



## Involving People Living with HIV: Support to PLWH organisations in Cameroon

### The Context

In Sub-Saharan Africa, more than 25 million people are infected with the HI-Virus. Persons living with HIV (PLWH) are often powerful catalysts in the fight against the epidemic, supporting those who are also affected and assisting others in remaining HIV-negative. In many sub-Saharan African countries, denial, fear, and stigmatization have for a long time undermined the involvement of PLWH. Often, their needs and their capacities are not sufficiently recognized by policy-makers. The importance of "Greater Involvement of PLWH" (GIPA) was acknowledged at international level at the Paris AIDS Summit in 1994. Inspired by this initiative, the GTZ-supported health programme in Cameroon, a country severely affected by the HIV epidemic, has focused on empowering PLWH by ensuring their involvement in the national response to AIDS at all levels.



To download the full version of this report and modules and materials developed by this project, go to <http://hiv.prg.googlepages.com/reviewedpublications>

PLWH representatives at RéCAP

### The role of organisations of People Living with HIV (PLWH)

Support groups of PLWH play a key role in empowering their members to play an active role in HIV prevention, care and impact mitigation. In Cameroon, the GTZ health programme has supported PLWH organisations and the building of their national network since the mid-1990ies. Starting with one group in 1994, there are now 73 PLWH organisations in all provinces of Cameroon. Varying in their size and scope of activities, they pursue the common goal to improve the quality of life of PLWH by providing mutual support and care and by fighting stigma and discrimination. Members of PLWH support groups are mainly young women, the age group and the sex most vulnerable to HIV infection in Sub-Saharan Africa. With technical assistance by GTZ, PLWH organisations have developed the capacity to provide services ranging from psychosocial support, voluntary counselling and testing to home-based care and prevention campaigns.

In August 2000, Cameroon's PLWH organisations founded a National Network called RéCAP+ (Réseau Camerounais des Associations de Personnes vivant avec le VIH/SIDA).

Through RéCAP+, PLWH are today represented at all levels of policy-making and programming concerning HIV and AIDS in Cameroon (e.g. in the National AIDS Council and the Country Coordinating Mechanism).

### German HIV Practice Collection

The German HIV Practice Collection is edited by the German HIV Peer Review Group (PRG), an initiative of AIDS experts working in the context of German and international development cooperation. Approaches published in this collection have been peer-reviewed and approved by PRG members on the basis of a set of criteria for 'good practice'.

The BMZ-commissioned project "Strengthening the German contribution to the global AIDS response" serves as Secretariat to the PRG and moderates its internet platform at <http://hiv.prg.googlepages.com/home>

PRG membership is open to AIDS experts and development cooperation planners and practitioners with an interest in German contributions to the AIDS response in developing countries. For more information, contact the Secretary of the Peer Review Group at [aidsprg@gtz.de](mailto:aidsprg@gtz.de)

Peer-reviewed

## Promising Practices

The GTZ-supported health programme has provided substantial financial and technical support to RéCAP+ from its inception. In the course of their collaboration, a number of promising practices have been developed that could serve as a model for projects in countries where PLWH are not yet sufficiently involved in the national response to the epidemic:

- **Supporting the creation of new PLWH organisations**

The GTZ health programme promotes the creation of PLWH organisations by organising open workshops for PLWH in different parts of the country, particularly in regions without active PLWH organisations. The workshops focus on the concept of “living positively” and on the advantages of getting organised in PLWH support groups. Because of the omnipresent stigma and discrimination against PLWH, the recruitment of participants for these workshops is not easy. This is why the GTZ team and RéCAP+ use different channels (e.g. health and social workers and traditional authorities) to encourage PLWH to participate.

- **Ensuring Political Representation**

The GTZ health programme has supported RéCAP+'s claim for PLWH-representation in all major HIV/AIDS-related policy- and programming bodies in Cameroon. Today, representatives of RéCAP+ are permanent members of the National AIDS Control Committee and the Country Coordinating Mechanism of the GFATM. Here, they “give a human face” to the epidemic and have a prominent voice in the development and implementation of the national response to AIDS.

- **Capacity Building**

GTZ, in cooperation with RéCAP+, has developed training modules for PLWH organisations, building administrative, management and communication skills as well as the capacity to provide Home Based Care and pre- and post-test counselling at all public VCT (voluntary testing and counselling) centres.

- **Supporting Advocacy and Campaigning**

Supported by GTZ, RéCAP+ plays a key role in the organisation of public HIV/AIDS events in Cameroon, like the World AIDS Day and the Annual Cameroon Week of the Fight against AIDS. Through a range of activities, RéCAP+ members increase the visibility of PLWH and public awareness for their strengths and needs. Public testimonies have been particularly effective in raising awareness and empathy for PLWH.



*Member of a PLWH organisation who presents her testimony to raise awareness on HIV and AIDS*

*“I am Lucie Tsamo Zambou. It was in 1999 that I discovered my serological status and – like any person who became aware at that time, when there were no services and no information on HIV – I found myself a bit lost. Until the day I came across four seropositive women with whom we formed an association taking care of people living with HIV/AIDS called SunAids. During that period, we understood that we had things to do and that through those things we could live positively with the HIV infection. This gave me the courage and the will to live. I now share my experience with others who join me and we continue to live, together.”*

Lucie Tsamo Zambou, President of RéCAP+,  
Cameroon

## The Impact

- **Greater Involvement of PLWH in Decision-making**  
Today in Cameroon, PLWH are represented in the major decision-making bodies concerned with the response to HIV/AIDS on national, regional and local level. Many organisations in the field of HIV/AIDS are now actively recruiting PLWH. Overall, the better representation of PLWH has led to more community involvement in the fight against the epidemic.
- **Better Care and Support for PLWH**  
The GTZ-supported campaign for the creation of local PLWH organisations has resulted in an exponential increase in their number, from the three founding organisations in the year 2000 to 73 organisations in 2004 all ten provinces of Cameroon. Given the psychosocial support and information they receive in their groups, organised PLWH today enjoy a higher quality of life. After the Voluntary Counselling and Testing provided by PLWH organisations, people appear to cope better with a positive test result: The number of suicides after positive test results has significantly decreased in Cameroon.
- **Prevention of new HIV-infections**  
PLWH who are members of support groups report using condoms more frequently than those who are not organised. It appears that membership in a PLWH group, and the access to information and “positive living” it entails, can help prevent new infections.
- **Better Access to Antiretroviral Treatment (ARV) in Cameroon**  
The RéCAP+ campaign for access to antiretroviral treatment for PLWH in Cameroon has led to important results. Prices for treatment went down drastically so that in December 2004, 12.000 out of 95.000 PLWH in need had access to ARV. In addition, it has been shown that PLWH who are organized in groups show better compliance with treatment of opportunistic infections as well as with ARV, improving their health and preventing the development of resistant viral strains.
- **Greater Public Awareness for the Rights of PLWH**  
In Cameroon, the establishment of RéCAP+ has led to more public awareness of the problems but also the strengths of PLWH. Many of the testimonies



documented by RéCAP+ show that in recent years stigma and discrimination have decreased.

## Lessons learnt and Perspectives

- PLWH organisations in Cameroon differ in experience and capacities. In order to avoid hierarchies between member groups, capacity building needs to target weaker organisations in rural regions in particular.
- With the increase in funding from various sources for PLWH organisations, the risk of misuse and corruption has also increased. As financial resources from different donors increase, governance capacities and procedures need to be developed and monitored. As technical agency, GTZ is well-positioned to provide support in this area.
- As PLWH organisations and their national networks grow, effective monitoring and evaluation systems must be established in order to identify the effectiveness of interventions and the transparent use of funds.
- PLWH support groups can play a key role in ensuring equitable access to ARV treatment programmes. In Cameroon, RéCAP+ now faces the challenge to become a major actor in ARV programming, linking VCT and treatment services and enhancing patients' compliance with ARV treatment.

## German HIV Peer Review

Supporting PLWH organisations and their networks is a *promising practice* according to the following criteria:

1. **Effectiveness:** The support to the creation and capacity development of PLWH organisations and to PLWHs' political representation in Cameroon has resulted in the existence of a nationwide network of PLWH organisations, providing mutual support, facilitating access to care and ensuring the active participation of PLWH in all committees defining the national response to the epidemic.

WHO Director General visiting RéCAP+,  
November 2006



2. **Transferability:** The GTZ-support has enabled RéCAP+ to provide technical assistance to its member organisations and, more recently, to other, less experienced national networks of PLWH organisations. The exponential increase of PLWH organisations in Cameroon in response to the GTZ-RéCAP+ workshops in different regions, and the interest in their expertise by similar networks in neighbouring countries, indicate that the developed practices can effectively be adapted to different regional contexts.
3. **Empowerment:** Many documented testimonies by PLWH in Cameroon confirm that they feel empowered by their membership in a PLWH organisation, by the concept of “living positively” and by the public recognition PLWH representatives of RéCAP+ have received in recent years. PLWH organisations are powerful instruments against stigma and discrimination because they allow PLWH to be open about their status, to find out about their needs and rights and to jointly aim for their realisation.
4. **Gender Awareness:** In Subsaharan Africa, young women are the group most vulnerable to and affected by HIV and AIDS. They are also the group most represented in PLWH organisations, a fact which indicates their need for the social support offered by these groups and for the benefits they draw from them. HIV and AIDS and gender inequality are closely linked: PLWH organisations that empower their female members are an effective means to address this double challenge.
5. **Sustainability:** This GTZ-approach has focussed on enabling PLWH organisations and their networks to raise public awareness for their needs and rights, to become involved in HIV/AIDS-related policy debates, to raise funding for their activities, and to distribute and use these according to good governance principles. Today, RéCAP+ and its member organisations receive funding from many different sources and are firmly established members of HIV/AIDS committees at all levels.

#### Tools on the internet

The following tools and materials were developed in the course of this project and can be downloaded at

<http://hiv.prg.googlepages.com/toolbox-involvingpeoplelivingwithhiv>

- Training modules for PLWH organisations on “Living positively”; treatment literacy, Home Based Care (french)
- Statutes and Internal Regulations of RéCAP+ (french)
- Statutes and Internal Regulations of one association (as an example) (french)

#### Contacts and credits

##### Expert responsible for the approach

Dr. Flavien Ndonko Tiokou  
E [flaviennndonko@yahoo.fr](mailto:flaviennndonko@yahoo.fr)

##### Published by:

The German HIV Peer Review Group  
Supraregional Project ‘Strengthening the German contribution to the global AIDS response’  
Responsible: Dr. Thomas Kirsch-Woik  
Deutsche Gesellschaft für  
Technische Zusammenarbeit (GTZ) GmbH  
Dag-Hammarskjöld-Weg 1-5  
65760 Eschborn / Germany  
E [aidsprg@gtz.de](mailto:aidsprg@gtz.de)  
I <http://hiv.prg.googlepages.com/home>

##### Contact at GTZ

Health, Education and Social Protection Division  
Supraregional Project “Strengthening the German contribution to the global AIDS response”  
E [aids.ms@gtz.de](mailto:aids.ms@gtz.de)  
I [www.gtz.de/aids](http://www.gtz.de/aids)

##### Contact Person in the Federal Ministry for Economic Cooperation and Development (BMZ)

Dr. Jochen Böhmer, Section 311  
E [jochen.boehmer@bmz.bund.de](mailto:jochen.boehmer@bmz.bund.de)

Writers: Johanna Offe, Anna von Roenne

Photos: Flavien Ndonko Tiokou,  
WHO Multimedia Centre

Eschborn, first edition: February 2006,  
this edition: December 2007

