EUROPEAN HIV NURSING CONFERENCE

19-20 October 2014 • Barcelona, Spain
Remember the early 80’s?
Health Literacy and Stigma

Julian Hows

Monday 20th October 14.00- 14.45
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!
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
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

Sexual and Reproductive Health and Rights
Social and Economic Support
Empowerment
Preventing New Infections
Human Rights
Gender Equality
Measuring Impact
Health Promotion and Access
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

![Criminalization of Transmission and Exposure in Europe and Central Asia](chart)

(Data from GNP+ Global Criminalization Scan, 2010)

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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 ADVOCACY, 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

‘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.
“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.”
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.

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## Country and Sample Size

<table>
<thead>
<tr>
<th>Africa</th>
<th>Asia Pacific</th>
<th>Europe</th>
<th>Latin America</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cameroon (1200)</td>
<td>Bangladesh (238)</td>
<td>Belarus (370)</td>
<td>Argentina</td>
</tr>
<tr>
<td>Ethiopia (2300)</td>
<td>Cambodia</td>
<td>Estonia (300)</td>
<td>Colombia</td>
</tr>
<tr>
<td>Kenya (1086)</td>
<td>China (2096)</td>
<td>Greece (TBC)</td>
<td>Dominican Republic</td>
</tr>
<tr>
<td>Malawi</td>
<td>Malaysia (600)</td>
<td>Moldova (403)</td>
<td>(1000)</td>
</tr>
<tr>
<td>Nigeria (720)</td>
<td>Myanmar (324)</td>
<td>Poland (504)</td>
<td>Ecuador (497)</td>
</tr>
<tr>
<td>Rwanda (1530)</td>
<td>Pakistan (300)</td>
<td>Portugal (1000)</td>
<td>El Salvador</td>
</tr>
<tr>
<td>Senegal</td>
<td>Philippines (80)</td>
<td>Russia (600)</td>
<td>Mexico</td>
</tr>
<tr>
<td>South Africa</td>
<td>Sri Lanka (120)</td>
<td>Turkey (100)</td>
<td></td>
</tr>
<tr>
<td>Swaziland</td>
<td>Thailand</td>
<td>Ukraine (1500)</td>
<td></td>
</tr>
<tr>
<td>Zambia (854)</td>
<td>Fiji (100)</td>
<td>UK (867)</td>
<td>Paraguay (256)</td>
</tr>
</tbody>
</table>

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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
- An 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 ‘too’ late
- They are denied treatment because of who they are
- It is not in place

The results

- More infections
- Greater costs to all concerned

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HIV-related Stigma: Late Testing, Late Treatment

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

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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

<table>
<thead>
<tr>
<th>Country</th>
<th>Gossiped about in the last 12 months</th>
<th>Gossip was related to HIV status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estonia</td>
<td>63%</td>
<td>39%</td>
</tr>
<tr>
<td>Moldova</td>
<td>38%</td>
<td>50%</td>
</tr>
<tr>
<td>Poland</td>
<td>52%</td>
<td>20%</td>
</tr>
<tr>
<td>Turkey</td>
<td>70%</td>
<td>66%</td>
</tr>
<tr>
<td>Ukraine</td>
<td>59%</td>
<td>68%</td>
</tr>
<tr>
<td>Zambia</td>
<td>75%</td>
<td>90%</td>
</tr>
<tr>
<td>UK</td>
<td>63%</td>
<td>77%</td>
</tr>
</tbody>
</table>
## Employment Discrimination

<table>
<thead>
<tr>
<th>Country</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estonia</td>
<td>7%</td>
</tr>
<tr>
<td>Moldova</td>
<td>5%</td>
</tr>
<tr>
<td>Poland</td>
<td>11%</td>
</tr>
<tr>
<td>Turkey</td>
<td>12%</td>
</tr>
<tr>
<td>Ukraine</td>
<td>8%</td>
</tr>
</tbody>
</table>

*Were refused employment or work opportunities in the last 12 months because of HIV status*
Denied health services because of HIV status in the last 12 months

<table>
<thead>
<tr>
<th>Country</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estonia and Philippines</td>
<td>8%</td>
</tr>
<tr>
<td>China</td>
<td>12%</td>
</tr>
<tr>
<td>Paraguay and UK</td>
<td>17%</td>
</tr>
<tr>
<td>Moldova</td>
<td>14%</td>
</tr>
<tr>
<td>Poland, Turkey, and Ukraine</td>
<td>20%</td>
</tr>
</tbody>
</table>
Internalized Stigma

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

<table>
<thead>
<tr>
<th>Country Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rwanda and Turkey</td>
<td>8-10%</td>
</tr>
<tr>
<td>Bangladesh and Moldova</td>
<td>17-21%</td>
</tr>
<tr>
<td>Paraguay</td>
<td>38-40%</td>
</tr>
<tr>
<td>Estonia</td>
<td>11-17%</td>
</tr>
<tr>
<td>Poland and Ukraine</td>
<td>18-26%</td>
</tr>
</tbody>
</table>
Testing because of symptoms of HIV was the 2\textsuperscript{nd} or 3\textsuperscript{rd} most common reason for testing

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

*Other countries with high percentages: Bangladesh, China, Philippines, Dominican Republic, Myanmar, Turkey, Paraguay, Ukraine, Estonia, Poland.*
# Issues with HIV Testing

## Tested under Coercion or without Consent

<table>
<thead>
<tr>
<th>Country</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estonia</td>
<td>34%</td>
</tr>
<tr>
<td>Moldova</td>
<td>52%</td>
</tr>
<tr>
<td>Paraguay</td>
<td>24%</td>
</tr>
<tr>
<td>Philippines</td>
<td>44%</td>
</tr>
<tr>
<td>Poland</td>
<td>29%</td>
</tr>
<tr>
<td>Turkey</td>
<td>66%</td>
</tr>
<tr>
<td>Ukraine</td>
<td>31%</td>
</tr>
<tr>
<td>Country</td>
<td>Percentage</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Myanmar</td>
<td>15 to 20%</td>
</tr>
<tr>
<td>China, Estonia, Moldova,</td>
<td>31 to 40%</td>
</tr>
<tr>
<td>Philippines, Ukraine, UK</td>
<td></td>
</tr>
<tr>
<td>Dominican Republic</td>
<td>21 to 30%</td>
</tr>
<tr>
<td>Poland</td>
<td>41 to 50%</td>
</tr>
<tr>
<td>Turkey</td>
<td>More than 75%</td>
</tr>
</tbody>
</table>
## Effecting Change

<table>
<thead>
<tr>
<th>Country</th>
<th>Confronted someone who stigmatized you in the last 12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estonia and Poland</td>
<td>29%</td>
</tr>
<tr>
<td>Moldova and Ukraine</td>
<td>37%</td>
</tr>
<tr>
<td>Turkey</td>
<td>47%</td>
</tr>
<tr>
<td>Kenya</td>
<td>62%</td>
</tr>
</tbody>
</table>
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/Veranstaltung/en/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

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Driving a community-based response to the HIV epidemic and increasing the testing and treatment uptake
Lessons learned from a country experience in Estonia
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)
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
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.

- **Supervisory Board**
  - Michael Weinstein
  - Igor Sobolev
  - Rodney Wright

- **Management Board**

- **Administrator**

- **Medical staff**
  - Tamara Dmitrijeva
  - Juta Kogan

- **Support staff**
  - Janitor, security
  - Advocacy manager

- **Corporate Executive**
  - Jekaterina Voinova

- **EHPV personnel**
  - (psycho-social services provider)
  - Aleksandra Barsukova
  - Jekaterina Smirnova
  - Natalja Dehhant
  - Svetlana Judina
  - Jelena Antonova
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

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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
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 ...
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
“Guess it comes down to a simple choice really. Get busy living, or get busy dying.”

- From the movie *The Shawshank Redemption*
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
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

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”.

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Further resources:

www.gnpplus.net
www.stigmaindex.org
www.criminalisation.gnpplus.net

jhowes@gnpplus.net

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

Thank you