



EHPV

Eesti HIV-positiivsete võrgustik
Estonian Network of PLWH

Findings from the PLHIV Stigma Index in Estonia Jekaterina Voinova

Workshop on People Living with HIV Stigma Index
May 26th, 2011. 14.00 - 18.00.
Nokia Concert Hall, Yellow room



**HIV IN EUROPEAN REGION-
UNITY AND DIVERSITY
MAY 25-27**

Acknowledgements

- 300 People living with HIV who shared their personal feelings, fears, and experiences.
- NGO Convictus Eesti for cooperation and support (interviewing in prisons)
- Infectious disease department in West-Tallinn Central Hospital
- Ministry of Justice
- Julian Hovs, program officer GNP+
- Igor Sobolev, Chair of the Board of Estonian Network of PLWH (final report)

Thanks



HIV in Europe supported the research undertaken



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

The People Living with HIV Stigma Index in Estonia 2011

Research conducted by Estonian Network of PLWH, with technical and financial support:

- **Global Network of People Living with HIV (GNP +)**
- **International Community of Women Living with HIV (ICW)**
- **International Planned Parenthood Federation (IPPF)**
- **UNAIDS**

Who are the founding partners of the Index

- **HIV in Europe**

Financially Supported the in country roll-out process, including an additional study incorporated into the Stigma Index focusing on barriers to testing and uptake of care

Methodology

- **Globally**
 - The People Living with HIV Stigma Index was developed for and by PLHIV by the founding partners – in consultation with PLHIV worldwide and research institutions
- **Nationally**
 - The research protocol was 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

Methodology

- **participatory research process, including `side by side' interviewing**
- **8 interviewers (PLWH), 3 Supervisor (PLWH), 2 coordinators (PLWH)**
- **training for research team:**

Studying the questionnaire and user guide, training in interviewing and recording cases; guidance for action in complex emotional situations and redirecting people to support and medical services.

3-day workshop September 2010



Team building session



Evening session on stress management



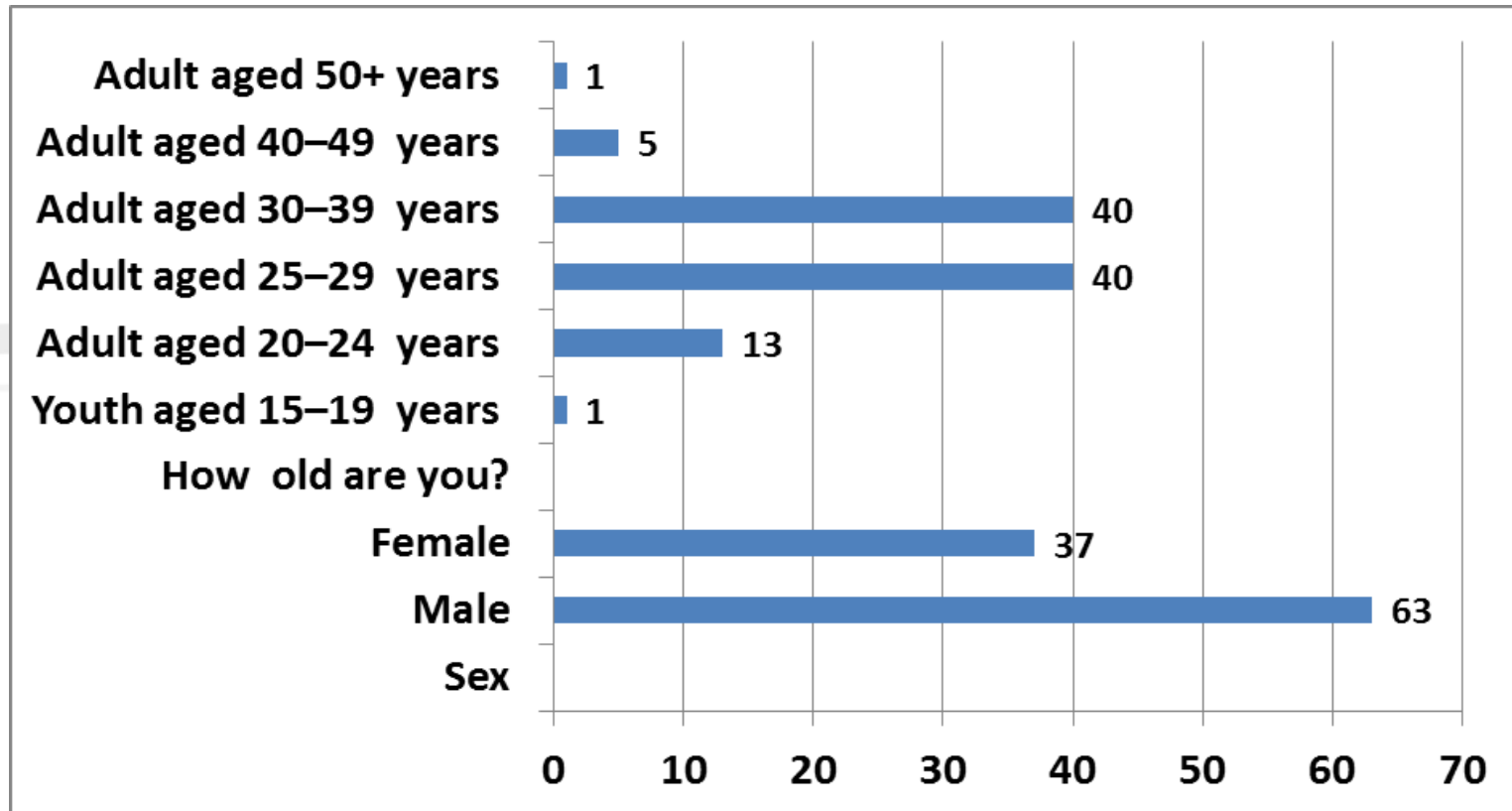
Sampling

- Tallinn (N=102)
- Tartu (N=24)
- Narva (N=100)
- Kohtla-Järve (N=50)
- Tartu prison (N=16)
- Harku prison (N=8)

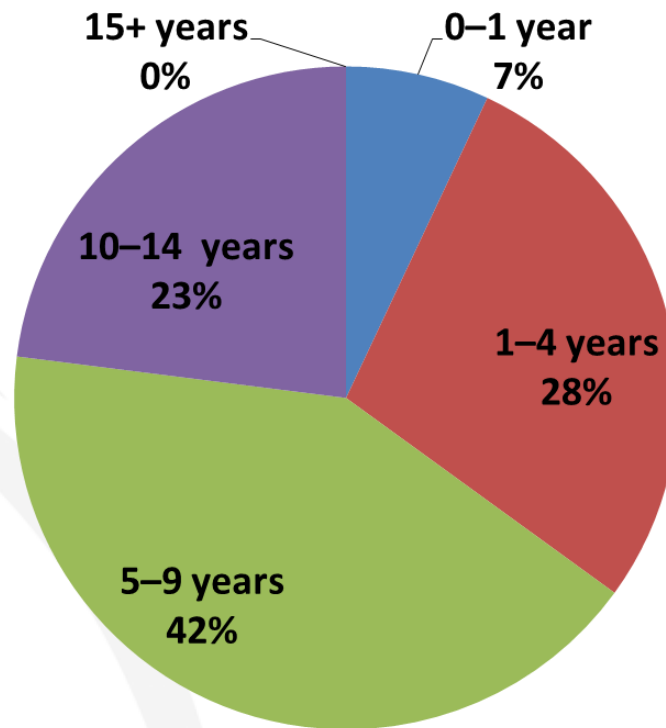
Total - 300

PASW Statistics 10.0 program was used for analysis.

Age and Sex distribution



Distribution of respondents by duration of HIV+ status



Finding Respondents

we were assisted in finding potential interviewees by:

- **peer counselors**
- **employees of infectious-disease hospitals**
- **employees of probation supervision**
- **employees of syringe exchange programs**
- **employees of other organizations in Tallinn, Narva, Tartu and Kohtla-Jarve.**

Results

- **psychological and physical violence (23%)**
- **breaches of confidentiality and fears surrounding possible breaches**
- **common manifestations of stigma included being the subject of gossiping, oral harassment and threatening behaviour**
- **internalised stigma:**

This included self isolation, wishing to give up living, studying, career opportunities, sexual intimacy, and not accessing necessary medical help, making choices not to have or pursue a full family life – including having children

Initial Conclusions what is needed ?

- **access to psycho-emotional and social support**
- **medical workers should be tutored to keep confidentiality/ be unprejudiced towards PLHIV**
- **the data and the process used will be utilized to ensure programming and advocacy initiatives result in the implementation of practices and policy that is grounded in the real life experiences and perspectives of people living with HIV.**

Thank you for your attention

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The PLHIV Stigma Index has now been implemented nationally in 30 countries lead by PLHIV organisations in those countries - working in partnership with government, other civil society organisations and research institutions
More information can be accessed at: www.stigmaindex.org and www.gnpplus.net



This is an initiative of four founding partners

