

# Survey of issues faced by women living with HIV in Europe and Central Asia:

## *Preliminary findings*

July 2010

[www.wecareplus.net](http://www.wecareplus.net)

This survey was conducted by and for women living with HIV on an entirely voluntary basis. We give grateful thanks to all participants, supporters and contributors.



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# Survey of issues faced by women living with HIV in Europe and Central Asia:

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### 1) Why do a survey?

Women from Europe and Central Asia came together at a meeting in Vienna, Austria at the end of 2009 to explore how to ensure their voices are heard at the forthcoming International AIDS Conference July 2010. A significant outcome from this meeting was the formation of WECARE+ (Women of Europe and Central Asia Regions plus). WECARE+ is a network of women from across the region who want to make linkages, share learning, share experiences and seek solutions for the issues that affect our lives. The organisation is in its formative stages and will be launched at the Women's Networking Zone in Vienna on Tuesday 20<sup>th</sup> July 2010. More information can be found here: <http://www.womeneurope.net>

In order to have accurate and up to date information on the issues that women are facing across the region, we decided to ask them.

### 2) Survey planning and design

Given the limitations of human and financial resources to undertake the study, we decided to limit the translation to **five languages** – English, German, Russian, Portuguese and Polish. Draft questions were drawn up using other surveys based on a similar ethos, eg [The People Living with HIV Stigma Index](#). These were discussed amongst a small group of women living with HIV and a medical doctor. Once an agreed balance between qualitative and quantitative questions was agreed upon, the survey was translated into four languages. Volunteer translators, to whom we are extremely grateful for giving up their time and expertise, worked hard to enable us to produce the survey. We used 'Survey Monkey' to collect the data during May 2010. The link to the survey was circulated amongst a variety of listservs and contacts by women involved in WECARE+. Finally the four surveys on 'Survey Monkey' were collated in excel (quantitative data) and word (qualitative data) to enable us to write this report.

### 3) Selecting the sample

We hoped to get a total of 100 completed surveys from UK, Germany, Russia, Ukraine, Portugal and Poland. This was thought to be a good geographical spread whilst not making the collation of data and translation of responses into English too unrealistic. We recognise that in statistical terms this may not be a robust number since we at best represent 6% of the target population in the United Kingdom and at worst the data is quite insignificant. For instance, there was only 1 respondent from Poland.

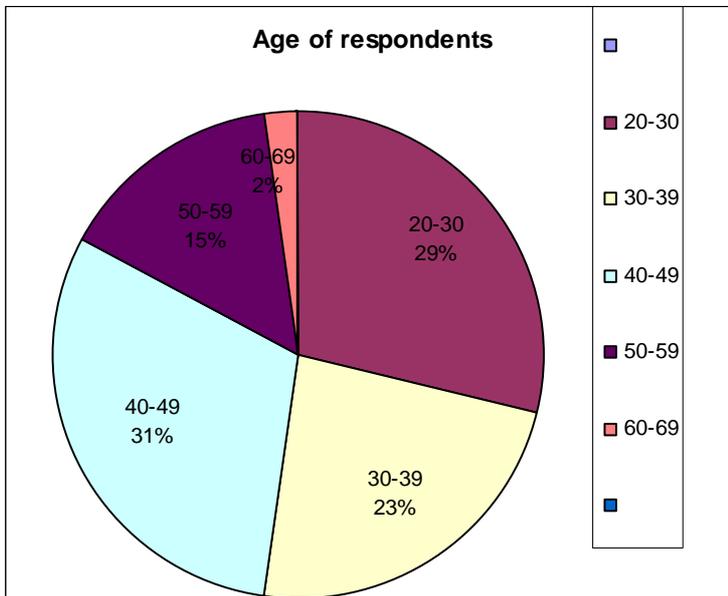
Nonetheless, we had an overwhelming response from women across the region who were very keen to tell us about their experiences. In total **165 women living with HIV responded**. The principal findings are set out below.

### 4) Initial findings

Much of the information is based on averages for the region, highlighting significant differences. There is a lot more data that could be extracted and put to good use. However without the expertise of a statistician and the necessary resources, we are not able to do much more than is presented here.

#### 4.i) Age of respondents

The age of the respondents shows that 29% were under 30. The biggest group were women between 40 and 49.



(Age in years).

#### 4.ii) Geographical spread

The geographical spread can be seen in the chart below.

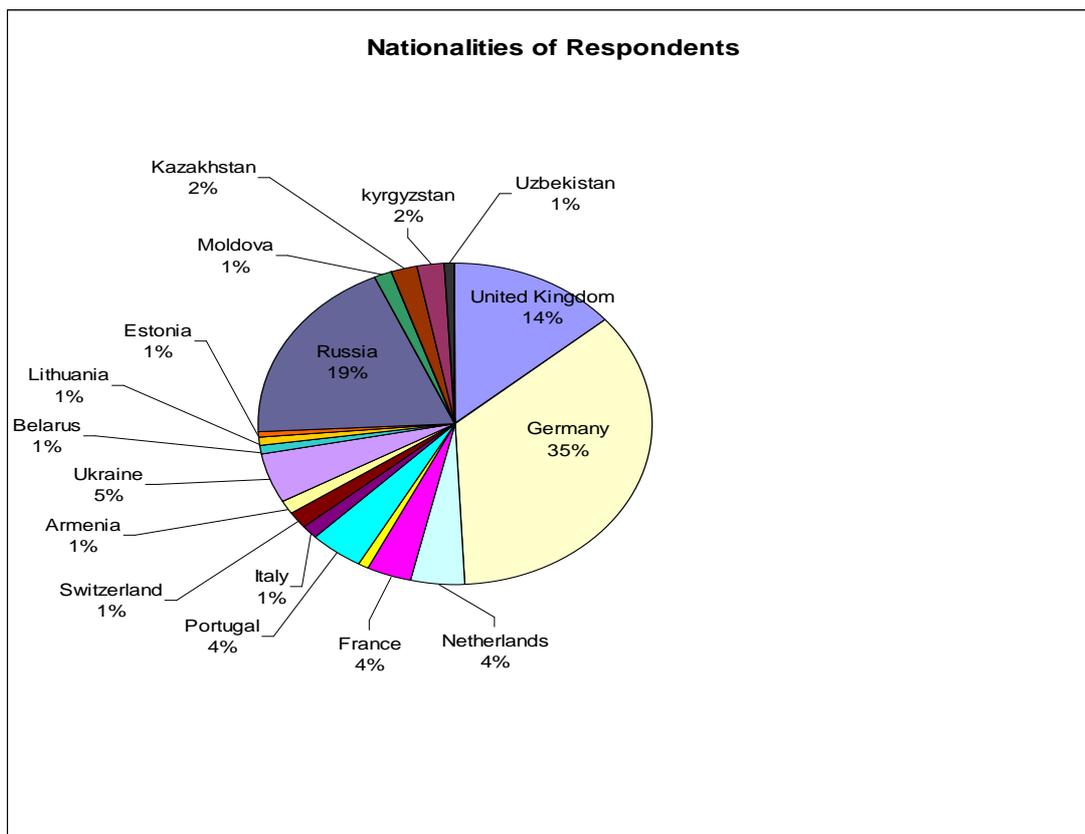
*"[I am] ..Unhappy that I have to justify my HIV diagnosis with questions about how I got it. [German-speaking participant May 2010]*

*"My boss hugged me when I found out about my diagnosis; my dentist and my gynecologist are great." [German-speaking participant May 2010]*

*"No confidentiality in AIDS centres." [Russian-speaking participant May 2010]*

*"I will never forget how much fear I had to disclose my diagnosis with my siblings. I never imagined that my siblings would reach their hand out to me so caring, loving and yet sad. They gave me courage. That was the greatest for me." [German-speaking participant May 2010]*

*"A female physician from the HIV centre Frankfurt trusted me despite my drug dependency." [German-speaking participant May 2010]*

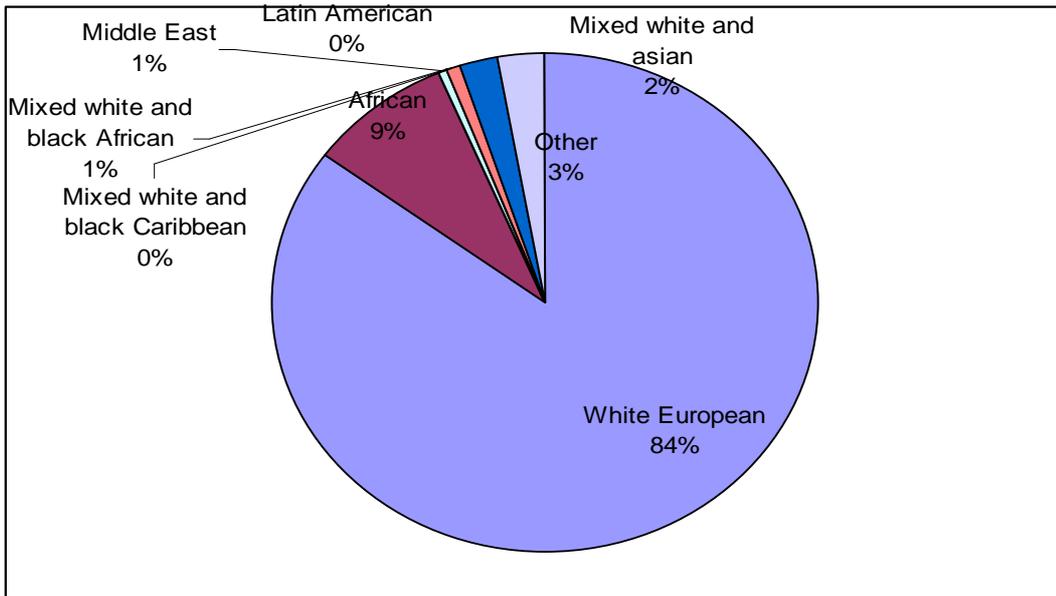


#### 4. iii) Diagnosis and Disclosure

Nearly half of the women surveyed received their diagnosis **10 years ago** or more. This general statement does mask some points worthy of note, namely that only 22% of women from the Russian survey fall in to this category the majority of Russian-speaking respondents (56%) fall into the 5-10 year category. From all of the surveys we only got 0.6% who were diagnosed in the last 6 months which is a weakness of a survey of this kind that was distributed amongst groups of activists and not through support user services or medical facilities.

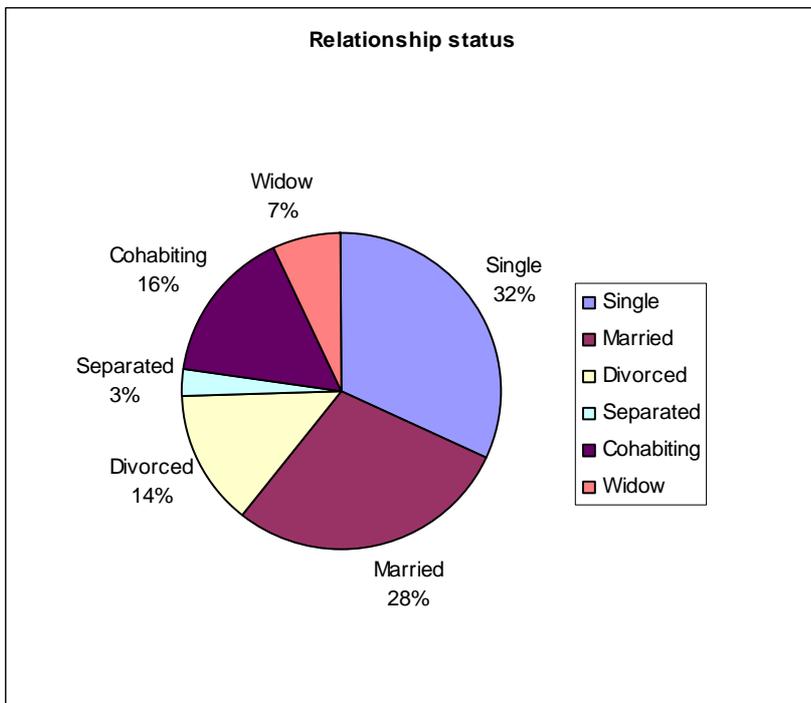
#### 4. iv) Ethnic Background

[The UK Health Protection Agency](#) indicates that around 70% of women living with HIV in the UK were born in Africa. Therefore our survey clearly does not reflect this. We were very surprised nonetheless to learn that the UN does not hold figures for the number of women living across Europe who were born in Africa. This to us seems like a strange omission, given the numbers involved. Other categories identified by respondents outside those given below, were “white African”, “white Gypsy” and “Korean”.



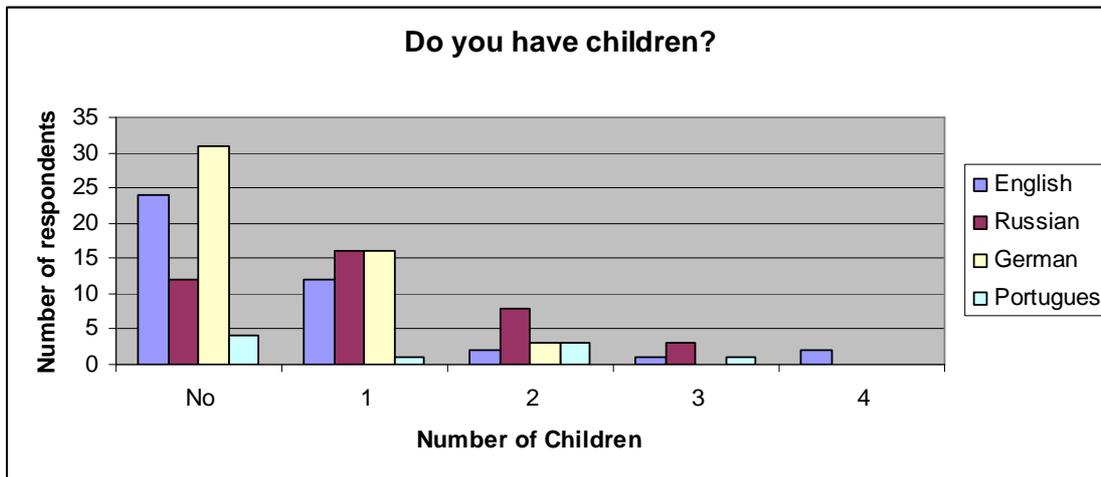
**4.v) Relationship status**

There were quite large variations in this category. 32% of English and German speakers were married or cohabiting. Of the Portuguese speakers 44% were married or cohabiting and the Russian-speaking respondents in this category numbered 63%.



#### 4.vi) Children

The chart below shows the number of respondents with their own children or children in their care. We also asked the respondents who have children if their children are HIV positive. Six said they were. Four of these were Russian speakers.



#### 4. vii) Disclosure

Only 14% of women reported that they are ‘open’ about their status and that everyone knows it. In general, most people had disclosed to some family (77%) and some friends( 73%). However, women that had disclosed to their work colleagues numbered just 34%, to their religious group 8%, or to their neighbours 5%. 51% had chosen to tell their partners. Across the board, the lowest numbers in each category were reported from the English speakers. This would indicate that women who are largely living in the UK have the lowest levels of disclosure and therefore the lowest levels of support.

#### 4. viii) ‘Vulnerable groups’

A third of all respondents reported being or at one time having been an **injecting drug user**. This was highest amongst Russian and Portuguese speakers at 44%. Additionally, 47% reported that they were, or had once been, the partner of an injecting drug user. This figure rises as high as 70% amongst the Russian-speaking respondents.

*“Before I was IDU (7 years) then I found out about my status I really stigmatised myself, today thank God I’m free from addiction, around 9 years without drugs and alcohol and cigarettes. Also I live comfortably with my status and work for organisation ... helping people like me (PLHIV IDU and their relatives).” [Russian-speaking participant May 2010]*

*“For women who are on substitution therapy hospital care is not accessible, also in AIDS centres there is no substitution therapy. Also who want to give birth, they can’t realise their dream to become a mother, because in our country you can’t get the right medicine you need.” [Russian-speaking participant May 2010]*

A **third** of all respondents say they had experienced **gender based violence**, the highest numbers amongst the Russian- (27%) and Portuguese-speaking respondents (37%). 19% of women reported that they had experienced this amongst the English- and German-speaking respondents.

*“Women who are victims of sexual violence are at a higher risk of being exposed to HIV, and the lack of condom used and forced nature of rape means that women are immediately more vulnerable to HIV infection.”  
[English-speaking participant May 2010]*

12% of women reported that they were, or had at one time been a **sex worker**. This figure rose to 22% among the Portuguese-speaking respondents, 16.3% from the German-speaking respondents, 9.3% from the Russian-speaking respondents, and 7.5% from the English-speaking respondents. No questions were asked about trafficking. However it is interesting to note that some of the Portuguese-speaking respondents were from Russian speaking countries.

10% of all respondents reported having spent time in **prison** at some point. 12% of English-speaking

*“[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]*

respondents, 11% of Portuguese-speaking respondents, 9% of Russian-speaking respondents and 8% of German-speaking respondents reported this.

#### **4. ix) Date of acquiring HIV**

We also asked participants for the year they believed they had **contracted** HIV. 7% didn’t know, 4% believed it was before 1982, 25% believed it was between 1982- 89, 25% between 1990-99 and 38% 2000-10. The first date given by one of the Russian-speaking respondents was 1994. Most Russian-speakers believed they had contracted HIV between 1998 until 2008. Dates from other respondents were more evenly distributed.

#### **4. x) Counselling**

44% of women reported that **counselling** was available when they were diagnosed. However 56% said they did not have this opportunity. The English-speaking respondents had most opportunity, at 57%, and the Portuguese-speaking respondents fared worst at 22%. However, even for the English-speaking respondents this number is still very low. We did not ask what form the counselling took, ie whether it was pre- or post-testing or where it took place (for instance in a sexual health facility or a maternity setting). Nor did we ask how long they had access to counselling, whether it was subsidised and by whom. **Mental health** issues also came out quite strongly in the qualitative parts of the survey.

#### 4. xi) Routes of transmission

*“We are very good in this country at providing physical health care to all women HIV+ or not but there is little counselling and support and little specifically for women with HIV”. [English-speaking participant May 2010]*

*“For me while I have been unwell due to HIV as it was found after I already had symptoms but currently it is the emotional/mental aspects of having HIV that are the main issue for me and the lack of support from those who truly know what it is like to live with HIV.” [English-speaking participant May 2010]*

*“Excellent carer, psychological support when needed, there is always someone there for me” [German-speaking participant May 2010]*

*“Mental health issues for positive women are huge - the shock of diagnosis, the post-traumatic chronic stress of living with a diagnosis and not being able to share it freely with others - as women with cancer can thankfully do if they want - are hugely under-estimated and under-supported”. [English-speaking participant May 2010].*

*“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]*

The participants were asked how they believed they had acquired HIV. They were allowed to tick more than one box. It seems multiple box ticking caused some confusion but we believe the data to still be relevant.

Route of Transmission	English-speaking	Russian-speaking	German-speaking	Portuguese-speaking
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%

Additional options were offered, such as having sex with a woman or with a transgender person or with a sex worker (male/female/transgender). However the responses to these routes of transmission were not significant.

Concerns about **criminal transmission** of HIV were raised by several women.

*"[Criminalisation] is stopping many women I know from daring to enter into new relationships, because of the fear of violence from partners and the fear of criminalisation. This is tragic because they are the most lovely women and are missing out on loving relationships and - often - on becoming mothers, which is their right, because of these legal threats." [English-speaking participant May 2010]*

*"... lack of substitution milk for HIV+ women in the Russian Federation... By giving natural milk to the child a mother can transmit the virus in a concentration that is high enough for her to infect the child and she is criminally responsible for transmission in Russian Federation" [Russian-speaking participant May 2010]*

*"Infecting someone else with HIV on purpose is juridically seen as heavy injury. Other infections are not considered such even when there is no treatment available." [English-speaking participant May 2010]*

#### 4. xii) Current Health

Nearly three quarters of the women reported being in good or **excellent health** at present, with the remainder divided between "ok health" (20%) and 5 % reporting "poor health". English-speaking respondents reported the best health and Portuguese-speaking respondents reported the worst health.

*"It is very difficult to work and lead positive lifestyle after treatment of hepatitis C." [Portuguese-speaking participant May 2010]*

*"After rehabilitation my HIV status has stabilised. But hepatitis C is progressing quickly." [English-speaking participant May 2010]*

\*Further examination of the data would allow cross analysis with instances of **co-infection** (with Hepatitis C and/or TB or other conditions – see section 4.xiv below) and or disability,( both related to HIV and not related), to try and unpack the reasons for these results based on this data set.

Over half of the women reported satisfaction with their **access to health services** in their country. A further 25% were neither satisfied or dissatisfied and 20% reported dissatisfaction. These averages mask such variations as German-speaking respondents and English-speaking respondents reporting satisfaction levels as high as 65% and 63% respectively and 32% of Russian-speaking respondents reporting dissatisfaction.

*"I need a pause from therapy every couple of years" [German-speaking participant May 2010]*

*"Am critical that medication is(was) only made for men" [German-speaking participant May 2010]*

*"Absence of treatment for hepatitis ...Stoppage in ARV deliveries, low educational level of doctors in AIDS centres in the regions of Russia there is a small population, lack of medical staff at all in AIDS centres" [Russian-speaking participant May 2010]*

*"Friendly and responsible staff in AIDS centres" [Russian-speaking participant May 2010]*

*"[I am] Happy with the advice through the AIDS Initiative, it has reduced anxiety. However, am confused over some things...E.g. if you go on the internet and there is contradictory info from what the actual medical care says.... If medications now really are good and well tolerated, why then does one have to wait to get medication? That makes me an uncertain ...I would prefer it if I could take some medication now. Here things are unclear. ..is it because of reasons of cost that medication is withheld from me ...if I were a rich person, would the doctors then proceed differently? [German-speaking participant May 2010]*

*"I have the privilege to live in one of the richest countries of the world, with a health system that finances the medications important for my survival. I am thankful for that every day." [German-speaking participant May 2010]*

Some of the common medical conditions / **opportunistic infections** that women reported included shingles, migraine, depression, fungal infections (oral thrush), bacterial infections, genital herpes, mouth ulcers, PCP and pneumonia.

#### **4. xiii) Anti-retroviral therapy**

Three quarters of the women surveyed are taking **ART**. Again, however there is significant variation. 87% of German-speaking respondents and just 56% amongst Russian-speaking respondents reported that they were taking ART. This variation could be down to a number of reasons. For instance, it may be because it is not thought necessary yet to take medication; (there is also variation in the point at which it is advised to start medication: WHO guidelines state that medication should be started when a CD4 count drops below 200, whilst the British HIV Association (BHIVA) in the UK recommends ART when the CD4 count drops below 300); choosing not to take medication and the availability of the medication in the right combinations. 10% of women reported difficulty in supply of medication, which could lead to treatment interruption. In more general terms, nearly a third of women believed they faced limitations in health care because of their HIV status.

#### 4. xiv) Other conditions

58% of women reported co-infection with Hepatitis C with numbers, being highest amongst Portuguese and Russian-speaking respondents.

“Co-infections”	English-speaking	Russian-speaking	German-speaking	Portuguese-speaking	Average
TB	17%	10%	9%	40%	<b>19%</b>
Hepatitis B	17%	35%	32%	20%	<b>26%</b>
Hepatitis C	28%	90%	32%	80%	<b>58%</b>
Recurring malaria	6%	0%	3%	0%	<b>2%</b>
Cervical dysplasia or cervical cancer	11%	10%	24%	20%	<b>16%</b>
Other significant HIV-related health issues	44%	25%	56%	20%	<b>36%</b>

One of the most significant findings from the quantitative data was the variation in access to health provision across the region. This will, of course, influence these results. For instance, the availability of ‘Pap smears’ for cervical cancer screening is not consistent across the region.

An overall average of 70% of the respondents reported being **sexually active**. 90% of Russian-speaking respondents reported being sexually active, whilst 56% of the Portuguese-speaking respondents reported this.

#### 4. xv) Attitudes from Health Care Professionals

Nearly two thirds of women reported poor attitudes from medical professionals, with dentists (51%) and social services (25%) and family planning services (28%) being considered as worst. Amongst Portuguese-speakers, dental (83%) and social services (67%) were considered the worst. Russian-speakers identified hospital staff (78%) and family planning (40%) services. For the English-speaking respondents, hospital staff (53%) and dental services (37%) were mentioned as having poor attitudes. For German-speaking respondents, family planning and hospital staff were identified as having the worst attitudes.

*“I found out about my HIV status during pregnancy when I was 18” [Russian-speaking participant May 2010]*

#### 4. xvi) Sexual and reproductive health

Amongst the Russian-speaking participants, there seemed to be great variation in the availability of ARTs, both during pregnancy and in general. The treatment of women living with HIV varied enormously - from the choices available to them in relation to where to give birth, to the availability of information about treatment options and advice for caring for their newborn child (including breastfeeding).

*"In the 18th week of pregnancy they do not give ARV treatment even if the viral load 15 000 relating to No606 law from 19/12/03, that says that ARV only can be given on the 28<sup>th</sup> week.... In the 18th week of pregnancy they do not give ARV treatment even if the viral load 15 000 relating to No606 law from 19/12/03, that says that ARV only can be given on the 28<sup>th</sup> week." [Russian-speaking participant May 2010]*

*"Breach of rights of pregnant women in choice of the maternity hospital... HIV+ women of Kazan must give a birth only in particular maternity hospital, where conditions are poor and there is discrimination. There were no refurbishment for at least 5 years, and beds are very different from normal hospital." [Russian-speaking participant May 2010]*

*"There are no appliances for obstetrics, even like gloves." [Russian-speaking participant May 2010]*

*"The HIV test for a child from positive women is taken when the child is 18 months old, whereas in other countries it's done at 3 months old." [Russian-speaking participant May 2010]*

*"Problems with substitution of milk for child" [Russian-speaking participant May 2010]*

*"[I] took it badly that my son at that time couldn't come naturally into the world and that I couldn't/shouldn't breastfeed him" [German-speaking participant May 2010]*

*"I have to search for gynaecologists who are adequately treating HIV+ women" [Russian-speaking participant May 2010]*

*"There is no free treatment for sexual health" [Russian-speaking participant May 2010]*

*"Stoppage of vital drugs for pregnant women and kids. Rights of PLHIV for health is under threat as results of lack of access to treatment." [Russian-speaking participant May 2010]*

*"With a reference from Aids centre i can go to hospital and check my sexual health and even get free medicine." [Russian-speaking participant May 2010]*

*"I can register in women clinic when pregnant and also can choose a doctor myself." [Russian-speaking participant May 2010]*

*"Limited choice for young women for where to give birth, and access family planning because of their status." [Russian-speaking participant May 2010]*

*"Limited organisation who do artificial insemination" [Russian-speaking participant May 2010]*

*"HIV-related care is good; however only because in Heilbronn there is an engaged doctor in the hospital ... But it's far worse when it comes to doctors specialising in women's health. I have to travel to Frankfurt to find a doctor who knows about HIV and the possibly resulting problems for women" [German-speaking participant May 2010]*

#### 4. xvii) Disability

More analysis of the data is needed for this area, to do this issue justice.

#### 4. xviii) Asylum seekers/ refugees

8 women reported being or having been asylum seekers. 5 of these were in the UK. There is more analysis required here, to do this issue justice

#### 4. xix) Support

Russian- and German-speakers have the most access to peer support (at 89%), whereas in Portugal this stands at just 63%. In total, 60% of respondents reported access to women's groups (86% of English-speakers and 20% of Portuguese-speakers). Only 35% reported access to a heterosexual group. 9% reported access to a youth group. Only amongst the English speakers was there reported a group for women who have sex with women. Russian-speakers reported the best access for injecting drug user groups at 36% with only 2.4% in Germany. Most women confirmed that these support services were provided at a time that suited them

*"The Aids Support Organization has made me stronger and I now give AIDS prevention sessions in schools. This is like a therapy for me but it also boosts my self-esteem. I am doing something meaningful."* [German-speaking participant May 2010]

*"The local AIDS NGO who supported me so strongly when I had to apply for retirement while my head was busy with other things such as dealing with my meds and confronting death/dying."* [German-speaking participant May 2010]

*"The most support I got was from other PLHIV who are actively engaged in the cause."* [German-speaking participant May 2010]

*"Through AIDSHilfe/the internet I have access to information independent of the pharmaceutical companies."* [German-speaking participant May 2010]

#### 4. xx) Stigma and discrimination

The discrimination we face and the stigma we feel is different in different settings, these are some of the experiences women shared in the medical; family & friends; intimate relationships; and church settings.

##### a) Medical setting

*“Stigma, poverty, lack of knowledge among women are barriers to access to services especially in villages.” [Russian-speaking participant May 2010]*

*“It's the "virgin/whore" mentality - either we must be innocent victims or we must deserve it. Yet we are neither - we are just women with a bug in our bodies. This dichotomy is universal in all cultures and is what drives stigma and discrimination against us - it is easier for others to label us and then they don't have to contemplate the possibility that HIV might affect them or a woman or girl they are close to. I don't blame them - but this is the reality we face through lack of sufficient awareness-raising and a real debate and understanding around these issues in all our lives.” [English-speaking participant May 2010]*

*“Bulimia” [when asked what was a strategy that I adopted to deal with stigma]. [English-speaking participant May 2010]*

*“..... My self esteem has been permanently damaged by stigma and that really saddens me” [English-speaking participant May 2010]*

*“Judgmental attitudes medical personnel, especially in antenatal clinics.” [Portuguese-speaking participant May 2010]*

*“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-speaking participant May 2010]*

*“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-speaking participant May 2010]*

*“In a sexual health clinic, when I was there for investigation and the result came back positive they just stopped treating me and just sent me home.” [Russian-speaking participant May 2010]*

*“After delivery the midwife in the hospital was shouting about my diagnosis, she forbade my friend from sitting on my bed with comments that she can catch HIV from me...” [Russian-speaking participant May 2010]*

*“Main source of stigma – medical workers” [Russian-speaking participant May 2010]*

*“When I was in a maternity ward a nurse came to do some tests and asked me why I was in “luxus” ward. I told her my diagnosis, she smiled: “it does not matter; half of our doctors have hepatitis”. [Russian-speaking participant May 2010]*

b) Work place

*“My HIV infection doesn’t confine me in the least. Only professionally is it hard because I come from the health sector” [German-speaking participant May 2010]*

*“Doesn’t affect my day to day living. I am a professional doing a full time job.” [English-speaking participant May 2010]*

*“..in the university clinic there is constant discriminatory treatment of positive women – for instance no sharing of the breakfast table, separated toilets.” [German-speaking participant May 2010]*

c) Rights

*“Breach of the right to be best and loving care, (in line with section 1 in 127 family codex of Russian Federation carers can be only adult of any gender, excluding anyone who is not able to perform parental rights as result of medical condition)... A person who has infectious disease cannot be a carer until they are under medical supervision. HIV and Hepatitis are infection diseases – means that HIV infected person cannot be a carer, the same for someone with Hepatitis. But latest research shows that person living with HIV or hepatitis who are under medical supervision and who live a healthy life and follow all the guidance from the doctors can live a full and healthy life and be an active member of society.” [Russian-speaking participant May 2010]*

d) Family & friends

*“I am not stigmatised by friends because of my past behaviour (unsafe sex) but perceived past behaviour - ie. but you must have injected drugs.” [English-speaking participant May 2010].*

*“I have a great number of friends who are in the media and through them am able to get clear messages to global and local communities.” [English-speaking participant May 2010].*

*“I am lucky that I have support of my family and friends so can speak out I know many other women who cannot because of stigma and fear for their children.” [English-speaking participant May 2010].*

*“My friends supported me, they did not pity me.” [Russian-speaking participant May 2010]*

*“Friends and work colleagues have accepted my infection as something normal and keep on seeing the human being in me and not only the infection.” [German-speaking participant May 2010].*

*“I disclosed to my family as I thought I was dying and they were all OK and have been very supportive. I have been involved with HIV organisations in the UK and that made it easier to feel accepted. My friends back in Africa know, and some have contacted me first to disclose their own status.” [English-speaking participant May 2010]*

e) Intimate relationships

*"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-speaking participant May 2010].*

*"Sexual partners don't want their friends to know" [English-speaking participant May 2010].*

*"My spouse (negative), whom I told immediately, thought, 'We have accomplished so much together and we will also accomplish that.' I was very happy about his reaction." [German-speaking participant May 2010].*

*"When I told my step mom and husband and my young brother that I am positive I felt well supported. It was completely normal that I would tell them." [German-speaking participant May 2010].*

*"In relationships the parents of my ex-partner were instrumental in our separation, in all relationships thereafter to avoid rejection and discrimination I abandon the relationships." [Portuguese-speaking participant May 2010].*

*"Stigma was more the avoidance of relationships" [Portuguese-speaking participant May 2010].*

*"I don't have relationships then I don't have to disclose/ face rejection". [English-speaking participant May 2010].*

*"I avoid situations when I may be rejected sexually or otherwise." [English-speaking participant May 2010].*

*"Also I live in a small rural community and most have been great about me and my husband being now HIV+ - but we have lived here over 25 years and are well known and i have done in the past much voluntary work in the community." [English-speaking participant May 2010].*

f) Religious group

*"I have experienced verbal abuse from people and had a bad time when I first told my church was told not share from the same communion cup and to be wary of who I tell my status to. This was from the elders of the church." [English-speaking participant May 2010]*

#### 4. xxi) Overcoming stigma

We asked the participants to suggest strategies they have developed for overcoming stigma and they included the following:-

- Through my spiritual practice, by practising self acceptance, by not looking to something outside of myself to tell me I'm ok.
- By talking to people I feel safe with when I experience feelings of shame, normally triggered by an outside influence.
- I work a twelve step programme which at the very core is about spiritual practice. I am powerless over people, places and things, I continue to learn not giving my power away to negative forces, be that a person, place (institution) or thing. All I can do is change myself, my perception, and empower my self
- Psychotherapy
- Positive affirmations
- Diary writing
- Doing things that make me feel good and are good for me
- Being selfish
- I've confronted and worked on it in therapy, therefore I managed to overcome it.
- I worked on my personal development through support groups and work with psychologists
- Not to tell everyone
- I simply do not internalize them. Any shame/stigma imposed on me is the others problem not mine I have no shame at being HIV+, I did nothing to get it more than any other woman who does not have it.
- My main coping strategy is through working in the sector myself and trying to improve the situation faced by others.
- Confidence, leadership and knowledge of rights.
- I run trainings for overcoming stigma in HIV/AIDS during which everyone can experience the shock of diagnosis, then from feedback forms I heard that this helped to change attitude towards HIV.
- Ask for help from human rights defenders
- Inform people about HIV
- Read the Bible and pray and look for answers
- Prayers, patience, calmness.

#### 5. Conclusions

There was a wonderful willingness and trust in this process from the participants, who really welcomed a channel through which to be able to have their voices heard. As such, WECARE+ has a responsibility to use this information in a constructive and innovative way to bring about lasting improvement in their lives.

## 6. Recommendations

Some of the clear recommendations coming from this data set and the experience of collecting it are:

- ✓ Elaboration of this data - examine the particular situation of different nationalities, ethnic groups, age groups, faith groups and different groupings of women (for example women who are or have been sex workers, women who use or have used drugs, partners of people who use drugs and women who have reported different times since their diagnosis or time of contracting HIV).
- ✓ Further examination of the data would allow cross analysis with instances of co-infection and or disability - both related to HIV and not related - to try and unpack the reasons for these results, based on this data set.
- ✓ There are great differences in the availability of treatment across the region, and even where it is universal the suitability of it for *women* has been questioned.
- ✓ Treatment literacy ranges greatly, even within language groups, which is where cross-referencing of responses across different groups would be useful.
- ✓ Counselling at the time of diagnosis varies greatly. It would be interesting to probe deeper to see what patterns there are around this.
- ✓ Difficulties with access to other medical services, particularly sexual and reproductive health services, remains problematic in all countries, because of discriminating attitudes.
- ✓ Experiences of discrimination are similar across the respondents and made more complex by additional layers of discrimination relating to gender inequality, gender violence, belonging to a “key population”, and social/ economic/political status.
- ✓ Stigma, both internal and external, and devaluation of self can be seen in many of the correspondents. This clearly shows that stigma does not improve and possibly gets worse, despite the improved access to ARTs.
- ✓ This data set can be used to highlight some of the gaps currently existing in data: for example, those of young women, disclosure in the workplace, psychological issues and the point at which counselling is sought to help overcome the effects of stigmatising attitudes and behaviours.
- ✓ Lessons can be learnt from the methodology used to gather this data and to improve on that for subsequent surveys.
- ✓ There is great scope for sharing experiences on prevention, support, care and treatment across the region – a kind of regional peer education.

This report forms the blueprint for the work of WECARE+ across the region.



wishes to thank all women involved in all aspects of this survey.

We welcome ideas, suggestions and funding opportunities to enable us to extract more detailed information from this data.

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