



ICW IAVI PARTNERSHIP ON GENDER & SEX IN HIV RESEARCH 2015



International Community of Women Living with HIV (ICW)

Partners: IAVI, ICW-Kenya, AVAC

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Narrative Report

'My knowledge on research has increased and I am glad we have set priorities that we can share with researchers and those investing in research'

ICW member, October 3, 2014, post evaluation form

'It is important for me to marry the priorities of women with the research I am doing.'

Researcher, October 3, 2014, post evaluation form

The International Community of Women Living with HIV (ICW), in partnership with the International AIDS Vaccine Initiative (IAVI) saw this collaboration as an opportunity to create several dialogue platforms between researchers and women living with HIV and to create further possibilities for collaboration.

Our work together through this grant allowed us to deepen women's knowledge on the existing research agenda; build on existing understandings of research processes and refine a research agenda with priorities for women living with HIV, through the creation of these unique spaces for direct engagement and dialogue with researchers to demystify the research processes and politics for women living with HIV.

ICW, is a network of individual women living with HIV in ten regions and over 120 countries. ICW envision a world where all women living with HIV live our lives free from gender oppression, realizing and claiming our full rights inclusive of sexual, reproductive, legal, social, economic and health rights. ICW is the only worldwide network run for and by woman and adolescent girls living with HIV.

We have over 15,000 diverse women and girls who are members of the ICW network. As such, ICW was uniquely positioned to plan and implement this program that was developed in partnerships with IAVI.

Many ICW members had some familiarity with research processes, having participated in trials and research, including clinical and social science research, educational activities and capacity-building to improve the quality of treatment and services offered in healthcare settings. However, for many women the experience is frequently in one direction, with researchers seeking information from women living with HIV and very little reciprocity about what sort of questions ought to be asked and what pieces of research would address key areas of concern to women living with HIV.

In partnership with IAVI we believe we have successfully implemented a model where we can engage women within their level of experience and understanding and create opportunities for exchange and two-way communication between researchers and those they frequently conduct studies on. We are excited to continue to implement this type of programming throughout our network.

Objectives and Key Activities

1. Foster a long-term working relationship between women and gender stakeholders and research partners by establishing regular mechanisms/forums for discussions on gender/sex in HIV Research.

Specific activities for 2014 included:

a. Satellite Sessions at IAS 2014 to discuss gender/sex issues in HIV research:

Key Deliverables

1. 50 Women living with HIV were able to raise their concerns and issues about the ways in which research is and is not meeting their needs.
2. An Opportunity for ICW to map and build consensus and understanding amongst women and the research community about the unmet research needs of women living with HIV.

During AIDS 2014 in Melbourne, Australia ICW and IAVI partnered on a special session in the Community Village's Women's Networking Zone (WNZ) titled *Women Setting the Agenda*. This session was strategically placed in the WNZ as this particular section of the conference creates an inviting and safe space for learning and exploration and has historically high traffic for women living with HIV and other community allies interested in women's issues.



The session included a panel discussion with four women living with HIV on from diverse regions as well as Prince Bahati, Director of Research Preparedness, Policy & Advocacy from IAVI. This session was attended by approximately 50 participants. Although the session was not focus group per se, the exchange created a space for women living with HIV to raise their concerns and issues about the ways in which research is and is not meeting their needs. The session was live streamed and put on YouTube so that ICW members and other stakeholders could access it and spark community discussion.

Based on the success of this session and the enthusiasm, we were very excited to move forward on other joint sessions to continue to map and build consensus and understanding amongst women and the research community about the unmet research needs of women living with HIV.

YouTube session link: https://www.youtube.com/watch?v=x43du_whAYE

b. Satellite Sessions at Research 4 Prevention Conference 2014 to discuss gender/sex issues in New Prevention Technologies:

Key Deliverables

1. Increased knowledge among ICW members on PrEP and how it should be rolled out or scaled up to reach different populations.
2. Researches heard from lived experience of Women Living with HIV rather than the usual text book evidence, a situation that will inform future research design.
3. ICW members provided genuine feedback on research methodologies and current practices that are not always inclusive of women's voices.

Participating in this conference allowed for an important exchange of the lived experiences and women living with HIV and researchers. who often make decisions based on textbook evidence rather than the realities that impact most on our lives. The women interacted with researchers and policy makers from all over the world in workshops, symposiums and informally at the advocates corner and were able to provide genuine feedback on research methodologies and current practices that are not always inclusive of women's voices.





ICW members attended a pre-conference sessions on 26th and 27th October. An important Update on PrEP was presented and discussion on how PrEP should be rolled out or scaled up to reach different populations.

<http://www.unaids.org/en/resources/presscentre/featurestories/2014/october/20141029prep/>

The advocates meeting on 27th October 2014 was a highlight of the conference. Discussion on how to get updates on current prevention options and various ways advocates can participate during the conference and also be engaged in advocacy work after the conference were made.

Meeting with Women interested in the PrEP agenda on 27th was an opportunity to understand what is happening in other countries but also deliberate on action plan to advocate for PrEP roll out among women.

The Advocates Corner gave women an opportunity to meet and network with other advocates as well as a safe space to discuss how the conference and presentations made impact on our work at country level. On 30th ICW members met researchers at the advocates' corner. Some of the discussions were around ensuring research answers and questions that concern women and girls living with HIV. The issue of life long treatment for pregnant positive women was raised by young women as a concern among young women living with HIV. Adherence to prevention tools is key to addressing underlying barriers to utilizations of services as shown in different trials on microbicides targeting young women.

c. Joint op-ed or reports on Gender & Sex issues in HIV research:

Key Deliverables

1. Think piece written by women who are living with HIV.
2. Document published on ICW Website and used as tool for training participants.
3. Currently identifying opportunities for the think piece to be published as in Op-ED.
4. The op-ed speaks to the success of biomedical research taking into considerations the missed opportunities in focusing on the social realities faced by communities in e.g. stigma that erodes the gains of biomedical interventions including the successes of some research trials.

A team of ICW members, Welbourne, Paxton, Matheson, Thomas, Mthembu co-wrote a think piece titled ***'Where women with HIV lead, researchers (eventually) follow'***. While this paper has yet to be officially published, it has been distributed at our events and to program participants. We continue to seek opportunities for further development of think pieces on key research subjects and for this to be published.

Over the past two decades, biomedical research on HIV has taken us to the point where science can theoretically control this virus. Unfortunately, because of the stigma and other factors that are inherently related to HIV, science alone cannot solve the HIV pandemic, that continues to be the major cause of death of women between 24–40 years globally.



2. Enhance the potential for robust participation by women and girls in the HIV research process by building their knowledge and understanding of biomedical HIV research.

Key Deliverables

1. Participants gained a thorough understanding of research components and their potential roles in future research and were able to articulate how they could engage with research processes.
2. Participants gained thorough understanding of current research on prevention technologies and cure/vaccines.

a. One regional research literacy training for ICW and partners networks in East Africa. A collection of FAQ and concerns of women will be compiled:

Key Deliverables

1. 25 women from Eastern Africa participated in the research literacy training.
2. Identified gaps in gendered focus on research and the consequences of poor participation of women living with HIV and the implication on the quality of research.
3. A very clear Research agenda/needs for women were identified and strategies of bridging the gap between women living with HIV and researchers discussed and presented by participants (see Research agenda below).

In October 2014 IAVI and ICW convened women living with HIV from across the East African Region to explore issues in research, deepen the understanding of the participants and to identify key concerns of women living with HIV.

The three-day training, titled Women Setting the Agenda Bridging the Gaps between Gender, HIV & Research Workshop included participants from Uganda, Kenya, Zimbabwe, (The Zimbabwean participant had effectively participated in R4P and we saw it important to bring her to this meeting for sharing of best practices and continuity in engagement around research and women living with HIV) Rwanda and Tanzania. The session began with a brainstorming session about some of the participant's impressions, concerns and priorities, particularly around the key issues of HIV Prevention, Microbicides, PreP, and Hormonal Contraceptives. The outcomes of these sessions resulted in the development of an initial set of Research Priorities.

The program included a research literacy session where the components of biomedical research, behavioral and social sciences research, and implementation science. Through out the sessions we reviewed key terminology, research phases and IAVI provided in depth explanations and exploration of current relevant research including cure research, microbicides and planned research on hormonal contraception. Importantly, the literacy training included interactive sessions on good participatory practices and the role of women in research. Case studies in research were presented and the participants had an opportunity to examine the research process and consider various options for engagement.

The women raised the following key ideas and questions as a result of this session:

- What is the knowledge level for women living with HIV on issues around researchers and the processes and when to engage?
- Do women have a communication plan for engaging with researchers?
- Involvement of advocates and activists should be done from the onset of the research process.

As a part of this workshop women living with HIV were engaged to think about Gender & Sex in HIV Research and in particular how to approach bridging the gap between women, girls and researchers. Further, women work-shopped why gender and sex matters in research and deepened their collective understanding of the impact of lack of a gendered focus in research has on the quality and usefulness of research and the consequences of poor participation of women in research. Participants were divided into three groups to identify and prioritize research needs for women living with HIV.



Identified Research Agenda

The set of specific research issues including for example hormonal contraception were deemed to be too specific to be actionable, instead the specific unmet research needs of women living with HIV that were identified through the workshop formed the basis of the following plan that was developed to ensure that the needs of women living with HIV are reflected in research.

1. Knowledge Sharing and Research Literacy

What

- Women Living with HIV equipped with skills and knowledge on basic research methodologies.
- Women Living with HIV are trained as trainers (ToT) on Research literacy to promote greater and meaningful involvement of women and girls living with HIV in research processes.

How

- Design and develop a program on research literacy.
- Develop a knowledge hub for knowledge sharing for women and communication on research issues and outcomes directly affecting Women and adolescent Girls living with HIV.
- Develop formal and structured partnerships with our research allies.
- Identify and develop Resource mobilization strategies.



Desired Outcome

- Increased Women Living with HIV participating in research.
- Women Living with HIV have a good understanding on research methodologies as well as their rights as research participants.
- Women Living with HIV who can help shape and support their communities to take the lead on the development of new prevention technologies and other innovative research activities.

2. Family Planning Access and Choice

What

- Increased research on family planning method mix for women and girls living with HIV.
- Increased information dissemination of family planning options for women and girls living with HIV.
- Research on the relationship of ARV and Family planning and speed up of ECHO trial.

How

- Legislation of Family Planning policies that are responsive to the needs of women and girls living with HIV.
- Prioritize advocacy for funding for ECHO research.
- Create community support for increased uptake of SRH commodities by WLHIV.
- Develop a clear advocacy strategy for social mobilization for demand creation.

Desired Outcome

- Increased access and uptake of SRH commodities and research by women living with HIV.

3. Sustainable Resource Planning for Women and HIV Research

What

- Deliberate resource allocation to fund local researchers.

How

- Participation in National budget making and allocation processes.
- Networking and collaboration with networks and organisation with similar interest in research.
- Exchange program.
- Knowledge management.
- Applying alternative resource mobilization strategies.
- Advocacy for domestic financing for locally based researchers.

Expected outcome

- Increased funding base.
- Organizational growth.
- Long term multilateral, bilateral funding resources for WLHIV research.
- Verifiable monitoring, evaluation and learning documentation.



On the last day of the workshop the participants presented their research issues as well as these key areas of concern to an invited set of researchers and key stakeholders. Then the researchers had an opportunity to reflect on this agenda and to present their own specific work. The session concluded with a question and answer session, an open dialogue and plenary discussion with researchers. After the training a detailed report was produced and disseminated to the participants.

At the end of the training we held in Nairobi, the participants made a commitment individually and on behalf of their networks to continue the work begun at the training. Since the training we know that the research agenda developed by attendees at the October workshop was submitted by ICW Eastern Africa to a regional planning mechanism to determine priorities for the region and additionally IAVI worked to present the agenda in local forums.

- b. Two web based/Face-to-Face forums with researchers to answer specific questions from groups of women living with HIV– A joint FAQ or Fact sheet will be developed and refined with scientists.**

Key Deliverables

1. Six virtual forums were convened with one presentation on the cure delivered to ICW members.
2. An ICW fact sheet on “Women living with HIV and Research” developed from the conversations from the forum.

In total six joint meetings were convened virtually between ICW and IAVI including three collaborative meetings with AVAC partners to plan and prepare for the regional convening in Nairobi and for the R4P Conference in Cape Town. These sessions were critical to building on knowledge and tools that had already been completed. Including an ICW led fact sheet that was developed and proof read by local women in the region to ensure language was easy to understand and culturally appropriate.



In addition to this there were opportunities created for researchers to come together with women living with HIV and other stakeholders at the convening in Nairobi during for entire day of ideas sharing and regional planning, the session at AIDS 2014, during the daily advocate's lunches at R4P that ICW participated in as well as the other events at R4P.

- c. **Develop and disseminate FAQs and IEC materials that address women's issues on New Prevention Technologies through ICW and partners' networks.**

Key Deliverables

1. ICW worked with local women in the East African region to develop a simple research basics questions and answers fact sheet entitled "Demystifying Research" This was given to the regional representatives who were attending the literacy training in Nairobi.
2. Fact sheet disseminated to whole of ICW network ,list serve and published on ICW Website.

ICW worked with IAVI and AVAC to see what resources existed for research literacy and specifically what materials would be explored and where there may be some gaps in resources. ICW worked with local women in Kenya to develop a simple research basics questions and answers fact sheet entitled 'Demystifying Research' was given to the regional representatives who were attending the literacy training in Nairobi and to disseminate to their networks.

3. Build capacity of a core group of advocates to mobilize and educate more women to increase participation in HIV research, Policy and Advocacy that ensure equitable access to products by women and girls. Specific activities for 2014 included:

- a. **Training of 10 selected advocates on HIV research, Policy and Advocacy related to Gender & Sex in HIV research.**

Key Deliverables

1. Able to offer and deliver training to Training to 25 women living with HIV rather than the 10 estimated.
2. Supporting 4 women including one young woman to attend and participate in the R4P conference in Capetown.
3. Increased participation and dialogue on "Women living with HIV and Research" at high level meetings, conferences and workshops e.g. the inter-agency technical task team and identification of research gaps during WHO ARV Guidelines review processes.
4. Identified 10 women living with HIV to participate in the WHO ARV Guideline review process.

Through our first training we were able to provide training to 25 women living with HIV and of those original 25 we were able to ensure that 4 women attended and participated in the R4P conference in Capetown. Participants have since used their new knowledge base to ensure that high level meetings, conferences and workshop include a dialogue on research and women living with HIV.

This is an ongoing commitment to representation of women living with HIV and research often fall off the agenda. Women have also advocated at forums like the interagency technical task team and WHO ARV Guidelines review processes and have had the confidence and knowledge to identify the gaps.

- b. Create alliance with a network of female or gender sensitive scientists/researchers/policy makers to advance policy and advocacy issues related to gender/sex in HIV research.**

Key Deliverables

1. Participants from the regional training participated in the AVAC regional partners forum where they were able to articulate the research needs of ICW member and engage in dialogue with researchers on Prep and vaccine initiatives.
2. This is ongoing with approaches being made to partner with researchers and to support women to engage in and have information relating to current trials on prevention technologies.
3. One advocacy workshop facilitated by AVAC on the cure for ICW members.

This deliverable is in progress and will be ongoing. It was exciting to see many of the women who were engaged in the research literacy training gain their confidence and want to be involved in more research opportunities. We saw our members engage with other researchers and feel more confident to continue to build on these partnerships. Following the AIDS 2014 session, a number of researchers approached ICW to develop proposals in collaboration.

We currently have two proposals for submission, and two research projects that are in progress in collaboration with the Global Office as well as a number of other conversations happening via email, skype calls and advocacy working group meetings.

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ICW



Conclusion and Next Steps

'I have increased knowledge around research. I have learned that I can reach out to researchers and not wait to be called.'

ICW member, October 3, 2014, post evaluation form

'It was great learning to hear directly from the community, the priorities and what they expect from us as researchers.'

Researcher, October 3, 2014, post evaluation form

Working on this partnership was incredibly rewarding for ICW. We could see the excitement of our ICW membership to engage in many of these diverse opportunities to dialogue. Many of the participants are continuing to be engaged and requesting more opportunities for involvement. ICW is committed to working with researchers and our community to improve the lives of women living with HIV the society at large.

We learned from this collaboration that we are uniquely positioned to best support the community to be the agents of change to support researchers to engage in research that will have the greatest impact in the HIV movement.

While ICW and IAVI have explored this in this small pilot we are looking forward to building on this progress made and lessons learned.

1. Expand this pilot to do research literacy trainings for women living with HIV and convening with women living with HIV and researchers from Southern Africa, Central Africa, Caribbean and the Asian Pacific region.
2. Replicate the session Women Setting the Agenda from AIDS 2014 conference and deliver during the ICASA, ICAAP and AIDS 2016 conferences.
3. Engage and expand ICW's meaningful participation in research and support country networks to participate in research trails and develop skills as peer researchers.
4. Increase Support ICW involvement and writing in academic and scientific journals.

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Demystifying Research:

A CALL TO ACTION FOR WOMEN LIVING WITH HIV TO ENGAGE!

What is research?

Research is searching for and gathering information, usually to answer a particular question or problem. Research uses a predefined set of activities such as surveys, focus groups, or clinical trials to answer the question. There are many methods of collecting evidence to answer the question, including both quantitative (using numbers and statistics) and qualitative methods (stories and experiences), and many methods to analyze the data collected.

But who decides what research questions to ask, and who decides what evidence to collect?

Many people think of research as a highly complicated process of investigation that should be conducted only by those possessing specialized knowledge or skills. What we fail to acknowledge is that without the input of women and particularly women living with HIV, HIV related research efforts frequently do not answer those questions most important to women or reflect the needs or experiences of women.

Why should women living with HIV get involved in research?

Women are currently under-represented in HIV research. Women living with HIV face different issues than men including, unique complications of infection, side effects that impact our bodies differently (inclusive to transgender people) as well as unique concerns around pregnancy and reproductive health.

- Worldwide, women constitute more than half of all people living with HIV.
- For women in their reproductive years (ages 15–49), HIV/AIDS is the leading cause of death.
- Women are at least twice more likely to acquire HIV from men during sexual intercourse than vice versa.
- A study in South Africa found that young women who experienced intimate partner violence were 50% more likely to have acquired HIV than women who had not experienced violence.
- In 2013, 70% of pregnant women living with HIV received effective antiretroviral medicines to prevent the transmission of HIV to their children.
- In sub-Saharan Africa, women constitute 58% of all people living with HIV.
- In 2013, almost 60% of all new HIV infections among young people aged 15–24 occurred among adolescent girls and young women.¹

¹ Sources: *UNAIDS Gap Report 2014*, available at: http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS_Gap_report_en.pdf ; *UNAIDS Fact Sheet 2014*, available at: http://www.unaids.org/en/media/unaids/contentassets/documents/factsheet/2014/20140716_FactSheet_en.pdf

How will research better serve women and girls living with HIV, when they are meaningfully engaged in research processes?

Without the participation of women and girls in research, biological and gender differences may not be integrated in the design and implementation of the entire research process. Research may not reflect differences in effectiveness and side effects between men and women. Biological distinctions between women and men, such as differences in viral load and rates of male-female versus female-male transmission, may impact the effect of treatments and medicines. In addition, gender-related social and economic factors affecting future access to and use of HIV drugs and vaccine by women may not be integrated into policy.

It is vitally important for women living with HIV to be involved meaningfully at all stages of the research process to understand and address the needs and issues affecting women living with HIV. Engagement of women living with HIV will ensure that their needs and questions are answered and to provide informed guidance and advice about their lived experiences and the issues impacting women and girls.

Networks of women living with HIV, in particular, have the capacity to provide critical gender and sex analysis of proposed studies. We can leverage grass-root and community networks of women to educate and build capacity for better engagement of women in HIV research and we can leverage better partnerships with scientists in translating gender/sex sensitive research into policy and practices for the benefit of women living with HIV and other women and girls. It is past due time for research about and for women living with HIV, research of highest quality which speaks to women's bodies and needs and designed around our lives.

What are Gender and Sex issues affecting women and women living with HIV in Research?

Sex refers to the biological and physiological differences between men and women, while gender refers to social norms related to how men and women are expected to behave. Gender relates to the accepted roles, sexual norms and identity that are described as masculine or feminine. Gender roles and norms are specific to a culture and often change over time. While sex – the physical characteristics that differentiate male from female – does not change, gender norms, gender roles and gender relations can be shaped through interventions or through social and political changes.

For example, participation in certain research may exclude pregnant women or condition participation of women with use of contraception due to biological differences. However, other gender issues (such as Gender roles, Gender Based Violence, forced sterilizations of women living with HIV, concerns of fertility and side effect on the body, stigma, confidentiality, adherence, etc.) may differently affect women's participation in and outcome of research and should be addressed in the design and conduct of HIV research.

IAS recommendations on Gender and Sex in HIV research recommend the following:

- Sound scientific data should be sex disaggregated
- Men and Women should be included in the study
- Gender/Sex differences and similarities should be analysed
- Implications for men and women should be analysed.

Women advocates should amplify advocacy on gender/sex in HIV research at all opportunities by asking the following questions:

- Were men AND women included in the study?
- Are gender/sex differences and similarities analysed?
- Are the implications for men and women discussed?
- Were women living with HIV involved in the design, conduct and dissemination of the research?

Where women with HIV lead, researchers (eventually) follow

Over the past two decades, biomedical research on HIV has taken us to the point where science can theoretically control this virus. Unfortunately, because of the stigma that is inherently related to HIV, science alone cannot solve the HIV pandemic, that continues to be the major cause of death of women between 24–40 years globally

Women, Hiv and Pregnancy

A key area of concern for women with HIV, policy-makers and researchers alike has been pregnancy and keeping babies free of HIV. Yet women have been treated as objects of research, regarded as a threat and a challenge rather than active agents of change, determined to keep our babies HIV free. This is emotive territory. Researchers don't like emotion. They don't get trained to measure it. But to deal with these huge issues of life, sex and death, it is essential to deal not just with data and to view people as objects, but also to grapple with the realities of women's lives as we navigate these highly charged waters. World renowned physician and Fellow of the Royal Society Professor Michael Alpers, who eradicated kuru in Papua New Guinea, recognized over 50 years ago that research without emotional involvement was impossible². He understood from the outset that it was critical not to blame or threaten or criminalize[ref] those involved but instead to build the trust of those most affected by the condition, in order to be able to understand at first hand the pathways, (through caregivers, to their children), that kuru took. Through this close long-term relationship with the Fore community, Professor Alpers eventually succeeded in eradicating this disease. This huge breakthrough has had international benefit, leading to the understanding and control of other diseases³.

From this example we have much to learn. Today, ever-increasing numbers of women are diagnosed as HIV-positive during pregnancy, a very challenging and emotional time.

Women who are diagnosed with HIV during pregnancy, and are provided with anti-retroviral therapy (ART) throughout their pregnancy, have far less than 2% chance of having a child with HIV, even with a normal vaginal delivery [ref] and if they continue with ART can live long and healthy lives. However, women put on ART for life at point of diagnosis during pregnancy are, in fact, five times more likely to be lost to follow up as are other women [ref]. So women have the means of controlling HIV, but something is stopping them from taking the medicine.

Women living with HIV are unlikely to transmit the virus to others unless through unprotected sex. This can easily be remedied by their partners taking charge of their own health and wearing a condom. So the major challenge to loss to follow-up, is HIV drug resistance for the woman, and transmission of HIV to newborn infants.

2 <http://www.youtube.com/watch?v=geqcjzKDAw>

3 http://www.youtube.com/watch?v=vw_tClcS6To

Studies conducted by women with HIV reveal that women probably are lost to follow up because of fear of gender-based violence from healthcare providers⁴ [ref- ALN report with Promise] and/or from within the family [ref – COWLHA report] if they say they have been diagnosed with HIV. However these reports have not yet entered the mainstream consciousness of many scientists investigating Option B+ roll-out [Tenthani et al].

There has been some progress. In a rapid assessment of Option B+ in Southern Africa, presented at the AIDS 2014 Conference in Melbourne, it was stated that when there was community engagement, loss to follow-up decreased⁵. Other studies indicate the loss to follow-up of pregnant women diagnosed as HIV-positive is highest in the under 20 year olds⁶.

There is far too often a mismatch between what is offered women – with good intent – and what women really need and want. By way of example, a great deal of anecdotal evidence exists about the value of mentor mothers programs, especially when they are created and led by women living with HIV from the communities where they operate [refs to Uganda, UK]. These programs are rooted deeply in the community, attuned to the fundamental issues affecting the women concerned, able to withstand the ebbs and flows of funding, and consequently have long-term sustainability. However, to get such community-led and community-focused programs, which reach from the community into healthcare settings, into UN and national policies, is a challenge because women who have created these programs rarely have access to funds to create the measurable scientific evidence which donors require. Instead, internationally rolled-out programs with recourse to large funds, medical expertise and representation on global bodies, and seek instead to reach from healthcare settings into communities, are prioritized over women's grassroots-led efforts.

There has, to date, been no study of the value of women living with HIV as mentor mothers as opposed to women who have no contact with peers at point of diagnosis. It is perhaps time that women living with HIV are funded and supported to conduct this important piece of scientific research. ICW proposes a matched control study in two sub-Saharan African countries, Uganda and Malawi, on the difference in loss to follow-up of women who are diagnosed during pregnancy and immediately referred to community-led mentor mother programs, and women who do not receive a similar referral to peer support.

Quantity vs Quality of Care

Whilst treatment access for pregnant women is essential for the duration of the pregnancy, there is huge hype around long-term treatment as prevention, without consideration of whether continuing on treatment for life beyond the pregnancy is needed or is the best option for each woman concerned. For many of us, it was several years between our diagnosis and our needing to start on ART. There are many medical conditions where the best care involves watchful waiting, with the caring guidance of well-trained professionals. We would argue strongly that HIV is one of them. To initiate treatment before being psychologically ready or before it is physically safe to do so is likely to result in poor adherence, drug resistance and feelings of failure. This is true for

4 APN+, 2012. *Positive and pregnant - How dare you*. A study on access to reproductive and maternal health care for women living with HIV in Asia – Findings from six countries: Bangladesh, Cambodia, India, Indonesia, Nepal, Viet Nam <http://www.apnplus.org/main/share/publication/APN+%20Reproductive%20and%20Maternal%20Health%20Report%20A4%2013%20April.pdf>

5 Tweya H, Gugsu S, Hosseinipour M, *Loss to follow-up among women in PMTCT Option B+ programme in Lilongwe, Malawi: understanding outcomes and reasons*. Abstract THAX0101 AIDS 2014

6 Okawa S, Chirwa M, Ishikawa N, *Operational challenge: linkages from prevention of mother-to-child transmission services to care and treatment services in Zambia*. Abstract THAX0103 AIDS 2014

any medical condition, not just for HIV. How much better to support women to start treatment when we truly need it for our own health, when we feel safe and supported to do so by health staff, partners and other family members and are thus able to build the commitment to taking medication – which is not without its side-effects – for life.

Despite repeated requests for *quality of care* and *adherence levels* to be measured amidst all the Option B+ hype, there is an insistence that numbers of scripts written to initiate women on treatment, and quality of this data collection alone is the only remit of the global steering group on M&E of the Global Plan⁷.

Beyond Pregnancy – Women, HIV and the Rest of Life

Women with HIV have the rest of our lives to live before and beyond our pregnancies and our children. Yet there is scant attention paid by the global AIDS research or policy world to the rest of our lives.

Let us consider cervical cancer, an opportunistic infection experienced by many women with HIV. Researchers are certainly aware of this issue, yet presumably because this cancer affects empty wombs – wombs with no babies – their research findings are yet to impact AIDS policy and money.

There are also a lot of unanswered questions about breast cancer in the context of AIDS and about what it means, for women, to be aging with HIV. There are many questions being asked by young women who have grown up with HIV about the effects of long-term treatment on their own bodies, on their fertility and on their children. Some young women who were born with HIV, are already experiencing bone density and kidney issues from many years on treatment. Older women with HIV face bone density reduction and potential cardiac problems. Treatment is not a walk in the park and should not be viewed lightly.

And there is also now growing evidence that women might be getting HIV and dying of AIDS sooner because of hormonal contraceptives [ref]. This speaks to the need for science to focus on a holistic health approach to keep women alive and well.

In Conclusion

As Melinda Gates eloquently explained in Science Magazine [ref], the world of science and related development without a gender lens is two-dimensional and it is critical to bring a gender lens to development to make the difference we all seek to achieve. Women with HIV have been arguing this for over twenty years.

There needs to be a paradigm shift amongst scientific researchers, global policy makers and donors alike. As Professor Michael Alpers realized over 50 years ago, it is critical to involve oneself closely with those most affected by a condition to understand at firsthand disease pathways. If Michael Alpers could work *with* and *learn from* community members, so can everyone. Fortunately many women with HIV around the world are activists, trying to ensure that other women do not have to go through what we have experienced. Our current ‘anecdotes’, once funded and formally researched, will become tomorrow’s ‘evidence’. Where women with HIV lead, researchers (eventually) will follow. If we walk this path together, we can reduce the time lag and make great things happen.

⁷ app.who.int/ini/bitstream/1065/75341/1/9789241504270-eng.pdf

Financial Report

IAVI GRANT NO. 2035 FINAL REPORT

Income	USD
Amount received	14,000.00
Amount to invoice	14,869.00
Total Funding	28,869.00
Expense Communications	
Website	1,423.53
Finance cost	19.40
Soft wares	1,000.00
Teleconference lines	1,000.00
Total communications	3,442.93
Trainings and meetings	
Accommodation	1,818.92
Air tickets	2,431.00
Ground transport and Visa	1,414.81
Meetings and conferences	6,346.47
Per Diem	2,595.80
Stationery and rapporteur costs	119.00
Travel insurance	51.41
Total Training cost	14,777.41
Materials and development	
ISC chair/member stipends	500.00
Staff	
Administrative Personnel	2,950.00
Communications	2,000.00
Global advocacy officer	5,200.00
Total staff cost	10,150.00
Total Expense	28,870.34



