In Focus...

Women’s issues dominate plenary? YES!

The first predominantly female plenary of the conference opened with a grounded discussion of vaccine development, and proceeded with a presentation by Zambian paediatrician Chewe Luo. Dr. Luo focused on several national programme options, and shed a particularly positive light on Malawi’s B+ initiative, which advocates lifelong treatment of women living with HIV beginning with diagnosis at pregnancy.

Sceptics of the B+ programme maintain that a lifetime regimen for high CD4 count women, particularly in areas where access to care is limited, could lead to low adherence and the possibility of resistance to medication. There is also a question of resource allocation; will the level of investment in the minority of women who seek prenatal care lead to a disparity between them and other women and men in their communities? Women who are sick should be treated, B+ however, raises the question of whether we should treat women who are infected, but not yet ill.

Dr. Luo was followed by Linda Scruggs, a local HIV activist. Scruggs relayed the difficult road that had led her to the Wednesday morning stage. She began by describing the ‘cold November day’ in 1992, when she received her HIV diagnosis. At the time, Scruggs was pregnant with her youngest child. Her physician informed her that if she kept the child, she could not expect to live more than three years and, with an abortion, she might live five. She was twenty-five years old. In a day when a newly diagnosed patient of her age will be told with confidence that they can expect another fifty two years of life, anecdotes like these are a chilling reminder of how far we have come. Scruggs, however, would have been remiss if she did not note the fraught road ahead, and particularly the continuing marginalisation and gender disparities. In a resounding call to action, Scruggs did not ask for a place at the table of HIV planning and prevention, she demanded it, on behalf of all women.

If Scruggs appealed to the personal struggles of the HIV epidemic, Dr. Rao Gupta of UNICEF brought the conversation back to epidemiological strategy. In particular, she focused on what could be called the ‘lost years’ of the lives of young women, when it comes to socio-medical analysis. Studies have well-documented the first five years of girls’ lives, but the academy does not find these girls again until they reach eighteen. Dr. Rao Gupta called for initiatives focused on girls between ages ten and fourteen, a period in which
she maintains their sexual attitudes and practices are still malleable, and they are likely still HIV-negative. Between ages ten and nineteen, girls make up 60% of the global epidemic. Even in Eastern Europe and Central Asia, where the disease is often portrayed as a man’s affliction, girls make up 44% of the youth epidemic. With numbers like these, provided by Dr. Rao Gupta, the quote on which she ended her presentation has particular resonance: ‘we invest so much in keeping children alive in the first decade of life; we must not lose them in the second’.

Indeed, to echo Dr. Rao Gupta, it is not enough to strive for an ‘AIDS free world’. We must strive for a just world, free of AIDS.

Ida is a professor of anthropology, Jonah is a public health researcher, and Zena is an epidemiologist of Columbia University.

The trials and tribulations of vaccine research

Dr. Barton Haynes who has been working to find an effective vaccine against HIV for 27 years, gave us an intriguing account of the rocky path these studies have followed. Effort has succeeded effort, clues pursued that turned out to be blind alleys. However, something new was learned with each disappointment, which is the way of science. From the most recent experiences what was termed ‘broadly neutralising antibodies’ emerged as potentially crucial phenomena. Next Dr. Haynes, with admirable clarity, outlined the next steps to pursue this lead by the collaborating scientific teams.

While guarded optimism promises the eventual success of this research, we clearly have to be patient. Because a powerful vaccine would seem to offer the most effective preventive method to eliminate HIV, and there is every reason to facilitate and fund this essential research, yet we cannot relinquish or even delay any or all other preventive methods, like those discussed by Dr. Chewe and Dr. Geeta Rao Gupta.

Zena is an epidemiologist of Columbia University.

Intergenerational dialogue on young women and SRHR

‘I remember growing-up in the village; I remember loving the feeling of going to school. My father demanded that I leave school, because it is no place for girls. He thought it would be better if I get married to an older man’. This was the story told about a young Tanzanian woman, who was forced into an early marriage at the tender age of 10.

The story of the Tanzanian woman’s story was narrated by three story tellers, each reading a section of her experience during an Intergenerational Dialogue on Young Women and SRHR convened by the World YWCA in the WNZ on Wednesday. In narrating the story by different women, a clear message that gender-based violence is not limited to women from a certain group, country or ethnicity was portrayed.

‘I don’t remember my wedding. I remember feeling moments when that fat man and his belly was on me. I remember being afraid and alone when guests were no longer around. I hear some women like it when men touch them, I don’t’, continued the narrators. ‘He beats and rapes me and tells me girls aren’t good for anything. I felt like I was good for nothing. I remember the day I walked to the clinic. It is far but I have walked that distance many times’, the story continues. She says she remembers consenting to an HIV test. The nurse gave her a look of judgement, pity and scorn. ‘You’re positive’, she said. ‘I don’t remember walking home from that clinic’.

This is but one of the many stories of violence against women shared during the conference. According to the World YWCA, girls are the first to be pulled-out of school. They end-up with no work, are forced into early marriages, and are at risk of acquiring HIV through sex work to provide for their children.

Talks, policies and high level meeting are held annually. However, these seem to have little effect on the lived experiences of so many women and girls at a community level. Women’s and girls’ risks to violence and abuses, as well as ‘harmful practices’, such as ‘early marriage’, and risk of HIV exposure and transmission seem unabated, despite the many commitments…

Sirka is with ARASA.
News from the Global Village…

Female condoms = sexual pleasure…?

Never has female condom use been made to sound as pleasurable and exotic as was presented at the dialogue on sexual pleasure on female condoms in the Global Village on Wednesday.

‘I have a sex toy to show you from India, which has two rings. One ring rubs against the clitoris and the other ring goes inside and it makes you tickle at the back of your eyeballs’. These were the words of Anne Philpott a representative from the Pleasure Project, describing the female condom. She says the condom allows for deep thrust and makes it nice and smooth, while gently rubbing and demonstrating with her hands.

The Pleasure Project believes that if you eroticise safer sex, more people will practise it. The idea is to have fun, while practising safer sex. Another female condom demonstrated was the ‘Cupid’, a female condom exotically described and demonstrated. Cupid comes fitted with a sponge. The sponge helps to keep the condom in place and provides a cushion for men who prefer to be pushing against something during intercourse. Female condoms come in all sorts of sizes and shapes. A funnel shaped condom was made for women who feel the ring is too big to insert. It stretches and also keeps the condom in place. Women are encouraged to try them all, and to programme pleasure into condom negotiation.

The organisers of the session, however, said that female condoms are always referred to and demonstrated far too clinically. ‘When you open the packet, you don’t know where to put it, where the cervix is, and how to insert it. Don’t hold the condom with your fingertips. Rub it, hold it. It heats up with body temperature and men love it’, said one of the female condom demonstrators.

The session has shown that female condom use can indeed be pleasurable, exotic, and sexy…and sex can be ‘fun’ and ‘safe’ at the same time – which is a great concept! The question that remains is how adaptable is this concept, given that most women live in a societal context in which female condoms are extremely scarce, and women have little to no power to negotiate conditions of sex and condom use…

Sirka is with ARASA.

News from the ‘margins’…

Building lesbian & WSW visibility in the HIV response...

Where are the lesbians? – Is but one of the questions raised for a long time. Yet, lesbian women and women who have sex with women are still invisible and left out from the response to HIV, despite the growing knowledge and evidence that lesbian and women who have sex with women are at risk of HIV exposure and transmission.

Come join us for a discussion at the LGBTI Networking Zone in the Global Village to further interrogate as to why lesbian and women who have sex with women are continuously left out and kept invisible in national and global responses to HIV, and what needs to be done to make a difference and to ensure inclusion.

Thursday, 26 July 2012
15:30-16:30
LGBTI Networking Zone

Speakers include:

• Gloria Careaga, ILGA LAC, Mexico
• Linda Baumann, OutRight, Namibia
• Maria Sjödin, RFSL—Swedish Federation for Lesbian, Gay, Bisexual and Transgender Rights, Sweden – (To Be Confirmed)

Moderator ;
• Mabel Bianco – FEIM / IAWC / Women
women’s role in violence

Waimar Tun’s presentation on ‘gender norms and their contribution to the prevention of HIV programming in Zambia’ in Wednesday’s session Gender: Reducing Vulnerability and Reinforcing Empowerment Opportunities reiterated the rhetoric that continues to be used in discussions about Sub-Saharan Africa. Gender-based violence and social barriers not only contribute to the high prevalence of HIV in the region, but also impede women’s ability to access education and seek support.

The social factors that increase women’s vulnerability to HIV are the usual: sexual and gender-based violence, economic disparities and lacking capacity for condom negotiation. As seen in other parts of Sub-Saharan Africa, women in Zambia who are 20-29 years old are twice as likely to be HIV positive, than their male counterparts. It seems we’ve heard this all before…and little change is occurring.

Tun however brought a refreshing element to the table by presenting the Zambia-led Prevention Initiative (ZPI)’s recent survey that investigates both female and male’s perceptions of rape myths and gender-based violence.

ZPI is an organisation that focuses on increasing the use of community-level interventions through targeted approaches that address gender-based violence and power imbalances that strip women of their basic human rights and contribute to the transmission of HIV. Throughout July and August 2011, ZPI conducted a baseline survey that took place in eight provinces throughout Zambia and questioned over 2,000 randomly selected men and women. The survey focused on gender-based violence and rape myths that blame women in justification of rape and/or violence. The survey’s intention was to collect a better understanding of the population’s perceptions of women’s role in violence and rape.

ZPI’s survey was composed of statements that blame women for the sexual violence they experience and participants were asked if they agreed or disagreed. For example: ‘if a woman doesn’t physically fight back, you can’t say it’s rape’. 48% of participants, men and women, agreed with this statement. Other questions evaluated attitudes on gender norms. These questions were rated on the Gender Equitable Men Scale and included statements like, ‘wife beating is acceptable when: she refuses sex, argues with the man, fails to perform chores’ etc. ZPI found that about 40% of both men and women support inequitable gender norms, over 40% of respondents agreed with at least two of the rape myths, and men with over two sexual partners are more likely to approve of inequitable norms.

68% of women surveyed in Zambia have experienced either sexual or physical violence in their lifetime and less than 20% reported the abuse. The agreement of inequitable gender norms and, therefore, the justification of sexual and physical violence greatly impede women’s access to care and, as Tun says, if women go to the authorities, people will look at them and blame them for the rape they experienced.

Although the barriers to accessing support were briefly expelled upon in Tun’s presentation, lack of educational services is, of course, a major factor. The Population Council outside of ZPI has done research showing that it is feasible to work with law enforcement and government agencies to provide comprehensive care to the survivors of gender-based violence. Zambia, in 2011, passed the Anti-GBV Act, and in May 2012, the Zambian government adopted national guidelines for the treatment of survivors of GBV.

However, until the 48% of the population that believes ‘if a woman doesn’t physically fight back, you can’t say it’s rape’, receives education and services that change their minds, policy will only go so far. Both gender-based violence prevention services and comprehensive support and care programmes have to become a priority if minds are going to be changed…and tides going to be turned for women and girls.

Sierra is with the AIDS Legal Network, South Africa.
Women’s Voices... Women in the Zone...

Global Village as an important component of the International AIDS Society Conference, the Women’s Networking Zone (WNZ) has been a place for formal sessions and workshops on issues facing women in the HIV epidemic and response, as well as a place for conversation and networking, brainstorming, and socialising with new and old friends and partners. In 2012, the WNZ is bigger and more active than ever; here women ‘in the Zone’ reflect on what the space has to offer – beyond tasteful decorations, lots of information and publications, comfortable chairs and a cup of tea.

Anna Mwalagho, Kenya and Silver Springs, MD, USA

When I entered the Zone this morning I was greeted with the welcoming vision and sonorous vocal stylings of Anna, a poet and singer originally from Kenya and now living in the U.S.A. ‘I’m an artist’ she explains, ‘I write about socio-economic issues in Africa – and AIDS is a socio-economic issue. When I first heard of the AIDS Conference six years ago, I had already written the poem you just heard. But this is my first time at the IAS Conference’. Anna found her way to the WNZ after performing at the Women’s Gala at the Carnegie Library. ‘Art’, she explains ‘can sometimes portray the missing element that gets missed in other conference settings’. Anna’s poem explains the ways in which HIV impacts a whole family; often women are the most infected but also the most affected, because they have to take care of their loved ones…I’m glad to see women represented at the conference, but I’d like to see a Men’s Gala or Men’s Networking Zone, to see that men are doing something. The burden shouldn’t be only on women’.

Maria de Bruyn

Maria is a researcher and advocate for women’s sexual and reproductive rights. After speaking at a session aimed at developing a research agenda for women living with HIV, she finished answering follow-up questions about abortion rights for women living with HIV. ‘I’ve attended a number of sessions in the Women’s Networking Zone that should be heard by a larger audience, and which, frankly, should be included in the official conference programme’. She explained that this year seemed particularly sparse on women’s issues outside of the Global Village and the WNZ. ‘There aren’t as many sessions on reproductive health and rights, and sessions don’t include non-conforming women. If a woman isn’t a mother or pregnant, if she’s a young woman or a lesbian…then she is underrepresented. I was shocked when I realised that the findings for the Global Commission on HIV and the Law didn’t include any recommendations about violence against women who have sex with women (WSW). Men who have sex with men are in there, but women are left out.’

UPCOMING EVENTS

Thursday, 26 July

07:00-08:30  From Evidence to Programming: Gender and Gender-Based Violence in the HIV and AIDS Response  
Mini Room 1

What Africa Teaches Us: PEPFAR’s Transformation of the U.S. Domestic HIV Response  
Mini Room 2

08:40-10:30  Plenary: Dynamics of the Epidemic in Context  
Session Room 1

11:00-12:30  Challenges in Scaling-Up PMTCT  
Session Room 2

The Oldest Profession: Is Sex Work, Work?  
Session Room 8

Bad Manners at the Bedside: Stigma and Discrimination in Health Care Settings  
Session Room 3

Community Participation in Policy Dialogue  
Mini Room 9

Everything You Have Ever Wanted To Know About Pleasurable Safe Sex, But Were Afraid to Ask or How to Put the Sexy Back in Your Safer Sex Programmes  
Mini Room 5

How to Integrate Human Rights into Treatment for Prevention Programmes  
Mini Room 4

13:00-18:00  Seeking Justice: Litigating the Forcible Sterilization of Women Living with HIV  
GV Session Room 1

14:30-16:00  From Promise to Programmes: Treatment as Prevention  
Session Room 2

HIV Women Throughout the Lifespan  
Session Room 4

16:30-18:00  The Future of HIV Prevention, Health and Human Rights, in Gay, other MSM and Transgender Communities: Towards More effective Approaches with ICTs in a Web 2.0 World  
Session Room 7

18:30-20:30  Exploring Alcohol Use, Gender-based Violence and HIV/AIDS  
Mini Room 9

Manju Chatani-Gada

Coming off a session provoking dialogue with young women about prevention, Manju, Senior Programme Manager at Global Advocacy for HIV Prevention (AVAC) shares: ‘This is the third session I’ve been part of in the Women’s Networking Zone. It’s a great space for discussion and dialogue. The first session was about hormonal contraception and HIV, and one about PrEP and what PrEP means for women. We worked with Sister Love and the Athena Network. For this session, it was wonderful, comfortable couches and atmosphere. We had young women here who were very engaged. On the role of the WNZ in the larger conference, she explains, ‘the Global Village helps balance the conference…’I’d like to see even more participation in the Global Village. Women’s issues [in terms of prevention] are in the conference, in multi-sectoral sessions and satellite sessions. But if I had to look at subgroups – say young women and HIV positive women it’s good to have more balance’.
Late yesterday evening, a small group of women from Africa and the United States met to share lessons learned in efforts to help women live positively with HIV. Facilitators Angelina and Ophelia from the organisation of Women for Positive Action drew on participants’ personal experiences and a ‘case study’ of a young Nigerian woman to expand our knowledge of best practices and develop critical responses for women newly diagnosed.

The organisation is a global initiative designed to address specific concerns of women living and working with HIV, provide education and support and enhanced quality of life in the specific country contexts facing infected and affected women. The Women for Positive Action is made up of healthcare professionals, women living with HIV, and community group representatives from across Canada, Europe, Latin America and South Africa. The initiative aims to empower, educate and support women with HIV and the professionals and community advocates/leaders involved in their treatment. The group explores issues facing women with HIV and provides meaningful education-based support to respond to these needs and to contribute towards an enhanced quality of life for women with HIV.

Ophelia, originally from Zambia, shared her story; now ‘somewhere past forty’, she learned she was HIV positive when she was 17 years old. She is now the mother of two grown children and serves on the board of Women for Positive Action. Angelina got her diagnosis in her twenties before becoming a mother and activist with the organisation.

Participants were presented with a case study of ‘Mary Anne’, a young 23-year-old woman presenting at an STI clinic for screening. The hypothetical woman has a history of sexual assault and a male partner who has tested HIV negative.

Participants in the exercise – who range from women who have lived for years with a positive diagnosis, to researchers in the field of women and care, to the sister of a newly diagnosed woman just getting started in learning about life with HIV – discussed ‘Mary Anne’s’ possible concerns and her path forward. Facilitators help ‘turn the tide’ by providing up-to-date information on everything from transmission mechanisms, to cultural considerations, xenophobia, to the potential medical and legal consequences of breastfeeding for positive women on treatment.

Meanwhile, women brought information gleaned in other conference sessions to bare on ‘Mary Anne’s’ complicated case. Said one, an experienced researcher in the field

I learned today in a session – I never thought about before – but many women don’t want to have sex when they are pregnant, and often cultural norms are such that sex is bad for the pregnancy. At the same time, their husbands and partners are encouraged to seek sex outside the relationship. If they become infected during this time, it means that their most infectious period, the time when an antibody test is still ineffective, will occur during a woman’s pregnancy, putting her and the baby at risk, not only of infection, but of not receiving proper care and antenatal ART.

By the end of the session, ‘Mary Anne’ – and the workshop participants – are in a much better position. ‘Mary Anne’ has disclosed to a supportive partner, protected her child from HIV transmission and herself from stigma in her community by exclusively breastfeeding for six months. One workshop participant said

I’m glad to know about the choices women have...I really had no idea!

By centering women’s choices and providing them with the necessary information, Women for Positive Action is helping to ‘turn the tide’ for women living with HIV.

Kate is an anthropologist and writer, who lives in Brooklyn, NY and frequently works in Durban, South Africa.

Women for Action will be hosting another session on Thursday, 26 July 2012, focusing on the Emotional well-being in women living with HIV, from 14:30-15:30, with Ophelia Haanyama Ørum (Sweden) and Ulrike Sonnenberg-Schwan (Germany)

*For more information Women for Positive Action, please visit the website www.womenforpositiveaction.org.
Fusing science with human rights...

There has been much speculation at this conference of how to fuse science with human rights. Dr. John Ong’ech, from the Kenyatta N. Hospital in Nairobi Kenya, is making strides towards doing just that.

Dr. Ong’ech focuses on pre-conception care, unintended pregnancy and family planning. Ten years ago Ong’ech observed a common trend amongst his female patients living with HIV. A quarter of the women desired to have a baby in the future so he created a pregnancy and HIV screening tool, or guideline, that specialised in HIV comprehensive care clinic (CCC) for both concordant and discordant couples.

As introduced during the session on Maximising Reproductive Possibilities and Choices for Women Living with HIV, the pregnancy and HIV screening tool clearly expounds different steps for healthcare providers and services involved in family planning to follow, clearly spelling-out advice specifically allocated for different circumstances depending on the couple’s scenario: whether both partners are positive, the male is positive and female negative, or vice versa. By using the HIV screening tool, it becomes the couple’s responsibility to discover the best way to become pregnant, and the healthcare sectors’ responsibility to present safe options. Men are involved in the process of conception, beyond the obvious physical part, and discuss the plan of action that is best for both partner’s health. In order for the screening to work, both partners have to consent to learn their HIV statuses, creating an important dialogue.

Dr. Ong’ech’s method is fundamentally based on integrating science and the protection of human rights. There is lacking knowledge amongst women on the existence of safe family planning options, but with this HIV screening tool, women living with HIV can effectively identify their reproductive health needs and rights, and healthcare workers are provided with clear guidelines for providing quality care for the couple.

It is essential to protect human rights while ensuring quality health care is provided but Dr. Ong’ech also recommends involving peer support groups and other reproductive health services in the process. By using Dr. Ong’ech’s screening process and steps, there has been a reported 2% of preterm deliveries or miscarriages and no fetal abnormalities, indicating that the integration of healthcare and human right sectors is feasible.

Regional Voices: HIV testing for wives in Pakistan

Ayesh Khan focused her presentation on the inability of wives in Pakistan to get tested for HIV during the session Gender: Reducing Vulnerability and Reinforcing Empowerment Opportunities. Like too many countries in the world, Pakistani women struggle against the confinements set upon them by a patriotic, conservative society. In fact, women’s mobility in Pakistan is so restricted, information is so lacking, and cultural barriers are so strong, it is estimated that less than ten percent of women in Pakistan are in the position to make their own healthcare decisions, without first consulting a man.

Stigma, conservatism, financial constraints, and little conviction to discuss sex and HIV, result in many women not getting tested. Khan and her team selected, through voluntary recruitment, 138 HIV positive married men who had been on treatment for more than six months to bring their wives to the clinic to get tested. Of the 138, 60% had wives who did not know their status or had never been tested. Only 29% of the men participating had disclosed their positive status to their partner, and even after learning their status, only 8% were using condoms. With $14 given to the 138 men upfront, for 38% had reported travel cost as the reason their wives had never been tested, Khan’s team asked the participants to bring their wives with them to the clinic.

68% complied, 22% reported bringing their wives to a different clinic, and 20% took the money and ran. The most noteworthy aspect of this study was that 94 women were given the choice to have an HIV test – a choice, they would not have otherwise had. Khan saw an increase in disclosure to their partners, as well as an increase in condom use.

Women are entitled and have the right to have the autonomy over their bodies and decisions affecting their bodies. However, this is not the reality for many women in many societies. Gender norms are just not evolving quickly enough, and women remain to be ‘disempowered’, whilst women’s access to health services, including HIV testing, often depends on the man’s permission.

Sierra Mead

Sierra is with the AIDS Legal Network, South Africa.
In my opinion...

What’s the story, morning glory?

Monitoring and evaluation (M&E) are two words that seem to provoke one of two reactions in many of us working in the field of HIV. Either our eyes glaze over, or we cast around for an escape route. The language and mechanisms of monitoring and evaluation seem technical, jargonistic, intimidating and remote from the realities of our lives.

Donor demands for results and impacts put pressure on under-resourced and over-stretched programme staff, and for those of us working in advocacy networks, M&E poses an additional range of challenges: advocacy is notoriously difficult to quantify, since the outcomes of our work are long-term and usually impossible to attribute to a single agent or action. Networks and organisations often value processes as much as outcomes, and it’s often in processes that much of what we consider the meaningful outcomes of our work are embedded. But often when we report on these, we are told that these are just stories, and do not constitute the kind of evidence donors and policy makers are looking for.

As a person who loves M&E, I nevertheless grapple with these issues continuously. M&E and advocacy are intricately linked, and informing our advocacy efforts and – to my mind – should be a stronger motivation for doing M&E, than pleasing our donors. Story-telling is both a powerful tool for women’s advocacy and a vital starting point for women’s empowerment. The process and experience of being listened to, believed and accepted – not to mention finding that others may share similar experiences – can be a changing moment in and of itself, and may be the first step towards healing, claiming ownership of our experiences, and realising our own agency as women. Women’s networks and organisations are well-placed to provide safe spaces for this kind of story telling.

The Women’s Networking Zone is another space where women tell our stories. Sessions tend to be informal and intimate, with an emphasis on dialogue, interaction and sharing. While the WNZ doesn’t constitute the safe/closed space that community organising can and should provide, it is still considerably less intimidating, than some of the more formal conference spaces, where the emphasis tends to be on science and ‘objective’ evidence. As a result, the WNZ is a space in which many stories are told, and women speak from their experience, and their own and ‘owned’ knowledge, rather than from the results of a comprehensive literature review, or randomised control trial.

So it was remarkable to sit and listen (and weep openly) to Linda Scruggs telling her story in the conference plenary session this morning. Story-teller extraordinaire, Linda spoke from the heart about her experiences of living with HIV. Her delivery was unscientific, subjective, funny, heartbreaking and intensely, immensely human. And her story spoke poignantly and forcefully to the complex mutually reinforcing intersections of HIV and gender, and the need for a gender transformative HIV response, without using power-points, statistics or graphs. Her story touched on the stories of so many women living with and affected by HIV. Decisions on whether, how and when to have children, often in the face of discouragement, or worse, of healthcare providers; judgement, self-stigma, loss of self-esteem; drug and alcohol issues that result in exclusion from services; gender-based violence, including sexual violence and rape; sex work; the need for solidarity and safety; women’s individual and collective agency; and the inspiring leadership of women living with HIV. It was a story that raised the house to our feet and brought tears to many eyes.

High level indicators, M&E and accountability frameworks don’t tell these stories. Indicators don’t often count the number of women who have agonised over whether or not to continue a pregnancy; felt afraid to enter a new relationship; felt alone, unloved and unlovable. Or the women who have reached out to other women, listened, grown and gained strength with and from one another; gone back to school, become role models and advocates. But these stories can help us shape the indicators that we do use, and how we use them.

And they can help us mould our advocacy agendas, influence policy, and ultimately shape the HIV response. Core HIV indicators now capture data on women’s experiences of intimate partner violence, as a result of the hundreds and thousands of women living with and affected by HIV who told their stories of gender-based violence. One woman’s story of being forcibly sterilised, because of her HIV status, became 3 stories, became 30 stories, became a movement and a core issue among HIV and women’s rights activists and advocates, and is becoming recognised by global policy makers and high level agenda setting agencies.

Don’t let’s stop telling stories as part of our research, monitoring and evaluation. They are the most powerful tools we have.

Luisa is an independent consultant and a women’s rights advocate.

...story-telling is both a powerful tool for women’s advocacy and a vital starting point for women’s empowerment...

...one woman’s story... became 3 stories, became 30 stories, became a movement...

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