



# EHPV

Eesti HIV-positiivsete võrgustik  
Estonian Network of PLWH

## PEOPLE LIVING WITH HIV STIGMA INDEX ESTONIA: ADVOCACY INITIATIVES AND RESULTS

Jekaterina Voinova, Igor Sobolev, Julian Hows  
The Estonian Network of PLWH  
Global Network of People Living with HIV

*High Level Meeting on HIV and Human Rights in the European Union  
and its neighboring countries*

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*Hoolime Eestimaa inimestest*

# THANKS

To 300 People living with HIV in Estonia, who shared their personal feelings, fears, and experiences.



HIV in Europe supported the research undertaken

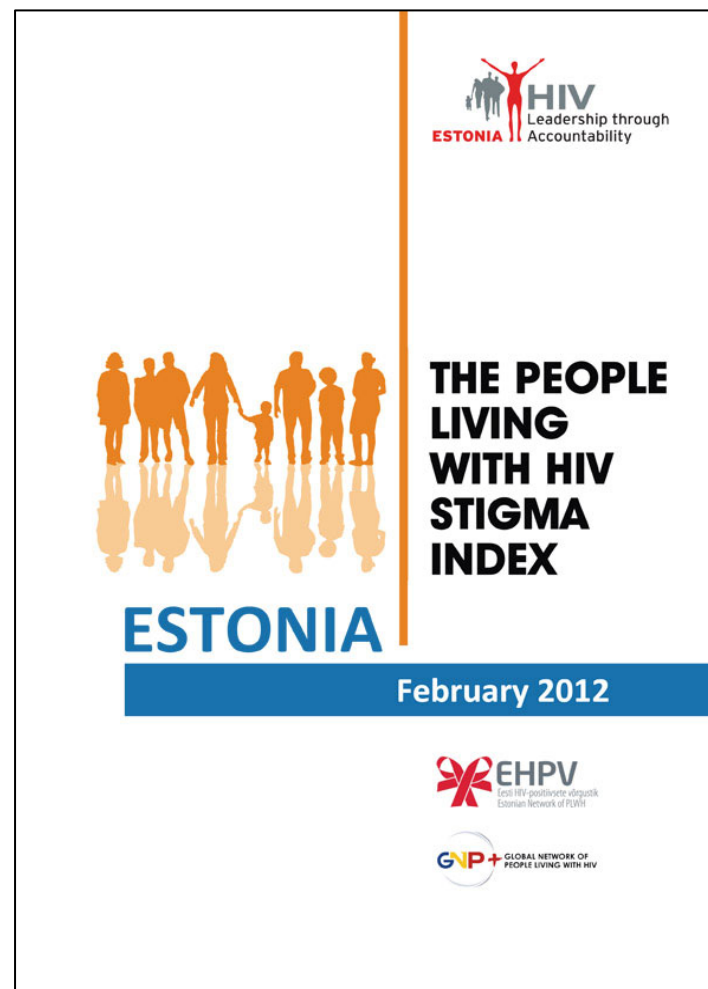
Technical support provided by GNP+ for the in country implementation of this research

AIDS Healthcare Foundation for financial and technical support of advocacy activities.

AHF

## THE PEOPLE LIVING WITH HIV STIGMA INDEX IN ESTONIA 2011

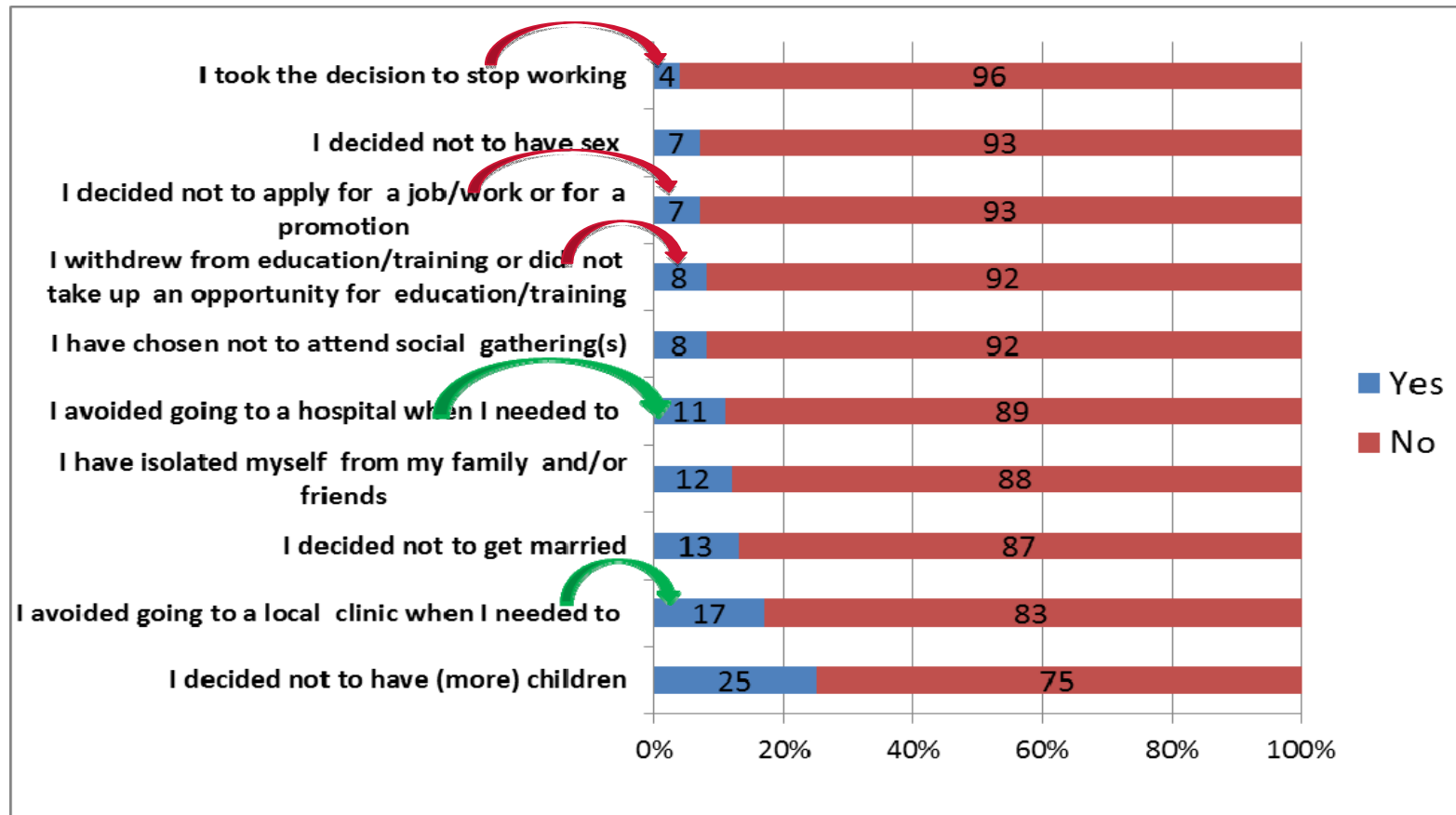
- The research protocol approved by the Tallinn Medical Research Ethics Committee
- Basic tools - a structured questionnaire and informed consent form in Estonian and Russian languages.
- Data Collection November-December 2010
- Total sample – 300, including 24 prisoners .
- Interviewing in Tartu male prison and Harku female prison.



# MAIN RESULTS

- ✓ Psychological and physical violence
- ✓ Common manifestations of stigma included being the subject of gossiping, oral harassment and threatening.
- ✓ Internalised stigma on high level: low self-esteem, blamings, feelings of shame and guilty, suicidal feelings...
- ✓ Respondents don't believe that their medical records are kept confidential
- ✓ Health care professional advised to PLWH not to have a child
- ✓ Health care professionals coerced PLWH into being sterilized

## DECISIONS, RESIGNATIONS AND AVOIDANCES HOW STIGMA STOPPED PLHIV LEADING FULL LIVES



In relation to study and employment: 8% (n=23) withdrew from education or training, 7% (n=21) decided not to apply for a job or a promotion because of their HIV status and 4% (n=13) gave up their job.

## ACCESS TO WORK AND EDUCATION

### Employment status

66% (n=199) of respondents were unemployed

26% (n=88) are employed either part- or full-time with an additional 2% (n=5) describing themselves as self-employed

6% (n=18) undertaking casual work

There are relatively more women than men among the unemployed (75%, n=83 compared to 61%, n=116)

#### Lost a job or another source of income during last 12 months

	Frequency	%
Never	91	71
Once	15	12
A few times	20	15
Often	3	2
TOTAL	129	100

# HIV TESTING AND DIAGNOSIS

## The decision to undergo HIV test

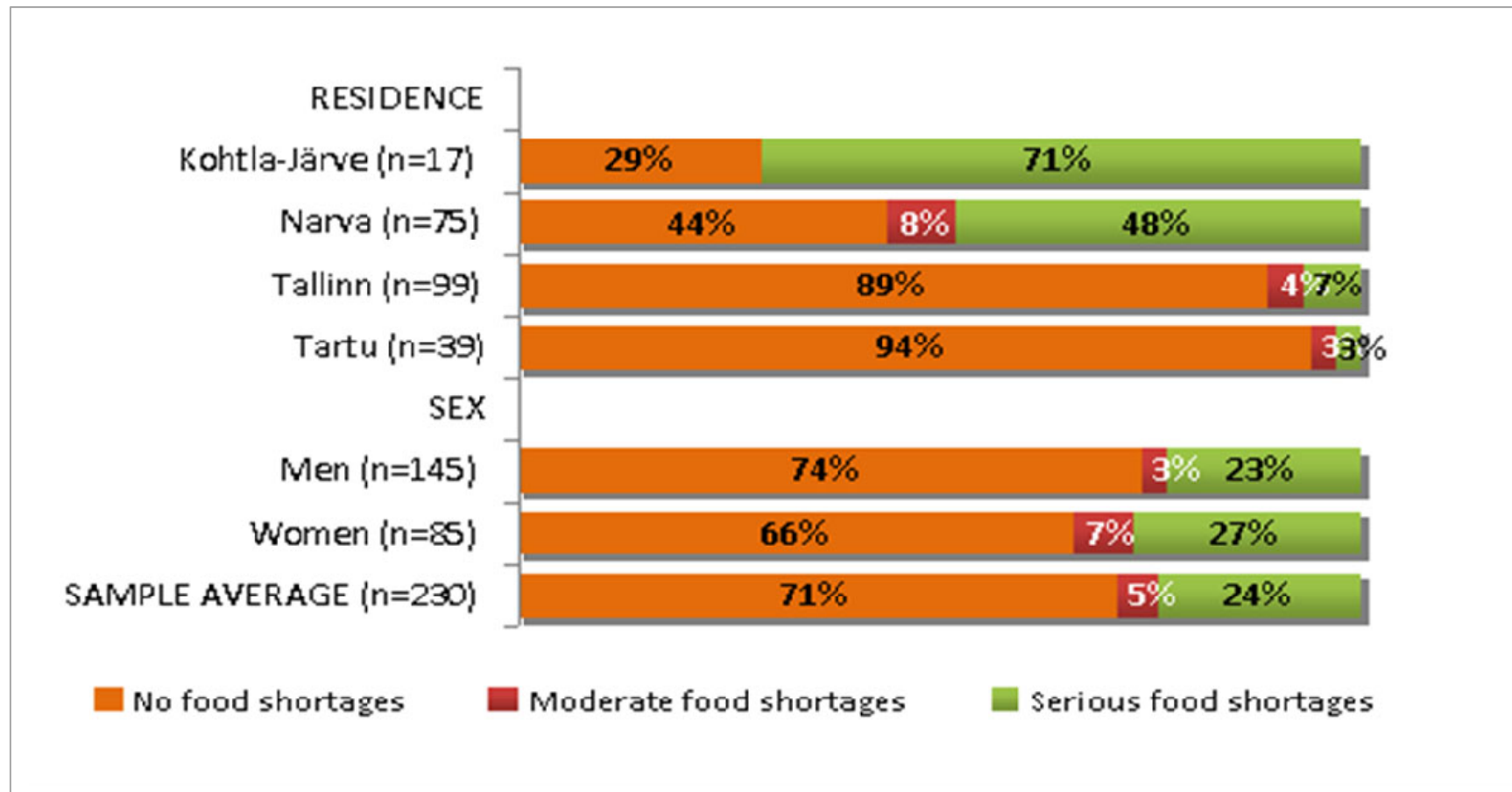
Yes, I took the decision myself to be tested (i.e. it was voluntary)	I took the decision to be tested, but it was under pressure from others	I was made to take an HIV test (coercion)	I was tested without my knowledge – I only found out after the test had been done
<b>63% (n=189)</b>	<b>9% (n=26)</b>	<b>10% (n=31)</b>	<b>18% (n=53)</b>

## Counselling during HIV-testing

I received both pre- and post-HIV test counselling	I only received pre-test HIV counselling	I only received post-test HIV counselling	I did not receive any counselling when I had an HIV test
<b>32% (n=96)</b>	<b>2% (n=6)</b>	<b>32% (n=97)</b>	<b>34% (n=101)</b>

## FOOD SECURITY AND INSECURITY

Food shortages in the last month by sex and location of the respondents

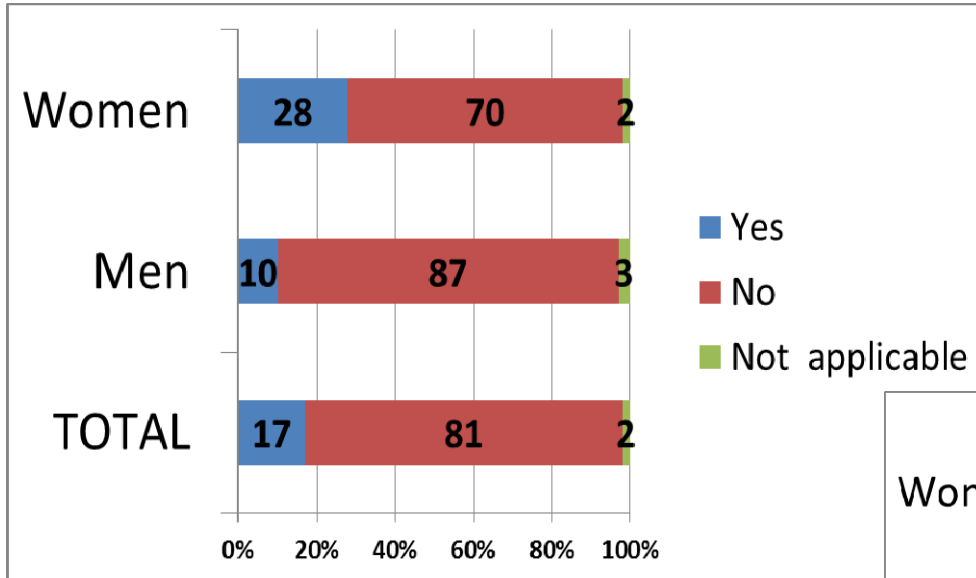


'Serious shortage of food' - 3 or more days during last month respondent's household did not have enough to eat.

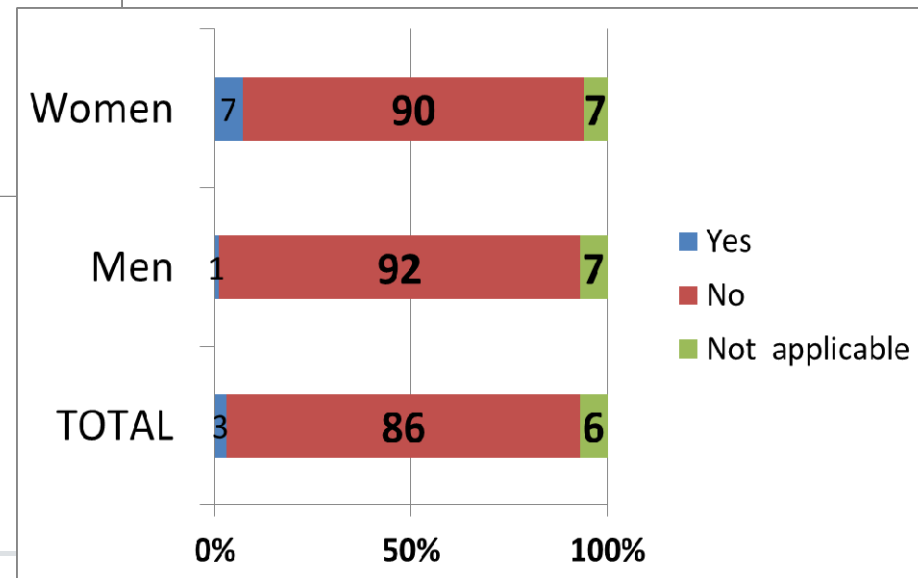


# REPRODUCTIVE RIGHTS

Health care professional advised not to have a child



Has a health care professional ever coerced you into **being sterilized** since you were diagnosed as HIV-positive?



# ADVOCACY RESULTS

- 1. Participation of ENPLWH in developing the guidance to HIV testing and referral of PLWH to treatment:**
  - ✓ Results from STIGMA INDEX study was used as additional evidence which proved the importance of guidance creation.
  - ✓ Ministry of Social Affairs made new guidance and ENPLWH had opportunity to make recommendations, especially was pointed out counseling component.
  - ✓ Rapid HIV testing was included into guidelines as primary HIV testing method.

Guidance is available at web-site of Ministry [www.sm.ee](http://www.sm.ee)

# ADVOCACY INITIATIVES AND RESULTS

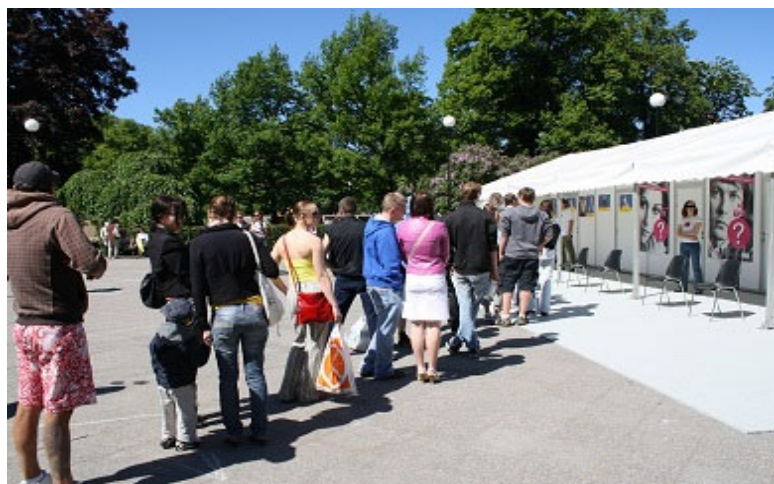
## 2. Test&Treat Project - HIV testing and treatment linkage

- Initiate ARV treatment in time for those who need it
- To access psycho-social support services

Massive rapid testing events in Estonia: public places, gay clubs, needle exchange points, NGOs providing services for sex workers, truck parkings, schools, music festivals.....

Since January 2013 linkage manager participates in every testing event!

All newly diagnosed HIV cases in 2013 were connected to HIV treatment sites!



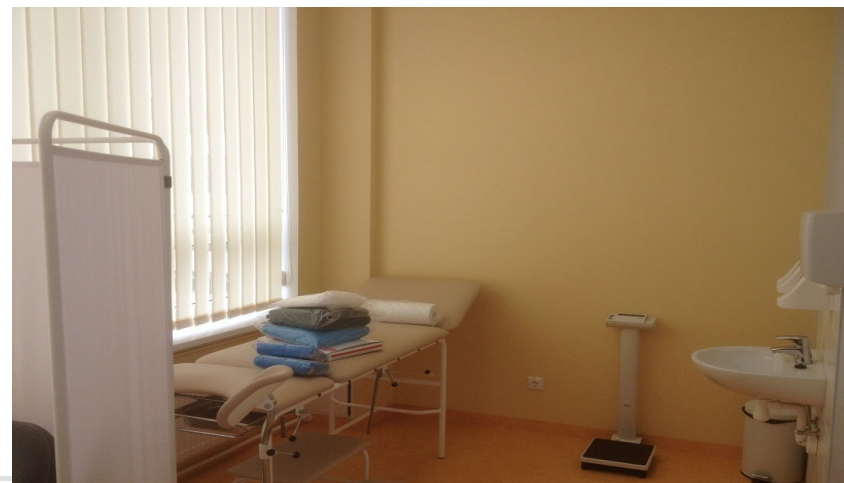
# Linda HIV Foundation



3. Results from STIGMA INDEX study were used as additional evidence which proved the extreme need and importance to create new model of HIV treatment in Estonia (client centred).

**2013 June private clinic for HIV treatment will be opened in Narva. It's managed by people living with HIV. It's the first HIV clinic operated by HIV-positive people in Europe.**

January 2012, AHF and Estonian Network of PLWH registered Linda HIV Foundation, an Estonian entity which operates Linda Clinic in Narva.



## LINDA CLINIC SERVICES:

- HIV counseling and testing
- Antiretroviral therapy
- Treatment of opportunistic infections
- CD4 and other laboratory tests
- Medical screening
- Distribution of condoms and lube
- Psychosocial support services, including counseling, treatment.

## ADVOCACY ACTIVITIES

### 4. Initiative “HIV is not spread by working”

Our goal: EHPV is looking for 100 companies in Estonia whose internal working climate and personnel policies does not discriminate HIV-positive people. EHPV wants to publicize and promote those companies as ‘good employers’ to the HIV-positive community.

Diplomas with the sign: Our company is friendly towards HIV-positive people



*Hoolime Eestimaat inimestest*

# ADVOCACY INITIATIVES AND RESULTS

## 5. Training program for PLWH to decrease level of internalized stigma :

- ✓ March 2012 began first training program. Participants contracted as volunteers and peer counsellors on stigma and discrimination issues for one year. Total coverage of 1 training program is 100 PLWH.
- ✓ New counsellors will be involved as volunteers in regularly held events of massive rapid testing.



## CHANGING ATTITUDE

6. One of the study conclusion - Medical workers should be tutored to keep confidentiality/ be unprejudiced towards PLHIV.

EHPV organized regular meetings with:

- medical staff of Estonian hospitals
- Estonian Union of Infectious Diseases
- Estonian Association of Young Doctors





## WORLD AIDS DAY 2012

Estonian Network of PLWH lighted 112 candles in front of the Parliament.  
No one from the Parliament joined invitation to light the candles!

**7 messages from PLWH and 2 directly connected to stigma and discrimination:**

People living with HIV should have same rights and opportunities on labor market, as all others.

The government should help to eliminate HIV-myths and stigma and make sure that the needs of HIV-positive community will be heard and considered.



# ADVOCACY INITIATIVES AND RESULTS

Film „I’m positive. HIV positive“ English subtitles.

<http://www.youtube.com/watch?v=g34DieFgIKI>

Cut of 3 minutes during presentation!

THE PLHIV STIGMA INDEX HAS NOW BEEN IMPLEMENTED NATIONALLY IN 30 COUNTRIES LEAD BY PLHIV ORGANISATIONS IN THOSE COUNTRIES - WORKING IN PARTNERSHIP WITH GOVERNMENT AND OTHER CIVIL SOCIETY ORGANISATIONS AND RESEARCH INSTITUTIONS  
MORE INFORMATION CAN BE ACCESSED AT: [WWW.STIGMA INDEX.ORG](http://WWW.STIGMA INDEX.ORG) AND [WWW.GNPPLUS.NET](http://WWW.GNPPLUS.NET)



**THE PEOPLE  
LIVING  
WITH HIV  
STIGMA  
INDEX**

This is an initiative of four founding partners



**ICWGlobal**



International Community of  
Women Living With HIV/AIDS



*Hoolime Eestimaa inimestest*

# THANK YOU FOR YOUR ATTENTION

- Estonian Network of PLWH
- [ehpv@ehpv.ee](mailto:ehpv@ehpv.ee)
- [Jekaterina.voinova@ehpv.ee](mailto:Jekaterina.voinova@ehpv.ee)
- [www.ehpv.ee](http://www.ehpv.ee)
- Head office: Mardi 3, 10145, Tallinn
- Telephone: (+372) 58078037
- (+372) 6615130
- Fax: (+372) 6615130

