Report of the 3rd Positive Leadership Summit

16 & 17 July

Durban, South Africa
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November 2016
# Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immune deficiency syndrome</td>
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<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
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<tr>
<td>ARV</td>
<td>Antiretroviral</td>
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<tr>
<td>CBO</td>
<td>Community Based Organisation</td>
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<tr>
<td>COWLHA</td>
<td>The Coalition of Women Living with HIV and AIDS in Malawi</td>
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<td>CYSRA Uganda</td>
<td>Uganda Youth Coalition on Adolescent SRHR and HIV</td>
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<td>EHRN</td>
<td>European Harm Reduction Network</td>
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<td>GBV</td>
<td>Gender-based Violence</td>
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<td>GNP+</td>
<td>Global Network of People Living with HIV</td>
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<td>GIPA</td>
<td>Greater Involvement of People Living with HIV</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>INPUD</td>
<td>International Network of People who Use Drugs</td>
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<td>ITPC</td>
<td>International Treatment Preparedness Coalition</td>
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<tr>
<td>LIC</td>
<td>Low Income Country</td>
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<tr>
<td>JCW+</td>
<td>Jamaican Community of Women Living with HIV</td>
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<tr>
<td>LGBTI</td>
<td>Lesbian, Gay, Bisexual, Transgender and Intersex</td>
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<tr>
<td>MIPA</td>
<td>Meaningful Involvement of People Living with HIV</td>
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<td>MDG</td>
<td>Millennium Development Goals</td>
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<td>MIC</td>
<td>Middle Income Country</td>
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<td>MSM</td>
<td>Men who have sex with men</td>
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<td>NACOPHA</td>
<td>The National Council of People Living with HIV</td>
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<td>NCD</td>
<td>Non-Communicable Disease</td>
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<td>PrEP</td>
<td>Pre-Exposure Prophylaxis</td>
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<td>PWN</td>
<td>Positive Women’s Network</td>
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<tr>
<td>RCNF</td>
<td>Robert Carr Civil society Networks Fund</td>
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<tr>
<td>SRH</td>
<td>Sexual Reproductive Health</td>
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<td>SRHR</td>
<td>Sexual Reproductive Health and Rights</td>
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<tr>
<td>TAC</td>
<td>Treatment Action Campaign</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>UNYPHA</td>
<td>Uganda Network of Young People Living with HIV</td>
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<td>USAID</td>
<td>United States Agency for International Development</td>
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<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>Y+</td>
<td>The Global Network of Young People Living with HIV</td>
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<td>YFS</td>
<td>Youth Friendly Services</td>
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INTRODUCTION

“LIVING 2016 was the greatest experience for me. I met amazing people from different countries and backgrounds who are living positively with HIV. It truly touched me to be in a room full of people, feeling safe and supported to talk about my life with HIV.”

Two hundred and fifty-eight people living with HIV from 78 countries came together in Durban to participate in LIVING 2016 the Positive Leadership Summit, prior to the International AIDS Conference, AIDS 2016. They engaged in two days of intensive discussion, sharing, learning, celebrating and strategising. This report shares the Summit’s highlights, the main points emerging from the discussions, and ends with summary outcomes, action points and concerns for the future. Section 1 provides background information about LIVING 2016, including its aims, participants and its programme, while Sections 8 and 9 summarise the key conclusions and points to be taken forward.

Background to LIVING 2016 – The Positive Leadership Summit

Since 1986 international gatherings of people living with HIV have been critical to strengthening the involvement of people living with HIV and enabling them to build a movement, seek common strategies and identify strategic advocacy opportunities. These meetings also provide an important forum to share knowledge and experiences and to strengthen the leadership capacity of individuals in the movement. In 2008 the international conference was reconceptualised as the “LIVING Positive Leadership Summit” and has been held since on a four yearly basis. In 2012 it was held in Washington and in 2016 in Durban (each time just prior to the International AIDS Conferences to maximise linkages between the events).

The 2012 LIVING Positive Leadership Summit focused on advocacy and developed a comprehensive advocacy agenda to guide and strengthen the movement. LIVING 2012 also raised a number of key issues and questions for the future including: the need to revitalise the Greater Involvement of People living with HIV (GIPA), how to join forces and find synergies with those working on related health priorities such non-communicable diseases, how to balance public health goals with the rights of the individual to make health choices, how to ensure gains are made in advancing human rights and the broader social justice agenda, and how to ensure communities have the resources necessary to participate and act.

The programme for LIVING 2016 was developed in a changing and challenging context. The Millennium Development Goals (MDGs) have been followed up by the Sustainable Development Goals. These include many of the same aspirations as the MDGs and place new emphasis on access to health care and on individual rights and responsibilities. Integration of the new international goals and their implications for national programmes is still developing. International development strategies are shifting in response to these new goals and also to other political and economic pressures.

The epidemic is by no means over. In spite of the global effort to improve access to treatment, fewer than half the people living with HIV are accessing treatment. In some regions and areas incidence is rising and some groups continue to be especially vulnerable both in terms of HIV incidence and mortality from AIDS. The rise of extremist ideas has resulted in an increase in human rights violations and AIDS-related stigma in some regions and countries. So, in spite of gains, there are still huge challenges to be confronted. And the conditions are often unfavourable to confronting these challenges and may be getting worse. The economic and political climate, competing priorities and donor fatigue have resulted in less funding for the response and less funding for the work of grassroots organisations and public interest groups.
LIVING provides a learning and activist space which brings people living with HIV together to confront the challenges they face and share knowledge and experiences, to build on common motivation and to plan together to achieve universal access to prevention, treatment, care and support. The LIVING Positive Leadership Summit provides a crucial and unique forum and strengthens the movement of people living with HIV by bringing hundreds of them together in a safe and energising environment. Its timing, in advance of the International AIDS Conference, also helps to strengthen the input of those living with HIV into the International Conference, it brings reality to these debates and helps to maximise the relevance and impact of the Conference on the global response.

The LIVING Partnership is a collaboration of many organisations, committed to strengthening the movement of people living with HIV, and their communities. In 2016 the partnership consists of the Global Network of People Living with HIV, the Global Forum on MSM and HIV, the International Community of Women Living with HIV, the International AIDS Society, the International HIV/AIDS Alliance, the International Treatment Preparedness Coalition, the South African National Association of People Living with AIDS, the Positive Women Network, the Treatment Action Campaign, the United Nation’s Joint Program on HIV/AIDS, the World Health Organization and Y+ (the Global Network of Young People Living with HIV).

The LIVING 2016 Positive Leadership Summit was made possible by the hard work and commitment of all who were involved in organising, planning and mobilising for the Summit. The generous financial support of a number of donors was also absolutely crucial. These donors include: the United States Agency of International Development; The Public Health Agency of Canada; the Ministry of Foreign Affairs of the Netherlands; the Global Fund to Fight AIDS, Tuberculosis and Malaria; the World Health Organization; the International HIV/AIDS Alliance; and the United Nation’s Joint Program on HIV/AIDS.

LIVING 2016 was planned in close consultation with partners around the world. The 2016 Summit Steering Group was made up of representatives of the LIVING International Partnership1 and was mandated to take all key decisions in relation to resource allocation, participation, and programming. This group consisted primarily of people living with HIV. It met on a bi-weekly basis for a period of five months in the run up to LIVING 2016. The Steering Group selected two co-chairs of the Summit, Prudence Mabele of the Positive Women’s Network South Africa as national co-chair, and Jaime Luna of Y+ as international co-chair.

Two subgroups of the Steering Group, a Programme Working Group and a Fundraising Working Group took on much of the preparatory work needed to support the Steering Group, following the same type of meeting schedule as the Steering Group. The Programme Working Group, in particular, invested considerable time in preparing for LIVING 2016, including holding a face-to-face meeting at the Amsterdam office of the Global Network of People Living with HIV (GNP+). In a sign of their commitment, members covered their own travel costs.

The purpose of the Summit

LIVING 2016 took place at a critical juncture in the global response in terms of policies and programming. Internationally and nationally a number of new strategies and plans are being rolled out: the Sustainable Development Goals are being taken up by donors and countries; the UN’s General Assembly High Level Meeting on Ending AIDS preceded the Summit; UNAIDS’s Fast-Track Initiative, The Global Fund’s new strategic plan, and PEPFAR’s new Country Operational Plans are all being rolled out. These plans are unfolding in a context of countries being called upon to finance their HIV responses with domestic funds while facing the challenge of implementing the new WHO treatment guidelines. These shifts are creating a new architecture and policy backdrop for the goal of eliminating AIDS as a public health threat by 2030. LIVING 2016 created the opportunity to energise people living with HIV to ensure that progress is made and policy makers and key actors are held accountable for meeting-agreed targets and achieving success in the global response.

LIVING 2016 was planned to produce concrete results, aiming, in particular, to achieve the following:

- continue to energise the movement of people living with HIV;
- ensure evidence-informed discussions on priority themes identified;
- formulate positions on these priority themes;
- articulate processes and mechanisms for collective action to operationalise these positions;
- inform and influence the discussion during AIDS 2016 and ensure voice of people living with HIV during the conference;
- create a forum for people living with HIV to express their views and strengthen their leadership.

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1 A list of members of the LIVING International Partnership can be found in Annex 1.
Participation at the Summit

The Summit was attended by 258 participants. From the 270 originally registered, 12 people did not obtain visas to attend, despite receiving assistance from GNP+ in making their travel arrangements. Most participants came from the African region (105) and Uganda was the country with the most participants (24). The pie chart below shows participation from different regions.

Most people fell into the age group of 30-39 years, followed by people between 40-49 years. But there were also 61 people under 30, which represents strong youth participation.

In terms of gender, 117 participants identified as women and 126 as men. 15 people identified as Trans*.

The data above are condensed from a rigorous evaluation of LIVING 2016 which drew on detailed responses from 171 participants. The results of the evaluation are available as a separate document.

The Summit programme

The programme was specifically designed to support the knowledge needs of emerging or newly engaged positive leaders, and to result in concrete positions and actions for people living with HIV to promote activism, movement building, and influence service delivery and policy. The programme\(^1\) was developed around five main themes, which were discussed in concurrent sessions:

1. Access to Quality and Rights Based Services
2. Stigma, Discrimination, Criminalisation and Violence
3. Access to Treatment – Facts, Funding and Reality
4. Sexual and Reproductive Health And Rights
5. Greater Involvement of People Living with HIV

For each theme, a number of key questions were identified. These were addressed in the concurrent sessions through three different lenses to ensure all participants could choose the sessions most relevant and interesting to them. The three lenses allowed for: a) an introductory level for people newer to the movement or wishing to go back to basics; b) a level that looked at issues through an activist/movement-building lens and considered how to take issues up and forward; and c) a lens that focused on influencing policy and service delivery.

Three plenary sessions brought people together, provided coherence and established common ground. The opening plenary invited reflection on achievements to date and challenges ahead. This session asked participants to consider how to keep the movement strong and relevant in the face of key challenges. The second plenary focused on very specific issues and gave voice to people most affected by HIV (including young people and sex workers); the third plenary session allowed for discussion of the conference conclusions, provided a forum to discuss follow up actions and identify important gaps. This final session also provided key donors the opportunity to give feedback and input into the Summit.

\(^1\) The Conference Programme is attached in Annex 2.
The Conference was officially opened by Prudence Mabele, the Executive Director of the Positive Women’s Network and the LIVING 2016 national co-chair. She welcomed participants to South Africa on behalf of South African organisations of people living with HIV: the Positive Women’s Network (PWN); the National Association of People Living with HIV; and the Treatment Action Campaign (TAC). All three organisations were co-sponsors of LIVING 2016.

Prudence explained that these three national organisations of people living with HIV coordinate and work closely together to ensure that the issues and perspectives of people living with HIV are represented at national and provincial levels. People living with HIV have always played an instrumental role in the South African HIV response and have provided critical leadership in defining a response that is relevant, appropriate and ambitious. She stressed that the Positive Leadership Summit comes at an important moment in the history of people living with HIV, and at a critical moment for the HIV response.

Prudence looked forward to the challenges of the Summit and she noted there was some cause for celebration and for moments of self-congratulation and appreciation of the way in which South Africa has responded to the HIV epidemic and built the largest ARV programme in the world. However she stressed that there was also a huge amount of work to be done. She hoped that all participants would share their experiences with South Africans living with HIV and also use the opportunity to learn from them. She trusted that the momentum created by LIVING 2016 would be carried forward into the International AIDS Conference and provide impetus and direction for the future of the movement. After her warm welcome, participants took 16 seconds of silence, one second for every year since the first International Conference in Durban, which aimed to break the silence surrounding AIDS and galvanise the global response.

In an opening speech entitled “A movement in crisis or a movement of opportunity?” Shaun Mellors went on to reflect on the growth and development of the movement of people living with HIV and their determination to call decision makers to account, to have their rights recognised and to be acknowledged as part of the solution rather than the problem.

Shaun is a longstanding positive leader and is currently Director of Knowledge and Influence at the International HIV/AIDS Alliance. He summarised some key achievements but argued that the movement is faced with a crisis. People’s lives are still at risk, but there is a danger that the anger and energy that initially characterised the movement has faded and that solidarity is waning. Globally, the movement shares ambitious targets and grandiose slogans, but the rhetoric is not matched by resources and political commitment. The collective global response seems to be weakening and there is not a clear and agreed pathway to achieve the targets that must be met to end AIDS by 2030.

At this critical time, global networks of people living with HIV are struggling to find resources and to be effective. Regional and national networks face similar problems, and in some cases, have collapsed or failed to maintain accountability to the people they should represent. The movement has to address these issues openly and turn this moment of crisis into a moment of opportunity.

Janet Bihla, the Global youth representative from the All-In partnership and a Y+ member from Zimbabwe, also spoke. She described how young people are mobilising and coming together to gain access to prevention, treatment, care and support. She challenged participants to share knowledge and expertise with young people to ensure that they develop the skills needed to take the movement forward. She asked them whether they were already training and empowering young people and encouraged them to see themselves as mentors to young leaders and future leaders.
Cecilia Chung of the Transgender Law Center in San Francisco and co-Chair of GNP+ spoke in the place of Jaime Luna, the International co-Chair of LIVING 2016, who had faced an unexpected and difficult travel delay. She posed tough questions: “Are we just following in step with public health and development agencies? Are we accepting the political environments that kick us out of our homes, jail us and beat us, sometimes kill us, all for the sake of diplomacy or losing what we have? Are our interventions with young people making a difference and are they really with young people or still for young people? Are we addressing sexism, homo- and transphobia, racism and classism in our communities?”

She expressed her excitement about the Summit emphasizing that the two-day meeting was not an end in itself but a tool for the collective activism of people living with HIV. She explained that the programme had been specially designed to explore the rich texture of the experiences of people living with HIV, from all parts of world and from all kinds of different multiple identities, and to draw fully on their expertise.

Daughtie Ogutu from the African Sex Worker Alliance (formerly SWEAT) closed the opening plenary. Daughtie drew attention to the levels of violence that sex workers face and how this increases levels of vulnerability. She also focused on the discrimination that sex workers frequently encounter when accessing health services. Laws that are intended to protect people are often used to criminalise and discriminate. The Plenary speakers identified key challenges for Summit participants and the broader movement of people living with HIV. They urged them to:

- Build a coalition with common vision and purpose. Key global, regional and national structures must break out of their silos and create a common platform for action and solidarity.
- Strengthen two-way accountability between representatives and their constituencies. How can they represent PLHIV better and what support do they need in their role?
- Develop a collective strategy to achieve 30 million people on treatment by 2020. This should include a strong voice on issues such as “test and treat”, common strategies to improve treatment literacy to ensure that people stay on treatment, and common tools and strategies for community monitoring. There must be a clearer response to challenges around intellectual property and access.
- Build solidarity that overrides differences together with a clear strategy and coordinated approach to engage around clear priorities at global, regional and national levels.
- Focus on communities and ensure that community demands are expressed in the form of common goals for community involvement and resources.
- Strengthen work with young people living with HIV by empowering, mentoring and ensuring they are fully involved, and moving over to make space when needed.
- Oppose criminalisation and fight stigma and discrimination wherever it is encountered.

Our plenary speakers (from left to right): Janet Bihla; Prudence Mabele; Cecilia Chung; Shaun Mellors; Daughtie Ogutu.
The concurrent sessions on access to quality and rights-based services focused both on the quantity and capacity of services and on the quality of the services. To achieve treatment and prevention targets, services must have the capacity to deal with the demand and to provide services of high quality with the full involvement of people living with HIV. These sessions were developed around three different sub-themes, each looking at specific issues as they relate to the engagement of people living with HIV:

1. The role of people living with HIV in promoting treatment literacy
2. How people living with HIV can ensure strong and resilient community systems for health
3. Community service delivery – the role of people living with HIV
   • What do the treatment guidelines say?
   •Bringing the Guidelines to life – successful examples of community service delivery.

Concurrent sessions had facilitators who gave initial introductions to the topic and introduced speakers who made short presentations. These were followed by group work and discussion.

**The role of people living with HIV in promoting treatment literacy**

In this session facilitated by Ron MacInnis, who is Technical Director, Health and HIV at Palladium, Andy Seale, a consultant at the WHO, first presented the WHO guidelines. He reviewed how the first published treatment guidelines in 2003 have evolved to reflect advances in science and the availability of new medicines. The guidance is aimed at programme managers and people living with HIV within the response. For many people living with HIV the information needs to be further adapted.

Today 17 million people are on treatment compared with 773,000 in 2000. The challenges of implementing and continuing to up-scale are huge. The new WHO guidelines reflect the scale of the challenge and they are simplified and aim to ensure that people are tested earlier and closer to home, acknowledging that treatment is better and that service delivery should be tailored to people’s needs. Andy stressed that treatment literacy tools developed by and with people living with HIV have been shown to be the most effective and that this was important in improving the quality of services. Another important lesson has been that people react differently to treatment and sometimes these complexities are hard to cover in international guidelines.

**The importance of treatment literacy and support in maintaining adherence**

The next presenter was Edo Agustian from Indonesia, of the International Network of People who Use Drugs (INPUD) and board member of GNP+. Edo argued that each country needs to have updated, accessible, locally relevant, simplified treatment information and to ensure that it is disseminated and discussed. Without this there is a fear that the new guidelines could be misinterpreted or that people could be coerced into starting treatment before they were ready to do so. There are misperceptions about the importance of viral load testing as key to attaining targets and individual health. There are also concerns about how equity can be guarded in the roll-out of the new WHO Guidelines.

**The role of people living with HIV in service delivery**

An overview of technical guidance related to treatment, care and service access

In this overview, Annie Banda, director of COWLHA then spoke from the perspective of her experience in Malawi. She stressed that ensuring that people know about treatment and are well informed is very important. Treat-
ment has to start with the individual and adherence is key. People living with HIV can give a positive example in the community by showing that treatment can keep you active, beautiful and energetic. It is important to communicate at community level and people must be able to discuss in local language and in simple, lay terms, so that they can understand what treatment can mean for them.

Discussion focussed on:

- Monitoring implementation of treatment guidelines
- Increasing literacy
- Strengthening our role in service delivery

Points to take forward:

Support groups need to be strengthened.
- Treat-all is not well received by everyone.
- Treatment literacy tools developed by and with people living with HIV have been shown to be the most effective. They lead to improved health outcomes and better adherence to drug regimes.
- Stock-outs are more common than we care to admit and we need to understand their real-life implications.
- Treatment literacy is about much more than the Guidelines – it is about understanding the setting and the person.

How people living with HIV can ensure strong and resilient community systems for health

The state of funding for community systems strengthening

This was the first presentation in this session, facilitated by Daughtie Ogutu and Christian Hui. Christian is from the Canadian Positive People’s Network. This presentation from Nicholas Niwagaba of the UNYPA argued that community organisations and networks have a unique ability to interact with affected communities, react quickly to community needs and issues, and engage with affected and vulnerable groups. They provide direct services to communities and advocate for improved programming and policy environments. Community systems are particularly relevant in challenging environments and conflict or post-conflict situations where health systems maybe severely weakened.

Core funding is necessary to ensure the sustainability of CBOs and other community actors and, in addition, funds for implementation are needed to support service delivery activities, documentation and advocacy work and also to support capacity building through training and technical support.
Activities for community systems strengthening have been supported by the Global Fund, PEPFAR, bilateral donors (e.g. Dutch, Swedish, Norwegians) and some foundations (e.g. Elton John AIDS, Gates and Ford Foundations).

In addition UN agencies have been supportive technical partners. It is very unclear who will bridge the gap with the Global Fund moving out of middle-income countries. Potentially there are a number of ways to close the funding gap, such as working with local businesses, working with local government and linking health activities to projects that promote employment and business opportunities. But it is very unclear whether this will provide sufficient resources and momentum.

Strengthening the capacity of national, regional and global networks – are networks still a good way to organise?

For Javier Hourcade Bellocq of the International HIV/AIDS Alliance, networks can be very effective as communications vehicles and as tools for getting people together. Networks should be initiators and catalysts rather than programme implementers. Much of the traditional thinking about networks needs to be updated to include developments in social networking and communications technology. Well-used and transparent Networks can be important in giving voice to groups who are not being heard, but there are issues around accountability and transparency and we need to acknowledge these and encourage change and a new generation of leaders. Community funding programmes are badly needed. There are many successful examples, but we have to learn from them and work to develop strong, well-resourced community systems.

Emerging voices networks and priorities – perspectives from the Middle East and North Africa

Souhaila Bensaid presented next. Souhaila is a Positive Women Representative in North Africa for ICW and part of Tunisia’s Country Coordinating Mechanism for the Global Fund. She observed that HIV is decreasing in some regions, but in the MENA region it is still increasing. The current political climate is unstable, and this increases problems around access to services and contributes to a climate in which criminalisation and stigma flourish. In many countries in the region there is no access to services of any kind for people living with HIV, and refugees are particularly vulner-
able. Access to medicines is very poor. Only one in five women has access to care and prevention, and there is a high rate of vertical transmission. In spite of the difficult situation, there are hopeful signs, and there is a change in the UN rhetoric that now recognises the need for the community response. As a movement it is very important to maintain healthy and accountable networks and to empower the next generation and ensure the development of new leadership.

Discussion focussed on:

- Identifying concrete advocacy strategies that PLHIV can implement to influence funding priorities.
- Identifying models for collective action on advocacy, service delivery, and monitoring.

Points to take forward:

- Use social media in a planned way to put pressure on global, regional, national and local governments. It is important to get up to speed and use new media strategically.
- Share your skills, train, mentor people—stop holding onto fixed positions—that’s not a ‘we’ approach’!
- How to support and get resources for those in war/post-conflict areas? Community systems strengthening is especially important in providing access to services in post-conflict situations.
- Legal frameworks can help to counter discriminatory policies.
- Develop strategies (and resources) to ensure that the withdrawal of the Global Fund from middle-income counties does not leave vulnerable groups with no access to care, treatment or prevention.

Community service delivery – the role of people living with HIV

What do the Treatment Guidelines say?

This was the first presentation in the session facilitated by Sarah Feegan, Chair of Positive Women Victoria (Australia). A number of experiences were discussed bringing positive examples to light, but also illustrating the scale and nature of the challenges involved. In the first presentation, Sita Shanti set the stage by covering more ground on the Guidelines. In September 2015 WHO issued new treatment guidance that recommended that anyone living with HIV should begin treatment as soon after diagnosis as possible. This recommendation is made on the basis of findings that confirm that early use of ART prolongs healthy life and reduces the risk of transmission. WHO also recommends preventive treatment for people at substantial risk of HIV. The Guidelines stress the need for adequate testing and treatment and for adherence support to encourage people to maintain their care. This implies earlier treatment, treatment closer to the communities and work with communities to ensure that roll-out is feasible and supported in communities. Under the new Guidelines, the number of people eligible for treatment is expected to rise from 28 million to 37 million.

Exploring community engagement in delivering support via the Global Fund to help people access care and treatment and maintain that engagement

Daisy David of World Vision International in India looked at opportunities to support community engagement in service delivery through a programme supported by the Global Fund. The treatment support programme was started in 1990 to get people to start and adhere to medication. Funding has increased over the years, as has the number of PWHIV. Treatment is provided according to the WHO Guidelines, via local health centres, which provide access to testing, counselling, care and treatment. Communities have been involved in this programme at district, regional and national level for the past 15 years. Common problems experienced include: frequent stock-outs which interrupt treatment; a high loss to follow up rate and inadequate resources for CD4 counts and viral load testing. Children are poorly served and, in general, treatment literacy levels are poor. The quality of services provided is not consistent. Access to treatment has improved but users of the services complain that many health workers in government-approved facilities are unfriendly and that their attitude creates a barrier that prevents some people accessing care in these facilities.

Bringing the Guidelines to life – successful examples of community service delivery

In this presentation Olive Edwards shared the experiences of the Jamaican Community of Women Living with HIV (JCW+). She focused on the fact that to implement the guidelines successfully it is essential to support people in their communities and address issues around stigma and associated non-disclosure. Women’s advocacy groups have addressed these issues by moving from “testimonies for the dead” to “living testimonies” revolving around handcrafted
quilts which are used as symbols of sexual health and HIV-related issues. These are discussed in schools and also in communities. This approach has been expanded to include sexual rights and gender-based violence. The sale of quilts also encourages women to learn new skills and allows them to generate some income and become more self-sufficient.

The “Positive Journey Kit” from Australia was described and demonstrated to the group. The kit explores a lifespan of experiences and was developed as an action research project by Positive Women Victoria. It consists of five booklets addressing diagnosis, disclosure and discrimination, new relationships, taking care of ourselves, and the future. The kit also provides a booklet on resources and support services, a personal journal for women to record their own journeys, affirmation cards and tips for the journey from other women living with HIV.

Discussion in this session focussed on:

- How to reinforce the role of HIV community networks in scaling up these services.
- How to advocate for more resources for these types of service delivery approaches including ensuring appropriate training and support to networks of people living with HIV.
- Identifying what is needed to improve linkage to, and retention in, care.

Points to take forward:

- Educate each other through lived experience rather than telling others what to do.
- Build opportunities into support programmes for people to improve their situation and develop new skills while they learn and support each other.
- Support people to find ways to initiate conversations about HIV which do not require self-disclosure.
- Find ways to demonstrate high quality interventions and to encourage effective user feedback to facilities if there are stock-outs, delays, or if staff are unhelpful or unfriendly.
- Increase treatment literacy via new media and peer-to-peer education.
- Monitor the roll-out and implementation of treatment guidelines involving women in dialogue about issues which affect women’s treatment.
In regions where HIV chiefly affects key populations, stigma still remains a huge problem and affected groups continue to be stigmatised and often criminalised. In many middle-income countries international support has been largely withdrawn, but government support to the response is lacking. A practical workshop and concurrent sessions focused on stigma, criminalisation and violence and encouraged participants to reflect on complex questions in relation to policy, service provision and personal experience.

Living openly with HIV is not easy. In many parts of the world, speaking about HIV is still considered a taboo, and people living with HIV are routinely judged, criticised and discriminated against. Further, stigma comes not only from outside but also from within. Self-stigma can exacerbate anxiety and depression, leading to disempowerment, destroying careers, and fracturing friendships, love and sexual life. The session discussed how to break through the barriers of self-stigma, heal and enjoy living with a positive self-image.

Different community-led research tools on stigma, criminalisation and human rights violations against people living with HIV have been developed over the past decade. The question remains, however, have they been useful in advocacy against discrimination and violations? How can they be improved and made more effective? How can we address harmful laws and policies, which marginalise populations and worsen the HIV epidemic?

From within: dealing with HIV self-stigma

In the course of a well-attended workshop facilitated by Prudence Mabele, Christian Hui of the Canadian Positive People Network and Raoul Fransen of ICSS, participants were encouraged to draw upon their own experiences and share them with a view to understanding self-stigma and its impact on the lives of people living with HIV and on HIV prevention and programming.

Raoul asked each participant to introduce him or herself by saying one word defining self-stigma. People mentioned a wide variety of words to capture the essence and emotion of stigma. Prudence explained different types of stigmas (perceived stigma, interiorised or self-stigma). She asked whether participants recognised the distinctions she was making.

Exclusion Circle Game Exercise:

The exclusion circle game exercise is a learning tool developed by the Committee for Accessible AIDS Treatment (CAAT) for a community-based participatory action research intervention study. The aim is to address the social exclusion and stigma associated with HIV. The exercise was led by Christian and Prudence. The objective of the game is to enhance collective resonance and empathy, promote critical reflection and dialogue, and motivate collective action to address social exclusion. The game begins with all participants inside a circle, each with a randomly colour-coded card. The colour of the card represents a specific, lived experience associated with racism, patriarchy, homophobia, transphobia, HIV stigma, etc. Participants who hold a marginalised status card are asked to leave the circle in sequence and go to designated spaces where they are excluded from the activity. Eventually, only a few of the participants are left in the circle. Participants then debrief others about their experience of exclusion.

In the session at LIVING, the experiential game received positive feedback from the participants as it helped them understand the impact of social exclusion and how stigma impacts both the individual and broader society.
Group work focussed on:

- Understanding self-stigma – what it is, and how it affects people
- Countering and coping with self-stigma

Participants identified a number of issues to take forward.

- The silence surrounding HIV still needs to be broken.
- Integration of support groups and community-based associations continues to be crucial.
- If older people are able to set an example and be open about their HIV status, this will help young people to overcome self-stigma.
- It helps if people who are financially comfortable and face less risk are open about their status. This helps others who are less comfortable to overcome self-stigma.
- People living with HIV can set a positive example and fight all forms of stigma and discrimination (e.g. sexual orientation, way of life).
- Advocacy and fighting for your rights are both crucial for PLHIV and also for their other identities.

Community Designed tools – What is their impact on stigma and discrimination

The Stigma Index: choices and changes

Chris Mallouris of the Community Mobilization Team at UNAIDS and Alistair Hudson, Coordinator of the Stigma Index UK, presented various country experiences in the course of this session facilitated by Laurel Sprague of GNP+ North America and researcher with HIV Justice Network, and Florence Anam, in charge of communications at ICW Global.

In the United Kingdom the People Living with HIV Stigma Index (www.stigmaindex.org) has been carried out twice, in 2009 and 2015. In 2009 it was conducted face to face and in 2015 an online version was devised based on the original index. The Stigma Index is a PLHIV-led process and survey designed to quantify experiences of stigma with a view to identifying areas for advocacy and interventions. In the UK, between the two surveys there were significant changes in the landscape leading to a bigger and more diverse group of stakeholders and the presence of more cross-sector support organisations (such as academia and public...
One key issue was that 25% of the HIV-specific organisations had ceased to exist in the period between the two surveys and this raised questions about the future of those that remained.

**Advocacy based on the lived realities of people living with HIV**

Florence Anam, responsible for communications at ICW Global in Kenya, presented findings from research in Uganda where the Stigma Research Index had also been carried out twice, in 2009 and 2012. In an innovation, the interviewers applying the 2012 questionnaire had used mobile phone technology to record the responses alongside paper copies. This had made it possible to ensure instant uploading of data, quicker processing and better data integrity. In Uganda the survey itself had served as an important opportunity to engage with donors and develop advocacy messages challenging the Government to strengthen the national response. As a result of the advocacy, PEPFAR headquarters rejected or ‘red-lit’ the PEPFAR Country Operational Plan (COP) in 2012, and required a massive revision of the Plan. This revision focused on accelerating treatment scale up and the treatment and prevention needs of most-at-risk populations, and expansion of high impact prevention.

**Community-led research in the Ukraine**

Olena Stryzak of Positive Women Ukraine presented research carried out in the Ukraine in 2013 to collect information and to identify the dynamics of stigma and discrimination and the realisation of human rights as seen by people living with HIV. The women-led community-based research team collected data from 1,000 positive women on the sexual and reproductive health, gender equality and human rights, gender-based violence (GBV), and the economic and political opportunities of women living with HIV in Ukraine. The research was unique, as it was the first time that this kind of activity had been organised and conducted (in the Ukraine) by women living with or affected by HIV.

The results are still being finalised, but preliminary results show only 3% of the focus group participants believe that the State is fulfilling its duties towards people living with HIV. Addressing GBV and violations of women’s rights is a 100% priority both for women activists and service providers.
LIVING participants actively contributed to the discussions

Discussion focused on:

- Experiences from other countries which had used the Stigma Research Index
- Ways in which the tool might be adapted or adjusted
- How to answer critics of the tool and engage them in discussion

Points to take forward:

- The Stigma Index is a participatory tool that allows us to learn but also creates advocacy opportunities.
- It is important not to focus on negative language and negative experiences in confronting stigma. Language needs to be inclusive and grounded in solutions.
- Ensure that research tools include the experiences of young people (and those born with HIV), key populations, displaced communities and SRHR.
- It is important that research does not lead to strengthened stigma and does not have negative consequences for researchers.

Overcoming the barriers of invisibility and harmful laws and practices

Why is addressing criminalisation so important for key populations?

This session was facilitated by Edwin Bernard of the UK-based HIV Justice Network and Cecilia Chung. They began with an overview stating: “The common link among participants is the fact that we’re living with HIV. However, we need to see a broader landscape”. Members of Key Population Groups are criminalised for their identity (e.g. being transgender), for their will to live in other countries (migrants), for accessing health services, for being people who use drugs or who sell sex. HIV criminalisation impacts in different ways on each key population depending on who they are and in which region or country they live. In this sense they have a double identity and a double challenge both as PLHIV and as members of a key population. It is important to confront these challenges and identify strategies to counter or mitigate criminalisation. Drug policy reform could be useful as one example of best practice.
The people with HIV most vulnerable to HIV criminalisation are key populations, notably sex workers, migrants, injecting drug users, prisoners and, in some settings, men who have sex with men. A real breakthrough discussion is taking place, including here at LIVING 2016 where there is a growing understanding of intersectionality or overlapping discrimination. In efforts to end HIV criminalisation it is important to address punitive and abusive laws against all key populations.

**Criminalisation of same sex relations – based on a study from MENA**

According to Elie Balan of the M-Coalition in Lebanon there are two types of laws in the MENA region which criminalise MSM relationships: those which state clearly that these relationships are illegal and those which just suggest it. The latter are usually interpreted at the discretion of law enforcement officers. Various terms are used to refer to same sex relations, such as: indecency promotion; gangs of moral sabotage; threat to public safety; perverted religious sect; and unnatural sex.

How ambiguous laws are interpreted is not always predictable. In Lebanon judges have, on several occasions, refused to rule that same sex practices among men are against the law. In Egypt the police try to round-up MSM or to create situations of entrapment. In addition to criminal law there is also Islamic Shari'a law, and under this law, the Islamic State or Daesh, have imposed very harsh prosecutions and punishments. Providing appropriate services in a climate of oppression and criminalisation is highly challenging. One positive example is in Lebanon where the Speak Up initiative works with local NGOs and networks, and uses international medical and labour agreements signed by the country to protect PLHIV.

**Community-based human rights monitoring – REAct**

Gavin Reid of the International HIV/AIDS Alliance presented REAct (Rights Evidence Action). This is a tool developed by the Alliance as part of the Link Up programme to respond to issues relating to criminalisation and human rights violations. It is a secure IT-based human rights monitoring and response system owned and managed by grassroots organisations. REAct helps respond to human rights barriers to accessing HIV services by collecting relevant evidence in order to identify and provide or refer to individual emergency support. It was also designed to inform human rights-based HIV programmes and generate evidence for advocacy and future programming.
To date, over 35 CBOs are providing direct emergency responses and REAct is being led by organisations of PLHIV (South Africa and Lebanon), Sex Workers (Uganda, South Africa and Myanmar), LGBT (Zimbabwe, Uganda, South Africa, Burundi and India) and organisations supporting migrants (Lebanon). In 2015, 465 cases were documented and responded to or referred. Over 50% were met with emergency responses and over 45% with legal service provision or referral.

Discussion focused on the potential benefits of tools to collect data on human rights in terms of:

- generating information of the human rights situation
- generating enhanced evidence for funders and donors
- being able to provide a rapid response to laws that are being proposed and a focus for advocacy, and
- personal history

Points to take forward:

- There is a need to document initiatives and efforts that are working on HIV criminalisation, so we can share and learn.
- Data collection is essential to advocate for policy change and criminalising laws, as it is difficult to reach out to parliamentarians and legislators.
- Criminalisation should be seen as a broader challenge not only related to people living with HIV but also to other groups easily targeted.
- The need to come up with better tools and skills to reach out to people suffering from criminalisation.
- The need to increase services to provide support (legal, psychological, emotional) to those who face criminalisation (including PLHIV, drug users and sex workers).
This next series of concurrent sessions covered access to treatment, and funding for treatment, as well as policy frameworks and barriers to HIV treatment. Treatment is one of the cornerstones of a successful HIV response. With medication becoming better tolerated and effective, and with the advent of treatment as prevention, maximising treatment access has become an even higher priority. One major barrier to universal treatment is the high price of medicines which is the direct result of intellectual property laws. This session asked how to effectively challenge intellectual property rights to serve people rather than profits?

Competing priorities in international development, peace and security make the realisation of a fully funded HIV response a serious challenge. International donors count on domestic investment and are phasing out support to middle-income countries. Is there an alternative to accepting the trend of reduced global funding from donors as unavoidable? Are there opportunities to negotiate with donors? Does negotiation imply becoming complicit in life or death decisions? Should the movement focus on activism or does it have to become more pragmatic?

Understanding the basics – intellectual property issues

Understanding intellectual property and why pricing matters to treatment access

Loon Gangte of ITPC and the Delhi Network of Positive People explained the basic concepts and issues in relation to intellectual property and treatment access. The role of patents in creating a monopoly sell-
ers’ market was described. Loon also presented the patent situation in relation to a range of HIV drugs. He described the role of PLHIV activist groups in successful campaigns to lower prices and the importance of continued activism on issues of access and social justice. This was illustrated by examining the historic drop in prices of early HIV medicines as a result of activist campaigns and legal challenges.

Discussion focused on: finding practical ways of increasing knowledge and effectiveness and the need to develop more understanding and identify experts in a very complex area.

Points to take forward:

- Understand the concept of patent laws
- The importance of knowing each country’s policy on patent laws
- Encourage people to know what treatment they are on, who pays for it and how
- Strengthen our community systems so that it is possible to think global but act local

The dollars and sense of treatment funding – where is it going to come from?

This session facilitated by Rachel Ong and Duncan Moeketse looked at perspectives from different regions. Rachel is the Communications Focal Point for the Communities Delegation to the Board of the Global Fund and Duncan is from Y+ in South Africa. The session sought to cover where donors are pulling out, the situation of domestic financing and how community organisations are responding.

What are the right strategies for ensuring continued investment in the Global Fund and to address transitions away from middle-income countries? How do we increase domestic investments in lower-income countries, including services for people from key populations?

Rachel explained how the Global Fund is financed by country money. CBOs have to keep up the pressure on donor governments to maintain and/or increase contributions. To address the Fund transitioning out of MICs there needs to be a more coordinated response of PLHIV networks (working at national, regional, global level). There should be a focus on countries that are transitioning out and where the response is at extreme risk as bilateral and multilateral donors pull out of funding for national programmes. Income classification should not be the only basis for how countries are classified and “eligible” for funding. PLHIV and others need to advocate that it is essential to use health indicators and poverty indicators as well as aggregated country income data. This is critical in order to protect gains made in countering HIV and AIDS and to ensure that global targets can be met.

There is some funding from various other mechanisms including $100 million from PEPFAR and the Robert Carr Civil Society Networks Fund (RCNF) but these do not provide long-term funding. It is important to call on donors to come together to address need on a long-term basis and to support innovative funding mechanisms in countries to ensure sustainable income that includes domestic finance.

People living with HIV should get involved in monitoring country investments (from donors and domestic) to ensure funding goes to the right populations and areas. There is a need for networks of people living with HIV to work with other civil society based organisations to monitor country funding, and identify critical gaps in funding. Joint monitoring is particularly important in the light of the shift towards “country ownership”, and the demand for countries to pay for their health programmes and services, as well as for commodities.

For sustainable financing to work the legal environment must be conducive to interventions and programming. Investments need to go towards legal reform interventions, but these will not succeed if there is only short-term funding. This is especially important for transitioning countries where key populations are criminalised and governments provide no services for them.

Gracia Violeta Ross Quiroga, from the Bolivian Network of People Living with HIV and AIDS and the Communities Delegation to the Board of UNITAID, presented the funding situation in her region, Latin America. She stated that donor fatigue is a reality that has to be dealt with and that it is important to be realistic and recognise that donor priorities do shift. To counter donor fatigue PLHIV need to present both a clear vision of what can be achieved and personal stories that bring the issues to life. Donors need to be convinced to continue funding in spite of the fact that there is no quick fix.

Latin America is one of the regions most affected by donor withdrawal, given that nearly all of the countries are middle-income countries (MIC) and that Global Fund support for these is ending. In Bolivia alone this will lead to a US$ 9 million funding gap. Some CBOs are successfully pursuing access issues as human rights issues and taking their government to court. But, given the pressure on health systems and health budgets, securing domestic funding remains a huge challenge. In many MICs key population groups are stigmatised and criminalised and the prospects of domestic funds being allocated to provide services for them are very poor.
Discussion focussed on:

- How to encourage governments to allocate more resources to Key Population programmes
- Ways of promoting legal reform to improve position of members of Key Populations
- Civil societies and people living with HIV should ensure that they are included in the government decision-making agencies and monitor the use of funds intended for Key Population programmes to ensure that they are spent as planned and not diverted to other activities

Points to take forward:

- Income classification should be the only basis for how countries are classified and receive funding
- People living with HIV need to advocate for long-term funding and sustainable transitioning
- Alliances with other civil society organisations need to be developed to monitor financing and spending
- Legal reform is essential if sustainable financing is to result in positive health outcomes

Developing an HIV positive critique of policy and finance frameworks

Overview of Fast-Track initiative resource needs?

David Barr covered the new targets in this first presentation of three in this session facilitated by Javier Hourcade Bellocq. UNAIDS 90-90-90 targets seek to have 90% of PLWHIV on treatment by 2020. To achieve this target domestic and international investment in HIV programmes in low- and middle-income countries will need to increase by about one third, from an estimated US$ 19.2 billion available in 2014 to US$ 26.2 billion by 2020. Participants discussed the reality behind the rhetoric of this target.

In 2015, donor government HIV funding in low- and middle-income countries fell for the first time in five years (by about US$ 1 billion). Low-income countries will increase domestic funding for the response from $200 million to $900 million per year—a 450% increase. Russia has the fastest growing epidemic in the world but they are excluded from international fund-
ing. Levels of funding going to low-income countries are inadequate to cover all costs so there is a real danger that countries will use the money to buy pills but will not have the resources to provide support services. The lack of critical analysis of Fast-Track and lack of guidance from WHO about how to scale up when resources are insufficient to meet the expanded guidelines is a serious problem and could cause more harm than good.

**How to ensure that domestic funding for HIV funds the right things**

Deogratius Rutatwa from NACOPHA spoke next. The experiences shared illustrated how PLHIV groups could advocate for additional domestic resources for the national response and how they could also influence priorities in relation to where that money goes. Consultation with PLHIV groups will lead to an increased emphasis on services to combat stigma and ensure that there is some balance is what it provided. The AIDS Trust Fund in Tanzania has been established to coordinate and leverage funding for the response. The Trust Fund is in consultation with CBOs and their performance will be monitored to ensure accountability.

He discussed how to ensure inclusiveness and the active participation and involvement of different stakeholders (PLHIV in particular) in policy and decision making, supporting and pressing for laws and policies allowing PLHIV to have a voice in determining resources allocations on appropriate interventions and actions to achieve the global targets. He stressed that prioritisation of interventions to be funded must be guided by the updated WHO guidelines, national HIV responses, policy frameworks, political commitment, and mainstreaming of HIV in various public and private sectors.

**Points to take forward:**

- Activists should become more knowledgeable about patent laws and intellectual property issues so that they can make the case at home for compulsory licensing and social justice in relation to intellectual property
- Low- and middle-income countries will increase domestic funding for the response from $700 million to $3.7 billion per year—a 530% increase
- Innovative funding mechanisms are needed to boost the level of domestic funding
- PLHIV should be advocating for additional domestic resources and continued donor funds for the Global Fund; they should have a role in setting spending priorities and ensuring that not all programme money goes to medicines
- The WHO should link its targets to donor trends and available funding and give guidance on how countries can optimise work with insufficient funds
SECTION 5 SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

Sexual and reproductive health and rights have always been a central concern for people living with HIV. For a long time, society expected a positive HIV status to be the end of your sexual and reproductive life. In some communities, health care workers have even been sterilising women living with HIV without their knowledge or consent, and HIV+ or sero-discordant couples who decide to expand their families often face recrimination and discrimination. The medical profession continues to grapple with ethics when it comes to people living with HIV, particularly in regards to allowing people to make their own decisions about family planning. Advocacy for youth friendly services, and key population friendly and inclusive services is still much needed. Adolescents who are still discovering their own sexuality – and having to do so while living with HIV – deserve support. Yet services are often not adapted to meet the needs of adolescents and young girls, with sometimes deadly consequences as death rates among adolescents in Africa, for instance, are higher than among adults.

Holistic policy and programming analysis and advocacy on hot issues in the SRHR and HIV integration agenda

Rights violations – No more clinic sweepers doing obstetric care! What WLHIV have done to ensure maternal health care is top quality from conception to postnatal care.

This was a stimulating session facilitated by Jessica Whitbread of ICW Global. It started with a presentation on rights violations. Annie Banda presented on the situation of women and girls with HIV in Malawi. In some clinics in Malawi, for example, antenatal care is good, and nurses are engaged and supportive. At the time of birth, however there is often no one available, and in some cases clinic sweepers help out, having witnessed many births already.

Annie emphasised the basic rights to love, have sex and to have a husband and a child. Many people in Malawi and elsewhere think people living with HIV should not be sexually active or reproduce. She spoke of her personal experience of losing a husband to HIV, and of remarrying and having an HIV negative child. She stressed that HIV should not prevent someone from living, and that even in a police cell people have rights and should be able to claim their right to care and medication. All members of key populations should be encouraged and empowered to claim their rights. She stressed the importance of documenting rights violations. “Tell us your stories.”

Has the push for youth friendly services made a difference to young people living with HIV and young people living with HIV from key populations? What has worked? What hasn’t and what’s needed?

Annah Sango of Zimbabwe presented the concept of youth friendly services and explained what this involves. YFS attract young people to the facility and provide assistance. They include peer support and peer-trained nursing care. YFS means being non-judgemental and open to responding to all needs without stigma and discrimination. In other clinics, accessing condoms, care and appropriate information might be difficult for young people, hence the importance of YFS. Also, it is important YFS are able to deal with people with disabilities. Ideally they should contain recreational services and be staffed by nurses who are young at heart and able to respond appropriately to their needs. They need to be in an easily accessible location: it is important to think about whether these services make a difference wherever people are.
Annah recommended the following:

- Ensure nurses are paid a decent wage and that services are well staffed so that they are not overworked
- There should be psychologists and social workers present to deal with the range of psychosocial issues particular to young people
- Access to comprehensive sexuality education, both in and out of school, is important and confidentiality is essential in these services, which must treat people with respect and provide culturally appropriate care
- Sexuality education should be interlinked with service provision
- Services should be integrated, free or low cost and accessible. Young people are not ‘one size fits all’

You are as sexy and desirable as you always were: A celebration of gender and sexual diversity and HIV

Jessica Whitbread presented the interconnections between gender and sexuality and HIV, and the need to celebrate. Sex is fun. We all have desires for our bodies and for contact. We yearn for each other, in all our diversity. Sometimes we identify as different things at different times of our lives. Sex and lust are natural and should be celebrated.

Often HIV is acquired during a time and during an act of love, passion or lust. For some HIV is the result of sexual violence, and these people may need help to move through the trauma to be able to reclaim their sexuality. How much is known about sex post-diagnosis?

It is not easy to see a positive picture or perspective. Who does a good job of talking about sex and HIV in a positive way? Most media images are extremely negative. Where were the sex-positive messages? It seems as if there is always an underlying cautionary current (criminalisation, disclosure, prevention issues). If the focus is very much on not spreading HIV this can make PLHIV feel as if they are someone to be feared. Jessica advocated the case for identifying sex-positive messaging, and messages that disrupt and challenge common assumptions and the stereotypes of the mainstream media.

The discussion focused on:

- exchange of experiences about YFS and sexuality in relation to living with HIV
- difficulties experienced in raising these issues in schools
- comparisons between countries

Participants chatting during a tea-break
Points to take forward:

- Understand what type of SRH care works for people living with HIV
- Know the impact of youth friendly services
- Ensure age-appropriate and sensitive services are available for young people
- Ensure that people with HIV are aware of their human rights and empowered to claim them and speak out when they are withheld
- Ensure that peer-delivered support is an integral part of treatment and care services
- Work together to challenge stigma and to claim and enjoy sexual rights and freedom, as people living with HIV
- Address and support others to address any underlying self-stigma, so that it is the possible to challenge it outside

Ensuring positive involvement in defining and shaping SRHR Services: essential case studies

**Honey, have you forgotten young key populations in decision making?**

This session provided the opportunity to present and discuss a number of case studies. Resty Nalwanga of UNYPA and Musah Lumumba of CYSRA-Uganda presented together. They broadly described the challenges of young people living with HIV:

- the lack of attention to the continuum of care and treatment models that only focus on ARVs; the high death rates among young people living with HIV
- forced and coerced sterilisation of young women
- the lack of funding for youth organisations
- stigma, discrimination and criminalisation of young people from key populations; and
- tokenistic involvement

They then presented the *Flower of Participation*, which is quite similar to the *Tree of Participation*, showing the different levels of participation from low (decoration and tokenism) to high (youth-initiated shared decisions with adults). Resty and Musah then explained how to go from visibility and recognition to solution. If adults want youth to participate they need to examine issues of diversity, expectations, needs, experiences and capacity. They then need to define the partnership and its goals clearly, commit to meaningful youth participation, share power to make decisions and then consult, learn, redefine, share, coordinate and act together.

Resty and Musah then covered some of the successes of the LINK UP and Our Realities Our Needs projects. Examples include young people being involved in concept note development of the Global Fund in Zimbabwe and Uganda. There is a National Minimum Service package for ALHIV in Uganda, and there are national SRHR and HIV working groups in Uganda, Kenya, and Cameroon. A National Pediatric Conference and Youth Pre-Conference was held in Uganda. The presenters then concluded with a list of current opportunities.

Group work examined the barriers to SRH: the age of consent for youth accessing treatment; access to antenatal services; stigma and discrimination; and self-stigma. Participants then went through specific challenges in their respective countries. Some examples were discussed. In Gambia, boys and girls access services at the same location and the quality of services is an issue. In Argentina, society’s macho culture hinders expression and forces people to conform. Young people do not have access to safe and legal abortion. In remote rural areas of Namibia youth are not getting information and services at all. In Tunisia people face cultural issues, for instance, women cannot request female condoms, there are stock-outs of condoms, knowledge on rights is lacking, and there is little confidentiality.

A number of solutions were suggested and discussed:

- Raise awareness of rights
- Make use people who can form a bridge and talk to the community
- Antenatal care should serve both mother and father
- Take services to the community. Make SRH services for young people part of other events
- Ensure flexibility in healthcare access with one-stop shop services
- Translate comprehensive information into local languages
- Provide constant training and engagement between people living with HIV and their service providers and hold them accountable for their discriminating attitudes
- Enforce laws and policies that protect/support young people
- Encourage self-esteem
- Prioritise referrals and peer-to-peer follow up and continue the cycle of training
- Sexual education in school will improve confidence
Points to take forward:

• Programmes have a long way to go before they are truly engaging young people. It is important to re-evaluate how that engagement is being done
• Youth organisations have very little funding. How legitimate is the engagement principle if this is the case?
• Youth-led advocacy yields results; it needs support
• Young people want and deserve good services that provide for the FULL range of their SRHR needs, and this needs to be unhindered by ideology
• Young people need to know their rights

Our neglected issues in the SRHR Agenda: how can integration deliver for, and promote the rights of, people living with HIV

This session was facilitated by Nicholas Niwagaba and Alice Welbourn of Salamander Trust in the UK. Nicholas introduced the session. He explained that integration of SRHR services remains a struggle and that there is a need to break the barriers. Stigma and discrimination still represent obstacles to integration.

The broader lens of SRHR helps to highlight human rights issues and we need to take the opportunity to advocate together and build awareness of rights.

Integrated service delivery: policies, tools and practice of SRH and HIV integration on policy and service delivery

Kevin Osborne of the International AIDS Society started by telling participants that at the beginning HIV clients were generally thought not to be very concerned with SRH services. This has changed. Linking SRH and HIV has come a long way since the first commitments on growing linkages between these two areas in 2004. He presented information on the Interagency Working Group on SRH and HIV Linkages. This working group has been developing a number of resources that can be used by advocates and programme managers alike to:

• show country progress on the broad range of SRHR and HIV Linkages areas by displaying existing country data in these areas and combining this data in a single composite score through an Index
• share resources and best practice
• support rights-based and comprehensive integrated service provision of SRHR and HIV services, and
• strengthen guidelines on SRHR
He next presented the HIV and SRHR linkages “Info- graphic Snapshots”. They provide an overview of national level data for 25+ countries on: enabling environment (policy and legal); health systems; integrated service delivery; and adolescents and youth key populations. They include excerpts on laws and on stigma and discrimination. Next, he presented the SRHR and HIV Linkages Index. It provides a composite measure of country progress and can be used to support advocacy for improved SRHR and HIV Linkages and decision making about where to focus programming and improve data collection. Sixty countries are included in the Index. All are countries that have shown an interest in SRH and HIV Linkages previously (e.g., have completed a Rapid Assessment on SRH and HIV Linkages) and/or are a donor priority country (PEPFAR and Global Fund to Fight AIDS, TB and Malaria). The Index includes 30 indicators for 30 countries across three domains: enabling environment; health service; and integration level.

Kevin introduced the SRH and HIV Linkages e-Toolkit that guides users through SRH and HIV Linkages resources. It particularly highlights human rights. Kevin finished with information on upcoming documents, all at www.srhhivlinkages.org: Updated SRHR guidelines for women living with HIV; Integrated EMTCT Commodities Package; Updated Job Aid; and Integration Guidance.

**Why PrEP matters for the positive community**

Leo Schenk of the magazine Hello Gorgeous first introduced participants to Pre-Exposure Prophylaxis (PrEP), explaining that it involves taking Truvada once a day or in between sex. With PrEP people can have sex without being in fear of being infected by HIV. There has been much discussion on the effectiveness of PrEP but this is now well established. PrEP has been shown to have 92 to 96% effectiveness. There has been one known case of someone on PrEP who got infected anyway, but PrEP appears highly effective.

Leo then went on to explain the side effects. There are differences between side effects among people living with HIV and HIV negative people using PrEP. Some people experience nausea during the first couple of weeks. In some cases, changes in kidney function and bone density have been reported.
So, who is PrEP for? Leo explained that it is for all WHO “at-risk groups”, but PrEP should be available for everybody who is sexually active and wants to protect him/herself that way. It provides more control of one’s sexual health. PrEP is available in the US, France, Kenya, Israel, Canada, South Africa and Peru.

What future PrEP innovations are expected?

- An injectable PrEP which will protect you for a longer period of time
- A Vaginal Ring, a thin, transparent, flexible ring that you insert into the vagina yourself to provide protection
- PrEP with the HIV drug Dapivirine

Discussion focused on questions relating to the costs, benefits when compared with condoms, issues relating to STIs particularly multi-resistant gonorrhea, and how to increase access to PrEP.

It was stressed that PrEP can be liberating and can reduce fear and stigma. PrEP can do to stigma what an undetectable viral load can do in breaking down self-stigma. It will take more time and effort to break down stigma once and for all, but PrEP is and can be a beginning of the end of HIV-stigma.

PrEP is about engagement. Through the years people living with HIV have been at the forefront of advocacy and getting things done. The involvement and commitment of PLHIV to PrEP and other new prevention tools comes almost naturally. It is stressed that PLHIV have been at the forefront of new developments and should work together to make this prevention pill available. There are already a number of examples of groups working together to advocate the use of PrEP, or to help set up a service structure for its delivery. For example the Poz&Proud manifesto in 2006 on making PrEP available. In England there is the PrEPster team and in the Netherlands the PrEPnow! team. In the Netherlands, the Minister of Health is not yet interested in making PrEP available. Leo said that this delay will maintain 1,000 new HIV-infections per year, most of them among gay men. “PrEP is about protecting our partners, our families, our babies and our peers from contracting HIV. We should make it our priority to make services accessible to have a choice in what way protection is offered.”

Alice Welbourn spoke about a series of hot topics relevant to women living with HIV and how they relate to their rights. She started with a discussion of eliminating Mother to Child Transmission (eMTCT). She explained her doubts about this concept, as this view of perinatal transmission tends to focus on women as being responsible for the transmission of HIV. The word eliminating was one that made her uncomfortable and can be used against women and against their rights.

Alice reviewed forced and coerced sterilisation of women living with HIV. Too many women have been sterilised after their HIV diagnosis. She emphasised that this is a form of violence against women with HIV and that there is an urgent need to end forced sterilisation. Men living with HIV were not sterilised, only women!

She then went on to discuss hormonal contraception and HIV. There is uncertainty about whether there is an increased risk of becoming infected with HIV when using hormonal contraception. It is important to know whether women using hormonal contraception become more vulnerable and whether contraceptive implants are less effective in women using ARVs. The ECHO trial is ongoing and might help to answer these questions, but more research is needed and the WHO should be consistent in its messaging on these topics.

Alice then reviewed success stories, such as “Building a safe house on firm ground”, a global values and preferences survey regarding the sexual and reproductive health and human rights of women living with HIV. The results of the survey were not surprising for those who know the issues, but they still shock. Eighty-nine percent reported experiencing at least one type of violence and higher levels of violence are experienced post-diagnosis in health settings and in the community. Women living with HIV report mental health issues before HIV diagnosis, and experience a higher number of mental health issues after diagnosis. Mental health issues affect their ability to enjoy their right to sexual and reproductive health and to access services.
Alice provided recommendations:

- It is crucial to sensitise service providers to the rights of women living with HIV
- Increase access to quality support for women who have experienced GBV
- Ensure effective mechanisms for complaints and redress in health care services
- Provide a post-rape care and support package
- Provide harm reduction and address alcohol use
- It is crucial policymakers fund peer support and interventions to challenge GBV and promote human rights

Discussion focused on:

- Why are so few countries taking up PrEP
- What PrEP could mean for women and how can they become more involved, and
- The need to unite people around issues such as GBV including forced sterilisation

Points to take forward:

- There is a need for all of us to work together, and it should start with every one of us
- Leadership of the different movements (GNP+, ICW) should come together and find new ways to build and support common messages
- Integration should start by integrating with each other (for example actively including women in PrEP negotiations)
- Human rights is the fundamental issue for making linkages between HIV and SRHR services successful
SECTION 6  GREATER INVOLVEMENT OF PEOPLE LIVING WITH HIV

Mluleki Zazini of NAPWA South Africa and Kim Davis of Globally Aware and Living Positive Victoria facilitated this session. From as early as 1983, people living with HIV have demanded involvement in the decisions that affect their lives. After all these decades this demand is still relevant. But involvement also brings with it responsibility: responsibility to mentor each other to bring actual value to political and policy discussions; and responsibility to make our voices representative of the diverse voices of people living with HIV. Moving forward we need to think about how we can make GIPA work in authoritative political, social and religious settings.

The facilitators explained that the idea that the personal experiences of people living with HIV could and should be translated into helping to shape a response to the AIDS epidemic was first voiced by people living with HIV/AIDS in 1983 at a national AIDS conference in Denver, USA. During this conference, HIV-positive activists announced a set of principles destined to revolutionise the way the world responds to an epidemic. The “Denver Principles” set forth standards for human rights and self-empowerment in a health crisis, but importantly they also created a framework for engagement, participation and listening. “We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasionally “patients,” a term which implies passivity, helplessness, and dependence upon the care of others. We are “People with AIDS.” These principles have been the basis from which PLHIV have claimed the right to be part of decision-making processes and included in shaping the global response.

MENA – a different experience?

Rita Wahab of Vivre Positif and MENA Rosa in Lebanon presented. She described the MENA region’s implementation of Global Fund programming from 2013. At this time Morocco only had a support group, but the other countries had their own networks in place (Lebanon, Tunisia, Algeria). This was the first time they worked together to strengthen these organisations. They joined forces to strengthen the involvement, care and treatment of PLHIV.

They identified three benefits from increased involvement. Firstly, interventions were tailored to the needs of PLHIV. Secondly, targeted interventions were implemented by and for PLHIV to improve HIV treatment literacy and adherence and access to quality care and support. Thirdly, there was a marked increase in the self-confidence and self-determination of participants, and reductions in self-stigma. The confidence and credibility of individuals, groups and organisations were strengthened and beneficiaries became leaders. Challenges included the difficulty of being publicly open in countries where levels of stigma are high. There was a lack of skills, of sustainable and independent organisations, and of organisations prepared to involve PLHIV.

One lesson learnt was that meaningful involvement begins at grass-roots level and that women are emerging as leaders and making changes in the region. Another lesson learnt was that a little money goes a long way, and that there is real potential to make positive social change in wider society by challenging some of the societal and cultural practices and restrictions.

Leaving no person behind – GIPA through mentorship

Allen Kyendikuwa of CYSRA Uganda highlighted that implementing GIPA through mentorship programmes can be very important. Experiences from Uganda were discussed. The mentor is a person who helps someone else by sharing knowledge and modelling positive behaviours. The mentor needs to be dependable, engaged and empathetic, attuned to the needs of the person they are mentoring.

In Uganda it was found that the mentoring of the newly diagnosed to provide information to those who do not have HIV can change the course of new infections. Newly diagnosed people are given support so that they become informed and organised and can effect sustainable change. They can be proactive in involving others in their well-being and these positive examples breed success.
Are we doing enough to ensure global solidarity? How do we strengthen our collectiveness?

Sophie Dilmitis of Women for the Global Fund spoke on this topic and issued a call to recognise each individual person as a part of a global collective family. She urged that the movement should recognise differences and similarities and promote human rights for everyone. Participation and accountability should be promoted in all areas. GIPA does not limit the involvement of others. Everyone needs to be an advocate for more resources and not pitch one group against the other. She asked how the movement could find its voice again and stressed that liberation should bind the movement together. There is no contradiction between global responsibility and our individual connections.

She drew attention to the 2010 meeting for all key populations and felt this was a positive example for the future. Initially there was anxiety about working with each other outside the familiar silos. But agreement was reached, progress made and ways to work together found. Respect for each other has increased and people are learning from each other.

There is a need to balance medical approaches and human rights approaches. Identity is sometimes important and sometimes not. The movement’s constituencies and communities are diverse, so it is important that they get to know each other and speak about, and to, each other’s issues.

She asked “What would our shared agenda look like if we were to move in that direction?”

Points to take forward

- PLHIV involvement in all areas makes a difference - we must have a voice and a seat at any table that is discussing our needs, care, rights or treatment
- How do we support and encourage young people to be involved in a time when they are perhaps becoming less visible because of effective medication. They are the voices of the future but need to be supported to make their voices heard
- Peer-delivered support and capacity building is incredibly effective - care and treatment delivery must have peer support included so that people can learn from each other and their lived experience
- GIPA should be a foundation to support MIPA; this is more than just a tick-box exercise. PLHIV are the experts in this field and know first-hand what works and what doesn’t. “If there is only room for one positive voice at a meeting then that one voice has to understand and appreciate the wide and complex needs of all who live with HIV, so that no one is left behind.”
The second conference plenary session focused on specific issues from the voices of people most affected by HIV, like young people and sex workers.

**The voice of young people**

L’Orangelis Thomas Negrón, of Taller Salud in Puerto Rico, began this plenary session with an energetic discussion of her experiences as a young person living with HIV. She shared her frustration with being invited to speak to public health professionals and various other professional meetings about her life story, and how she has been moving forward not to be “tokenised” by others. She discussed the medication needs of young people living with HIV; how available medications may not always work for young people born with HIV; how some young people are the last to know they are living with HIV (many family members know this before young people know it themselves); how there are abundant ongoing studies on the biological/clinical issues facing YLHIV but very few studies about the psychosocial needs of YLHIV. She called on the global community to stop “infantilising” young people living with HIV, as they are young people moving into adulthood, and like all people, anxious to understand and explore their sexuality. She ended with a rallying cry “There is no political freedom without sexual freedom”.

**The Sexual Reproductive Health and Rights (SRHR) needs of female drug users living with HIV**

Sveta Moroz of the Eurasian Women’s Network on AIDS presented good practices from community programmes to address the SRHR needs of female drug users living with HIV. In Eastern Europe and Central Asia, drug users make up the highest percentage of those living with HIV, and programmes in the region (where they exist) are not effectively targeting women. She shared data from across the Region (primarily from Ukraine and Moldova) showing how more men than women living with HIV are accessing treatment, and how the rate of MTCT is nearly 11%. Women in the region living with HIV have poor access to HIV and Hepatitis C screening. In addition, women who inject drugs have poor access to sterile injecting equipment and condoms, and only an extremely small percentage of women who use drugs access opioid substitution treatment. They face high degrees of stigmatisation at all levels – in the family, in medical institutions, in society, by law enforcement agencies.

Recognition of the sexual and reproductive health and rights of women who use drugs is lacking, and the violence against them is made invisible. There is an absence of supportive services to mitigate and support women who experience gender-based violence. This state of affairs is compounded by poor access to maternal healthcare and other human rights violations including the provision of misleading information about the effects of drugs during pregnancy and coerced abortion and sterilisation. Drug use alone can result in women having their children removed from their custody, regardless of their parenting ability and often at great detriment to both mother and child.

Sveta stressed the need to demand services and ensure consistency with gender equality, human rights and public health frameworks. It is essential that SRHR services are available, affordable and evidence-based and that critical that women using them are not subject to any form of coercion. She urged for an end to legislation that makes drug use alone a sufficient reason to remove children from their parents’ custody and to legislation that seeks to punish women for using drugs during pregnancy.

**What the Trans* community has been doing to fight for their human rights and overcome stigma and challenges in access**

Cecilia Chung described what the Trans* community has been doing to fight for their human rights, overcome stigma, and confront challenges in accessing treatment and care. She described some of the very specific issues facing transgender persons: transgender women are 49 times more likely to acquire HIV than someone from the general population. Access to
HIV prevention, treatment and care of Trans* people is rendered incredibly difficult by the failure to break through the binary definition of gender. Only 18 countries have gender recognition laws: in most LIC and MIC countries, gender identity is not recognised.

Cecilia shared some findings from her work with the Positively Trans (T+) survey of transgender policy advocacy needs. “This survey is a ground-breaking opportunity to highlight not only our needs, but also our resilience when there are few resources available. We are ready to offer policy makers, providers and legislators our own solutions.”

**Sex workers’ perspectives and links between the sex workers’ and the broader women’s movement(s)**

Daughtie Ogutu discussed the links between sex workers and the broader women’s rights movement. She observed how at the AIDS 2000 Conference in Durban, there were no African sex workers, and now at AIDS 2016 there are more than 200 sex workers attending.

She expressed frustration with the anti-trafficking movement and its “mission of saving” sex workers. She noted the example of the Swedish model. Since 1999 Sweden has criminalised the purchase of sex, while leaving the selling of it legal. This established a model that has moved the EU parliament to resolve to reduce demand for sex work by criminalising its purchase, and is a model that has been adopted by Norway, Iceland, Canada and Northern Ireland, and more recently, France. According to Daughtie, the Swedish model takes away the livelihood of women. She said “I don’t need saving”. Daughtie wants support to advance the human rights of her fellow sex workers. We need to decriminalise sex work.

Daughtie shared how the networks of sex workers in Africa are moving forward with other women’s rights and human rights institutions (UN Women and Amnesty International) to advance the rights of sex workers, including drafting a decriminalisation of sex work policy. In addition, radical feminists in Eastern and South Africa are supporting the capacity building of sex workers. For Daughtie “until women of all walks of life are free of exclusion and violence then no woman will be free.”

Points to take forward:

- Sexual and reproductive health and reproductive rights must be recognised fully as human rights
- The need to recognise the intersectionality of the experiences of women living with HIV.
- It is important to recognise and address the specific needs and rights of women who use drugs who are also living with HIV
- SRHR services must be available, affordable, evidence-based, and free from coercion for all women
- There is a need to advocate for a move away from the binary definition of gender
- It is important to set up more coalitions with human rights organisations to overcome legal, policy and regulatory barriers to access to HIV prevention, treatment care and support
The final plenary session considered some of the main themes of the discussions in the other plenaries and the concurrent sessions, and reflected on how to move forward, setting priorities for the future of the movement and its role in the global response to HIV. The two days of the Summit had seen passionate and informed discussions on a very wide range of topics that concern the diverse community of people living with HIV. Not all of them were summarised in this final plenary session but all of the reports and points to take forward will inform future strategies and plans. A number of key donors were also invited to give feedback at the end of the Summit.

Findings from LIVING 2016

Jaime Luna presented the findings of LIVING 2016. Jaime reminded participants that the International AIDS Conference followed on from LIVING. “We need to speak with one voice and be heard there.” He reminded participants that they should draw on our passion as activists and challenge the AIDS conference when people living with HIV are not included on panels.

He referred to the agreed global targets that should be achieved in the next 14 years although funding is currently not secured and is declining. This is a context in which donor and Global Fund decisions based
on IMF criteria mean that countries in transition will not be eligible for funding. Countries are being transitioned out, not because of their readiness, but because of changed donor priorities. This will come at a high price for communities and people living with HIV.

He drew attention to the strong youth movement and to the fact that it is achieving real results. The recent example of Turkey shows the power of the social media and he urged participants to learn from this and harness the medium.

Jaime reiterated the key challenges of the opening session which had been validated and strengthened by much of the discussion at the Summit:

- A strong future requires global networks that are relevant, accountable and resourced. Working in a coalition with a common and ambitious vision and purpose
- Accountability: the movement needs to be more accountable to each other and to demand accountability from those who speak in the name of PLHIV
- To achieve 30 million people on treatment by 2020 it is important to have a collective strategy that articulates how and what has to be done, that focuses on treatment literacy, innovative and equitable access and adherence and retention support; in addition, this strategy should address issues related to the various treatment agendas such as test and treat, PrEP and the quality of services
- Solidarity is essential and discrimination must be challenged wherever it is encountered: the movement must ensure that actions unite rather than divide, to grow a strong and viable movement; the voices of PLHIV must be given political space and the movement must be well-resourced to ensure that people living with HIV have a voice as priorities change, programmes adapt and the role of national governments increases

- to ensure that issues of equity will be addressed in the roll out of the guidelines
- to clarify issues relating to PrEP, and
- to ensure that people in all countries have access to updated, accessible, locally relevant, simplified treatment literacy tools that are widely disseminated and discussed

Community designed tools: what impact on reducing stigma and discrimination?

The Stigma Index is a participatory research tool that allows us to learn about the stigma situation in a certain context and develop advocacy for change. Its use can also be important in empowering and including PLHIV. The Index also gives rise to some resistance from people who trivialise it. But it is a rigorous tool that has been shown to be useful. It is important to consider sensitive ethical considerations and the language used while conducting research. People should be protected from any possible trauma and it is important to use hopeful and solution-oriented language.

HIV is with us and the movement must continue to break the silence and speak out to ensure that stigma is confronted and PLHIV do not accept shame or stigma but live positively, demand rights and have a voice in decisions.

There is a real need to document initiatives and efforts that are working against HIV criminalisation. Case studies and data are important when advocating for policy change and for the removal of criminalising laws. Otherwise the efforts are diffused and it becomes more difficult to reach out to parliamentarians and legislators.

Criminalisation is a broader challenge: PLHIV should work effectively with others who are unjustly criminalised because of their identity or sexual orientation. Better tools and skills are needed to enable us to reach out to people suffering criminalisation. Support services (legal, psychological, emotional) are urgently needed for those facing criminalisation.

Sexual and reproductive health and rights

Addressing human rights issues is critical to success in establishing linkages between SRHR and HIV services. Successes have already been achieved in this area. The movement should build on these, using human rights and common interests to link different agendas and develop common strategies. Communities should use the existing examples of SRHR and HIV service linkages as an advocacy tool to improve the level of

Treatment literacy

The updated WHO Guidelines have been discussed in several sessions. In developing them PLHIV have been able to give input. A number of issues that need additional attention and advocacy have been identified:

- to ensure that the new guidelines are well understood and are never used as the basis for coercion in relation wither to testing or treatment
integration further. Integration should start by working with each other within the global community of people living with HIV.

**Sustainable funding for access to quality services and medicines**

For sustainable financing to work, legal environments must be conducive to interventions and programming. This is especially important in transitioning countries where key populations are criminalised and governments do not provide services for key populations.

Income classification cannot be the only basis for how countries are classified as “eligible” for funding. Health and poverty indicators should be used to supplement the basic country income classification. If groups of people are excluded in middle-income and high-income countries the target of ending AIDS by 2030 cannot be met.

A more coordinated response is needed from PLHIV networks (at the national, regional and global levels) to focus on countries that are transitioning and at extreme risk. PLHIV networks need to be involved in monitoring country investments (from donors and domestic sources) and can play a critical role in identifying resource gaps and monitoring spending on investment for key populations.

**The Greater Involvement of People Living with HIV**

There are risks in what has been achieved to date and it is important to keep the essence of GIPA burning and critical. It is important to find new ways of making the presence of PLHIV felt, giving new energy to discussions and making space for new voices and new leaders to come forward. PLHIV involvement in all areas makes a difference; PLHIV must have a voice and a seat at any table that is discussing our needs, care, rights or treatment. If there is only room for one positive voice at a meeting then that one voice has to understand and appreciate the wide and complex needs of all who live with HIV, so that no one is left behind.

Peer-delivered support and capacity building is incredibly effective; care and treatment delivery must be backed up with peer support included so that people learn from each other and their lived experience. PLHIV are the experts in this field and know first-hand what works and what doesn’t.

How does the movement support and encourage young people to be involved in a time when they are perhaps becoming less visible, thanks to effective medication? They are the voice of the future but they need to be supported to make their voices heard. In promoting GIPA, the movement has to move forward and look for ways to develop new leaders.

**Feedback from key donors that supported LIVING 2016**

Dr Gottfried Hirnschall, Director of the HIV/AIDS Department of the World Health Organization, reviewed the important way in which WHO has engaged with people living with HIV and the specific forms of engagement still needed. He said that since the first Durban AIDS Conference in 2000 there has been a massive expansion in access to HIV treatment with 17 million people now accessing antiretroviral therapy compared to only 773,000 sixteen years ago. While there is much to celebrate, there are challenges to be faced and these challenges need to be faced together.

Many people living with HIV shaped the latest WHO treatment guidelines which are focused on treating all people with HIV. WHO organised a quality survey through GNP+ and more than 200 people living with HIV took part in this global consultation process. He stressed that it is important that the guidance is implemented in full partnership with communities of people living with HIV.

The WHO heard from people living with HIV that encouraging early treatment initiation is acceptable when people living with HIV are supported to make their own treatment decisions. Work ensuring support for maintaining adherence, including guarding
against stock-outs and addressing the stigma and discrimination that undermine treatment access and adherence, is needed.

The WHO is committed to continue to work closely with people living with HIV to get feedback, concerns and advice to further implement Treat All. As treatment is accelerated it is important that adequate measures are in place to ensure quality and to ensure people living with HIV are supported in their health decisions. There is a need to protect against the emergence of HIV-related drug resistance through a focus on quality of drugs and measures to guard against stock-outs. And frontline health workers must have the information and skills required to identify, address and avoid stigma and discrimination effectively. Health workers living with HIV should be appropriately supported so they can continue to work. It is critical that all people living with HIV including people from key populations—men who have sex with men, transgender people, people who inject drugs and sex workers—are increasingly supported in meaningful involvement in the HIV response. As national programmes become increasingly integrated into health systems this must remain a priority.

Dr. Hirschall then introduced some of the WHO sessions at the upcoming IAC. These will be immediate opportunities for engagement. He looked forward to further collaboration with the community of people living with HIV and to continuing being challenged by the Community. “Together we will find the solutions required to address the urgency of scale-up while protecting individual and community rights and ensuring the quality we all need for success.”

Dr Louis Loures next gave feedback from UNAIDS. UNAIDS stressed that this is a critical juncture in the AIDS response and that we know what it will take to end the epidemic and have the tools and the knowledge. However the window of opportunity to act is small and the necessary financial resources are not lined up. He reminded the meeting of the bold targets for treatment (agreed by all UN member states in the Political Declaration 2016) but stressed that to reach that bold treatment target there is a need to acknowledge inequities and to act for change. The treatment targets will only be reached if 90-90-90 is achieved across all key populations of people living with HIV.

UNAIDS reaffirmed its commitment to the GIPA principle and will continue to ensure that PLHIV and communities are actively involved in design and implementation of responses. People living with HIV have played a crucial role in shaping the AIDS response: by advocating, by mobilising all of us, by challenging us to think outside of the box, by delivering services alongside government services. People living with HIV are women, girls, boys, gay men, sex workers, transgender people, prisoners, people who use drugs.

There is a need to scale up prevention services and ensure the human rights of everyone, with people living with HIV as partners. “You, the people living with HIV engaged in the response to AIDS, can provide the solution – on how to provide services that reach everyone, by keeping all of us accountable, and by informing us of emerging priorities and helping develop the strategies to get to ending AIDS by 2030”

Dr Deborah Birx, Ambassador at Large and U.S. Global AIDS Coordinator, gave feedback from the US government. She stressed the importance of addressing issues of access and human rights in order to effectively programme (test and treat) and support all community members regardless of race, gender, age
or sexual orientation. She also drew attention to the critical need for accurate size estimates for all populations at risk for HIV including Key Populations (e.g. gay and bisexual men, transwomen, and sex workers). There is a need for estimates that are grounded in truth and not artificially reduced to improve coverage numbers. It is important to ensure clinical cascades are age, gender and risk group disaggregated so that all barriers to full access can be identified and effectively addressed. A Key Population Fund could help to ensure all barriers to access are addressed in an open and transformative manner.

Finally, Ambassador Birx expressed how grateful she was for the active engagement of PLHIV organisations in the Country Operation Plan development and review, and undertook to continue to improve the process so all voices are heard at each stage.

**Closing comments**

Javier Hourcade Bellocq and Marama Pala provided closing comments. They urged that the pre-conferences speak with one voice and use the passion of activism. They stressed the need to challenge the conference if PLHIV are not included on panels. They dwelt on the fact that the global community has agreed targets to be achieved in the next 14 years, with less funding. He emphasised that countries are losing funding as the result of donor fatigue and global decisions based on IMF criteria. Countries are being transitioned out of the Global Fund not because of their readiness but because of changed donor priorities. Communities and PLHIV will pay a high price for this and we will have to continue to argue and advocate for all people to have access to quality treatment.

Finally Javier and Marama thanked USAID, The Public Health Agency of Canada, The Netherlands Ministry of Foreign Affairs, the Global Fund, the WHO, the International HIV/AIDS Alliance and UNAIDS for supporting LIVING 2016, and above all they thanked all who had worked to make the Summit a success and participated in its many debates which are critical for the future of PLHIV in the Global Response.

**Participants’ reactions**

The participant evaluation (to which two thirds of the participants contributed) confirmed that the Summit was very highly valued. 91% of respondents were satisfied or very satisfied with the Summit and 70% felt that the Summit had fulfilled expectations and achieved expected outputs. It was very clear from the participants evaluation that the Summit was hugely important as a “safe place” specifically to discuss the concerns of people living with HIV and a valued opportunity to network and learn. Participants were also positive about the role of the Summit as a venue from which to develop plans and a common voice. LIVING continues to be a forum which strengthens the capacity and the voice of PLHIV in the global response to HIV.
LIVING 2016 gave an important impetus to the Living Partnership to move forward, building on work done and past successes, whilst critically reappraising current strategies in the light of the changing and challenging context.

A number of issues clearly emerged as continuing or emerging priorities for the future. Some of these issues are overarching and others more specific. Some need to be addressed at global and some at local level – many need to be addressed across the levels and to be reinforced and echoed throughout the movement to create the momentum for change.

These issues will be further discussed, reviewed and modified in consultation with partners. An overview will be made of who is doing what in these areas, who can take a lead in specific areas, how to work together with limited resources and which are the urgent priorities which can be taken up and followed up in the near future.

**Overarching issues – Building the movement to meet the challenges of the future**

The overarching issues mentioned below were recurrent themes during LIVING 2016 and many people stressed the need for revival or regeneration of the broad movement of people living with HIV. Some specific action points were discussed but these concerns were not always accompanied by concrete ideas about how they could be addressed; however it seems important to take up these challenges and contribute to the development of clear strategies both to address these overarching concerns directly and also to see that they are consistently considered when planning around the specific priorities that emerged from LIVING 2016.

**Coalition building and inclusion**

Ensuring that the movement is open and inclusive is critical to success. Coalitions with other organisations and networks can multiply the strength and the volume of the voice of PLHIV. Alliances with others can also add important expertise and access to different levels of decision making and help to multiply influence and effectiveness.

- We should develop one common platform across existing networks (in particular GNP+, ICW and ITPC) to work together for action, solidarity and progress
- If we create new, or make use of existing collaborative platforms for the different networks, especially the global networks, we can avoid working in silos
- A consistent effort needs to be made to ensure that young leaders and activists are welcome, are strengthened, listened to and mentored. Equally the full involvement of activists and leaders from key populations will be critical to meeting the challenges of the coming years

**Accountability and good governance**

During LIVING 2016, concerns were raised about the accountability of PLHIV organisations and networks to the people they represent. These organisations and networks need to be exemplary and there is a need to share good practice and ideas about how to build accountability.

- We should develop mechanisms that will strengthen two-way accountability between representatives and their constituencies; the leadership of the various governance structures could lead a coherent collaborative strategy of what representation involves
The Greater Involvement of PLHIV was the subject of specific sessions during LIVING, and was also a recurring theme in many sessions. Finding a way to bring new meaning, vitality and inclusiveness to GIPA will be important in determining the strength of the movement and its capacity to move the agenda forward in the current challenging context.

- Find concrete ways to encourage young people to become more involved; they are often less visible because of effective medication but the movement needs them
- Explore the difficult but very important problem of how to realise GIPA in countries where there is a high degree of stigmatization and criminalisation
- Promote the idea that people representing PLHIV represent the whole diverse community and not just one interest group

### Areas emerging as specific priorities

#### 1) The need to develop clear perspectives and strategies on the community perspective.

The continuing roll-out of treatment, the emphasis on early treatment close to the community and the increasing reliance on domestic financing are all factors which make it essential that communities are well organised and resourced to meet the demands on them and to demand appropriate high-quality services. This will require consistent efforts to strengthen community systems with special attention for support group strengthening, the integration of self-support groups and community-based associations, treatment literacy and peer mentoring.

**Specific action points**

- Promote the development of treatment literacy tools developed by PLHIV as evidence shows that they are associated with better outcomes and treatment retention
- Use social media and develop tools that PLHIV can use to communicate gaps and to use in advocacy (e.g. developing simple local mechanisms to monitor and give feedback on stock-outs)
- Ensure that the potential of communities, in conflict and post-conflict areas, is harnessed and resourced
- Document, and establish the exchange of, good community practices, strengthen the capacity of community organisations and build mentor schemes and peer-to-peer education and support groups

#### 2) The potential impact of Treat-All.

The new WHO Treatment Guidelines and the intention to treat all people as soon as they test positive was generally seen as a major step forward, but a number of concerns have been expressed about the potential impact on human rights, equity and the continuum of care. LIVING 2016 sought clarity and suggested some specific action points:

- Clear human rights-based communications are needed to allay fears that Treat-All strategies will lead to coercion and undue pressure on people to test and to treat; advocacy directed at WHO and governments can ensure appropriate messages
- LIVING 2016 urged that equity should remain a priority in implementation of the new Guidelines

### Strategy development and joint learning

Attention was drawn, throughout the meeting, to the need to develop shared strategies that help to connect target groups and all groups of PLHIV and that cut across the various levels of influence. These shared strategies should be developed around simple messages that convey key issues.

For instance, implementation of the new WHO Treatment Guidelines calls for global advocacy aimed at WHO, the Global Fund and major donors. But this also requires national and regional advocacy and information campaigns, and intensive work at community level, all to ensure that PLHIV can influence planning and implementation and that their lived experience shapes programme planning.

- Contribute to the development of a broad collective strategy that clearly articulates how people living with HIV are going to work to achieve the ambitious target of 30 million people on treatment by 2020 (including their joint power to work in the areas of treatment literacy, equitable access, intellectual property, adherence and retention support, test and treat, government commitments, community monitoring etc.). This strategy should help to link the global, national and community work of the movement and to link broader policy and rights debates with the issues determining the quality of services and access to them.
• Community and national advocacy is needed to maintain focus on quality of services and the continuum of care; LIVING 2016 expressed concern that these might suffer as a result of the rising cost of medicines to Treat-All
• Promote strategies and document best practices on how to improve treatment literacy and improve uptake of testing and treatment initiation and retention; PLHIV have valuable experience in what works and how best to reach target groups (working with WHO to clarify changes in recommendations about the role of viral load monitoring is one very practical example)

3) Information gathering and advocacy regarding the effects of Global Fund withdrawal from middle-income countries.

The Global Fund has been a major player in the global AIDS response, providing around 20% of global funding. A new Global Fund eligibility policy means that many middle-income countries and countries with lower HIV prevalence will soon have to ‘transition out’ of the Fund’s portfolio, on the basis that their governments should pay for their own HIV/AIDS responses. Little is known about how such a transition will affect access to treatment but there is great concern about the challenge of achieving new and more ambitious treatment targets without a strategy for financing implementation. Most urgent are concerns about the effects on key populations, as many of the countries concerned criminalise and marginalise key populations and do not see them as priority groups.

4) Global advocacy to mitigate the Global Fund eligibility policy and criteria.

• There must be advocacy to ensure that eligibility criteria do not only look at overall country income status which says nothing about equity or the needs of key populations. Criteria should be broadened to ensure that access programmes can still be enhanced for underserved groups in middle-income countries and that transition periods are used to guarantee continuity, equity and the sustainability of the global response.

5) Encouraging domestic funding through innovative funding mechanism and promoting national political commitment to access.

• Identify and promote examples of innovative funding mechanisms that can leverage funding
• Train activists on patent laws and intellectual property and link with experts in this area so that there can be strong advocacy, both globally and nationally, to keep the costs of treatment down
• Monitor domestic priority setting to ensure that the needs of key Populations are addressed and continuum of care financed (not just medicines)

6) Working to end criminalisation and stigmatisation.

• Share successes and find new strategies to realise GIPA and achieve rights in countries where stigmatisation and criminalisation is high (e.g. working with human rights and international workers’ rights and patients’ rights charter)
• Document human rights abuses and make stories known
• Support campaigns for legal reform to create the legal foundations to end stigma and criminalisation
• Self-reflection about how PLHIV respond to others’ experiences of stigma; promote solidarity and joint action with other groups vulnerable to stigma
• Work with tools and best practices to reduce stigma and self-stigma
• Work with tools and documentation of best practices to maximise intersectionality and move away from binary definitions of gender
7) Promoting the need for integrated HIV / SRHR services that are available, affordable, evidence-based, and free from coercion and interlinked with sexual education.

- Advocating youth friendly services and promoting examples of good practice
- Ensure that sexual and reproductive rights are respected and that women do not face additional stigma (e.g. document and give publicity to forced sterilisation and other forms of coercion)

8) PrEP

- Disseminate information about PrEP and advocacy for its inclusion in services
- Ensure that PLHIV (including women and KPs) are included in policy making about the role of PrEP in national programmes and services

More discussion is needed, actions and aims need to be further defined, and strategic choices must be made about how to make the maximum impact with the available resources. But these issues outline the framework of an action and advocacy agenda to which the movement of PLHIV must make a contribution in order to shape the global response to AIDS. This contribution must ensure that there is a focus on achieving global targets with regard to equity and human rights and with the full involvement of PLHIV from the community level through to the global policy arena.
ANNEX 1 LIVING INTERNATIONAL PARTNERSHIP REPRESENTATIVES

Andy Seale, WHO
Chris Mallouris, UNAIDS
Christian Hui, GNP+NA & Canadian Positive People Network
George Ayala, MSMGF
Jaime Luna, GNP+ Board & Y+
Jennifer Bushee, GNP+ Secretariat
Jessica Whitbread, ICW Global
Shaun Mellors, International HIV/AIDS Alliance
Solange Baptiste Simon, ITPC
Winfield Tannis-Abbott, GNP+ Board & CRN+
WELCOME

Thank you for joining us at LIVING 2016, the Positive Leadership Summit. We are honoured to be able to organise this conference of people living with HIV in Durban, South Africa. Durban is an historically important city for the movement of people living with HIV. We are continuing the legacy.

Starting in 1986, the international conferences of people living with HIV have strengthened the HIV movement, built HIV positive leadership and skills, nurtured sharing of experiences, and developed joint priorities and a global advocacy agenda. The LIVING Positive Leadership Summit takes place every four years as a two-day conference prior to the International AIDS Conference.

LIVING is an activist space that brings together the knowledge and experience of people with HIV and supports us to develop a common voice and plan for action to get to truly universal access to prevention, treatment, care and support. The Summit programme strongly supports the knowledge needs of emerging or newly engaged positive leaders.

THE LIVING2016 PARTNERSHIP

The LIVING 2016 Partnership is a collaborative effort of organisations committed to strengthening the movement of people living with HIV and their communities.

The LIVING 2016 partnership consists of the Global Network of People living with HIV (LIVING custodian), the Global Forum on MSM and HIV, the International Community of Women Living with HIV, the International AIDS Society, the International HIV/AIDS Alliance, the International Treatment Preparedness Coalition, the National Association of People With AIDS, the Positive Women Network, the Treatment Action Campaign, the United Nations Joint Program on HIV/AIDS, the World Health Organization, and the Global Network of Young People Living with HIV (Y+).

ACKNOWLEDGEMENTS

The LIVING 2016 Positive Leadership Summit has been made possible with the kind financial support from the following donors: the United States Agency for International Development; the Public Health Agency of Canada; the Ministry of Foreign Affairs of the Netherlands; the Global Fund to Fights AIDS, Tuberculosis and Malaria; the World Health Organization; the International HIV/AIDS Alliance; and the United Nations Joint Program on HIV/AIDS.
## SATURDAY 16 JULY 2016

### Meeting Room 22

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>08h00 - 09h00</td>
<td>Registration</td>
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| 09h00 - 10h00| Opening, Plenary 1  
Plenary chairs: Prudence Mabele & Jaime Luna  
1. Welcome to South Africa: The Heart of the HIV Response  
   Plenary chairs: Prudence Mabele & Jaime Luna  
2. A Movement in Crisis or a Movement of Opportunity—a Critical Reflection  
   Speaker: Shaun Mellors  
3. Solidarity among All People Living with and Affected by HIV: a Commitment to Human Rights  
   Speaker: Morolake Odetinyobo (TBC)  
4. From Visibility and Recognition to Solution: How Young People Living with HIV Are Mobilising Themselves to Gain Access to Prevention, Treatment, Care and Support  
   Speaker: Cédric Nininahazwe |
| 10h00 - 10h30| Tea/Coffee and networking                                              |
| 10h30 - 12h30| Concurrent Sessions on Access to Quality and Rights Based Services  
**Location: MR22**  
Session 1: Our Role as People Living with HIV in Promoting Treatment Literacy  
Facilitators: Ron Macinnis & Lillian Mworeko  
Presentations:  
1. Overview of global technical guidance related to treatment, care and service access  
   Presenter: Andy Seale  
2. The importance of treatment literacy and support services in maintaining adherence  
   Presenter: Edou Agustian  
3. The role of people living with HIV in service delivery  
   Presenter: Annie Banda  
Group work focussing on:  
• Monitoring implementation of treatment guidelines  
• Increasing literacy  
• Strengthening our role in service delivery  
Session 2: How People Living with HIV Can Ensure Strong and Resilient Community Systems for Health  
Facilitators: Daughtie Ogutu & Christian Hui  
Presentations:  
1. The state of funding for Community Systems Strengthening? Where is it going to come from?  
   Presenter: Nicholas Niwagaba  
2. Strengthening capacity of national, regional and global networks? Are networks still a good way to organise?  
   Presenters: Javier Hourcade Bellocq  
3. Emerging voices, networks and priorities—perspectives from MENA  
   Presenter: Souhaila Bensaid  
Group work focussing on:  
• What concrete advocacy strategies can PLHIV implement to influence funding priorities?  
• What are models for collective action on advocacy, service delivery, monitoring |

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<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>12h30 - 13h00</td>
<td>Lunch</td>
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| 13h00 - 15h00| Concurrent Sessions on Access to Quality and Rights Based Services  
**Location: BR6**  
Session 1: Our Role as People Living with HIV in Promoting Treatment Literacy  
Facilitators: Ron Macinnis & Lillian Mworeko  
Presentations:  
1. Overview of global technical guidance related to treatment, care and service access  
   Presenter: Andy Seale  
2. The importance of treatment literacy and support services in maintaining adherence  
   Presenter: Edou Agustian  
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• What concrete advocacy strategies can PLHIV implement to influence funding priorities?  
• What are models for collective action on advocacy, service delivery, monitoring |
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<tr>
<th>Location</th>
<th>Session 3: Community Service Delivery—the Role of People Living with HIV</th>
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<tbody>
<tr>
<td>BR8</td>
<td>Facilitators: EriKa Castellanos &amp; Sarah Feegan</td>
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<td>Presentations:</td>
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<tr>
<td></td>
<td>1. What do the treatment guidelines say?</td>
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<td>Presenter: Sita Shanti</td>
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<td>2. Bringing the Guidelines to life—successful examples of community service delivery</td>
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<td>Presenter: Olive Edwards</td>
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<td>3. Bringing the Guidelines to life—more successful examples of community service delivery</td>
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<td>Presenter: Cédric Nininahazawale</td>
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<td>Group work focussing on:</td>
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<td></td>
<td>• How do we reinforce the role of HIV community networks in scaling up these services?</td>
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<td>• How do we advocate for more resources for these types of service delivery approaches including ensuring appropriate training and support to networks of people living with HIV?</td>
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<td>• What is needed to improve linkage to and retention in care?</td>
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<tr>
<th>12h30</th>
<th>Lunch and Networking</th>
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<tr>
<td>13h30</td>
<td>Special Lunch with representatives of the Global Fund, Office of the Global AIDS Coordinator (OGAC) and the Canadian Government.</td>
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<tr>
<th>Location</th>
<th>Session 4: Self-Stigma Workshop: From Within – Dealing with HIV Self-Stigma</th>
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<tbody>
<tr>
<td>MR22</td>
<td>Facilitators: Prudence Mabele, Raoul Fransen &amp; Silvia Petretti</td>
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<tr>
<td></td>
<td>Session description:</td>
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<td></td>
<td>A practical workshop that focusses on issues related to self-stigma, whilst also exploring how the reality and leadership of people living with HIV should inform policy and programming on this issue. This workshop will help participants to understand and define self-stigma and how it contributes to the ongoing challenges in HIV prevention and treatment programming.</td>
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<td></td>
<td>This interactive workshop draws upon personal lived experiences from PLWHIV on self-stigma.</td>
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<td></td>
<td>• Individually: To empower people living with HIV to better understand their role in addressing self-stigma in their own lives.</td>
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<td>• Collectively: To empower people living with HIV to better understand their role in addressing self-stigma in their own lives.</td>
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<td>• Advocacy: To develop a community of advocacy practice among about self-stigma.</td>
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<td>Group work focussing on:</td>
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<td>• Workplace</td>
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<td>• Intimate, sexual life</td>
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<td>• Agency</td>
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<tr>
<th>Location</th>
<th>Session 5: Community Designed Tools – What Impact on Reducing Stigma and Discrimination?</th>
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<tr>
<td>BR6</td>
<td>Facilitators: Laurel Sprague &amp; Florence Anam</td>
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<td>Presentations:</td>
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<tr>
<td></td>
<td>1. Advocacy based on the lived realities of people living with HIV</td>
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<td>Presenter: Margaret Happy</td>
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<td>2. Doing community-led research</td>
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<td>Presenter: Olena Stryzak</td>
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<td>3. Stigma Index: choices and changes</td>
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<td>Presenter: Chris Mallouris</td>
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<td>Presenter: Alastair Hudson</td>
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<td>Group work focussing on:</td>
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<td></td>
<td>Review and provide feedback on updated PLHV Stigma Index</td>
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<tr>
<th>Location</th>
<th>Session 6: Overcoming the Barriers of Invisibility and Harmful Laws and Policies</th>
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<tr>
<td>BR8</td>
<td>Facilitators: Edwin Bernard &amp; Cecilia Chung</td>
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<td></td>
<td>Presentations:</td>
</tr>
<tr>
<td></td>
<td>1. Why is addressing criminalisation so important for key populations?</td>
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<td>Presenters: Overview by Edwin and Cecilia</td>
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</table>
Session 7: Understanding the Basics: Intellectual Property Issues
Facilitator: Loon Gangte
Presentation:
Understanding intellectual property and why pricing matters to treatment access
Presenter: Loon Gangte
Group work focussing on:
Finding practical ways of increasing our knowledge and effectiveness.

Session 8: The Dollars and Sense of Treatment Funding—Where is it Going to Come from?
Facilitators: Rachel Ong & Duncan Moeketse
Session description:
Perspectives from different regions: regional reports on funding; where are donors pulling out and what it is the impact, what is the state of domestic investment; how are community organizations responding: examples from the field.
Panel discussion focusing on in-country experiences and group work focussing on following issues:
• Inside out: how do we develop “outsider” and “insider” strategies in our Global Fund and resource mobilization work? Strategies to impact “successful transitions” in middle income countries?
• Increasing domestic investments in lower income countries, including services for people from key populations.

Session 9: Developing an HIV Positive Critique of Policy and Finance Frameworks
Facilitator: Javier Hourcade Bellocq
Presentations:
1. Overview of Fast Track initiative resource needs?
   Presenter: David Barr
2. The why and what of transitioning—what impact on PLHIV?
   Presenter: TBD
3. How to ensure domestic funding for HIV fund the right things?
   Presenter: Deogratius Peter Rutatwa

Welcome Reception and Networking Event
For confirmed delegates only
### Session 10: Holistic Policy and Programming Analysis and Advocacy on Hot Issues in the SRHR and HIV Integration Agenda

**Facilitator:** Makena Henguva

**Presentations:**

1. **No more clinic sweepers doing obstetric care! What WLHIV have done to ensure maternal health care promotes rights and is top quality from conception to postnatal care.**
   **Presenters:** Annie Banda

2. **Has the push for youth friendly services made a difference for young people living with HIV and young people living with HIV from key populations? What has worked? What hasn’t and what’s needed?**
   **Presenters:** Annah Sango

3. **Who is doing a good job at promoting positive sexuality and sexual pleasure? How can we do it in our programming too? Examples of initiatives and good practices**
   **Presenter:** Jessica Whitbread

### Session 11: Ensuring Positive Involvement in Defining and Shaping SRHR Services: Essential Case Studies

**Location:** BR6

**Session 11:** Ensuring Positive Involvement in Defining and Shaping SRHR Services: Essential Case Studies

**Presentations:**

1. **Young people living with HIV from key populations involvement in high level national decision making: Examples of strategies from the Link-Up programme Y+ Our Realities Our Needs project**
   **Presenters:** Resty Nalwanga

2. **Collective advocacy of networks of women living with HIV and broader feminist organisations: the benefits of cross-movement building**
   **Presenter:** TBD

3. **Demanding accountability at the clinic: women living with HIV participating in health advisory committees and other accountability mechanisms**
   **Presenter:** Imen Mughozi

### Session 12: Our Neglected Issues in the SRHR Agenda: How Can Integration Deliver for and Promote the Rights of People Living with HIV

**Facilitators:** Nicholas Niwagaba
Lunch and networking
Special Lunch hosted by UNITAID, BR 15

Tea/Coffee and networking

Concurrent sessions on GIPA and for networking and wrap up

Session 13: The Road Well Travelled: Understanding what GIPA is and why it is important
Facilitators: Mluleki Zazini & Kim Davies

Presentations:
1. The road well-travelled – a historical perspective
   Presenter: Martin Choo
2. Leaving no person behind – GIPA through mentorship
   Presenter: Allen Kyendikuwa
3. MENA – a different experience?
   Presenter: Rita Wahab
4. Are we doing enough to ensure global solidarity? How do we strengthen our collectiveness?
   Presenter: TBD

Group work focussing on:
• How do we continue to champion GIPA and is it still important?
• How do we provide support to people living with HIV representing our voice?
• How we demand and enable accountability?

Location: MR22

12h30 Lunch and networking
13h00 Special Lunch hosted by UNITAID, BR 15
13h30 Concurrent sessions on GIPA and for networking and wrap up
15h30

Location: BR6
Facilitators Group: Pulling Together Outcomes and Action Items from LIVING 2016

Location: BR8
Open Networking Session – World Café

Tea/Coffee and networking

16h00 Closing Plenary
17h00

Closing Plenary
Plenary chairs: Marama Pala & Javier Hourcade Bellocq

1. Summit Outcomes and Action Items: Our Advocacy Agenda
   Plenary chairs: Marama Pala & Javier Hourcade Bellocq

2. Special Speakers:
   • Ambassador Deborah L. Birx, U.S. Global AIDS Coordinator
   • Luiz Loures, UNAIDS
   • Gottfried Hirschall, WHO

3. “End AIDS by 2030”: What Does It Mean for Those of Us Put at the Margins in the Context of Increasing Inequalities
   Presenters: Marama Pala & Javier Hourcade Bellocq
ANNEX 3 COMMUNICATIONS LIVING2016

GNP+ managed the communications around and promotion of LIVING 2016 The Positive Leadership Summit. The communications concerned branding, online communications, social media outreach and participant communications. This is a short report of the communications plan and its results.

BRANDING

GNP+ created a special logo for LIVING2016. The logo took inspiration from South African bead handicraft which includes red ribbons in a flag design. In the LIVING logo the colours of the South African flag were used. The logo was used in online materials and email signatures. The Concept Note of the Summit also included a light design for fundraising purposes.

Online logo:

Logo for print reports:

Email banner:
To promote the Summit, GNP+ created a special website section on its own website: www.gnpplus.net/living2016

The section included semi-static pages containing information on the Summit, Issues, Partnership and How to Apply. In addition, there is a news section where updates around the Summit are posted. From February to August there were 15 stories. The How to Apply section linked to a separate survey monkey questionnaire which took people through the registration form.

Onsite branding:

This included beach flags and roll up banners, as well as signage inside the conference centre to provide direction to the break out rooms. The main table and speakers table in the plenary room included large panels with the logo on them. A special PowerPoint template for the Summit’s presentations was created and used.

We also printed promotional leaflets for our satellite, and included an advertisement in the GNP+ Roadmap for People living with HIV which went into 10,000 conference bags.
SOCIAL MEDIA OUTREACH

Twitter and Facebook were the primary social media used to promote LIVING2016 and communicate about it. With some 46 messages on these two social media channels between February and July we reached almost 29,000 people (measurement end of August 2016).

We encouraged participants to report their own experiences during LIVING2016 and use their own social media accounts as much as possible using the hashtag, #LIVING2016. Ahead of the Summit we shared with the participants “Guidelines on Social Media and Privacy” to protect people living with HIV participating in the Summit from unwanted exposure.

Though we were not able to monitor Instagram or Facebook, we did research the number of times the hashtag #LIVING2016 was used on Twitter. Between 16 July and 22 July there were 321 tweets using this hashtag. The reach of these tweets is unknown to us.

PARTICIPANT COMMUNICATIONS

GNP+ had direct communications with participants, potential participants and other interested people. This was mainly through a direct mailing list. After an initial call for participation a branded newsletter was created for those who were accepted to participate in the summit. Four newsletters were sent out, containing twelve directly relevant stories and nine related stories. To promote and report upon LIVING 2016 we sent eight messages through our mailing lists, reaching over 10,000 people.

 MEDIA EXPOSURE

Prior to the LIVING2016 Summit we had contact with seven journalists living with HIV who participated in the Summit. The journalists were from:

- Positive magazine: quarterly, South Africa – article expected in Autumn issue, Facebook post in social media coverage
- Amar Ujala: Hindi newspaper, India
- Nigerian Federal Radio Cooperation: News item available on Soundcloud, long report not yet received
- MyFaboulousDisease/theBody.com: Vlogger Mark S. King reported for own blog and multiple websites. Did some filming at LIVING, but did not use the material
- Out.com/Advocate.com/HIVhero.org: US website, reposted news release
- A freelancer from Zambia
In addition, other organisations and speakers’ organisations wrote about the Summit. A few examples:

- http://www.aidsalliance.org/blog/769-breaking-the-silence
- http://www.nacopho.or.tz/resource/publication/38/
- https://www.aidshilfe.de/meldung/ aids2016-news-ticker-durban (German)
- http://www.aidshilfe.de/de/was-wir-tun/lobbying/iac.php (German)

Aside from using social media, several participants blogged from the pre-conference. Some of them are:

- https://lizziejordan.com/2016/08/01/living2016-pre-conference/comment-page-1/
- https://flosithiv.com/tag/living2016/ (2 articles, German)
- http://vivacazuza.org.br/blog/ecos-de-durban-viver-reviver-pensar-repensar (Portuguese)
- http://www.corresponsalesclave.org/2016/07/living-2016-%C2%BFun-movimiento.html (Spanish)

Our press release was picked up by different media such as:

- http://kbctv.co.ke/blog/2016/07/14/leaders-living-with-hiv-gather-for-change-at-living-2016-summit/
- https://advocatehiv.wordpress.com/2016/07/22/conference-daily-review-pre-conferences/

Our press conference took place on Thursday 21nd of July, four days after the conference. This was attended mostly by community reporters and activists. Elton John’s press conference simultaneously with our press conference contributed to low attendance of main stream media.

This final LIVING 2016 Report will be sent to all donors and participants.