



CLAIM change stories



COMMUNITY-LED ACCOUNTABILITY INFLUENCE AND MONITORING



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INTRODUCTION

CLAIM CHANGE STORIES

Through the Community-Led Accountability, Influence and Monitoring programme (CLAIM), GNP+ supports people living with HIV to fully claim their space in Global Fund processes and claim their role in ensuring that Global Fund grants are developed, implemented, and monitored in ways that are effective and inclusive.

The CLAIM programme is supported by the Global Fund Community, Rights and Gender Strategic Initiative. It is a collaboration between GNP+ and networks of people living with HIV in various countries



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People living with HIV lead the way in Eswatini:

Harnessing the power of community engagement

Positive Women Together in Action (PWTA), is a community-based organisation which aims to advance the needs and rights of women and girls living with HIV in Eswatini. In the absence of a functioning national network of people living with HIV in Eswatini, over the last three years, PWTA has also played a leading convening role in the country, creating a wider platform for community voices and priorities.

The Problem:

Despite the Global Fund's evolving commitment to community engagement and leadership, communities of people living with and most affected by HIV in Eswatini have historically been sidelined during Global Fund grant development and implementation processes. People living with HIV were involved in the process of developing the Global Fund funding request for the period 2021-2023 for the first time. However, while this provided an opportunity to voice community priorities – some of which were included in the grant – communities continued to feel sidelined during the implementation of the grant, and the process has not met their expectations of, and entitlement to, investment in community leadership.

Most community-based and led organisations (CBOs/CLOs) in Eswatini are small and do not meet the eligibility criteria to apply to be sub-recipients (SRs), responsible for implementation of the grant. They have also been side-lined in the process of choosing SRs and agreeing the terms of reference for these organisations – including how they would be expected to engage with, build the capacity of, and promote the leadership of CBOs/CLOs. The SRs tasked with delivering the 2021-2023 grant in Eswatini are NGOs that do not work directly with communities on the ground and are not felt to represent those most affected by HIV.

Despite attempts by CBOs/CLOs to negotiate ways of working together, there has been a failure by grant recipients to engage with them, and a lack of transparency and accountability towards them. This has resulted in a situation of mistrust, where communities were reluctant to engage in the process leading to the next funding round, because they felt that the Global Fund was not working for them.



Support through CLAIM has enabled PWTA to hold regular community forums with women living with HIV to discuss issues and gaps in the current grant's implementation and priorities for the new funding round; and to act as a liaison between community representatives on the Country Coordinating Mechanism (CCM) and communities of people living with HIV.

Despite this, as the Global Fund Grant Cycle 7 (GC7) approached, there was a sense of disillusionment and disengagement from the people living with HIV community, who felt that there was no point being involved in developing the funding request for GC7, that nothing would change.

To address this, the Global Fund provided technical assistance, led by PATA (an independent organisation based in South Africa), to enhance community engagement in GC7. PWTA formed a task group of CBOs and CLOs representing people living with HIV and key populations, as well as communities affected by TB and the organisations implementing the current Global Fund grant. This provided a platform for all affected communities to ensure their priorities were included in the GC7 funding request. The priorities agreed through the process included community-led research, monitoring, and advocacy, and capacity building for CBOs/CLOs, and the re-establishment of a national umbrella network of people living with HIV.

Learning:

CLAIM supported PWTA to convene civil society in Eswatini to challenge the ways in which CBOs and CLOs had felt sidelined in Global Fund mechanisms and processes. This was a major step towards developing a process and structure that genuinely creates space for and is accountable to community.

The technical assistance requested by PWTA created an opportunity for constituencies affected by HIV and TB to come together in their diversity and agree on a set of priorities. It provided space for the community to air their grievances, and to be listened to and heard by the principal recipients and members of the CCM in Eswatini with support from the Global Fund Secretariat and country team.



The resulting Funding Request and Community Annex that were submitted to the Global Fund were more strongly inclusive of costed community priorities than previous grants submissions – areas relating to community systems and responses were particularly well represented.

There is still a question mark around whether and how CBOs/CLOs will benefit from these, and whether the funds for these activities will be sub-granted to communities or continue to be controlled by the same organisations implementing the current grant. The process highlighted the importance of making sure there is a capacity building budget for community organisations, not just for SRs implementing the grant.

More still needs to be done to support community organisations to articulate their role in the delivery of HIV and TB prevention and treatment programmes and PRs and SRs in the country need to commit to ensuring that community organisations receive this support.

The <u>Community Forum Guide</u> and other tools used by PWTA are available on the GNP+ website. PWTA can be contacted on <u>positivewomentogether@gmail.com</u> or tel. (268) 76364366



Increasing participation in Indonesia:

Building bridges from grassroots activists to national decision makers

Jaringan Indonesia Positif (JIP), works to improve the health rights of people living with HIV in Indonesia through a peer support system. They are guided by the principle of meaningful involvement and aim to empower people living with HIV to be actively involved in decisions that affect their lives and prospects.

The Problem:

Indonesia is geographically unique – covering two continents, with a population of around 275 million people, spread across five major islands and inhabiting around 6000 other islands. The logistical challenges, time, and costs of bringing people together in person are huge. Before CLAIM was implemented in Indonesia, JIP had a strong structure with local level activists working across the provinces. These activists were aware of challenges within their communities and worked to raise those issues at provincial and district level. JIP was also highly active centrally advocating in national decision–making spaces. However, the structures did not exist to effectively join the two up. Many people were unable to attend the regular regional meetings and, as a result, the needs and priorities of communities at the grassroots were not always raised in national decision–making conversations.



During the COVID pandemic, HIV activists in Indonesia began using virtual tools and platforms to communicate. Although the technology had existed before, this was the first time it was really used in this way. JIP found virtual meetings worked particularly well for them, so once the impact of COVID began to ease, JIP decided to continue holding them.

To strengthen engagement with Global Fund processes, JIP organised meetings and training sessions with their regional secretariats. This helped to build their capacity to act as implementers for the CLAIM project and enabled them to lead and conduct advocacy with policy makers in their regions. JIP activists were already meeting quarterly within their own provinces to raise their concerns with local stakeholders. JIP set up a system of virtual national meetings to sit alongside this, also taking place each quarter. Each of these national meetings follows a hybrid format where participants can join in person or virtually. Representatives from all the provinces can attend the meetings, as well as national JIP staff and, sometimes, other stakeholders are invited too. On average around 200 participants join each quarter. The meetings provide an opportunity for activists to give updates on progress since the last meeting and to share the challenges they are facing. JIP feeds the information gathered during these meetings into its discussions with the Global Fund Country Coordinating Mechanism (CCM) members. By working this way, JIP hopes to: 1) engage the community in global fund processes including the development of the funding request, grant making, planning and implementation; 2) identify and resolve problems faced at provincial level; and 3) ensure regional voices are heard at the national level.

One issue that has been raised repeatedly in the virtual meetings is a problem procuring medicines. Many different provinces have reported problems with local level stock outs. Various systems are used to monitor levels of stock at district level, some manual and some digital and the district and provincial level data is not synchronised. As a result of the stockouts, JIP has receiving reports of adherence difficulties and worsening side effects. To address these challenges, JIP is advocating for one unified digital system that can be used by all the key stakeholders at national, provincial and district level. This could be used for all medicines not just those relating to HIV.

"I am proud of the work that we have done to create systems to link communities and decision makers.

We are now seeing much wider and more meaningful, community involvement than before."

Rosidin Marshall Alharbi, Jaringan Indonesia Positif

Learning:

Each country faces different practical challenges. It is important to adapt ways of working to ensure that these do not become a barrier preventing the meaningful engagement of communities in decision making.

Local activists at grassroot level were encouraged and supported to meet with key stakeholders at district level and to work to find solutions together. They were then supported to address these concerns at higher levels, both provincial and national.

For local level activists in Indonesia, the answer was partly about training to ensure they understood Global Fund processes. Equally important was the creation of a new structure to give those activist regular opportunities to learn about developments relating to the Global Fund and to share their priorities and concerns. Hybrid meetings have been a major step towards broadening participation in Indonesia.

Find out more:

<u>Tips and Tricks for Virtual Meetings</u> and other CLAIM tools are available on the GNP+ website. JIP can be contacted by email at <u>secretariat@jip.or.id</u>



Community Forums in Malawi:

Developing shared advocacy priorities among communities of people living with HIV

Malawi Network of People Living with HIV (MANET+), is the coordinating body for organisations of people living with HIV in Malawi. It works to build solidarity and promote effective networking among HIV organisations. One of its key goals is to encourage the meaningful participation of people living with HIV in decisions that affect their lives.

The Problem:

Before CLAIM was implemented in Malawi, MANET+ was already involved in Global Fund decision making processes. MANET+ had participated in the evolution of the Global Fund's country coordinating mechanism (CCM) in Malawi bringing civil society organisations (CSOs) together to give their input into the evolution process and a MANET+ member was vice chair of the CCM oversight committee. However, there was no structure or systems in place moving forward to ensure that the broader community of people living with HIV in Malawi could have a voice in Global Fund processes and be meaningfully engaged in its decision making.



In 2021, MANET+ began holding regular Community Forums. The Forums were designed to facilitate communication and coordination among people living with HIV and, critically, to develop a shared advocacy agenda with clear priorities and recommendations that could be used to influence HIV and health-related processes, including those connected to the Global Fund.

The Community Forums are held four times a year across different regions of Malawi. They allow members of the community of people living with HIV to come together in one place and share their ideas, concerns, priorities, and recommendations for the design and roll out of Global Fund grants. The early Community Forums were attended by an expert who informed the participants about the working of the Global Fund and outlined how the funding cycle in Malawi works and the opportunities for influence, engagement, and oversight.

Subsequent Community Forums provided a vital space for participants to exchange information, discuss emerging issues and strategize collectively. Forums were attended by local and regional representatives of organisations of people living with HIV including the Coalition of Women Living with HIV and AIDS in Malawi (COWLHA), ICW, the youth network (Y Plus), female sex workers and teachers living with HIV. Through the Forums a set of advocacy priorities was agreed upon that MANET+ was able to use in their negotiations to shape Malawi's funding request to the Global Fund that was submitted in March 2023. MANET+ also created an advocacy strategy to ensure that civil society was coordinated and targeted in its advocacy.

The advocacy was successful. Most of the priority issues agreed by the community were included in the final funding request to the Global Fund. For example, one issue that had been raised in the Community Forums was the need for more differentiated service delivery models (DSD) to better reach vulnerable populations. MANET+ developed detailed guidelines on DSD to support this advocacy goal and worked alongside government and other stakeholders to help to draft sections of the funding request to include DSD models. As a result, the next grant from the Global Fund is set to include money to maintain and expand existing differentiated services (such as drop-in centres and teen clubs) as well as establishing new ones, including community anti-retroviral treatment distribution points.



"CLAIM has enabled us to be more strategic. Working together as one community of people living with HIV, we have been able to ensure that our priorities are included in the next Global Fund grant."

Lawrence Khonyongwa, Executive Director MANET+

Learning:

The networks of people living with HIV in Malawi are under-staffed and under-resourced. Despite this, through CLAIM, MANET+ has shown it is possible to bring civil society together to advocate with one voice and to successfully influence national decision-making processes. The key steps in the process were first to inform the community about Global Fund processes. Second, to hold regular community forums including representatives from as many diverse organisations of people living with HIV as possible. And finally, to develop a shared advocacy set of advocacy priorities and an accompanying advocacy strategy.

Find out more:

The <u>Community Forum Guide</u> and other tools used by MANET+ are available on the GNP+ website. MANET+ can be contacted on <u>manetplusmw@gmail.com</u>

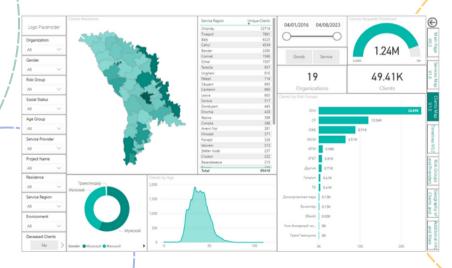
Evidence-based advocacy in Moldova:

Using data from the HIV scorecard to shape policies and programmes

Positive Initiative is an organisation of people living with or affected by HIV in Moldova. It works to bring all relevant stakeholders together to strengthen community systems and influence public opinion and policy. Their vision is an environment where human life is valued and everyone, regardless of their vulnerability, has the rights and opportunities needed to lead a decent life.

The Problem:

In 2021, a new tool was introduced to monitor the HIV response in Moldova – the HIV Scorecard. The scorecard was developed by the UNAIDS Country Office and Positive Initiative and other local civil society organizations with support from the Ministry of Health, Labour and Social Protection and the National Programme for the Prevention and Control of HIV/AIDS and Sexually Transmitted Infections. It was created to ensure open, transparent, and collective state and community-led monitoring of the HIV response, producing real time data. The tool allows health programme managers, organisations working in the field of HIV, communities, and other stakeholders to monitor the effectiveness of HIV-related programmes and to share best practices. The data gathered via the Scorecard can be used for reporting and to set national priorities. In 2022, the community also started using Business Intelligence tools to help with the data collection and analysis. With access to all this new data, Positive Initiative had to develop systems to ensure that the data was used to shape their advocacy and create more effective prevention, treatment, and retention services.



In Moldova, civil society engage with Global Fund processes through a body called the Committee of Key Affected Populations (CKAP). Positive Initiative held training sessions for members of CKAP to strengthen their capacity to interpret and use research findings and data. Using the data from the Scorecard, Positive Initiative was able to see which services and goods were most in demand among various populations and use this evidence to decide on their advocacy priorities.

For example, Positive Initiative piloted a new service providing preventative tools for non-injecting drug users. By analysing the data, they were able to adjust the pilot and increase its effectiveness without waiting for it to be completed. The data has also been used to monitor HIV treatment adherence. The Scorecard collects information on the reasons why people discontinue taking antiretroviral treatment. This data can be used to adapt services and improve adherence rates.

Community representatives took part in discussions that led to the development of the municipal programme on HIV/AIDS and sexually transmitted infection prevention and control for 2022-2025. Data from the Scorecard showed that a large number of people accessing HIV prevention, care, and support services, concentrated in the municipality of Chişinău, needed a wider package of services that were not covered by existing funding. As a result, community representatives successfully advocated for the municipal programme to include funding for these additional services for key affected populations.

In 2023, community representatives were involved in the development of the next funding application to the Global Fund. They used data from the Scorecard to decide what to include in the funding request and to show which interventions are most likely to be effective.

"The new data has been a game changer in our fight against HIV in Moldova. It allows us to see in real time where our efforts are ineffective or effective and what is most needed, enabling us to adjust our strategies quickly. With this tool, we are not just collecting data; we are using it to save lives and improve the quality of life for those affected by HIV."

Alina Cojocari, Positive Initiative



Learning:

Real-time data and modern data analytics tools have combined to become a powerful instrument for advocacy, planning, and improving the provision of vital services to key populations and people living with HIV in Moldova. Certain factors have been key to this success:

- Before any data collection begins it is important to consider how the information will be used.
 This enables the right decisions to be made about what data to collect and what tools.
- The data must be disaggregated to enable a more detailed understanding of the HIV response and the experiences of different populations. It must also be depersonalised so that confidentiality is maintained.
- Data collected in real-time is particularly valuable. It allows for rapid strategy adjustments, improvements to processes, and an overall increase in the effectiveness of programmes.
- Community training in the use of data is crucial. It enables community representatives to make evidence-based decisions about their work and their advocacy priorities.

Find out more:

The <u>Community Forum Guide</u> and other tools used by Positive Initiative are available on the GNP+ website.

Advocating for evidenceinformed interventions in Nigeria:

Learning from the People Living with HIV Stigma Index

The Network of People Living with HIV and AIDS in Nigeria (NEPWHAN), is the coordinating body for organisations of people living with HIV. It works to empower, strengthen, and coordinate all support groups, State networks, constituencies, associations, and organisations of people living with HIV and AIDS in Nigeria to contribute meaningfully to the national response.

The Problem:

NEPWHAN is actively involved in community-led monitoring and has implemented the PLHIV Stigma Index study to measure levels of stigma experienced by people living with HIV in the county. NEPWHAN has also taken on a significant role in the Country Coordinating Mechanism for the Global Fund, representing communities of people living with HIV. However, these strands of work were broadly separate before CLAIM was implemented in Nigeria and the concerns highlighted through the Stigma Index were not being addressed through Global Fund grants.

Change:

In 2022, NEPWHAN began holding Community Forums to bring together people living with HIV to discuss their experiences of seeking healthcare and to identify their needs. The Forums were designed to improve communication and coordination among people living with HIV, and to develop a shared advocacy agenda with clear priorities and recommendations that could be used to influence HIV and health-related processes, including those connected to the Global Fund. In November 2022, a two-day meeting was held, bringing together people from a wide range of communities living with and affected by HIV and key populations including ASWHAN, APYIN, the Key Population Secretariat, DHRAN, Youth Rise, I-Heal, No More AIDS, and other groups from the LGBTIQ+ community and people who use drugs. During the two-day meeting, participants were given detailed information about the Global Fund and how it works, including a presentation on the "Grant Cycle 7" process (known as GC7). There were also discussions around the findings of the PLHIV Stigma Index Survey 2.0.



In addition, community leaders from all the States in Nigeria were brought together in two regional meetings – one in the north and one in the south – to be given detailed information about GC7, the activities proposed in the grant and their potential roles in implementing the grant. All the diverse community representatives at the meetings worked together to review the findings of the PLHIV Stigma Index survey and identified essential and innovative programmes for scale-up that speak to the needs of people living with HIV and key populations. The meeting culminated in a session that looked at all community priorities and began to develop one shared advocacy agenda and a strategy for how to influence Global Fund processes in Nigeria.

In February and March of 2023, there were a series of GC7 meetings in Nigeria to discuss community priorities for inclusion in the next funding request to the Global Fund. Drawing on the work that had begun the previous November, NEPWHAN helped to bring together representatives from diverse communities living with HIV and key populations. Together they identified a list of challenges facing people living with HIV that they wanted to see included in the next Global Fund grant for Nigeria. For each of the concerns that they raised they also proposed specific interventions.

For example, one of the findings of the Stigma Index research was that some people living with HIV were reluctant to access health services because of the unethical conduct of some healthcare workers who do not respect their right to confidentiality and disclose the HIV status of their clients. The 2021 Stigma Index Survey reported that more than 25% of respondents experienced HIV status disclosure without their consent. To address this, one of the interventions that was recommended by community representatives for inclusion in the new Global Fund grant was the development and integration of training materials for rights-based, gender-sensitive and people-centred services into pre- and in-service training of all health-care providers. This was just one of the interventions that communities succeeded in getting included in the final request that was submitted to the Global Fund.

Learning:

"We were able to make a clear argument based on our own evidence of the experiences of people living with HIV in Nigeria." Abdulkadir Ibrahim, NEPWHAN

NEPWHAN has been involved in many initiatives to monitor services and better understand the experiences of people living with HIV in Nigeria. This project has shown how important it is to use the evidence gathered through this work to try and improve the lives of people living with HIV. Using the data from the Stigma Index survey, NEPWHAN was able to identify problems with existing healthcare services for people living with HIV and advocate for new interventions to address those problems. By engaging with Global Fund processes, NEPWHAN has also found a source of funding for the new interventions.

Civil society came together very effectively in Nigeria during the GC7 processes. Not only were people from all the States consulted but also leaders of key populations and diverse communities of people living with HIV were engaged in the dialogue. They were able to develop one shared advocacy agenda and, as a result, a stronger voice in the negotiations.

NEPWHAN played an important part in bringing civil society together and ensuring that communities of people living with HIV had all the information they needed to understand, and fully engage in the GC7 funding request process.

Find out more:

The <u>Community Forum Guide</u> and other tools used by NEPWHAN are available on the GNP+ website. NEPWHAN can be contacted on tel.: +234 (0) 803 548 0141 or via their website <u>www.nepwhan.org</u>



Building a case for differentiated service delivery models in Pakistan:

Community engagement in Global Fund processes

The Association of People Living with HIV and AIDS in Pakistan (APLHIV), works to improve the quality of life of people living with HIV, affected by HIV, associated populations, the TB community, people infected and affected by TB and associated key populations and their families, ensuring their active participation in society and contribution to the HIV and TB responses.

The Problem:

During the COVID-19 pandemic, health systems were under immense pressure, and communities became increasingly involved in service delivery, adapting traditional ways of providing HIV treatment and support services to ensure that people living with HIV continued to have access to the healthcare they needed. It became clear that there were many advantages to offering more differentiated service delivery (DSD) models, but the structures were not in place to allow this.

Change:

In 2021, APLHIV decided to produce some guidelines on DSD models for Pakistan. A consultant was employed to research the different options and a Consultative Forum was created to offer guidance – this involved people living with HIV, advocates, leading members of key populations, community-based organisations working on HIV prevention, civil society organisations and other stakeholders including representatives from UNAIDS, World Health Organisation (WHO) and the United Nations Development Programme.





The guidelines were finalised and launched in October 2021. By following a thorough and inclusive consultative process, APLHIV was able to secure the endorsement of all the key civil society stakeholders as well as representatives of the National AIDS Council and the Ministry of Health.

APLHIV then undertook a series of activities with two main aims: to improve understanding of DSD models of service delivery; and to educate key stakeholders about Global Fund processes. The first step was a training session for all community-based organisations (CBOs) engaged in service delivery for Global Fund grants, as well as representatives from civil society organisations (CSOs), and members of the Global Fund's Country Coordinating Mechanism (CCM).

The training explained the rationale behind DSD models and the importance of adopting a DSD approach in Pakistan. Next, APLHIV produced two case studies, highlighting areas where differentiated models are needed, and shared these widely with decision makers. Then regional workshops were held to inform community activists about Global Fund processes within Pakistan and opportunities for engagement in decision-making. Alongside this, APLHIV worked to strengthen the Pakistan CSO Partnership Forum. By holding national and provincial level workshops, they were able to strengthen alliances between members of the Forum and their representatives in the CCM.

In early 2023, Pakistan began the process of developing a funding request for its next grant from the Global Fund. APLHIV coordinated a comprehensive consultative process for civil society, involving around 300 people from across the country. This led to the development of a joint advocacy report and strategy. Following this, civil society representatives were actively involved in the funding request development process. Almost all the key priorities highlighted in the report were included in the final country funding request submitted to the Global Fund. Significantly, this included a request for funds to provide antiretroviral medications through CBOs, continuum of preventive care sites and API HIV themselves.

"We are proud to have organised our biggest ever consultation and to have seen all the community priorities that were agreed included in the funding request."

Asghar Satti, National Coordinator, APLHIV

Learning:

APLHIV took the time to develop a persuasive case for DSD service delivery approaches in Pakistan. The guidelines they produced were the foundation of all their advocacy. Using these guidelines, they engaged with stakeholders and persuaded them of the advantages that DSD approaches could bring.

APLHIV also worked strategically to engage representatives from the community of people living with HIV and key populations in Global Fund processes. Consultations were held throughout different regions of the country and determined efforts were made to ensure that diverse communities were represented. Trainings were an important part of the process, ensuring that people had the knowledge and skills needed to be active participant in the decision-making process.

Find out more:

Tools to support community engagement in Global Fund processes used by APLHIV are available here on the GNP+ website.

APLHIV can be contacted on info@theaplhiv.org.pk or tel. +92 51 0800 22209



COMMUNITY-LED ACCOUNTABILITY INFLUENCE AND MONITORING



