KHANA
អង្គការសម្ព័ន្ធភាពខ្មែរប្រយុទ្ធនឹងជំងឺអេដស៍
Khmer HIV/AIDS NGO Alliance

Mid-Term Review: Home and Community Based Care for PLHA & OVC 2005

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Executive Summary

The overall purpose of this report is to review the Global Fund of Fighting for AIV/AIDS, Tuberculosis and Malaria GFATM supported the Khmer HIV/AIDS NGO Alliance (KHANA) programs and its partner activities, focusing on inputs, processes and achievements, as well as lessons learned and documenting and making recommendations regarding future programming. KHANA has been supporting 32 home care teams, 8 home care networks and 12 provincial people living with HIV/AIDS (PLHA) networks managed by Non-Governmental Organisation (NGO) partners in different provinces with technical supports and capacity building being provided through training workshops and one-on-one visits to each of these partners.

The objectives of this review were to: 1) analyze the process of program implementation focusing on capacity building and technical support provided by KHANA, and service delivery or field activities carried out by its partners; 2) identify problems and constraints that have been encountered by both KHANA and its partners; 3) analyze the changes which have occurred for the beneficiaries at individual, household and community levels; and 4) identify important lessons learned and make recommendations for future program improvement.

A qualitative research method was used for data collection, consisting of a literature review (program documents, guidelines, reports and other relevant documents), field visits to the community, observations of activities, semi-structured interviews with Home Care Team (HCT) staff, Home Care Network (HCN), Provincial PLHA Network (PPN+) and key-informant interviews with PLHA in the communities. A total of 7 HCTs, 4 HCNs, 5 PPN+ and 17 PLHAs were randomly selected.

The findings of this evaluation have shown that the technical and financial assistance provided by KHANA to fund home-based care activities have achieved the following outcomes:

- Increased capacity of staff in technical skills related to home-based care activities. Knowledge gained through training workshop on basic home care activities and develop ment of general understanding on HIV/AIDS, tuberculosis (TB) and anti-retroviral (ARV) treatment guidelines has increased the confidence of HCT staff.

- There is an increased number of PLHA involved in home-based care. This means that PLHA were more willing to reveal their status and accept the activities and benefits pro vided to them.

- Through the home care program, PLHA were empowered in their communities so that they were not shunned as a result of the stigma and discrimination associated with the dis ease. Through regular HCT visits and Self-Help Group meetings, PLHA were encouraged to make their voices heard and their feelings known in their communities. Home-based care activities have given PLHA the *hope* and *expectation* that they can live their lives nor mally, like any other people in the community.

- Welfare supports provided by KHANA to a large extent have helped to alleviate the eco nomic burden of PLHA and their families. PLHA were given the opportunity to generate income through loans to start up small businesses and raise livestock.

- Home-based care activities help to reduce stigma and discrimination towards PLHA in their communities through Information, Education, and Communications (IEC) materials and peer-education on HIV/AIDS, especially by providing information about the trans mission of the disease.

- The main achievement of home-based care is that it was able to respond to the varied and changing needs of PLHA depending on their individual situations. PLHA, under the care of the home-based care program, could receive **comprehensive services** such as: basic care at home, access to medical services, psychological support, anti-retroviral treatment (ART), TB, welfare support and support for income generation and education. It is only through this comprehensive services framework that stigma and discrimination toward PLHA can be reduced.

Although all partner NGOs have experienced tremendous success in delivering care and supports to PLHA and the community at large, there were challenges and constraints encountered in the implementation of home-based care activities. These constraints and challenges include: 1) time constraints on activities that were planned to run within a specific time frame in the work plan; 2) financial constraints in terms of covering costs for referring patients to appropriate services and limited transportation costs for HCT staff to travel to village in remote or difficult-to-reach areas; 3) mobility of PLHA_moving in and out of the village for job opportunities made it difficult for HCT to conduct follow-up with patients; 4) motivation of HCT staff decreases when they have to provide care and support to increasing numbers of PLHA, especially when they have a limited budget for travel to distant areas; and 5) preparing and writing quarterly reports required a large input of time and HCT did not receive sufficient training.

Recommendations:

1. Collaboration between partner NGOs and HCN needs to be strengthened. HCN needs to be more involved with HCT rather just providing a single training session or waiting for the report.
2. There is a need to provide some financial incentive for leaders of the Self-Help Groups.
3. Since an increasing number of PLHA are coming to receive home care while the number of HCT staff remains the same, the workload for HCT staff has increased and they often have to sacrifice quality of the services provided in order to provide services for all PLHA. Thus there is a need to either recruit more staff or to increase their salaries in order to motivate them and to prevent them from resigning from their positions.
4. There is a need for refresher training on Continuum of Care (CoC) for HCT, HCN and PPN+.
5. HCT and PPN+ need to develop effective strategies to reach out to middle-income and/or government employees living with HIV/AIDS. While it would not be necessary to provide them financial and welfare support, they should at least be provided with counselling and ARV treatment management.
6. The budget should be more flexible so that HCT can allocate funds to cover other activities that they believe to be an important part of home-based care. The situation in the real world should not be rigidly determined by the budget category.

1. Background

The Khmer HIV/AIDS NGO Alliance (KHANA) received GFATM funds to support partner recipients in implementing the following activities: 1) the home-based care program by providing care and support to people living with HIV/AIDS (PLHA) and orphans and vulnerable children (OVC) through partner Non-Governmental Organisations' (NGOs) Home Care Teams, and by strengthening Provincial Home Care Network activities and Provincial PLHA Networks activities and 2) by helping to build the capacity of partner NGOs and Community-Based Organisations (CBOs) involved in home-based care programs.

Until now KHANA has provided technical and financial supports to 32 Home Care Teams (HCT) through 45 local NGOs/CBO (Community Based Organization) in 16 target Provinces. These HCTs work in 27 operational health districts in collaboration with 86 Health Centres, which cover 1,034 villages in total. The functions of HCT are divided into two areas, medical care and psycho-social supports. In the medical arena, HCT provides clinical care to PLHA, which involves 1) giving medication to patients for minor illnesses, 2) providing nursing and palliative care for patients, referring patients to health services for opportunistic infections (OI), anti-retroviral (ARV) medications, tuberculosis (TB) treatment, CD4 counts; and 4) conducting nursing care training for village volunteers. For psycho-social support, HCT provides 1) counselling to PLHA so that they can better cope with their diseases and live their lives in a normal state of mind; 2) welfare support, including food and housing, to PLHA and OVC; 3) and financial support in the form of allowances, loans to set up small businesses, and seed funding for income generation. From January to June 130 PLHA families have been awarded a small grant ($30) to establish a small business that will help them generate income. Examples of small businesses run by PLHA include: silk weaving, handicrafts, groceries; and pig, chicken and rabbit farms.

Forming and participating in Self-Help-Groups (SHG) are also one of the core components of home-based care and support. SHG are composed of PLHA at the village level. SHG provide an opportunity for PLHA to support one another. In addition, they also help the home-based care teams to mobilize community support, to transfer information from the team to PLHA in villages, and to advocate for the rights of PLHA. There were 206 PLHA self-help group formed through collaborations between home care teams and provincial PLHA networks (PPN+) and Provincial Home Care Networks (HCN).

In addition to implementing care and support activities, partner NGOs were involved in preventive activities in the community. One preventive activity was to provide community education such as basic HIV/AIDS/sexually transmitted infection (STI)/TB knowledge and to change people's behaviours towards PLHA in the community. A total of 8,300 community people have received education provided by home-based care teams, which include peer educators, volunteers and monks. 862 peer educators were trained. Peer educators play an active role in community education by raising awareness of HIV/AIDS issues amongst community members and reducing stigma and discrimination at the village level.

Currently, through KHANA supported projects, 3,605 PLHAs have received care and support services from home-based care teams. A total of 3,109 PLHAs have been referred for services such as TB, STIs, Voluntary Confidential Counselling and Testing (VCCT), OIs, CD4 count and ARV. Out of these, 650 PLHAs have received ARV from available sources –Medecins Sans Frontieres MSF /France; ;Master of development ManagementMDM; ESTHER (The name of care HIV/AIDS center); Center of Hope; MSF/Belgium; which are located in Phnom Penh (Russian Hospital, Calmette Hospital, Samdech Euv Hospital), Takeo and Siem Reap. 340 PLHA have received TB treatment support Direct Oral Treatment Supervision (DOTS) through the support of the home care teams.[1]

In addition, 5,437 OVCs have received care and support from the home and community based care programs supported by KHANA through various activities such as generating income for OVC who have neither father nor mother, seeking foster care, providing welfare support, conducting the Happy-Happy Program; providing access to education, clothes and school materials, and appropriate counselling.

Strengthening the Provincial Home Care Network (HCN) is another component of the home-based care program supported by KHANA. Eight HCNs have been established by KHANA in collaboration with National Center for HIV/AIDS, STD and Dermatology NCHADS and the Provincial Health Departments (PHD) in eight target provinces: Takeo, Siem Reap, Banteay Mean Chey, Pursat, Kampong Thom, Sihanoukville, Prey Veng and Svay Rieng. The HCN played important roles in supporting the coordination of home-based care activities in the provinces. The networks coordinated the activities of all home-based care programs, including those not supported by KHANA. They also provided training and support to home care teams on technical issues.

Another component of the home-based care program established and supported by KHANA is the Provincial PLHA Network (PPN+). There are 12 PPN+ functioning in the 12 target Provincesof Siem Reap, Battambang, Kampong Cham, Kampong Thom, Pursat, Banteay Mean Chey, Sihanoukville, Kandal, Takeo, Svay Rieng, Prey Veng and Kampot. This network plays an important role in promoting the active involvement of PLHA in the response to HIV/AIDS and in empowering PLHA to make their voices heard through advocacy activities. In addition, the networks also support PLHAs in the provinces in solving problems they may encounter, such as seeking support services and accessing additional information on care and support. The network coordinators also ensure that the activities of PLHA in the provinces are linked with the national network of Cambodian People living with HIV/AIDS (CPN+).

In addition to providing technical and financial support to the home-based care program in target areas, KHANA was involved in the capacity building of partner NGOs in terms of work organization structure, financial management and technical skills. These technical supports were provided in various forms: 1) training workshops on basic and advanced home-based care, basic counselling, pain management, ARV, financial management, project review, and monitoring and evaluation (M&E)

strategies; 2) technical support visits by KHANA staff to partner NGOs to monitor the progress of activities, identify and solve problems or constraints encountered by partner NGOs, and to identify further needs in the future; 3) exchange visits between partner NGOs involved in home-based care programs to learn how other programs function; and 4) regional knowledge sharing between other countries, particularly Thailand and Kobe, Japan.

Other capacity building provided by KHANA was in the form of personal contact through telephone calls and visits to the KHANA office in Phnom Penh to discuss and clarify any issues, problems or constraints their partner NGOs might have encountered.

2. Goals and objectives

It is significant at this stage to evaluate the effectiveness and outcomes of the activities provided by KHANA to its partner NGOs, how these activities have been implemented in the communities, how the communities themselves feel about the home-based care activities, and what benefits they received from these activities. Thus, the goals of this evaluation project were: 1) to review the GFATM supported KHANA programs and its partner activities, focusing on inputs, processes and achievements as well as lessons learned; and 2) to document and make recommendations for future programming.
Specific objectives were:

1. To analyze the process of program implementation focusing on capacity building and technical support provided by KHANA, and service delivery of field activities carried out by its partners;
2. To identify problems and constraints that have been encountered by both KHANA and its partners;
3. To analyze the changes which have occurred among the beneficiaries at individual, household and community levels; and
4. To identify important lessons learned and make recommendations for future program improvement.

3. Methodology

A qualitative research method was used for data collection, which consisted of a literature review (program documents, guidelines, reports and other relevant documents), field visits to the community, observations of activities, semi-structured interviews with HCT staff, HCN, PPN+ and key-informant interviews with PLHA in the communities. Semi-structured interviews with HCT, HCN and PPN+ focused on the inputs KHANA provided to home-based care projects (technical support, financial support, and capacity building), on the process of activities that have been implemented up to now, and on the achievements experienced and the barriers partners encountered by NGOs, HCN and PPN+ in the implementation of home care activities in the communities.

Interviews with PLHA focused on services they received from the home care program, what their

feelings are towards the activities of home care teams, and how they perceive home-based care activities have helped to reduce the stigma and discrimination they experience in the communities in which they live.

3.1 Sample selection

In selecting samples for the interviews, KHANA took the following steps:

Step 1: Since all 14 provinces have different home-based care programs, KHANA categorized the provinces according to existing programs: provinces that have all three HCT, HCN and PPN+, provinces that have just HCT and PPN+, and provinces that have only HCT.

Step 2: After categorizing all the provinces according to the existing program(s), KHANA randomly selected provinces from each category:

- 4 out of 8 provinces that have all three HCT, HCN & PPN+ (Banteay Meanchey,
- Kompong Thom, Prey Veng, Sihanoukville);
- 1 out of 3 provinces that have only HCT and PPN+ (Kandal); and
- 2 out of 4 provinces that have only HCT (Pailin and Phnom Penh).

Step 3: Since in some provinces KHANA supports more than one NGO on a home-based care program, KHANA then randomly selected one NGO in each selected province. A total of seven HCTs, four HCNs, and five PPN+ were selected. A semi-structured interview questionnaire was used for each group in order to obtain data. The interviews were conducted in a group involving team leaders, team members and in some cases the directors of the organizations.

KHANA also interviewed 17 PLHAs. To select PLHA, KHANA obtained a name list of PLHA under the care and support of HCT and then randomly selected five from the list. However the problem with random selection of PLHA for the interview was that the patients selected were not home when KHANA got there and some were living very far away. Since KHANA had a short period of time in the field, it was not possible for them to wait for the patients or to travel great distances to locate the patients. In some cases, staff simply asked the HCT to take them to meet with patients that had received ARV and patients not receiving ARV in order to make comparisons on how they were feeling about their condition and how they perceived the activities of the home-based care program. Most importantly KHANA wanted to know how the home-based care program helped to reduce stigma and discrimination towards PLHA in their communities.

Interviews with HCT, HCN, and PPN+ staff were tape-recorded and hand written on the questionnaire. Due to time constraints, it was not possible to do a full transcript of interviews for analysis. Analysis was done using qualitative techniques by coding individual interviews, searching for themes and patterns

related to the topic of the study. The interviews with the PLHA were written in field notes and analysis was done similarly, by looking for themes and patterns related to their feelings and attitudes toward home-care activities in the communities.

Interviews were also carried out with KHANA's Program Officers to obtain information on what supports and activities they had implemented as well as any problems and constraints they had encountered in providing supports to partner NGOs and home-based care networks.

4. Findings

4.1 Structure of home-based care program

The home-based care program has three components: the Home Care Team, the Provincial Home Care Network and the Provincial PLHA Network. These three components have different structures and responsibilities, but they interact and collaborate with one another.

4.1.1 Home Care Team (HCT)

According to KHANA's home care team model, the structure of the team consists of two part-time employees, three full-time NGO staff; and between five and ten community volunteers. The core team can be split into smaller teams, having just one health center staff member and one NGO staff member working collaboratively with volunteers in the community.

It is following this model that partner NGOs organized their home care teams. However, most partner NGOs established their home-based care program prior to KHANA's support and some have applied their old models, with some modifications, to fit with KHANA's model. For example, Sihanouk Hospital Center of Hope (SHCH) used a slightly different model. SHCH home care team consisted of one team leader, two social workers (one full-time and one part-time SHCH staff member), three nurses (two full-time SHCH staff and one part-time Municipal Health Department staff) and four volunteers (one PLHA and three local authorities from the commune).Khmer Women's Coorperation for development KWCD in Sihanoukville also used a different model from KHANA's home care team model. The KWCD home care team consisted of an extra Community Assistant (CA) from the village that was covered by the home care team. The Community Assistant was a PLHA who was responsible for gathering people in the community for meetings, visiting PLHA families, providing feedback to KWCD, finding new PLHA cases and helping to bring patients to KWCD or the hospital.

These two examples indicated that not all home care teams used the same home-based care model proposed by KHANA.

In terms of the roles and responsibilities of home care team staff, similar roles were described by all HCT KHANA interviewed. The team leaders were responsible for developing work plans, conducting

follow-up activities, building the capacity of volunteers, visiting patients and writing reports.

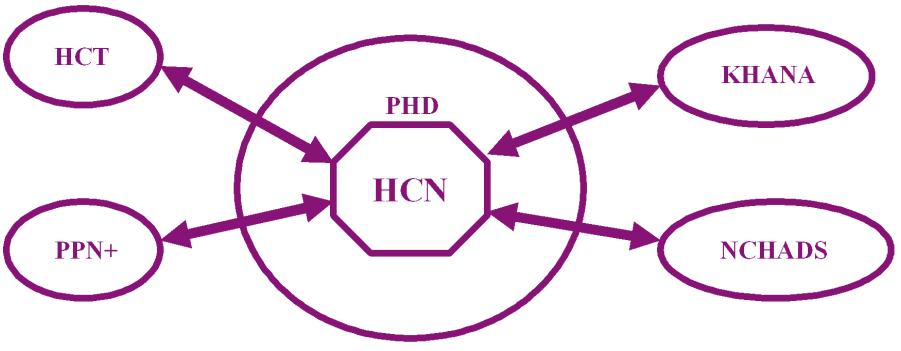
The health centre staff were responsible for providing clinical care to patients, including clinical management, nursing care, and general health education to patients and families, and training care-givers/families on nursing care, palliative care, linking HIV and TB through referral systems; and referring patients to other services such as VCT, STD SCI, OI, CD4 count and ARV treatment. For their part-time jobs, health center staff received a monthly salary of $50 per month.

NGO staff in the home care team were usually responsible for providing psycho-social support including HIV/AIDS education for families and community members, counselling for patients and family members, supporting PLHA in forming Self-Help-Groups (SHG), supporting children affected by AIDS, and welfare support and supports for funerals to PLHA who died from the disease. The salary for NGO staff varied according to the NGO.

Volunteers also played an important role in the HCT. Not all NGOs recruited the same type of volunteer to be in the home care team. Usually the volunteers were PLHA, village chiefs, Village Health Support Group VHSG and monks. Each type of volunteer played a different role; for example the PLHA were involved in leading SHG, sharing his/her personal experiences with the group of PLHA, and facilitating in referring PLHA to health services; the village chiefs were involved in networking with other villages in relation to home care activities, disseminating information on HIV/AIDS during village meetings, helping to find new cases of PLHA, and helping to reduce the stigma and discrimination in the village by modelling close interaction with PLHA; whereas monks were particularly involved in religious activities such as meditation, paying home visits to patients who were coming to the end of their lives, performing funeral rituals and helping to disseminate information on HIV/AIDS during religious festivals. All the Team volunteers received monthly allowance of $15.

4.1.2 Provincial Home Care Network (HCN)

HCN consists of only one person who is a Government staff member working as Provincial AIDS Coordinator in the Provincial Health Department. HCN was established by KHANA in collaboration with NCHADS and local NGOs. Currently there are eight HCN functioning in different provinces.



The roles and responsibilities of HCN include fostering collaboration and facilitation between NGOs and the government, collecting data from partner NGOs to prepare reports for KHANA and NCHADS, involvement in home care activities, participating in COC technical meetings and providing training on home-based care activities to HCT and PPN+. The HCN coordinator in Sihanoukville mentioned that he was also involved in selecting PLHA for ARV treatment.

4.1.3 Provincial PLHA Network (PPN+)

Until now 12 PPN+ have been established by KHANA in collaboration with other partner NGOs in different provinces. The structure of the Provincial PLHA Network consisted of two PLHAs: one coordinator and one assistant, in addition to volunteer team leaders of SHG. PPN+ have an independent working office in a rented house, not in any NGO or government facilities. PPN+ closely collaborated with HCT and also networked with the HCN. PPN+ not only carried out activities in target areas but also in any area that had PLHA. For example, PPN+ in Banteay Meanchey reported that they had set up three self-help groups in Preneat Preah (two groups with 27 PLHA) and Phnom Sruk districts (one group with nine PLHA) - areas that were not covered by KHANA's funding or any other NGO.

The roles and responsibilities of PPN+ included: 1) coordinating PLHA activities in the provinces; 2) disseminating information to PLHA; 3) supporting the establishment of PLHA self-help groups; 4) organizing and coordinating monthly meetings of SHG; 5) helping to strengthen the capacity of PLHA; 6) helping to solve any problem PLHA might have; 7) mobilizing resources to support PLHAs; 8) organizing campaigns in the provinces; and 9) participating in COC meetings. One of the main tasks of PPN+ was to promote the active involvement of PLHA in the response to HIV/AIDS and to empower them to make their voices heard through advocacy activities.

PPN+ staff were also responsible for referring PLHA to appropriate services, but sometimes this was not the case. All four PPN+ KHANA interviewed mentioned that they could only refer PLHA to home care teams in the first instance because they did not have any budget to cover transportation for the patients.

4.2 Technical supports provided by KHANA

4.2.1 Supports provided to HCT

KHANA provided supports to HCT in three areas - technical support related to home care activities; financial support and capacity building of the NGO itself.

For the technical support component KHANA asked each HCT to list all the support they had received from KHANA and in what forms the support was provided. The following support activities were mentioned:

- Training workshop on basic and advanced home care (ARV guidelines and quality care);

- Training on psychological counselling;
- General knowledge on HIV/AIDS and prevention;
- Pain management workshop;
- Financial management workshop;
- Training on how conduct project reviews;
- Monitoring and Evaluation training;
- Training on referral procedures;
- OVC activities; and
- Workshops on sharing experiences.

When asked about the methods of technical support KHANA to provided to partner NGOs, respondents from all HCTs mentioned the following:

- Workshops were conducted in Phnom Penh, either at KHANA's office or in other places;
- KHANA program officers (PO) made field visits to each individual NGO (two or three every quarter);
- Annual meetings were held with partner NGOs to share or receive new information;
- Exchange visits to NGOs in other provinces took place to learn about new activities and to share experiences (twice a year);
- Spot checks were conducted by KHANA PO;
- Participated in a retreat to Sihanoukville; and
- Phone calls were made for urgent matters and for specific advice on reports.

With regard to the financial support component, all HCTs mentioned that they received funds for materials and equipment such as motorbikes, computers, printers, office supplies and office furniture. Computers and motorbikes were mentioned as being among the most valuable commodities. HCT in Sihanoukville complained that they only received one motorbike, which was not enough for their staff to do fieldwork, and this made it difficult for them to carry out their work in villages far from town.

Another component of financial support provided by KHANA for the implementation of home care activities that was mentioned by HCT included funds for welfare support to PLHA and OVC, food provided by the World Food Program through KHANA, funds for small income generation for PLHA, money to repair dilapidated homes of PLHA, transportation money for referring PLHA to health services, and monthly incentives for volunteers and salaries for HCT staff.

In terms of technical capacity building provided by KHANA to partner NGOs, most importantly mentioned by all HCTs were: preparing quarterly reports, monitoring and evaluation strategies, project reviews and development of work plans. HCT staff said that the ability to monitor and evaluate their activities was a crucial part of the capacity building provided by KHANA - a capacity that they were lacking in the past. Several HCTs also noted that they lacked project review skills, and added that it was the most difficult task to accomplish because they felt that the training they received was not enough. HCT leaders found project review activities to be the most time consuming and complicated.

4.2.2 Support provided to HCN

In terms of the technical support provided by KHANA, all HCN interviewed mentioned that they had participated in several workshops on OIs management, ARV treatment guidelines, basic home care programs, counselling, and training of trainers on home-based care activities. HCN stated that these workshops were very useful for them.

HCN also mentioned that they had received technical support from KHANA through field visits of KHANA staff coming to examine and assist in developing work plans. Developing annual and quarterly work plans, monitoring strategies and writing reports were crucial components of capacity building of HCN. Exchange visit activity was also mentioned by HCN as an important aspect of the capacity building provided by KHANA. Through ex-change, HCN were able to learn about home-based care programs in other areas and to hear about the different experiences of HCN in other provinces. Participating in a retreat in Sihanoukville was also

mentioned by Home Care Team HCT as a way to share experiences from other people working in home-based care activities.

With regard to the financial support component, HCN reported that they received funds for materials and equipment such motorbikes, computers, printers, office supplies, office equipment, telephone and monthly salaries. One HCN in Sihanoukville mentioned that these kinds of support gave him more status than other staff working in the PHD office because he had more office supplies and a higher salary than PHD staff.

4.2.3 Support provided to PPN+

While interviewing PPN+ in the four provinces, KHANA found PPN+ staff well organized in term of both their work space and the organization of their work. The level of their commitment to their work was also impressive. When asked what kind of support they received from KHANA, they mentioned that they had participated in training workshops on program management, financial management, basic knowledge on HIV/AIDS and ARV management, and counselling and advocacy for PLHA. They also mentioned exchange visits to other provinces and study tours to Thailand to share experiences with other networks of PLHA.

Another form of technical support provided by KHANA was field visits by KHANA program officers at their offices. PPN+ stressed that one-on-one training was a very helpful and important part of their technical training. Through field visits they were able to learn much more and receive guidance to help solve problems on a one-to-one basis.

With regard to the financial support component, PPN+ mentioned that they had received funding for their salaries, for office rental, motorbikes, computers, printers and office supplies. They also mentioned that they had received money for English language and computer courses.

4.3 Activities implemented by HCT, HCN and PPN+

4.3.1 Activities of the Home Care Team

In order to determine to what extent the support provided by KHANA has helped partner NGOs in their implementation of home-based care, each HCT was asked to list all the activities they had carried out to this point and to describe in detail how those activities were carried out. All HCTs mentioned similar activities.

One of the main components of home care activities carried out by HCT was providing counselling to PLHA. Through counselling, PLHA were encouraged to be strong and to have hope that they could live long lives like any other person if they took good care of themselves. Counselling was sometimes also provided to family members of PLHA.

Providing medical treatment to PLHA for minor illnesses, nursing care and palliative care were included in the home visits carried out by HCT. The staff visited patients with a home care kit containing medication for treating minor illnesses, nursing care equipment and condoms. During KHANA's field visit to PLHA in the Borie Kila slum area in Phnom Penh, the home care team staff person we met in the community did not have his home care kit bag because it was broken, so he kept all the medication in a regular handbag. When a man in the area asked him for a condom, the HCT told the man that he did not have any condoms. The HCT then explained to us that the handbag did not enough have space to hold everything. He said that he had requested a new kit bag two months before but had yet to receive one and so had to use his personal bag.

Referring PLHA to appropriate health services for things such as OI, TB, CD4 counts and ARV treatment, and referring suspected cases to VCT was also part of the clinical care provided by HCT during their regular home visits to PLHA in the village. Some HCTs stated that they also visited patients who they referred to the hospital for follow-up. When asked how often they referred patients to services, HCT stated that it varied depending on individual cases and the stage of the disease.

Providing education on HIV/AIDS to communities_was also important, in addition to the care and support of home-based care activities. Providing education on basic knowledge of HIV/AIDS, TB and STI is one of the preventive activities carried out by the HCT. Education was provided through village meetings, IEC materials and peer-education groups.

Forming Self-Help Groups of PLHA at the village level was also mentioned among activities carried out by HCT. SHGs were formed in collaboration with the PPN+. The purpose of the SHG was to provide an opportunity for PLHA to support one another by sharing their personal experiences and finding ways to cope with the disease. The SHG were also involved in disseminating information they received from home-based care to the communities and in advocacy for the rights of PLHA. Monthly SHG meetings were usually held in public places such as temples, schools or at the NGO office. In each SGH there was a team leader who was responsible for mobilizing all PLHA to attend the meeting. The SGH team leader also acted as the group representative by attending workshops provided by KHANA and HCN, and in village meetings.

Providing social assistance to OVC is another essential component of HCT. Some of the activities mentioned include seeking foster care, providing welfare supports, organizing Happy-Happy events and providing clothes and school materials. No HCT mentioned anything about generating income for OVC who had no father or mother.

All HCTs interviewed mentioned providing social assistance to PLHA such as skills development, providing welfare supports, repairing homes, small income generation activities and collecting funds from donation boxes. Providing these types of social assistance, to a large extent, had helped to release PLHA and their families from economic burden. During our field visits to the communities, PLHA and their families expressed deep appreciation for these types of support received through home-based care.

Other kinds of activities that were carried out by HCT in conjunction with the home-based care activities listed above, was their participation in special events such as World AIDS Day, International Candlelight Day the candle light event and the Mondul Mith Chuoy Mith (Friend Helps Friend Center) MMM meeting.

4.3.2 Activities of the Home Care Network

With regard to the HCN, some of the activities they have implemented since the start of KHANA's support include the following:

- Providing technical training to HCT on the national guideline for basic home care activities, particularly on CoC;
- Providing training to HCT on ARV treatment and management, focusing on drug side-effects, follow-up treatment, and referral of people experiencing side-effects to appropriate services;
- Collaborating with all HCTs in the provinces on different sites, so that the coverage is complete, but does not overlap;
- Providing training to MMM;
- Going on field visits to communities to observe the work of HCT; and
- Coordinating with HCT and PPN+ for special events such as World AIDS Day and International Candlelight Day.

4.3.3 Activities of PPN+

Four PPN+ were established in late 2004 in Kandal, Sihanoukville, Kompong Thom and Banteay Meanchey. PPN+ in Prey Veng was initiated in January 2005. Until now the four PPN+ started in 2004 have implemented various activities such as establishing networks with local NGOs and HCN; forming SHG in the provinces; collecting data on PLHA from all partner NGOs; gathering information from communities to find new cases; organizing and participating in monthly SHG meetings; being involved in MMM and CoC meetings, visiting PLHA homes in the village; helping distribute welfare support to PLHA; and participating in special events such as World AIDS Day and International Candlelight Day.

PPN+ in Sihanoukville mentioned that they had helped find foster care for ten children affected by AIDS (CAA), sending them to Happy Tree NGO in Phnom Penh. Out of the ten CAA they sent one had returned to Sihanoukville and three had died. Although finding foster care for CAA was not part of their job description, they stated that they felt obligated to help these children.

4.4 Outcome of technical and financial support provided by KHANA

Building and strengthening the capacity of HCT staff was mentioned as the most important input that KHANA has provided to partner NGOs, particularly in providing skills in planning for the implementation of activities; preparing and organizing documents; monitoring and evaluation; and report writing and financial management. Gaining knowledge through training workshops on basic

home care activities and building their general understanding of HIV/AIDS, TB, and ARV treatment guidelines has increased the confidence of HCT staff.

> "*Technical support provided by KHANA has helped our organization a lot, from having no background to having enough skill especially in the field of HIV/AIDS. It has given us a step ahead in the implementation of our home-based care program. Now our efforts have been recognized by government staff at the provincial health department. They often come to us for help and support related to home-based care activities*" (Director of Social Environment Agricultural development Organization SEADO, Banteay Meanchey).

Establishing networks between the government and other NGOs in sharing information and experiences was also mentioned as an important aspect of the implementation of home-based care activities. Through annual partner NGO meetings and study tours, HCT were able to learn new skills and gain experienced from other NGOs. As one respondent put it, "*knowing what other NGOs are doing and where other NGOs are implementing home-based care activities in the same province helped us to avoid doing the same thing and we can also gain experience from one another*" (Buddhist for development BFD staff, Kompong Thom). Thus, working in collaboration with government health personnel, other NGOs, local authorities and the communities themselves made the home-based care program achieve its goal—that is, helping PLHA to cope with their physical pain and suffering.

Financial support provided by KHANA to a large extent has helped partner NGOs to successfully implement home-based care activities in local communities. The financial incentive has no doubt increased the motivation of HCT staff to carry out their work more effectively. Welfare support provided through home care teams has certainly helped to alleviate the economic burden of poor families affected by HIV/AIDS, and it serves as a gesture indicating that PLHA were being cared for.

As for HCN, they found that the technical and financial assistance provided by KHANA afforded them the opportunity to be directly involved with the home-based care activities at the community level, rather than simply sitting in the PAO office waiting to collect data; furthermore, they had the opportunity to go into the field to gain first-hand experience and also to acquaint themselves with the activities of other organisations. In particular, establishing networks with NGOs implementing home-based care activities and other activities related to HIV/ÁIDS was crucial in bridging the information gap between NGOs and government departments. Most HCN stated that it was important for them to share reliable and up-to-date information between NGOs and the government.

The main achievement of PPN+ lies in the fact that it brought PLHA together to share their personal experiences and to learn from one another's strengths. Bringing PLHA together not only provided them with the sense that they were not alone but also empowered them to live their lives normally, as other people in the community do. PPN+ staff themselves act as role models to the PLHA community, demonstrating that PLHA can still live normal lives, able to work and play important roles in the community and in society as a whole. And this has been achieved through the home-based care program. As one PPN+ in Banteay Meanchey stated, "*It is only through HCT that PPN+ was able to bring PLHA together and give them all the support they needed and give them comfort that they are not alone, by providing them with hope in their lives that they can live like everyone else.*"

4.5 Community perception of home-based care project

As part of this evaluation, KHANA also interviewed PLHA in the community to get a sense of how they perceived their lives living with HIV/AIDS before and after the implementation of home-based care activities in their communities, particularly regarding how other people in the community treated them once their status was revealed.

In interviews, most respondents stated that before the home care team came to the community they experienced a great deal of discrimination from people in the village. One woman in Banteay Meanchey stated:

> "*Before my husband died, people in the village did not want to talk to us and they did not want us to come close to them. They did not want to eat or talk to us because they were afraid of getting the disease. After my husband died I went to get a blood test and it was positive. I was scared and did not want to live. I tried to hide my status but people knew that I had got the disease from my husband, so they were afraid to associate with me.*"

Another woman in Sihanoukville stated:

> "*When people discovered that I had AIDS they did not want their children to play with my son because they were afraid that their children would also get AIDS. Some children made fun of my son at school. He was always sad when he came back from school. I really felt bad and didn't know what to do.*"

When people in the community discriminate against PLHA it is usually associated with the physical appearance of the patients, particularly with visible symptoms. One patient stated:

"When my husband was still alive he was very sick with rashes all over his body and he was very skinny. People knew that he had AIDS. I went to get a blood test and was found to be positive, but I don't have all the symptoms that he had. When I told people that I also had AIDS, no one believed me because I was not like my husband. I looked healthy and my skin was smooth. I sell Khmer noodle for a living, and I often told my customers that I had AIDS but they didn't believe me. They still come to eat my noodles everyday."

Thus the discrimination toward PLHA may be perceived in some ways associated with visible manifestations of the disease, compounded by the lack of knowledge among the people in community about the modes of disease transmission, which they believe could occur through touch and eating together.

PLHA interviewed mentioned that the situation had now changed regarding stigma and discrimination toward PLHA in their communities. They felt that more people in the community had begun to understand the disease so they were less afraid of getting it. People in the community had begun to develop more compassion for PLHA than they had before. Some of the factors that led to the reduction of discrimination toward PLHA achieved through home-based care activities were:

- Education on HIV/AIDS provided directly to the community by HCT through IEC materials, peer-education and village meetings. Although the community also received information through radio or television, direct communication and interaction through home-based care activities was more effective.

- Medical care provided through HCT helped patients to take good care of themselves, which has led to the reduction of OIs. When PLHA appeared to be healthy both physically and emotionally, and were able to perform daily tasks, people in the community perceived them as healthy and were less afraid of getting the disease.

- Receiving ARV treatment played a major role in reducing discrimination toward PLHA in the community, because the medicine helped to prolong the lives of PLHA and helped to prevent the development of OIs. PLHA equated getting ARV as having "*hope*" and "*living longer.*" Although PLHA knew that ARV treatment would not cure them of the disease, and realized that they would have to take the medication for the rest of their lives, they had a sense of *hope* that they could *live longer* like other people.

- Providing social and welfare support to PLHA through HCT indicated to the community that PLHA were being cared for by outsiders. In particular, the regular home visits made by HCT had given PLHA a sense of dignity and the feeling that they were not alone in coping with their illnesses. The close interaction between PLHA and HCT had shown people in the community that it was safe to interact and socialize with PLHA; thus it helped to confirm to the community that HIV/AIDS was not transmitted through social interaction.

4.6 Problems and constraints encountered in home-based care activities

Although all partner NGOs experienced tremendous success in delivering care and supports to PLHA and the community at large, they encountered challenges and constraints in the implementation of home-based care activities. In the interviews several challenges and constraints were identified, including:

1. Time constraints: The activities were planned within a specific time frame in the work plan proposed to KHANA, but in reality some of the activities required more time and energy. HCT also found that some activities that were not listed in the work plan were also important, but because of time constraints they could not carry out those activities. Thus they felt tied to the activities and timelines set out in the work plan.

2. Financial constraints: Most partner NGOs expressed some problems related to the fixed budget line given by KHANA in the implementation of activities. They felt that the funds provided by KHANA were only intended to support a certain number of PLHA, but in reality they were encountering more PLHA that needed support, particularly PLHA living outside the coverage areas. When PLHA started to ask for financial support for small income generation, the HCT were confronted with the difficulty of telling them that they could only support a certain number of people and that they would have to wait. Since many PLHA were very poor, they felt that it was hard to deny them, so they ended up giving their own pocket money to the patients.

a. Limited funds to support transportation costs for patients referred to health services was another problem HCT had to face. KHANA only provided US$1 to each referred case per month but in fact PLHA who were in a severe condition had to be referred at least two or three times per month. Since there was insufficient money provided by KHANA for transportation, and since most of the budget was allocated for certain activities, it was difficult for HCT to allocate the money to cover patients who needed to be referred to health services more than once, and some PLHA were living at a distance that would cost more than US$1 to get them to health services at the referral hospitals. In particular, when they had to organize a Self-Help Group meeting, some PLHA did not want to show up because there was no budget to cover their transportation to attend the meeting.

b. Another budget constraint faced by HCT was the limited transportation costs provided for HCT staff to travel to villages in remote areas or areas that were difficult to reach. HCT had to spend much time and energy and pay the extra fuel cost to get there. This was especially difficult during the wet season.

3. The mobility of PLHA: The mobility of PLHA from one place to another was identified as one of the major challenges that HCT encountered. The migration in and out of the village for job opportunities made it difficult for HCT to conduct follow-up with patients. As for poor PLHA living in slum areas in Phnom Penh, they tended not to be home during the day because they had to make their living in the city. In some cases, as in Sihanoukville, poor PLHA were evicted from their homes.

4. Motivation of HCT staff: Some partner NGO staff members were not sufficiently motivated to perform certain activities, especially when they had to work in villages that were far away and the transportation budget provided by KHANA was very limited.

5. Preparing and writing quarterly reports: Most HCT expressed the view that preparing and writing up reports were the most difficult tasks they had to perform because the data form was too complicated and required too much detail. In particular with the project review, HCT mentioned that it required a lot of time and that they had not received enough training.

6. HCN also found it difficult to prepare and write reports because they had to wait for partner NGOs to send them the data. HCN complained that partner NGOs tended to be very slow in providing the data.

7. Since the role of HCN is to establish networks between and work in collaboration with NGOs and the government sector, they found it very difficult to make choices regarding their involvement in activities occurring at the same time.

8. Because they had only two staff working, PPN+ found this limited their ability to carry out their activities. When there was a meeting the PPN+ coordinator would have to attend and the assistant go to the field so there was no one at the office. In this situation the office had to be closed.

9. PPN+ also had difficulties in collaborating with PHD and the Provincial AIDS office because they felt that their position as PLHA Network was only recently established and that they did not have enough confidence to talk to those at the PHD level.

10. KHANA's PO indicated that partner NGOs tended to be slow in responding to requests, especially in providing monitoring reports;

5. Recommendations

1. Collaboration between partner NGOs and HCN needs to be strengthened. HCN needs to be involved more with HCT rather than just providing single training sessions or waiting for the report. Information between partner NGOs and HCN needs to flow both ways.

2. There is a need to provide some financial incentives for leaders of Self-Help Groups.

3. Since there is an increasing number of PLHA coming out to receive home care while the number of HCT staff remains the same, HCT staff have an increased workload and they often have to sacrifice quality of care in order to reach to all PLHA. Therefore, there is a need to recruit more staff or to increase their salaries in order to motivate them and to prevent them from resigning from their positions.

4. Refresh er training on CoC should be provided to HCT.

5. HCT and PPN+ should develop effective strategies to reach out to middle-income and/or government employees living with HIV/AIDS. Although it would not be necessary to provide them with financial and welfare support, at least counselling and ARV treatment management should be provided.

6. The budget should be more flexible so that HCT can allocate funds to cover other activities that they believe to be an important part of home-based care. The situation in the real world should not be controlled by rigid budget categories.

6. Lessons Learned

1. Staff have increased their technical capacity, particularly in relation to home-based care activities.

2. There is an increased number of PLHA involved in home based care - that is PLHA were coming out and opening up because they wanted to be cared for and supported. However, it was mentioned by HCT that PLHA who are financially better off and have positions in the government do not want to be involved in the home care program because they want to hide their status.

3. Through the home-based care program PLHA were empowered in the communities so that they were not shunned as a result of the stigma and discrimination associated with the disease. Through HCT regular visits and Self-Help Group meetings, PLHA were encouraged to make their voices heard and express their feelings to their communities. It has given PLHA the *hope* and *expectation* that they can live normal lives like other people in the community.

4. Welfare supports provided by KHANA to a large extent have helped to alleviate the economic burden of PLHA. PLHA were given the opportunity to generate income through loans to start up small businesses and raise livestock for their livelihood.

5. Providing counselling and teaching PLHA how to care for themselves has certainly given PLHA a great deal of *hope* and the *expectation* that they can live long lives, like other people in the community.

6. Home-based care activities have helped to reduce stigma and discrimination toward PLHA in the communities through IEC materials and peer-education on HIV/AIDS, especially knowledge of disease transmission. The advantage of providing education to home-based care groups, compared to other media such as radio and television, is the direct contact between the community and educators. People in the community have a tendency to believe more when they receive information through personal contact.

7. The overall achievement of home-based care is that it responded to the varied and changing needs of PLHA depending on their individual situations. PLHA, under the care of home-based care program, could receive comprehensive services such as: basic care at home, access to medical services, psychological support, ART, TB treatment, welfare support and support for income generation. It was only through this comprehensive services framework that stigma and discrimination toward PLHA could be reduced.

Annex 2.

No.	Province/City	Home Care Team			HC Network	PLHA Network
		# of Partners	# of Projects	# of Teams		
1	Banteay Meanchey	1	1	2	1	1
2	Battambang	4	4	6	0	1
3	Kampong Cham	2	2	6	0	1
4	Kampong Chhnang	1	1	2	0	0
5	Kampong Speu	2	2	4	0	0
6	Kampong Thom	2	3	8	1	1
7	Kampot	0	0	0	0	1
8	Kandal	3	4	7	0	1
9	Pailin	1	1	1	0	0
10	Phnom Penh	2	2	2	0	0
11	Prey Veng	2	2	5	1	1
12	Pursat	2	2	6	1	1
13	Siem Reap	3	3	3	1	1
14	Sihanoukville	1	1	2	1	1
15	Svay Rieng	1	1	4	1	1
16	Takeo	2	3	11	1	1
Total		29	32	69	8	12