HIV Treatment Literacy in Post 2015: Empowering PLWHV to Optimize and Improve Quality of Care

Meeting Report

Date of Meeting: 9th and 11th March 2016

Venue: MCK Lodge, Chilanga

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Contents

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
ANC	Antenatal Care
CHAZ	Churches Health Association of Zambia
CSO	Civil Society Organisations
DACA	District AIDS Coordinating Advisor
DATF	District AIDS Task force
eMTCT	Elimination of Mother to Child Transmission
FDC	Fixed Dose Combination
FP	Family Planning
GFATM	Global Fund to Fight AIDS, TB and Malaria
HIV	Human Immune Virus
IEC	Information and Education Communication
JSI	John Snow
MOH	Ministry of Health
PMTCT	Prevention of Mother to Child Transmission
NAC	National AIDS council
NAPOIE	National ART Program Outcome and Impact Evaluation
NZP+	Network of Zambian people Living with HIV
PEPFAR	Presidents Emergency Plan For AIDS Relief
PLHIV	People Living with HIV
PLHWA	People Living with HIV and AIDS
PrEP	Pre-Exposure Prophylaxis
SADC	Southern Africa Development Community
SDG	Sustainable development Goals
TALC	Treatment Advocacy and Literacy Campaign
TB	Tuberculosis
UNAIDS	United Nations Programme on HIV and AIDS
UNICEF	United Nations Children Emergency Fund
VCT	Voluntary Counselling and testing
ZAF	Zambia Air Force
ZAMPHIA	Zambia Population based HIV Impact Assessment
ZANERELA	Zambia Network of Religious Leaders living with and affected by HIV
ZDHS	Zambia Demographic Health Survey
ZINGO	Zambia Interfaith Networking Group On HIV and AIDS

1 Acknowledgments

NZP+ would like to thank FHI360 for the support provided to make this meeting a reality. Without their support this meeting would not have taken place. Particularly Dr. Prisca Kasonde and Ms Mary Lombe for their invaluable technical support. We would also like to thank The African Community Advisory Board (AFROCAB) for providing technical and other support for this meeting. NZP+ would also like to thank Mclean Musonda Kabwe for compiling this report.

NZP+ would also like to thank all the partners who participated and presented during the meeting. Lastly but not the least we would like to thank all participants from NZP+ district chapters who attended the meeting and contributed to the execution of its objectives. We recognise the invaluable support everyone has rendered not only during this meeting but even in the everyday programs and actions of NZP+ and its served communities.

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2 Summary

This report captures the presentations, discussions and shared experiences that took place during the treatment optimisation meeting which was held from 9th to 11th March 2016 at MCK Lodge in Chilanga, Lusaka. The meeting was organized by the Network of Zambian People Living with HIV and AIDS with support from FHI360. The report model presents the facts and narratives presented, thoughts shared by attendees and closes with recommendations from the participants drawn from both the information shared and their personal and professional experiences.

Since the introduction of free of ART, Zambia has made tremendous progress in the care of People Living with HIV (PLHIV). During this period, the Government has increased access to antiretroviral treatment (ART) from 2000 in 2005/6 to approximately 700,000 people living with HIV on ART as at December 2015. With these successes, there have also been numerous challenges at individual, community and service delivery levels.

At the individual level, there have been challenges regarding the number of regimens that PLHIV have had to take over the period of time since ART delivery started and this includes the adverse effects of some regimens such as Stavudine (d4T). Other challenges have included switching from one regimen to another (e.g Emtracitabine to Lamivudine, Fixed Dose combinations to single dose regimens). With little education, information and support amongst some of the PLHIV especially those on treatment, these challenges have added to some of the difficulties to treatment adherence and retention in care for people living with HIV. Observations have also revealed that most PLHIV do not know or are unable to identify their regimens by name or class.

At the community level, the reduction in the number of community adherence supporters has exacerbated these challenges. The adherence supporters played an important role providing treatment literacy and encouraging early testing and linkage to care. Challenges at the service delivery level are well documented and include inadequate Human Resource to meet the increasing demand for HIV care leaving health care providers being overwhelmed with work.

While Government and other implementing partners are trying to address these gaps, the networks of PLHIV have not been fully engaged nor adequately trained and resourced to play a meaningful role. The recently announced 2016 WHO HIV treatment guidelines include 10 new recommendations to improve the quality and efficiency of services for people living with HIV and these include:

- The differentiated care framework to address the diverse needs of PLHIV;

- Alternative strategies to community delivery of ART to accommodate the growing number of people on ART
- Principles for improving the quality of care and providing people-centered care.

It is against this background that the Network of Zambian People living with HIV (NZP+) sees the need to provide up to date knowledge and information to its membership, so that they are able to better care for their own health, support others in their community, effectively engage and participate in processes leading to Zambia adopting the 2016 WHO guidelines. In order to fill this role effectively, the Network of Zambian People Living with HIV and its membership and indeed other PLHIV will need to be trained, empowered and resourced in the areas of HIV Treatment Literacy in the Post 2015 era with the aim of empowering PLHV to optimise treatment and improve quality of care.

2.1 Objectives of the Meeting

i. To increase knowledge on treatment optimisation, care and support of PLHIV
ii. To understand, assess and strengthen community based care models
iii. To identify opportunities for advocacy and greater engagement with key stakeholders and national programme implementers

2.2 Expected Outcomes

i. To improve partnership and collaboration with MoH and other implementing agencies.
ii. PLHIV have a better understanding of the national ART programme;
iii. PLHIV and other participants will be able to grasp how the UN 90 90 90 treatment targets can be achieved and the responsibilities of both duty bearers and community roles in the target cascade

2.3 Participating Organisations and their Representatives

i. Network of Zambia People Living Positively with HIV/AIDS - NZP+
ii. Transbantu Association Zambia - TBZ
iii. Zambia Network of Religious Leaders Living with and Affected by HIV/AIDS - ZANARELA

iv. The Lotus Identity - TLI

v. Engender Center

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3 Training Narrative

3.1 Opening Remarks

Dr Harold Witola, Director of Programmes at the National AIDS council, gave the opening remarks on behalf of the Director General of National AIDS Council. Dr. Witola mentioned that the optimisation of treatment needs and must be recognized as a key policy issue. He reminded the participants that the current National AIDS Policy expired in 2010 and since then a lot has happened and a lot of shifts have happened and hence the need for the new policy which CSOs and Community organisations must take the lead to ensure a new policy in developed. He gave an example that when the expired policy was developed and implemented, there was no talk of self-testing, community ARTs, test and treat. However, in the current response there has been change and which must respond to 2030 vision and this is the more reason why there are calls for change in policy and stakeholder involvement for a unified response. The need for unified response has led to the 90- 90- 90 Strategy by the UNAIDS. For all this to happen, there must be a lot of push from the HIV community and change in the way things are done by improving and taking advantage of new technology. Services must be closer to the people meaning testing centers must be accessible to the community. For instance, in cases of rape or unprotected sex, women must readily access the services without fear of being stigmatised and discriminated against. This calls for change in attitudes at all levels. In addition, Dr. Witola mentioned that in order for us to reach optimal levels of testing, people must be ready to test themselves. This can be achieved through linkages between VCT, PMTCT, etc. optimizing community support services is therefore key. In this case, NAC is seeking to revise the AIDS policy which will consider issues of self-test, community testing, support and treatment. This cannot be done without the backing of the policy and all stakeholders including community members. Policy makers and the affected community must be involved in order for the country to have a robust and effective policy. Support is needed from all stakeholders including the line ministries like the ministry of mother and child health. On the other hand, the NASF 2011 -2015 mid-term review in 2013 had required to remove some strategies like home based care because we didn't have bed ridden patients anymore. Therefore the new strategic plan of 2014 to 2016 was birthed.

Going forward, what are the strategies we should be focusing on? These must be Service delivery, community systems strengthening. Dr Witola's opening remarks were followed by questions from the participants and some of these and responses are highlighted below.

3.1.1 Participants' Questions and Feedback

i. **Lack of HIV workplace policy in some organisations which affects access to treatment and care.** NAC responded that employees must have systems that support self-esteem and non-victimization. There must be worker informed needs that translate into more responsive actions in the policy. We must do away with such archaic activities like Friday t-shirts, brochures, lunches and workplace policies must now reflect the global trends.

ii. **Community radio stations sometimes are not giving information that is responsive to the needs of PLHIV**. NAC has structures at District AIDS Task Force (DATF) through which information is given to the community. Community radio stations are under-utilized and there is need to think about what can be done to change this. Community advocates and DATF must engage radio stations more actively to ensure that this change comes forth and identify what has worked and what needs to be revised. Discussions are undergoing with UNICEF to improve dissemination of information at community radio stations.

iii. **Does the NAC and its supporting structures have ventures or actions to support PLWHA economically just like the way the Republican President is supporting the marketeers.** Caution was expressed by the NAC to avoid getting into the trap of stigma by singling out their plight only. Further, NAC advised the PLWHA pressure groups to be innovative in making their demands for support. Use strategic influential people who are close to the President. The First Lady, Vice President and others.

iv. **Taking ART to the community has more cons than pros.** NAC responded that ZAMBART is doing a study whether this is working or not. But indicators show that this is working. For instance, in Zimbabwe, PLWHA are actually being used to dispensing ART to the affected. Follow ups are essential for sustainability of the ART system and organisations like NZP+ is a resource that can be utilised through its established structures. Another challenge is the community that is influenced by church leaders to stop intake of ART. This must be stopped by such actions as advocating for a law to prosecute these pastors and church leaders.

v. **What is the position of the District AIDS Coordinating Advisors (DACA)**. These still exist but are now being employed by the councils. About 66 councils are waiting for their internal process to take place before they can employ the DACAS.

vi. **In Livingstone at Libuyu clinic, there is a loss of 4500 out of the 5000 on treatment who are not accessing follow-ups.** There is a need for NZP+ to access financial support to actively make a change in this regard. NAC will engage with relevant stakeholders. For instance, NAC would like it to be the principal recipient of the global fund as Churches Health Association of Zambia (CHAZ) concentrate on faith based organisation leaving out other CSOs.

vii. Update on the AIDS fund because the Ministry of Health (MoH) did not want to have a small fund but a larger one that would have a component of HIV/AIDS to be effectively supported.

PRESENTATIONS

The opening remarks were followed by presentations from various cooperating partners

as indicated below

3.2 Adult Art Updates - 2005 To 2015

This presentation from the Ministry of health representative highlighted the strides, interventions, challenges and lessons encountered in the administering of ARTs in Zambia to the affected. The presentation also showcased statistics in order to give a snap shot of the current situation. To begin with, the following is the status of the burden of HIV/AIDS.

a) HIV prevalence in ZDHS's showing declining prevalence trends in the population 15-49years olds via household survey (2001 - 6%, 2007 - 14%, 2014 - 13%)

b) NTBPS found average 6.8% via mobile testing in 15 and older participants

c) Estimated number of infected people by 2015: 1,300,000 (Spectrum 2015)

d) TB/HIV co-infection still high at 60%

e) TB is still the major cause of mortality among HIV patients

f) UTH mortality data of 2014 , 42% of deaths in ICD 1 were attributable to HIV related TB

g) Baseline CD4 cell counts very low at 164 (IQR +/- 44)

h) IPT in patient initiated early on ART and INH resulted in 44% lower risk of death compared to 35% in those with deferred ART without IPT

During the presentation it was highlighted that some progress and milestones have been achieved in addressing some of the above challenges. Thus there has been a decade of ART in the public sector in Zambia since 2004 resulting in rapid scale up through;

a) adopting simplified and standardized ART delivery models,
b) Task shifting and de-centralizing to health centre level
c) Global financial support Presidents Emergency Plan For AIDS Relief (PEPFAR) and Global Fund to Fight AIDS, TB and Malaria (GFATM)
d) Cheap generic antiretroviral medication in fixed dose combinations
e) National Electronic Patient Record system (SmartCare™)

Additionally it was alluded that working with local and international stakeholders has amplified the HIV response. UNAIDS is one example with its 90/90/90 model that effectively captures all aspects of testing, treatment and care. The model aims to:

- Diagnose 90% of the people with HIV
- Treat 90%of people diagnosed with HIV
- Achieve 90% undetectable viral load in 90% of people on HIV treatment by 2020.

In order to achieve greater impact for reduced infections, Zambia has scaled up on the existing models including the 90/90/90 by proposing the following actions towards the target goal of "Accelerated achievement of an AIDS-free generation by 2030":

a) Rapidly scale up HIV treatment to cover 80% of PLWHA by 2017
b) Rapidly scale treatment 90:90:90 by 2020, virtual test and treat
c) Rapidly scale up combination HIV prevention including PreP for High risk populations
d) Integration of ART with TB/HIV, FP and ANC (Option B+)
e) 3Is roll out/ Gene Xpert
f) SmartCare institutionalization
g) Community ART delivery model to decongest health Care facilities and improve retention
h) Scale up routine viral load

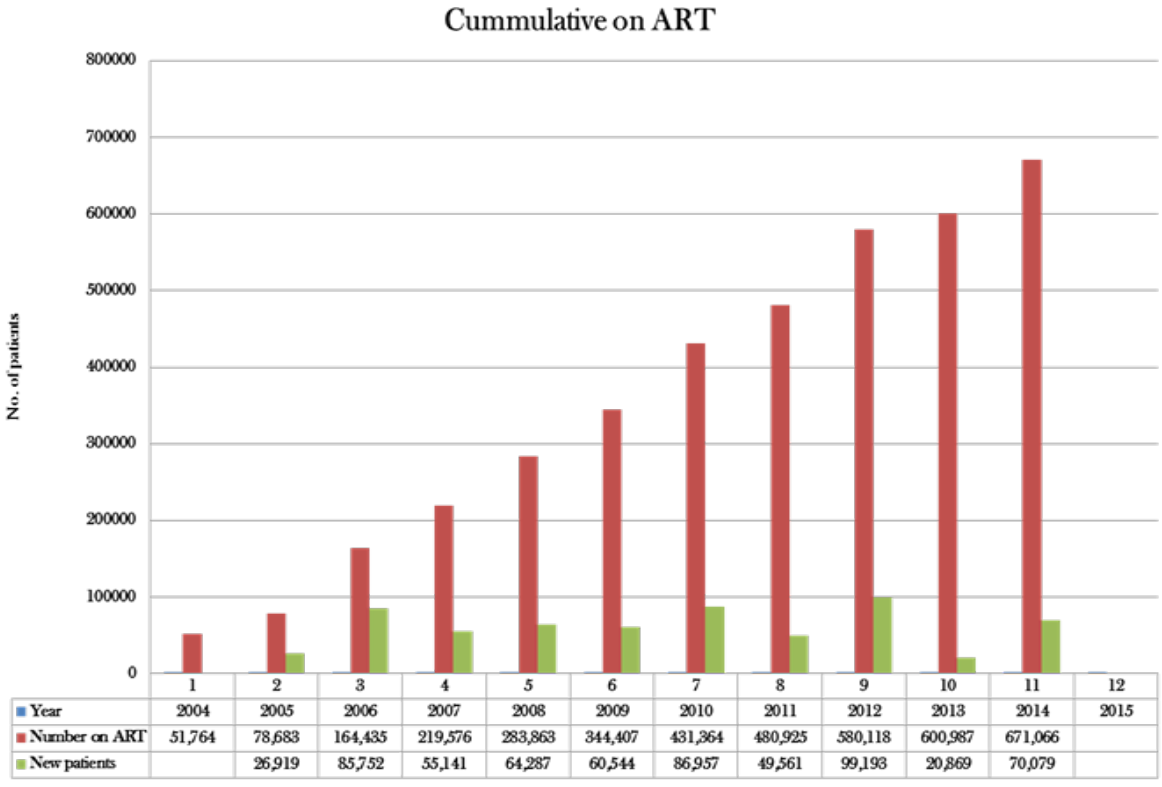
3.2.1 Traditional Vs. Community ART Models

The presentation highlighted that in the past, access to treatment was one tracked and ineffective especially when the AIDS pandemic became rife. There was therefore need to overhaul the model in order to respond to the rising challenges as shown illustrated below;

Early ART Model to Mobile ART Models	Mixed ART Model
System overstretched	Stable patients on ART for 6 months referred to the community for pick-ups
Quality of care poor	New and older sick patients followed up in clinic
Increase loss to follow up /poor retention	Clinics decongested
2013 - 582 sites	Better quality of care poor
2014 - 604 sites	Reduced loss to follow up /improved retention

The graph below shows the cumulative number of patients on ART over the years

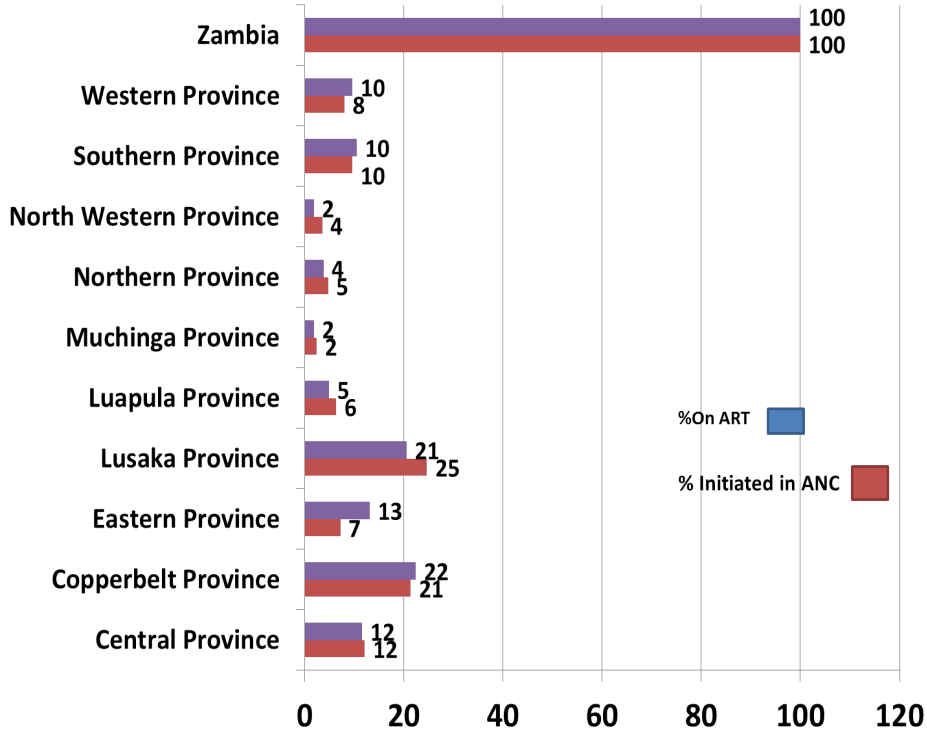
i. Cumulative on ART



	1	2	3	4	5	6	7	8	9	10	11	12
Year	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Number on ART	51,764	78,683	164,435	219,576	283,863	344,407	431,364	480,925	580,118	600,987	671,066	
New patients		26,919	85,752	55,141	64,287	60,544	86,957	49,561	99,193	20,869	70,079	

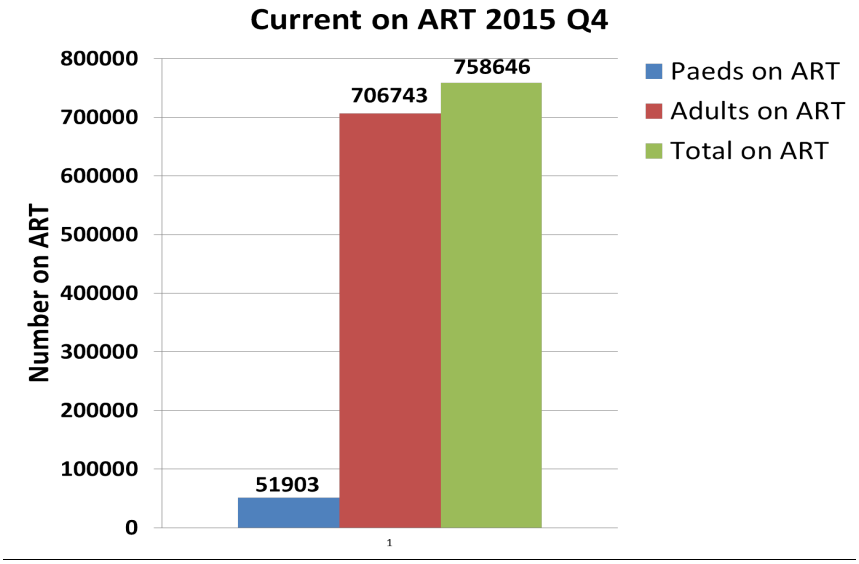
Number of women accessing antenatal care

ii. PMTCT Care



The graph above indicates that in some provinces, more women are accessing antenatal care and not ART. This shows that they may not be testing for HIV and deliberately not accessing ART care.

iii. The graph below shows the cumulative number of adults and children on



The above indicates that the number of children on ART is noticeably lower compared to the national total of people on ART.

3.2.2 Core elements of Community based ART in Zambia

This is anchored on two principles namely

- Phased implementation of community-based ART using different models
- Assess the acceptability, feasibility and efficacy of various approaches

The benefits of the community based ART model are;

i. Reduced number of stable individual ART patient visits to primary health centers

ii. Provision of specific services (e.g. adherence counseling, medication pick-ups, counseling and testing) in a community setting

iii. Utilization of non-professional (lay) health care workers for a majority of community-based service activities

iv. Maintenance of clinic-oversight of all service processes

v. Maintenance of routine service and outcomes data utilizing existing (SmartCare oriented) health information platforms

3.2.3 Current Research Efforts

i. National ART Program Outcome and Impact Evaluation (NAPOIE) to understand interventions and outcomes

ii. Zambia Population based HIV Impact Assessment (ZAMPHIA) through Household level questionnaire and Biomarkers and HIV (Prevalence and Incidence), Syphilis (Exposure and Active), Hep. B, HIVDR, ARV Metabolites.

iii. Community ART models and Test and Start via consulting Implications on ARVs, CTX and INH

3.2.4 World Health Organisation Recommendations

i. The number of patients on ART

ii. Option B+- lifelong ART for pregnant and Breastfeeding women

iii. ART consolidated treatment guidelines widening eligibility through:

- Discordance
- Hepatitis B Virus and TB / HIV Co-infection
- cART for children 0-15years
- Increase of CD4 threshold from 350 to 500

3.3 Fast Track the AIDS Response in Zambia by UNAIDS

Stemming from the above narrative on the current trends in ART access and management, the country has realized the importance of fast tracking the AIDS response for a greater impact. The country data indicates that 13% of the population is estimated to be living with HIV. In terms of prevalence, the people living with HIV between 15 and 49 years of age varies provincially. Copperbelt has the highest prevalence with 18.2% of its population living with HIV, followed by Lusaka with 16.3% with Western province is third place with 15.4%, Muchinga and North Western round off the list with 6.4% and 7.2% respectively. Therefore Zambia like many other countries is committed to ending AIDS by 2030 and therefore is committed to the Fast Track Strategy which is a Sustainable Development Agenda that addresses the following:

- The 2030 Agenda for Sustainable Development reflects the interdependence and complexity of a changing world and the imperative for global collective action.
- In shifting from so-called development for the poorest countries to sustainable development for all, the global agenda which has expanded scope and complexity. As a set of indivisible goals, the SDGs give all stakeholders a mandate for integration of efforts.
- The AIDS response is no exception: the epidemic cannot be ended without addressing the determinants of health and vulnerability, and the holistic needs of people at risk of and living with HIV
- People living with HIV often live in fragile communities, and are most affected by discrimination, inequality and instability.

In fast tracking the AIDS response, the UNAIDS Strategy 2016 – 2021 has goals but critical of which are;

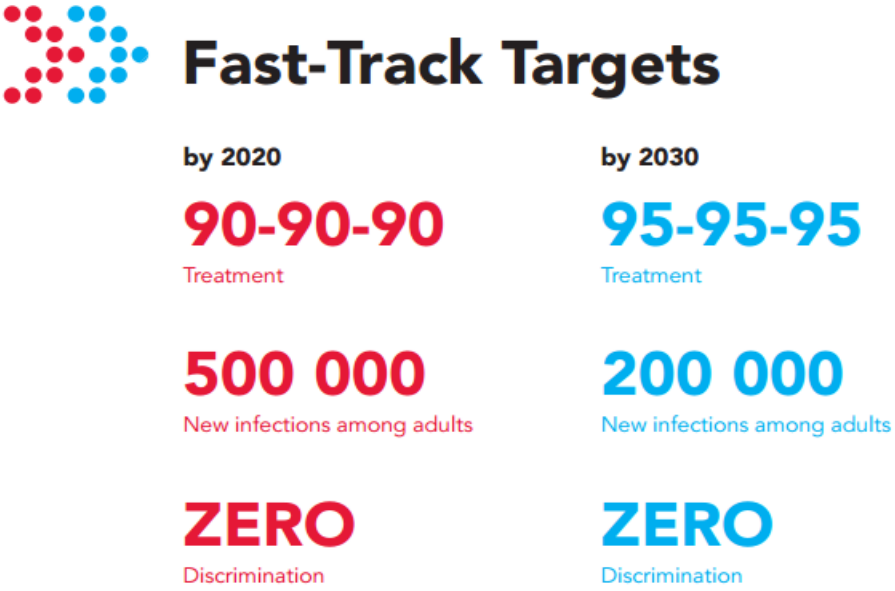
Goal 3: Ensure healthy lives and promote well-being for all at all ages

Goal 5: Achieve gender equality and empower all women and girls

Goal 10: Reduce inequalities

Goal 16: Promote just, peaceful and inclusive societies

Goal 17: Revitalize the global partnership for sustainable development.



3.3.1 90/90/90 Target by 2020 which translates into

90% of people living with HIV know their HIV status,

90% of people who know their status are receiving treatment and

90% of people on HIV treatment have suppressed viral load so their immune system remains strong and they are no longer infectious.

3.3.2 Role of Civil Society

i. Community awareness on the importance of testing
ii. Community preparedness for people living with HIV to access ART services
iii. Create demand for PLHIV to access viral load testing

3.3.3 How can we implement the Fast Track Approach?

Principles of Fast Track - An Accelerated Implementation Agenda:

i. Setting highly ambitious HIV prevention and treatment targets—aiming to reach maximum numbers in the shortest amount of time

ii. Highly-effective programme interventions in locations and populations with the highest HIV burdens

iii. Discarding what does not work, adopting new ways of delivering services including community service delivery, fostering innovation and early adoption of new technologies and methods

iv. HIV service delivery in the intensity and quality needed to reach the ambitious targets within the short time frame of the next five years

v. People centered, zero discrimination.

3.3.4 UNAIDS 2016–2021 Strategy: Targets for 2020

Target 1: 90% of people (children, adolescents and adults) living with HIV know their status, 90% of people living with HIV who know their status are receiving treatment and 90% of people on treatment have suppressed viral loads

Target 2: Zero new HIV infections among children and mothers are alive and well

Target 3: 90% of young people are empowered with the skills, knowledge and capability to protect themselves from HIV

Target 4: 90% of women and men, especially young people and those in high-prevalence settings, have access to HIV combination prevention and sexual and reproductive health services

Target 5: 27 million additional men in high-prevalence settings are voluntarily medically circumcised, as part of integrated sexual and reproductive health services for men

Target 6: 90% of key populations, including sex workers, men who have sex with men, people who inject drugs, transgender people and prisoners, as well as migrants, have access to HIV combination prevention services

Target 7: 90% of women and girls live free from gender inequality and gender-based violence to mitigate the risk and impact of HIV

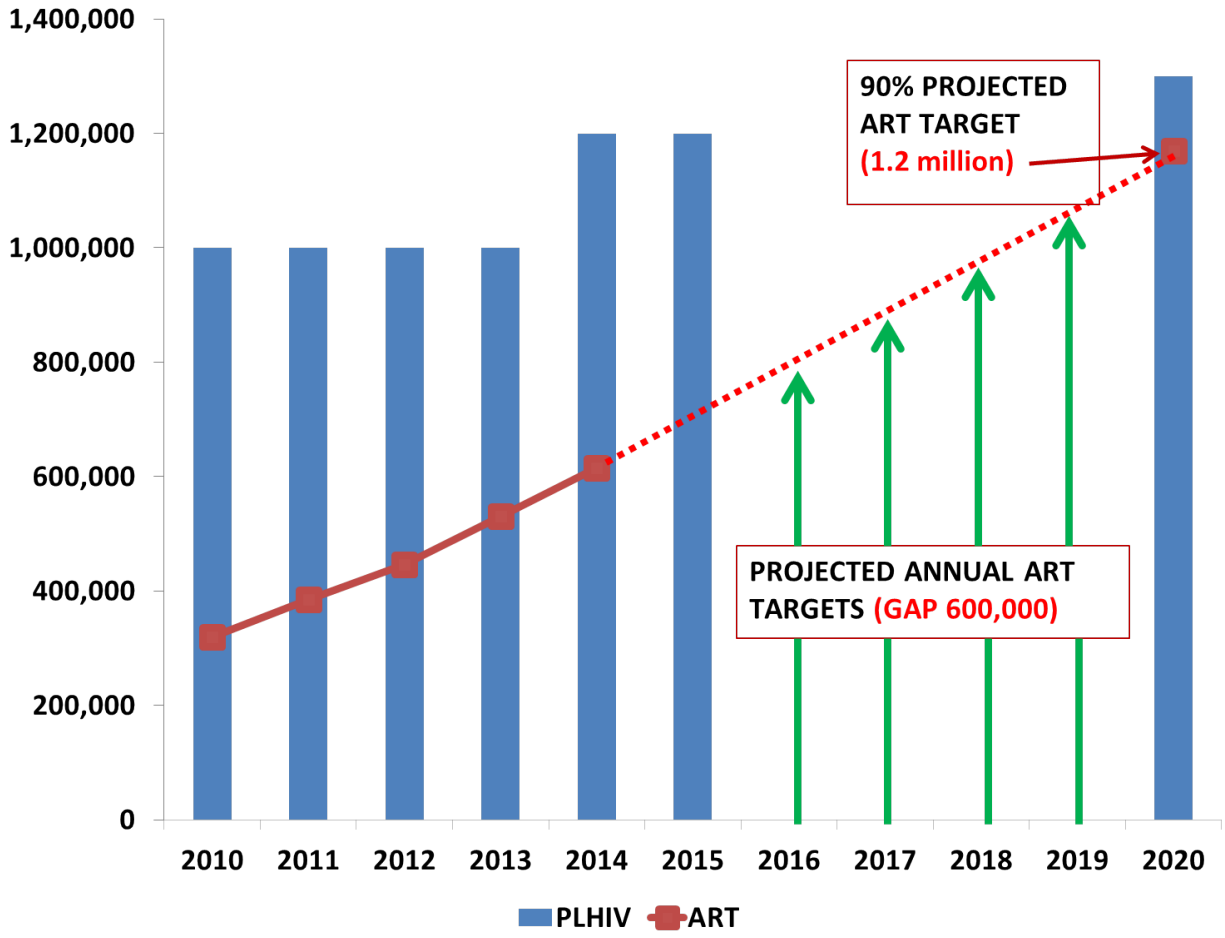
Target 8: 90% of people living with, at risk of and affected by HIV report no discrimination, especially in health, education and workplace settings

Target 9: Overall financial investments for the AIDS response in low- and middle-income countries reach at least US$ 30 billion, with continued increase from the current levels of domestic public sources

Target 10: 75% of people living with, at risk of and affected by HIV, who are in need, benefit from HIV-sensitive social protection.

It is worth noting that if Zambia embarks on this strategy by 2030, it will have brought down new infections to just under 3000. However, if this is not done and older less effective models keep being employed, new infections will be 44,500 by the year 2030.

*The blue bars on the left indicate National Projected Scenarios is the model is not used.



3.3.5 Summary of the Model:

Fast Track Ending the AIDS epidemic by 2030

- Ending the AIDS epidemic: priority for post 2015 agenda
- Fast Track Strategy—speed combined with location and population
- Fragile-five year window –Investment
- Ambitious 2020 HIV treatment and prevention targets
- Zero discrimination - Leaving no one behind

Low hanging fruit: Full implementation of eMTCT

- Politically it is the right thing to do
- Economically is more feasible to invest $300 to prevent MTCT than spending later $300,000 on ART
- Programmatically; 50% babies will die before they celebrate their 2nd birthday
- Children have the right to be born HIV free.

3.4 Treatment Literacy in Post 2015 presented by Treatment Advocacy and Literacy campaign

This section of the meeting is very cardinal to the objectives set forth because if treatment is to be effective, appropriate knowledge is required. This knowledge is essential for all stakeholders including those uninfected. Any patient on ART will have family or friend support system and these too need this knowledge in order to provide full rounded support that includes adherence, nutrition and follow-ups.

3.4.1 What is HIV Treatment Literacy?

ART Treatment Literacy is the knowledge passed on to HIV+ people and their partners, buddies, housemates and community members to educate them about:-

- HIV lifecycle
- Available ART regimens
- Benefits of taking ART and side effects
- Prevention measures of HIV infection and re-infection
- Where and how ART services can be accessed

3.4.2 Strategies Used in Treatment Literacy

- Policy review
- Research
- Health Talks
- Community meetings
- Drama
- Media (electronic and print)
- Litigation (Lessons learnt from cases that have been taken to the courts of law)

3.4.3 Conducting Treatment Literacy

i. Taking science into communities and support groups

- HIV lifecycle
- Available ART regimens, benefits and side effects
- Prevention measures of HIV infection and re-infection

- Community education using door to door sensitization, community meetings, drama

ii. Drug laws

- Trips and patents
- Drug pricing- generics

3.4.4 Current Gaps

- Very few donors still provide resources to develop IEC materials (posters, brochures and newsletters)
- New patients initiated on ART have very little ART treatment literacy and hence have challenges with adherence and identification of medication
- People in the community do not know where to access ART related services due to unavailability of IEC materials
- Some service providers prescribe the wrong treatment to patients because they are not treatment literate

3.4.5 Importance of Treatment Optimization

- Treatment optimization is important to activists and communities because it provides the opportunity for them to monitor the quality of health services that they receive from the state.
- There should be equity in the access of health services.

3.4.6 Application of the Law

Zambian constitution has enshrined Health care, food, water and social security as some of our basic human rights:

(1) Everyone has the right to have access to-

(a) Health care services, including reproductive health care;

(b) Sufficient food and water, and

(c) Social security, including, if they are unable to support themselves and their dependants, appropriate social assistance

(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights; and

(3) No one may be refused emergency medical treatment.

In addition the following are the cases to consider;

- *ZAF Officers vs The State*
- *Mwanza vs The State*
- *Bulaya vs The State*
- *Kapoko vs The state*

3.4.7 Benefits of Treatment Literacy

- Improved Adherence
- Prolonged lives
- Healthy lifestyles- “back to work”
- Knowing PLHIV and health rights
- Reduced drug prices
- Generic drug production
- Change in political will (Hon Kasonde, NZP+ & CSHF)
- Identification and addressing of gaps in the health systems
- PLHIV meaningful contribution s to the development of the National AIDS strategic plan
- PLHIV meaningful contribution s in the quantification and drug procurement process.

3.4.8 Areas of In Need of Improvement

- Better treatment regimens and FDC especially for paediatrics
- TB/HIV integration
- Early initiation of treatment
- Targeted interventions to combat stigma
- Provision of care and support to recently diagnosed people
- Improved prevention tools
- Improved Funding for health
- Challenge the SADC trade laws

3.5 Treatment Optimization

3.6 Drugs Supply Chain Management presented by JSI

The purpose of this presentation is to analyze how treatment optimisation fits into the drug supply and uptake system conducted by the government through the Medical Stores. This has a bearing on

the availability, accessibility and efficiency of treatment for the affected. Every supply chain system must have the following fundamentals:

- The right drug in all aspects and fitting the description
- In the right quantity
- Of uncompromised quality
- Efficient distribution at the right time and to the right place
- It must be seamless with manageable challenges
- As good as the things that are put in it

3.6.1 Activities Supporting the Supply Chain:

a) **Policy formulation and direction** – It is common knowledge that treatment protocols keep changing and this affects the end users. These are beyond the control of the users as conformity must be observed to international and national protocols. This now leads to policy adoption and implementation but which must ensure that this is translated into information the end users can understand. For instance, clients must understand why they are being given a different drug instead of one they got previously.

b) **System design and implementation** – the success of the system is dependent on the feedback of the target group. The system must also be responsive to population growth and other factors. The system must not be static but flexible and responsive.

c) **Forecasting and Quantification** – this is informed by the responsiveness of the users/group. This way, it works in a guided way and focused on specific goals. For instance, this informs the procurement on the right quantity of drugs to buy, the demand for them and where gaps needing attention are.

d) **Procurement** – based on the information above, this leads to the right procurement of the drugs with a buffer period of about seven months at the end of the year. This is to take care of any delays and other unforeseen challenges and therefore prevent drug shortages. This process must respond to the health centers' specific needs and not determined by Medical Stores.

Results of the Meeting based on Objectives

1) To increase knowledge on treatment optimisation, care and support of PLHIV

   Knowledge on this was covered by the presentation on treatment optimization

2) To understand, assess and strengthen community based care models – this was covered under the traditional and community ART models, with the mixed model highlighted as the best because of its ability to take into consideration patient follow-ups, accessibility to health centres and reduction in inefficiency.

3) To identify opportunities for advocacy and greater engagement with key stakeholders and national programme implementers -

4 Lived Realities of the Affected

The meeting was an opportunity to share lived experiences of both PLHIV and others who attended the meeting, personally and by others in their communities. These realities are significant because they speak to the challenges faced by the clients.

1. A 17 year old teenager in Kafue who was born HIV positive and is on ART has been inconsistent in taking the drugs because he says the treatment makes him weak. This is becoming common where many patients are not taking the drugs due to poor nutrition and limited access to food.
2. Closely related to the above, is the neglect of the needs of child patients on ART. There is no support system in terms of counselling and many of them actually stop drug intake due to anger at their parents for giving them the virus and fatigue from taking drugs.
3. In Livingstone at Libuyu clinic, there are currently 5000 clients on ART register but only 500 are collecting the drugs. This means that these are lost to follow and need to be captured and brought back to access the drugs. This is an opportunity for NZP+ to be empowered by National AIDS Council and close this gap
4. In 2010, 2 Zambia Air Force officers were tested for HIV without their consent and knowledge and when they were found positive, they were dismissed from employment. By then they were taking ART and experiencing side effects. NZP+ Livingstone Chapter with support from Legal Resource Foundation, they were compensated with K10,000 and are now under NZP+ local support group.

5 Recommendations

1. Within the communities, there must be systems and structures that can detect treatment failure. These include capacitating health care providers with technical and financial support and use of expert patients who are able to support those affected by treatment failure.
2. There is need to stop isolating HIV as a stand-alone problem but one that co-exists with other social problems such as poverty, gender power roles, discrimination both at community and professional levels.
3. The District Councils which are now managing the DATF should include other key players and stakeholder in ensuring that their actions have greater impact and responsive to everyone.
4. The use of technology must be amplified to address the inefficiencies of data capture and access to treatment. For instance, TALC has the End AIDS Portal which clients use to access treatment. This is at pilot stage.
5. Every patient must personalize their viral load information and know exactly what the test means.
6. Action Plans for Optimization:

Issue	**Proposed Solution**	**Action**
Lack of integrated services	Integrating services at health centers	Facilitate and advocate for dialogue meetings with government and other stakeholders with a view to establish integrated services.
Drug and testing kit stock outs	Stock up on shortages	Advocate the relevant authorities on the issue
Poor filing system	Digitize the system to make it more efficient	Mobilize resources, advocate for support from government
Self-stigma of clients, parent/child disclosure	Utilize influential role models who have come out in the open on their status	engage ZANARELA, ZINGO, TALC and champions, use of local media, road shows
Poor interpretation of policies to the public	Capacity building of health care providers	Sensitization of policies to the public through the media, radio stations and IEC materials

Long distance to ART centers	Roll out and scale up community model	• Community awareness, lobbying and dialogue • Decentralization of ART Centers • Increasing number of ART centers and facilities
Overburdened providers and limited skilled staff	Lift wage freeze to encourage more staff to the work	• Advocacy and Dialogue • Training more health care providers
High levels of illiteracy on ART treatment	Enhance ART treatment literacy in health centers, support groups, churches and community at large	intensify resource mobilization, target gate keepers, utilize expert patients, create linkages between s/g and health facilities
Lost to follow	family engagement, utilise support groups	door to door sensitisation
Stigma	Sensitize clients/affected community on the benefits of accessing services	Create awareness among PLWHA through skilled patients and community support groups