# Post Test Clubs in Nairobi, Kenya
## towards a model for PLHIV grassroots support



MEDECINS SANS FRONTIERES
ARTSEN ZONDER GRENZEN

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*Report prepared by Médecins Sans Frontières (Belgium),*

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# CONTENT

# EXECUTIVE SUMMARY

In the nineties, Kenyan People Living With HIV/AIDS (PLHIV) started to organize themselves in support groups, ready to provide psychosocial support to their peers. These first Kenyan groups were set up and managed by (health care) professionals, not by the PLHIV themselves. As prices of antiretrovirals (ARVs) began to drop and became available for a much larger group of people, PLHIV became active advocates for scaling up access to treatment. MSF-Belgium, active in Kenya since 1996, supported the cause of these (grassroots) groups. To break with the past of self-help groups aiming for (mainly) material support, the name "Post Test Club" was adopted.

The PTC is a community based association of volunteers affected by HIV, who support one another in daily life. PTCs provide psychosocial support to peers, channel HIV-related information and health education to PLHIV, link up with the health clinics (for referrals, health talks, defaulter tracing), engage in advocacy work and participate in health promotion activities. Most PTCs share a set of standard characteristics: they organize regular meetings, are registered as Community Based Organisations and lack budgetary means.

Today over a 100 PTCs exist. Many have organised themselves in one of two networks: NNEPOTEC or KIPOTEC. These give a direction and a clear identity to PTCs. They help to harmonise working practices and act as an intermediary between members and external partners and organisations.

None of the PTCs or networks has received government recognition so far. This despite the fact that over the past years the Kenyan government has increasingly recognized the importance of involving PLHIV in the fight against HIV/AIDS on a community level. The PTC networks consider such recognition of crucial importance, initially to be able to promote Treatment Literacy for the benefit of PLHIV and communities in general.

The Nairobi PTC experience can be regarded as a model. No similar network of independent PLHIV grassroots organisations, created in a poor urban environment, exists elsewhere. Their strength lies in empowering their mostly disadvantaged members to become passionate activists, not only in their communities, but also on higher governing levels.

Having PTCs and their "expert patients" contribute to the delivery of (chronic) healthcare, and providing them with the means and resources for it, could turn out to be very beneficial for the under-resourced national health system, if it wants to cope with the ever increasing burden of HIV.

However, the PTCs experience is still young and many challenges remain: most PTCs are not yet sustainable in the long run. They often lack vision and identity, capacity and good leadership, but are also challenged by a lack of funds and the fact that they are purely volunteer-based. They need to build up their networking skills, install monitoring and evaluation procedures and develop the PTC networks further. Throughout, HIV/AIDS must remain the core of their mission.

# OBJECTIVE OF THIS DOCUMENT

The active participation of people living with a chronic disease in the management of their condition is a cornerstone of the care process. As such, the role of People Living With HIV/AIDS (PLHIV) in providing peer support has been widely accepted and encouraged in many countries across the world.

But PLHIV need (to do) more than that: they need to be aware of and advocate for access to the best possible care. This means for them to have access to up-to-date information, including policies regarding HIV, and access to counselling and support to help them manage their condition and adhere to treatment. Sharing experiences with others can be eye-opening, leading to a different approach in living with HIV/AIDS.

The Post Test Clubs, initiated in 2005 in Nairobi, have shown to be interesting platforms to deal with some of these challenges. Because of their unique place in between the community, the patients and the care providers, they have shown to be active players in the care process, health education or psychosocial assistance.

Though because these PTCs have not existed for a very long time, much more needs to be understood about the needs and roles of these patient groups in their environment, and this from the point of view of the community, the care providers and the patients themselves.

With this report we aim at:

- a better understanding of PTCs by identifying their current role(s), vision and activities;
- identifying strengths and challenges of PTCs;
- drafting recommendations on the possible improvement of PTC functioning, the participation of partner organisations (care givers, communities, donors…) and see if a possible replication or scaling up of the PTC model would be desirable.

The fight against HIV/AIDS remains a critical challenge for Kenya. The active involvement of people infected and affected with the virus is crucial to successfully achieve the country's development objectives.

> *"We are the problem -*
>
> *We are the solution"*
>
> *- PTC leaders*

# 1. HISTORY

## 1.1    HIV/AIDS in Kenya

Like many other countries in Sub Saharan Africa, Kenya has been severely affected by HIV/AIDS. The first case of AIDS was diagnosed in 1984. Since then HIV/AIDS has been detected in all parts of the country. The impact of the disease on the population and on the entire economy has grown tremendously over the years. Consequently the progressive improvement of the health status of the population has been halted and started to deteriorate by the early 90s.[1]

The national prevalence of HIV/AIDS in Kenya is thought to have peaked in 1996/1997 at around 9%, and the urban prevalence peaked in 1995 at around 14%.[2,3] In 2006 the adult HIV prevalence (15-49 years of age) in Kenya was estimated at 5.1%, down from 6.8% in 2003. HIV prevalence varies markedly throughout the country with the highest prevalence in 2006 found in Nairobi, the capital city (10.1%), followed by Nyanza province (7.8%).[4]

In 2006 it was estimated that 934,000 people were living with HIV in Kenya, 102,000 of who were children under 15 years of age. Approximately 66% of adults living with HIV in Kenya in 2006 were women. An estimated 85,000 adults and children died of AIDS in Kenya that year, and the living orphan[i] count was 2.4 million.[4]

The proportion of PLHIV receiving antiretroviral (ARV) drugs is increasing. By April 2007, 56% of the estimated 250,000 people in need of ARVs received the drugs. In 2003 this percentage was only 4%. By the end of 2008, the government expects to have 200,000 people on antiretroviral treatment (ART). With so many people on treatment, the country's health systems will need to be reinforced and restructured, ready to tackle chronic diseases. The involvement of patients in the battle against the virus will be the cornerstone of a successful strategy.[5]

## 1.2    From Support Group to PTC

The first support groups for PLHIV were created in the US in the early eighties. These groups of volunteers were organised at the local level to educate their communities on HIV prevention and to care for those living with the virus, through psychosocial support and the mobilisation of "buddies". They were based on the concept of Patient Support Groups (PSG) for major chronic conditions such as arthritis and diabetes, or self-help groups like Alcoholics Anonymous.

In the nineties, Kenyan PLHIV support groups started to see the daylight, set up and run by "professionals" (counsellors, nurses, religious leaders, or even NGOs), based on the perceived "needs" of patients in their clinics. Members however, were rarely involved in the running of the group. It was also a time when ARVs were not or scarcely available. To date, there continues to be little participation from PLHIV. Support groups are known for their food incentives, which is the main motivation for people to come.

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[i] Orphan meaning having lost one or both parents.

With the reduction of ARV prices early 2003 and the subsequent availability of the drugs for a much larger group of people, HIV became a chronic disease. At the same time, more and more patients started to disclose their status in public. They felt the desire to form activist groups to defend their cause for treatment and care, thereby catalyzing the process of stigma reduction.[6]



A small group who spearheaded public testimonies, decided to form the Kenya Organization of People Living with HIV/AIDS (KOPLWA)[6]. New groups quickly followed, such as KOYLWA, SIPHOG and PETAC. Members of these support groups which were all based in the informal settlement of Kibera, became very active advocates: they started door to door activities, provided health talks in clinics and organised awareness raising activities in their community.

The Belgian section of Médecins Sans Frontières (MSF), active in Kibera since 1996, supported the idea of genuine grassroots groups and has since been encouraging their activities in the form of Treatment Literacy and other trainings. To indicate a clear change of vision between the support groups, mainly driven by external actors and focused on material support, and these new groups formed by and characterized by the active involvement of PLHIC, the name Post Test Club (PTC) was chosen.

Together with PLHIV, MSF was able to reach the community in bigger numbers and with better ambassadors. The emphasis lay on active involvement of the HIV positive person: he or she would be in charge of running the group, allow members the freedom to express themselves and grow, and therefore have more relevance to the people around them. MSF wanted to get them out of the hospital, and into the community.

Generally destitute, often low-literate and suffering from a life-long illness, the PTC members would be enabled to better self-manage their health and that of their community. Through the education and empowerment of patients and PTCs, MSF aimed

to contribute to improved disease prevention, health care and support for PLHIV and their communities in and around Nairobi.[7]

## 1.3    MSF involvement

MSF has been running HIV/AIDS care clinics in different parts of the world since the 90's, and has currently around 100,000[8] patients on ART in its projects worldwide. In Kenya, MSF has been running HIV projects in Nairobi and Western Kenya.

The MSF HIV programme in Nairobi started in 1996 at a time when ARVs were largely available in western countries, but inaccessible in high prevalence countries due to the prohibitive cost of the drugs. During these first years, MSF ran a program of psychosocial and palliative care in the major slums of the capital (including Kibera) and in Mbagathi District Hospital (MDH).

A home based care programme had to ensure the links between community and health centres via community nurses, by training community health workers who would visit PLHIV and refer them in case of need, and by working with family care givers who assured daily care for PLHIV at home. Counselling sessions would reduce stress and anxiety and help PLHIV to plan their future, promote positive living and preventive behaviour change. For this, MSF collaborated with a local NGO, the Kenya AIDS Society (KAS), specialised in psychological (peer) support.[9]

MSF organised patient groups inside its clinics, presided by consultants, but these were far from formal. People visiting the clinic would be invited to join in, resulting in very heterogeneous groups coming together for a psychological support session.

With ARVs becoming widely available, MSF shifted its program towards a mainly curative approach of the disease in early 2003. The care system in the clinics was due for a paradigm shift from acute to chronic care. New approaches for dealing with patients needed to be adopted. Care procedures in the clinics needed to be changed (appointment books, patient record files…). Patients (and carers) needed to be educated on adherence, side effects of drugs etc. Communities had to be informed and educated as to reduce stigma. The PTCs were seen as a possible interface between the different stakeholders and MSF started to encourage its patients to join and/or create a PTC of their own.[7]

## 1.4    Towards an independent entity

Today, over a hundred PTCs exist throughout Nairobi (and even beyond), many of which have organised themselves into a networks: either KIPOTEC (Kibera Network of PTCs) or NNEPOTEC (Nairobi Network of PTCs). The idea of networks emerged when large PTCs split up into smaller groups, and felt the need to maintain contact.

Among the PTCs, MSF has identified and trained dozens of people to become so-called "expert patients": they facilitate Treatment Literacy trainings for PLHIV, attitude trainings for targeted community groups, carry out and coach other PTC members to give health talks in waiting bays.[7]

We have now come to a point where the PTC development has either the potential to grow in the direction of a more sustainable, independent and reliable actor in the provision of information, support and care, or to remain a fragile and unstable movement depending on the motivation and efforts of a few individuals. The will and the dynamism are clearly present among these often-disadvantaged groups of people, but the funds, vision and skills to achieve well-defined targets are largely lacking.[7]

## 1.5    Government approach

The empowered, participatory approach is one of the core principles of the Kenyan National HIV/AIDS Strategic Plan (KNASP). It focuses on the involvement of PLHIV at the highest levels in the development and coordination of the HIV/AIDS response; strengthening the capacity of PLHIV organisations to be involved in prevention, treatment and care and initiatives to lessen socio-economic problems; and supporting the creation of representative and effective PLHIV organisations at all levels.[3] A guiding principle has been the Greater Involvement of People Living With HIV/AIDS (GIPA)[ii]. The Kenyan government committed itself to several international GIPA agreements, and is one in only five countries that has drafted GIPA guidelines.[10]

To this avail, the National AIDS Control Council's (NACC)[iii] reformed its overall structure through the establishment of 210 CACCs (Constituency AIDS Control Committees). The goal of the CACCs is to have total mobilization of communities in Kenya, within each Constituency, for active involvement in prevention of new HIV infections, mitigation of socio-economic impact of HIV/AIDS as well as providing care and support for people infected and affected by HIV/AIDS. With the declaration of the Total War Against HIV and AIDS (TOWA), CACCs play an important role in the fight against HIV/AIDS as they are the entry points to the community.[11]

The government is now also using "expert patients" in its health centres and training some of them as community health workers. Grassroots organizations are even to some extend implicated in the higher decision-making process: the National Empowerment Network of PLHIV in Kenya (NEPHAK) is a member of the second highest decision-making organ of the national response to HIV/AIDS: the Inter-agency Coordination Committee (ICC), and has two PLHIV as members statutorily.

However no other PLHIV organisation has so far received government recognition. There are few mechanisms permitting or encouraging PLHIV experiences, perceptions and skills. This is partly because no major global, regional or national campaigns have yet been carried out to raise awareness and understanding of GIPA.[12]

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[ii] Basically, GIPA means 1/ recognizing the important contribution people infected or affected by HIV/AIDS can make in the response to the epidemic and 2/ creating space within society for their involvement and active participation in all aspects of that response. There is a recent trend towards MIPA (Meaningful Involvement of PLHIV), but in this document we will stick to GIPA as it originally was the guiding principle.

[iii] In Kenya, NACC coordinates all activities and organizations that deal with HIV/AIDS.

HIV/AIDS has changed how the community experiences health. While at first people felt they had no role to play (it was up to the experts), PLHIV are now starting to see the essence of participating in health issues (they have become the experts).[13] They should be treated with respect by the local health office and accepted as experts who know better than many health workers the drivers of risk behaviour, and the barriers to access prevention, care and treatment in their local environment.[14] PTCs are the perfect example of GIPA in action, and should be promoted by the government as such.

# 2. THE PTC MODEL

## 2.1    Concept

The Post Test Club is an association of volunteers who are infected with HIV and who support one another in life. They meet to share information and experiences which help them to take care of their own health and deal with issues such as stigma and discrimination. PTCs encourage PLHIV to be active in improving their quality of life. PTCs foster the spirit of "volunteerism" through the GIPA principle.

People living openly with HIV/AIDS are well placed to provide ongoing assistance to those who test positive, as they had to address all the "living positively"[iv] issues themselves under similar circumstances. People who test positive need repeated assurance that they can live many years without any symptoms and, with treatment, many more years after that. They need to know they can remain in control of their own lives and regain their self-confidence and dignity.[15]

At the same time, PTCs can offer public awareness about HIV/AIDS, fight stigma and provide powerful advocates in the community for effective prevention campaigns, for psychosocial support to the newly diagnosed, and educating families and communities on how they can support people to take ART. At the health clinic level, for example, PTC members are giving "Health Talks" (HT) in the waiting areas. Most topics covered are related to HIV/AIDS.

Not all people who test HIV positive are able to become a resource in their community, but many do and contribute to reducing the stigma associated with HIV by being open about their status.

PTCs benefit individuals and society more broadly by:

- ◆    providing psychological support, especially to newly diagnosed clients
- ◆    giving information and health education to PLHIV
- ◆    linking up with the health clinic (for referrals, Health Talks, defaulter tracing)
- ◆    involving in Treatment Literacy trainings (both as trainees and as trainers)
- ◆    participating in health promotion activities
- ◆    engaging in lobby and advocacy activities
- ◆    giving feedback on activities to health facilities and partners

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[iv] As a result of medical advances, PLHIV are now able to live healthily with the disease. HIV/AIDS is a major medical condition, but is not necessarily a death sentence. Having dependable sources of counselling and (peer) support can help PLHIV lead a happier, more fulfilling life.

## 2.2     Organisational set-up

Depending on whether or not they have been registered as a Community Based Organisation (CBO)[v], the PTCs are organised very differently. CBOs are required to have a set management structure and have a certain amount of members, while non-registered PTCs can choose their own set-up. A large number of the latter only have a PTC leader (elected or nominated). Those who organise income-generating activities (IGA) or have another (small) source of income may also have appointed a treasurer.

PTC members are recruited in different ways: via Health Talks at the clinics, through referral by the clinic counsellors, via word of mouth and through poster campaigns.

A majority of the PTCs have joined together in a formal network, in order to share updates on treatment and care, learn from each other and support each other in activities. Existing networks are NNEPOTEC and KIPOTEC which link over 80 PTCs in Kibera and other parts of Nairobi. Both networks are registered as CBOs and are financed through small membership fees. There is also NEPHAK, which is much larger, and aims to unite all kinds of PLHIV support groups. Up to date, it is the only PLHIV network recognized by the government[16] and other donor funding agencies, willing to support PLHIV.

↘ **KIPOTEC** (°2006) is a well-organized network (it has the advantage of working in a small area) of approximately 30 PTCs within Kibera, with an elected executive committee (no board), regular meetings and with member PTCs that conduct activities together. KIPOTEC is owned by all PTCs affiliated to it. KIPOTEC is affiliated to NEPHAK.

### KIPOTEC Structure



*Dashed lines indicate part of structure which is not yet in place.*

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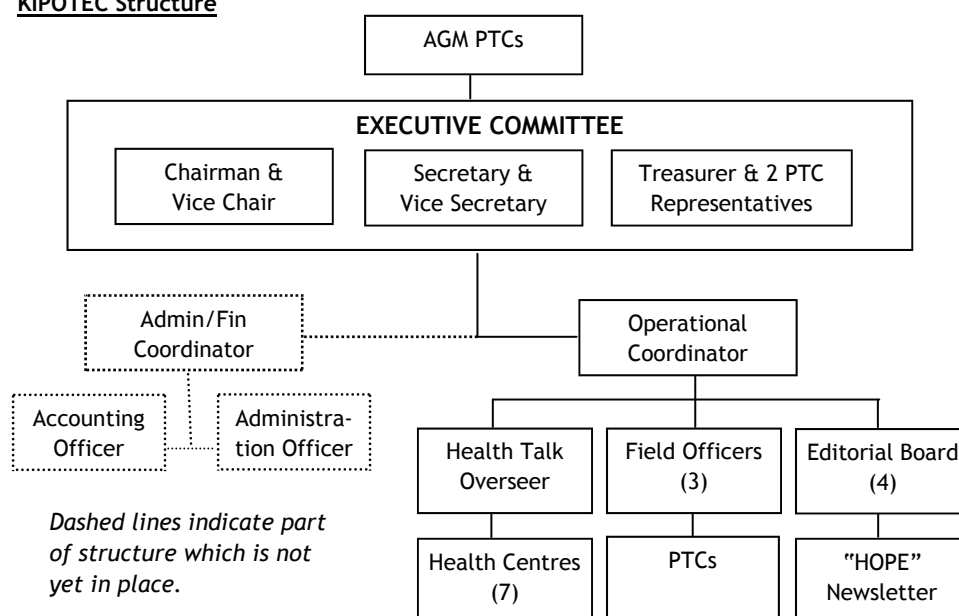
[v] CBOs are formed when people in a community come together in self help activities for development. Projects of the CBOs often yield immediate results because they are planned and executed by the very people who feel the needs. This should ensure sustainability of the projects.

KIPOTECs role is to:

- inform, assemble and coordinate Kibera PTCs
- liaise with members via PTCs (not with individual members).
- work with organisations to get funding
- be a motor for awareness raising activities
- be a resource centre/mentor for PTCs
- work on lobby and advocacy and act as a watchdog



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KIPOTEC has divided Kibera into three zones. Each of the three **volunteer field officers** is in charge of a region and visits PTCs on behalf of KIPOTEC. If the network wants to send a message to the PTCs, the **operational coordinator** will contact the field officers, who in turn will inform the PTC leaders or bring the message directly to PTC meetings. This way messages trickle down to members in an efficient way. The field officers also respond to small conflicts.

KIPOTEC coordinates Health Talks in seven facilities across Kibera. In each centre someone has been put in charge of HT. His/her task is to draft a monthly schedule and report to the overseer, who in turn report to the coordinator. The **Health Talk Overseer** is in charge of coordinating the Health Talks. He/she also checks whether the Health Talks are taking place and if they are conform to the program. All of this is done in agreement with the health facilities.

The **Editorial Board** consists of an Editor in Chief, vice Editor and two members. They produce a quarterly newsletter "Hope", to document PTC activities and highlight events in the Kibera community. All PTC members are invited to write texts and participate. The newsletter is distributed among members, partner organisations and stakeholders.

Two **volunteers** man the KIPOTEC office during office hours to give information upon request. In due time, these volunteers will become the accounting and administration officers, dealing with the networks' finance and administrative issues, under the supervision of an Administration/Finance Coordinator, who in turn will be accountable to the Secretary.

↘ **NNEPOTEC** (°2006) is a network with national ambitions, but currently consists mainly of Nairobi based PTCs. The network is a regulating and supervising body of member PTCs. Its main purpose is to empower PLHIV by providing them with information on HIV/AIDS and GIPA issues, and representing them at a national level. It also aims to monitor the PTCs and help out in conflict situations. Currently 54 PTCs are officially registered with NNEPOTEC and rely on the network for factual information on HIV, capacity building (Treatment Literacy, attitude trainings and enhancing leadership skills) and advice. Some 70 others are following NNEPOTEC's activities, but have not registered yet.

NNEPOTEC is linked to the MDH HIV clinic (where MSF is working), as most of its PTC members are receiving treatment and care here. The MDH patients come from all over Nairobi, hence the justification of NNEPOTEC existence as a Nairobi PTC network.

**NNEPOTEC Structure[vi]**
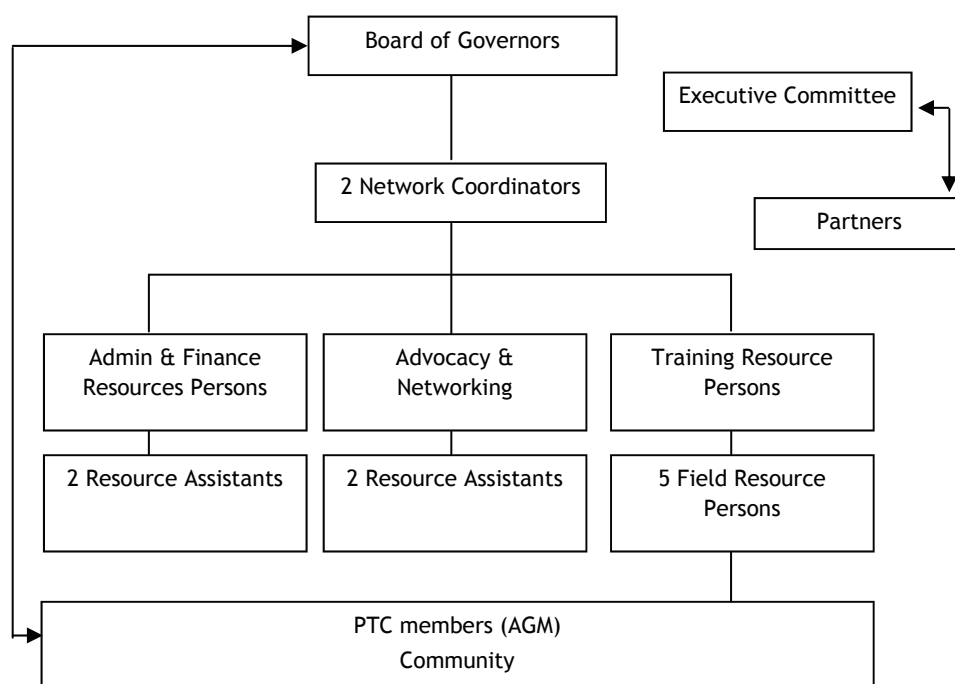


The **Board of Governors** provides technical support to the network and Executive Committee, fundraising for the network and conflict resolution.

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[vi] This is the structure proposed in NNEPOTEC's Strategic Plan 2008-10. Not all of it is yet in place.

The **Executive Committee** creates subcommittees to provide specific technical support and evaluates the activities, ensures stakeholders attend meetings and other forums.

**Network Coordinators** support and devise the implementation strategy, prepare work plans and set priorities. They coordinate the working of the resource persons and oversee the implementation of the activities. They also liaise with the Executive Committee and monitor progress and reporting on network activities.

**Administration & Finances resource persons** will keep the finance and records of all activities, oversee that the activities planned are within the budget. They also provide conflict resolutions for the resource persons.

**Advocacy & Networking Resource person:** Identifies issues affecting PTC members and plans advocacy strategies. Ensures good public relation with partners at all levels.

**Training Resource Person:** Coordinates, organises and implements PTC member and community trainings. Liaises with other partners, administration & finance persons.

**Field Resource Persons:** Organizes and implements member and community trainings.

↘ **NEPHAK** is a non-profit making, voluntary body, by and for PLHIV. It counts PTCs as its members but is not specifically aimed at PTCs. It was officially registered in July 2003, in response to the growing need to bind individual and organizational PLHIV efforts in Kenya. NEPHAK's overall goal is to improve the quality of life of PLHIV through coordination of PLHIV activities in Kenya and act as their voice.

Today NEPHAK is designed as a grassroots movement, responding to the impact of HIV on individual families and communities. NEPHAK has representatives from all the 9 regions/ provinces in the country elected at the last delegate's conference held in September 2004. It provides trainings, funding and assistance to its members.

There is room for more collaboration between the three networks - and especially between NNEPOTEC and KIPOTEC. Instead of complementing one another, there is a lot of misunderstanding and competition.

### 2.3    Activities

↘ *Psychosocial support to peers*

The main PTC activity is providing psychosocial support and information to individuals. Infection often results in loss of socio-economic status, employment and mobility. Counselling and social support can help people and their carers cope more effectively with each stage of the infection, enhance adherence to treatment regimens, improve the quality of life and prevent further transmission of HIV. With ample support, PLHIV are more likely to be able to respond adequately to the stress of being infected and are less likely to develop serious mental health problems.[17]

In PTCs this psychosocial support can take many forms: weekly PTC meetings during which members are encouraged to talk about their ordeals, or visits to the homes of members when they are taken ill. Some people have no social networks outside of the PTCs and rely heavily on their membership. The weekly meetings are also used to increase the members' knowledge about their disease as well as helping them to overcome daily challenges (assertiveness, disclosure, stress management…).

↘ *Treatment Literacy*

Treatment Literacy makes people knowledgeable about their disease and treatment and aware of their rights and the political, economical and social context they live in. It empowers them to become catalysts of change. For example, in South Africa mass support for the Treatment Action Campaign (see p 19) came out of support groups and Treatment Literacy.

> *"Knowledge is power. Learn to get to know everything about the HIV virus and you will manage it better"* - Alice

Self-empowerment in its simplest form means taking charge of your own life, illness and care. People with HIV/AIDS need to view themselves as the experts about what they need. Self-empowerment is best exemplified by an attitude that your life is not over or going to end soon simply because you have been diagnosed with HIV/AIDS. Transforming powerlessness into self-empowerment includes encouragement, and developing the skills for self-sufficiency, while eliminating the future need for charity.

↘ *Awareness raising and community outreach*

> *"Speaking in front of people about my status has helped me to accept it. I can't run away, people come to my house to ask questions. Everybody knows."* - Florencius

From the daily contacts with patients, it has become clear that ignorance and misconceptions regarding HIV/AIDS or related health issues are still widespread and prevent many people from seeking appropriate treatment and/or adhering to it.[7]

One way to implement GIPA and raise awareness is to involve PLHIV in outreach activities (like door-to-door[vii]), help them become "co-care providers", have them offer peer counselling and give testimonies. PTC members are visible in the community. As role models, they show they can live together with others.

PLHIV volunteering to give Health Talks at the clinics' waiting bay are motivated by the idea of sharing their knowledge with the community and reducing stigma. It also encourages them to face their status and talk in front of a crowd. The added value for the patients is that they feel more comfortable because the volunteer is part of the

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[vii] Door-to-door: activity where PTC members go from house to house to explain HIV/AIDS to the inhabitants, to convince them to get tested and to reduce stigma and discrimination.

community, and has first hand experience of what they are going through. An extra advantage is that Health Talks create awareness about the existence of PTCs.

Other outreach activities worthwhile mentioning are the organisation of World AIDS Day, road shows with theatre and dance, body-mapping exhibitions, home and hospital visits...

↘ **Co-provision in care**

With the advent of ART, HIV became a chronic disease. Thousands of people have since been put on life saving treatment, which they will have to continue for the rest of their lives. This is a big challenge for the health systems in developing countries that until now have been dealing mostly with acute episodes of illnesses. To relieve some of the burden, it is crucial that patients (and thus the PTCs) take over some of the responsibilities from healthcare providers. This is possible thanks to more patients becoming treatment literate, and therefore more involved in their disease.

The chronic disease model of WHO[18] proposes a framework for better management of chronic diseases. Health care providers, patients and their family and the community form the building blocks of this model.
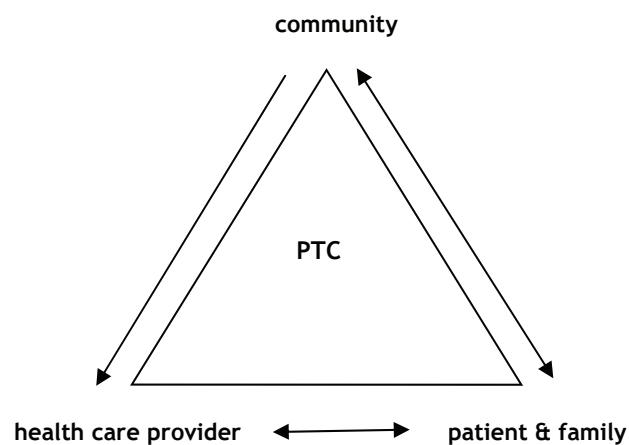


PTC members are being gradually empowered and trained to take on an active role in the management of their disease. Such "expert patients" can prevent patients from returning to the clinic when they don't need medical care and refer them when they show signs of becoming ill.

PTCs have for example engaged in the active tracing of individuals who have interrupted their treatment (defaulter tracing), in collaboration with the health facilities. It is important that these defaulters can be identified early, and are brought back for care.

Quite some PTC members have also been trained by the Ministry of Health (MoH) as Community Health Workers (CHW), since the MoH has been emphasising a shift from facility based health education and care to the community level. CHW follow up on discharged patients, check if people take drugs as prescribed and provide Home Based Care (HBC). Their focus is not necessarily on PLHIV, as they have also been trained to

work with other diseases and conditions. The reality however, shows that PLHIV are their main target group. Because CHW are to form the link between community and health facility, there is quite some role confusion with the PTCs.

Health care workers tend to see the expert patient as a form of competition, and are not always keen on involving them.

↘ *Advocacy and lobbying*

One of the PTC objectives is to lobby and advocate for policies, laws or actions that will advance the cause of PLHIV in Kenya. It is expected that PTC networks will be able to influence the policies and practices of the Kenyan Government

> *"As an activist you need to be prepared to give the truth and be rejected" - Sylvia*

(GoK), development institutions, health care providers and other actors in the development arena, leading to greater impact and appropriate partnership with public health efforts.

Their current focus is to get recognition for TL at national and regional level, and to be acknowledged as PTCs.  PTCs participated in events like the World Social Forum, and take part in demonstrations, commemo-rations and forums to raise issues that affect PLHIV.

Compared to some other countries (see South Africa or Thailand, p 19) PLHIV in Kenya do not (yet) have the same clout when it comes to activism. The main activist group would be NEPHAK, which strongly advocates for[19]:

- ♦ Access to treatment and healthcare
- ♦ Recognition of the rights of PLHIV
- ♦ Capacity building of PLHIV groups
- ♦ Greater involvement of PLHIV in all spheres of the fight against HIV/AIDS.
- ♦ Resource mobilisation
- ♦ End to stigma and discrimination

↘ *Income Generating Activities (IGA)*

Depending on the needs of its members, several PTCs have started Income Generating Activities (IGA). Some make handicrafts for commercial purposes, others have started micro finance projects, owned and managed by the club members.

## 2.4     The PTC in detail

A clear PTC "model" with certain fixed criteria does not exist today. However, most PTCs do share a set of standard characteristics.[viii]

The average PTC consists out of 5 to 20 active members, who usually live in the same neighbourhood or village (70%) and meet three times a month or more (65%). Only 10% of PTCs gathers monthly or less. Members meet in a variety of locations: health centres

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[viii] Results based on the PTC Leader Questionnaire (Dec 2008), 48 PTCs submitted their answers.

(27%), schools (21%), churches (19%) or member's homes (17%). Meetings last an average of two hours.

A person who is HIV positive can join a PTC even if s/he is not ready to be open about his/ her HIV status. PTCs can be arranged for people of different age groups, for young women, men, discordant couples, married couples, widowers, teachers, priests, military and others. The large majority of the members is between 15 and 49 years old, which is also the population group most infected with the virus. The majority is female: this is often explained as less men are ready to open up about their status, more women are infected and less women are employed (and can thus invest time in PTCs).

The big majority of PTCs (83%) does not have a regular income. Those who claim to have an income, generate this from small membership fees and IGA. PTCs are usually linked to a network (89%), whether this be NNEPOTEC, KIPOTEC or NEPHAK (has fewest members).

PTCs do not have to be registered as a CBO to exist. However, more and more PTCs are doing it (75%), in order to become a recognized entity and be able to receive funding.

About 2 in 3 PTCs were created in 2006 or 2007. Some 20% was created in 2005, and 15% already existed (as Support Groups) before this year. Virtually all PTC leaders (95%) believe their PTC will still be active at the end of 2008 and think most of their members are in it for the long term (57%). Those who don't believe in the continuation of their PTC indicate lack of member motivation as the main reason.

As PTCs are evolving, they also start to develop their own agenda, away from the objectives of their support organisation (such as MSF)[ix]. Almost one in four PTCs (23%) has for example started developing income-generating activities (IGA) to provide additional member support.

However, psychological support and group therapy remain the core of PTC activities (31,4%). Treatment Literacy during meetings takes up 18% of the time, while member support (such as merry go rounds, loans & savings,…) uses 17%. When the PTC gets into the community, most of their time is invested in awareness raising and outreach activities, such as door-do-door (33%), followed by home and hospital visits (24%) and Health Talks in clinics (17,6%). Another 10% of their time goes to defaulter tracing. Other recurrent activities include advocacy work (4%) and participating in campaigns and events (4%).

Their vision is mainly centred around empowerment of members (almost 30%) and fighting stigma and discrimination in the community (20%). PTCs generally do not have an outside agenda. Although this is clear when it comes to politics, several do have a religious agenda, mostly those PTCs that are facilitated by churches. Certain topics are being avoided (like condom use or adherence) when religious visitors attend the meetings.

To reach their vision[x], PTCs feel they need additional (financial, material, technical)

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[ix] See p 27 on partner organizations

[x] Several answers to this question were possible (PTC Leader Questionnaire, Dec 2008).

support (50%) and more capacity-building/empowerment through TL, extra trainings and correct information (60%). They also realize they will need more motivation, commitment and cooperation from their members (15%), and more collaboration between PTCs (8%).

Most PTCs collaborate with a number of (partner) organisations (mainly MSF (36%) and Amref (16%)) and health centres (19%), but also with churches, MoH and even the university of Nairobi.

## 2.5     Other models

Similar concepts have been developed in other countries around the world, such as Uganda, South Africa, Malawi or Thailand. However, these PTCs are not always independent grassroots movements, often benefiting from government or other support, and act in an environment that differs from the Nairobi one (very poor urban population).

The PLHIV movement in Thailand for example is a movement of the rural poor, most of whom are farm or factory labourers, housewives or unemployed people. PLHIV groups were first established in the early 1990s as a means of providing mutual support. There are about 600 of them, mostly hospital-based with a nurse supervisor and receiving funding from the Ministry of Public Health or from local government. NGOs and PLHIV groups have played a key role in changing Thailand's response to HIV/AIDS since the first cases were detected over 15 years ago. The increased involvement as co-providers in care has also contributed to a positive change in the attitude of health care staff. A few years ago, health care for AIDS was mainly provided from specialist centres; many staff at district level were unable to provide even basic care. Today, nearly every hospital in Thailand sees it as its responsibility to provide care for PLHIV. Furthermore, there are now greater opportunities for PLHIV to work in health care provision, although this role is not yet accepted throughout the country.[20]

The Treatment Action Campaign (TAC) in South Africa has been working for greater access to ART for all South Africans, by raising public awareness on issues related to the availability, affordability and use of HIV treatments. TAC is an advocacy network, with a unique capacity of mobilising PLHIV for their actions. TAC has not been providing peer support in the traditional "PTC sense", but is a network that has been promoting Treatment Literacy throughout the different layers of society. It has been empowering its members and has an impressive networking capacity (religious leaders, political stakeholders, academics, NGOs, CBOs…). All through, it has also been intensively collaborating with MSF.

Other organizations, such as Lea Toto and IMC in Kenya, have equally invested in independent support groups, but objectives are often very different. While they initially came together to provide peer support, the main activity has shifted towards IGA – and the groups are supported in this by the initiating organizations, for example through providing micro credits or bookkeeping trainings, lessons in candle making or basket weaving. The Lea Toto groups are led by counselors, and show more similarities with traditional support groups than with PTCs.  Some of the groups are also doing outreach activities, such as door-to-door (but once again initiated by the organization and not by the members themselves). Individual interests are often overshadowing those of the community in these groups.

# 3. MAIN SUCCESSES AND CHALLENGES

### 3.1 Activities

The Nairobi PTC experience can be regarded as a model since one will not find a similar network of independent PLHIV grassroots organisations, created in a poor urban environment elsewhere. Their uniqueness lies also in the fact that they are partners in health care and education, and based on volunteerism. Their strength lies in empowering their mostly disadvantaged members to become passionate activists in their communities and on higher levels.

The PTCs and their networks are not a real activist movement yet, such as TAC in South Africa, but neither are they organised by external organisations, such as the (former) patient support groups. The PTC model as initiated by MSF has been followed by Amref in Kibera, who now also partners with PTCs and KIPOTEC.

↘ **Psychosocial support** is the main activity of the PTCs and is also their biggest achievement so far. The challenge lies in finding the right balance between the patients' individual needs, and the needs of the group, or even the community.

↘ To date there has been no coordinated national response to the need for **Treatment Literacy**. A range of organisations are conducting TL for various audiences including patients, health care workers, community and religious leaders. WHO reports that Treatment Literacy is very low and is associated with high levels of stigma among health care workers and the general population in Kenya.[21,22] MSF's experience shows that people who have followed TL will better manage their health and that of their community. PTCs do not have the capacity yet to systematically organise TL, but this could happen gradually. PTCs want Treatment Literacy to be recognized at the national level and to become an essential component of the HIV care package.

↘ Although there is a link between the health care provider and the PTC, this link is not sufficiently defined yet and/or has been instigated by the care providers (mainly). Patients should take a more active role through the PTCs in the wole care process (**co-providers in care**).

Health professionals are overwhelmed with responsibilities that could be shared, to the benefit of both the patients and the services. PTCs, support groups in VCT centers and organizations delivering home based care (HBC) services could and should play a prominent role here.[13] A number of PTCs are already delivering home based support. It is difficult to estimate the success of this aid, but it does confirm one of the objectives of the PTC: being a link between clinic and community.

↘ PTCs feel they have already been at the forefront in terms of **advocacy work** and affecting society, for example by appealing to individuals to change their attitude and behaviour towards PLHIV. Numerous religious leaders have opened their venues to PTC meetings. An increasing number of PLHIV is also going public with their status.

They could however increase their ambitions, and ascend to a higher advocacy/lobby

level. MSF has been introducing PTCs at a district level, and some PLHIV are currently getting more involved at a national level (budget sector hearings, treatment issues). But at the moment only NEPHAK has been identified by NACC as its top-level representative.

A concrete challenge related to advocacy activities and networking, will be the withdrawal of MSF from Mbagathi District Hospital. NNEPOTEC can take up the task of advocating for continued free quality of care for PLHIV (such as free OI drugs, counselling…).

↘ The benefits of IGA in PTCs are generally very low. On top of that, PTCs who only invest in **IGA** activities have no added value for the larger network or the community. PTCs can get involved in IGA, but should be aware that a money based approach to activism does not work.

## 3.2 Sustainability

The considerable investment in health promotion, Treatment Literacy, patient support and PTC capacity-building by partner organisations is to a great extent motivated by a quest for sustainability. Helping PLHIV to become knowledgeable, skilled and outspoken is key for them to manage their life-long disease in a resource-poor setting. This should help them and their communities to take more responsibility
for their own health on a long-term basis.[7]

The continuous scaling-up of PTCs in and outside of Nairobi proves there is a real need and want for PTCs. However, the following factors remain obstacles in the way to self-sustainability:

> *"Don't leave us like orphans in the jungle"*
> *– Bethwell*

- ♦ vision and identity
- ♦ capacity-building
- ♦ leadership
- ♦ volunteerism & member participation
- ♦ funds
- ♦ networking

↘ *Vision and identity*

A lot of PTCs continue to be perceived as MSF entities, instead of community groups. Not only are they perceived as such, but PTCs themselves also suffer from the MSF "dependency syndrome". The absence of a clear mission can lead to PTCs having a diluted sense of purpose and to unfocused PTC gatherings.

It is increasingly important for PTCs to have and follow their own agenda, and work as partners, not beneficiaries. The challenge will however be for them to find a balance

between HIV/AIDS related activities, and other activities such as IGA.

The PTC identity will remain a challenge in the future, as long as they do not have independent grants to function. It is a fragile situation: a donor could recognize the value of these groups and want to use them for their own benefit, in return for money. It is possible that a donor driven PTC would consider abandoning its vision.

↘ *Capacity-building*

At the moment, PTCs stand and fall with the qualities of some individuals, which makes them extremely fragile. Quite some PTCs lack the know-how and resources to maximize their potential as most members have not enjoyed higher education. By providing them with skills (or develop existing skills), increasing their self-confidence, and promoting their ability to identify and meet their own and others' needs, people can be encouraged to become more involved in their community and the wider society. In this same logic, leaders also need to transfer knowledge and skills to their members, so these can either take over or form new PTCs, thus encouraging the establishment of a real grassroots movement.

High turnover within volunteer networks, especially those who provide capacity-building for their members, is a reality. For those whose capacity has been built, this has often resulted in job opportunities. This can be considered an achievement, but is equally a challenge.

↘ *Leadership*

The issue of leadership has been a problem for quite some time for the PTCs. A lot of PTCs disintegrate or cease to exist by lack of good leadership.

Not everyone has the potential to become a leader. A bad leader can take the group in the wrong direction. He might not be able to define a vision or goals for the group. He may be absent most of the time, does not know what is going on in the group and makes the group lag behind. Often his/her expectations are based on personal gain and not on the benefits for the group. A lot of PTC leaders lack skills in governance, organisational development and resource mobilisation. There is no clear division of roles in their PTCs.

> *"We should treat our group as CD4s: make sure they're going up, not down"*
> *- PTC leader*

↘ *Volunteerism & member participation*

PTCs have fostered the spirit of volunteerism through the GIPA principle. The idea is to have quality membership, and not a maximum of members. Those that fall out in the long term lack the necessary motivation to make a difference. However, this also leads to high turnover of experienced and qualified members.

Turnover is to be expected in volunteer organisations and can create opportunities for

organisational change, but high rates of turnover can hinder the capacity of the PTCs to deliver the quality or range of activities they have been investing in. It is therefore important that PTCs learn how to deal with this turnover, by transferring their knowledge and working on capacity building.



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Volunteering does not simply happen. Members who are unsupported, uncoordinated and not well-managed are unlikely to feel positive about the PTC experience. Volunteer members who give a lot and receive little could mean the downfall of the PTC.[23]

Motivation and mobilization of members will always be a challenge in a poor urban environment, because the individual has other priorities: food, money, work. Sometimes the challenge can be as simple as finding transport to get to the PTC. On top of that, the needs of each member change with time: psychosocial support, financial support, capacity building… A dynamic PTC is able to adapt to these needs as they surface.

↘ *Funds*

Even though some PTC activities provide a (small) source of income for the members (Health Talks, facilitation of trainings, IGA, sponsored events), none of the PTCs have a reliable source of income.

This financial weakness of PTCs, with a heavy reliance on volunteerism, is a challenge. Most members are unemployed, live below the poverty line and are investing their own resources into the PTC. Continuing the networks (and therefore the PTCs) without proper funding, does not seem an option.

Lack of finances, donor bureaucracy and lack of skills in proposal writing are all constraints to access funding. To date, no PTC or network (except for NEPHAK) has been accorded grants. Only few proposals have been written.

Luckily, more and more possibilities impose themselves. NACC has recently organised a "funding workshop" and some PTC members were able to participate. The recent TOWA project funding (by the World Bank) which supports the KNASP, or the Global Fund grants seem an ideal source for PTCs to tap into (NGOs are too big for these grants), especially for their networks, who can then channel the money to their members according to need. Once such grant has been obtained, it can pave the way for other donor applications.[24]

The prospects for PTC funding are good, but it is not just a matter of submitting a proposal. The networks must engage in the processes which influence what interventions will be funded. The national response coordinated by NACC for example is fully inclusive; all stakeholders are encouraged to participate in consultation and planning process.[25]

At the moment no grants are foreseen for Treatment Literacy, but good advocacy could change this. At present 170,000 PLHIV are on ART in Kenya and this is expected to rise to 200,000 by the end of 2008. This makes it essential that Treatment Literacy to promote adherence is supported widely.[25]

Once the funds have been obtained, PTCs will no doubt attract a lot of new members and will have to find a way to deal with that.

↘ *Networking*

> *"Maybe our contribution to the community has not been loud as such, but there have been changes" – Bethwell*

The PTCs and the networks in particular have started to make connections and build relationships outside of their community. Networking with groups who have similar interests is a great way to explore new options, learn more about the domain of HIV/AIDS, gather insights from peers and grow professionally. Knowing the right people at the right time can be very beneficial to the PTCs in reaching their objectives.

Funding should not be the only motivation behind such collaborations.

### 3.3 Monitoring & Evaluation

It is important to be able to report accurate, timely and comparable data to partner organisations, stakeholders, donors and communities. This information is useful to understand the outcome and effectiveness of the work done by PTCs and can be used to secure funding for the expansion of their work, and therefore enhance and scale up their community work.

The capacity for PTCs to monitor their performance and document the results achieved has been far from adequate.

One tool at the disposal of PTCs, is the NACC M&E tool (COPBAR form[xii]), but few PTCs are

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[xii] Community Based Programme Activity report: is filled quarterly by implementers with community based interventions. Submitting regular M&E reports to NACC through its decentralized structures (CACC) can help with funding and recognition.

currently making use of it. Other evaluation methods are fairly ad hoc: pre- and post training tests, feedback from external organisations, quarterly forums,…

Once a good evaluation system is in place, the PTCs will be able to see whether their activities are effective, and what needs to be improved in order to reach their goals.

## 3.4 Set-up of a network

The added value of a network is that it gives a sense of identity and direction to PTCs, harmonises working practices and acts as an intermediary between its members and external partners and organisations. It communicates decisions and offers the advantage that tasks can be shared equally amongst members. A strong network can also direct weaker member PTCs.

KIPOTEC is a relatively young network, but has grown tremendously in the past year. It has managed to unite a large number of Kibera-based PTCs to work together and has received recognition. It has empowered PLHIV through Treatment Literacy, Health Talks, awareness raising, defaulter tracing skills, lobby and advocacy and stigma reduction. It has standardised the work of the PTC members and has facilitated linkages with other organisations within and outside Kibera through the District Health Forum.

KIPOTEC accepts its member PTCs to attract donors or collaborate with other organisations, as long as that does not interfere with the objectives of the network.

KIPOTEC's ambitions however go further: it strives to monitor and evaluate the work of PTCs within the community, lobby and advocate for Treatment Literacy, fundamental rights and access to affordable treatment. It wants to network even more with other organisations for the benefit of PLHIV and the community and organise mass outreach campaigns. One of its biggest challenges at the moment is to mobilize (financial) resources to sustain activities.

NNEPOTEC is an equally ambitious network with national aspirations, but this has not yet resulted in an apparent identity. There is no clear dichotomy between PTCs and NNEPOTEC. At times NNEPOTEC seems to be operating at the same level as PTCs, forgetting its coordinating function. It is possible NNEPOTEC could have a bigger potential on a higher level, thanks to the geographical dispersion of its members.

The networks need to establish a strong link between each other to enable them to:

- ♦ market the networks to non-member PTCs

- ♦ lobby together/collaborate with other organisations at different levels

- ♦ share experiences, lessons learned

- ♦ work together with national bodies (like NACC, NASCOP, NEPHAK and others dealing with health issues)

Both networks are open, transparent and ready to question themselves.

### 3.5    Post Elections Violence: a particular challenge

Incumbent president Mwai Kibaki claimed victory in controversial presidential elections in December 2007. His swearing-in for a second term in office prompted a wave of violence and unrest across the country. Some 500,000 people were said to have been displaced, and over 1,300 others were killed. On February 28th a power-sharing agreement was signed between the president and his main opponent, Raila Odinga.



In the week following the start of the post elections violence (PEV), some PTC members visited Internally Displaced Persons (IDP) camps. Their main concern was to find out the needs of PLHIV. In Jamhuri camp, Nairobi,  for example they were able to identify 96 PLHIV/TB patients.

Several PTC members were among the IDPs. They encountered a variety of problems: no balanced diet (lack of food), no or not enough drugs, adherence issues (some would stretch their supplies, others did not know their treatment regime or the name of their healthcare provider which made it impossible to refer them) and stigmatisation.

The visiting PTC members were confronted with many HIV+ IDPs that had not had treatment literacy trainings. Most were not PTC members, had not disclosed, were in denial and unmotivated to adhere correctly to their drugs. Sexual activity in the camps lead to new infections and re-infections. Many of the PLHIV IDPs lacked basic information on treatment regimes, on where to get drugs or how to deal with missed appointments. Sometimes they had even forgotten the name of their PTC.

There was also the ignorance of the service providers. Some organisations, calling themselves partners in the fight against HIV/AIDS, did not handle HIV/AIDS as an epidemic during PEV: they would force people to disclose their status (display drugs and patient cards) to get assistance (food, medical care).

Inside the PTCs the challenge lied mostly with the lack of communication: they ran out of touch with many of their members. Another issue was the presence of tribalism in some PTCs that prevented members from coming to meetings as they lost their confidence in co-members.

A PTC of 12 members was created in Jamhuri camp, and psychosocial support was provided. The PTC members also managed to provide a link between the health facility and the PLHIV, so they could assure treatment continuation.

During PEV, it became clear that PTC empowered IDPs felt stronger and more confident, but also that PTCs should be apolitical and neutral. PTCs learned that co-existence must be possible as it is HIV/AIDS which is binding them.

# 4. ROLE AND ADDED VALUE OF PARTNER ORGANISATIONS

To enable PLHIV to share their knowledge and experiences, several partner organisations/ healthcare providers such as MSF, Amref and Care-Kenya, have been building the capacity and competence of the PTC members, through counselling, communication, leadership and facilitation skills (as well as material and (limited) financial support). These trainings help empowered PLHIV to understand the role of PTCs within the HIV/AIDS management. The outsourcing of certain activities to PTCs helps the partners to reach communities in a larger and better way in terms of HIV/AIDS prevention and care.



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To address the specific PTC challenges, two different strategies have been used[7]:

- A strategy of direct support: adapted approaches and materials are developed to better inform and accompany patients, as well as a direct assistance to PLHIV organized in PTCs (used by MSF, Lea Toto, IMC).

- A strategy of institutional development: to develop the capacity of PTCs and their networks to perform a number of health promotion related activities independently. (used by MSF, Care-Kenya, Amref)

From the point of view of the healthcare provider, the empowerment of patients self-managing their health will eventually form one of the cornerstones of a more effective disease and care program.

Treatment Literacy for example is believed to be one of the most critical aspects in successful treatment. This is why MSF for one has channelled its efforts to providing quality Treatment Literacy and related trainings to patients as well as building the capacity of "expert patients" at PTC level to facilitate and organise trainings themselves. When asked, 66,7% of the MSF patients confirmed having joined a PTC [26, xiv].

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[xiv] In total, only 23% of the total MSF cohort was asked this question. It is probable that the final percentage lies quite a bit lower.

MSF is eager to continue collaborating with the PTCs, and prepared to provide technical support and capacity-building. On the longer term (three years), MSF hopes to retreat from daily organisation and technical support and work alongside the PTCs as equal partners. This will require PTCs to become more independent and sustainable.

One of the future challenges will be to prevent and deal with treatment fatigue. A large observational study has shown that 1 in 6 people interrupt or halt treatment for at least six months within two years of starting ART. Treatment fatigue is not the only reason, but an important one. Interruption can lead to resistance and the need for second line or even third line treatment.[27] Before MSF pulls out of the partnership, it will need reassurances that PTCs can play a role in promoting lifelong adherence.

It is important that partner organisations keep the debate and critical reflection going within the PTCs. Trust and openness between partners is crucial. They need to work as a team, for consensus and consultation, with mutual respect for each others organizational mission as well as for the expectations and limits of each partner.

# 5. RECOMMENDATIONS FOR THE FUTURE

⊙ PTCs and networks should focus on a limited range of **high quality activities and services** and ensure their availability. The PTCs core activity must remain basic member support (like the Patient Support Groups their concept is based on). Once they have this under control, they may extend their activities (awareness raising, community outreach, co-provision in care). The bottom line is capacity and quality.

⊙ Make the organisations clear and transparent, which will require good governance structures and procedures. Structurally, there is a need to **better distinguish between two distinct levels**: on the one side individual PTCs and on the other the network. The latter is in charge of capacity-building, funding, institutional development, advocacy, partnerships and networking, and communicating information. The former take activities and psychosocial/member support on board. The networks must develop clear partnership agendas for member PTCs.

⊙ The networks need to share their recently developed **vision, mission statement and strategy** with their members, but also with (future) partners and stakeholders, so all know what they stand for. They'll also have to create a sustainable **monitoring and evaluation** system for members and network. Regular monitoring of members should also avoid briefcase CBOs of slipping into the system.

⊙ **Voluntary work** must remain the backbone of the PTCs. The benefits for **volunteer members** need to be emphasized rather than the needs of the PTC. Whatever the nature of their commitment, volunteers are likely to perform better and be more satisfied when the organization genuinely values them.

⊙ Question the fact whether or not PTCs only want PLHIV to be involved as **members**. There are many HIV negative people ready to contribute to supporting PLHIV and their communities. PTCs could benefit from the expertise of outsiders, who are willing to donate their time on a volunteer basis (for example for writing proposals or computer lessons). These do not necessarily have to be taken from partner organisations, as they might have their own interests at heart.

⊙ A system of **mentorship** could help new members integrate and identify with the PTC. An appointed member should help them to get acquainted with the vision and objectives of the PTC. An encounter before the first session will help new members to feel more secure and welcome. Home visits can be part of this familiarisation. Other strategies to scale up membership can also be considered.

⊙ Define basic criteria for choosing a **PTC leader**. Is the PTC looking for someone dynamic and visionary, or rather someone to support it in IGA? Be explicit on the qualities and competencies a leader should posses. Members themselves must take charge when they feel their leader does not meet expectations. The important thing is that s/he helps the PTCs to progress and that s/he is part of the group.

⊙ Any **funding** should cover the basic requirements for a PTC or network to be operational, and incentives could be given to members in return for activities such as

trainings or facilitations. This way of working offsets the risks of abuse of funding, and avoids unrealistic expectations about PTCs providing an income for their members.

◉    The PTC networks need to be seen as important players if they want to make a difference, engaging policy makers and showing them they understand issues at any level. They should exploit their position as a grassroots movement, which currently catches on well with donors and policy makers. They have to make sure they are visible and position themselves. Initiatives to integrate PLHIV groups on a **higher government level** can not only be top down, but PTC networks need also to work their way upwards via CACC, NACC and NASCOP, or even NEPHAK.

It is the only way for PTC networks to have an impact on government policy and on the provision of affordable and good quality health care (free drugs for Opportunistic Infections (OI), TL, quality counselling,…), and it could help them access funding.

◉    **Brand recognition** is of crucial importance to the PTCs. When saying "Treatment Literacy", "PTC" needs to be at the top of the mind. But it has to be the networks representing the PTCs on these higher levels: big bodies do not want to deal with individuals and small groups. This means NNEPOTEC and KIPOTEC will need to work together to achieve this goal and define a mutual strategy.

◉    If PLHIV want health services that address their demands, they will have to provide regular feedback (as "expert patients") to healthcare services, but also on other levels (CACC, NACC,…). This is also a way to become **partners in healthcare**.

◉    Use the PTC and expert patient potential as a way to expand the **public health system** infrastructure. The GoK, together with WHO, UNAIDS, the Global Fund and other important stakeholders need to develop a budget for treatment and TL that includes funding for the NGOs and CBOs that will prepare communities for treatment and bring them to the patients where the patients need them.[13]

# CONCLUSION

With this report we have tried:

1° to understand the current role and vision of the PTCs

2° to identify their strengths and challenges PTCs

3° to draft recommendations for possible improvement of PTC functioning, for partner organisations with regard to their future role in the development and for scaling up of the PTC model.

The study has shown that the PTCs can be vectors:

♦ for Treatment Literacy and other trainings which are valuable complements to medical care and contribute to patients better adhering to treatment.

♦ for sharing experiences among peers and receiving encouragement to overcome stigma and discrimination.

♦ for PLHIV to play a prominent role in community sensitization, promotion of health care services (and to criticize them if necessary), outreach activities, Health Talks, prevention and defaulter tracing.

♦ for influencing policies at national level and networking and collaborating with other organizations.

♦ for mobilizing the community, for example by linking up with different groups to provide TL. PTCs have positioned themselves as groups of people who can provide basic information to the community.

Making PTCs and their expert patients responsible for a certain level of care undertaken in the community, and providing them with the means and resources for it, could turn out to be very beneficial for the weak national health system, which has to cope with a lack of human resources for health (rationalization of care, which is the main objective of Treatment Literacy).

From the outset it was clear that the specific setting of the PTCs in Kenya (poor urban environment) makes their challenges different from those of other PLHIV peer support groups elsewhere. The financial weakness of most PTCs, with a heavy reliance on volunteerism, is putting great pressure on them as well. Most members are unemployed, live below the poverty line and are investing their own resources into the PTC. If not properly supported, the community component of HIV/AIDS care cannot be sustained.

Because the PTCs are relying on individuals, a well defined model for the PTCs is a precondition for its successful deployment. This implies:

♦ HIV/AIDS must remain the core of their mission

♦ a clear separation between PTCs and networks, including partnership agenda's

♦ to remain voluntary based

- ♦ a careful selection of leaders

- ♦ the appointment of mentors for new members

- ♦ capacity-building for members

- ♦ become partners in healthcare

For the networks more specifically, it implies:

- ♦ integration on a higher government level

- ♦ brand recognition

The PTCs have helped MSF and other partner organisations to reach out to the community in an effective way. But it has also become clear that the PTCs are unable to provide standard quality activities and have a limited capacity for expansion. The extension of the work of the partner organisation is – at least for the time being – a more realistic scenario than trying to shift certain tasks.

The PEV period provided a dramatic example of how the PTCs – as community based networks – were able to provide support during the crisis. Similar crises are a potential risk for continued ARV treatment. The PTC network responded to the challenge of adherence and showed that PTCs are a robust community based mechanism which can contribute to sustain ART in emergency or crisis situations.

Finally, we are of the opinion that the recommendations should be translated into a well communicated plan with clear targets and deliveries so that PTCs can adhere to it and become strong advocates of their own destiny. Because they are quite unique in their set-up, the Nairobi PTCs can serve as a model for other HIV/AIDS support groups elsewhere. It is in their hands to make this reality come true.

# ANNEXES

**ACRONYMS & ABBREVIATIONS**

| | |
|---|---|
| ART | Antiretroviral Treatment |
| ARV(s) | Antiretrovirals |
| CACC | Constituency AIDS Control Committee |
| CBO | Community Based Organisation |
| CCC | Comprehensive Care Centre |
| CHW | Community Health Worker |
| COPBAR | Community Based Programme Activity Report |
| GIPA | Greater Involvement of People Living With HIV/AIDS |
| GoK | Government of Kenya |
| HBC | Home Based Care |
| HCBC | Home and Community Based Care |
| HP | Health Promotion |
| ICC | Inter-agency Coordination Committee |
| IDP | Internally Displaced Person |
| IEC | Information Education Communication |
| IGA | Income Generating Activities |
| KIPOTEC | Kibera Network of Post Test Clubs |
| KNASP | Kenya National HIV/AIDS Strategic Plan |
| KOPLWA | Kenya Organization of People Living With HIV/AIDS |
| MDH | Mbagathi District Hospital |
| MIPA | Meaningful Involvement of People Living With HIV/AIDS |
| MoH | Ministry of Health |
| MSF | Médecins Sans Frontières |
| MSFB | Médecins Sans Frontières Belgium |
| NACC | National AIDS Control Council |
| NASCOP | National HIV/AIDS and STD Control Program of Kenya |
| NEPHAK | Nairobi Empowerment Network of PLHIV in Kenya |
| NNEPOTEC | Nairobi Network of Post Test Clubs |
| NGO | Non Governmental Organization |
| OI | Opportunistic Infections |
| PEV | Post Elections Violence |
| PLHIV | People Living With HIV/AIDS |
| PMTCT | Prevention of Mother-to-Child Transmission |

| TL | Treatment Literacy |
| ToT | Training of Trainers |
| STD | Sexually Transmitted Diseases |
| TAC | Treatment Action Campaign |
| TB | Tuberculosis |
| TOWA | Total War Against HIV/AIDS |
| WAD | World AIDS Day |
| WHO | World Health Organisation |
| PTC | Post Test Club |

## TERMS OF REFERENCE

### ↘ Context

MSF has been closely involved in endorsing the creation and development of Post Test Clubs in Nairobi, the prime objectives being to provide correct and relevant information to PLHIV about their disease as well as offering access to further support. A network of active PTCs and 'expert patients' has been successfully developed, but today solicits the question "where to now?". The report must allow MSF to make decisions on its future investments in PTCs.

### ↘ Objective

A document on the PTC-MSF experience, from the start until today, describing:

- History
- current organisational set-up, mapping & activities
- threats and challenges (capacities, shortcomings, sustainability)
- MSF's role and added value, expectations and future involvement (scaling up, replication of model)
- Recommendations

The document will mainly focus on the PTC's that rely on MSF's involvement, but will also implicate some of the other PTC's in order to define the specificity of the "MSF" PTCs.

We have to keep in mind that a qualitative study will be conducted (more or less at the same time) cc the impact of Treatment Literacy on adherence. The results of this study will equally impact on MSF's role and future involvement in the PTCs. Ideally we should be able to integrate its conclusions into the descriptive document.

### ↘ Methodology

Interviews with different stakeholders (AMREF, Riara, IMC, Care, MoH, DFID, NEPHAK,…), PTC members, community leaders, health centers and churches, questionnaire for the PTCs, literature study (secondary sources).

### ↘ Target group

The document will be used for external lobbying towards different HIV/AIDS actors in Kenya, in order for the model to be replicated.

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**Eva Kongs**
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