



2nd WECARE+ MEETING - 17th July 2011 Rome

Background:

WECARE+ (Women with HIV in Europe and Central Asia Region) was created in October 2009 at a meeting in Vienna in preparation for the International AIDS Conference (IAC) Vienna 2010.

At the 2009 meeting many women with HIV, and advocates for the rights of women with HIV, from various European and Central Asian countries, shared their experiences and gathered a sense that there were common challenges for positive women in this region. By the end of the meeting the decision was made to create a regional network with the aim of continuing sharing experiences and to put issues for women in Europe and Central Asia on the political agenda. The first step of the newly born network was to carry out a [survey](#) to shed more light on the experiences faced by positive women in the region. The survey was launched in July 2010 at the Women Networking Zone at the IAC in Vienna.

Since the first meeting WECARE+ members have joined a closed Yahoo Group to continue the dialogue and share information.

The opportunity to hold a second WECARE+ meeting was created by the convergence of a large number of positive women in Rome for the 6th IAS Conference on HIV Pathogenesis, Treatment and Prevention. This was the first time that such a large number of women with HIV participated to the IAS conference, which is perceived mainly a 'scientific conference', where strong community participation is not encouraged.

The participation of women was possible because of the synergy of the SHE+ programme (Strong HIV Positive Empowered) by BMS (<http://blog.ias2011.org/post/2011/06/20/The-SHE-Programme-European-Launch-Watch-out-Europe-Here-SHE-Comes-An-Affiliated-Event-of-IAS-2011.aspx>) and the support of the Global Coalition of Women and AIDS, who provided funding to the Women Networking Zone activities (http://www.wecareplus.net/index.php/page/Rome_2011/en). SHE+ and The Women Networking Zone supported nearly 80 positive women, with a large contingent of young activists, from all over the world, to come to Rome as well as giving financial support for a temporary post (one day a week) for Silvia Petretti from Positively UK (www.positivelyuk.org) to coordinate the WECARE+ meeting.

Silvia Petretti met with the WECARE+ board just before the meeting. The board asked her to include in the agenda discussion on membership and vision statement. This was an additional challenge because of the limited time available for the meeting (3 hours).

Meeting Structure

The meeting was attended by around 50 women from 12 countries (Italy, UK, Ireland, Tajikistan, Russia, Ukraine, Spain, Portugal, Germany, Armenia, Poland, Romania). Translation was provided by volunteers from the different groups.



The aims of the meeting were:

- Increase knowledge of challenges faced by women living with HIV in Europe and Central Asia and share strategies to overcome them.
- Increase knowledge of advocacy tools available and the capacity to advocate for the rights of women living with HIV in Europe and Central Asia.
- Drafting a Vision Statement

This was done through the following agenda:

- 1) Introductions and ground rules
- 2) Small groups discussion: challenges and strategies to address them
- 3) Identity and Membership of WECARE+
- 4) Drafting a Vision Statement
- 5) Closing and Evaluation

1) Ground Rules

- ✓ Have Fun
- ✓ Listen to each other
- ✓ Agree to disagree
- ✓ Speak Slowly
- ✓ Contribute ideas (especially if you see it differently)
- ✓ Mobiles off/silent
- ✓ Learning from each-other
- ✓ Get feedback from everyone
- ✓ Respect for difference
- ✓ Apologies, but try to stay till the end
- ✓ Confidentiality
- ✓ No judgement

2) Challenges and Strategies to Address Them

The groups were formed on regional criteria and also on specific issues we divided in:

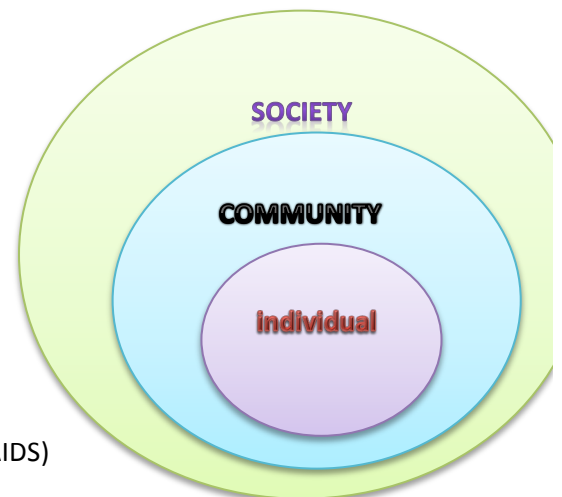
- Western Europe,
- Eastern Europe and Central Asia
- African Women living in Europe.

There were also two additional presentations by the UK representatives, one on the main challenges and solutions for young women, this was presented by four women under 30 (Appendix 1), and a second presentation on issues for women living with HIV who are in prison (Appendix 2).

Eastern Europe and Central Asia Group

CHALLENGES

- 1) Stigma
 - Self-stigma
 - Related-stigma (family)
 - Multiple stigma (drug use, sex work, prison, LGBT)
 - Social status (workplace, care, health-workers)
- 2) MIWA (Meaningful Involvement of Women with HIV and AIDS)
- 3) Sexual and Reproductive Health and Rights



STRATEGIES:

- 1) Raising awareness education
 - Society
 - People Living with HIV
 - Networking
- 2) Legal Frameworks
 - Social Care and Support
 - HIV care and treatment
 - Gender sensitivity
- 3) Advocacy: National/ Local / Regional

Western Europe

This group prioritized five challenges and also identified several more:

1) Medicalized model of care

There is an assumption that provision of medical care and ARVs are sufficient for a good quality of life. The complex psychosocial needs of women living with HIV are often ignored and women are left with many unmet needs and very isolated.

2) Stigma

In all its forms, but reinforced by other form of oppression including sexism, poverty, racism, prejudices towards women who are/have been in prison and women who are/have been using drugs.

3) Criminalization

This includes the criminalization of drug use, sex work and also the prosecution for criminal transmission of HIV

4) Lack of funds

Especially the lack of funds for work that focuses on women with HIV.

5) Lack of understanding of the connection between violence against women and HIV

Other challenges for women with HIV: women are not a priority and even when they are represented or consulted it is not sufficient and there is often tokenism. As a consequence frequently there is an oversimplification of issues by policy/decision makers who know very little of the reality of the lives of women with HIV. Moreover even when there are good policies sometimes they are not put into practice. There are additional issues for people without legal status, concerns and anxieties around ageing. Also the trend towards 'normalization' of HIV and the attempt to define it as a chronic condition, just like diabetes, often acts as a further barrier to understand the complex issues women with HIV face in their everyday lives.

The first step to overcome those obstacles is to ensure women are visible (MIWA Meaningful involvement of women with HIV).

The group felt that there was not time for working out more strategies

Challenges for African women living with HIV residing in Europe

1. Uncertain Immigration status and or restrictive immigrations policies – many African HIV positive women struggle to look after themselves, their families & or get involved in 'activism' because their priority is to make sure they (and their families) are

settled in the chosen country of residence. Without an immigration status, HIV positive women feel that they can't engage with anything else.

2. Social issues – Once the immigration status is sorted (a process that can sometimes take years) African women living with HIV have to then navigate the health system, get training & or education and seek jobs. There is a significantly high rate of unemployment among the HIV positive African communities due to stigma & discrimination and racism. It is incredibly difficult to ask somebody without recourse to public funds or a paying job to get involved in advocacy or anything else for that matter.
3. Involved but not effectively – not all African women living with HIV have Immigration challenges and many others have gone on to become residents in their countries of choice. Additionally, there are many women who support each other or other people at community level. Unfortunately, the community level support and or one to one informal support is not enough to support advocacy work, campaigns or policy change. There are just not enough African women living with HIV working at the level where issues are being debated and policies are taking shape. This maybe to lack of confidence to engage in policy discussions, lack of knowledge of where & when these discussions are taking place & or unfair representation.

Possible strategies for moving forward

1. Training and up-skilling of African women living with HIV to promote the meaningful involvement of African women at all levels. (Fffena, a project by the AHPN does this at some level though is does it for both African women and men living with HIV)
2. African women living with HIV in Europe are not a homogenous group so it is difficult to have a uniting vision to rally around and to ensure meaningful involvement. It is important to have a clear vision on what needs to be achieved.
3. No one really knows how many women living with HIV there are living in Europe. It is important for some sort of research to go take place at each country level not only to be aware of numbers but more crucially the needs from country to country and how the policies in each country hinder or facilitate the HIV+ African women's chosen agenda.

Young People

The presentation by Positively Youth, a project by Positively UK which has at its centre young people living with HIV who act as peer mentors highlighted the following challenges and the strategies used to overcome them.

Challenges:

- 1) Young people are not accessing support services.
- 2) Young people find transitioning from paediatric to adults services difficult where steps are not in place.



- 3) Young people feel unconfident in taking full responsibilities of their health and making informed health decisions.

Solutions:

- 1) Provide peer led support in clinics for hard to reach and isolated young people.
- 2) Working with health care professional to establish transitioning steps providing a seamless transition for young people.
- 3) By having positive mentors in place: it empowers and enables young people to take control of their health and become more involved.

The outcomes of this process are:

- Health care professional and young people effectively managing transition
- Increased ability in managing HIV diagnosis
- Better Adherence
- Reduced Isolation

Women in Prison

Positively UK has been providing peer support in Holloway prison for over 20 years, HMP Downview for 6 years and HMP Bronzefield for the last year.

Challenges:

- 1) High levels of stigma and discrimination in Prisons and Detention centres, leaving women isolated and traumatised and violated of their human rights.
- 2) Disruption of ARVs because of management of medication within prison pharmacy settings regarding prescribing and distribution.
- 3) Denial of the existence of the factors contributing to the spread of HIV in prison: unsafe sexual activities, drug use, sharing of needles, ineffective policies, poor prison management.

Strategies

- 1) Providing peer support helping women move forward from a place of isolation and fear to empowerment and safety.
- 2) Advocating for the rights of women with HIV who are in prison, working closely with healthcare providers in prison and women with HIV.
- 3) Providing education around management and adherence and informing the women detained of their human rights.
- 4) Being a voice for women with HIV in prison by actively contributing to policy making raising specific issues for HIV positive women in prison.
- 5) Delivering educational programs to prison staff raising awareness and knowledge to facilitate a more structured supportive environment for women living with HIV in UK prisons



3) Identity and Membership of WECARE+

There was a long discussion on 'Who' WECARE+ is and whether membership should be restricted uniquely to women who are living with HIV.

It was felt that WECARE+ is a linking body for women who advocate for the rights and dignity of women living with HIV in Europe and Central Asia. In order to fulfil this a role WECARE+ needs to work closely with existing network of women living with HIV such as ICW Global and GNP+. It was stressed that it is important not to duplicate work, or 'reinvent the wheel'. It was also noted that WECARE+ is a network of leaders and advocates for the rights of women living with HIV and not a support group. As such it can be have a more open membership.

At the closure of the discussion there was a consensus that WECARE+ membership should be open to all women who want to play an active role in advancing the rights of women living with HIV, including those who are HIV negative or untested. However, it was also felt that women living with HIV should still hold a central role in the network.

More discussion is needed to clarify roles and level of membership of untested and negative women, and how they can support and promote MIWA (Meaningful Involvement of Women Living with HIV).

Creating a Vision Statement

A vision statement is a short sentence that describes 'the dream' we are trying to make a reality through our network.

It was once again stressed that WECARE+ is a network of leaders who aim to push the issues faced by women living with HIV on the political agenda. WECARE+ uniqueness is that it has at its centre women who live with HIV and that it is fully committed to include women in all our diversity, especially women from key populations which are made most vulnerable to HIV. WECARE+ is especially committed to support women with HIV to take responsibility and to use openness about HIV status as a strategy to end stigma.

Some of the proposed Vision Statements are:

- "WECARE+ for each other"
- "Women in Europe not vulnerable to HIV"
- "Living our lives with dignity and respect for human rights"
- "Women as a leading force in the HIV response"
- "United for equality through the HIV response"
- "European and Central Asian women united for the rights of women living with HIV"
- "Working for equality for women living with HIV"

It was agreed that more discussion on the vision statement will happen through the Yahoo group.

Advocacy Materials distributed.

In order to support the advocacy efforts of women living with HIV the following materials were distributed:

Policy Brief ‘Put Your Money Where Your Mouth Is’ on investment in the meaningful participation of Women living with HIV (as illustrated by the ICW Tree of Participation), produced by Salamander Trust in consultation with and endorsement from over 60 networks of women living with HIV globally, and translated into English, French, Russian, Spanish, and Italian.

In Women’s Words Action Agenda: highlighting the five priority issues identified by women through the virtual consultation, and providing a ‘state of the response’ analysis of 10 Building Blocks for an effective HIV Response for women and girls. Coordinated by ATHENA and GCWA and with support from UNAIDS and UN Women

SHE toolkit: SHE+ (Strong HIV positive Empowered) is a toolkit to provide peer support to women living with HIV in clinical setting developed by women living with HIV in partnership with health care providers. The toolkit is unique in addressing the specific unmet needs of women living with HIV and will be translated in all major European languages and have a dedicated multilingual website to be launched at the end of September (www.shetoshe.com). Not all the WECARE+ members participated to the SHE+ launch that focused on Western Europe so extra sets were made available.

Positively Young: a one off edition of Positively UK magazine produced by young people living with HIV and focusing on issues for young positive women in the UK.

WECARE+ leaflet: highlighting the findings of the survey conducted in 2010 and to be used to promote the network widely.

Evaluation

Anonymous evaluation forms were available in 5 languages (Spanish, French, English, Portuguese, Italian) and filled by 24 participants.

Q1. On a scale of 1 to 10 (1 is nothing 10 is very much) how much do you feel you know about challenges for positive women in Europe and Central Asia?

Respondent	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Before	3	9	7	8	9	8	5	8	7	8	4	7	10	7	10	3	4	2
After	7	9	9	9	10	9	9	10	9	10	8	9	10	8	10	5	7	7

Respondent	19	20	21	22	23	24
Before	7	3	7	7	4	8
After	8	5	8	7	8	9

Q2. On a scale of 1 to 10 (1 is nothing 10 is very much) how do you rate your confidence to act as an advocate for women living with HIV in Europe and Central Asia?

Respondent	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Before	1	10	9	9	10	6	8	8	3	8	4	9	9	5	10	4	6	4
After	5	10	9	9	10	7	8	8	7	8	7	10	9	6	10	8	7	9

Respondent	19	20	21	22	23	24
Before	7	2	9	8	1	8
After	8	6	9	8	4	8

Q3. How many people will you share with what you have learnt at this meeting?

Nobody	1 to 5	5 to 20	More than 20
	1	10	13

Q4. Is there anything else you would like to say about the WECARE+ meeting?

1. As it's early days I understand the confusion around each other's understanding. I feel it was well conducted, especially given the language barriers.
2. (blank)
3. We need more meetings for making decisions about WECARE+
4. (Blank)
5. (blank)
6. About the member – I feel the core must be HIV+ women and open to other organizations and people that work with HIV people (all effective work) but not organizations or persons working for PLHIV.
7. (blank)
8. Changed my mind about femininity
9. I would like that WECARE+ would be supported by anyone who cares for the rights of women living with HIV
10. Nice atmosphere
11. There was a few presentations it was something new for me (young people, women in the prison. It was very interesting for me. It will be useful in my work. And I have a lot of ideas to discuss in my organization
12. A very positive forum discussing very important issues. It is important that we are all working with the same passion. Important element around defining 'who' and 'What' we do

13. It was very well facilitated but most of the issues have not been dealt with due to lack of time
14. This was little time (to discuss challenges) and little amount information discussed. I am very happy that we could be and appreciate the fact that I could be a part of it. I wish it could be longer
15. Good facilitator
16. This is very important and we want to be involved in common activities
17. Good learning, but I still feel I need to learn so much more
18. (blank)
19. Great discussion
20. (blank)
21. There are still a lot of challenges Europe that we seem not to know> I already advocate for women and others living with HIV . I think we all need patience and continue to work with each other and draw what we can from our negative support friends.
22. (blank)
23. I have a broad understanding of the issues faced by WLHIV in Europe and Central Asia but would find case studies illustrating the issues highlighted to enable more effective advocacy. I felt the late change to the agenda complicated the morning. It meant we started to talk about very important issues which need plenty of time for discussion (vision, mission etc.) and reflection at late stage I am pleased we have agreed to continue this discussions . I would like to see women from more European countries participate: France, Netherlands Nordic countries etc. And I would hope that positive women from Germany would also be able to participate.
24. Good facilitator. Friendly environment.

25. Q5. What didn't go well for you?

1. I got a bit confused at times
2. Too long discussion about who was the "WE" we are ALL living with HIV in some way and most of any support comes from negative or untested people
3. Would have wished for few more concrete decisions
4. I found the meeting very enriching and many of the things that were said were a real eye-opener for me
5. There should be more people
6. (blank)
7. Not legitimate, strange temporary, confused, mixed feelings
8. (blank)
9. (blank)
10. (Blank)
11. My language barrier
12. Drawn out discussion
13. What WECARE is and what it aims to do and achieve

14. Not much support and willingness to work together from the other representative from the countries I represented. Language barrier was a big challenge for me in Portugal. Also there does not seem to be a lot of other positive women there that are willing to work with.
15. (blank)
16. We still do not understand the membership, who we are. But we have hope now.
17. Air conditioning
18. (blank)
19. (blank)
20. (blank)
21. Discussions the time was short
22. (blank)
23. (blank)
24. Language barrier

Q6. What was the best thing about the WECARE+ meeting?

1. Learning about WECARE
2. A feeling of community
3. The attendance of many women
4. Sharing different opinions and information from such diverse backgrounds
5. At least we could meet and discuss some important issues.
6. Know members
7. Group work
8. To put together women from different areas of Europe and different reality. Diversity
9. (blank)
10. (blank)
11. That we can meet women from another country and tell our problem and feel we are the same, and have same problem. Thank you. ;-)
12. Meeting other women. Structure. Learning new info for my organisation.
13. Discussing what the issues are and why we exist as women. It is a great way of meeting others again.
14. The fact that I was (hopefully am) again in touch with other positive women activists and the opportunity to continue work in this field. Thank you. XXX
15. (blank)
16. 16 Great Organization! Open and transparency. Good leaders!
17. Learning and networking
18. (blank)
19. Long live WECARE
20. (blank)
21. Time
22. (blank)



23. Well organized . Great (and unique) to meet other women living with HIV in Europe and Central Asia and learn about their issues.
24. Experience exchange. Vision. Mission. Discussion

Summary

The second WECARE+ meeting, in spite of the very limited time available for in depth discussion, highlighted several important issues for the future development of the network:

- ❖ Women living with HIV in Europe and Central Asia value this kind of meeting/network and consider it an important skill building and networking opportunity.
- ❖ Women participating in the meeting will discuss the content of the meeting with large groups of women (51% of respondents will share with over 20 women).
- ❖ All working groups identified MIWA (Meaningful Involvement of Women living with HIV) as a core strategy to ensure the rights of all women living with HIV, in our diversity, are upheld.
- ❖ Very little is known about African women living with HIV in Europe and Central Asia. WECARE+ could work on a research project on this.
- ❖ Membership of the network should be open to untested and negative women. However, women living with HIV should play a central role in order to actively promote MIWA. Further discussion on yahoo group will highlight how this will translate into action.
- ❖ Preliminary discussion on vision/mission statement was insightful but needs to be continued on yahoo group and future meetings.
- ❖ Transparency and accountability and representation should be promoted and criteria for election/participation to future meetings should be developed.
- ❖ Better representation of all European countries needs to be achieved.
- ❖ The meeting provided a safe space for 5 young women living with HIV to present about youth peer lead work, with focus on transition from children to adult services.
- ❖ Sharing of good practices for peer support of women with HIV in prison.

