HIV
Leadership through
Accountability

HIV Leadership Through Accountability

Planning & Review Meeting of Networks of People Living with HIV and Civil Society Partners

Hilton Hotel, Nairobi, Kenya, 25-29 July 2011

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
AFRICASO	African AIDS Services Organisations
CATAG	Central Africa Treatment Action Group
CS	Civil Society
CSO	Civil Society organisation
CS Platform	National civil society advocacy campaign platform
DfID	(UK Government) Department for International Development
HIV	Human Immunodeficiency Virus
JOTHI	National network of PLHIV in Indonesia
GBP	Great Britain Pound
GNP+	Global Network of People Living with HIV
GTF	Governance and Transparency Fund (of DfID)
HIV	Human Immunodeficiency Virus
ILO	International Labour Organisation
M&E	Monitoring and Evaluation
MANET+	Malawi Network of People Living with HIV/AIDS
MANASO	Malawi Network of AIDS Organisations
MoU	Memorandum of Understanding
MOV	Means of Verification
MSM	Men who have Sex with Men
NACOPHA	National Council of People Living with HIV/AIDS in Tanzania
NAPWA	National Association of People Living with HIV/AIDS in South Africa
NAC	National AIDS Council/Commission
NEP+	Network of Networks of HIV Positives in Ethiopia
NEPHAK	National Empowerment Network of People Living with HIV/AIDS in Kenya
NEPWHAN	Network of People Living With HIV/AIDS in Nigeria
Network	National network of PLHIV
NGO	Non-Governmental Organisation
NZP+	Network of Zambian People Living with HIV
PCB	UNAIDS Programme Coordinating Body
PHDP	Positive Health, Dignity and Prevention
PLHIV	People Living with HIV
PUD	People who use drugs
RéCAP+	Le Réseau Camerounais des Associations de Personnes Vivants avec le VIH (Cameroonian Network of Associations of People Living with HIV)
RNP+	Réseau National des Personnes Vivant avec le VIH/SIDA du Sénégal (Senegalese Network of Associations of People Living with HIV)
SRHR	Sexual and Reproductive Health and Rights
SMART	Specific, Measurable, Attainable, Relevant and Time-bound
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS

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Day One:
The LTA programme and evidence-gathering tools

"***The most significant thing we've learnt through the HIV Leadership Through Accountability programme is that networks of people living with HIV and AIDS can go out on their own, model, research and collect the data and evidence to inform advocacy***" said Nelson Otwoma of the National Empowerment Network of People Living with HIV in Kenya (*NEPHAK*) as he opened the 3rd HIV Leadership through Accountability Planning and Review Meeting, held from 25-29 July in Nairobi. "***Now we have our own evidence that is going to drive advocacy for universal access***."

Launched in 2008, the HIV Leadership through Accountability programme (LTA) supports advocacy for good governance, and universal access to prevention, treatment, care and support in 11 participating countries (nine in Africa) in two ways:

1) Supporting **national networks of people living with HIV (PLHIV)** to strengthen evidence-informed advocacy, policy and programming — through the adaptation and implementation of five evidence-generating tools to assess:

  1) the greater involvement of PLHIV (GIPA) (the GIPA Report Card)
  2) HIV stigma (the PLHIV Stigma Index)
  3) human rights (Human Rights Count!)
  4) sexual & reproductive health rights (SRHR Guidance Package), and
  5) HIV criminalization issues (the Global Criminalisation Scan) —

and to increase their engagement at the national policy making level (*activities primarily supported by the Global Network of People Living with HIV (GNP+)*); and

2) Creating an enabling environment and campaign platforms to support the strengthened coordination and participation of **civil society** in the development of advocacy and effective HIV responses (*with support from the World AIDS Campaign (WAC)*).

Kenya was one of the first countries to join the LTA programme, and as Nelson and others would reiterate during the meeting, the experience has dramatically increased their organisations' capacity. The in-country partners have developed expertise on how to conduct research, and in the process, they have formed strategic partnerships with other organisations engaged in the HIV response. Engaging in the LTA programme has established their project management capacity and demonstrated their financial accountability, and dramatically increased their visibility — which is critically important in mobilising resources to sustain their work as they launch advocacy campaigns. For more information please see case study #1 on page 56.

The 3rd HIV LTA Planning and Review Meeting marked **a new stage in the evolution of the LTA programme, with the first round of countries that joined the programme sharing their expertise and taking on mentorship roles to the other countries**. In addition, they shared key findings and strategized about how civil society and the national networks of PLHIV should work together to plan and implement evidence-based advocacy and campaigns. Using tools such as the LTA website (www.hivleadership.org), the in-country partners also committed to continue sharing their experiences to support each other as programmes increasingly engage in advocacy and development of services to meet the needs of key populations and PLHIV.

Sharing 'burning issues' and building solidarity

"*The reason we gather here this week is very important, particularly for PLHIV*," said Nelson, before describing a number of the critical challenges facing the PLHIV in Kenya and other countries (see case study 1). After an exercise led by Rukia Cornelius of the World AIDS Campaign, where everyone shared their dreams of a better world for their children — a world free of discrimination, racism or gender-based violence and where people have access to their basic needs, including the right to health — participants described burning issues' faced in their countries, echoing many of Nelson's concerns.

Some burning issues were specific to the individual countries and sub-regions. For instance, famine is posing a substantial threat to people living with HIV in East Africa — while conflict in the region has led to an movements of vulnerable refugees with little awareness or knowledge of HIV. The movement of people due to changing economic opportunities leads to distinctly different challenges to the HIV response in Zambia than Moldova. While Indonesia is uniquely challenged by the need to develop HIV responses effective for an ethnically and culturally diverse, and geographically very widely dispersed population.

Other burning issues are common to most of the countries, with concerns about resources and the sustainability of the HIV response as well as treaties that may limit access to affordable generic antiretrovirals (ARVs) and other essential medications most PLHIV rely on. The changing paradigm of HIV 'treatment as prevention' seems to come with risks and benefits to PLHIV, increasing their need to be involved in policy development. Stigma and discrimination remain eternal challenges for people living with HIV and key populations at risk of HIV, such as men who have sex with men (MSM), sex workers (SW) and people who use drugs (PUD). Increasing criminalisation of key populations and PLHIV threaten the HIV response. [See appendix A for burning issues.]

"*It's important for us to understand the contexts and to see the similarities across our countries. It allows solidarity to happen around issues*," Rukia said, which helped get many of the issues into the 2011 UN High Level Political Declaration on HIV and AIDS.

One significant difference between the countries was that the in-country partners joined the LTA programme at different times — with the 1st round of networks, from Zambia, Nigeria and Kenya (along with the first civil society platform also in Kenya) joining during the first year, so **countries are at different stages of implementing the programme.** This has proven to be an advantage, as countries joining more recently can learn from the more experienced countries.

Consequently, as GNP+'s Georgina Caswell pointed out, the planning meeting's objectives differed depending upon when the countries joined the programme. For the countries most recently joining LTA (3rd round countries), the objective of the meeting was to learn more about the programme. Round 1 and 2 countries, who have already implemented most or all the research, could discuss 'what's next,' including coming together with civil society to make the most of their findings for joint advocacy and how to mobilise resources for those activities.

Review of the LTA programme so far

In the LTA programme, the work of the networks and the CS platforms should be mutually supportive and goes in parallel during the first stage of the process, the networks lead on evidence-gathering research while the civil society campaign platforms bring together diverse key civil society players and map out national issues. During the second phase, the networks and civil society should come together to discuss how the evidence from the research should inform the advocacy work of the platforms and networks; as well as informing regional advocacy agendas. There have been some hurdles along the way, coordinating the activities of the PLHIV networks and civil society, but the programme is based on the underlying model logic of '**learning by doing**.'

"*What we've seen, and it's very important, is that although the national networks lead on the research, they should involve civil society advocacy partners – and link to human rights organizations, research institutes, civil society organizations that can reach key populations. It's* *also very important that the national network of PLHIV have a significant presence in the campaign platform, so that, again, there's a really good joint support*," said Gavin Reid of GNP+. "*The emphasis here is that civil society organizations and other stakeholders and diverse communities meet and work together with the Networks of PLHIV— not just meeting in parallel but putting PLHIV at the centre of how we do things*," said Linda Mafu of WAC. The civil society platform should develop an advocacy agenda based upon the research from the networks, so that issues affecting PLHIV are embedded in the campaign.

"*The bottom line for us, is to ensure that there's universal access to HIV Prevention, Treatment, Care and Support services without discrimination*," said Linda. The ultimate purpose of the advocacy is "*so that* we improve the quality of life for PLHIV," she said.

Lessons learned from implementation have led to some changes in the LTA programme. The original plan was to involve 15 countries but during a recent midterm review, it was decided to rather invest more in the current eleven countries. The programme, running five years overall, had intended to run for just two years in each country. Now, GNP+ and WAC plan to continue some degree of engagement with countries completing the second year, (until the programme ends on 31st March 2013), hoping to strengthen relationships between countries regionally and globally.

"*We're trying to develop a model of how we can strengthen each other*," Gavin said. It is important to pool expertise about how to best mobilise resources to support advocacy, use evidence to develop advocacy campaigns, and measure the effectiveness of those campaigns. GNP+ and WAC are developing tools to support countries, and "*as we get more evidence, reports and recommendations, we will do our utmost to share those as well as encouraging you to share how we overcome challenges and turn them into successes; to reinforce how we campaign in our country, not just with the evidence that's coming out of our own country but from our neighbouring countries; to look at best practice, and how we share that*," said Gavin.

Introduction to the 5 evidence-gathering tools

"*In the past, civil society has been known to make statements about issues affecting PLHIV. There was only one problem — there was no evidence to back their statements up,"* said Peter Nweke of the Network of People Living with HIV/ADS (NEPWHAN) in Nigeria, giving an overview on the evidence-generating tools for the new in-country partners. "***That's what these five tools were meant to address — to create an evidence base for advocacy for policy change***."

The Global Criminalisation Scan documents laws, judicial practices and cases studies regarding the criminalisation of HIV transmission and exposure, key populations or that restrict the movement of PLHIV. It is particularly relevant given the recent wave of criminalisation / 'model laws' in Africa. Preliminary results from the first round countries show a lack of awareness and knowledge of specific laws, which do exist here and there.

The GIPA Report Card provides an opportunity for key stakeholders to assess the application of the GIPA principle in their countries. In the first round countries implementing the LTA, eighty-one organisations were sampled.

General findings include lack of awareness among stakeholders and PLHIV, while poverty and stigma are significant barriers to GIPA. In particular, PLHIV networks at the grassroots level lack an understanding of the GIPA principle and its value — which limits GIPA at the local level.

Human Rights Count! documents human rights violations against PLHIV on the basis of their HIV status or presumed status. Peter said a significant amount work is required to train interviewers on human rights — the interviewer must be able to recognise what are human rights and when human rights violations have occurred.

The Sexual and Reproductive Health and Rights Guidance Package recognises rights of PLHIV to health, satisfying sex lives and to have children. The first round national networks identified different key groups and developed methodology for SRHR needs of serodiscordant couples in Nigeria; women in PMTCT programmes in Kenya, and adolescents living with HIV in Zambia.

The PLHIV Stigma Index measures trends in the stigma and discrimination experienced by PLHIV. The scale of the research can be challenging — over 2,300 PLHIV were interviewed in the three first round countries — but helps expand network capacity.

Peter noted that questionnaire itself is designed to be an empowering experience for the respondents and interviewers — and probably addresses the singularly most important issue confronting PLHIV: "*This one particular issue, stigma, cuts across all the rest — it drives each and every aspect of these other issues*," he said.

Implementing the Evidence-Gathering Tools

Network representatives from other first and second round countries described the process of implementing the evidence-gathering tools in much more detail. Case studies on their reports are posted online - some of the key lessons learned follow:

GIPA Report Card

“*What we learned from the process: we didn’t [tape] record the interviews, the interviews were hand-written, so we missed out on a lot of information; and in data analysis, we could not split the views of PLHIV and non-PLHIV*,” said Kunyima Banda of the Network of Zambian People Living with HIV (NZP+).

“*The Zambian Network was the first to implement that version of the report card — it took three months. And when they got the findings, they realised — hang on a minute, we don’t know how many people are living with HIV or not, because we didn’t ask the question*,” said Georgina. But studies in subsequent countries have been adapted in light of this.

The GIPA studies also have a small sample size but are targeted to give a snapshot of PLHIV engagement in the HIV response — looking at GIPA in National AIDS Councils (NACs), UN agencies, NGO’s etc. “*When presenting the findings, it is really important that we are very clear about who was interviewed and who was spoken to, so that we are not misrepresenting the data*,” said Georgina. For more information please see case study #2 on page 56.

Global Criminalisation Scan

Data is collected in a couple ways — through desk research of legal databases and government sites looking for punitive laws and policies targeting PLHIV and key populations; and by sending questionnaires to key stakeholders, including networks of people living with HIV, HIV service organisations, government departments (Justice, Public Health) and officials, UN country representatives, and others working on the issues to document cases where these laws or policies have been enforced. Getting feedback from these stakeholders can be a challenge, possibly due to the technical nature of the legal information, according to Mluleki Zazini of NAPWA in South Africa — making the desk review scanning for press coverage critical. For more information please see case study #3 on page 58.

Sexual and Reproductive Health and Rights

"*So what makes the Sexual and Reproductive Health Rights tool different from the rest, is that the other four come with user guides and questionnaires, but in this study you need to develop a questionnaire and methodology for the specific group that you choose to be the subject for the study*," said Ludmila Untura, from the League of PLHIV in Moldova, which chose women living with HIV in rural parts of the country. This process may help Networks build some sort of partnership with the key population group that it has chosen to study. For more information please see case study #4 on page 59.

PLHIV Stigma Index

The limited funds GNP+ can provide for research are not always enough to perform the index on a nationwide scale, particularly in larger countries. Consequently, some partners have focused the research to one part of the country, later using the results to mobilise resources to scale up the research. Others might want to follow the example of the Network of Networks of HIV Positives in Ethiopian (NEP+), which secured funding from partners such as International Planned Parenthood Federation (IPPF), Catholic Organisation for Relief and Development Aid (CORDAID), UNAIDS and UNDP at the very inception of the study, in order to do the Index across their large and diverse country.

Ethiopia also demonstrated that it is a good idea to establish a multisectoral steering committee for the research programme, including the relevant government authorities, donors, UNAIDS, faith based organisations, academic institutions, and civil society organisations.

"*If we never involved the government, the ministry of health, and the Federal HIV control office, it would have been very difficult to get ethical clearance. If not already involved, it could be very difficult to get documents or information from the Ministry of Justice, the Courts, the police or the Human Rights Commission when you need it. When it comes to the practical implementation of the research, you need the right people from the organisations. It is very difficult for an organization of PLHIV to perform this research on their own, without the involvement of the right stakeholders*," said Dereje Asres of NEP+.

One concern about the research however is that it is not acceptable to omit questions from the Index questionnaire because they are perceived as being culturally objectionable. **Leaving out questions about key populations, such as MSM, perpetuates their invisibility and results in incomplete research.** For more information please see case study #5 on page 61.

The Human Rights Count!

Clear evidence of why these questions must be asked was provided by a following presentation on Human Rights Count! Study in Cameroon by Calorine Kenkem of RéCAP, which generated rich qualitative data (see case study).

She also clearly described the steps involved in this research: the project began with the selection of study sites and population, choosing PLHIV associations and care sites in areas with the highest burden of HIV (they eventually enrolled 200 PLHIV). Then they identified key partners — one legal consultant and an organisation to help manage the research. They posted an advert to their member PLHIV networks to recruit the interviewers. Criteria for interviews: experience working with organisations, some knowledge of human rights, and a high school degree. After hiring, the interviewers were given three days training. A consultant was hired to review and analyse the data. The study was then performed and data from the interviews were entered into the database. The data were then analysed and the report written. It is currently being reviewed before distribution. For more information please see case study #6 on page 63.

Some key factors affecting tool implementation

In the general discussion that followed, participants focused on a few key issues that can have substantial impact upon implementing the tools. For instance, the quality of training an interviewer receives affects the quality of the research.

Getting ethical approval can take a long time, given the bureaucracy in some of the countries. In some countries, there are different stages of ethical approval for different sorts of research. But networks shouldn't start their research on the presumption that they will get approval, because if they do not receive it, their research is invalidated. In addition, Mluleki pointed out, "*We are human rights advocates, and we need to uphold human rights*."

Day Two:
Civil society platforms and overall LTA programme management

Developing Civil Society Campaign Platforms

"***Whilst waiting for the results of the evidence-generating tools, civil society can work to tackle burning issues at hand***," said Nombasa Gxuluwe of the Ubuntu Bethu Civil Society Platform in the Eastern Cape Province of South Africa.

The LTA research takes several months to perform, and some of the civil society platforms were formed before the PLHIV networks could get started in some countries during the first years of the programme. Because of this, some civil society platforms went ahead with campaign development — in some cases, including PLHIV networks more than others. As the programme has matured, the networks of PLHIV have become more engaged in the platform — often agreeing on some content for initial campaigns that could be revisited once the results of the evidence-generating tools became available.

Partners have taken different approaches developing initial campaigns. Although committed to ongoing work on gender-based violence, Ubuntu Bethu identified a need at the local level to target before engaging in national policy advocacy. Nombasa said that staff working in one district heard about a high rate of mortality among PLHIV and TB in a village that didn't have its own clinic. So developing a close partnership and getting approval from the community, the platform launched the "Access to Health Campaign," lobbying the Department of Health, traditional leaders (chiefs) and recently, their King, to build a clinic — though so far without success (see case study).

Launching national campaigns requires a different process. In Kenya, where the first civil society platform in the LTA programme was established, a situational analyses was performed, according to Rosemary Mburu of the Kenya AIDS NGOs Consortium (KANCO). "*But instead of forever dealing with the consequences, you need to look at the root causes. For instance, why are fewer than 50% of PLHIV in need of ART in Kenya receiving it?*" Once root causes are identified, issue selection was guided by considerations such as urgency, value for money, and the window of opportunity.

"*We choose to advocate for a specific budget line for ARVs in the 2010-2011 national budget. Why? It was an issue of urgency. Globally, we were going through an economic crisis. Nationally, our Global Fund Round 9 application had just been rejected and PEPFAR was flat-lined, so there were no new enrolments on ART.* ***It was very urgent for us to pressure the national government to secure domestic finances for ARV provision****. Of all the things that we could advocate for, we thought that would give us the most value for money*," she said. Finally, there was a limited window of opportunity of about six months until the government would release its national budget.

"*To the surprise of many, we succeeded. By the end of the period, we had a budget line of about US $120,000, not a lot, but it is a good precedent*," she said. (See case study).

James Kayo of the Central African Treatment Action Group (CATAG) said that in Cameroon, baseline research was conducted to identify burning issues, and to characterise the needs of civil society in the country. The study identified grave concerns about the sustainability of the ART rollout, and found that civil society efforts were poorly coordinated in Cameroon with little capacity to run effective advocacy campaigns.

So the Cameroonian Campaigners Meeting was convened to engage a broad cross-section of civil society including the national PLHIV network (RéCAP+) in a civil society platform. They issued a joint declaration demanding the government commit to providing universal access to HIV prevention, care, support and treatment; and developed a campaign work plan focused on three issues 1) access to quality ART, and treatment for opportunistic infections 2) stigma and discrimination and 3) capacity building among civil society.

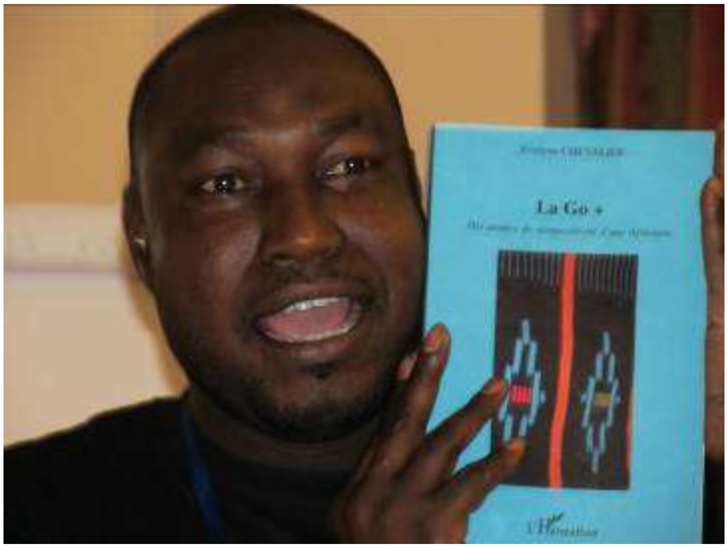
Subsequently, they ran a successful campaign to replace d4T, due to its toxicity, in ART regimens; and established an e-forum that has substantially improved communication and coordination among members — enabling them to quickly respond to reports of ARV stock-outs. Now that the RéCAP+ has implemented the evidence-generating tools, there will be a meeting to share the findings with all the other members of the civil society platform, to jointly develop and implement an evidence-based campaigning work plan.

The Regional Platform - Africa Roadmap to Universal Access

Regional and global solidarity is also a consideration when choosing a national campaign, though the evidence the LTA programme generates should also feed into regional and global advocacy. The Africa Roadmap to Universal Access could be a forum for this.

The Roadmap was established when civil society representatives from several countries, and some regional networks of PLHIV met in Nairobi in 2009, according to Innocent Laison of AFRICASO. They agreed on three key areas for civil society intervention.

1) Create sustainability in healthcare funding — pressure governments to meeting their Abuja Declaration commitments (allocating 15% of the national budget to health), and investigate creative financing to find domestic resources for the HIV response.
2) Address the human rights and HIV-related needs of key populations. "*You can't ignore that we have key populations, MSM, sex workers, people who use drugs, migrants: all of these people are suffering to get access to care*," said Innocent.
3) Advocating for universal access by December 2010 and to achieving the health-related Millennium Development Goals.



"*Universal access was supposed to happen by December 2010*," said Innocent, but the Roadmap has continued to be pushed at the African Union meeting in Windhoek, and the UN High Level Meeting on HIV (UNGASS) in New York.

However, when the Roadmap was first established, "*there were no plans to incorporate the evidence that would be coming from the networks research*," said Rosemary Mburu (KANCO). Now that the LTA programme participants are developing evidence-informed campaigns, they need to have a greater input in the development of regional campaigns.

The participants made a few suggestions to better leverage their agenda. First, strong and clear linkages needed to be made between the regional and national platforms, with a work plan that demonstrates how LTA is being integrated into that work. Better monitoring and evaluation is needed on campaigns' effectiveness, to show how well they have addressed needs identified by the network's research. Finally, developing good south-south collaborations — especially strategic alliances between LTA countries — should strengthen the LTA partners' voice and ability to steer the regional agenda.

Civil society platforms and PLHIV networks: What has worked and how to work together better

The alignment of civil society and the PLHIV networks has improved over the course of the LTA programme, and new partners can build upon lessons learned by the first and second year countries. To facilitate this, participants formed discussion groups by region, so that veteran countries could share what worked well for them, and help identify opportunities for civil society and the networks to work together better.

What has worked?

- Using the steering committee development process and engagement to promote and strengthen the programme and optimise buy-in. Members of civil society should be engaged so they are up-to-date with the progress on the network's research, which will be important for campaign development and joint planning. Building consensus among the committee members in the programme's goals and strategies leads to greater acceptance of the research findings and willingness to help implement the recommendations — making the success of the resulting campaigns more likely. "***These key stakeholders need to be included from the very beginning — not after the research begins***," said Michel Irogo of RéCAP+.
- Localising the effort (in South Africa): The range and number of HIV-related stakeholders on the national stage (with competing interests and agendas) may prove a

challenge to coordinate. NAPWA and the Ubuntu Bethu Civil Society decided to localise efforts to a limited 'geographical area,' involving partners in their community who felt affected by issues being researched. This helped sell the idea quickly.

- Developing effective mechanisms for communication between civil society, the PLHIV networks and others partners — such as the e-board in Cameroon — can dramatically improve understanding and coordination of efforts.
- Using participation in the programme to develop both network and civil society capacity, for research among PLHIV networks, but also for financial and programme management — which improves competence and reliability.
- Using the focus areas for research (for the SRHR Package Guidance) as an opportunity to develop special partnerships related to the targeted populations, including civil society organisations working with that population.
- Using the programme to train and develop experts and leaders among PLHIV strengthens the voice of the networks in the civil society platform
- Leveraging the programme to position PLHIV as network representatives in national, regional and global decision-making processes for the HIV response. These individuals then become critical allies for successful advocacy campaigns.

What could work better?

- Retaining the capacity developed in the trained PLHIV interviewers. Many of the skills acquired and the experiences gathered have been lost upon the conclusion of the research projects. Programmes need to devise a way to retain trained staff, either finding them roles in the networks or in resulting campaigns.
- Keep partners/steering committee members actively engaged in the project so they do not become disinterested by the time campaigning begins: "*It may be prudent to actively engage partners in certain activities, so that they aren't just passive participants but feel actively engaged in the whole process, to keep the fire burning*," said Justin Dzonzi of the Malawian Network of People Living with HIV and AIDS+ (MANET+) who reported back on the experiences of the Southern African region and Moldova.
- Giving PLHIV networks a leadership role in the civil society platforms. Civil society platforms have at times pursued agendas without adequate PLHIV engagement — but the networks must be more than simply engaged, they should be driving the process.

Ukuthwala - Stolen Innocence

"*That man tried to force himself on me. I didn't want to sleep with him, but he did it to me anyway. I fought with him… My parents told me to stay in my marriage, because that's just how marriage is. In marriage there is abuse*," said a young woman from the Eastern Cape, interviewed as part of a 24-minute documentary film produced for the Ubuntu Bethu Civil Society Platform's campaign against sexual violence in their community.

The film addresses the practice of Ukuthwala — the abduction and rape of young girls to force their parents into marriage negotiations — which some defend as a 'traditional practice.' As the film describes, despite some of the most progressive laws relating to gender rights in the world, sexual violence is commonplace in South Africa making young women particularly vulnerable to HIV. The campaigning tool has now been put on the HIV Leadership through Accountability website and Ubuntu Bethu is in negotiations with broadcasters to have it screened nationally. They also plan to show it at community meetings to facilitate discussions, and to show it to services tasked with protecting the public, such as the police services, the medical profession, traditional leaders, and churches, which up until now have done little to protect these girls. For more information please see case study #7 on page 65.

Documenting activities with the LTA website

This film is clearly a powerful tool for communication — but by posting the film on the LTA website, the Ubuntu Bethu Civil Society Platform is engaging in another form of communication — documenting its activities in the LTA programme for other participants and the programme's funders (the UK DFID).

The website has been developed to make the programme as transparent and as accountable as possible (English, French, and the Indonesian language Bahasa). It provides current information regarding each research area (e.g., the most recent data from the Global Criminalization Scan) and is intended to be a resource for in-country partners to share information or materials such as posters, presentations, and news pertinent to the programme in their respective countries. Each countries' research reports will be posted and can be downloaded, along with all of the LTA programme reports, including the annual reports, the midterm review, and programme resources, such as the tracking tools.

The website can host discussion forums so that programme participants can seek guidance or for advice from their colleagues in other countries, who can in turn, share their expertise and build supportive relationships with their colleagues.

Gavin encouraged in-country partners to post short updates (up to 300 words with pictures) to the site. These could report general news about their programmes, document specific activities, such as trainings that have recently taken place, or describe advocacy or challenges the programme or PLHIV are facing. Posting news increases visibility —and may help partners access support and resources) — and could alert the LTA programme to emerging issues, while showing how the programme is progressing. The stories can also be ‘re-purposed’ for their own websites, newsletters and campaign materials.

Splitting up by country, participants took a few minutes to draft sample stories using a simple template: ***What is the news** item*, which is also *the headline)*; ***why and how*** (background and process), and the ***‘so what?’*** linking the story to the main LTA issues —what does this mean for others in that situation, for the country and advocacy efforts?

After reporting back and fine tuning, the stories were posted to the website by the following morning. The example from Nigeria follows the template well.

NEPWHAN Tackles Human Rights Violations

Priscilla, a 23 year old graduate from Nigeria College of Aviation Technology (Zaira), qualified as an air hostess but her certificate/license to practice was withdrawn by the College because she was found to be HIV-positive.*

Two weeks after graduation, Priscilla received a call from the College Authority to return the certificate/license to enable them to correct an error. She returned it but did not receive the license/certificate within the designated time. When Priscilla applied for a job and needed to attach photocopies of her licence/certificate to the application, she was formally informed that her licence/certificate had been withdrawn because she was found to be HIV-positive, which is against the Regulations of the Aviation Industry.

The case was reported to NEPWHAN who took it up with the relevant authorities. The House Committee on HIV, Tuberculosis and Malaria invited the Director-General of Nigeria Civil Aviation Authority to explain the reason for the withdrawal. The Director-General recommended an in-house settlement of the case, which includes employing Priscilla and sponsoring further education.

This case represents one of many human rights violations experienced by people living with HIV in Nigeria. NEPWHAN are documenting these cases through the Human Rights Count! and advocating for protective policies and measures for HIV-positive people in Nigeria.

**Priscilla is not her real name. Her name has been changed in this news piece to protect her confidentiality.*

Day 3:
Planning and mobilising resources

Representatives from civil society and PLHIV networks separated on Wednesday to discuss monitoring and evaluation, the development of work plans and resource mobilisation.

Monitoring and Evaluation: Tracking Tools for the PLHIV Networks

"*GNP+ is the principal recipient of funding from DFID, which requires that some monitoring and evaluation be in place for this programme*," said Marsel Kuzyakov of GNP+, explaining reporting requirements for the networks joining the LTA programme.

Upon signing a memorandum of understanding (MoU) and a letter of agreement (LoA) between the network and GNP+, detailing their respective responsibilities regarding the reporting and funding, a baseline assessment is performed to provide a snapshot of the network before it starts the programme: *How is the network's board composed? How does it meet? What does it have authority over? When was the last set of financial accounts? What type of programmes does the network run? Who are its partners? Do they include women's groups, human right's organizations, key populations?* At the end of the programme, a second evaluation will be performed to see how the network was affected, what worked and what didn't, and identify areas for improvement.

Next, the network, in consultation with GNP+, uses the tracking tool to develop a work plan for the programme and a budget breakdown (more below). There is a set amount available for the programme and for each of the five tools. However, the work involved in the tasks to perform the study will vary so the network must work out how much of the fixed amount for each study will be allocated to each task. The key tasks and steps in the work plan are already listed for the partners, who only need to develop a timeline and budget for each of the steps, though additional steps may be needed in some settings. For example, programmes that don't typically undergo audits may need to include an item for that in their budget breakdown. About 10% of the funding is provided to help cover organisational expenses, and a small amount for the overall programme coordination and to cover costs such as setting up a bank account, the internet connections or hosting a website. Once the work plan is approved, countries receive the first funding instalment.

There are four more or less quarterly instalments of the funding. For each subsequent instalments, a progress report needs to be submitted consisting of two parts: 1) a short narrative of where the network is in the process of programme development and looking at each of the tools, and 2) an update on the expenses to date, provided by the network's financial officer, using the same tracking tool and the budget breakdown (comparing actual expenses to the budget by line). This allows both GNP+ and the partner to see the progress, and whether any part of the plan needs to be amended — such as the budget breakdown based upon actual expenses. However, programmes cannot change the specific allocations for the tools, because of DFID's rigid reporting requirements.

The report narrative should be provided by the programme's focal point, the individual nominated at the start of the programme to work with GNP+, and who will be responsible for coordinating the programme roll-out in the country. Marsel noted that this role was found to be virtually full-time in the first and second round countries — **the LTA programme was quite challenging for the countries who didn't have a person dedicated full-time to the focal point role**. Selection of the focal point requires *careful* consideration. He or she will need to have experience in programme management and needs to speak good English.

The focal point needs to be in frequent contact with GNP+ (preferably via Skype). In addition, there will be several opportunities for GNP+ and the countries to come together, such as the annual Planning and Review Meeting, a mid-year liaison meeting with programme focal points to review progress of the work and to support each other. The GNP+ programme team also makes two technical support visits to the countries per year.

Once all five research studies have been implemented, a more detailed final narrative report — covering the whole process from the beginning to that point in time, as well as the audited financial report (networks that already have annual audits need only to submit a separate statement from the auditor only on the programme funds).

The money: In the LoA, the funding is listed in British pounds, £73,950 in total, but the instalments will be in Euros. Since DFID needs the reporting and the budget breakdown worked out in British pounds, the tracking tool includes columns for pounds, euros and the local currency, and formulas for currency conversions (the euro conversion is based upon a fixed exchange rate (the average annual rate for the previous year) so that the spread sheet generates the conversions automatically. The value used for the local currency calculation will need to be routinely adjusted.

As a result of the midterm review process, and the decision to limit the number of countries in the LTA programme, funding was freed up for each of the eleven countries. Based upon the experience of round one and two countries, the amount made available to the round three countries to perform each tool has been increased. The round one and two countries will receive an equivalent amount of funding, directed partly to support campaigning, advocacy and lobbying — though these amounts are not great — and partly to support them to mobilise their own resources.

Country-to-country technical support for planning

Kenly Sikwese, who was involved in the implementation of the evidence-generating tools in Zambia, walked the less-experienced countries through the practical use of the tracking tool to develop work plans and budgets, and for reporting

Some of the first expenses will be organisational or planning costs — which should be budgeted from the funds allocated for that purpose. "*You receive the organisation or planning amount in whatever instalments you agree upon. Your job is to break it down for the items you will need to plan your programme: How much are your stakeholder meetings going to cost you? To set up regional coordinators, etc. You should not use any of the money allocated for implementing the tools for planning purposes!*" he stressed.

How much is needed for the implementation tasks varies substantially from country to country — e.g., some countries need to translate and adapt tools into multiple languages. But the available funding is the same, so there will be less to spend on other tasks. If the budget is too tight, unforeseen expenses can lead to a shortfall— and Kenly warned, "***keep careful track of currency fluctuations and conversions because you may be getting less money in your local currency than you expect***."

But using the tracking tool to develop a work plan simplifies detecting discrepancies — and fulfilling the LTA's programmes reporting requirements.

"***Your work plan is what you use for the actual monitoring, and for your reporting. When you carry out your tasks, your record it***," he said. "*Using the tracking tool for budgeting could identify and document a resource gaps, and the need for additional funding for some activities.*

Being able to point to these gaps using the tracking tool can strengthen the network's case when they go to donors seeking to mobilise more resources," he said.

The other critical aspect of the work plan is deciding on reasonable timelines. Based upon his experience in Nigeria, Peter said **networks should remember their other commitments**.

"*If you look at the activities, there is a lot to do. But especially if your organization has ongoing activities or projects, you must be very careful to plan enough time. One of the challenges I had was that the LTA programme came in at the kick-off of the Global Fund which was taking a lot of time as well*," he said.

To foster country-country support, the participants separated in groups by region for an exercise preparing a sample work plan and budget for one of the research tools — so that again, the more veteran countries could share their expertise with the third year countries.

Resource Mobilisation

In country-partners are beginning to leverage their participation in the LTA programme to mobilise resources for advocacy, further research and developing services for PLHIV.

Additional resources may be needed to perform, expand and/or repeat research to inform organisational strategic plans, or to document specific needs to guide the development of National Strategic Plans and priorities. In-country partners may need to raise funds to keep cost overruns from jeopardising the LTA work. Finally, significant funds may be needed for Campaigning, Advocacy and Lobbying (CAL).

It is critical to start thinking about what resources may be required for the advocacy and campaigns as soon as the networks begin completing their research. But while new funds may be needed, there may be a number of ways to use the evidence for advocacy that cost little or nothing — for example, there may be processes already underway in country or regionally that can be simply be adapted to the evidence. Many networks have ongoing fundraising and development efforts in place to support their work (which may change somewhat in light of the LTA findings). Also not all resources are financial — some involve skills, human resources, or the development of partnerships.

To help networks identify resources for advocacy, GNP+ is developing a resource mobilization framework. "*But it won't be a magic bullet for funding*," Gavin said.

"*The Framework is built on looking at your organization and country context in some guided ways to enable you to more effectively develop strategies to apply for funds*," he said. It is currently being field-tested by NEPWAN and NEPHAK. Once it is refined, it will be shared with the LTA networks, and then networks beyond the programme.

"*For the time being, GNP+ can provide templates and share experience*", Gavin said "*so programmes don't have to start from scratch. We're also happy for you to share resource mobilization proposals, and share them with us for our input*." he said.

"*I got this invitation to participate in a proposal development which looked a lot like what we had just conducted on the SRHR study*," said Peter. "*I realized that we were qualified for it but that* ***we needed some technical support. I immediately got in touch with GNP+, and based on the support we got we were able to access the grant****. It's a small grant, but it complements what we were doing and now we are implementing it*."

Even if proposals are rejected, pooling fundraising experiences with GNP+ and the other in-country partners could help others develop more effective proposals. Gavin said GNP+ could also help networks think creatively about how to approach different partners such as UNFPA, UNDP, and the Population Council — as some networks with limited capacity before participating in the LTA programme, have already successfully done.

"*For me the LTA programme is God-sent. You would never have imagined that we would sit with partners like this*," said Rahab Manwiki of NEPHAK. "*When we started the programme in 2009, we were being auctioned*." (Fortunately, the local network civil society, KANCO, came to their aid.)

As soon as their results started to become available, however, opportunities began to spring up for the formerly struggling organisation, including support from:

- The joint UN team to work on a stigma reduction strategy in the Northeast,
- USAID, training NEPHAK members as trainers to implement HIV prevention activities for PLHIVs,
- UNDP, which is paying Rahab's salary at NEPHAK,

- The National AIDS Control Council, training hundreds of NEPHAK members as trainers to roll-out of GIPA in 12 counties out of 47 counties in Kenya,
- UNAIDS, potentially to support a national PLHIV Stigma Index including previously unreached key populations, including MSM, PUD, and sex workers
- The World Bank and the National AIDS Control Council to pursue justice for cases of human rights violations identified in the Human Rights Count! Study.

"***Before GNP+ came to the national network, we had never had such visibility***," she said (see case study). Implementing the tools has led to opportunities in other countries too.

Kunyima reported that the NZP+ had been contacted by the Catholic Mission Hospitals to perform the PLHIV Stigma Index at one of its mission hospitals where many priests have been dying from HIV. As a result of their SRHR study in adolescents with HIV, a partnership has been formed with the Regional HIV Psychosocial Support to develop psychosocial tools for adolescents with HIV that UNICEF has also shown an interest in supporting, and a partnership formed with Planned Parenthood to train young people living with HIV as counsellors. NZP+ has also made a point of getting the data they've generated included in Zambia's National Strategic Framework.

As a result of a RéCAP+'s PLHIV Stigma Index research in Cameroon, a funder is now providing funding to six national PLHIV networks that are not part of the LTA programme to perform the PLHIV Stigma Index in their countries. Kenly said that networks should also approach UNAIDS, which committed to support the implementation of the PLHIV Stigma Index in countries at the Programme Coordinating Board meeting in 2010.)

Other networks have mobilised technical assistance. "*Partners like the UN, USAID have always been too willing, especially when it does not involve funding, to invest in their human resources in the form of consultancies*," said Peter. "*So we are always rich when it comes to idea gathering — we have that in abundance*."

In South Africa, Mluleki Zazini said NAPWA has received funding support for researchers and consultants in their research studies, free technical support from research institutions and training from ARASA. They've also secured funding to complete the PLHIV Stigma Index, from the Department of Social Development in South Africa.

Raising large sums of money can be a mixed blessing however. One issue is dependency. The Ethiopian network reported huge success raising resources to perform their research on a national scale, "*millions of dollars from The Global Fund, from PEPFAR, CDC, USAID. But the lifetime is very short – the maximum of 2 or 3 years. We are thinking, what will happen to us after 3 years or 2 years? It's our concern*," said Dereje.

“*PLHIV networks will never be sustainable while they are dependent on donor funds*,” said Edward Ogenyi, who believes that since the networks have been developed out of sheer necessity, as part of the national response to HIV, they deserve their share of government funding for the response. Consequently, NEPWHAN met with the National Agency for Control of AIDS (NACA) and successfully advocated that they create a line item for PLHIV as part of the 2011 budget.

“*As long as government release funds to NACA, we will also have a share, no matter how small. Once that budget line item has been created, you can advocate to increase the amount*,” he said.

Also as networks develop and provide more support services for PLHIV, they are becoming an integral part of the health system, and as such should be contracted and funded by their governments. These services should thus be self-sufficient. Some networks are looking at novel forms of income-generation to become self-sufficient.

Non-governmental organisations that survive for long periods of time, often have some profit-oriented business sustaining them, pointed out Omar Syarif of JOTHI in Indonesia, whose organisation is investigating establishing an independent profit oriented business. Other networks exploring income generation include RÉCAP+ Cameroon and NAPWA. However, there were concerns that such activities could divide organisational focus — and that if the business fails, it could take the network down with it.

There may also be fundraising within the network’s own country, especially in middle-income countries, from foundations, private individuals and corporations.

“*But when you’re fundraising it’s not just about the money*,” said Rahab, striking a cautionary note. “***It’s also about the human factor. Resource mobilization is also about your capacity – are you able to write proposals and get funding?***”

NEPHAK is actively trying to develop organisational capacity, working with the regional AIDS Training Network (ATN), which is performing a capacity assessment of the network. Based on their findings, ATN will then provide mentoring and coaching to address areas of weakness limiting NEPHAK’s ability to fundraise and manage funds.

“*Are you able to manage the resources?* ***You really have to be accountable for funding from donors because nobody wants to give you money, which you are not able to account for****. So we need to keep this in mind. If as a Network, you have people who cannot manage your money, then we may not be able to fundraise as an organisation*,” she said.

What roles, responsibilities, resources and partnerships are needed for LTA?

"*As the Network, it's one of our core mandates to carry out evidence-based advocacy*," said Safari Mbewe of MANET+. "*The LTA Programme will just compliment what we are already doing. Then since advocacy is about numbers, obviously we will need to go to civil society, depending upon the nature of the issue that we are dealing with*."

Safari described a clear vision of the collaboration needed between networks and civil society to implement evidence-based advocacy, during a discussion among networks members about the roles responsibilities, resources, and partnerships needed to implement the LTA programme. Other participants noted the challenge it can sometimes be to get civil society organisations to take PLHIV priorities on board, while others bemoaned the absence of a unified civil society platform in their countries.

"*Our challenge has been, who is this civil society?*" said Peter describing the situation in Nigeria. "*We have not been able to identify it, even though we had a meeting with UNDP and WAC, and had a meeting pulling some key organisations together. We need somebody to take the lead. I'm looking for WAC to set up a structure (platform) that will be responsible for setting tasks and duties.*"

But in the absence of a campaign platform, the PLHIV network often must take the lead.

"*We must recognize where agendas* [of PLHIV networks and CS platforms] *meet and where agendas don't meet. Some action plans weren't pursued as much as they could have been because there were a lot of partners – it takes a lot of time managing a lot of partners. Our emphasis is to continue to support the national networks in pursuing that, but also to encourage national networks to take the lead in doing their own advocacy*," said Gavin.

To facilitate network driven advocacy, GNP+ is working with UNAIDS, UNDP, AFRICASO, the World AIDS Campaign, and the International HIV Alliance to develop a Campaigning, Advocacy, Lobbying (CAL) Guide (see below).

Civil society sessions - Learning and Sharing

The sessions focussed on learning and sharing, particularly for the Round 3 countries that are currently starting the LTA programme in their respective countries.

Discussion about the LTA programme functioning in country and questions of clarity from civil society partners

- How WAC and GNP+ started in Zambia as it comes across as different programmes?
  Response: There were considerable challenges with how the LTA programme started in the first year. WAC had started the work in Zambia before GNP+ came in; so there wasn't a sense from the start that it is one programme. We have definitely learnt from that experience.
- Could you provide additional clarity around the role of the civil society platform according to the LTA programme?
  Response: The role of the civil society platform is to support the PLHIV networks and where possible in the evidence gathering tools, generating the content. Civil society should lead on developing or strengthening the advocacy agenda and its implementation. We recognise that the PLHIV networks form part of civil society, but it must be reiterated that the programme is set up to ensure we strengthen the capacity of PLHIV first and foremost.
- Do we implement all tools or do we prioritise?
  Response: We make sure countries understand all the tools and then we prioritise based on country need. In some countries it might be all 5 tools.
- Comment: The PLHIV networks are not equipped for research so the research produced was not of a quality that the country could use in campaigning.
- Concern - There aren't enough financial resources to drive the advocacy plans forward. Governments and even most donors won't fund advocacy is what some partners have found.
  Response: GNP+ has produced a resource mobilisation guide which they are sharing with PLHIV networks. I would strongly recommend that civil society partners familiarise themselves with this and if possible adapt for their own use. We will continue to find opportunities for funding for in country work.

Developing Campaign Work plans

Planning – What worked, what didn't?

- What worked?
  - Planning well in advance and communicating with all stakeholders especially PLHIV network to develop the agenda and assign responsibility to different partners.
  - Guard against World AIDS Day action planning.
  - Make sure in the discussions at the civil society platform meeting you present the evidence gathering tools and already make the links with advocacy. For eg. In Kenya we focused on the stigma because it was already an issue in the platform.

- What didn't?
  - The steering committee that was supposed to drive the plan forward didn't quite work. So you must ensure you allocate roles to each member.

Tools for planning – WAC shared with partners the CAL planning template that has a list of key questions to prompt and focus participants thinking. This should be adapted to the country context.

Reporting Mechanisms

One of the outcomes of the LTA mid-term review was that we need to improve on our reporting and monitoring and evaluation of the programme.

Tools for reporting – WAC shared with partners the monthly and quarterly reporting templates and worked out a cycle for reporting. In addition to this we informed the meeting about the possibility of generating regular stories or cases from country partners on progress made that can be shared on the LTA website and with DFID and other stakeholders. There was a general agreement about this.

Communication

There was general consensus that we need to improve on our regular communication, both country but also regional. The request from partners were:

- Monthly touch-base meeting (skype call) with each country.
- 3 monthly skype call of all countries together; this should be preceded by the sharing of quarterly reports so we can prepare for the calls. The first call is set for November 2011.

- Country partners will improve on sharing any news and updates from country on specific campaigns or successes.

Integrating the global processes into our country and regional work "Zero Document"

We then had a session on the June 2011 High Level Meeting (HLM) – Political Declaration. "Linking the outcomes to our in country and regional campaigning" asking what this means for our advocacy?

This discussion was lead by Innocent Laison from AfriCaso who was nominated to represent civil society in the HLM process. We recognised the need for civil society to ensure that the commitments their states made are turned into a monitoring process of its implementation an example was made of through the National Strategic Planning process. In 2012 countries need to report on the achievements against the declaration, this should be seen as a mobilising moment for civil society. Several Articles from the declaration were highlighted as advocacy opportunities for example – 100% prevention of vertical transmission (ZERO not 50%); elimination of punitive laws and zero stigma and discrimination. We then had a similar, but much shorter presentation with the broader meeting on Day 4 to allow everyone to get a sense of how the political declaration can be used in country and linked to the LTA evidence gathering tools.

Day 4:
Using Research Finding for advocacy

The results now streaming from the networks' research studies will provide a more solid evidence base for that advocacy. Some key findings were presented Thursday morning.

The GIPA Report Card in Nigeria: "*Considerable strides have been made in Nigeria towards the meaningful involvement of PLHIV in decisions affecting them as a group*," said Peter, presenting the findings of the GIPA Report Card in his country. "*It's not perfect, but something real is going on*." But there were problems: GIPA was less likely below the federal level: organisations at the state level 'were uninterested,' and others had good policies but inadequate funding for implementation.

This study also distinguished whether respondents were HIV positive or negative (in contrast to some GIPA studies described earlier in this report). Notably, people living with HIV were more likely than HIV-negative people to think that their engagement at the level of national policy development was not meaningful. But what was keeping PLHIV out of policy setting positions? Their own fear of being stigmatised was the most commonly reported barrier to the greater involvement of PLHIV in Nigeria's HIV response, followed by poverty.

"*When we're talking about poverty, this is understandable, where people don't have the chance to become skilled or get good quality of instruction*," Innocent remarked during the following discussion. On the other hand "***in many African countries, some other people living with HIV and well educated, are still hiding their status. We need to convince them to help and assist — but they don't want to be part of the network***."

But it doesn't have to be this way, James pointed out. "*In Burundi, the network of PLHIV is a special one where people living with HIV are recruited at a high level of society*." Indeed, the highest military officer in the country is president of the network. "*You can have a member of Parliament who is an active member of the network, you have got teachers, you have lecturers who are part of the network – it depends upon the context*."

When studies produce evidence on several issues, how should they be prioritised? How should LTA research findings be used to develop recommendations, and how should these be applied to advocacy?

Sexual and Reproductive Health and Rights of Adolescents with HIV in Zambia: In the case of NZP+'s research into the sexual health and reproductive needs of adolescents with HIV, the study's recommendations are directly related to the findings. '

Parents or guardians of adolescents with HIV are poorly equipped to deal with their adolescent child's sexual and reproductive health needs — who usually turn to their peers for information and support. Adolescents with HIV face a number of barriers accessing SRH information and services, including concerns about privacy and confidentiality at the health facility. But, "*living with HIV does not hamper future aspirations of founding families and having biological children. Many of the adolescents in the study setting consider these as rights,*" Kunyima, said, presenting the studies findings. For more information please see case study #9 on page 66.

The study's recommendations? Advocate for supportive policies and laws; promote adolescent support groups; integrate SRHR and HIV services to increase access to SRHR; equip parents and guardians with the knowledge and skills to support their children; improve access to non-judgmental counselling, fight stigma and advocate for the SRHR for all people living with HIV, including adolescents.

The network is already directly implementing one recommendation by setting up adolescent support groups in partnership with an organisation specialising in psychosocial support. For more information please see case study #9 on page 67.

PLHIV Stigma Index in Cameroon: Sexual Health and Reproductive Rights for people living with HIV were also identified as an issue in RéCAP+'s PLHIV Stigma Index study in Cameroon — but only in the north of the country where most of the population is Muslim. In this region, several HIV-positive women came out to tell interviewers that they had been forced to have abortions at some point during their pregnancy.

The main finding in this large study, which included 1300 respondents from all over Cameroon, was that stigma is ubiquitous: in families and in the workplace — with more than one out of five people losing their jobs due to their HIV status.

"***Knowing your status is often the cause of stigma***," said Calorine who presented the study. "*If people are not aware of your status, then you do not face any discrimination. But the moment you know, if you tell other people, you begin facing stigma and discrimination. There's also internal stigma. 54% of respondents are actually scared of being made fun of, and to be targeted by insults. This has the effect of basically making them retreat socially*."

Among the study's recommendations: Establish anti-stigma interventions targeting employers and health workers. In particular, RéCAP+ called upon the Health Minister to take action against healthcare workers who do not respect human rights of PLHIV. PLHIV also need to develop their own messages against the stigma and discrimination; be engaged in programme development from onset through implementation; and encouraged PLHIV to become trainers and educators. Finally, as stigma is a powerful incentive against testing, a campaign is needed on the benefits of getting tested and knowing one's status, and to improve the quality of counselling at testing sites.

Global Criminalization Scan in Ethiopia: "*Ethiopia does not have a special legislation dealing with the issue of criminalizing acts of transmission of or exposure to HIV*," said Tigabe Alemayehu of NEP+ who presented the findings of the Global Criminalisation Scan. Prosecution is however possible through a provision of the Criminal Code which criminalizes acts of deliberate or negligent spreading of communicable diseases. Only four cases could be documented — three involved rape.

"*There is no discrimination of a person who is living with HIV, or a person living without HIV – all have a right to work, enter and reside in the country*," said Tigabe. However, same sexual activity is criminalized, and punishable with imprisonment.

Human Rights Count! in South Africa: NAPWA has implemented the Human Rights Count! tool in a study with 174 respondents in three sub-districts of Oliver Tambo District in the Eastern Cape, South Africa. The study is still being finalised, but Mluleki Zazini of NAPWA reported a number of human rights violations of PLHIV had been identified including loss of employment, refusal of work managers and school authorities to allow adults and students living with HIV to visit their clinic for care during work/school hours. At one health facility, healthcare workers were not providing PLHIV certificates to get their social grants. Most people living with HIV in the districts are unaware of their human rights or how to advocate them.

Some preliminary recommendations, include demanding that people who violate the rights of PLHIV be brought to justice; and to capacitate and empower PLHIV to demand their human rights. And in response to reports, NAPWA picketed one health facility where people were being denied social grants, resulting in the person responsible being suspended.

How can the evidence be used for advocacy?

NEPHAK's Advocacy in Kenya: "*After getting the research results, we 'piggy-back'on other programme activities, and do capacity building*," said Rahab, describing how NEPHAK has moved its advocacy forward since completing the research phase of the programme. NEPHAK had developed a strategic plan that established the development of the capacity of networks and PLHIV groups as a core organisational goal. This positioned them to leverage the research findings for GIPA, Positive Health, Dignity and Prevention, and Stigma Reduction activities.

The GIPA results came out at an opportune time while the GIPA guidelines were being developed "*so it energized the process*," she said. NEPHAK used the results for social mobilisation and to leverage participation in the national HIV, TB and Malaria response. Although NEPHAK is helping to implement Kenya's Positive with Prevention Programme, "*it's just about prevention – the use of condoms, etc. You cannot bring in all the other aspects of Sexual and Reproductive Health, access to family planning. So we are looking at how we can change the programme to Positive Health, Dignity and Prevention*," said Rahab.

As noted earlier, since the programme, NEPHAK have been able to develop partnerships and take part in dialogue with civil society and government, including high-level engagement with parliamentarians. For more information please see case study #8 on page 66.

The advocacy plan for the SRHR Guidance Package in Moldova: Women living with HIV in rural Moldova have poor access to sexual and reproductive health services according to the preliminary findings of research performed by the League. The study found several reasons for this, including women's poverty, poor awareness of their rights, transport costs and the long travel distances to access services. Moreover, the healthcare workers treated the women poorly. Additionally, there was little interaction between reproductive health services providers, hospitals, and organisations providing services to PLHIV.

The League has already developed an advocacy plan based upon this evidence, with the aim of improving access for women living with HIV to reproductive health services and to a PMTCT programme in Moldova .

The advocacy plan objectives:

- Create a state programme providing access to reproductive health services to HIV-positive women
- Decentralization of reproductive health service providers, with expanded capacity and training of providers of reproductive health services and PMTCT
- Protect the rights of HIV-positive women

The steps:

1. Create a state programme involving several strategies including community mobilisation and capacity development of HIV-positive women. Activities engaging government and international NGO-partners include issuing the final SRHR report, analysing current programmes, organising a roundtable to develop recommendations for the HIV programme to submit to the Country Coordinating Mechanism. The report will be promoted in the media, including organising radio and TV spots on reproductive health and vertical transmission, and meetings between women with HIV and the media.
2. To facilitate decentralisation, the League will establish permanent training courses on SRHR and PMTCT for health care providers, social workers and NGO staff, engage women living with HIV, and address stigma and discrimination in the reproductive health services.
3. To improve the protection of women rights, the League will identify gaps in and amend HIV-related legislation, and engage the political leadership.

The League's plan has a very clear focused plan (a campaign, if you will) and could serve as a model for the other partners, particularly if successful.

Discussions to inform a Campaigning, Advocacy & Lobbying Guide

> "*Don't raise your voice, improve your argument*" – Archbishop Desmond Tutu
>
> *"The triumph of anything is a matter of organisation"* — Kurt Vonnegut

"*What do we mean by campaigning, advocacy and lobbying? What do we mean by evidence-based – it's a term that's thrown around,*" said Gareth Rossiter, an education specialist, who is writing GNP+'s evidence-based Campaigning, Advocacy and Lobbying (CAL) Guide. The rest of the day was dedicated to discussions to inform the guide's development, engaging the in-country partners in the process so the tool supports their needs.

"*For the purposes of a useful guide, I need your input and ideas about what would be a useful tool for you to use in your organiser – what would be useful to go into it? What is going to be useful to go into the guide that you would find helpful in doing your work?*" he said. '*What are the range of skills knowledge that we require in order to be effective in campaigning, advocacy and lobbying? That is what needs to go into the guide*."

Gareth unpacked some of the jargon being used. **Campaign**, he said, is a military term, listing several definitions: An operation, or series of operations, energetically pursued to accomplish a purpose; a series of coordinated activities, such as public speaking and demonstrating designed to achieve a single objective; a systematic course of aggressive activities for some specific purpose.

Advocacy, on the other hand is a political process – by an organization (or individual) aiming at influencing public policy and resource allocation. It involves:

- Questioning the way policy is administered
- Participating in the agenda setting
- Targeting political, system (not meeting needs)
- Including and engaging Civil Society
- Proposing policy solutions
- Opening up the space for public argument

'**Evidence-based**' is a term from medical science, suggesting something is objective, demonstrated by the scientific method, rather than merely subjective. Gareth pointed out, quite correctly, that while the tools provide evidence about what the needs are: "*we don't have definitive answers about what is evidence-based best practice. We don't have enough research around that,*" he said. [Indeed, this is part of the challenge in developing advocacy campaigns… just because research with the tools may identify a need, strategies to deal with the needs may be untested].

Despite having evidence, decisions about how to use that evidence for effective advocacy may need to be guided by experiences coming from successful advocacy and campaigns. One of the best ways to extract this best practice is through stories.

"*What we live with all the time is a whole lot of complexity — and stories enable us to unpack and understand that complexity*," Gareth said.

Consequently, he had participants select a partner to interview (using the appreciate enquiry technique) and find stories that could potentially be used for the guide. The interviewer was to record the best quotes, and aspects of the story he or she heard, while the person interviewed was supposed to focus on a time in their work that had made them most excited, feel proud about themselves, and feel that they were really doing something extremely valuable.

Interviewers who felt they had heard 'a story that needs to be told,' were asked to report the story back. The rationale was that those were the experiences that should be built upon in the Guide. The following story is one example.

Research involving PLHIV brings tangible benefits.

Kunyima tells a story from Zambia:

"Planning for advocacy including the mobilising of resources, is the key to success."

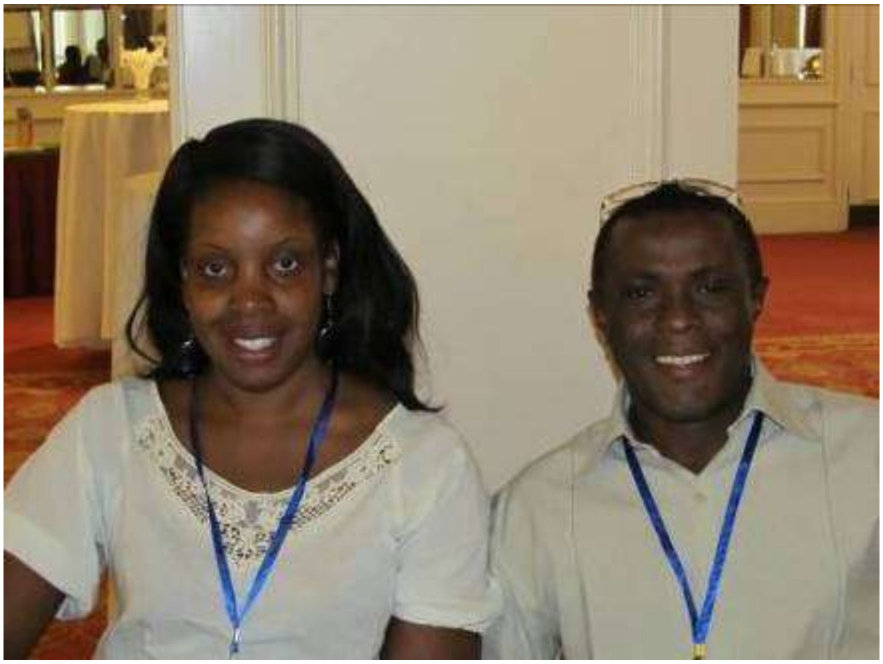
"Putting people living with HIV at the centre of the response ensures ownership of the process and therefore greater chances of success."

"You have to account when you work with communities. It is important to go beyond consultation. Good feedback enables communities to see the results of their involvement."

The NZP+ secretariat was getting reports from their membership that their were "gaps" in treatment and in access to treatment. We included this in our strategic plan in 2006 and planned for it. Once we had raised funds we were able to activate our plans in 2007

In 2007 NZP+ undertook research to investigate access by people living with HIV to medical services. The need for the research had been identified by *membership of the networks. And now the research was being conducted by PLHIV in support groups and district chapters.*

The exercise was extraordinarily empowering for all concerned. Kunyima reported on the opportunity it afforded her to provide support to the support groups with information, guidance and moral support. The process was extraordinary in that it provided an avenue for support groups to b connected to matters at the national level and to policy makers.



The research led also to material changes. There are new CD4 machines across the country making this testing more accessible.

Kuniyma's "Images of the Future"
Kunyima envisaged a future in Zambia where:
100% of people in need of treatment have access to ART.
80% of Zambians know their status
Many people are joining support groups

In a final exercise to get input for the CAL Guide, Gareth asked the participants to write down for him about what skills and knowledge they think is needed for effective advocacy campaigns, as well as abilities that they would like to have enhanced.

The CAL Guide will be used to help networks of PLHIV and the CS platforms use the evidence that is gathered by the 5 LTA tools in advocacy to change laws, policies, programmes and practices.

Day 5:
Next Steps

Opportunities for Advocacy

To help propel everyone at the LTA meeting towards more effective advocacy upon returning to their home countries, Friday was devoted to discussing opportunities for mobilisation and campaigning in the near and immediate future.

Participants began by identifying key upcoming events or opportunities in their countries — many cut across settings. For instance, World AIDS Day provides an obvious forum to share research findings or push an advocacy agenda. In Cameroon, they use the whole week to organize the activities around AIDS. Candlelight memorials also represent opportunities in several countries.

HIV conferences, whether national (Malawi, Tanzania, Indonesia, and Moldova — with a national conference and a meeting relating to women's issues) or regional or international, such as SAHARA in South Africa and ICASA in Addis Ababa, offer opportunities to share research findings, strategize and develop partnerships. A following session was dedicated to discussing developing a common PLHIV-centred advocacy agenda to pursue at ICASA.

On the political front, a number of countries have presidential or general elections scheduled in the near future (Senegal, Kenya, Zambia, Cameroon) when potential policy makers may be more accessible, and there is a chance to get candidates to commit to the HIV response and PLHIV advocacy agenda. Whenever a new government has been elected is a good time to redouble lobbying efforts, as Peter said his network would be doing to obtain passage of the anti-Stigma Bill in Nigeria. Meanwhile, the opening of parliamentary and national assembly sessions also provides a moment to launch campaigns and other advocacy.

The political situation makes advocacy particularly challenging in some countries, but Rosemary, who facilitated the session, stressed the solidarity offered by the other in-country partners: "*We really understand some of the challenges you might experience, but also encourage you to keep pushing and to know that you're not alone – this is a whole family here of people who are more than ready to support you – people with ideas, or tactics that you may call upon to support you*," she said.

Several participants mentioned that National AIDS Council and National AIDS strategy reviews are coming up in their countries (Malawi, Senegal, Tanzania), Global Fund applications, or that their countries were drafting or soon to draft new national strategic plans (Kenya, South Africa).

"***The review or development of the national strategic plans is one of the key opportunities we have identified here***," said Rosemary. "*If we are not involved, we miss out a lot, because once the country moves forward with the plan and it gets funded, there may be no further opportunities to get our agenda included and funded*."

As results from the networks research have become available, some countries are organizing events and meetings specifically to disseminating their findings (Nigeria, Zambia, Cameroon) or to launch related campaigns. Some countries that do not yet have data from the research, already have campaigns underway or starting up, such as the anti-HIV stigma campaign in Senegal.

To boost the likelihood of advocacy messages reaching the broad public, some in-country partners are launching strategies to improve coverage of their campaigns by local media.

"*We're building a new partnership with the media, because we've realized now that without the media working with us, we may not be able to achieve as much. So we're engaging the media during events to call the nation's attention on the burning issues*," said Peter. In Indonesia, JOTHI is holding media briefings and press conference, while in Tanzania, UNAIDS is providing support for a dialogue between the HIV community with the owners and editors of the media.

Unique situations have arisen in some countries that must be addressed. For instance, in Senegal, the World Bank is soon to discontinue funding for a programme for OVCs that gets the children into schools, so there is a need and an opportunity for advocacy to sustain this important effort. Meanwhile, other countries have specific events that represent unique opportunities for advocacy such as Holiday without AIDS in Cameroon, Farmer's Day in Tanzania, Men's Day in South Africa, and the upcoming '16 days of Activism' in Malawi.

Some events represent opportunities for regional or global solidarity. For instance, Kenly and Georgina noted the Global Commission on HIV and the Law that was holding an Africa Regional Dialogue in Johannesburg, shortly after the LTA meeting. Omar mentioned the importance of the ASEAN Summit (the regional body consisting of 10 countries in South-East Asia) that will be held in Bali in November, alongside with the G20 Meeting, where activists hope to have a mass protest rally addressing how trade agreements limiting access to essential medications will have an impact on public health in resource-constrained countries. Georgina reported that the UNAIDS PCB NGO delegation was looking for candidates from the Africa Region and Eastern Europe, representing a major advocacy opportunity.

The need for global advocacy around several issues — three of which specifically concern prevention — is particularly pressing:

1) WHO guidance on discordant couples' counselling and testing was supposed to have been launched at the International AIDS Society meeting in Rome, but was delayed because of the recent data on 'Treatment as Prevention' and on pre-exposure prophylaxis (PrEP). So there is no guidance on counselling, testing and treatment for prevention to support discordant couples.
2) Likewise, there is a need to develop guidance on PrEP, which WHO is working on. PLHIV networks need to be involved.
3) The global plan to prevent vertical transmission, and to support the health and survival of HIV-positive mothers, was launched at the high-level meeting. "*We advocated massively for the role of HIV-positive women in that plan; women are now in there and now we need to support the delivery*," said Georgina.
4) Treatment 2.0 – WHO and UNAIDS have called for the implementation of a new treatment and prevention model to achieve universal and sustainable access to HIV prevention, testing, support, care and treatment: Treatment 2.0. One of the chief pillars of the strategy is community mobilization — the meaningful engagement of PLHIV in designing and delivering services including treatment central to Treatment 2.0's success. PLHIV networks

> and civil society need to articulate and claim their role in Treatment 2.0, and demand the resources needed to develop the capacity to fulfil their expanded role in care delivery.

At a workshop on Treatment 2.0 in Johannesburg, James said that UNAIDS and WHO had committed to sponsor the same sort of meeting at the sub-regional level, which would present opportunities to get more treatment activists engaged.

"*It should also be possible to get the support of UNAIDS to organize a small meeting of individuals to sit down to review these documents*," said Edward, referring to Treatment 2.0 and the other guidelines coming out, "*to simplify them in such a way that everybody can understand the language, and then explore how to leverage them for advocacy on the issues*."

Opportunities and approach to advocacy, "on the road to ICASA"

"*ICASA is a regional advocacy opportunity for African civil society and PLHIV*," said Dereje, who explained that NEP+ is a member of the local organising committee. Along with a scientific programme, there will be a community track presenting an opportunity for PLHIV and civil society to share their successes and challenges, discuss the greater involvement of PLHIV, as well as what can be done to sustain the HIV response in the current economic climate.

There will also be a 'leadership programme' — and Dereje pointed out that Addis Ababa is the seat of the African Union and the UN in Africa. So ICASA will serve as a unique "*advocacy platform to bring various partners together: African leaders, donors, civil society, faith-based organisations, PLHIV and others to discuss accountability, to create a political agenda, and mobilise leadership*," he said.

In-country partners discussed how they might make the most of the opportunity provided by ICASA. “*There are plenty of slots in the programme for skills building or case study sessions*,” said Rukia who noted that Linda from WAC and Innocent from AFRICASO sit upon a community working group and could take any input from the LTA programme partners back to the conference organisers.

One idea floated was whether there should be a common position paper put together by and for the PLHIV Networks that could feed into a civil society platform.

“*We should put together a paper that highlights data that we’ve collected on the very specific issues that affect people’s day to day lives i.e. stigma issues, human rights issues in a very specific sense*,” said Kenly. “*This could be packaged in a way that can be shared with the wider community, as issues that are affecting PLHIV in Africa. ICASA would be the ideal place to share that. We could utilize this moment, as the LTA programme, to get some very important messages through. It’s a very big opportunity, and if we mobilize ourselves, we could do something powerful*.”

Another issue was ICASA afforded a chance to consider broader representation and coordination of PLHIV networks in Africa, however, it was noted that LTA members could only speak for the networks present and that this could therefore only be the start of a longer conversation. In the meantime, the Networks and civil society can still work effectively work together as demonstrated by the success getting their agenda integrated into the 2011 Political Declaration at the UN High Level Meeting on HIV in June. But this accomplishment also represented an obligation for advocacy, as Rukia described in the next session of the meeting.

Using evidence to meet our commitments in the 2011 Political Declaration

"*We've all in some or other way been involved in the Political Declaration at the UN high-level meeting on HIV in June 2011. We signed onto this declaration and committed to making sure that this happens. So this is our document — we need to bring it home to our countries*," said Rukia, highlighting key points where the evidence coming from research could promote advocacy.

No. 27 Prevention with a particular mention of youth & No. 29 focusing more specifically on key populations (MSM, sex workers, PWUD)

"*Both points address prevention, #27 particularly in youth, which cuts across all the tools. Point 29 stresses the need to focus on key populations, but then leaves it up to countries to decide how and if. What does that say to us as activists, as advocates? Not good enough!"* said Rukia. "*How do we use the evidence that we gather from our tools to make sure that we put pressure on our countries, to address the issues of key affected populations using the Criminalization Scan, the Human Rights Count?"*

No.55 Leadership and financing a sustainable HIV response

Advocacy is required to make certain countries secure sustainable funding for health and HIV. "*We know how to track it; we do know how to engage with it. We know how to engage with our National Strategic Plans, our budget planning processes*," said Rukia, noting that the Tanzania AIDS Forum has been doing good work around budget tracking in its country, from which others could learn.

No. 64 Ending Vertical Transmission!

Tools including the Sexual Health & Reproductive Guidance Package link to this.

No. 66 Target 15 million on ART by 2015!

"*We know more than 15 million people need treatment but it's one of the only targeted numeric commitments they've made in this document. We need to monitor this*," she said, suggesting tools such as GIPA must be leveraged to make certain PLHIV are in positions to set and monitor the HIV response.

No. 71 TRIPS

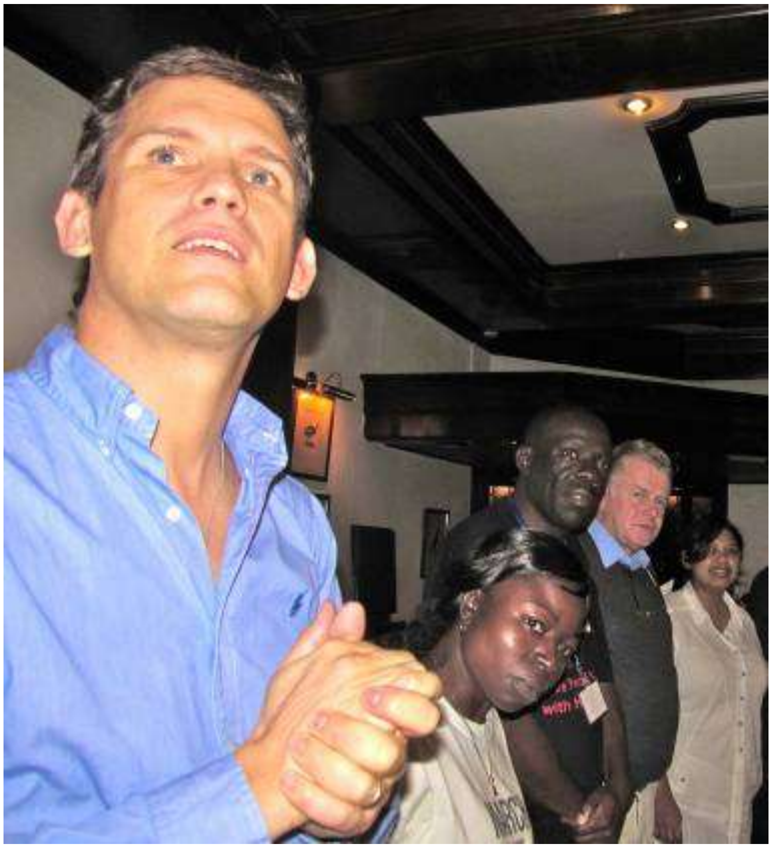
Omar again stressed the critical importance of ensuring access to affordable essential medications. PLHIV must be in positions to affect national policy (GIPA).

No 80/78 Eliminate punitive laws!
Use results from Human Rights Count! the Criminalisation Scan and Stigma Index.

No. 104 South-South exchange and regional support
"This is our collaboration between countries and at a regional level. It is how we are going to go to ICASA, how we are going to ask all of those States and African Commissions that are going to be represented there: 'You've committed – what have you done? What are you going to do?'" Rukia said. *"In 2012, countries have to report on the progress made in this document, so this is our mobilizing moment*."

4 things in four weeks

Participants then set very immediate and practical goals to complete within the next four weeks (see Table below). Partners from GNP+ and WAC took note of their plans and promised to hold them accountable.



Coming full circle and doing your part

To close the meeting, Rosemary called for everyone to form a circle, holding hands.

"This is a symbol of the family we are and that we are united for a cause. Wherever we go, this family will be behind you, and we can always count on each other," said Rosemary, *"and as we go, we are moving forward to change things and to make things happen."*

Rukia and Gavin thanked the participants for their engagement, for sharing a dream for a better world, and leading efforts to make it happen in their countries.

“*In closing the meeting, I just want to remind you that we were here for HIV Leadership and Accountability. We were here calling for accountability from our leaders, and amongst ourselves. This is our count down to zero [zero new infections, zero death, zero stigma and discrimination]. And the count-down-to-zero can be done*,” said Nelson; and asking everyone to repeat those words, “*it can be done, just do your part*,” he declared the meeting closed.

Appendices

Table of 4 things in 4 weeks

Partner	Activities	When	Any Needs?
GNP+	Posting meeting photos on flickr	5 Aug	
	Meeting Report	26 Aug	French translations
	Follow-up with networks on MoU's/LoA's	12 Aug	
	Follow-up regarding ICASA	12 Aug	
South Africa	Develop a report about this meeting	5 Aug	
	Alignment of LTA Programme in line with the report	12 Aug	
	Advocacy training strategy & board	19 Aug	
	Preparing advocacy campaigns meeting	26 Aug	
Malawi Networks	Finalise MoU, LoA	5 Aug	
	Provide the name of focal point	5 Aug	
	Complete budget plan	12 Aug	Guidance GNP+
	Introduce LTA to National AIDS Commission, Office of the President's Cabinet, & key partners like UNAIDS	17 Aug	
Nigeria	Have in-house meeting to debrief PMT	5 Aug	
	Upload LTA Tools on website	"	Electronic copies
	Send stories/pictures to GNP+ website	25 Aug	
	Engage media in a partnership meeting	30 Aug	
Senegal	Meeting with the board to discuss the LTA meeting and appoint a focal point	12 Aug	Mobilise resources for focal point
	Contract with GNP+	"	In French
	Meet with broader civil society to discuss the programme	15 Aug	Mobilise funding
	Start looking at the first tool and potential partners	25 Aug	
Cameroon	Share report re planning meeting with board/civil society	4 Aug	
	Meetings to prepare for workshop to present evidence to civil society	5, 26 Aug	
	Review focal point position	8 Aug	Sign contract
	Have a civil society workshop	31 Aug	Funding
Moldova	Finish (interview SRHR	31 July	
	Prepare final report (GIPA), Criminalization Scan	9 - 15 Aug	Consultant's input
	Prepare final report Human Rights Count! Stigma Index	15-31 Aug	"
	Meeting Advocacy group LEAEA; prepare preliminary advocacy plan	23-31 Aug	

Indonesia	Administrative issues, contract work plan & budget) → MoU with GNP+/WAC, focal points	5 Aug	Consultation w/GNP+ & WAC
	Planning Meeting with partners	15 Aug	First funding instalment
	Human Rights Training	16-19 Aug	
	Finalizing Tools Translation	26 Aug	
Kenya	Disseminate GIPA Guideline in 15 Counties	15 Aug	
	Disseminate PWP (PHDP) guidance package in 15 Counties	Aug 15	
	Review resource mobilization framework and tool work	19 Aug	Draft Framework
	Share a story	19 Aug	Photos
Malawi Civil Society - MANASO	Finalize and send a CS Platform budget	5 Aug	
	Finalize the agenda for the CS Platform	5 Aug	
	Finalize the participants list for the CS Platform	12 Aug	
	Introduction of the LTA Programme to WAC & OPC & other stakeholders	17 Aug	
Tanzania	Sign MoU & submit to GNP+	6 Aug	
	Submit to GNP+, the LTA Plan	23 Aug	
	Organizing Meeting for Setting the Instalment Steering Committee	29 Aug	Will need first instalment
	Develop ToR for Steering Committee	31Aug	
Ethiopia	Sharing LTA meeting outcomes for [KEP+] Staff	8 Aug	Materials / report
	Prepare final report for LTA Tools	20 Aug	
	Recruitment of focal person for LTA Tools implementation	20 Aug	TOR
	Reviewing issues for ICASA Meeting	25 Aug	
Zambia	Incorporate all tools into draft of SP	13 Aug	
	Follow-up on tracking tool and send to GNP+	22 Aug	
	Finalize stigma index report in consultation with GNP+	15 Aug	
	Follow-up GIPA Strategies with NAC in the 2011-2015 NASF	5 Aug	
Tanzania Civil Society	Familiarise with evidence tools & how they fit with current/future advocacy plans	6 Aug	
	Finalize database for TAF members including objectives	25 Aug	
	Organize meeting with NACOPHA on steering committee	29 Aug	
	Preliminary planning for platform network meeting	29 Aug	
World AIDS Campaign	Contribute to Report on LTA Meeting	5 Aug	
	Follow up with all countries on Planning, Reporting Agreements	12 Aug	
	Follow up on ICASA process and priorities, regarding community track	8 Aug	Input from PLHIV & civil society
	Planning CAL workshops finalize Cameroon 31/8-2/9	19 Aug	

LTA Planning and Review Meeting Agenda

Day 1: The LTA programme and evidence-gathering tools

The objectives of the day are:

- To meet one another and agree on objectives and the agenda of the meeting
- To familiarise Round 3 countries with the evidence-gathering tools and to share the process and the experience of Round 1 and 2 countries in undertaking evidence-gathering

Time	Item	Facilitators
09.30	Welcome and Logistics *(Nelson Otwoma, NEPHAK* and *Marsel Kuzyakov, GNP+)*	Linda Mafu (WAC)
09.45	Introduce Partners – what is your country context? Introduce yourself, your organisation and a burning issue in-country (5min max each) (*Rukia Cornelius, WAC)*	
11.30	Coffee	
11.45	Look at meeting Agenda and agree objectives of meeting for Networks (Rounds 1, 2, 3), Civil Society (CS), GNP+ & WAC (*Georgina Caswell, GNP+*)	
12.15	Introduce LTA Programme and outline programme aims/goals (e.g. What is the LTA, who leads, who partners, what outcomes, logframe and what has happened to date) (*Gavin Reid, GNP+ & Linda Mafu, WAC*)	
12.45	Introduction to 5 evidence-gathering tools (*Peter Nweke*, NEPWHAN)	
13.00	Lunch	
14.00	Present aims, methodology, key steps and case study on GIPA Report Card (*Kuniyma Banda, NZP+).*). Questions from Networks and CS partners	Peter Nweke (NEPWHAN)
14.30	Present aims, methodology, key steps and case study on SRHR (*Liudmila, The League*). Questions from Networks and CS partners	
15.00	Present aims, methodology, key steps and case study on PLHIV Stigma Index (*Dereje Asres, NEP+) .* Questions from Networks and CS partners	
15.30	Tea	
15.45	Present aims, methodology, key steps and case study on Criminalisation Scan(*Mluleki Zazini, NAPWA*) Questions from Networks and CS partners	
16.15	Present aims, methodology, key steps and case study on Human Rights Count! (C alorine Kenkem, RéCAP+*)* Questions from Networks and CS partners	
16.45	Wrap up Day 1 and close (Gavin Reid)	

Day 2: Civil society platforms and overall LTA programme management

The objectives of the day are:

- To familiarise Round 3 countries with the civil society campaign platforms and to share the process and the experience of Round 1 and 2 countries leading the civil society campaign platforms
- To familiarise Round 3 countries with the alignment between the work of networks of people living with HIV and civil society platforms and to learn from the experience of Round 1 and 2 countries;
- To re-familiarise all countries with communication, monitoring and reporting, and programme reporting processes.

<table>
<tr><th>Time</th><th colspan="2">Item</th><th>Facilitators</th></tr>
<tr><td>09.00</td><td colspan="2">Introduce Day 2</td><td>Nombasa Gxzuluwe (CS South Africa)</td></tr>
<tr><td>09.15</td><td colspan="2">Present aims, methodology, key steps and case study on Kenyan CS Platform (<i>Rosemary Mburu).</i> Questions from Networks and CS partners</td><td></td></tr>
<tr><td>09.45</td><td colspan="2">Present aims, methodology, key steps and case study on Ubuntu Bethu CS Platform (<i>Nombasa Gxuluwe).</i> Questions from Networks and CS partners</td><td></td></tr>
<tr><td>10.15</td><td colspan="2">Present aims, methodology, key steps and case study on CS Regional Platform – Africa Roadmap to Universal Access (<i>Rosemary Mburu and Innocent Laison) and Q&A</i></td><td></td></tr>
<tr><td>11.00</td><td colspan="2">Coffee</td><td></td></tr>
<tr><td>11.15</td><td colspan="2">Present aims, methodology, key steps and case study on Cameroonian CS Platform (<i>James Kayo).</i> Questions from Networks and CS partners</td><td></td></tr>
<tr><td>11.45</td><td colspan="2">Discussion about networks/CS partners alignment of exisiting workplans with LTA opportunities, threats, experiences & lessons learnt. (Linda Mafu)</td><td></td></tr>
<tr><td>13.00</td><td colspan="3">Lunch</td></tr>
<tr><td>14.00</td><td colspan="2">LTA website: 1 story 3 months (Gavin Reid)</td><td>Rahab Manwiki (NEPHAK)</td></tr>
<tr><td>14.50</td><td colspan="2">Overall programme M&E</td><td></td></tr>
<tr><td>15.10</td><td colspan="2">Tea</td><td></td></tr>
<tr><td></td><td>PLHIV Networks</td><td>CS Platforms</td><td></td></tr>
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15.30	Network M&E Arrangements (Marsel Kuzyakov)	Kenya Lessons learnt What worked in the implimentation of the tools Where can we improve South Africa What worked in the implimentation of the tools Where can we improve	
16.15	What and how to gather information for baseline. (Incl. epidemiology, CCM, treatment access) (Country Groups)	Regional . What worked in the regional Campaigning What can we do differently	
16.45	Wrap up Day 2 (Marsel Kuzyakov/Linda Mafu)		
17.00	Close		

Day 3: Planning

The objectives of the day are:

For the PLHIV networks

- To plan for next steps in the programme (from the starting point of each Round), with Round 2 and 3 countries offering supporting to Round 1 countries in the development of the tracking tool;
- To explore resource mobilisation for all networks of people living with HIV within the context of the LTA programme and to introduce the resource mobilisation toolkit for future input.

For the Civil Society Platforms

- To develop a standardised workplans
- To agree to M&E processes
- Explore communication between CS platforms and also with WAC

Time	**Item**		**Facilitators**
	PLHIV Networks	**CS Platforms**	Safari Mbewe, (MANET+) / Rosemary Mburu and Rukia Cornelius
09.00	Introduce Day 3	Introduce Day 3	
09.15	**Round 3** Exercise to look at previously used Tracking Tool **Round 2** Review implementation progress and co-create solutions to get the	Developing Campaigning work plans	

	job done **Round 1** (with Kenly): Discuss advocacy and specfic ways to embed LTA results and learning into broader network work		
10.00	**Round 3** (with Rahab and Kenly): Country Exercise to Develop a country workplan using the Tracking Tool (Part 1) **Round 2** (with Peter and Kuniyma): Continue as above	Reporting mechanisms	
11.00	Coffee		
11.15	**Round 3** Country Exercise to Develop a country workplan using the Tracking Tool (Part 2) **Rounds 1 & 2** Assist Round 3	Lobbying and advocacy using the Results from from the tools Kenya	
13.00	Lunch		
14.00	Resource Mobilisation (*Gavin Reid, GNP+)* – group work by country round looking at needs, what is available and creating strategies	Integrating the global processes into our work. The Zero document Rosemary , Allan Maleche	Calorine Kenkem (RéCAP+) / Innocent
15.45	Tea		
16.00	Discuss Roles, Responsibilities, Resources and Partnerships required in order to implement LTA (Gavin Reid)	Integrating global processes	
16.45	Wrap up Day 3 (Georgina Caswell)	Wrap up Day 3 (Rukia Cornelius)	
17.00	Close		

Day 4: Using Research Findings for Advocacy

The objectives of the day are:

- To learn about and discuss research findings from Round 2 and 3 countries;
- To explore how the research findings enable networks of people living with HIV and civil society to do advocacy from different angles;
- To provide input into the development of the campaigning, advocacy and lobbying (CAL) guide based on in-country experiences and needs.

Time	**Item**	**Facilitators**
09.15	Introduce Day 4	James Kayo (CS Cameroon)
09.30	Sharing key results from evidence-gathering tools . 5 minutes presentations: GIPA Report Card – NEPWHAN; SRHR – NZP+; PLHIV SI – RéCAP+; Criminalisation – NEP+; Human Rights Count! – NAPWA.	
11.00	Coffee	
11.15	How can the evidence be used for Advocacy and exploring the research findings from different angles – Introdung the Positive Health Dignity and Prevention framework. 2 case studies: (NEPHAK) & (The League)	
12.15	Evidence-based Campaigning, Advocacy and Lobbying (CAL) Guide – Part 1 (*Gareth Rossiter):* ensuring that the CAL Guide is based on in-country experiences and needs.	
13.00	Lunch	
14.00	CAL Guide Work - Part 2 (*Gareth Rossiter)*	Tigabe Alemayehu (NEP+)
16.00	Tea	
16.15	CAL Guide work - Part 3 (*Gareth Rossiter)*	
16.45	Wrap up Day 4 (Rahab Manwiki)	
17.00	Close	
18.30 – 19.30	Reception	

Day 5: Next Steps

The objectives of the day are:

- To identify upcoming advocacy opportunities at national, regional and international levels;
- To identify and document concrete actions for the next 4 weeks.

Time	Item	Facilitators
Before 09.00	Check out of rooms	
09.00	Introduce Day 5	Rosemary Mburu (CS Kenya)
09.15	Opportunities for Advocacy: Key mobilising moments in country, regionally and globally (*Innocent Laison*) and 5 minute presentation by NEP+ and discussion on ICASA 2011	
10.30	Coffee (please bring coffee into session)	
10.40	Concrete actions for the next 4 weeks (*Georgina Caswell, GNP+)*	
12.10	Close of Formal Meeting– (*Rosemary Mburu*) KANCO	
12.20	Lunch	
14.00 Onwards	One to one discussions regarding the CAL Guide and opportunity for further engagement and discussion. We will arrange a schedule for this time.	

Case Study # 1, Kenya

"Thanks to the HIV LTA programme, we now have an agenda to present to the CCM"

Participation in the HIV Leadership through Accountability (LTA) programme has helped NEPHAK (the National Empowerment Network of People Living with HIV/AIDS in Kenya), represent PLHIV better in the national HIV response, according to Nelson Otwoma of NEPHAK, by promoting the principle of the greater involvement of people living with HIV (GIPA) in the policy-making bodies — including Kenya's country coordinating mechanism (CCM) — and providing an evidence-base for advocacy.

"The evidence coming from the LTA programme has helped shaped the agenda I now pursue as a representative on the CCM," said Nelson, who is currently a representative of people living with HIV (PLHIV) on the CCM. Nelson described NEPHAK's evidence-based agenda at the opening of the HIV Leadership through Accountability (LTA) Planning and Review Meeting, held this July in Nairobi, Kenya.

Background

GIPA is a principle that aims to realize the rights of PLHIV to participate in any decision-making processes that affect their lives. PLHIV have first-hand experience in many of the factors that make people more vulnerable to HIV, and are the target of policy and health system response to HIV. The meaningful engagement of PLHIV should therefore increase the relevance, acceptability and effectiveness of HIV programmes. Promoting GIPA is one of NEPHAK's core missions.

Monitoring GIPA at the different levels of each country's HIV response can be complex, but a tool to assess GIPA has been developed by the Global Network of People Living with HIV (GNP+). Participants in the LTA programme have been provided support by GNP+ to perform research in their own countries using this tool, as well as other tools looking at HIV stigma, human rights violations, sexual and reproductive health and rights and criminalisation of HIV transmission or exposure.

NEPHAK joined the HIV LTA programme in 2009, and recently completed its research projects. After consultations with civil society, a more evidence-based advocacy agenda has been developed. Nelson described the agenda for which he is advocating:

- Demanding GIPA:"PLHIV, and other affected communities must be in the driving seat of the response to HIV/AIDS," said Nelson.
- Increasing human rights protections and fighting the criminalisation of HIV transmission or exposure: Though activists in Kenya have made important progress on human rights (for example, establishing an HIV/AIDS Tribunal — a special court to expeditiously

handle cases involving human rights violations for PLHIV), Section 24 of Kenya's HIV/AIDS Prevention and Control Act makes it against the law to 'wilfully transmit HIV (the definition of 'wilfully' being subject to interpretation).

- Promoting the sexual and reproductive health and rights of PLHIV: Nelson described a case where a nurse at a local ART site reacted in shock when a member of the PLHIV network informed her that she was pregnant: "the nurse almost fainted saying: 'You mean you still have sex! Even after you get HIV, you are continuing?' They don't understand that PLHIV need to live their full life or realize that PLHIV need families, and they need children. For them, the moment you are diagnosed with HIV, it is like 'forced early retirement from sex'. And people are not retiring!" he said.
- Advocating for Positive Health, Dignity and Prevention: As the above case illustrates, healthcare workers and policy makers may try to limit the rights of PLHIV for the sake of 'HIV prevention.' Funders persist in funding 'positive prevention' programmes that fail to engage PLHIV in developing programmes that affect them.
- Putting the 'right to health' to the test: Another success in Kenya is securing the right to health in Article 43 of the new constitution, but Nelson said the skills acquired in the LTA programme will be essential in creating a demand for treatment and determining whether the government is delivering on this right, or whether it exists only on paper.
- Fighting stigma: Stigma is one of the key barriers to universal access to treatment, care and prevention services, particularly where religion has stigmatised having HIV, as well as key populations affected by HIV.

NEPHAK plans to report on progress pursuing this agenda in news updates on the LTA website.

Case study #2, Zambia

The Network of Zambian People Living with HIV (NZP+) described the process and lessons learned as the pioneers of the GIPA Report Card study

The Network of Zambian People Living with HIV (NZP+) was one of the first countries to join the HIV Leadership through Accountability (LTA) Programme. As such, their experience adapting and performing the five LTA tools for evidence-based advocacy has proven invaluable to other PLHIV networks who have joined the programme.

Kunyima Banda of the Network of Zambian People Living with HIV (NZP+) reported on her network's experience using the GIPA Report Card, at the 3rd HIV Leadership through Accountability Meeting, held in Nairobi, Kenya in July. She first described the process:

"The first thing we did was identify the consultant who was going to do the data analysis," she said. Then, the network identified and made appointments with the respondents, who were mainly PLHIV within key national organisations that would participate in the study, and conducted the interviews.

Once the data were analysed, the findings were used to generate a report. The consultant disseminated the results to the network staff, which led to a stakeholder meeting to develop an advocacy action plan. At this point, the network participated in process developing the National AIDS Strategic Framework 2011-2015, which integrated their study findings.

Methodology: a randomised sampling approach was used to recruit respondents to ads posted on an e-discussion forum, and at a workshop for PLHIV. Respondents were from private sector (banks), public (in the government), bilateral/multilateral donors, the UN system, faith-based organisations, civil society organisations (CSO), and networks of PLHIV.

Twenty-nine adults were interviewed ranging from 27 to 54 years in age. Some were PLHIV, some were professionals working on HIV and some were both — in order to understand if GIPA was being implemented in their organisations).

With the benefit of hindsight, Kunyima said there were some things that could have been done better.

“What we learned from the process — the interviews were hand-written, we did not record the interviews, so we missed out on a lot of the information, and the data analysis that was done, did not split the views of PLHIV and non-PLHIV, so that did not inform us as to who was saying what for us to have a rich document,” she said.

They found, however, that the study population had a substantial knowledge of the GIPA principle and understood that meaningful engagement of PLHIV meant participation at all levels of the HIV response. However, poverty, stigma and discrimination, and low awareness of GIPA were reported to be barriers to GIPA, and also limit their access to services. Inadequate staffing and funding, as well as low skill levels among PLHIV also limit engagement.

“For people to be involved at different levels, they need to be skilled — and if people are not skilled enough, it is very difficult to meaningfully and effectively participate,” said Kunyima.

Nevertheless, the network concluded that there were clear opportunities for greater involvement, with a political environment that is conducive to support dialogue, advocacy and legislation in favour of PLHIV, and an HIV policy with strong commitments and necessary structures. The government has committed to be proactive in engaging PLHIV in the HIV response.

“There is also an opportunity for NZP+ — and this was an eye-opener for the organization because we got to hear what other organisations were saying about how we could improve — to make the involvement of PLHIV more meaningful,” said Kunyima, who said that one thing that could be done would be to provide more training to various stakeholders, who were aware of the GIPA principal, but found its application very difficult.

In the subsequent discussion at the meeting, several meeting participants didn’t understand why the data from PLHIV could not be disaggregated.

“The Zambian Network was the first to implement that version of the report card — it took three months. And when they got the findings, they realised — hang on a minute, we don’t know how many people are living with HIV or not, because we didn’t ask the question. The Nigerian Network was the first one to actually differentiate. So when you look at their report, you can see that whilst people not living with HIV - from NAC, UNAIDS - said PLHIV are meaningfully involved across the board, PLHIV interviewed, said its not meaningful, its on paper. So the analysis was much richer,” said Georgina Caswell, programme officer for GNP+, which helped develop the GIPA tool and partners in PLHIV networks in the LTA programme.

Other participants thought the sample size was inadequate to reach any valid conclusion — but this sort of research does not require large sample sizes.

“Every tool is different. The GIPA report card is meant to give a snapshot,” said Georgina. “You look at the leadership in the country, in the national response, and the guidance says that a certain number of interviews should be with UN agencies, a certain number should be with government officials, a certain number from networks of people living with HIV and so on, so the respondents reflect leadership in the national response. So there’s guidance on the different stakeholders to try to include, and then with those stakeholders, you should find the most senior person who is willing to respond to questions. It is a snapshot, and it’s quite qualitative, so there is a lot of description in the reports. But in presenting the findings, it is really important that we are very clear about who was interviewed and who was spoken to, so that we are not misrepresenting the data.”

Case Study #3, South Africa

NAPWA reports challenges getting feedback from stakeholders while conducting the Global Criminalisation Scan

After encountering difficulty getting feedback from a number of stakeholders in South Africa into whether there had been cases of people living with HIV persecuted for cases of HIV exposure or transmission, the National Association of People living with HIV/AIDS in South Africa (NAPWA) adapted their approach to conducting the Global Criminalisation Scan, NAPWA’s

Mluleki Zazini reported at the 3rd HIV Leadership through Accountability (LTA) Planning and Review Meeting, held this July in Nairobi, Kenya

The Global Criminalisation Scan is another evidence-generating research tool that does not require a large sample size to describe the laws and issues confronting people living with HIV in the countries where they live. Rather, data is collected in a couple ways — through desk research of legal databases and government sites looking for punitive laws and policies targeting PLHIV and key populations; and by sending questionnaires to key stakeholders, including networks of people living with HIV, HIV service organisations, government departments (Justice, Public Health) and officials, UN country representatives, and others working on the issues to document cases where these laws or policies have been enforced.

Getting feedback from some stakeholders can be a challenge, as South Africa's NAPWA discovered when attempting to implement the GCS, according to NAPWA's Mluleki Zazini. The network started out by identifying a focal person and regional administrator for GCS, and establishing a steering committee. After becoming familiar with the tool, 29 key stakeholder organisations were identified and contacted. However, response was very poor.

"The highly technical nature of the legal information sought could be one reason for the lack of response from some of the stakeholders in South Africa," said Mluleki. So NAPWA approached programme officers at the Global Network of People Living with HIV (GNP+) which is helping to coordinate the LTA programme. Together, they decided to put a greater emphasis on the desk review. Furthermore, the network is trying to compensate for poor response of the questionnaire by performing an exhaustive scanning for stories and articles related to the subject in the local media — while realising that press coverage may not perfectly reflect what is occurring, or frequency of events.

Case Study #4, Moldova

The League of PLHIV in Moldova Demonstrates How to Use the Sexual and Reproductive Health Rights Guidance Package for Research

"So what makes the Sexual and Reproductive Health Rights Guidance Package study different from the rest, is that the other four come with user guides and questionnaires, but in this study you need to develop a questionnaire and methodology for the specific group that you choose to be the subject for the study," said Ludmila Untura, from the League of PLHIV in Moldova, at the HIV Leadership through Accountability (LTA) Planning and Review Meeting, held this July in Nairobi, Kenya.

Ludmila gave a presentation on the process of setting up and conducting the SRHR tool in Moldova, an Eastern European nation between Ukraine and Romania, where most new HIV infections are now heterosexually acquired.

First, she said, the League held focus group discussions to decide how they wanted to approach the study and who would be the target group in the study. They decided that the theme of the study should be to assess the knowledge and understanding of the reproductive rights of PLHIV in Moldova, to determine what services were accessible by women and men; and to identify the barriers which prevent them from accessing these services. The target population to interview in the study, however, would be women with HIV, in rural Moldova —which is profoundly different in terms of access to services, income levels and so on, than in urban areas in the country.

Methodology: For the LTA overall in Moldova, the League created a coordinating group, and to provide technical expertise they've invited representatives from UNAIDS and the government agencies relevant to their research. They have hired coordinators in each region of the country from their own membership. They planned and carried out training of twenty-two of their members who serve as interviewers in all five studies.

For the SRHR study, a questionnaire was developed including 68 questions. Examples of questions included: What do you understand as Reproductive Rights? Have there been cases when you or your partner have experienced pressure from the health providers regard SRHR? What prevents men from accessing services (from the perspective of women)? And there were also questions about stigma and discrimination, and the right to have children.

They identified 55 individuals from their membership base to interview. Interviews are conducted at three sites: one in a hospital, which has a specific department for HIV-positive patients, that serves patients commuting from the entire country, and two sites are at offices of NGOs (which are part of the League) outside of the capital — these two sites have been the most successful. To date, 36 interviews have been performed and they are already entering the data for analysis.

Preliminary findings indicate that there's very little tolerance shown to PLHIV living in the rural areas. There are low levels of knowledge about SRHR among PLHIV; most live in poverty; there is a lack of confidentiality; which significantly limits access to the health services. The long distances between where people live and where they can access medical services is another significant barrier to access those services. There is a disconnect between the organisations and the NGOs dealing with reproductive health and rights in the country, and the health providers in the field.

Some of the findings are linked with the Stigma Index Study, which shows that 43% of those who have known their status for less than 5 years are already on ART, an indication that people come in late for HIV diagnosis.

The League plans to develop a practical programme to advocate and address the issues identified by the study.

"It is very clear that the League as an organization alone will not be able to address all of these issues, so it means there has to be a platform of all of the key players in the country working on this — however, we also understand that the League of PLHIV must lead on addressing these issues with decision makers and develop further programming with other organizations to address these issues," said Ludmila.

"What's unique about this particular tool is that the Network identifies the key population that it would like to work with. And the process has often helped to build some sort of partnership with the key population group that the Network has chosen to study," commented Georgina Caswell during the discussion that followed Ludmila's presentation. Georgina is a programme officer with the Global Network of People Living with HIV (GNP+) which helps coordinate the HIV LTA programme with PLHIV networks in different countries. "That's what's really interesting, the fact that it provides Networks with the flexibility to think about a group that you would like to work with, and to actually do that work."

Case Study #5, Ethiopia

Forming strategic partnerships can help increase the scale of research using the PLHIV Stigma Index according to the Network of Ethiopian PLHIV (NEP+)

The scale of performing the PLHIV Stigma Index is challenging for most networks — but rolling it out in a country the size of Ethiopia, with more than 80 million people, over one million of whom have HIV, was a herculean undertaking, according to Dereje Asres, of the Network of Ethiopian PLHIV (NEP+). He told participants at the HIV Leadership through Accountability (LTA) Planning and Review Meeting, held this July in Nairobi, Kenya that NEP+ had begun forming critical partnerships with potential funders before joining the LTA programme.

"We started investigating research with the HIV Stigma Index in our country in 2009 before we communicated with GNP+ (the Global Network of PLHIV which helps coordinate the LTA programme)," said Dereje Asres, Network of Ethiopian PLHIV (NEP+). Stigma and human rights were major issues in Ethiopia, and the network was already contemplating nationwide research. After learning about the PLHIV Stigma Index, NEP+ secured a commitment from International Planned Parenthood (IPPF) to support implementing the tool in Ethiopia. NEP+ met with the

Federal HIV/AIDS Prevention and Control Office, who gave them approval to conduct the stigma index research at the national level.

Formal funding proposals were drafted, since performing the research throughout Ethiopia would require considerably more funding than was available from the LTA Programme. A mapping exercise was conducted to identify national level stakeholders. Then a technical working committee including 14 NGOs, CBOs and GOs was held at the NEP+ offices to discuss standards for the country rollout, and discuss the draft proposal.

A core group was formed, chaired by NEP+, with the Federal HIV/AIDS Prevention and Control Office as vice chair, UNAIDS as secretary, with other members from faith based organisations, academic institutions, and civil society organisations. Terms of reference were developed for core group members who agreed to support NEP+ in day to day planning and implementation of the assessment, etc. The core group met on a weekly basis and began to look for an appropriate research partner to assist with the study. Sample size calculations suggested that to adequately represent urban and rural distribution of people who have tested HIV-positive would be 3376 (2474 in urban, 902 in rural settings).

The PLHIV Stigma Index questionnaire then had to be translated to the four major Ethiopian languages. Criteria were developed for data collectors and supervisors, who were then recruited (116 HIV-positive data collectors, 25 regional supervisors). Four national research coordinators were identified.

Training was performed in four phases since there were so many data collectors, supervisors and national coordinators. Support letters were obtained from the Ministry of Health and other partners to facilitate data collection process countrywide.

Dereje noted several challenges — first and foremost the budget was insufficient for the scale of research. “Three days of training for the data collector aren’t enough to cover all the issues in the tool,” he said. The implementation has been delayed for a variety of reasons. Another issue was getting ethical clearance.

He said he also believed that “some of the questions in the standard questionnaire do not fit the culture and traditions of Ethiopia.” In particular, he noted that questions regarding ‘transgender’ persons would not be understood, and said that data collectors were unwilling to ask them.

Other participants asked for clarification as to whether it was acceptable to remove questions that some might consider culturally objectionable from the questionnaire.

"For the LTA programme, it is possible to add certain questions that are specific to your context, but it is not possible to remove certain questions —not even if you think they might be difficult questions like questions about MSM. Even if you think it will be a difficult question, it is important that we get as full information as possible, and *it is important that those questions get asked,"* said Georgina Caswell, programme officer with GNP+.

Case Study #6, Cameroon

Les Droit Humans Comptent! — Making Certain Interviewers Understand Human Rights Violations, and ask all the tool's question, proves critical in Cameroon

A presentation on the implementation of the Human Rights Count! tool in Cameroon by Calorine Kenkem of RéCAP, one of the many francophone contributors at the HIV Leadership through Accountability (LTA) Planning and Review Meeting, held this July in Nairobi, Kenya, made it clear that it is critically important that interviewers can ask questions about sensitive topics, like the experience of men who have sex with men, and have a good understanding of what a human rights violation is.

"The Declaration of Human Rights was integrated into Cameroon's Constitution in 1996, so theoretically, the equality for human rights are recognized, at least on paper" Calorine said, though she noted there were no specific laws protecting the rights of people living with HIV.

However, in practice, human rights violations persist, and one of RéCAP's goals is to reduce human rights violations against people living with HIV. To inform and drive their advocacy, the organisation first needed to generate evidence to guide their advocacy with data on current human rights abuses related to HIV in Cameroon.

They generated this evidence with the Human Rights Count! Tool, with trained PLHIV using a questionnaire to interview other PLHIV about whether they had experienced human rights violations, and to share them if they had.

Steps involved: the project began with the selection of study sites and population, choosing PLHIV associations and care sites in areas with the highest burden of HIV (the study eventually enrolled 200 PLHIV). Then they identified key partners — one legal consultant and an organisation to help manage the trial. They posted an advert to the member PLHIV networks to recruit the interviewers. Criteria for interviews: experience working with organisations, some knowledge of human rights, and a high school degree, and an understanding of human rights. They were then hired and provided with three days training. A consultant was then employed to review and analyse the data. The study was then performed and data from the interviews were entered into the database. The data were then analysed and the report written. It is currently being reviewed before distribution.

Calorine said they didn’t encounter any major difficulties. There was some small delay in the analysis and data processing. They needed to differentiate between case of human rights violations in general and those which were specific to ones HIV status. 95 HIV-specific violations were documented out of 200 interviews.

These included the following:

- Violation of the right to privacy: ‘I went to meet with the pastor to ask him to pray for me. He demanded that I confess before the whole Church, recognizing that I have committed fornication.’
- ‘After the death of my husband, his family called me a witch, a criminal. They hurled insults and forced me out of the house at night. They claimed and took all the property that he had left.’
- Violation of health rights: ‘In 2007, I got sick. When I arrived at the hospital, the nurse said she would not see me because I had brought my illness on myself. The whole town knew that I'm gay.’
- Violation of the right to work: ‘I worked in an embassy as a secretary for three years. When I was diagnosed with HIV, I was simply and purely dismissed without any compensation.’

The study reached several recommendations that will be important for advocacy in Cameroon:

- Human rights must be promoted in the response to HIV: demand that staff at healthcare facilities provide universal access to high quality care for *all* PLHIV
- Train PLHIV on human rights and how to obtain justice and strengthen the collaboration between RéCAP+, support structures and legal services
- Set up a database on the rights of PLHIV in order to provide data to support advocacy with policy makers;
- Strengthen working relationships between government, development partners, civil society and the media to promote human rights for PLHIV;
- Lobby public and private institutions to formulate public policies and strategies of PLHIV against the HIV-related discrimination

Case Study #7, South Africa

The Access to Health Campaign Case Study Explores Initially Campaigning on a Local Level while Waiting for Research Results from PLHIV Network Partners

"Whilst waiting for the results of the evidence-generating tools, civil society can work to tackle burning issues at hand," said Nombasa Gxuluwe of the Ubuntu Bethu Civil Society Platform in the Eastern Cape Province of South Africa at the HIV Leadership through Accountability (LTA) Planning and Review Meeting, held this July in Nairobi, Kenya. In some countries, civil society platforms have gotten a head start in the LTA programme, before the PLHIV networks have become fully involved and well before the network's research produces data to inform advocacy campaign

This was the case in the Eastern Cape, where key stakeholders became engaged with the LTA programme in 2009, deciding initially to focus on two districts in the province where there was a clear need to address gender-based violence, and traditional practices such as forced marriages that increase the vulnerability of young women to HIV (these efforts are ongoing). In 2010, these stakeholders came together with NAPWA and formed the Ubuntu Bethu Civil Society Platform. Then the task team drew the Platform's attention to an underserved village in the district, where the mostly unemployed population have very limited access to health services, which was only intermittently served by a mobile clinic. Many of the younger people in the community are coinfected with HIV and TB, but because of the limited access to health services, there is a high default rate on both TB and HIV medication. Key HIV related services including HIV counselling and testing (HCT), CD4 cell count and viral load measurement, and treatment for opportunistic infections were inaccessible. At least 5 PLHIV and/or TB died within a three-month period in the community due to treatment default.

So the platform decided to launch the "Access to Health Campaign," advocating for a clinic built for the village. Actions taken included meeting with department of health (DOH) officials to investigate whether there was a plan for such a clinic, and if there was a way to get it prioritised, meeting with traditional leaders (chiefs) in the area to discuss their role, and met with the community to get their input on how best can the platform support the campaign.

The campaign hasn't achieved its aim yet. DOH tells the platform it is waiting on approval from the chiefs, while the chiefs — who refuse to meet with the platform — say the issue is in the DOH's hands. With community support, the platform has developed a petition, and the platform met with the King who committed to intervene and arrange a meeting between the platform and the chiefs. It is hoped that plans to build the clinic can be fast-tracked in future meetings.

Case Study #8, Kenya

Participation in the LTA programme has opened doors to new partnerships for NEPHAK and helped the organisation mobilise resources for Advocacy

"For me the LTA programme is God-sent. You would never have imagined that we would sit with partners like this," said Rahab Mmaniki of NEPHAK at the HIV Leadership through Accountability (LTA) Planning and Review Meeting, held this July in Nairobi, Kenya. "When we started the programme in 2009, we were being auctioned." (Fortunately, the local network of civil society organisations, KANCO, came to their aid.)

But NEPHAK went on to conduct the LTA programme research, and at the same time, developed a strategic plan that set as a core organisational goal the development of the capacity of Networks and PLHIV groups — which positioned them to leverage the research findings for GIPA; Positive Health, Dignity and Prevention; and Stigma Reduction activities.

As soon as their results started to become available, opportunities began to spring up for the formerly struggling organisation. NEPHAK was offered support by the joint UN team to work on a Stigma Reduction Strategy in the Northeast. NEPHAK was involved in the National AIDS STI and Control Programme that had just been launched, as part of the technical working group on Prevention with Positives. Rahab, who sits on the gender technical committee at the National AIDS Control Council, says she hopes to get changed into Positive Health, Dignity and Prevention — in both name and content). Nevertheless, to help in the rollout of PwP, NEPHAK members were trained as trainers of trainers with the support from USAID.

The UNDP is now paying Rahab's salary, and she is secunded to NEPHAK. With the support from UNDP, NEPHAK is now rolling out GIPA in 12 counties out of 47 counties. There is little funding to support GIPA, but the UN Team is willing to support it. As part of the rollout, the National AIDS Control Council has trained hundreds of the network members as ToTs for GIPA.

Later this year, UNAIDS wants to support performing a national PLHIV Stigma Index, which will include key populations, including MSM, people who use drugs, and sex workers— which previously NEPHAK had been unable to reach. With the support from the World Bank and the National AIDS Control Council, they've been able to do work on Human Rights (taking cases identified in their earlier study before the HIV/AIDS tribunal for arbitration).

"Before GNP+ came to the national network, we had never had such visibility," she said.

Case Study #9, Zambia

Research by the Network of Zambian People Living with HIV highlights the sexual and reproductive health and rights of adolescents living with HIV

Sexual and reproductive health and rights for people living with HIV have begun to receive greater recognition in the past few years, as a result of advocacy by people living with HIV. One group of people living with HIV remains neglected. Adolescents have particular needs in relation to sexual and reproductive health, and as recent research in Zambia shows, they require tailored responses.

For example, an aunt and legal guardian of a 15-year-old girl living with HIV told researchers conducting an exploratory quantitative study into the sexual and reproductive health needs of adolescents living with HIV:

"*My niece was going into depression a few years ago. We didn't know what the problem was until she told me that she was worried that her breasts would not grow normally like a woman, because of HIV.*"

"*My niece was going into depression a few years ago. We didn't know what the problem was until she told me that she was worried that her breasts would not grow normally like a woman, because of HIV.*"

"The needs and concerns of adolescents living with HIV are numerous. Understanding their puberty signs and fear of infertility in adulthood are some of the challenges that affect *even* those adolescents who are not sexually active," said Kunyima Banda of the Network of Zambian People Living with HIV (NZP+) who presented the key findings of this moving study at the 3rd HIV Leadership through Accountability Planning and Review Meeting, held from 25-29 July in Nairobi.

The research programme

With funding from DFID, the HIV Leadership through Accountability (LTA) programme supports advocacy for good governance, and universal access to HIV prevention, treatment, care and support in eleven participating countries (nine of which are in Africa). One component of the programme involves developing the capacity of networks of people living with HIV (PLHIV) to manage and perform research studies to strengthen the evidence base for advocacy in their countries. The studies are based on the adaptation and implementation of generic tools developed by the Global Network of People Living with HIV (GNP+) and partners that investigate issues such as HIV-related stigma, HIV-related human right violations, national laws affecting people living with HIV, and key populations at risk of HIV.

The study in Zambia stems from *Advancing the Sexual and Reproductive Health and Rights of PLHIV: A Guidance Package*, which addresses the rights of PLHIV to access sexual and reproductive health services, have satisfying sex lives and to have children. The package recommends that PLHIV networks select key focus groups in their countries and investigate their sexual and reproductive health rights, needs and barriers.

"In 2008, we had carried out a desk review of policies to understand the linkages between sexual and reproductive health (SRH) and HIV – and we found that there were minimal linkages. At the time, we had a lot of requests from us as an organisation, from parents and young people coming to seek information on this issue. And we realised, this was a completely neglected population. If you look at the demographics in our health services, it is mainly the ages 15 to 49. You'll see that age 16 and below is almost forgotten in health provision, in a lot of ways," said Kunyima.

The HIV prevalence in Zambia, with a population of a little over 12 million people, is 14.3%. The HIV prevalence among 15 to 19 year olds is 4.7%, and it is believed that around 82,000 of the estimated 1.4 million Zambians living with HIV are children. But there are no reliable estimates of HIV amongst adolescents (aged 10 to 19) – most of whom are believed to have been infected perinatally.

As Kunyima said, shockingly little is known about this population. So to learn more about the SRH needs of the adolescents, and what related policies, guidance, and SRH services were accessible to them, NZP+'s research team held focus group discussions with HIV-positive adolescents aged 10 to 14, and conducted in-depth interviews with Zambian policy makers, service providers, marriage counsellors, and the parents and guardians of the adolescents living in five residential areas of Lusaka.

Results

The SRH needs of adolescents with HIV are a policy and programmatic blind spot in Zambia.

There was a lack of policies or guidelines addressing the SRH needs and concerns of adolescents living with HIV. Government policies that discourage the provision of SRH services to adolescents in general have a particularly negative impact on HIV-infected young people. Those who are sexually active have challenges protecting their partners because the Zambian government is opposed to providing condoms to adolescents. But this is a dangerous policy when it also prevents those who are HIV-positive from accessing essential tools to prevent sexual transmission. Stigma and discrimination make it difficult for them to disclose their status in order to access SRH services.

They face a number of barriers accessing SRH information and services, including concerns about privacy and confidentiality within the health facility. But, Kunyima said, “living with HIV does not hamper future aspirations of forming families and having biological children. Many of the adolescents in the study setting consider these as rights.”

Cultural barriers make it difficult for parents and guardians to discuss these issues with their adolescent children.

“’It is taboo for me as a father to discuss such things with my daughter,’ the father of one HIV-positive 15 year-old said,” Kunyima reported, adding that most parents are poorly equipped to provide their children with accurate information or support anyway. Rather, most of the adolescents reported their own peers were the best available source of SRH information and support.

Recommendations

The study’s recommendations are directly related to the findings:

- Advocate for policies and laws that are supportive of SRH rights for adolescents living with HIV
- Promote HIV-positive adolescent support groups
- Integrate SRH and HIV services to increase HIV-positive adolescents’ access to SRH services
- Better equip parents and guardians with the knowledge and skills to support their HIV-positive children
- Improve access to non-judgmental counselling
- Fight stigma and advocate for the sexual health and reproductive rights of all people living with HIV, including adolescents.

Kunyima says the network also believes that further quantitative research is needed to add weight to their findings. If the network can mobilise more resources for research, they would like to perform a similar study among adolescents with HIV in rural settings (who are more likely not to be in school, and may not have as much access to a network of supportive peers).

Developing services

As a result of the study, the network has developed a partnership with Planned Parenthood to train young people living with HIV as peer counsellors. In addition, they have begun setting up adolescent support groups in partnership with the Regional HIV Psychosocial Support Organisation, which is helping them develop psychosocial tools for adolescents with HIV.

“Currently we have quite a number of support groups in Lusaka. We have a specific one with ten year olds and below, and others for older than ten. But even there we realised the needs were completely different. Because some of them are in school, some of them are still children – they don’t understand. Some of them are actually brought in by their parents *for us to disclose their status on their behalf*. So you are talking to this child and she doesn’t know she is HIV-positive. It was so difficult. This is a learning process for us, but the groups are there, and we are hoping to scale-up through this process. That is why we partnered with an organisation specialising in psychosocial support to develop psychosocial guidelines and tools to assist adolescents,” said Kunyima.