).

Examples

Main problems and challenges identified as arising from stigma and discrimination is the fear of disclosing HIV status:

"... discourages people to access health facilities and services". (Final report on PLHIV Stigma Index finding – Fiji Islands)

Criminalisation across Europe



THE PEOPLE LIVING WITH HIV STIGMA INDEX

Some questions to start …

Stigma is widely recognised as a barrier to achieving universal access to prevention, treatment, care and support.

1. How does stigma have an impact on all the work we do?
2. How should we measure stigma?
3. How is the *People Living with HIV Stigma Index* different from other research initiatives to measure stigma?

And How can the evidence generate change in ….

1 The lives of people living with HIV?
2 Programme responses such as testing?
3 Policies such as criminalisation?

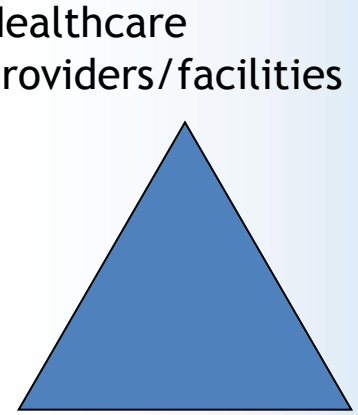
How should we measure stigma ?

Well, What have other indexes done

- Health Care Providers/Facilities Index
- Household and Community level attitudes

- Missing Gap:

  Asking PLHIV



How is the *Index* different from other research initiatives to measure stigma?

"THE STIGMA INDEX WILL HELP US DOCUMENT OUR OWN EXPERIENCES AND STRENGTHEN OUR ADVOCACY WORK. THIS IS A WAY THAT WE CAN START TO CHANGE THE CONVERSATION – WE WILL HAVE EVIDENCE TO BACK US UP."

What is the PLHIV Stigma Index ?

A way to understand experiences of stigma and discrimination, and how they change over time.

The process centres on PLHIV – making the Index a tool for, and by, PLHIV.

Key points:

- A Move away from 'boxed' responses
- Involves communities most vulnerable to infection (MSM, IDU, Migrants, Sex workers, women and young girls) effecting change at the 'personal' level
- Tool for GIPA enactment – informs ADVOVACY, ACTIVISM and CREATES PARTNERSHIPS FOR CHANGE

What does the index look like?

Factors of stigma and discrimination the questionnaire addresses:

1 Experience of Stigma & discrimination from others

2 Access to work and services

3 Internal stigma and fears

4 Rights, laws and policies

5 Effecting change

6 Testing & diagnosis

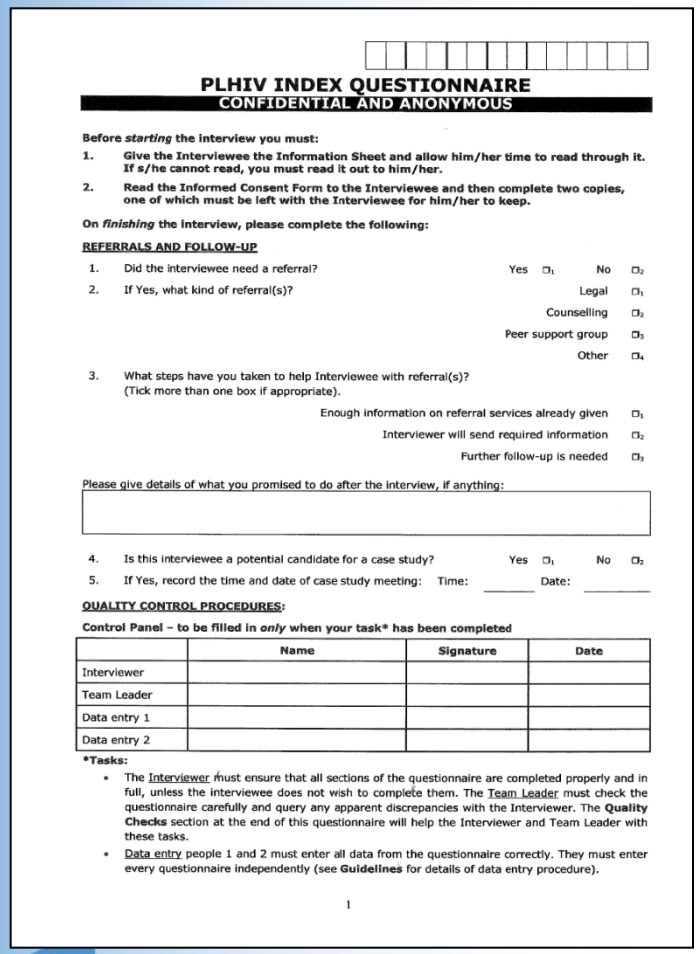
7 Disclosure & confidentiality

8 Treatment

9 Having children

10 Self-assessment of stigma & discrimination

The Questionnaire



PLHIV INDEX QUESTIONNAIRE
CONFIDENTIAL AND ANONYMOUS

Before *starting* the interview you must:

1. **Give the Interviewee the Information Sheet and allow him/her time to read through it. If s/he cannot read, you must read it out to him/her.**
2. **Read the Informed Consent Form to the Interviewee and then complete two copies, one of which must be left with the Interviewee for him/her to keep.**

On *finishing* the interview, please complete the following:

REFERRALS AND FOLLOW-UP

1. Did the interviewee need a referral? Yes ☐1 No ☐2
2. If Yes, what kind of referral(s)? Legal ☐1; Counselling ☐2; Peer support group ☐3; Other ☐4
3. What steps have you taken to help Interviewee with referral(s)? (Tick more than one box if appropriate). Enough information on referral services already given ☐1; Interviewer will send required information ☐2; Further follow-up is needed ☐3

Please give details of what you promised to do after the interview, if anything:

4. Is this interviewee a potential candidate for a case study? Yes ☐1 No ☐2
5. If Yes, record the time and date of case study meeting: Time: _____ Date: _____

QUALITY CONTROL PROCEDURES:

Control Panel – to be filled in *only* when your task* has been completed

	Name	Signature	Date
Interviewer			
Team Leader			
Data entry 1			
Data entry 2			

***Tasks:**

- The Interviewer must ensure that all sections of the questionnaire are completed properly and in full, unless the interviewee does not wish to complete them. The Team Leader must check the questionnaire carefully and query any apparent discrepancies with the Interviewer. The **Quality Checks** section at the end of this questionnaire will help the Interviewer and Team Leader with these tasks.
- Data entry people 1 and 2 must enter all data from the questionnaire correctly. They must enter every questionnaire independently (see **Guidelines** for details of data entry procedure).

1

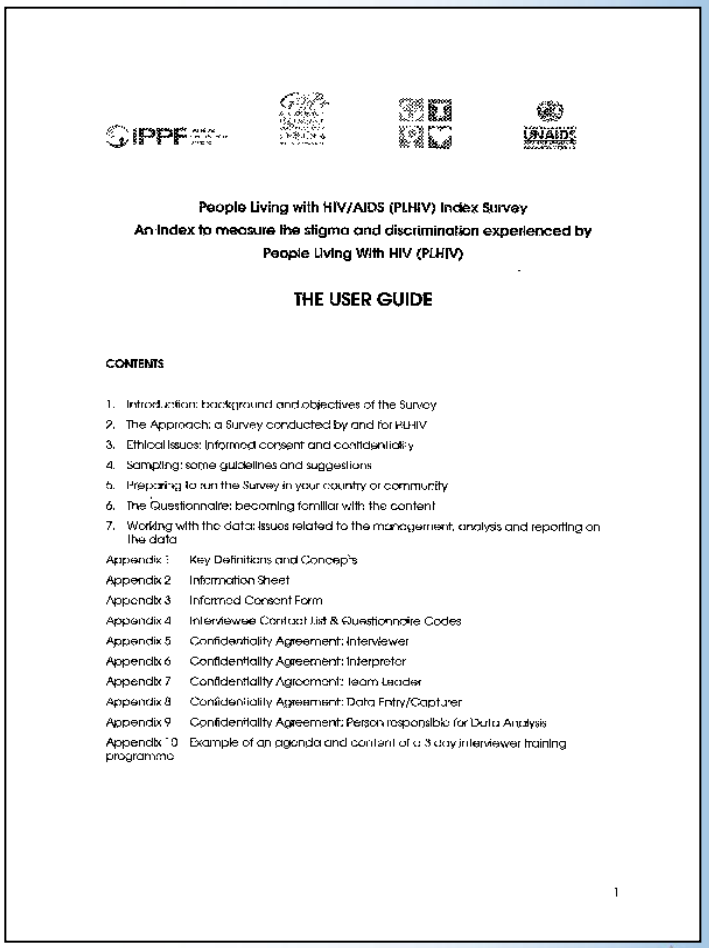
'Side by side' approach: The questionnaire is done with, not to, PLHIV. This is key to ensuring the Index is an empowering process.

Not having a blank sheet approach: follow-up and referral is key for ensuring that the interviewee 'gains' something by the process

GIPA: Key to the Index is recognising PLHIV are agents for change.

The Userguide:

- The Userguide supports the implementation of the questionnaire.
- It gives guidance on ethical considerations, confidentiality and practical issues such as population sampling.
- This is key to the Index being a free-standing tool adaptable to local circumstance and needs but still robust.

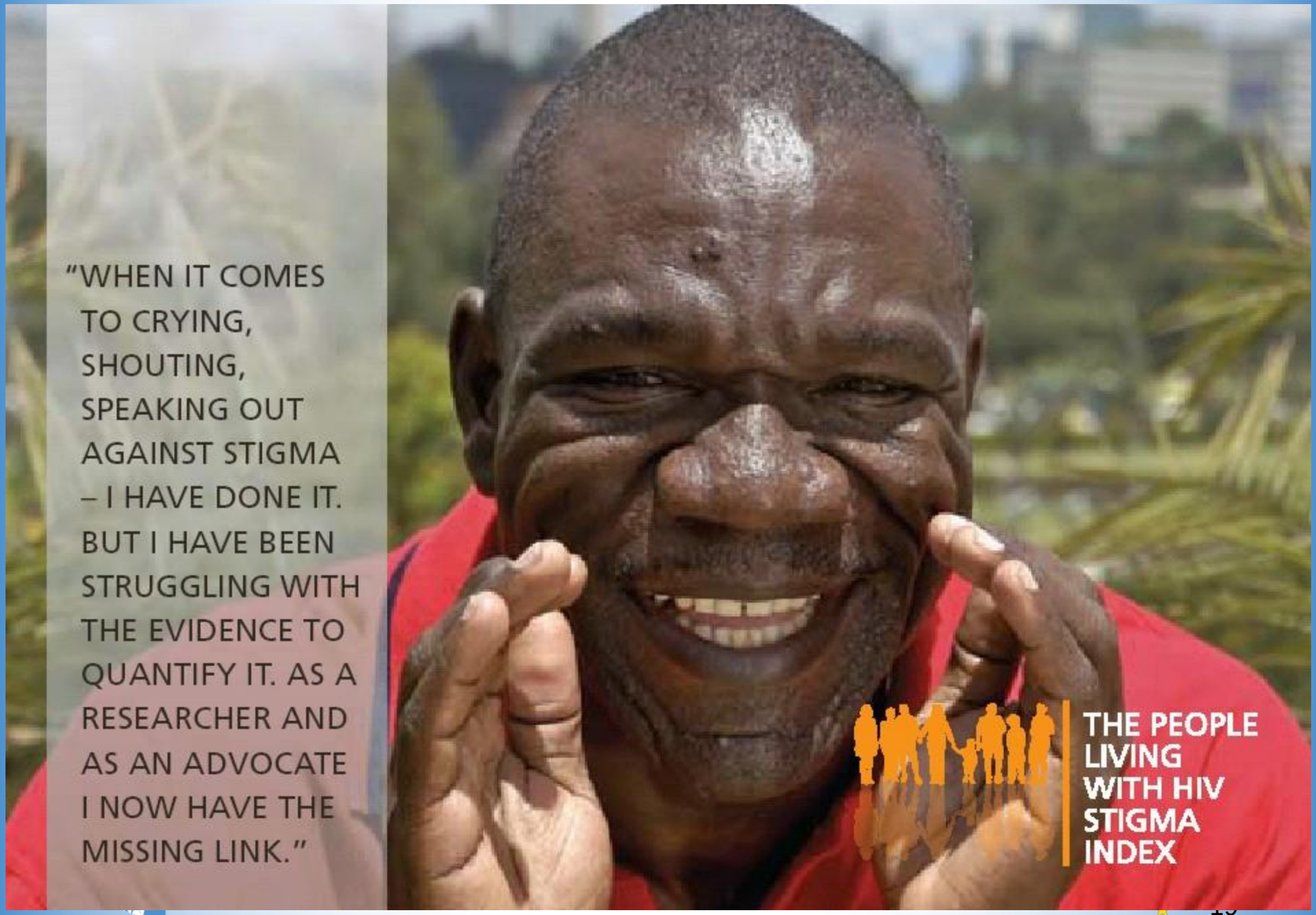


People Living with HIV/AIDS (PLHIV) Index Survey
An index to measure the stigma and discrimination experienced by People Living With HIV (PLHIV)

THE USER GUIDE

CONTENTS

1


"WHEN IT COMES TO CRYING, SHOUTING, SPEAKING OUT AGAINST STIGMA – I HAVE DONE IT. BUT I HAVE BEEN STRUGGLING WITH THE EVIDENCE TO QUANTIFY IT. AS A RESEARCHER AND AS AN ADVOCATE I NOW HAVE THE MISSING LINK."
THE PEOPLE LIVING WITH HIV STIGMA INDEX

Finally : the Impact of the INDEX

1. **Evidence to improve policies** and ensure that policies are grounded in the realities of living with HIV. The findings from the Index will be used to promote the human rights of people living with HIV and advocate for policy change on key issues including the criminalization of HIV transmission

2. **Improved programmes influenced by the perspectives of people living with HIV** to better meet the needs of people living with HIV and increased access to, and uptake of, services

3. **Models best practice for the greater involvement of people living with HIV (GIPA)** by putting people living with HIV at the centre of the process and ensuring that it remains by and for people living with HIV throughout all stages of implementation

Country and Sample Size

Africa

Cameroon (1200)

Ethiopia (2300)

Kenya (1086)

Malawi

Nigeria (720)

Rwanda (1530)

Senegal

South Africa

Swaziland

Zambia (854)

Asia Pacific

Bangladesh (238)

Cambodia

China (2096)

Malaysia (600)

Myanmar (324)

Pakistan (300)

Philippines (80)

Sri Lanka (120)

Thailand

Fiji (100)

Europe

Belarus (370)

Estonia (300)

Greece (TBC)

Moldova (403)

Poland (504)

Portugal (1000)

Russia (600)

Turkey (100)

Ukraine (1500)

UK (867)

Latin America

Argentina

Colombia

Dominican Republic (1000)

Ecuador (497)

El Salvador

Mexico

Paraguay (256)

Selection of Participants

- Purposive sampling
- Focus
  - 3% of the number of people living with HIV in a country or sub-country region
  - Inclusion of key populations
- Goal
  - Data that is broadly indicative of the range of experiences of PLHIV in an area

Interpreting Results across Countries

- Differences in results can be related to differences in the:
  - Collection of samples
  - Key population portion of the sample
  - Disclosure of one's HIV status

Why do people test later than is useful ?
Why do people access HIV care later than is useful, or not at all?

People test later because …

Exclusion, availability

Services are unfriendly

There is no confidentiality

A HIV+ positive test may result in loss - income, loss home , physical violence

People Access treatment later or are unable to do so even though they 'clinically' need it

Often when it is 'to' late They are denied treatment because of who they are

It is not in place

The results

More infections

Greater costs to all concerned

HIV-related Stigma:

A cross analysis of findings from the People Living with HIV Stigma Index in Estonia, Moldova, Poland, Turkey, and Ukraine

Late Testing, Late Treatment

POZİTİF YAŞAM DERNEĞİ 2005

Всеукраїнська Мережа ЛЖВ
All-Ukrainian Network of PLWH

SIEĆ PLUS

EHPV
Eesti HIV-positiivsete võrgustik
Estonian Network of PLWH

Лига ЛЖВ Республика Молдова
League of People living with HIV
Republic of Moldova

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The five specific questions added to the existing PLHIV Stigma Index were:

•How long did you wait between the time you first thought you should get an HIV test and the time you took the HIV test? *(time scale)*

•Did fears about how other people (for example, your friends, family, employer, or community) would respond if you tested positive make you hesitate to get tested? Yes/No

•Were you afraid that any of the following would occur if you tested positive? *(Multiple choice, multiple responses possible).*

•How long did you wait between the time you tested positive and the time that you started seeing a health professional for your HIV infection-whether or not you started medications at that time? *(time scale)*

•If there was a gap in time between your HIV positive test and the time you started receiving care, indicate the reason(s) for the delay. *(Multiple choice, multiple responses possible).*

Summary

- Respondents expressed many fears that could delay uptake of both testing and care; predominant among these were anticipated social stigma and fear of mistreatment by healthcare workers.
- Those respondents who belonged to key populations expressed generally higher levels of fear overall, and, specifically, more fears of discrimination by healthcare workers, criminalisation, and family and community violence.

Social Stigma related to HIV

Country	Gossiped about in the last 12 months	Gossip was related to HIV status
Estonia	63%	39%
Moldova	38%	50%
Poland	52%	20%
Turkey	70%	66%
Ukraine	59%	68%
Zambia	75%	90%
UK	63%	77%

Employment Discrimination

Were refused employment or work opportunities in the last 12 months because of HIV status	
Estonia	7%
Moldova	5%
Poland	11%
Turkey	12%
Ukraine	8%

Discrimination by Health Care Workers

Denied health services because of HIV status in the last 12 months

Estonia and Philippines	8%
China	12%
Paraguay and UK	17%
Moldova	14%
Poland, Turkey, and Ukraine	20%

Internalized Stigma

I avoided going to a local clinic or a hospital when I needed to (in the last 12 months)

Rwanda and Turkey	8-10%
Bangladesh and Moldova	17-21%
Paraguay	38-40%
Estonia	11-17%
Poland and Ukraine	18-26%

Reasons for HIV Testing

*Testing because of symptoms of HIV was the 2nd or 3rd most common reason for testing

Employment	Symptoms of HIV infection	I just wanted to know	Other
Bangladesh (27%)	China (18%)	Kenya (30%)	Moldova (34%)*
Philippines (45%)	Dominican Republic (29%)	Myanmar (69%)*	Turkey (43%)*
	Paraguay (40%)	Ukraine (33%)*	
		Estonia (43%)	
		Poland (38%)*	

Issues with HIV Testing

Tested under Coercion or without Consent	
Estonia	34%
Moldova	52 %
Paraguay	24%
Philippines	44%
Poland	29%
Turkey	66%
Ukraine	31%

Issues with HIV Counseling

Received no pre- or post-test counseling	
Myanmar	15 to 20%
China, Estonia, Moldova, Philippines, Ukraine, UK	31 to 40%
Dominican Republic	21 to 30%
Poland	41 to 50%
Turkey	More than 75%

Effecting Change

Country	Confronted someone who stigmatized you in the last 12 months
Estonia and Poland	29%
Moldova and Ukraine	37%
Turkey	47%
Kenya	62%

Using the Stigma Index for Advocacy

- Poland
  - Results presented at multiple conferences throughout Poland, including conference of leading scientists from the Polish AIDS Society and during the national meeting of PLHIV
  - Results published on website and in the National AIDS Center electronic journal
  - Sections written up and sent to relevant government agencies and NGO's

Portugal – discrimination in health care services

- 79 respondents report being denied health care due to their HIV status. Intravenous drug users (IDU) report the highest rate of refusal of health services (13%), followed by men who have sex with men (MSM), transgender and sex workers (10%).
- 147 respondents reported being advised not to have children (25% of women and 28% of sex workers), and 59 reported being pressured to undergo serialization.
- 11% of respondents report that confidentiality regarding health information was violated without their consent, with 30% report not being sure if this happened. This situation is especially present amongst inmates (18%).

Using the Stigma Index for Advocacy

- Turkey
  - Focus on issues of social security, violence, sexuality education, legal code, raising awareness about stigma
  - Lobbying, educating, and petitioning MPs
  - Meetings and dialogue with members of national government, state organizations, and civil society to share results of this and other research
  - Inviting CSOs from other issue areas to work collaboratively to address gov't and identify approaches for further advocacy

Belarus

- Stigma and discrimination are barriers to effective HIV treatment and care in Belarus. Results of the Stigma Index Survey conducted among people living with HIV (PLHIV) reveal that 40.5% of respondents experienced disclosure of their diagnosis and confidentiality breach by health care workers (HCW); 15.5% were refused medical care.

Germany

" positive vote "(" positive voices ") is the German roll-out of the international PLHIV Stigma Index initiative. Starting in October 2011 1148 People living with HIV were interviewed on Their experiences with stigmatization and discrimination. The main results of the peer research project in English are available now

http://www.aidshilfe.de/de/Treffpunkt/Veranstaltungen/Positive-Begegnungen

Three examples of increasing health Literacy

'The forums are a life line to me. They make a huge difference to my life'.

myHIV.org.uk

HVN
HIV VERENIGING NEDERLAND

Driving a community-based response to the HIV epidemic and increasing the testing and treatment uptake

Lessons learned from a country experience in Estonia

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HIV in Estonia

- Total population of Estonia – 1.32 million
- Total HIV cases in Estonia – 8,702 (UNAIDS country progress report 2014)
- Patients on ART in Estonia - 2,691(idem)

Situation in Narva

- Narva is the third largest city in Estonia - 64,667 residents.
- Registered HIV cases in Narva – 2,056 (3,13 % of total Narva population)
- Registered HIV+ patients in Narva Hospital – 981
- 634 on ART (Tartu University, December 2013)

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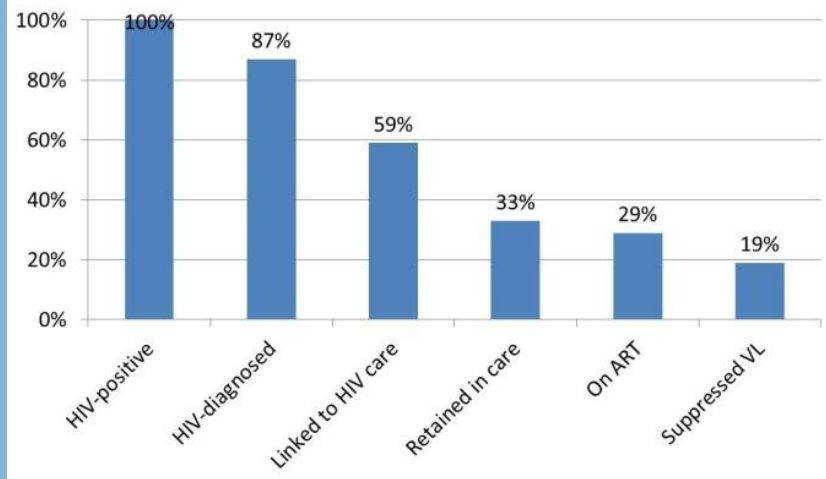
Narva:

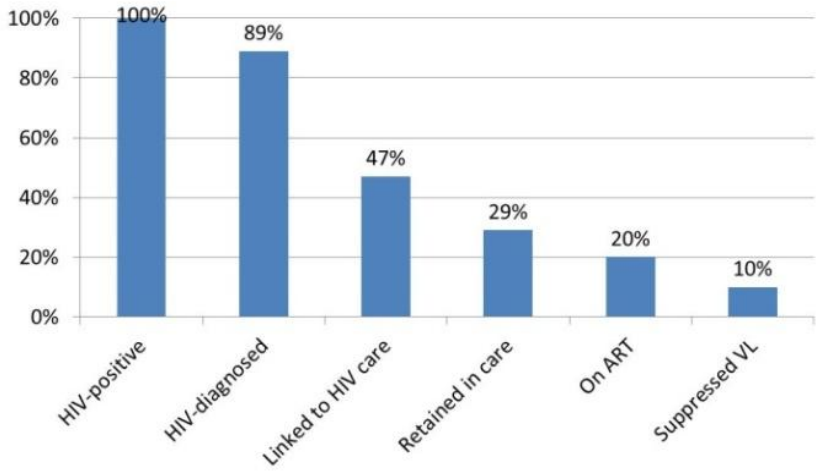
- With 3,13 % the highest HIV rate in the European Union
- 25% of all PLHIV in Estonia live in Narva; >50% of all PLHIV live in the county of Idu-Virumaa, of which Narva is the largest city
- High drug burden: highest rate of PWID of Estonia (national prevalence of PWID 15-49 yrs: 0,9%)
- About 53,800 inhabitants belong to the Russian minority in Estonia (93%)
- Sharp decline in population, continuously rising unemployment
- One infectious diseases specialist in a part time position
- Stigma in healthcare settings: Stigma Index 2012 points out barriers to access testing and treatment

LINDA KLIINIK
AHF · EHPV

HIV treatment cascade, Estonia



HIV treatment cascade, Narva



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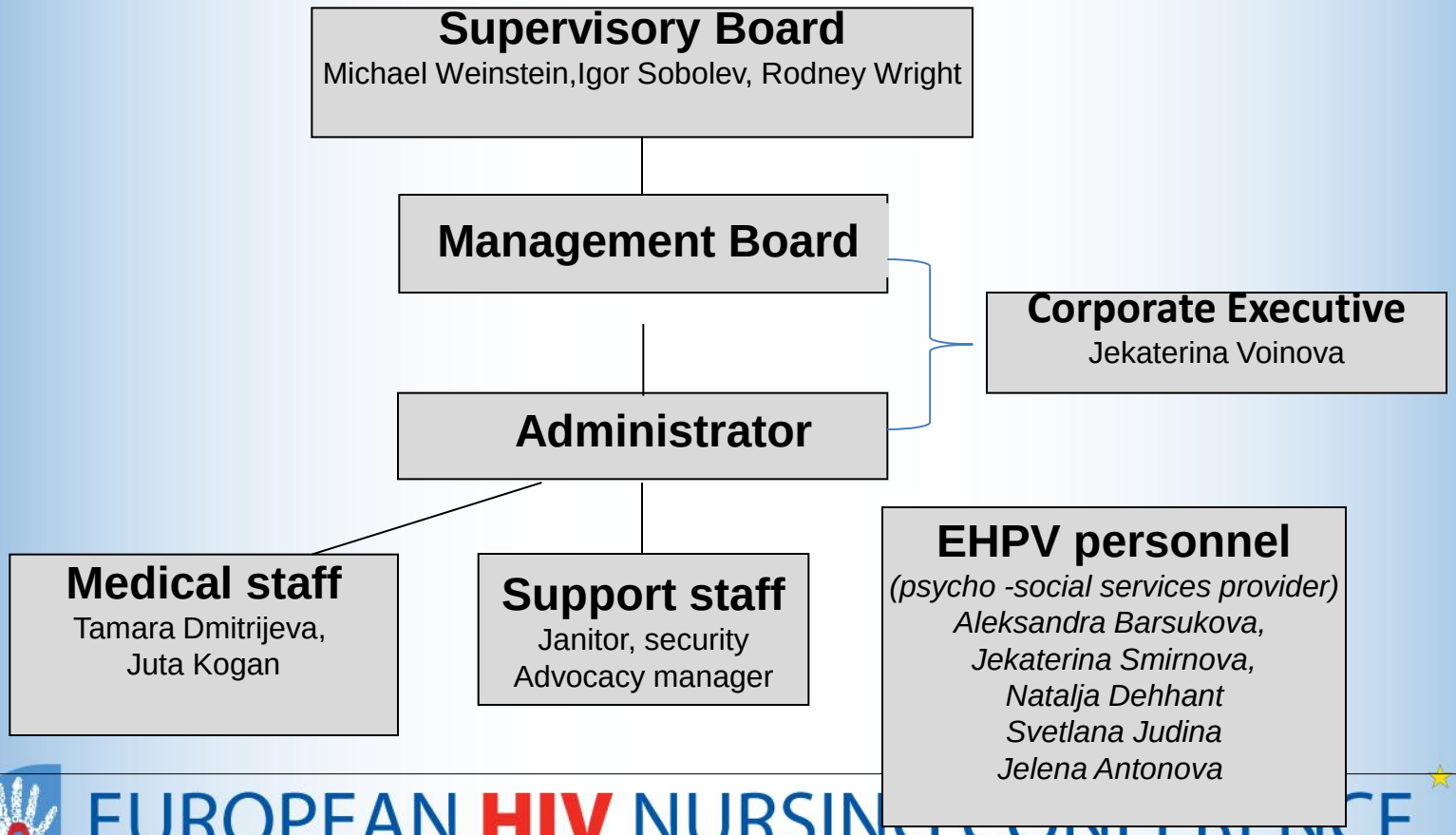
Tartu University, 2014

Estonian network of people living with HIV testing programme:

- Outreach testing
- Rapid INSTI tests
- In collaboration with National Institute for Health Development
- 2013: 10,722 people got tested nationally with seroprevalence of 3.25%, 78% linked to care
- 2014: 5 602 people got tested with seroprevalence of 4%, >80% linked to care
- National prevalence: 0.65%
- National prevalence among adult population: 1.2%

Linda HIV Foundation

Linda HIV Foundation (LHF) was registered in Estonia in January 2012 to operate Linda Clinic in Narva.



Linda Clinic premises

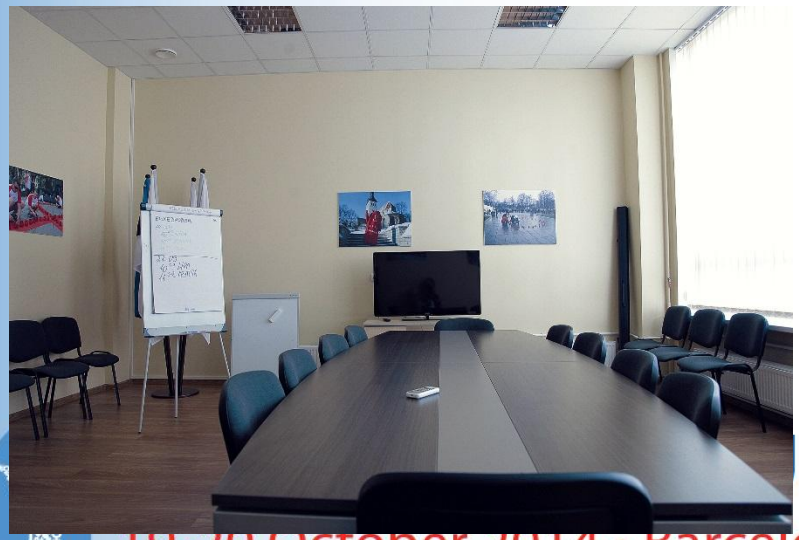
Narva, Linda str. 4, 6 floor.

Lease agreement with Narva municipality

Good location – town center, near Municipality, boarder station, church, university...

Social Welfare Department and Labor Market are in the same building.

Renovation



Linda Clinic

Linda clinic – clinic for treatment and care of HIV positive people.

It`s the first HIV clinic managed and operated by HIV-positive people in Europe.

All HIV-related services are **free of charge** to patients.

All services are provided in an outpatient basis.

Patient statistics:

- Current client uptake: 113 patients
- 56 on ART
- 58% PWID
- 41% accessing services through EHPV testing programme
- 59% through 2 clinics in the region

No ARVs for Linda Clinic

- Estonian Ministry of Social Affairs is blocking access to ARVs for the Linda Clinic, despite previous agreements
- Our patients receive their drugs through Narva hospital
- We are fighting the decision of the MoSA since October 2013 in several ways:

Press conference in Tallinn, October 2013

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So what next and how
can we work together?

PEOPLE LIVING WITH HIV ARE...

...experts in knowing (from their lived reality) the effects that stigma and discrimination have had, and continue to have, on testing, treatment, and care ...

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OptTEST
OPTIMISING TESTING AND LINKAGE TO CARE FOR HIV ACROSS EUROPE

Co-funded by the 2nd Health Programme of the European Union

OptTEST Kick-off Meeting. 2nd Sept 2014
Jean Monet Building,
EU Commission,
Luxembourg

Stigma and legal barriers to the provision of HIV testing treatment and care services

from Desire to Reality

PEOPLE LIVING WITH HIV ARE...

GNP+

> “Guess it comes down to a simple choice really. Get busy living, or get busy dying.”
>
> - From the movie *The Shawshank Redemption*

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Overview

- **Objective**

To increase knowledge on the effect stigma and discrimination (as well as structural legal barriers to HIV testing) has on uptake of HIV testing, treatment , and care particularly in most affected groups (key populations) and regions by 2016.

- **Methods**

Enabling networks of PLHIV to use their own data to inform advocacy and build partnerships with health care providers

Identifying legal and regulatory barriers to take up and availability of testing , treatment and care services

- **Activities**

Methodology developed to document strategies, advocacy tools created , illustrative and innovative case studies researched and produced; all that address HIV related stigma and discrimination

- **Outputs**

Best Practice Manual on evidence based interventions to reduce HIV related Stigma

Best Practice Toolkit to facilitate a more supportive legal and regulatory environment

Countries

- **Stigma Index Countries that are part of the EU project**

Estonia, Germany, Greece, Poland, Portugal

Stigma Index Countries that are not part of this (funding) but that will be used for analysis and comparison purposes

- **Belarus, Ukraine**

Countries that will be looked at in relation to the legal and regulatory barriers

- All of the EU countries plus countries in the wider Europe

Legal and Regulatory Barriers

Our current definition

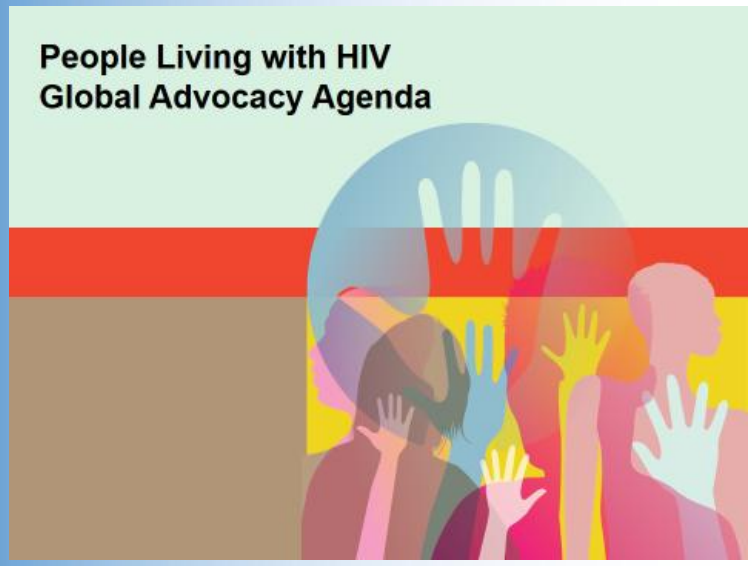
- **Criminal Law and Public Health regulations as they relate to people with HIV and Key populations**

- **Regulations that govern HIV Testing and access to the treatment continuum**

A last thought

We are in a state of emergency!

If we don't act now new infections will rise; we will never achieve "universal access", "get to zero" or "end AIDS".



Over three decades into this epidemic:
we are angry that still 4500 of us are dying of AIDS-related illnesses every day. People without access to treatment die!

www.hivadvocacynow.org

Further resources:

www.gnpplus.net

www.stigmaindex.org

www.criminalisation.gnpplus.net

jhows@gnpplus.net

And of course I hope to see you signed up to the declaration at www.hivadvocacynow.org

Thank you