

Most Significant Result Analysis¹

GTF Number	361
Grant Holder	The Global Network of People Living with HIV (GNP+)
1.Result statement	Evidence from 50 pieces of research carried out by people living with HIV and AIDS, across 10 countries with high HIV prevalence rates has been used to feed into National AIDS Action Plans and United Nations General Assembly Special Sessions. In this way this research has informed changes in law, policy and practice with relevance for over 15 million people living with HIV.

2.Context and Theory of Change

Key elements of context

- HIV disproportionately affects certain key populations;
- HIV becoming a development issue;
- Role of Civil Society to give those populations a voice in policy making is key;
- HIV Civil Society in tender state and not fully committing to The Greater Involvement of People living with HIV/AIDS (GIPA) principles;
- Civil Society not particularly confident or skilled to engage with government and parliament;
- Policy makers adverse to critique by Civil Society in some countries;
- Lack of investigative media;
- Governments committed to GIPA principles but policy not resulting in action;
- Governments have made commitments at UN level to Universal Access for all populations;
- Universal Access targets concrete but negotiable;
- Some level of transparency and accountability of the process leading to Universal Access.

Theory of change

Discrimination, stigmatization and human rights violations of People Living with HIV (PLHIV) are a reality in many countries of the world. While Civil Society organisations and PLHIV networks have campaigned against these abuses, they have done so often individually and most importantly without verifiable evidence. Countries were selected based on a standardised selection catalogue including criteria such as the HIV prevalence rate. Regional PLHIV networks were closely involved in the selection of 10 countries.

GNP+, in cooperation with partners developed 5 evidence gathering tools (see section 3) to facilitate strong evidence-based campaigning for programme and policy change at country level. The theory of change envisaged that the research together with additional institutional strengthening by GNP+ would enable PLHIV networks to substantially improve their capacity. Subsequently, the PLHIV network would cooperate with the broader Civil Society platforms created by World AIDS Campaign International (WACI) to powerfully campaign on issues

¹ The UK Government's Department for International Development (DFID) provided funding for the Governance and Transparency Fund. All views expressed in this analysis should be considered as those of the grant holder alone, and do not necessarily represent the views of DFID or KPMG.

identified by the research.

Participation

- Civil Society organisations and other partners;
- PLHIV at community level, with wide representation (including geographic spread);
- Government agencies, parliamentarians, and decision-makers (e.g. Ministries of Health, Education and Labour);
- UN, donors

3. Approaches, methods and tools

The programme approach distinguished between two elements: research and evidence-based campaigning. GNP+ was responsible for the first element and WACI for the second one. The role of WACI was to invite Civil Society groups and establish a Civil Society platform. GNP+ convened national PLHIV networks and developed action plans for the 5 research tools. Subsequently national PLHIV networks and Civil Society platforms agreed joint messages based on needs emerging from research and presented results at national events like World AIDS day.

The 5 tools comprised:

The People Living with HIV Stigma Index (developed by GNP+, ICW, IPPF, UNAIDS) – collects and examines HIV-related stigma experienced by PLHIV, exploring its direct and indirect impacts on individuals. The Index is able to measure geographical, demographic and temporal trends.

Global Criminalisation Scan - documents existing legislation on criminalisation of HIV transmission and cases when the laws have been used to criminalise persons with HIV. Furthermore, the Global Criminalisation Scan supports the development of appropriate advocacy and actions to respond to current legislation.

The Greater Involvement of People living with HIV/AIDS (GIPA) Report Card (developed by GNP+, ICW, UNAIDS) - identifies existing levels of the application of the GIPA principle in-country and provides insights on how the participation of PLHIV can be made more meaningful.

Human Rights Count! (developed by GNP+ and Regional Networks of PLHIV) – is a new evidence gathering tool which aims to document cases of HIV-related human rights violations experienced by women, men and excluded individuals living with HIV.

Advancing the Sexual and Reproductive Health and Rights of People Living with HIV: A Guidance Package - was developed by EngenderHealth, GNP+, ICW, IPPF, UNAIDS and Young Positive. The Guidance Package raises awareness of sexual and reproductive health and rights of PLHIV and provides 12 practical programmatic recommendations for responses aimed at the general population.

4. The experience of implementation

The Leadership Through Accountability (LTA) programme successfully accomplished its target to undertake 50 pieces of research in its 10 active partner countries. Research was undertaken by PLHIV rather than established research institutes, with a strong element of

empowerment, capacity building and at the same time significant financial savings. In total, more than 16,000 PLHIV (over 50% women) have now participated in the research as: programme managers, budgets holders, researchers, data entry clerks or participants. The 50 separate pieces of research that have been implemented have enabled 10 PLHIV networks to model, research and collect evidence to inform advocacy for Universal Access to HIV prevention, treatment, care and support. Section 5 further elaborates on the outcomes and impact of evidence-based advocacy, with over 4.7m PLHIV benefitting already from better access to services or positive changes in the policy environment.

Challenges

While the experience in undertaking research in the 10 programme countries is unique for each country and for each research tool, some general implementation challenges emerged.

The engagement of partners in-country was a time-consuming process, particularly in terms of establishing Civil Society platforms. This process took longer than envisaged. However, undertaking the research took even longer. PLHIV had to be trained in undertaking the research, locations selected, and data collected and analysed. To maintain the momentum of the programme at country level, initial campaigning around broad policy issues became at times delinked from evidence-based campaigning on issues emerging from research. In Cameroon for example, an advocacy action plan tailored for campaigning around research results was not implemented as research came too late in the programme cycle.

In Ethiopia, Nigeria and Zambia, the Civil Society platform could not be established due to specific challenges in those countries such as competing interest or capacity issues. PLHIV networks successfully undertook the research but full-fledged campaigning through a wider alliance of Civil Society Organisations would have further added value. In Indonesia, the PLHIV network disintegrated at the time of the LTA programme and the engagement was stopped shortly after the programme launch in the country. Without the network and its active engagement and ownership, the programme could not be implemented any longer.

Success stories

Good examples of Civil Society platforms and PLHIV networks agreeing and lobbying around a broad message based on evidence provided by the 5 tools are presented below:

Zambia: Following research and campaigning both Human Rights Count and the PLHIV Stigma Index have been incorporated into Zambian UNGASS reporting.

Cameroon: The Ministry of Public Health committed to provide an increase in funding from April 2013 in order to provide optimal treatment to all PLHIV following a campaign by the Civil Society platform for access to PLHIV treatment, which was linked to the GIPA principles and research on Human Rights Count.

5. Long-term Impact on people's lives

More than 16,000 People living with HIV have been empowered through their participation in LTA research.

Over 4.7m people living with HIV in the 10 target countries benefit already from the results of the LTA programme. Concrete and quantifiable changes are emerging in improved access to

services and quality of treatment, access to justice or changes in the policy environment. Potentially 15 million PLHIV will benefit. The ultimate impact will be Universal Access and enhanced livelihoods free of discrimination and stigmatisation. The results already achieved include:

Changes in access to services and quality of treatment for 633,352 People living with HIV:

- **Cameroon:** In October 2009, the PLHIV network launched the Yaoundé declaration on the side effects of d4T in the current ART medicine. The phasing out of d4T started in October 2010 thanks to continuing campaigning of a united civil society, strengthened by the LTA programme. The phase out was finalised in February 2011. Number of beneficiaries on ART: 89,000²
- **Ethiopia:** Following the strengthening of NEP+ by the LTA programme, the network managed to mobilize PEPFAR funding of \$5 million to engage 450 HIV+ case managers over 5 years. To date 380 case managers have been recruited to provide health education to PLHIV and communities about how to access services and to carry out treatment registration. Direct beneficiaries: 76,000 (minimum)
- **Malawi:** The Civil Society Platform, in a joint advocacy effort with the network of PLHIV (MANET+), used the LTA evidence on human rights to persuade policy makers to phase out use of Stavudine (d4T) as a therapy option, in line with current World Health Organisation guidelines³. The phase out plan will be completed in July 2013. Number of beneficiaries on ART: 450,000⁴
- **Senegal,** the decision to focus on health financing followed a government announcement of their intention to decrease health spending to six per cent of the budget. LTA partners met with policy makers and other leaders to reverse this decision. Through the collective efforts of the platform and other stakeholders, government agreed not to decrease the health budget. Number of beneficiaries: 18,352 PLHIV on ART in Senegal⁵.

Changes in access to justice for 73 People living with HIV:

- **Kenya:** 20 Human Rights violations of PLHIV addressed.
- **South Africa:** So far 30 girls have been saved from forced marriages.
- **Tanzania:** 23 of cases of stigmatisation and discrimination of PLHIV have been taken to court.

Changes in policy environment affecting 4,080,000 People living with HIV

- **Nigeria:** Civil society in Nigeria has been lobbying their government on the need to pass the draft “Anti-discrimination Bill” for eight years but government appeared not to see the importance. Using the LTA evidence, the national network together with broader civil society, was able to clearly demonstrate the extent of discrimination. After a Stakeholders’ forum on the Proposed HIV/AIDS anti-Discrimination Act, the criminalisation clauses were removed and in addition the scope was expanded to cover the workplace, schools, correctional institutions, religious institutions and society at large. Number of beneficiaries: 3,100,000 PLHIV⁶

² National AIDS Control Committee, 2010: The impact of HIV and AIDS in Cameroon through 2020

³ <http://www.who.int/hiv/topics/treatment/d4t-phase-out-management-guiding-principles.pdf>

⁴ <http://www.manoonline.gov.mw/index.php/national/health/item/3174-450-thousand-people-on-art-in-malawi>: quoting Edith Mkawa, Principal Secretary for Nutrition HIV and AIDS in the Office of the President and Cabinet

⁵ <http://www.unaids.org/en/resources/presscentre/featurestories/2012/october/20121011senegal/>

⁶ National Agency for the control of AIDS, UNAIDS, 2011: Brief on the HIV response in Nigeria, factsheet 2011

- **Zambia:** PLHIV provided inputs on Zambia's Anti-discrimination Act with the result that anti-discrimination is now included in draft constitution for the first time. Number of beneficiaries: 980,000 PLHIV

6. Value for money

The total cost of the programmes has been £4,099, 669 (the programme budget). Within this total the cost of implementing the 5 research tools in 10 countries has been £929,377 (23%).

Economy

Concrete examples of the way costs have been controlled emerge from the recent LTA programme meeting in Dakar, Senegal to share research results. By requesting more than one quote for translation services, the programme managed to accomplish savings of 56%. For accommodation, a rebate of 15% was negotiated. The programme also managed to make savings for travel related expenses for the Dakar meeting by purchasing refundable airline tickets only. A total of 4 flights of a total value of € 4,730.50 had to be cancelled at short notice due to unforeseen reasons. Airline refunds amounted to € 4,499.42 after the payment of cancellation fees, representing a significant amount of money that was saved.

Efficiency

Section 5 above presents estimates that suggest that already a total of 4.7 million PLHIV have benefitted from the programme. Applying the total programme budget to this figure provides a cost per beneficiary of just below £1. It is estimated that in the longer term the programme can benefit 15 million PLHIV in the countries covered.

Effectiveness

It has not been possible to prepare calculations that illustrate the substantial value to individuals or society as a whole of the programme benefits highlighted in Section 5 covering for example improved access to services and quality of treatment, improved access to justice or changes in the policy environment tackling institutionalised discrimination. Importantly issues of measurement and attribution make this extremely difficult.

Equity:

The beneficiaries of the programme include significant groups of people who are often marginalised in society, especially in Africa (sex workers, MSM, prison inmates etc.)

7. Strength of evidence that result was achieved

Principle	Criteria	1	2	3	4	N/A	Comments	Score
1) Voice and Inclusion We present beneficiaries' views on the effects of the intervention, and identify who has been affected and how	1a. Are the perspectives of the most excluded and marginalised groups included in the evidence?				x		Yes, key populations like sex workers, MSM, drug users, prison inmates, youth, women were targeted for research	4 / 4
	1b. Are findings disaggregated according to sex, disability and other relevant social differences?				x		Disaggregation by sex and key population	4 / 4
	Total score for voice and inclusion:							8 / 8
2) Appropriateness We use methods that are justifiable given the nature of the intervention and purpose of the assessment	2a. Are the data collection methods relevant to the purpose of the enquiry and do they generate reliable data?				x		Standardized research tools, applied in all 10 countries	4 / 4
	2b. Are the data analysed in a systematic way that leads to convincing conclusions?				x		Data analysis process systematic and equally high quality across the 10 countries	4 / 4
	Total score for appropriateness:							8 / 8
3) Triangulation We make conclusions about the intervention's effects by using a mix of methods, data sources, and perspectives	3a. Are different data collection methodologies used and different types of data collected?				x		Each of the 5 research tools entails its own data collection methodology	4 / 4
	3b. Are the perspectives of different stakeholders compared and analysed in establishing if and how change has occurred?				x		Different key populations are included in the research; baseline is established; assessment of change can take place when research is repeated	4 / 4
	Total score for triangulation:							8 / 8
4) Contribution We can show how change happened and explain how we contributed to it	4a. Is a point of comparison used to show that change has happened (eg. a baseline, a counterfactual, comparison with a similar group)?				x		The research constitutes a means of establishing baselines e.g. about stigmatisation. It is not about documenting change when applied for the first time, as happened in the 10 countries. A comparison with a similar group is not provided.	4 / 4
	4b. Is the explanation of how the intervention contributes to change explored?					x	The research established the baseline. At this stage the assessment of change is not relevant	0 / 4
	Total score for contribution:							4 / 8
5) Transparency We are open about the data sources and methods used, the results	5a. Is it clear who has collected and analysed the data, and is any potential bias they may have explained and justified?				x		Names of data collectors and analysts is available, including their profession and position e.g. in a PLHIV network which could influence the results	4 / 4

achieved, and the strengths and limitations of the evidence	5b. Is there a clear logical link between the conclusions presented and the data collected?				x		Clear link between quantitative results and the subsequent conclusions. Quantitative assessment helps to establish the logic between findings and conclusions.	4 / 4
								Total score for transparency: 8 / 8

Total Score for Result : 36