

Survey of issues faced by women living with HIV in Europe and Central Asia May 2010.

Preliminary findings

This survey was conducted by and for women living with HIV on an entirely voluntary basis.

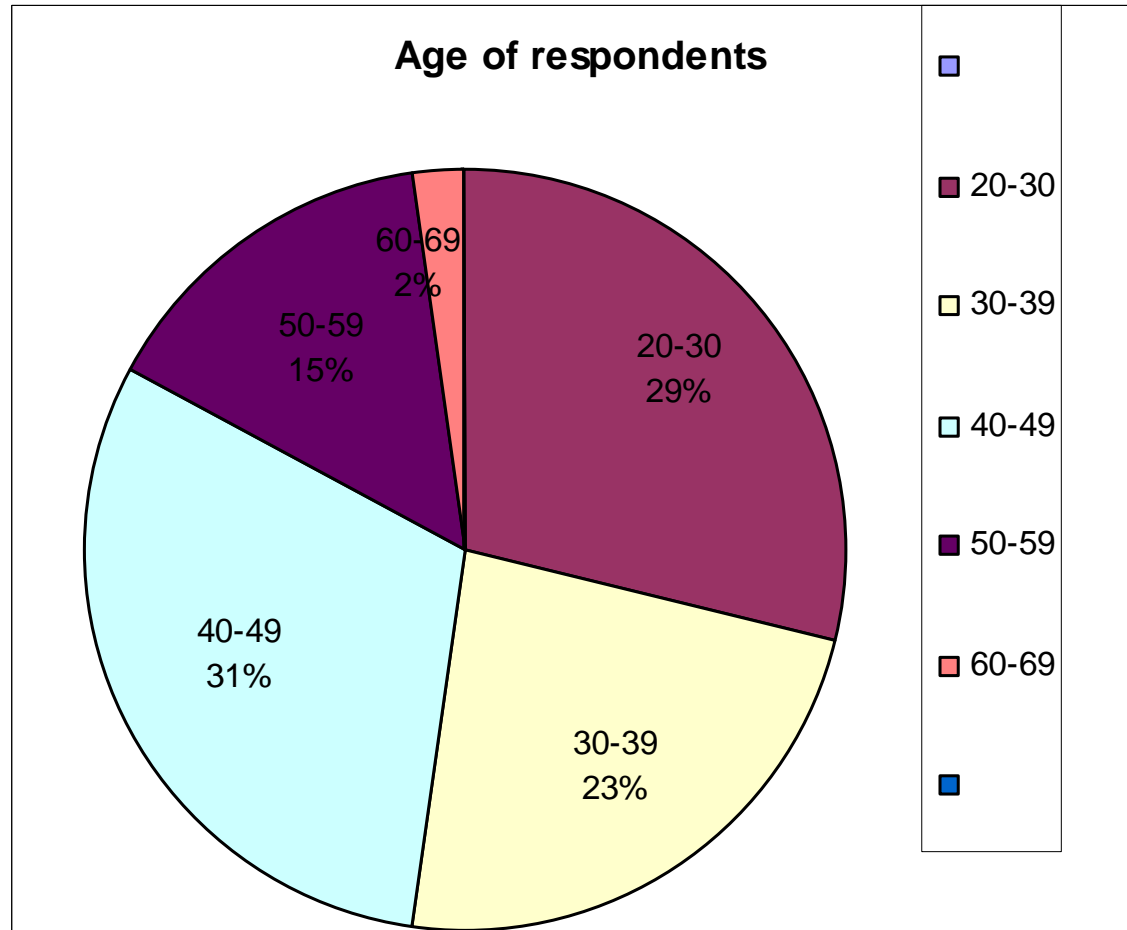
We give grateful thanks to all participants.



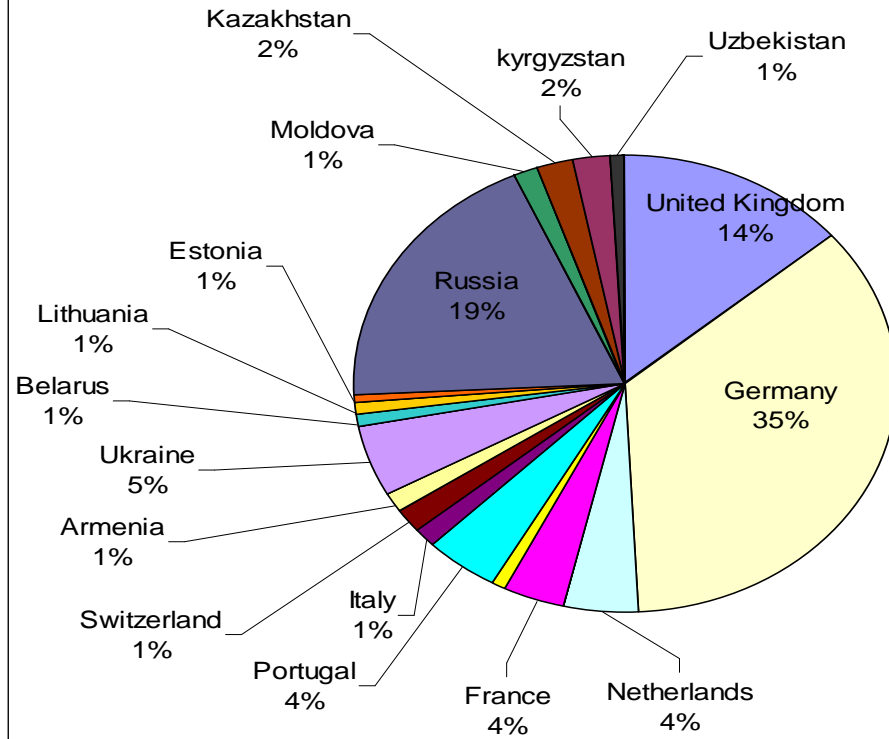
About the survey

- **1) Why do a survey?**
- **2) Survey planning and design**
- **3) Selecting the sample**
 - English
 - German
 - Russian
 - Portuguese

some findings



Nationalities of Respondents



more findings

- **Relationship** status: 32% of English and German speakers were married or cohabiting, Portuguese speakers 44%, Russian 63%.
- **Disclosure** 14% of women are 'open' about their status, 51% had chosen to tell their partners
- a third had experienced **gender based violence**

Key populations

- *“[In the UK] A review carried out in 2006 made no mention of women living with HIV in the prison system, it being noted as not an issue, very few women in prison living with the virus. Mental ill health plays a huge part when incarcerated, and undiagnosed post traumatic stress leaves a women reacting to trauma time and time again. The isolation felt in prison after receiving or living with HIV has a considerable impact on a woman’s mental health. Localised HIV policy needs to be implemented in to prisons.” [English-speaking participant May 2010]*

Counselling

- 44% of women reported that **counselling** was available at diagnosis
- English-speaking respondents 57%
- Portuguese-speaking respondents 22%.
- **Mental health** issues also came out quite strongly in the qualitative parts of the survey.

- *“I have psychotherapy to help me overcome a sense of shame.” [English-speaking participant May 2010]*
- *“Lack of psychologists” [Russian-speaking participant May 2010]*
- *“Had AIDS, but I have got better again through combination therapy, regular hospital stay, more often because of psychological problems (depression).” [German-speaking participant May 2010]*

Routes of transmission

	English	Russian	German	Portuguese
Sex with a man	70%	46%	79%	67%
Sex with injecting drug user	12.5%	37%	17%	0%
Injecting drug use	15%	20%	8%	33%
Blood products	2.5%	0%	8%	0%
At birth	0%	0%	4%	0%
Don't know	2.5%	7%	0%	0%

Attitudes from Health Care Professionals

Two thirds of women reported poor attitudes from medical professionals

- dentists (51%),
- social services (25%)
- family planning (28%)

Russian-speaking participants

May 2010

- *“There are no appliances for obstetrics, even like gloves.”*
- *“The HIV test for a child from positive women is taken when the child is 18 months old, whereas in other countries its done at 3 months old.”*
- *“Problems with substitution of milk for child”*

- *“With a reference from Aids centre i can go to hospital and check my sexual health and even get free medicine.”*
- *“I can register in women clinic when pregnant and also can choose a doctor myself.”*
- *“Limited choice for young women for where to give birth, and access family planning because of their status.”*
- *Limited organisation who do artificial insemination”*

Stigma and discrimination

- *“If I call ambulance I do not tell them my diagnosis as they simply will not come, and I haven’t disclosed at all to my local GP it is a secret.” Russian*
- *“At hospital I still have yellow stickers “Danger of infection” put on all my blood samples. I am told that this is to protect the phlebotomists. But they should be adopting universal precautions.” English*

Stigma and discrimination

- *“My husband reacted remarkably well to the info of my infection. He just said that he could understand that this was a problem for me but that it was not a problem for him.” [German].*
- *“I don't have relationships then I don't have to disclose/ face rejection”. [English].*
- *“I avoid situations when I may be rejected sexually or otherwise.” [English]*

Overcoming stigma

- spiritual practice, read the Bible and pray
- practising self acceptance,
- talking to people I feel safe with
- a twelve step programme
- psychotherapy
- positive affirmations
- diary writing

Overcoming stigma 2

- Doing things that make me feel good
- Being selfish
- Not to tell everyone
- Confidence, leadership and knowledge of rights.
- Ask for help from human rights defenders
- Inform people about HIV

Recommendations 1

- Elaboration of these data
- Treatment availability
- Treatment literacy
- Counselling
- Access to other medical services
- Stigma reduction
- Complex layers of discrimination

Recommendations 2

- Data gaps eg young women, disclosure in the workplace, psychological issues...
- Lessons can be learnt from the methodology
- Scope for sharing experiences across the region