



An Evaluation of the MoH/NGO  
**Home Care Programme  
for People with HIV/AIDS  
in Cambodia**

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# ABBREVIATIONS AND ACRONYMS

<b>AIDS</b>	Acquired Immune Deficiency Syndrome	<b>MSF</b>	Medécins Sans Frontières
<b>ALLIANCE</b>	International HIV/AIDS Alliance	<b>MoWVA</b>	Ministry of Women's & Veterans' Affairs
<b>ARI</b>	Acute Respiratory Infection	<b>NAA</b>	National AIDS Authority
<b>ARV</b>	Anti-retroviral	<b>NAC</b>	National AIDS Committee
<b>BWAP</b>	Battambang Women's AIDS Project	<b>NAP</b>	National AIDS Programme
<b>CRC</b>	Cambodian Red Cross	<b>NAS</b>	National AIDS Secretariat
<b>CSW</b>	Commercial Sex Worker	<b>NCHADS</b>	National Centre for HIV/AIDS, Dermatology & STDs
<b>DFID</b>	Department for International Development	<b>NGO</b>	Non-government Organisation
<b>DoH</b>	Department of Health	<b>PAO</b>	Provincial AIDS Office
<b>DOTS</b>	Directly Observed Treatments, Short Course	<b>PAC</b>	Provincial AIDS Committee
<b>EC</b>	European Commission	<b>PAS</b>	Provincial AIDS Secretariat
<b>FC</b>	French Co-operation	<b>PCM</b>	(Home Care) Project Committee Meeting
<b>FHI</b>	Family Health International	<b>PLA</b>	Participatory Learning & Action
<b>HACC</b>	HIV/AIDS Co-ordinating Committee	<b>PLHA</b>	People Living with HIV/AIDS
<b>HCNG</b>	Home Care Network Group	<b>QSA</b>	Quaker Services Australia
<b>HCT</b>	Home Care Team	<b>RCG</b>	Royal Cambodian Government
<b>HIV</b>	Human Immunodeficiency Virus	<b>SSC</b>	Social Services of Cambodia
<b>HOPE</b>	Sihanouk Hospital Center of Hope	<b>STD</b>	Sexually Transmitted Disease
<b>IDA</b>	Indradevi Association	<b>STI</b>	Sexually transmitted Infection
<b>INGO</b>	International Non-Government Organisation	<b>TB</b>	Tuberculosis
<b>KHANA</b>	Khmer HIV/AIDS NGO Alliance	<b>UNAIDS</b>	United Nations Programme on HIV/AIDS
<b>KRDA</b>	Khmer Rural Development Agency	<b>USAID</b>	U.S Agency for International Development
<b>MEDICAM</b>	Membership Organisation for NGOs Active in the Health Sector	<b>VCT</b>	Voluntary Counselling & Testing
<b>MHD</b>	Municipal Health Department (Phnom Penh)	<b>VDC</b>	Village Development Committee
<b>MoH</b>	Ministry of Health	<b>VHV</b>	Village Health Volunteers
<b>MPA</b>	Minimum Package of Activities	<b>WB</b>	World Bank
		<b>WHO</b>	World Health Organisation
		<b>WOMEN</b>	Women's Organisation for Modern Economy & Nursing
		<b>WV</b>	World Vision

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# EXECUTIVE SUMMARY

## Background

*Cambodia is reported to have one of the fastest growing HIV prevalence rates in the world. Results from the latest Surveillance Survey<sup>1</sup> indicate that approximately 170,000 Cambodians are now infected with HIV, giving an adult HIV prevalence rate of around 3.5%.*

The impact of the rapid spread of the epidemic in Cambodia is drastic. During the year 2000, an estimated 12,000 people with AIDS will seek care and support, thus increasing the pressure on a health care system that currently provides a total of 8,500 beds for all medical conditions<sup>2</sup>.

In 1998, as part of the response to the growing HIV/AIDS epidemic, the Cambodian Ministry of Health (MoH) established a partnership with a group of NGOs to develop and implement Cambodia's first HIV/AIDS oriented home care programme. The first year pilot phase was supported by the United Kingdom's Department for International Development (DFID) and the World Health Organization (WHO). Subsequently, the Khmer HIV/AIDS NGO Alliance (KHANA), together with NGOs World Vision and Maryknoll, have supported the MoH and its NGO partners to provide home-

based care in Phnom Penh, as well as establishing a pilot home care initiative in Battambang Province.

As KHANA's primary international partner, the International HIV/AIDS Alliance (the Alliance) consulted with the MoH/NCHADS<sup>3</sup> and commissioned this evaluation in February 2000. The evaluation team was led by an independent consultant contracted by the Alliance, and included members from USAID, NCHADS, the National Institute of Public Health and local NGOs. The evaluation was financed by USAID through the Alliance. The purpose of the evaluation was to assess the impact of two years of home care services, to provide an estimate of the programme costs and cost savings to PLHA and their families, and to identify the key components that need to be considered in order to successfully replicate or scale-up this approach.

The AIDS Care Unit of NCHADS is in the process of formulating a strategy for expanding the home care programme to selected Provinces<sup>4</sup>. With the agreement of MoH/NCHADS, the findings of this evaluation will be used to guide and shape this expansion strategy.

<sup>1</sup> Report on Sentinel Surveillance in Cambodia, NCHADS/MoH, 1999

<sup>2</sup> UNAIDS (2000) Country Profile, "The HIV/AIDS/STD situation and the national response in the Kingdom of Cambodia", 3rd Edition - February 2000

<sup>3</sup> National Centre for HIV/AIDS Dermatology and STD

<sup>4</sup> Ministry of Health/NCHADS Draft Strategic Plan for HIV/AIDS and STI Prevention and Care in Cambodia, 2001-2003

## Impact

The findings of the evaluation clearly demonstrate that the home care programme in Cambodia is having a significant positive impact at a number of levels:

- **it is reducing the suffering of people living with HIV/AIDS (PLHA) and improving the quality of their lives and the lives of their families and caregivers;**
- **it is increasing understanding of HIV/AIDS by helping to forge links between care and prevention and reducing discrimination against PLHA in the community;**
- **by providing social and economic support, it is helping to empower some of the poorest and most disadvantaged individuals and families in the community.**

*"The Home Care Team only gives us a little help, but it makes a big difference to us; I think it's the difference between life and death"*

[retired sex-worker, age 43, homeless, now married with 3 children; Wat Phnom]

Of the 100 PLHA interviewed in Phnom Penh, 85% said that they were better able to look after themselves, after being visited by the home care team.

83% said that home care visits had helped to improve how much they feel in control of their lives.

72% of PLHA said that home care visits had improved their general well-being and physical

health. Many said that, before home care visits began, they were bedridden.

63% of PLHA felt that the home care team had helped to change their outlook on the future.

*"Now I am getting visits from the home care team, my health has improved and I am back at work. In fact I am now looking for promotion"*

[man, age 31, Chamkarmon]

45% of PLHA said that the home care teams had increased their comfort in sharing information about their HIV status with others.

93% of family members of PLHA said the home care team had added to their knowledge of HIV/AIDS, particularly methods of transmission.

More family members (42%) than PLHA (33%) reported reduced discrimination by the community against them as a result of home care visits.

79% of caregivers felt that, following home care team involvement, they could cope better overall with having a PLHA in the family.

*"I used to be angry with her because I spent all my time and money looking after her. The home care team has given me encouragement and support. I now understand better and I can care for her. Without them, it would have been impossible"*

[husband of PLHA, Tuol Kork]

27% of PLHA (including a number of sex workers) said that they now use condoms as a result of their increased knowledge about HIV transmission.

*"After knowing that I am infected, I always ask all the clients to wear a condom"*

[female sex worker, age 23, Kilometre 9]

The time spent by the Home Care Teams in providing care and welfare support is felt to be important in releasing children from some of the burden of care.

*"The home care team help me continue with my business of selling food; before (they started visiting), I couldn't even get out of bed. Without (the HCT) my children would have to leave school to look after me."*

[widow; age 36; Tonlé Bassac]

## Costs

*The cost of delivering home care services in Cambodia compares favourably both with the cost of providing outpatient services in public health facilities and with the costs of home care programmes in other countries. In addition, it is clear from the evaluation that the home care programme is providing households of PLHA with benefits in terms of financial and time savings.*

The evaluation notes that the average cost of providing urban home-based care services is estimated as \$9.28 per home care visit, and \$14.60 per visit for rural services. Estimates (Bunna & Myers, 1999) indicate that the average costs of hospital outpatient services are \$15 per patient-episode. A more realistic comparison with hospital out-patient treatment is provided by the cost associated with addressing the health needs of the patient using home-based care, which the evaluation estimates as \$3.71 per home care visit.

It should be noted that the estimated cost per home care visit was determined by totalling **all** related programme costs together with

technical support costs from INGOs and LNGOs (including appropriate proportions of salaries, commodities, transport and overheads). Furthermore, the average cost per home care visit includes the costs of improving the emotional, educational and social well-being of the patient (in addition to improvements in physical well-being). It also includes the costs of prevention and liaison activities in the community and the costs of building both organisational and technical capacity of MoH and NGO partners in the programme.

The financial savings by households are primarily due to changes in the use of traditional healers and in the use of medicines. Families and care-givers reported average savings in time due to home care provision of 3-4 days per month, and cost savings ranging between \$0.80 - \$1.30 per week. Respondents receiving home care who continue to use traditional healers, reported savings due to decreased and/or more appropriate use of between \$5.30 - \$10.50 per week.

## Key Components

The evaluation identified a set of **key components** which have contributed significantly to the success of the programme, and which should ideally be incorporated in its expansion. These are outlined below.

This evaluation has noted that **strong partnerships** exist at a number of levels in the Home Care programme:

- between MoH/NCHADS, KHANA, World Vision and the local NGOs who participate in the programme
- between KHANA and their partner NGOs who support the Home Care Teams
- between the Home Care Teams and the Health Centres at which they are based
- between the government and NGO team members who implement the programme

Such partnerships have enabled scarce resources to be shared, and have ensured that the comparative advantages of each of the players have been effectively utilised. This has undoubtedly contributed to the cost effectiveness of the programme.

Findings from this evaluation indicate that the **selection of the right personnel** and achieving the right mix of skills and experience in the Home Care Teams is critical to successful team working and has been instrumental in providing a comprehensive service to PLHA and their families.

Launching the project only after **adequate and appropriate training**, supplemented by responsive, refresher training are key

components to maintain professionalism of home care provision.

The Home Care Teams themselves identified the **support from community leaders** as the most important factor contributing to the successful implementation of their work.

This evaluation found that **volunteers** are fulfilling a number of important roles in the home care programme, such as referring clients, facilitating access to local authorities and establishing links with community initiatives.

The findings of this evaluation demonstrate the importance of, and demand for a **supportive supervisory system** to address the management and medical needs of the providers of home-based care.

Participatory **reviews, monitoring and external evaluations** have helped shape and improve the home care programme.

A **flexible and responsive management** structure has helped to ensure that the outcomes of reviews are incorporated into the programme.

**Consistent technical and financial support** has resulted in increased capacity of the NGOs to better manage their Home Care Teams, and of both MoH and NGO staff of the Home Care Teams to better manage their work programmes.

**The Home Care Network** has played a vital role in helping to ensure co-ordination of support, improve linkages and assist the programme to better meet the increasing demands for improved care and support at low cost.

## **Key Recommendations** from the evaluation for improving and expanding the programme are summarised below:

### **Home Care Network**

It is recommended that:

- **The Home Care Network Group becomes an autonomous unit with its own resources in order to ensure co-ordination of technical support, improve links with other initiatives and facilitate monitoring.**
- **The Municipal Health Department AIDS Office begins to assume responsibility for co-ordinating the Home Care Network in Phnom Penh**
- **Because of its capacity and present involvement in the programme, KHANA is approached to provide technical and financial support to facilitate the expansion and relocation of the Home Care Network Group**

### **Home Care Activities**

It is recommended that:

- **The Home Care Network Group initiates a review process to clarify and agree strategic priorities for home care activities and to rationalise the roles and responsibilities of the home care teams**
- **The Home Care Network Group reviews with the HCTs the system of monitoring and reporting patient numbers and team activities**

- **MoH includes drugs used in Home Care Kits in the Essential Drugs list**

- **Central Medical Stores initiates steps to provide drugs for Home Care Kits through Health Centres**
- **The Home Care Network Group initiates a discussion on the criteria for home care provision of prophylactic Bactrim to HIV patients in Cambodia, ensuring that there are clear guidelines for selection and monitoring of patients.**

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### **Referrals, Supervision and Training**

It is recommended that:

- **The Home Care Network Group strengthens the hospital referral system by reinstating the system of attaching each of the HCTs to one of the main referral hospitals in Phnom Penh.**
- **Referral hospitals provide supportive supervision to attached HCTs. Supervisors must be resourced and trained in facilitative supervision**
- **The HCNG implements a schedule of ongoing refresher training and orientations to deal with emerging issues facing HCTs. KHANA, NGOs, MoH and other ministries could act as resources with funding and support through the Home Care Network**

- The draft training pack used in initial training is updated and developed into a training resource pack for use when the home care programme is expanded
- The AIDS Care Handbook is translated into English and 1000 copies are printed for distribution to NGOs/IOs
- Pictures from the Home Care Stories are incorporated into a flipchart for teaching purposes by organisations working in the field of AIDS care.
- A module on "Managing Client Expectations" is included as part of the ongoing counselling training provided to HCTs

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#### **Volunteer Expansion**

It is recommended that:

- The Home Care Teams expand and strengthen Volunteer involvement in the Home Care programme in Phnom Penh and the Provinces
- The maximum number of Volunteers per team is increased from five to ten and Volunteers are encouraged not to work more than 10 days per month
- Volunteers begin to assume more of the social support responsibilities of home care provision, in addition to many of the non-patient-related activities
- The HCTs review and upgrade the skills of the Volunteers, to enable some to provide basic counselling to PLHA and to support peer counselling by PLHA

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#### **Programme Expansion**

It is recommended that:

- MoH/NCHADS takes the main co-ordinating role in expanding the home care programme in Cambodia
- NCHADS and partners ensure that key components of the home care model are incorporated when expanding the programme to the Provinces.
- NCHADS and partners examine the cost-benefits of different models for expansion. Adapting the current model to improve cost-effectiveness in rural areas should be seriously considered.
- MoH/NCHADS and partners support MoH/NGO Home Care Network Groups to co-ordinate activity at Provincial level.
- Donors explore the possibility of trialing a sub-sector-wide approach to funding the home care programme in Cambodia
- \* The Alliance increases its financial support to KHANA for building local NGO capacity, and maintains its present level of technical support
- The Alliance considers using the Cambodian Home Care Model in other AIDS care programmes that they support.

# 1 BACKGROUND

## 1.1 HIV/AIDS in Cambodia

*Cambodia has one of the fastest growing HIV prevalence rates in the world. Results from the latest Surveillance Survey<sup>1</sup> indicate that approximately 170,000 Cambodians are now infected with HIV, giving an adult HIV prevalence rate of around 3.5%.*

Cambodia has also one of the lowest rates of health utilisation in the world. Lack of funds for salaries, supplies and maintenance severely limits the amount of care and medicines which can be provided by the health system. For the poorest Cambodians, costs of health care account for approximately 28% of household expenditure<sup>2</sup>. The AIDS epidemic will further exacerbate this cost burden on many households.

The impact of the rapid spread of the epidemic in Cambodia is drastic. During the year 2000 an estimated 12,000 people with AIDS will seek care and support, thus increasing the pressure on a health care system that currently provides a total of only 8,500 beds for all medical conditions<sup>3</sup>.

The HIV/AIDS epidemic in Cambodia is still relatively recent. HIV was first reported in Cambodia in 1991 and the first cases of AIDS were diagnosed in late 1993. During that year the first 5-year National AIDS Plan was developed and the HIV/AIDS Co-ordinating Committee (HACC) was established by a consortium of international, national and local NGOs.

In 1998 the Ministry of Health established the National Centre for HIV/AIDS, Dermatology and STDs (NCHADS). The mandate of NCHADS is to oversee the response of the MoH as well as to provide technical support to other government

agencies and national partners. The National AIDS Authority (NAA), which replaced the National AIDS Committee (NAC) and National AIDS Secretariat (NAS), was established in January 1999 to oversee the national response, a key component of which is close co-operation between government and non-government agencies.

A 2-year National Strategic Plan for STD/HIV/AIDS was developed in 1998, under the co-ordination of MoH/NCHADS. This plan, which was a joint effort involving ministries, multilaterals and NGOs provides a framework for implementation and co-ordination for all partners contributing to the national response<sup>4</sup>. While Care and Support for PLHA is one of the 12 strategic areas, much of the focus is on policy, protocols, guidelines and mobilisation of donor support. The plan made no reference to government supported home care programmes.

In March 2000, MoH/NCHADS developed the first draft of their Strategic Plan for HIV/AIDS and STI Prevention and Care 2001-20035. AIDS Care, including Institutional and Home-based Care, is one of the eight areas of primary focus. Home-based Care has its own set of strategic goals, which include supporting the extension and expansion of the home-based care programme nation-wide, and the establishment of co-ordination mechanisms for its implementation. This Strategic Plan, which indicates what can and should be done in the health sector, is a significant step towards institutionalisation of Home-based Care in Cambodia.

<sup>1</sup> Report on Sentinel Surveillance in Cambodia, NCHADS/MoH, 1999

<sup>2</sup> Ministry of Health, 1998, The demand for health care in Cambodia: Concepts for future research, National Public Health and Research Institute

<sup>3</sup> UNAIDS (2000) Country Profile, "The HIV/AIDS/STD situation and the national response in the Kingdom of Cambodia", 3rd Edition - February 2000

<sup>4</sup> National Strategic Plan STD/HIV/AIDS, Prevention and Care in Cambodia, 1998-2000

## Concepts of Home-Based Care for PLHA

## 1.2

*The common misconception that people with HIV/AIDS will only benefit from highly specialised treatment, coupled with a general fear of contagion, has often resulted in vertical AIDS programmes, with a disproportionate emphasis on prevention, and with care being restricted to dedicated institutions. Evidence from other countries indicates that this approach, which encourages the attitude that PLHA should be segregated from the community, is inappropriate, unsustainable and unethical.*

### 1.2.1 | Comprehensive Care Across the Continuum

In an effort to address this issue WHO and others have, for the past decade, been promoting the concept of "Comprehensive Care Across the Continuum". This approach aims to link a network of providers and services to comprehensively address the care needs of PLHA and their caregivers in a range of environments. Comprehensive care should also include referrals between home or community and the hospital, and vice versa, effective discharge planning, and appropriate follow-up. As far as possible, the approach should consist of four interrelated elements<sup>5</sup>:

- **Clinical Management, including early diagnosis and rational treatment of HIV-related illnesses and follow-up care**
- **Nursing Care to promote and maintain hygiene, nutrition and infection control, to provide palliative care and health education to home carers**

- **Counselling, including psychosocial support to PLHA and their families, to reduce stress and anxiety, to promote positive living and risk reduction strategies, and to empower individuals to make informed choices for their futures**
- **Social Support, including material assistance, information and referral, linking into support groups and services.**

The continuum of care was envisaged as a dynamic set of support services that PLHA and their families can access. It should be noted that this is an idealised situation; the approach adopted in a particular country will depend on the prevailing needs of patients and the realities of health care provision.

### 1.2.2 | Lessons learned from other home care programmes

The limited number of evaluations of home care programmes to date have revealed a number of lessons learned:

- **ensure that any new initiative is integrated into existing or planned government health systems**
- **strong linkages should be established at the onset of the programme with hospitals and other health services**
- **home care staff should have an appropriate mix of clinical and psychosocial skills**

<sup>5</sup> Ministry of Health/NCHADS Draft Strategic Plan for HIV/AIDS and STI Prevention and Care in Cambodia, 2001-2003

<sup>6</sup> Osborne et al. "Models of care for patients with HIV/AIDS". AIDS 11, 1997

**in order to adequately address all the components of the approach**

- **labelling home care services as exclusive to PLHA can generate negative reactions from others and foster discrimination against PLHA**
- **support and care of HIV+ people is vital to maximise the impact of prevention activities. Any coherent response to the HIV/AIDS epidemic should seek to link care to prevention.**<sup>7</sup>

### 1.2.3 | Limitations of home care programmes

Home care programmes in other countries have generally been based on one or other of two models. Where there was a strong tradition of Community Based Organisations (CBOs), home care programmes have evolved using a grassroots approach. In other situations, where there are established government outreach programmes, home care for PLHA has been added as an additional activity. Both these approaches have limitations. Grassroots approaches are often limited in their capacity to scale up, and sometimes fail to make successful links with existing health structures. Evaluations of hospital outreach schemes report that they are relatively costly, often fail to mobilise community resources, and do not place sufficient emphasis on counselling and social support<sup>8</sup>.

A home care programme which, at the onset, links grassroots organisations with existing public health services, and encourages shared ownership is more likely to achieve sustainability, impact and cost effectiveness.

### 1.2.4 | The Cambodia situation

This approach of comprehensive care across the continuum has provided a successful framework for both policy and implementation of AIDS-related programmes in SE Asia, India and Sub-Saharan Africa. The approach is particularly suited to Cambodia<sup>9</sup>, which is characterised by:

- **a severe shortage of hospital beds to cope with the number of predicted AIDS patients (there are less than 1500 beds in Phnom Penh available for all medical conditions)**
- **a population where only an insignificant minority of PLHA are able to afford current prophylactic drug therapies**
- **a high incidence within PLHA of advanced opportunistic infections, largely untreated due to the low capacity of health services**
- **existing familiarity with the majority of common symptoms associated with HIV/AIDS**

Cambodia has a rapidly increasing number of PLHA presenting with a range of common symptoms including headaches, fever, diarrhoea, skin and oral infections and weight loss. The typical pattern of illness is a series of minor infections which will respond if the right treatment is provided, followed by more virulent infectious diseases leading to rapid decline and death.

Even if sufficient hospital beds were

<sup>7</sup> Gilks et al. "Care and Support for People with HIV/AIDS in Resource-Poor Settings", 1998

<sup>8</sup> Cost and Impact of Home-Based Care for People Living with HIV/AIDS in Zambia, 1994

<sup>9</sup> Joint Ministry of Health/NGO Pilot Project on Home and Community Care for People with HIV/AIDS, Cambodia, February 1998-February 1999.

available, there is a strong case to be made for managing minor illnesses at home, where the care is likely be cheaper and more convenient (for both patient and family), and where patients will be less exposed to other infections.

Similarly, as the patient approaches the terminal stage of the disease, many people express a preference for palliative care at home amongst family members, rather than the

anonymity (and expense) of death in hospital.<sup>10</sup>

The formative thinking behind the Home Care Model in Cambodia was based on the framework of continuum of care and its potential application to the Cambodia situation, coupled with an awareness of the limitations and lessons learned from other programmes. The following section provides an outline of the development of the Cambodia programme.

## The Home Care Model in Cambodia 1.3

### 1.3.1 | Origins

In early 1997, discussions on establishing home based care for PLHA in Cambodia, were initiated within WHO, and channelled through the HIV/AIDS Co-ordinating Committee (HACC) Sub-Group on Counselling & Care. These discussions sought to bring together local and international NGOs and involve MoH/MHD in developing a pilot project to be implemented initially in Phnom Penh. In bringing together the private and public sectors, it was felt that scarce resources could be shared, and the comparative advantage of different players could be utilised more effectively.<sup>11</sup>

There were a number of challenges to be faced in developing the home care project:

- **the HIV/AIDS epidemic in Cambodia was at a very early stage, and care was not yet on the national agenda. It was therefore difficult to find funding or motivation for anything other than prevention activities**
- **there was a need to bridge conceptual gaps between NGOs and the public sector, to build trust and to foster understanding of the limitations and potential resources of each of the players**
- **there were few, if any, hospital outreach services to which home care activities could be attached**
- **existing CBO activities were neither strong nor well institutionalised**
- **there were limited facilities for voluntary testing and counselling**
- **there was limited commitment from MOH/MHD for home based care for PLHA**
- **there was little enthusiasm from either management or physicians in the referral hospitals to be part of the continuum of care**

<sup>10</sup> AIDS Action, May 1996. "Home and Hospital"

<sup>11</sup> Joint Ministry of Health/NGO Pilot Project on Home and Community Care for People with HIV/AIDS, Cambodia, 1999, op.cit.

- **the National AIDS Programme was severely underfunded by the government**
- **although the NAP had funds for AIDS-related activities, there was no budget line for care and support to PLHA**

### 1.3.2 | Pilot Project

Against this backdrop, a one-year pilot home care project was launched in February 1998, implemented by a partnership of MoH and NGOs, with technical and financial support from DFID and WHO. The theoretical framework was the Continuum of Care, but the project design was based on lessons learned from other countries, particularly Thailand, Uganda and Zambia. The objectives of the project were foremost to pilot appropriate home care services for PLHA and other chronic conditions, but also to trial a model of health care in which NGOs and government acted in partnership.

Eight teams were formed, made up of staff from 7 NGOs and nurses from 8 health centres in Phnom Penh. The teams are based at the health centres (selected by MHD), but most of their work involves providing home-based care to patients and affected families in the communities served by their respective health centres. The pilot project was initiated and co-ordinated by the WHO Project Co-ordinator in close partnership with the AIDS Care Unit of NCHADS.

### 1.3.3 | Post-pilot Home Care Programme

WHO support to the project ended in February 1999, at the end of the pilot phase. Co-ordination of the project was taken over by the Ministry of Health, and the AIDS Care Unit of

NCHADS were given responsibility for implementation. KHANA, the linking organisation of the Alliance, assumed responsibility for providing technical and financial support to local NGOs, and continued to work in partnership with NCHADS.

The Home Care programme now consists of 10 urban Home Care Teams (HCTs), in Phnom Penh and a rural pilot of 1 HCT in Moug Russey District in Battambang Province. All the teams are composed of 2 government nurses working 50% time on the programme, and 3 NGO HIV/AIDS staff. The urban teams are located at 9 Municipal Health Centres spread throughout the city. For patient visits, each HCT splits into two groups of 2 staff, and patients are visited by one or other of the groups an average of 3 times per month. The teams carry simple medicines and supplies in specially designed Home Care Kits and provide palliative care to chronically ill patients, of whom PLHA now comprise approximately 80%. Counselling, education and welfare support are also part of the constellation of home care services provided by the teams.

Monitoring the urban programme is conducted by a group, representing NCHADS, MHD, KHANA, Health Centre Managers and the participating NGOs. Financially, each team is the responsibility of an NGO, and all team expenses, as well as salaries and transport costs of NGO staff, are administered through grants from KHANA (7 teams) and World Vision (3 teams). Salaries and transport costs of government staff are subsequently administered through the Municipal Health Department.

### 1.3.4 | Project Reviews

In July 1998, a participatory review of the project was conducted, with all stakeholders

given the opportunity to participate and to make recommendations. The recommendations included restructuring the teams to rationalise client case loads, restructuring the supervisory and feedback systems and providing further on-the-job training and updates. These outcomes were incorporated into the project implementation framework.

In December 1998, a 2-week evaluation of the project was carried out by a WHO consultant. The review concluded that home and community care for PLHA in Cambodia was essential and that the home care project should be strengthened in Phnom Penh and expanded to selected provinces. It was also recommended that a more rigorous evaluation should be conducted to analyse the mechanisms of the model and to assess the cost-effectiveness of the project.

A review<sup>12</sup> of the project was conducted by the Project Committee at the end of the pilot phase in Feb 1999. The review noted that the majority of the objectives had been met within the timeframe and concluded that patients, NGO and government partners, health staff and community leaders all reported a high level of satisfaction with the teams' activities, including their effect on community awareness of HIV transmission and prevention.

The review also concurred with recommendations of previous reviews, on the need to conduct a comprehensive evaluation of the home care programme in Cambodia. In particular, there was an identified need to evaluate the impact, cost and key components to help make decisions on expanding the programme nationally. The objectives and design of this evaluation are detailed in the following section.

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<sup>12</sup> Joint Ministry of Health/NGO Pilot Project on Home and Community Care for People with HIV/AIDS, Cambodia, 1999, op.cit.

# 2 EVALUATION DESIGN AND METHODOLOGY

## 2.1 Purpose of the evaluation

*The International HIV/AIDS Alliance commissioned the evaluation of the Home Care Model used by NGO/MoH Partners in Cambodia. The primary purpose of the evaluation, which was agreed in consultation with NCHADS, is to assist Home Care Partners in formulating a strategy to expand and improve care and support to families affected by HIV/AIDS in Cambodia. The evaluation may also be used by other Ministries, NGOs and international donors to shape national strategy on Home Care. It is intended that the evaluation provides a national overview, which will be supplemented by more localised findings from the KHANA Partner NGO Participatory Reviews in July 2000.*

The expanded focus on home-based care in the recent MoH/NCHADS Strategic Plan has resulted in increased donor interest in this area. The AIDS Care Unit of NCHADS is in the

process of formulating a strategy for expanding the Home Care programme to selected provinces. It was agreed, in consultation with NCHADS, that the findings of this evaluation will be used to help guide and shape the expansion strategy.

The evaluation was designed in consultation with NCHADS, KHANA, Alliance, USAID and the National Institute of Public Health (NIPH), with inputs from other stakeholders in the programme. The approach of Comprehensive Care Across the Continuum (outlined earlier in this report) provided the theoretical basis for the design. Other provisional issues to be evaluated were drawn from reviews of other home care projects and earlier reviews of the Cambodia pilot project, as well as preliminary discussions with the key stakeholders from government and non-government agencies.

## 2.2 Objectives

*The objectives of the evaluation were agreed with NCHADS and the Alliance, and were verified by other key stakeholders. The primary objectives are to evaluate:*

- **The impact of the programme in Phnom Penh and Battambang**
- **The cost of the programme and the cost savings to families of people affected by HIV/AIDS who receive Home Care**
- **The key components of the Home Care Model used in Cambodia that need to be considered in order to successfully replicate or scale-up this approach.**

## Design Framework

## 2.3

DATA SOURCES	IMPACT	PROGRAMME COSTS	COST SAVINGS	KEY COMPONENTS/ PROGRAMME STRENGTHENING & EXPANSION
<b>Patients &amp; families</b>	Case Studies of PLHA and families, In-Depth Interviews with PLHA and carers, Participant Observation of Home Care visits		Case Studies of PLHA and families, In-Depth Interviews with PLHA and families	Case Studies of PLHA and families, In-Depth Interviews with PLHA and families, Participant Observation of Home Care visits
<b>Community</b>	In-Depth Interviews and focus group discussions with community leaders (Phum Leaders, Village Headmen), Monks, Achar <sup>13</sup>			In-Depth Interviews and focus group discussions with Community Leaders (Phum Leaders, Village Headmen), Monks, Achar
<b>Home Care Teams</b>	Document Review, Focus Group Discussions with Home Care Teams	Document Review	Focus Group Discussions, Document review	Document Review, Focus Group Discussions with Home Care Teams, Attendance at monthly Home Care Team Co-ordinators meetings
<b>Volunteers</b>	Focus Group Discussions			Focus Group Discussions
<b>Health Centre Managers; Hospital Physicians</b>	In-Depth Interviews			In-Depth Interviews
<b>Partners / Other Stakeholders</b> (NCHADS, MoH, MAO, PAO, PAC, KHANA, Partner NGOs, WOMEN, IDA, KRDA, World Vision, Maryknoll, Servants, FHI, HOPE, MSF, UNAIDS, USAID, WHO, MHD, French Co-operation)	Key-Informant Interviews  Document Review	Document Review,  Key-Informant Interviews	Key-Informant Interviews	Key-Informant Interviews Attendance at monthly Home Care Network Co-ordination meetings, Document Review
<b>PLHA not receiving homecare</b>	In-Depth Interviews with PLHA attending hospital who are not receiving home care		In-Depth Interviews with PLHA attending hospital who are not receiving home care	

## 2.4 Evaluation Activities

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*The evaluation team consisted of a full-time team leader supported by a key representative from MoH/NCHADS, a Health Economist from USAID and two NGO representatives, all of whom were seconded part-time to the evaluation. In addition, specific evaluation inputs were provided by representatives from KHANA, FHI, Centre of Hope and NIPH.*

Over a 2 month period, the following evaluation activities were conducted in Phnom Penh and Battambang Province.

### Phnom Penh

- 12 Participant observations of home-care visits
- 100 In-depth interviews, using semi-structured questionnaires, with home-care patients and families
- 1 Case-study of PLHA
- 10 In-depth interviews, using semi-structured questionnaires with PLHA not receiving home care
- 4 Focus group discussions with home-care teams
- 1 Focus group discussion with home care volunteers
- 15 In-depth interviews with local community leaders, including village headmen, group leaders, monks, head of women's association, pagoda committee member, district governor
- 31 Key-informant interviews with stakeholders & partners
- 3 In-depth interviews with Health Centre Managers
- 2 In-depth interviews with Hospital Physicians

Attendance at 3 project/network co-ordination meetings

Attendance at 2 Home Care Team co-ordination meetings

Document review of HC guidelines, annual and monthly reports, financial records, referral forms, patient records, strategic plans, notes to project/network co-ordination meetings, notes to Home Care Team co-ordination meetings, workshop reports, previous evaluations.

## Battambang

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- 5 Participant observations of home-care visits
- 8 In-depth interviews, using semi-structured questionnaires, with home-care patients and families
- 1 case study of PLHA
- 7 In-depth interviews with PLHA who ceased to receive home care
- 2 Focus group discussions with KRDA home-care team and volunteers
- 1 Focus group discussion with community leaders from Ko Koh Commune
- 4 In-depth interviews with Hospital Directors, physicians, AIDS counsellor
- 5 In-depth interviews with representatives from Provincial AIDS Office. PAC, PAS, DoH

Document review of project reports, financial reports, notes to meetings, back to office reports.

## Data Collection **2.5**

### 2.5.1 In-depth interviews with patients and families

In Phnom Penh, each of the 10 Home Care Team Co-ordinators provided a list of patients who were currently being visited by their team. The Co-ordinators were asked to exclude non HIV/AIDS patients and those who were hospitalised or too ill to be able to answer questions. Ten patients were randomly selected from the list for each of the 10 teams, providing a sample of 100. It is estimated that there are approximately 500 patients who would have been suitable for interview, so the study sample represents some 20% of the population.

Of the 100 PLHA who were interviewed, 43 had family members present during the interviews, and a further 22 were accompanied by caregivers from outside the family. Specific questions in the interview guide were directed to these family members and caregivers.

The 100 in-depth interviews were conducted by 10 interviewers (10 interviews each) drawn from the Home Care Team Co-ordinators. The interviewers were supervised throughout the data collection period by 3 members of the Evaluation Team and the Alliance TA (C&S). The interviews were allocated by the Evaluation Team to ensure that the Team Co-ordinators did not interview patients from their own teams.



***Interviewing a home care patient in Phnom Penh.***

Members of the Home Care Teams accompanied the interviewers to the homes of the selected patients, but stayed outside during the interviews

The interviewers used a semi-structured questionnaire with both closed and open-ended questions (see Appendix 1a). The questionnaire was developed by the Evaluation Team with technical input from NIPH, NCHADS, KHANA and the Alliance. The questionnaire was translated into Khmer and pretested using home care patients not selected in the interview sample. The interviewers were trained by the Evaluation Team in interview techniques and how to use the questionnaire and were given practice in acting as interviewer and respondent.

The Evaluation Team supervised approximately one third of all the interviews conducted and reviewed the interviews immediately afterwards with the interviewers. Many of the interviewees lived in conditions of poverty, sometimes extreme poverty. Some were sex-workers, and a significant number were homeless. It was difficult, sometimes impossible, to conduct some of the interviews with any degree of privacy. Neighbours and/or family were often present and the interviewers sometimes had to change the subject or postpone sensitive questions until there was a greater measure of privacy. However, the supervisors and interviewers reported that confidentiality was often less of an issue than might have been expected. Many of

those interviewed were extremely open about their HIV status, and this seemed to be accepted by neighbours and relatives without comment or evidence of discrimination.

In Battambang, the members of the Evaluation Team conducted eight interviews with patients and families drawn from different communities throughout Moug Russey district where the KRDA Home Care Team operates. Convenience sampling was used to select the patients. The number of interviews was restricted by the limited time spent in Battambang, and the long distances travelled between interviews.

### **2.5.2 | Participant observation of home care visits**

In Phnom Penh 12 observations of home-care visits were conducted. Five of the ten home care teams were visited by members of the Evaluation Team and also by external evaluators seconded from FHI/Impact.

In Battambang, the Evaluation Team conducted 5 observations of home care visits with the Moug Russey Home Care Team.

The participant observations were guided by checklists developed by the Evaluation Team, in consultation with the external evaluators who had considerable experience and expertise in home-based care.

### **2.5.3 | In-depth interviews and focus group discussions with community leaders**

The Evaluation Team conducted a total of 15 interviews in Phnom Penh with local authority and community leaders, including village head-

men, women's association leaders, monks and achaa (lay priests), in the districts where the home care teams operate. The interviews were guided by a semi-structured questionnaire with both closed and open-ended questions (see Appendix 1b).

In Battambang, the Evaluation Team conducted a focus group discussion with 14 community leaders representing all 7 villages from Ko Koh Commune in Moug Russey District. The community leaders included the district governor, village headmen and village association leaders.

### **2.5.4 | In-depth interviews with PLHA who were not receiving home based care.**

For comparison purposes, a small number of PLHA who were not receiving home based care were interviewed. The numbers (10 in Phnom Penh, and 7 in Battambang) were too small to be considered a control group. Nevertheless, these interviews served to provide a useful basis for comparison and helped to triangulate findings from other data sources.

The numbers were restricted largely because of both logistic and ethical constraints in identifying and interviewing PLHA who were not being visited by home care teams. In Phnom Penh, 10 identified PLHA attending as out-patients or in-patients at Sihanouk Hospital were interviewed using a semi-structured questionnaire. The patients were first screened to ensure that they were not receiving home based care.

In Battambang, due to internal problems of the local NGO partner, one of the two home care teams ceased to operate 4 months ago,

after the team had been visiting patients for over 3 months. With the assistance of staff from the District hospital, 7 patients who had been receiving home care visits from the team were located, and interviewed using a semi-structured questionnaire. The objective was to discern what change (if any) there had been in the quality of their lives since the home care team had ceased visiting.

**2.5.5 | Focus group discussions with home care teams and volunteers.**

Four focus group discussions were held with all members (not including volunteers) of the home care teams in Phnom Penh, clustering either 2 or 3 teams together. The discussion guide is detailed in Appendix 1c of this report. A separate focus group discussion was held with a representative sample of 16 volunteers drawn from 8 of the home care teams.

Two focus group discussions were held with all the members (including volunteers) of the home care team in Moug Russey.

**2.5.6 | In-depth interviews with Health Centre Managers and Hospital Physicians**

In Phnom Penh, 3 Health Centre Managers and 2 hospital physicians were interviewed by the evaluation team, using open ended semi-structured questionnaires. In Battambang, the Evaluation Team interviewed 4 hospital managers and physicians.

**2.5.7 | Key informant interviews**

In addition to those listed above, a further 31 key informants in Phnom Penh and 5 in Battambang were interviewed by the Evaluation Team. The informants, who included programme managers, technical advisors, financial advisers, donors, and policy makers were purposively selected from MoH, MHD, NCHADS, KHANA, bilateral and multilateral donors, INGOs and local NGOs who are partners and/or stakeholders in the home care programme in Cambodia. The interviews elicited a range of issues deriving from the evaluation objectives.

**2.6 | Limitations of the evaluation**

*The absence both of baseline data and a comparable control group imposed methodological difficulties in evaluating the impact of the programme. The logistical and ethical difficulties associated with obtaining a suitable control group have been outlined elsewhere in the report.*

The measurement of impact therefore relied extensively on the perspectives of the PLHA who are the primary stakeholders in the home care programme. As the patient interviews were con-

ducted by the home care team co-ordinators, there was the possibility of interviewer bias. An effort was made to reduce bias by not allowing team co-ordinators to interview their own patients, and by close supervision of approximately one third of the interviews by the evaluation team.

There was some variation in the quality of the interviews, due largely to the lack of privacy, the sensitivity of the subject matter and the health status of the interviewees. Nevertheless, data collected in these interviews was triangulated

with data from other sources, and found to be consistent.

The presence of the evaluation team members during observations of home care visits may have affected the quality of the interactions between the home care team and the patients.

The quality of the monthly statistics on patient numbers and visits was sometimes inconsistent. On checking a sample of the home care record sheets with the monthly statistical summaries, some arithmetical errors were found. One of the home care teams counted every person they interacted with professionally (either a PLHA or merely someone in the community requesting information or

medicines) as a "patient". Another team counted any professional interaction as a "visit". The evaluation team attempted to correct these anomalies, in collaboration with the Khana staff and home care co-ordinators. When the number of patients and visits are averaged over 12 months for the 10 teams it is estimated that these errors will amount to less than 5%.

Finally, although the study explored impact related to improvements in a number of quality of life indicators for PLHA and their families, no attempt was made to measure lifespan or health status of PLHA visited by home care teams compared with those who did not receive visits.

# 3 IMPACT



*"Before the Home Care Team came I spent too much money on medicines and hospital visits; home care has changed my life; I can now look after myself and my child", [man, age 30; abandoned by wife when she discovered he had AIDS; Tonlé Bassac<sup>14</sup>]*

Interviews with approximately 120 PLHA, 60 family members and caregivers, 30 community leaders, and observations of 17 home care visits clearly demonstrate that the home care programme in Cambodia is having a significant impact at a number of levels.

• **It is reducing the suffering of PLHA and**

**improving the quality of their lives and the lives of their families and caregivers;**

- **it is increasing understanding of HIV/AIDS by helping to forge links between care and prevention, reducing discrimination against PLHA in the community;**
- **by providing social and economic support, it is helping to empower some of the poorest and most disadvantaged individuals and families in the community.**

The following sections of the report will explore impact indicators in more detail.

## People Living with HIV/AIDS (PLHA)

### 3.1

The primary stakeholders in the home care programme are PLHA, and it is with them that the programme is having the greatest impact.

*"Home Care is crucial to my life; if it wasn't for the Home Care Team I'm sure I would be dead by now", [woman, age 37, Tonlé Bassac]*

While HIV/AIDS is not itself a disease of poverty, it often flourishes in conditions of poverty. Poverty increases vulnerability to infection and limits the resources available to cope with disease. Poor people and marginalised groups often have the greatest difficulty accessing care and support services. Studies show that notions of blame for women with HIV may influence the amount and quality of care provid-

ed to women<sup>15</sup>. By treating women in their homes, the programme is increasing equitable access, and going some way to providing women-friendly services.

An increasing proportion of PLHA referred to the HCTs are women, who now make up 60% of home care patients in Phnom Penh. Because of the geographical areas in which the HCTs operate, the vast majority of PLHA visited by the HCTs are from the poorest and most vulnerable sections of society.

*"The Home Care Team only gives us a little help, but it makes a big difference to us; I think it's the difference between life and death", [retired sex-worker, age 43, homeless, now married with 3 children; Wat Phnom<sup>16</sup>]*



<sup>15</sup> Gilks et. al. 1998 op.cit.

<sup>16</sup> Area in Phnom Penh visited by one of the Home Care Teams

### 3.1.1 | Improved Quality of life

Specific measurements of changes in quality of life (QOL) for PLHA were beyond the scope of this evaluation. However, selected indicators from QOL tools<sup>17</sup> were included in the questionnaire used to guide the in-depth interviews with PLHA in Phnom Penh and Battambang.

Of the 100 PLHA interviewed in Phnom Penh, 85% said that they were better able to look after themselves, after being visited by the home care team.

*"They taught me which foods were good, showed me how to keep myself and my house clean and they explained why I should take more rest. I didn't know enough about these things"*

[woman, age 35, Kilometre 6<sup>18</sup>]

83% said that home care visits had helped to improve how much they feel in control of their lives.

*"I used to get annoyed very easily. I felt there was no hope. Now I am more hopeful and more at peace with myself"*

[man, age 37, Psar Dam Tkov<sup>19</sup>]

*"Before (I met the HCT), I wanted to kill myself, but after counselling I feel happier; I want to live longer; I want to spend time with my family"*

[woman, age 38, Doun Penh<sup>20</sup>]

72% said that home care visits had improved their general well-being and physical health. Many said that, before home care visits began, they were bedridden.

*"Before (home care visits started), I was seriously ill. I just slept in one place. I couldn't even find the energy to get up. I can now walk and do a little work"*

[man, age 37, Psar Dam Tkov]

63% felt that the home care team had helped to change their outlook on the future.

*"Now I am getting visits from (the HCT), my health has improved and I am back at work. In fact I am now looking for promotion"*

[man, age 31, Chamkar Mon<sup>21</sup>]

*"I was very weak when I found out I had AIDS; I also became very depressed. The Home Care Team gave me medicines and provided counselling. I now feel the same as other people; I can talk to others (about my HIV status)"*

[Pregnant woman, age 30, Tonle Bassac]



<sup>17</sup> "Psychosometric validation of the revised Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) quality of life instrument", Quality of Life Research; 1997, Vol6:572-584

<sup>18</sup> Area in Phnom Penh visited by one of the Home Care Teams

<sup>19</sup> Area in Phnom Penh visited by one of the Home Care Teams

<sup>20</sup> Area in Phnom Penh visited by one of the Home Care Teams

<sup>21</sup> Area in Phnom Penh visited by one of the Home Care Teams

When asked (in an open-ended question) how might things be different if they didn't have home care support, 92% of respondents feared that life without home-care support would be significantly more difficult. The main fears cited were:

- **isolation and having no-one to share their problems with**
- **not being able to access the medication provided by the teams**
- **rapid deterioration in their health**
- **increased stress and worries**
- **feeling hopeless**
- **loss of confidence**
- **being unsupported**
- **feeling discouraged and having no-one who cared for them.**

*"Before (home care visits) it was just hopeless; I wanted to kill myself. Now I just want to keep healthy and look for a job again"*

[man, age 41, Kilometre 6<sup>22</sup>]

### 3.1.2 | Reduced Discrimination

33% of PLHA said that the home care teams have been instrumental in reducing discrimination against them in the community. In addition, 31% felt that home care visits had improved the way in which they are treated by their families. It should be noted that these percentages indicate the extent to which existing discrimination had been reduced, specifically as a result of home care intervention. Discussions with the HCTs and observations of interactions between PLHA and their families revealed that, for many families, no discrimination existed even prior to the home care visits.

*"The neighbours, and even my own family, used to be afraid of my disease, but since education by the home care workers they are now more sympathetic with me. Some even come to visit me and bring me food"*

[woman, aged 34, Stung Meanchey<sup>23</sup>]

*"At first, my wife got angry with me when she found out (that I was HIV+), but now she is caring for me. The home care team talked with her; it helped a lot"*

[man, age 31, Wat Moha Montrey<sup>24</sup>]

Nevertheless, it is evident that discrimination against PLHA is still prevalent in urban communities, and a significant number of PLHA are still reluctant to reveal their HIV status. Half of those interviewed keep their HIV status secret from their community.

*"I keep it a secret, because I'm afraid they might hate me"*

[man, aged 37, Kilometre 9]

However, 45% said that the home care teams had increased their comfort in sharing information about their HIV status with others. In many cases the PLHA only share information with other patients in support groups. However, an increasing number are willing to 'go public'.

*"I now feel confident to tell others, so they can take more care and prevent themselves from this. I have even said this on television"*

[woman, aged 38, Doun Penh<sup>25</sup>]

79% of respondents said they have recommended, or would recommend the home care team to others.

<sup>22</sup> Area in Phnom Penh visited by one of the Home Care Teams

<sup>23</sup> Area in Phnom Penh visited by one of the Home Care Teams

<sup>24</sup> Area in Phnom Penh visited by one of the Home Care Teams

<sup>25</sup> Area in Phnom Penh visited by one of the Home Care Teams

## 3.2 Family

Forty three family members of PLHA were interviewed during the evaluation. Almost all (93%) said the home care team had added to their knowledge of HIV/AIDS, particularly methods of transmission. 42% felt that since home care visits, the attitude of the community towards the family had improved. More family members (42%) than PLHA (33%) reported reduced discrimination by the community against them as a result of home care visits.

*"Because of the home care team, things are better around us. Before, (the community) always used to discriminate against our family"*

[wife of PLHA, Psar Dam Tkov<sup>26</sup>]

79% of caregivers felt that, following home care team involvement, they could cope better overall with having a PLHA in the family.

*"I used to be angry with her because I spent all my time and money looking after her. The home care team has given me encouragement and support. I now understand better and I can care for her. Without them, it would have been impossible"*

[husband of PLHA, Tuol Kork<sup>27</sup>]

## 3.3 Community

Using a semi-structured, open ended questionnaire, the evaluation team interviewed 15 community leaders who knew of the HCTs, drawn from eight of the districts in Phnom Penh where the HCTs operate. The community leaders included village headmen, group leaders, monks, head of women's association, pagoda committee member, district governor.

All the community leaders were familiar with, and could list the main activities of the HCTs. The HCTs themselves generally initiated first contact with the community leaders, although one leader had sought out the HCT because he suspected that he was infected and wanted their assistance.

Two of the leaders said that they had not believed that there were any infected people in their communities and had initially been wary of contact with the HCTs. The HCTs concerned had persisted in their efforts to forge links with the community leaders, had gained their trust, and are now welcomed into the community. Meetings between the HCTs and community leaders generally occur twice or three times a month, although three leaders said that they meet the HCTs twice a week.

Twelve (80%) of the community leaders had referred families to the HCT in their areas, and it appears as if the number of referrals from community leaders is increasing.

<sup>26</sup> Area in Phnom Penh visited by one of the Home Care Teams

<sup>27</sup> Area in Phnom Penh visited by one of the Home Care Teams

The community leaders were unanimous in their appreciation of the work of the HCTs. They said that, despite some initial reticence, they were happy and proud to have HCTs working in their areas.

*"Their work is really helping my community by taking some of the burden from the patients, and also from the local authorities"*

[Village Headman, Krorl Kor Village, Kilometre 6]

*"To begin with, the local authorities would not allow the home care team into the community, but now the team is welcomed and respected"*

[Monk, Proyouvong Pagoda, Phnom Penh]

### 3.3.1 | Linking prevention and care

It was clear that the HCTs are helping to forge links between prevention and care in the communities in which they operate. Thirteen (87%) of the community leaders in Phnom Penh specifically mentioned that the HCTs were helping increase understanding of preventive measures. Three leaders noted that, until the HCTs started visiting, people didn't believe that there was AIDS in their area. Two leaders emphasised that most of the knowledge of HIV/AIDS and STDs in their areas was due to the HCTs.

*"People didn't believe we had AIDS here. Now they are more brave in talking about condoms and using them. Before, their knowledge about AIDS was just from television. The HCT have brought them the reality"*

[Village Headman, Cham Carmon, Phnom Penh]

Of the 100 PLHA interviewed, many said that they no longer had sexual relations. For some, the reason was the death of their partner, while others said that they had lost sexual desire because of illness. However, 27% (including a number of sex workers) said that they now use condoms as a result of their increased knowledge about HIV transmission.

*"After knowing that I am infected, I always ask all the clients to wear a condom"*

[female sex worker, age 23, Kilometre 9]

### 3.3.2 | Reducing discrimination

When the community leaders were asked what difference (if any) the HCT has on community attitudes towards PLHA, they mentioned reduced discrimination, reduced anger, reduced fear, and increased support, understanding and sympathy towards PLHA.

*"They (community members) used to be afraid of people with AIDS, but when they see the home care teams visiting patients, and they begin to understand about transmission, they don't fear the patients any more; they are showing compassion, visiting the patients and even giving them help"*

[Group Leader, Steung Meanchey Village, Phnom Penh]

Four of the leaders felt that it was important that the HCT didn't focus exclusively on PLHA, but visited other chronically ill patients. This confirms findings from a previous review of the programme<sup>28</sup>.

<sup>28</sup> Joint Ministry of Health/NGO Pilot Project on Home and Community Care for People with HIV/AIDS, Cambodia, 1999 op. cit.

### 3.3.3 | Community Mobilisation

It was evident that the HCTs had been influential in encouraging neighbours to provide encouragement and a little food and support to PLHA. However, the community leaders felt that there was little evidence of systematic

community mobilisation to support PLHA being initiated by the HCTs, and felt that this should be a future role of the home care programme. They suggested that volunteers, with appropriate support from the HCTs, could play a major role in identifying and forging links with existing community resources.

## 3.4 Children

*Children affected by AIDS are at the extreme end of the spectrum of vulnerability. As the sickness of the parent(s) progresses, the effect on the lives of their children is often drastic. They may have to leave school to care for their parents, and/or may have to start work. Some may have to leave home, even before the death of one or both parents. Discussions with HCTs reveal that dealing with issues related to children is becoming an increasing part of their workload.*

Although children were not a major focus of this evaluation, a short section of the questionnaire for PLHA was devoted to this issue. Of the 100 PLHA interviewed, 67 had children in the family. The findings outlined below refer to these 67 families.

- **In 21% of the families, children have had to start working since the patient became sick.**
- **In 30% of the families, the children have had to provide care, or take up major additional household duties.**

- **40% of the children have had to leave school, or take significant periods away from school.**
- **40% of the families said that since the patient became sick, the children have had to go without certain things (food, clothes, books etc).**
- **In 28% of the families, one or more children have had to leave home.**

The 67 families were asked if participating in the home care programme had resulted in any changes for the children in the household. 34% clearly stated that the home care programme has directly improved the quality of life of children in their families. Note that this should not be interpreted as meaning that 66% feel that the programme has had no effect on the quality of life of the children. It is often difficult (especially in an interview situation) to spontaneously make causal connections, for example linking home care provision to improved health of parent and improved capacity of family to provide care, to reduced burden on children, resulting on improved quality of life of the children.

For the 34% who acknowledge these causal connections, the time spent by the HCTs in providing care and welfare support is felt to be important in releasing children from some of the burden of care. The provision of money helps to buy clothes for the children and pay for schooling, while the provision of medicines helps to improve health and well-being of the parent, enabling them to devote energy to caring for the

children. Finally, psychosocial support helps foster more positive attitude about the future.

*"The Home Care Team help me continue with my business of selling food; before (they started visiting), I couldn't even get out of bed. Without (the HCT) my children would have to leave school to look after me."*  
 [widow; age 36; Tonlé Bassac]

## Health System **3.5**

Over 2000 families have been visited during the 2 years of the project. The total caseload of the ten Home Care Teams is now around 800 each month.

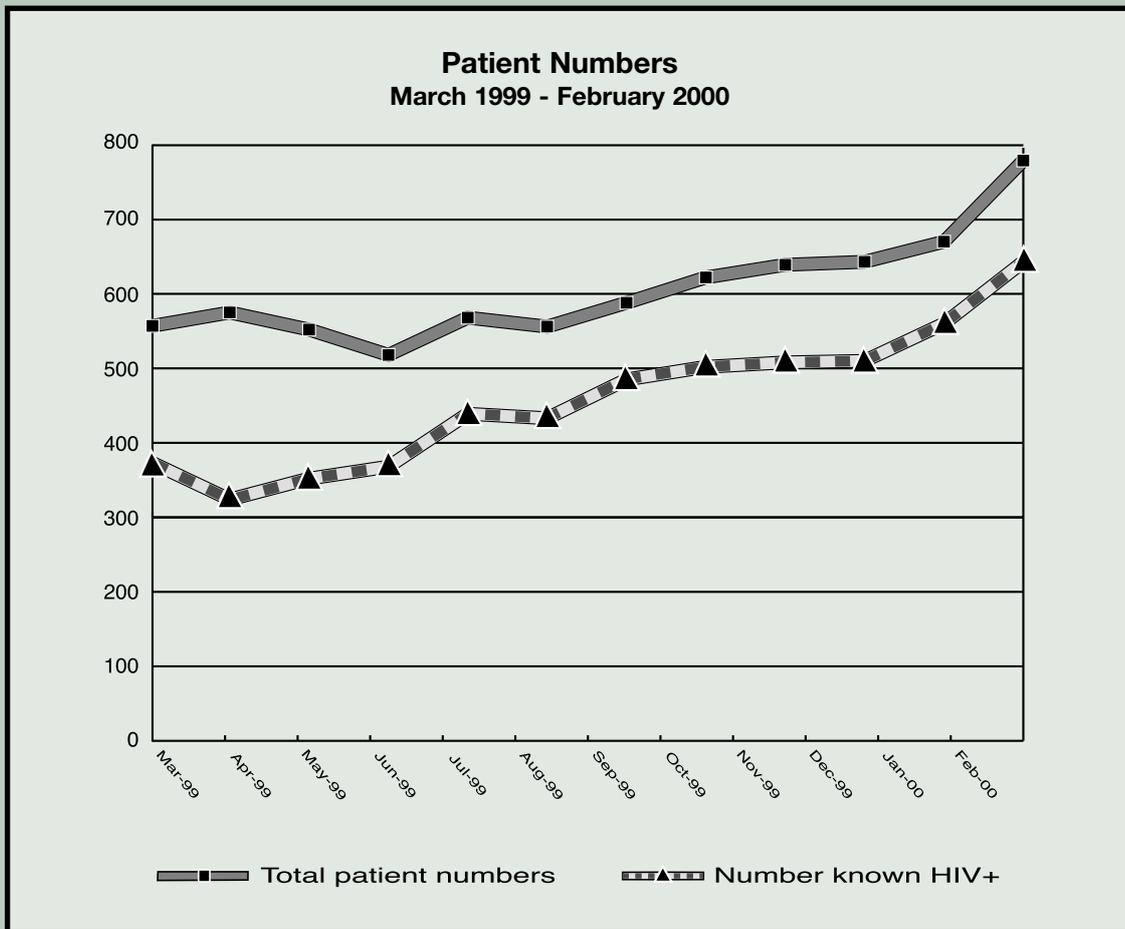
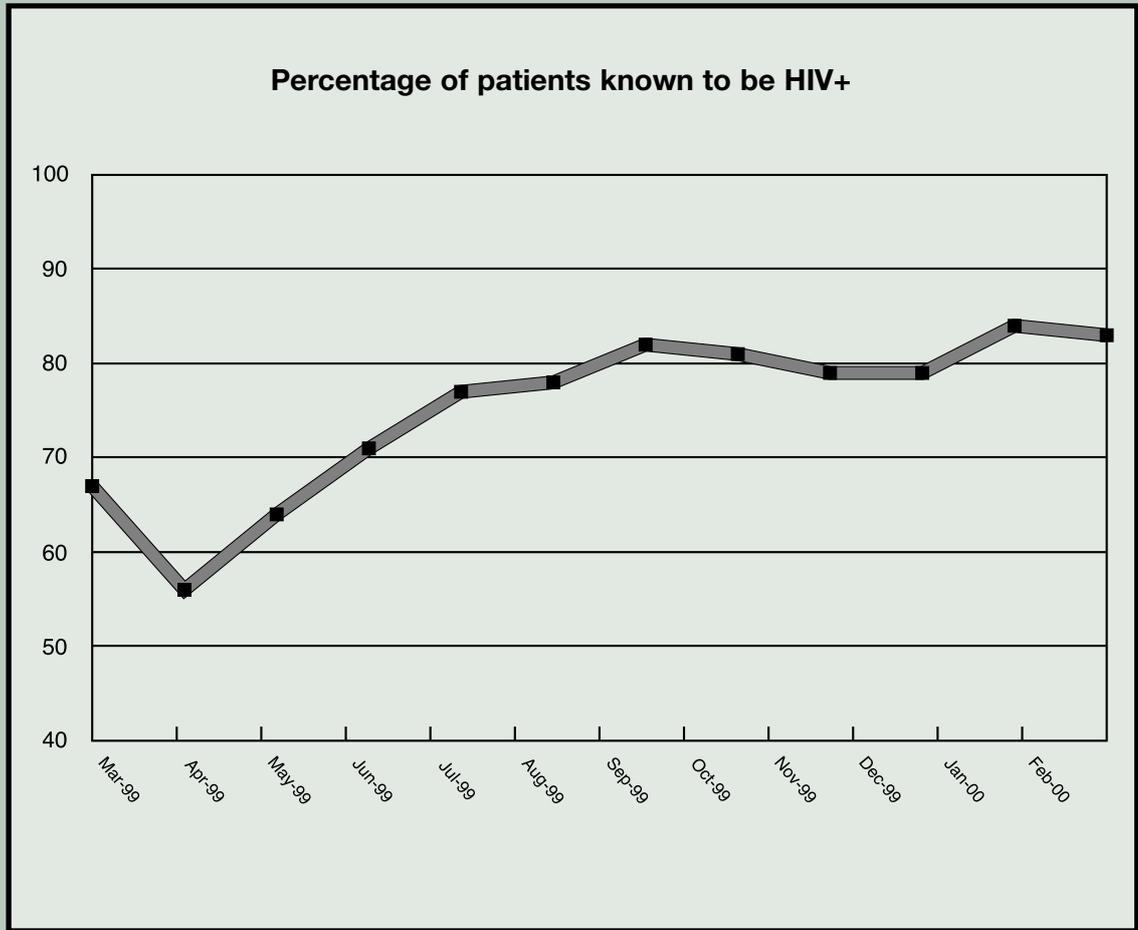


Figure 1



**Figure 2**

The proportion of HIV+ patients has increased over time and is now approximately 80%.

In discussions with HCTs, Health Centre managers, hospital physicians, community leaders, project partners, and with representatives from Ministry of Health, Municipal Health Department and multilaterals, all indicate that the Home Care Programme is having a positive impact on reducing the burden on the health system in Phnom Penh. However, in the absence of quantitative data, this is difficult to verify. In order to monitor impact on the health system it is recommended that data on home

care provision is incorporated into the monitoring and surveillance systems in Hospitals and Health Centres in Phnom Penh.

Nevertheless, there is some qualitative evidence that home-based care is making a difference. There are some indications from health centre and hospital staff that home care patients are presenting less frequently for minor problems. Senior representatives from MHD believe that the Home Care programme is helping to reduce the numbers of beds needed for AIDS patients in Phnom Penh, and indicate their full support to the programme.

### 3.5.1 | Access/coverage

Without comprehensive quantitative data on the numbers of PLHA in each of the districts in Phnom Penh in which the HCTs operate, it is difficult to measure the degree of coverage of the home care programme.

However, some rough estimates can be made from aggregated data. It is estimated that there are approximately 4000 people with symptomatic HIV infection<sup>29</sup>, of whom between 20%-30% (i.e. 800 - 1200) are living in Phnom Penh. The HCTs are currently visiting 800 patients, of whom about 80% (i.e. 640) are HIV+ and are generally symptomatic. These estimat-

ed figures indicate that the HCTs are reaching between 50%-80% of their target audience in the city.

Discussions with community leaders, with the HCTs and with the Volunteers during this evaluation support this estimate. Of the 15 community leaders interviewed in Phnom Penh, all felt that the HCTs were reaching the majority of PLHA in their communities

*"I would say that about 80% of the people with AIDS in my community are visited by the home care teams. The ones who miss out are those who live in the villas (houses occupied by upper-income group)"*  
[Village Governor, Cham Carmon]



# 4 COST ANALYSIS

## 4.1 Background

*This evaluation sought to estimate the cost savings to patients and families receiving home-based care. The evaluation also attempted to provide a comparison of the costs of providing home care services in the urban and rural programmes in Cambodia. Alternative approaches to providing care to PLHA are being piloted in many countries, in response to the increasing demands of the HIV/AIDS epidemic. The effectiveness of these approaches in improving the quality of life for individuals and families and the cost of delivering care services are being evaluated to assist program planners in understanding the future range of options of care to offer PLHA. Key difficulties cited in many overview papers<sup>30, 31</sup> on home care include issues of sustainability and concerns related to cost, quality and coverage of services.*

At present, there have been few estimates of the costs of providing home-based care, and these are generally limited to programmes in Africa. SAfAIDS reported that the time burden on care givers imposes the highest cost to the household, where caregivers typically spend 2-3 hours per day caring for the ill<sup>32</sup>. In 1993, a WHO study in Zambia found that the cost of a 3 person team home visit was \$26<sup>33</sup>.

Estimates in 1994 indicate that the cost of home care in Zimbabwe ranged from \$16 - \$23 per visit in urban areas and \$38 - \$42 per visit in rural areas. Further analysis reveals that up to

75% of those costs were transportation costs, particularly in rural areas<sup>34</sup>.

Gilkes, et al<sup>35</sup> concluded that hospital based home care programmes were not cost efficient since they could not cover all beneficiaries in need of care services. For example, in Zambia, the cost of the Chikankata Hospital home-based care programme in rural areas was estimated to be about \$1000 per client served. Again, the majority of those costs were transportation costs.

Community-based programmes have been found to be significantly less costly. For the Zambia Catholic Diocese Copperbelt home-based care programmes the cost of services were about \$5.50 per beneficiary. The largest item of expenditure (39%) for this community-based programme was welfare support for food, blankets, etc. Community-based programmes are assumed to be more cost-effective due to volunteerism and decreased time pressures of teams providing care as they are located near the communities they serve.

As far as we are aware, there is little or no reliable data on the costs of providing home based care in an Asian country.

The analysis provided in the following sections outlines the costs of delivering the home care programme described in this report. The analysis also provides an estimate of household level costs and the perceived cost benefits of the programme to patients and families.

<sup>30</sup> Woelk G et.al. (1997) Do we care? The cost and quality of home based care for HIV/AIDS patients and their communities in Zimbabwe, University of Zimbabwe, SAfAIDS, Ministry of Health & Child Welfare, Harare

<sup>31</sup> Foster, G et. al. (1999) Increased scope and decreased costs of home care. SAfAIDS News, Vol 7 No.3

<sup>32</sup> Lee, T (1999) Cost and cost-effectiveness of home care: Zimbabwe experience, SAfAIDS

<sup>33</sup> MoH Zambia/WHO (1994) Cost and impact of home based care for people living with HIV/AIDS in Zambia

<sup>34</sup> Hansen, K et.al (1998) The cost of home-based care for HIV/AIDS patients in Zimbabwe. AIDS Care, Vol 10, No.6.

<sup>35</sup> Gilks et. al. 1998 op.cit.

## Methods and Results 4.2

Programme costs were determined by tabulating all costs associated with the programme since its inception. In February 1999, at the end of the pilot phase, DFID/WHO support to the programme ceased, and financial and technical support was provided locally by KHANA, and by two INGOs - World Vision and Maryknoll. The cost analysis provided below focuses on the post-pilot period from February 1999 - February 2000. Programme cost analysis includes all relevant costs, direct and indirect, for KHANA, the MOH, the two INGOs and the local subgrantee NGOs involved in the programme.

One of the main vehicles for disbursing resources to implementing NGOs was via NGO grants and technical assistance. In Table 1 below, the technical assistance costs and NGO grant (programme) costs are disaggregated to determine indirect costs for the grantee NGOs. Table 2 provides information on the costs per visit

and costs per month per patient served for the urban and rural programmes. The cost per visit and cost per patient are based on available financial data held by KHANA and the partner NGOs, together with information obtained from in-depth interviews with programme managers on the level of effort of the programme for each of its program objectives. Costs for the urban programme based on level of effort are shown in Table 3.

For the household level income and financial information, household surveys were administered to 100 households participating in the home care programme to determine the changes in income, financial burdens, and time burdens faced by households coping with HIV infection. The survey was cross-sectional post-test only. A small sample (10) of hospital patients who did not receive home care services were also surveyed to try to establish an informal comparison.

**Table 1: Home Care Programme Cost: Post Pilot Phase**

	Urban Home Care Programme Costs (9.5 teams <sup>35</sup> )	Rural Home Care Programme Costs (1 team)	Total Urban and Rural:(10.5 teams)
<b>Technical Support and Capacity Building</b>	\$50,739	\$6,458	<b>\$57,197</b>
<b>Total Programme Costs (NGO Grants)</b>	\$100,765	\$15,614	<b>\$116,379</b>
Personnel	\$58,290	\$10,902	
Commodities	\$32,443	\$3,132	
Transport	\$10,032	\$1,580	
<b>Overhead</b>	\$31,552	\$4,974	<b>\$36,526</b>
<b>Total</b>	\$183,056	\$27,046	<b>\$210,102</b>
<b>Average cost per team per month</b>	\$1,606	\$2,254	<b>\$1,667</b>

TS and Capacity Building: group workshops and individual technical and organisational support visits, including percentage salaries of technical staff from the 2 INGOs; 5 LNGOs (including Khana) and NCHADS

Programme Costs: Personnel - Home Care Staff and Volunteers. Commodities - medicines and other materials in the Home Care Kits; patient welfare support; mobile telephone charges; stationery; support group costs and refreshments for community meetings. Transport - transportation for HCT staff for home care activities.

Overheads: percentage costs of INGO, LNGO, NCHADS and MoH rent, utilities, equipment, administration and non-technical staff.

<sup>35</sup> The tenth team in Phnom Penh has only been operating for 6 months, so costs were pro-rated

**Table 2: Home Care Programme Cost: Urban and Rural Areas**

	<b>Urban (Phnom Penh)</b>	<b>Rural (Battambang)</b>
<b>Programme costs</b>	(over 9.5 teams) \$183,056	(1 team) \$27,046
<b>Time period costed</b>	12 months	12 months
<b>Number of teams</b>	9.5	1
<b>Visits (average per team per month)</b>	173	154
<b>Patients (average per team per month)</b>	63	60
<b>Average cost per team per month</b>	\$1,606	\$2,254
<b>Average cost per patient per month</b>	\$25.50	\$37.60
<b>Average cost per visit</b>	\$9.28	\$14.60
<b>Per visit cost of patient-related activities</b>	\$6.58	\$10.39
<b>Per visit cost of addressing health needs of patient</b>	\$3.71	\$5.86

**Table 3: Urban Home Care Programme Cost by Programme Objective**

<b>Project Objective</b>	<b>% Level of Effort</b>	<b>Average Cost per Visit (Urban)</b>	<b>Average Cost per Patient per month (Urban)</b>
Improve Physical Well Being of Patients	40%	\$3.71	\$10.20
Improve Emotional Well Being of patients and families	15%	\$1.39	\$3.82
Improve Social Well Being of Patients and Families	8%	\$0.74	\$2.04
Improve Educational Well Being of Patients and Families	8%	\$0.74	\$2.04
<b>Total cost of patient-related activities</b>	<b>71%</b>	<b>\$6.58</b>	<b>\$18.11</b>
Non Patient Activity - Liaison with Community Leaders, etc	15%	\$1.39	\$3.83
Improve local NGO Capacity	10%	\$0.93	\$2.55
Improve MOH Capacity	4%	\$0.37	\$1.02
<b>TOTAL</b>	<b>100%</b>	<b>\$9.28</b>	<b>\$25.50</b>

## Cost Implications for Households

### 4.3

At the household level, families were asked questions about changes in household income and time available as a result of illness and care giving to PLHA. One hundred questionnaires were administered, with a 98% response rate for questions related to income and financial savings due to the home care programme. Of those who responded, all households stated that there was a decrease in earnings due to illness in the household, generally because the patient was less able/unable to work to earn income. The change in household income due to illness was reported to be from \$7.90 - 10.53 per week. Of the non-home-care participants who were interviewed in hospital, the reported range of decreased earnings was \$10 - \$20 per week.

When asked specifically if households visited by home care teams saved money on health care, 98% of respondents stated that they saved money, with a range of savings from \$0.80 - \$1.30 per week.

Of those respondents receiving home care who still use traditional healers, the range of financial savings due to decreased and/or more appropriate use ranged from \$5.30 to \$10.50 per week.

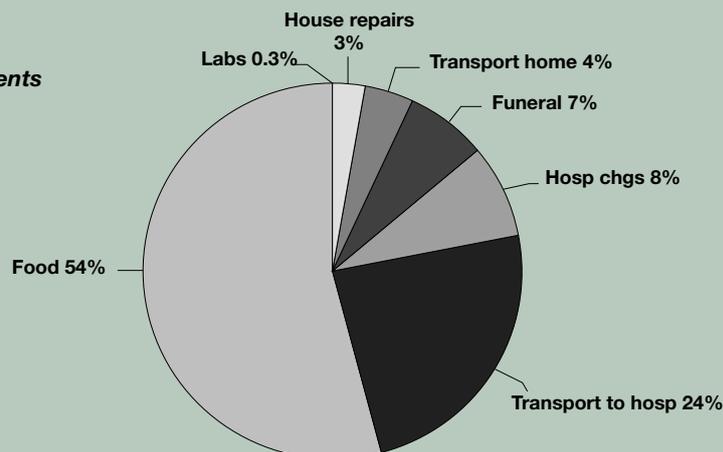
In addition to financial savings, respondents were asked about time savings due to the home care programme. 99% of respondents stated that they have more time available to them since they

began receiving visits. The average range of time saved was reported to be from 3 -4 days per month.

Providing care to PLHA can be a major burden on the household. 81% of respondents stated that they had care givers assisting them with their needs. Of the care-givers surveyed, 73% of those who care for PLHA stated that their incomes have decreased because of this duty. The range of financial decreases due to having to provide care was \$0.79 - \$1.05 per week. Of those who were not participating in the home care programme, 40% of caregivers reported a weekly decrease in earnings, ranging from \$5 - \$15. In terms of time savings, 100% of caregivers interviewed stated that the home care programme assisted by decreasing the time needed by the household to access medications and health facilities.

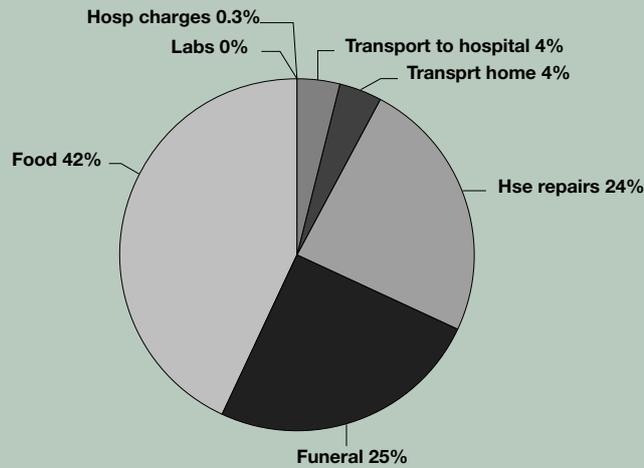
The home care programme also provides resources to households in need of welfare interventions such as food, transportation to health centre, etc. Figures 3 and 4 below indicate the welfare support provided by the urban and the rural programmes, based on household need. It is clear that the need for nutritionally appropriate food and for transport costs were the highest demands for resources among households receiving home-based care services.

**Figure 3**  
**Welfare Support to Patients**  
**(Phnom Penh)**



**Figure 4**

**Patient Support - Battambang**



## 4.4 Analysis and Conclusions

### 4.4.1 Cost and time savings to households

It is clear that the home care programme has provided households with significant benefits in terms of financial and time savings. The savings expressed by households participating in the programme are primarily due to changes in use of traditional healers and in the use of medicines provided by the HCTs.

The needs of households for basic food and resources was apparent in the use of welfare resources provided by the HCTs. Based on these needs it is clear that, for both the urban and the rural programme, in addition to basic medical care services, basic nutritional and welfare support is needed by households with PLHA. In the rural area, funeral expenses are also placing pressure on family expenditures as evidenced by the need for welfare for funeral costs.

### 4.4.2 Programme costs

In terms of programme costs, the cost of delivering services by the home care programme in Cambodia compares favourably with the cost of providing outpatient services. Given that the home care programme has multiple outputs, many of which result in benefits beyond improving the physical well-being of patients, it is important to try to associate programme costs with the appropriate outputs, based on level of effort. Table 3 highlights the relative levels of effort for each programme output and their resultant costs per visit and per patient.

This approach in associating programme outputs with cost per visit and cost per patient based on levels of effort is one way to begin appropriate cross-programme comparisons. Bunna & Myers<sup>36</sup> in 1999 estimated the costs of accessing out patient health care in Cambodia as \$15 per patient episode. This estimate was derived from data provided by a 1998 Ministry

<sup>36</sup> Bunna S and Myers CN "Estimated Economic Costs of AIDS in Cambodia", UNDP, 1999

<sup>37</sup> Ministry of Health 1998, "The demand for health care in Cambodia: Concepts for future research", National Public Health and Research Institute.

of Health study<sup>37</sup> on the demand for health care in Cambodia. This study notes that for an episode of illness, the majority of people bought medicine as their first course of action and the average amount paid was \$4.65. Of those who chose hospital as the first course of action, the average amount paid for an initial visit was \$17.30. Of those who bought medicine and continued seeking treatment, the most common course of action was going to hospital.

On average, respondents in the 1998 MoH study estimated paying \$7.30 for the first contact with any health care provider. For those who continued to seek care for the same episode of illness, the second contact was estimated to cost on average \$11.15, and the third, \$12.69.

Based on these responses, the rate of return was estimated to be 1.7. This indicates that when ill, a person seeks health care an average of 1.7 times for the same episode of illness. Applying the average costs, Bunna & Myers estimated that one episode of illness costs about \$15.

It should be emphasised that these figures refer to costs to the patient and not costs to the provider, so comparisons with the cost of home care provision should be treated with extreme caution.

The evaluation attempted to respond positively to the considerable, and perhaps disproportionate, interest in the cost of a home care visit in Cambodia. This estimate was achieved by compiling **all related costs** over the past 12 months incurred in implementing the programme and providing technical assistance.

Line items for salaries include an appropriate percentage of salaries of technical staff from the 2 INGOs; 5 LNGOs (including KHANA) and NCHADS. Technical Support and Capacity Building costs included group workshops and

individual technical and organisational support. Programme Costs include personnel (Home Care Staff and Volunteers). Costs of commodities include medicines and other materials in the Home Care Kits, patient welfare support, mobile telephone charges, stationery, support group costs and refreshments for community meetings. Transport costs reflected transportation for HCT staff for home care activities and visits. Overheads include a percentage of costs of INGO, LNGO, NCHADS and MoH rent, utilities, equipment, administration and non-technical staff.

The total cost figure was averaged over the past 12 months and divided by the number of teams (one of the urban HCTs only operated for half a year, hence there was 9.5 teams in the urban programme) to give an average cost per month per team of \$1606 for the urban programme and \$2254 for the rural programme. These figures were divided by the average number of home care visits per team per month for each of the 2 programmes, yielding an average cost per visit of \$9.28 in Phnom Penh and \$14.60 per visit in Battambang.

In making comparisons with the cost of outpatient services at hospitals, it should be noted that the home care figures include the costs of improving the emotional, educational and social well-being of the patient (in addition to improvements in physical well-being). They also include the costs of prevention and liaison activities in the community and the costs of building capacity of MoH and NGO partners in the programme.

A more realistic comparison with hospital out-patient treatment is provided by the cost associated with addressing the health needs of the patient using home-based care, which is estimated (based on level of effort) as \$3.71 per visit.

Given that the home care programme has many more benefits than just those related to the health of the patient, it is clear that when comparing costs against comparable objectives, the home care programme is significantly less expensive. Home care may be able to provide more services to patients while facility-based care may be able to provide the same service to more patients. This difference in programme approaches is important to note so cost comparisons can be applied more objectively.

**4.4.3 | Urban / rural cost comparisons**

The evaluation revealed that the cost of providing rural home care services is significantly (58%) higher than providing comparable services in Phnom Penh. The distribution of costs suggest that the need for technical support and the distance to deliver that support can require more resources in rural areas than in urban areas, especially in the initial phases of program start-up. It is assumed that these costs

will decrease as service delivery increases as a result of marginal changes with additional clients. Issues related to the rural programme are explored further in section 6 of this report. It should be noted that "rural programme" straddles a national highway (between Phnom Penh and Battambang). The programme environment should not therefore be construed as representing the realities of programming in most of rural Cambodia.

**4.4.4 | Cost comparisons with other home care programmes**

The evaluation reveals that the cost of the home care programme in Cambodia compares favourably with other community-based programmes and is significantly less expensive than facility-based programmes in other developing countries. Table 4 outlines available costs of (the limited number of) other home care programmes with cost assessments, compared with the Cambodia programme.

**Table 4: Cost of Home Care in Developing Countries**

Country	Cost per Visit (Urban)	Cost per Visit (Rural)	Cost per Client (Health Facility Based (OPD / Home Care)	Cost per Client (Community-Based Home Care)	Time Spent or Time Saved
Zimbabwe	\$16 -\$23	\$38-\$42			2-3hours per day spent for caregiving 11-25 hours per week
Zambia	\$26		\$1000	\$5.50	
Cambodia	\$9.28 \$3.71 for addressing health needs	\$14.64	\$15	\$10.20 for physical health \$25.50 for full home care service	Time Saved: 3-4 days per month

## Limitations of the Cost Analysis **4.5**

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*Without knowing the specific methods of cost analysis in other evaluations, it is difficult to provide meaningful cost comparisons across studies and settings. While illustrative comparisons are provided in this evaluation, it is difficult to assess the appropriateness of these comparisons as the methods of cost data collection and analysis are either unclear or*

*slightly different in the referenced studies. There were limitations in tabulating cost data in this evaluation, due to the retrospective nature of the data collection. We were not able to determine the exact expenditures per objective in the retrospective design and the cost per objective figures are estimated via key informant interviews.*

# 5 INPUTS AND PROCESS

## 5.1 The Home Care Network

*The Home Care Network in Phnom Penh (illustrated in Appendix II) now consists of 10 Home Care Teams (HCTs), of which seven receive financial and technical support from KHANA and three from World Vision. The seven Khana-supported teams are managed by 5 different local NGOs. The Home Care Network is co-ordinated through the AIDS Care Unit of NCHADS.*

Until March 2000 KHANA supported 2 teams through the MSF-supported CUHCA clinic, but following the closure of CUHCA, the teams themselves have formed their own local NGO, KOSHER, which KHANA is also now supporting. Maryknoll, an international NGO was supporting one team, but following a shift in January 2000 in their focus of activities, Maryknoll handed over the support of their team to WOMEN, a local NGO who were already receiving KHANA support.

The ability of WOMEN to expand the number of teams they manage, and the successful formation of KOSHER to manage 2 HCTs, are both indicators of improved local capacity within the Home Care Network, as direct outcomes of technical support provided by KHANA to the programme.

The teams are located at 9 Municipal Health Centres spread throughout the city. The health centres were selected by the Municipal Health Department, based on location, capacity and degree of commitment of support from the Health Centre Managers.

Monitoring of home care provision is conducted by a committee, representing NCHADS, MHD, KHANA, Health Centre Managers and the 6 participating NGOs, to whom the HCTs submit monthly reports. These reports are compiled by the Home Care Network Co-ordinator at NCHADS and reviewed at monthly meetings of what is presently called the "Project Committee". It is recommended that this is renamed the "Home-Care Network Group" (HCNG), to better reflect its function and the status of the programme. This term will be used in the remainder of the report.

During the pilot phase the HCNG was co-ordinated by the Project Co-ordinator, based at WHO. From February 1999, this responsibility was taken up by the Home Care Network Co-ordinator at NCHADS, with financial and technical support from KHANA.

### 5.1.1 Home Care Network Group Meetings

The evaluation team reviewed minutes of the HCNG Meetings (presently called Project Committee Meetings) for the past 12 months. In addition, members of the evaluation team participated in three HCNG Meetings during the course of the evaluation. It is appropriate for this evaluation to acknowledge and highlight the tremendous amount of professional commitment, time and effort put into these meetings by the members of the HCNG. As well as reviewing

the monthly HCT reports, participants at the meetings discuss ongoing and emerging issues, mostly raised by the HCTs, related to home care provision. The HCTs are represented at the meetings by the Home Care Network Co-ordinator who also chairs the meetings.

The evaluation team strongly concurs with both the HCNG and the HCTs themselves, that the HCNG Meetings are an essential component of the home care programme. The meetings serve a number of functions:

- they provide a feedback and support mechanism for sharing and addressing ongoing and emerging problems faced by the Home Care Teams. In the 3 meetings attended during the evaluation, the emerging problems of safe abortion for HIV+ mothers, and management of orphaned children were raised.
- they provide a communication mechanism between NCHADS, MHD, NGOs and the HCTs, for programme developments and innovations. Proposed developments include the use of Bactrim for prophylaxis and the establishment of closer linkages with the National TB Programme's DOTS team.
- they provide an overview and facilitate the co-ordination of home care activities within Phnom Penh, and elsewhere in Cambodia

***Lesson learned: Home Care Network Group Meetings provide feedback, co-ordination and support to the HCTs and are an important component of the home care programme.***

As the Home Care programme expands to meet the increasing demands for care and support, it is clear that a mechanism will be needed to plan for the expansion, co-ordinate activities and monitor outcomes. The Home Care Network Group is ideally placed to fulfil this role. In addition to continuing to provide feedback and support to the HCTs the Home Care Network Group will need to expand its role to provide a mechanism for:

- democratic planning and co-ordinating government and NGO partnerships
- assessing skills development needs and co-ordinating technical support and training
- strengthening links with other components of the referral network, including Voluntary Counselling & Testing, contraceptive services, STI services and TB services
- monitoring inputs, process, outcomes and impact.

Because of the important links between HIV/AIDS and TB, it is recommended that The National TB Hospital should be included in the list of collaborating institutions of the Home Care Network. It is further recommended that a representative from the Home Care Network Group is invited to be on the HIV/TB working group that is chaired by NCHADS.

**It is recommended that CENAT is included in the list of collaborating institutions of the Home Care Network**

**It is recommended that a representative from the Home Care Network Group is invited to be on the HIV/TB working group chaired by NCHADS**

The evaluation strongly recommends that organisations wishing to provide home-based care should be federated to the Home Care Network. This will go some way to ensuring quality, avoiding duplication of effort, facilitating co-ordination of activities and monitoring overall impact of home care provision.

**It is recommended that organisations wishing to provide home-based care are federated to the Home Care Network.**

In order to help the Home Care Network Group to begin to meet the increasing demands of expanding home care provision, the evaluation team recommends that the existing Home Care Network should be strengthened and institutionalised. However, there are dangers inherent in "over-institutionalising" the Network, perhaps by making it into a public sector committee. It is vital that the Home Care Network remains a responsive feedback, support, planning and co-ordination mechanism, as opposed to a bureaucracy.

**It is recommended that the Home Care Network is strengthened and institutionalised.**

#### **5.1.2 | Institutional base for the Home Care Network Group**

Because of the previous limited resources within the Municipal Health Department, the HCNG meetings have been held at NCHADS, and chaired by the Home Care Network Co-ordinator, who is also from NCHADS. The eval-

uation notes that, whilst NCHADS has done an excellent job in co-ordinating the Home Care Network, from an institutional perspective this responsibility should lie with the Municipal Health Department (MHD).

As the Home Care Teams are located in the MHD Health Centres, and given the expanded capacity of the MHD, the evaluation recommends that the Municipal AIDS Office would be a more appropriate institutional home for the Home Care Network Group. This relocation would be in line with ongoing Health Sector reforms and would enable the present Home Care Network Co-ordinator at NCHADS to devote more time to issues related to programme expansion.

**It is recommended that the Municipal AIDS Office begins to assume responsibility for co-ordinating the Home Care Network in Phnom Penh.**

#### **5.1.3 | Resourcing the Home Care Network Group**

Support to the Home Care Network Group itself is presently limited to salary and administrative support, provided by KHANA, to the Home Care Network Co-ordinator. The HCNG itself has no independent funds, and its ability to expand its role is therefore constrained.

In keeping with the recommendation to strengthen the Home Care Network, it is further recommended that the Home Care Network Group should become an autonomous unit, with its own resources and financial support.

**It is recommended that the Home Care Network Group becomes an autonomous unit, with its own resources and financial support**

In recommending that the HCNG becomes autonomous, it is important to acknowledge the key factors which contribute to its current effectiveness. Although the Network is co-ordinated from NCHADS, it retains external financial and technical assistance - originally from WHO, and since 1999 from KHANA. In moving the institutional base of the Home Care Network Group, as well as expanding its role, it will be important to ensure that this assistance not only continues, but is enhanced.

In the light of the proven track record of KHANA, and the experience of the home care programme of KHANA's current Technical Advisor, it is suggested that KHANA is approached to provide financial and technical support for an initial period of 6 months. It is suggested that funds would include salary and administrative support to the Home Care Network Co-ordinator, as is presently the case, together with additional resources to enable the Home Care Network Group to establish an independent identity. Technical support should be made available, initially to assist the transition from NCHADS to the Municipal Aids Office, and

then to build the capacity of the Home Care Network Group as a democratic planning and implementing partnership of NGO and government representatives.

**It is recommended that KHANA is approached to provide technical and financial support to facilitate the expansion and relocation of the Phnom Penh Home Care Network Group**

Given the important co-ordination role presently performed by the Home Care Network in Phnom Penh, the evaluation further recommends the establishment of Provincial Home Care Networks to co-ordinate the expansion of home care activities in the provinces. A key function of the Phnom Penh HCNG would then be to build the capacity of future Provincial Home Care Networks.

**It is recommended NCHADS considers establishing Provincial Home Care Networks to co-ordinate the expansion of home care activities to the provinces.**

## Home Care Team Formation

## 5.2

*Each home care team consists of 3 full-time NGO staff and 2 half-time government staff from the health centre. At the inception of the Pilot programme, both the NGOs and the health centres were asked to select interested staff members, who were then interviewed by a panel made up of representatives from the programme partners. A rating system was used to assess the interviewees' knowledge and attitudes towards PLHA, as well as their backgrounds. The 40 staff (initially there were 8*

*teams of 5), who were selected on merit, then discussed and signed an Agreement of Roles and Responsibilities.*

A small proportion of those who were selected were subsequently found to be unsuitable, and left the HCTs. Of the 40 staff originally selected, 35 are still working in the HCTs.

The home care staff, as well as the members of the Home Care Network Group have emphasised during this evaluation that the selection of the right staff for the home care teams is critical

to the success of the programme. The right set of attitudes of the team members towards PLHA (understanding, empathic, supportive, non-judgemental), is felt to be particularly important.

***Lesson learned: a competitive selection procedure for HCTs to ensure the right staff with the right set of attitudes towards PLHA is important to ensure quality home care provision***

Following selection, the first two weeks of training were largely devoted to team-building. This was partly to promote better understanding of the different strengths of NGO and MoH approaches to healthcare and development. It

was also felt that promoting good team spirit and collaboration from the beginning would help provide a support mechanism to alleviate the stresses which often arise in palliative care situations. Generally, staff from the same NGO stayed together in a team, but there was some mixing to achieve a good balance of skills, experience and gender within a team. This was necessary to meet the diverse needs of the home care programme.

***Lesson learned: achieving the right balance of skills, experience and gender within a team and fostering team support and collaboration are important inputs in setting up the home care programme***

## 5.3 Training and Resources

*For the initial home care training, the teams were divided into 2 mixed groups of 20. It was conducted in 3 one-week modules with the second week comprising a placement with an existing community health project.*

The training course was facilitated by a nurse-trainer from the MoH Master Trainer Programme. The trainers, who were drawn from a wide range of institutions, were encouraged to use participatory techniques including case studies and role plays as much as possible. The course contained modules on counselling, models of AIDS care, HIV/AIDS education for families, voluntary counselling & testing (VCT), home nursing care, hygiene, nutrition, use of drugs, managing symptoms, psychological problems, pain management, TB, traditional medicine, HIV/AIDS & children, working with volunteers, working with the community, and palliative care.

The lesson plans, handouts and summaries were compiled into a draft training pack in Khmer which is available at the AIDS Care Unit of NCHADS.

A participatory evaluation of the training course conducted immediately afterwards indicated a high degree of satisfaction by course participants in preparing them for their roles in the HCTs.

The consensus of HCT members interviewed during this evaluation, was that the initial training provided during start-up was essential preparation for their work in the home care programme.

***Lesson learned: comprehensive training for the HCTs, using participatory approaches where appropriate, is essential preparation for initiating a home care programme***

**It is recommended that the draft training pack used in initial training is updated and developed into a training resource pack for use when the home care programme is expanded.**

A heavily adapted Khmer version of WHO's "Handbook on AIDS Home Care" was one of the resources used during the training. This continues to be the main resource for the home care programme, with a copy being provided to each home care team member. Originally developed by NGOs in Africa, the handbook shows primary health workers how to manage symptoms in the home and how to use stories to teach about the realities of HIV/AIDS. The handbook has been extensively field tested and 5,000 copies have been printed by WHO for distribution by NCHADS. Because of the usefulness of this resource, it is recommended that the Handbook is re-translated into English and 1000 copies are printed for distribution to IOs and NGOs working in the field of AIDS Care. It is also recommended that the pictures from the "Home Care Stories" are incorporated into a flipchart for teaching purposes.

**It is recommended that the AIDS Care Handbook is translated into English and 1000 copies are printed for distribution to NGOs/IOs**

**It is recommended that pictures from Home Care Stories are incorporated into a flipchart for teaching purposes by organisations working in the field of AIDS care.**

In response to training needs identified during participatory reviews, KHANA and World Vision have supported and/or facilitated a series of further orientations and refresher training.

During September 1998 all HCT members underwent a 1-week placement in local hospitals and/or hospices to upgrade their diagnostic and treatment skills. The HCTs also hosted social workers from Social Services Cambodia to help improve their knowledge of HIV/AIDS.

In October and November 1999, with support from KHANA, all local NGO and government team members attended a 1-week basic counselling course. In addition, one NGO member and one government member of each team attended a 2-week post basic counselling course run by Quaker Services Australia (QSA) on contract from KHANA. KHANA has also contracted QSA to facilitate monthly counselling follow-up sessions with team members, where case studies are presented and discussed.

In the last quarter of 1999, KHANA ran a short course for HCTs in Appropriate Prescribing and contracted Douleurs sans Frontières to conduct a course for HCTs in Physiotherapy for Pain Relief.

The evaluation noted that these on-going training updates and orientations are helping the HCTs to provide a more professional service. However, a number of HCT staff still express a desire for further training. The team members perceived that their main skills/knowledge gaps were in clinical diagnosis and management of symptoms, in the appropriate use of pharmaceutical products, and in counselling.

In the light of recent and ongoing training, the evaluation team are of the opinion that further counselling training is not a high priority. Indeed, in the 17 observations of home care teams at work, the evaluation team were particularly impressed with the counselling skills of the home care staff, and noted that these were among some of the best they had observed in Cambodia.

It is believed however, that there is a case for upgrading skills in clinical diagnosis of common conditions related to HIV/AIDS. It is to the credit of the home care team staff that they recognise the need for better diagnostic skills, especially in a country where the prevailing medical ethos does not encourage sharing diagnosis with patients, and where self-prescription and treatment without diagnosis is common.

It is also felt that HCT staff should continue to receive ongoing refresher training in treatment regimes to enable them to deal with issues and answer questions from patients about medication, side effects, etc. A case study approach could be used to address individual issues as they arise.

It is evident that, with the increase in the AIDS epidemic and the widening profiles of PLHA, the HCTs will continue to face new issues and challenges. One issue which emerged during this evaluation is the increasing number of pregnant women who are HIV+ and who do not wish to continue the pregnancy. A second

challenge, which is becoming increasingly prevalent, is the number of children, many of whom are themselves HIV+, who have become, or who will soon become orphaned because of AIDS-related deaths.

It is recommended that the Home Care Network assumes responsibility for establishing and implementing a system of ongoing refresher training and orientations to deal with these emerging issues. Some training can be conducted on-the-job, while other issues can be dealt with during short workshops. It is believed that the Home Care Network can draw on existing skills and resources available in Cambodia, and it is suggested that KHANA, MoH, NGOs, and other ministries could play a major role in resourcing this.

**It is recommended that the Home Care Network implements a schedule of ongoing refresher training and orientations to deal with emerging issues facing HCTs. KHANA, MoH, NGOs and other ministries could act as resources with funding and support through the Home Care Network.**

## 5.4 Home Care Activities

*Observations and interviews conducted during this evaluation confirmed findings from a previous review, that approximately 80% of the HCT's time is spent in contact with patients and families, including local travel to visit the patients. The remaining 20% of the time of the HCTs is spent on activities which are not directly related to patients. These activities include liaison with community leaders, monks, health centres and hospitals, participating in NGO and homecare team meetings, community-based IEC activities,*

*identifying and establishing links with other community-based initiatives, etc.*

The majority of the patient contact time takes place in the patient's own living environment. Sometimes this is a permanent dwelling, but since the majority of the home care patients are extremely poor, the living environment is often a squatter settlement, a temporary shelter or a tarpaulin. Occasionally, patients visit the team at the health centre, and sometimes team members accompany patients to hospitals or testing centres.

Each HCT splits into two groups of 2 staff, and patients are visited by one of the groups an average of 3 times per month. The contact time with patients and families is devoted to providing the four main components of home care:

- **Clinical Management to improve the physical well-being of patients. This includes taking patients to hospital and testing centres, providing rational treatment of HIV-related illnesses using the home care kit, where appropriate, and providing follow-up care.**
- **Nursing Care and health education to patients and care-givers to promote and maintain hygiene, nutrition and infection control, and providing palliative and terminal care to PLHA**
- **Counselling, including psychosocial support to PLHA and their families, to improve the emotional well being of patients and families by reducing stress and anxiety and promoting positive living and risk reduction strategies**
- **Social Support, including material assistance, providing education & information, strengthening links with the community, and referral to support groups and services in order to improve the social well-being of patients and families.**



Figure 5

Each patient receives an average of three full home-care visits each month, with the actual number of visits, duration and activities performed being determined by the team according to the patient's needs. In addition, because the geographical areas in which they work are generally small, the HCT will often just "look in" on patients as they pass their homes<sup>38</sup>. Most patients are generally visited in this way at least once per week. Of the 100 patients interviewed during the evaluation, 98% said they were visited at least once per week and 84% said they were visited at least twice per week by the HCTs. Eighty eight per cent were happy with the frequency of visits they received, 11% wanted more visits, and 1% wanted less.

Given the present human resource capacity of the HCTs, maintaining the current number of visits places severe limitations on the number of patients who can be visited by the teams. Reviews with the teams indicate that 80 patients per team is a practical upper limit to their capacity, and most teams are now working at, or near to this limit.

Following the review of the project last year, checklists were developed for different types of home visits, although the evaluation team did not observe these being used systematically.

In a typical "maintenance" visit, lasting approximately 20 minutes, the team reviews the physical, educational and emotional status of the patient and family, prescribes medication where appropriate from the Home Care Kit (see Fig. 6), shows the patient and primary caregiver (if present) how to provide simple relief of symptoms, reinforces proper understanding of HIV/AIDS including prevention, and provides food and a small amount of money, where necessary, for transport to hospital and other material needs.

There are some emerging issues related to the provision of money by the HCTs to PLHA. At the onset of the project, the aim was to only provide small amounts of money against specific criteria, e.g. for transport to hospital, or in cases of destitution. While some HCTs still follow this approach, others provide a fixed sum (around \$0.30) to every patient on each visit. It could be argued that the majority of PLHA visited by the HCTs are poor and vulnerable, and the provision of small sums of money is a major factor in maintaining the quality of life of patients and families. Furthermore, an increasing percentage of patients visited are women, who are likely to be more vulnerable and in need of financial support.

However, there is a risk that routinely providing money to PLHA is fostering financial dependency, with the HCT acting as a financial support service. It is therefore recommended that the HCTs return to the original remit of providing food and materials, but only providing money against specific criteria. These criteria should be agreed within the Home Care Network so they are consistent across teams.

**It is recommended that HCTs should only provide money to PLHA against specific criteria which are agreed in consultation with the Home Care Network**

The 100 patients interviewed in Phnom Penh during the evaluation were asked, in an open-response question, what are the most important things about home care visits. 34% mentioned money, 13% mentioned transport, 5% mentioned food and 9% mentioned other materials. Far more important in patients' perceptions however, was the provision of medicine (mentioned by 58%),

and the feeling provided by the visits of being cared for and not being isolated (30%), and the encouragement and hope provided by counselling (40%). 11% mentioned education about HIV/AIDS and the importance of good hygiene and nutrition as being among the most important things about the home care visits.

Participant observations of home care visits, and focus group discussions with the HCTs revealed that there is a fairly standard set of activities performed by the teams related to clinical management, nursing care and counselling. However, there is an increasing diversity, both within and across the teams, in activities related to social support and non-patient-related activities.

Examples of social support activities include establishing and maintaining support groups for PLHA, providing food and money, helping patients to find accommodation and work, shopping and cooking for bedridden patients, doing simple house repairs, referring patients to other medical services.

Examples of activities not directly related to patients include liaising with local authorities, religious leaders, community organisations, traditional healers, testing centres, hospitals and health centres, conducting community-based IEC sessions on HIV/AIDS, providing condoms and education to sex workers, finding homes for orphaned children, visiting families of deceased patients, organising and attending funerals.

The above lists of activities, which are not exhaustive, are provided to illustrate the existing, and increasing, responsibilities being undertaken by the home care teams, in addition to meeting ongoing needs of patients and

families for effective clinical management, nursing care and counselling. There is clearly a limit to which the home care teams can continue to meet the increasing expectations of clients, particularly in view of the increasing client load as the epidemic expands.

**It is recommended that the HCNG includes a module on "Managing Client Expectations" as part of the ongoing counselling training provided to HCTs.**

As many of the home care teams are now working at their maximum recommended client load of 80 patients per team, there is a need to rationalise the way in which the teams operate. One solution may lie in expanding the involvement of volunteers in the programme, while another possible approach may be to improve linkages with social support organisations. These approaches will be explored further in sections 5.10 and 5.11 of this report.

There is also perhaps a need to re-examine the balance between the four components of home care provision, and to revisit one of the primary roles of the HCTs which is supporting the family to address their welfare problems rather than solving their problems for them. It is recommended that the Home Care Network Group initiates a review process, in which the roles and responsibilities of the Home Care Teams are re-examined and rationalised, and strategic priorities are agreed.

**It is recommended that the HCNG initiates a review process to clarify and agree strategic priorities for home care activities and to rationalise the roles and responsibilities of the Home Care Teams.**

## 5.5 Home Care Kit

The major resource for clinical management of symptoms and opportunistic infections is the Home Care Kit (see figure 6 below, and the photograph on page 16).

Figure 6

<b>Home Care Kit</b>	
<b>Paracetamol 500mg</b>	<b>Scissors</b>
<b>Potassium Permanganate 10mg sachets</b>	<b>Cotton Wool</b>
<b>10% Iodine Solution 30ml vials</b>	<b>Plastic Bags</b>
<b>Benzyl Benzoate 30ml</b>	<b>Elastic Bands</b>
<b>Gentian Violet 15ml vials</b>	<b>Cloths</b>
<b>Nystatin Suspension 25ml</b>	<b>Soap Powder</b>
<b>Loperamide</b>	<b>Household Bleach</b>
<b>Primperan</b>	<b>Hydrogen Peroxide 30ml vials</b>
<b>Promethazine 100ml</b>	<b>Matches</b>
<b>Multivitamin Tabs</b>	<b>Tweezers</b>
<b>Oral Rehydration Salts</b>	<b>Plasters</b>
<b>Bicarbonate of Soda 500mg Tabs</b>	<b>Micropore Tape</b>
<b>Menthol Balm</b>	<b>Safety Pins</b>
<b>Coconut Oil</b>	<b>Talcum Powder</b>
<b>Gloves</b>	<b>Condoms</b>
<b>Bandages</b>	

Each team has 2 kits so they can divide into two groups for home care visits. The health centre nurses are responsible for the upkeep of the kits and for recording the items used. The HCT Co-ordinators report when the stocks are low and replacement items, which are funded by KHANA through NGO grants, are distributed through NCHADS by the Home Care Network Co-ordinator.

Because Home-based Care Activities are not part of the minimum package of activities (MPA) of the MoH, there is no agreement with MoH Central Medical Stores to provide medicines and other items. At present, supplies for the kits are purchased in bulk from local pharmacies by the Home Care Co-ordinator, with money provided by the NGO grants. The quality and availability of these supplies varies

considerably, and the HCTs often complain of shortages and poor quality. Some Health Centres make up this shortfall when they have surplus supplies, but this cannot be relied upon.

It is recommended that MoH further integrates the Home Care programme into procurement plans so that Central Medical Stores are able to resource the drugs for the home care kits through the Health Centres. This would be a phased process which would initially involve the MoH including the drugs in the kits in the essential drugs list. The cost of Home Care Kit supplies for each team is approximately \$30 per month. This includes items not available at CMS, such as soap, cloths, etc. which would continue to be provided through the NGO's programme grants.

**It is recommended that MoH includes drugs used in Home Care Kits in the essential drugs list.**

**It is recommended that Central Medical Stores initiates steps to provide drugs for Home Care Kits through Health Centres.**

Many of the home care teams reported that their stocks of some medicines (especially Nystatin, Promethazine, Multivitamins and Paracetamol) are depleted long before the end of the month. Part of the reason lies in some team members responding to the pressure from non-home-care clients, who they encounter in the community, for medicines for pain relief and other minor symptoms. This is justified (by some teams at least) as enhancing community co-operation and avoiding discrimination against AIDS patients.

However, observations of home visits indicated that prescribing medicines by the teams to patients was not always rational, and that

there was sometimes a tendency to hand out a standard package of medication without adequate diagnosis. Whilst it should be noted that such practise is widespread in Cambodian health services, the evaluation team feels that this could be helped by more frequent and more supportive medical supervision. The issue of supervision will be addressed in section 4.9 of this report.

**It is recommended that the HCNG reviews the criteria and rationalises the process of prescribing medicines to patients.**

There is one further issue related to medication, which is pertinent to raise at this juncture. Recent research in Africa, supported by WHO and UNAIDS, has endorsed the regular use of cotrimoxazole (marketed as Bactrim) for prophylaxis for PLHA. The recommendation is that prophylaxis should be given life long for HIV+ adults and children, supported by a package of education, monitoring and follow up.

Recently, three of the HCTs have been trialing the provision of Bactrim for PLHA, under the supervision of the medical co-ordinator. This evaluation wholeheartedly supports this initiative, and recommends that Bactrim is provided by all the HCTs to all PLHA, supported by an appropriate package of training for the HCTs, and education, monitoring and follow-up for the patients. During the preparation of this report, MSF were approached to provide Bactrim to the HCTs.

**It is recommended that the Home Care Network Group reviews the criteria for home care provision of Bactrim to HIV patients in Cambodia, ensuring that there are clear guidelines for selection and monitoring of patients.**

## 5.6 Referrals

*A key component of the continuum of care is a functional referral system between hospitals, district-level health facilities, VCT and community support structures, including the home care teams themselves. This is necessary to enable PLHA to access the appropriate level of care, according to the stage of their illness, thus avoiding overburdening hospitals with minor ailments and ensuring more serious conditions are treated promptly.*

Acknowledging the importance of referrals for PLHA, significant efforts were made during, and subsequent to, the pilot phase to establish a viable referral system within Phnom Penh. Referral forms were developed, and the key staff at the main hospitals were consulted and briefed about the referral system.

The strategy was that patients would only be referred by HCTs to hospital when their condition required an intervention which could not be provided at home. It was anticipated that the hospitals would accept the judgement of the HCTs on the need for admission and would facilitate easy referral.

On discharge, patients would be referred by the hospitals back to the appropriate HCT, with continuity of care being maintained through the use of "yellow cards" containing patient data.

Despite concerted efforts by the HCTs and the HCNG, it appears that this component of the referral system is not working effectively. The home care programme has had limited success in institutionalising referrals to and from hospitals. The evaluation found that only 11% of patients were referred by hospitals, compared with 15% the previous year.

Furthermore, the HCTs frequently report problems encountered when taking patients to the main referral hospitals, and the patients themselves often refuse to go to hospital because of the long waiting times and perceived unwelcome reception from hospital staff.

Recently, the HCTs reported some difficulties encountered at Centre of Hope, when patients waited all day without being attended to. It appears that these difficulties arose because neither the HCTs nor the patients fully understand the "lottery system" employed by Hope for dealing with outpatients. This issue should easily be resolved through a meeting of HCT Co-ordinators and Hope medical staff.

At Calmette Hospital, on more than one occasion, staff have refused to accept HIV test results from approved VCT centres, even when the patient was accompanied by the HCT, and have insisted on the patients being re-tested.

It is perhaps unfair to highlight these two issues, as there have been problems with referrals to other institutions. It is believed that institutionalising the home care programme more firmly within MoH will help to resolve these problems.

During the pilot phase, each of the HCTs was attached to one of the four main referral hospitals (Calmette, Norodom Sihanouk, Municipal Hospital and Centre of Hope), according to geographical location. Each hospital designated contact staff, who were supposed to know, and be known by each member of the HCTs. It is strongly recommended that this system, which has long lapsed, is reinstated.

Each of the referral hospitals should work closely with their "partner" HCTs to provide medical supervision, and to agree a set of criteria for admission of a patient, or for the provision of outpatient treatment. This should help to improve the diagnostic skills of the HCTs and avoid unnecessary referrals.

It is believed that these strategies will help to improve the referral process and thus fill one major gap in the continuum of care.

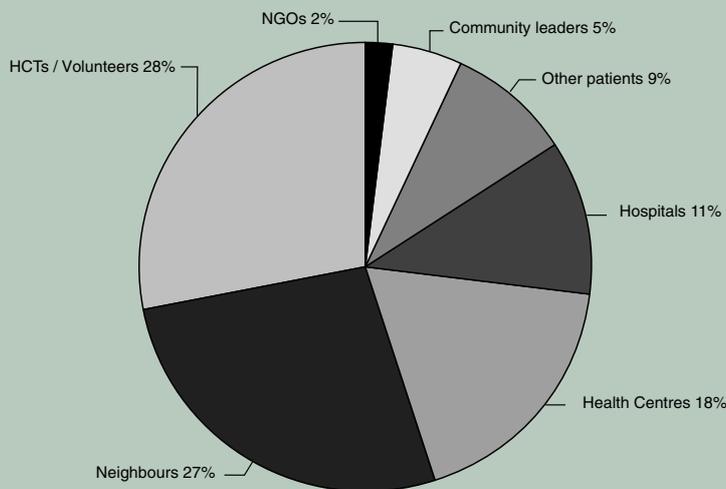
**It is recommended that the HCNG strengthens the hospital referral system by reinstating the system of attaching each of the HCTs to one of the main referral hospitals in Phnom Penh. The designated hospital**

**would then assume responsibility for medical supervision and facilitate referrals for their partner HCTs.**

On a positive note, the evaluation found that the vast majority of referrals of patients to the HCTs arise from within the community, with an increasing number coming from neighbours (27%), other patients (9%) and community leaders (5%). Many patients (28%) are found by the HCTs themselves, generally through their volunteers, but also through the weekly meetings where referrals are exchanged between the teams. Health Centres referred a further 18% of patients. (see figure 7 below).

Figure 7

Sources of referral



It is felt that the increasingly high levels of community-based referrals provides significant indicators of success of the programme. These process indicators are outlined below:

- increased referrals from neighbours and other patients indicates reduced discrimination against PLHA and increased trust in the HCTs
- increased referrals from volunteers indicates acceptance of the volunteers within the community and their successful involvement in the programme
- increased referrals from community leaders indicates support of the programme and confidence in the HCTs by local authorities

## 5.7 Record Keeping

*If continuity of care for PLHA is to be maintained throughout the illness then it is important that a simple but effective system of patient records should be established and maintained.*

From a perspective of providing care, it has become convenient to refer to five stages related to HIV infection:

- **people uninfected, but at risk**
- **asymptomatic HIV+**
- **early HIV disease**
- **severe disease equivalent to AIDS**
- **terminal illness**

During the pilot phase, a system of record keeping using specially designed "yellow cards" was developed. Each patient was assigned a card which was used to collect data on the location of the patient, history of the disease, present condition, family situation, and current

medication. The cards were held by the nearest HCT and were used for referrals when taking a patient for testing or to hospital. The cards also provided a record of the evolving condition of the patient and could be used for monitoring progress and planning appropriate home care visits.

During observations of home care visits, it was noted that, while some teams continued to use these cards, there was no pattern of consistent use in other teams. Given the breakdown in the referral system with hospitals, there is perhaps some justification for discontinuing using the cards. However, it was also noted that the standard of record-keeping was generally uneven and sometimes inadequate. Maintaining good patient records is important for client monitoring, prioritising needs, planning visit schedules and structuring the visits themselves.

**It is recommended that the Home Care Network Group reviews and strengthens the system of record keeping, planning and prioritising visits to patients.**

## 5.8 Monitoring & Reporting

### 5.8.1 Monitoring inputs and process

The issue of uneven quality of monthly data on patient numbers and team activities provided by the HCTs to the Home Care Network Group has been described in an earlier section of this report (Section 2.6, Methodology: Limitations of the Evaluation).

It is recommended that the monthly figures for patients, visits and team activities are quality reviewed before each monthly HCNG meeting, and that the HCTs reach a common understanding with the Home Care Network Co-ordinator on the definitions of a home care visit and a home care patient, for accounting purposes.

**It is recommended that the Home Care Network reviews with the HCTs the system of monitoring and reporting patient numbers and team activities.**

In addition to numbers of visits and patient numbers, the monthly team reports also provide data on referrals, deaths, volunteer activities, community contacts, expenditure, etc., all of which are useful for monitoring inputs and process.

### 5.8.2 | Monitoring impact

Apart from reviews and evaluations such as this one, there is no system in place to measure the impact of the programme on PLHA, families, communities or the health system. It is strongly recommended that the HCNG initiates a process to establish an impact monitoring system for the Home Care programme. Having a pilot monitoring system underway in Phnom Penh will provide valuable lessons in establishing a system in the Provinces, where capacity and resources may be more limited.

Decisions need to be made on:

- **what should be monitored (and why)?**
- **what are the most appropriate methods?**
- **who should conduct the monitoring?**
- **are any special skills required, and if so, who should help develop these skills?**
- **over what scale and timeframe may the different types of monitoring be appropriate?**

It is beyond the scope of this report to develop specific recommendations on the answers to these questions. However, the following suggestions are offered:

- **Selected Quality of Life (QoL) indicators would be most appropriate for measuring impact on PLHA and their families. Case studies could complement routine sampling of families visited by the HCTs.**
- **At the community level, support groups and community leaders could be involved in participatory impact monitoring activities, perhaps using PLA techniques and involving volunteers.**
- **At city level, the HCNG would need to liaise with hospitals and health centres to develop appropriate indicators and methods of verifying the impact of the programme.**

The HCTs have already begun a process of identifying indicators, and this will hopefully be continued during the forthcoming participatory local partner reviews in July. However, the difficulties in establishing even a simple but effective impact monitoring system should not be underestimated, and external resources and expertise in impact monitoring are likely to be required.

**It is recommended that the HCNG seeks technical support to facilitate the process of establishing an impact monitoring system for the Home Care programme, including developing appropriate indicators.**

## 5.9 Supervision

*Supervision is provided at two levels in the home care programme in Phnom Penh. Each team has a Team Coordinator for day-to-day supervision and receives twice-monthly visits from external supervisors. In addition to daily supervision of their own HCTs, they are also responsible for communicating information between the HCTs and the Home Care Network Co-ordinator.*

The Team Co-ordinators were initially selected by the Project committee, but are now elected by their own teams.

At the start of the pilot project, two medical doctors visited the teams once each month, to supervise team activities and provide clinical assistance to difficult cases. After the 6-month review, supervision was split into one visit for medical consultation, and one to supervise team management. Simple forms are used to assist the supervisors to give feedback on each aspect, and these are collated by the Home Care Network Co-ordinator and included in the monthly reports to the HCNG.

At present, management supervision is provided by some members of the HCNG and some of the Health Centre Managers. Medical supervision is provided by doctors on a rota basis drawn up each month by the Home Care Network Co-ordinator. However, it is becoming increasingly difficult to find doctors who are willing to provide medical supervision, even with the provision of a small honorarium to cover travel expenses.

Discussions with the HCTs clearly indicate that the HCTs place great value on supervision, and visits by supervisors are welcomed. All the HCTs were emphatic that they would like more medical supervision to assist them in dealing with

difficult medical cases and to help them improve their clinical and diagnostic skills, especially for TB. Enhanced management supervision would help to address issues of reporting and planning discussed earlier.

***Lesson learned: supportive supervision is a key component of the home care programme and is highly valued by the home care teams***

Given the present difficulties of finding supervisors, it is difficult to see how the demands for more supervision can be met using the existing system. Policy changes to integrate home care provision into the MoH system may help to facilitate the allocation of medical supervisors. However, the supervisory needs of the HCTs are for more facilitative and supportive supervision, rather than just more frequent supervision. Earlier sections of this report identified needs of the HCTs for refresher training and a supportive approach to supervision in a number of areas:- assessment of symptoms; analysis of needs; dispensing medication; reporting; prioritising; planning visits.

Following an earlier recommendation (Section 4.6) that each HCT is "attached" to an existing referral hospital, it is further recommended that each hospital is responsible for providing supervisory support to their HCTs. In order to provide good supervision, the supervisors themselves must be resourced and trained in supportive approaches to supervision. A set of tools and approaches has been developed by AVSC International which may help to address this issue.

***It is recommended that the referral hospitals provide supportive medical supervision***

**to their partner HCTs. The supervisors must be resourced and trained in facilitative supervision.**

There is also a possible pool of resources within the international and local NGO communities which could be drawn upon to provide

supervision to the HCTs and which could be resourced through the Home Care Network.

**It is recommended that the Home Care Network identifies and resources a pool of supervisors from government and NGOs to provide facilitative supervision to the HCTs.**

## Volunteers

## 5.10

*Beginning in August 1998, each HCT recruited 5 Volunteers to assist the team with their work. Each Volunteer is expected to work approximately 10 days per month, for which they receive a stipend of \$12.*

The Volunteers are recruited from the communities in which they live. They are often recommended by the local authorities in the community, and are interviewed by the HCTs and selected on merit as part of the recruitment process. The interviews assess their knowledge of HIV/AIDS and their attitude towards PLHA, and whether their families will agree to them working in this field.

The HCTs provide 60 hours of training, and the Volunteers are then attached to the teams. Most HCTs reported that they have identified many people keen to work as Volunteers. Some of the HCTs felt that they could use more Volunteers, but were restricted to a maximum of five by financial and management constraints.

Discussions held separately with the HCTs and with the Volunteers clearly demonstrated that the Volunteers are well integrated and play a number of important roles in the existing home care programme. It is felt that the role of Volunteers will be a key component of the programme when it is expanded to the provinces.

***Lesson learned: Volunteers play a number of important roles in the home care programme and are likely to be a key component in the expansion programme***

The HCTs were unanimous and unstinting in their praise for the work performed by the Volunteers. Because they are drawn from the community in which they live, the Volunteers are well placed to facilitate links with other community activities, to ensure access and accessibility of HCTs, and they are major sources of referral of new patients to the HCTs.

Unfortunately, there is quite a high turnover of Volunteers. Sometimes this is because they take up paid employment, but often it is because of illness or death, as many of the Volunteers are themselves HIV+. A number HCTs however, still have some of their original Volunteers from August 1998.

It is clear that the Volunteers generally work far longer than the 10 days per month originally allocated, with many working up to 20 days per month. In our observations of the home care activities, the Volunteers appeared to be professional and committed in their dealings with the patients.

Discussions with a representative sample of 16 volunteers drawn from eight of the HCTs revealed that they come from a variety of back-

grounds. Some were village leaders, others were students, while others were professionals willing to give spare time to the programme. A number revealed that they were HIV positive.

In addition to their work as part of the HCTs, the Volunteers felt that they were better placed to perform some roles which the HCTs were less able to undertake. The evaluation concurs with this view and notes that the Volunteers:

- **are a major source (perhaps *the* major source) of referral of new patients**
- **are trusted by the community and have good access to local authorities, pagodas, phum leaders etc**
- **often know about, and are able to develop links with other community level initiatives, such as micro-credit and food distribution programmes**
- **are well placed to identify and facilitate placements of orphans within the community**
- **often have good relationships with traditional healers, and are in a good position to help break down the mutual mistrust which sometimes exists between traditional healers and orthodox medical practitioners**

The Volunteers also made the valid point that, because they live in the community in which they work in home care, they are always potentially on call by the community.

*"We are on duty 24 hours a day, 7 days a week"*  
[Male Home Care Volunteer, Phnom Penh]

The Volunteers expressed the need for more training in stress management - for both the patients and themselves, and said they sometimes felt at risk in their work. One said that she had been repeatedly threatened by a brothel owner, who refused access to his sex workers; another had been involved in a motorbike accident while taking a patient to hospital; another had contracted TB since joining the programme. To address these issues, the Volunteers requested a basic package of health cover from the programme.

*"We take risks to take care of patients; sometimes we are exposed to dangers; we need some protection"*  
[Female Home Care Volunteer, Phnom Penh]

When asked why they continued to work as volunteers, despite the low remuneration and the perceived risks, their responses were unequivocal:

*"The future of Cambodia is in the hands of Cambodians; we want to help our people"*  
[Female Home Care Volunteer, Phnom Penh]

*"AIDS is a kind of cold war that we need to fight"*  
[Male Home Care Volunteer, Phnom Penh]

*"If we don't try to prevent AIDS and don't take care of its victims, there is no future for us or our children"*  
[Female Home Care Volunteer, Phnom Penh]

The Volunteers and the full-time HCT members all made a strong case for increasing the stipend for Volunteers from \$12 to \$20 per month, and for providing a basic package of health cover to all Volunteers. The consequences of adopting these suggestions however, should be carefully considered. A

stipend of \$20 per month, and the provision of health cover both signify a movement from 'volunteer status' into 'employment status'. This reduces community participation, increases the level of external intervention and raises issues of sustainability.

The evaluation team believes that increased volunteer input would be highly beneficial to the programme, but also believes that the costs and liabilities of increasing the number of days worked per month by the volunteers outweigh the benefits. The evaluation therefore suggests that there should be no upper limit on the numbers of volunteers who are attached to a HCT, but recommends that an increase from 5 to 10 would be sensible as a first step. One of the HCTs has already recruited an addition 5 Volunteers (who are all PLHA). The evaluation further recommends that Volunteers are reminded that they are not expected to work more than 10 days per month.

Because of the essential package of activities provided by the Volunteers, at minimal cost, we strongly recommend expanding and strengthening Volunteer involvement in the home care programme, both in Phnom Penh, but particularly in the provinces. In addition to clarifying more specific roles for the Volunteers, measures such as regular meetings and ID cards should be considered.

These measures would then enable the professional Home Care Team staff to move up to the next level of service provision, focusing on assessment, providing medical care and psychosocial support to PLHA, and management and supervision of the Volunteers. A "buddy system" could provide a support mechanism for day-to-day activities of the Volunteers. It is clear that an expanded system of Volunteers

would need careful planning and adequate resourcing, and would need to evolve over time.

**It is recommended that the Volunteer involvement in the Home Care programme in Phnom Penh and the Provinces is strengthened and expanded**

**It is recommended resources are provided for HCTs to increase the maximum number of Volunteers per team from 5 to 10, and that Volunteers are encouraged not to work more than 10 days per month**

**It is recommended that Volunteers begin to assume most of the social support responsibilities of home care provision, in addition to most of the non-patient-related activities**

**It is recommended that HCTs should review and upgrade the skills of the Volunteers, to enable some to provide basic counselling to PLHA and to support peer counselling by PLHA**

In addition, outside of urban settings, it is suggested that Volunteers are attached to the village, rather than to the Home Care Team. This issue is dealt with at greater length in Section 7.2 of this report.

## 5.11 Support groups and other linkages

*During the internal review of the programme in June 1999, the HCTs identified the need to establish support groups for PLHA. To date, six support groups have been established by the HCTs, with a total of approximately 200 members.*

Many of the support group members are also involved with home care, and some are Volunteers attached to the HCTs. The evaluation did not talk specifically to the support groups, but discussions with patients, volunteers and the HCTs indicate that the support groups are starting to become an important mechanism for education and psychological care.

While some HCTs are expanding their links within the community, there appears to be no strategic plans for identifying and establishing links with other community-based welfare and support initiatives. This will become increasingly important as the numbers of patients expand and their needs and expectations begin to

exceed what the HCTs can provide. As noted earlier in the report, the Volunteers can play a useful role here, given appropriate guidance and support. However, the HCTs are already fully stretched, and while the monthly meetings of the HCNG sometimes address issues of community links, the evaluation recommends that a more formal linking mechanism is established.

It is suggested that the HCNG identifies and funds one or more dedicated Community Liaison Officers, whose responsibility would be to map existing and new community resources, perhaps with the help of the Volunteers, and assist HCTs to facilitate the links between PLHA and these resources.

**It is recommended that that HCNG identifies and supports Community Liaison Officers to improve and expand links between HCTs and community-based welfare and support activities.**

## Caring for the Carers

## 5.12

*Providing professional home-based care is undoubtedly a stressful occupation. It takes great resilience to deal on a daily basis with PLHA, many of whom are chronically ill, some suffering from depression, and some requiring terminal care. Furthermore, expanding numbers of PLHA and increasing expectations for care, support and welfare can only add to stress levels within the HCTs.*

Focus group discussions with the HCTs revealed the perceived need for increased skills in stress management, both for PLHA but also for the HCTs themselves. All of the HCTs also indicated the need for increased and improved supervision and support.

Many of the HCTs raised concerns about health and safety at work. In order to address these, and other issues related to better support for the HCTs, the evaluation offers the following suggestions and recommendations:

- **HCNG should provide ongoing training in stress management to all HCTs**
- **HCNG should provide more opportunities for regular sharing of experiences and problem solving, perhaps by bringing together clusters of 2 or 3 HCTs**
- **NGOs/ MOH should provide motorcycle helmets to all members of the HCTs**
- **HCNG should investigate costs and benefits of providing a package of basic health cover to all HCT members. (MoH staff and some NGO staff already have such cover)**

**It is recommended that the HCNG addresses the concerns of HCTs related to health and safety at work.**

# 6 BATTAMBANG PILOT PROJECT

## 6.1 The Home Care Network

*In August 1999, two KHANA NGO partners, Battambang Women's AIDS Project (BWAP) and the Khmer Rural Development Agency (KRDA), each established a Home Care Team in partnership with local MoH staff, and with financial and technical support from KHANA. The BWAP/MoH team operated in Chai Serey, while KRDA, in collaboration with the District Referral Hospital set up a HCT in Moung Russey, approximately 50 km south of Battambang town. Both teams followed the same model as the Phnom Penh HCTs.*

Because of internal problems within the NGO, BWAP suspended operations in December 1999, and home care services in their district were discontinued. Following the recent resolution of the problems, it is anticipated that the BWAP team will shortly resume the provision of home care activities in their area. However, this evaluation focuses only on the activities of the KRDA/MoH team in Moung Russey.

The Moung Russey Home Care Team is based on the same model as the Phnom Penh teams. The team consists of 3 NGO members and 2 half-time government nurses from the local Referral Hospital. Because of renovations at the hospital, the team is based in the KRDA offices, although KHANA has recommended that they relocate to the hospital once space is available. Despite some initial problems, the Moung Russey team now appear to be working well as a joint MoH/NGO team.

The HCT seems to have established a good working relationship with the Referral Hospital, who provide medical supervision to the team. Referrals for the HCT generally come from the community, rather than from the hospital.

Although the caseload is smaller, the team spends more money on patient welfare than the Phnom Penh teams. The Home Care Team argue that the patients are poorer than in Phnom Penh, but the Evaluation Team saw little to justify this claim.

## 6.2 Impact

*It is clear that the programme in Moung Russey is having a major impact in improving the quality of the lives of PLHA, their families and caregivers, increasing understanding of HIV/AIDS*

*and reducing discrimination against PLHA.*

Discrimination against PLHA and their families seems less of a problem than in Phnom Penh, possibly because of closer and

longer-standing community relationships. During our limited visit, the evaluation team observed neighbours visiting patients and providing food and care.

*"Since the home care team started visiting me every week, I want to keep on living. The community takes care of me and visits me more than before"*  
[PLHA, Kansai Banteay]

*"My family now eats with me since the home care team counselled them and explained how HIV is transmitted"*  
[PLHA, Kear 3]

As part of the evaluation, 7 ex-patients from the suspended home-care team (BWAP) were traced and followed-up to evaluate what changes had occurred since the home care services had been discontinued some 4 months ago.

It was clear that the BWAP home-care services were badly missed by all the ex-patients visited. Five of the seven ex-patients said their physical health had deteriorated badly; they complained of recurrent fever, diarrhoea and skin problems. When asked what they missed most about the home care visits, medication and psychological support were most frequently mentioned.

## Community Links

## 6.3

*Because of the long distances involved, the HCT relies quite heavily on community organisations to provide support to PLHA. Wherever possible, the HCT tries to work with existing organisations, but have themselves established 12 community support organisations where none previously existed. Unlike Phnom Penh, where a number of PLHA live alone, almost all the rural PLHA have caregivers.*

The Home Care Team has established good relations with community leaders in the 9 Communes in which they operate. As part of the evaluation, the Evaluation Team conducted a focus group discussion with 14 community leaders representing all 7 villages in Ko Koh Commune. This group consisted of Village Headmen and Village Association Leaders.

The Home Care Team presently works in 5 of these 7 villages. The discussion with the community leaders highlighted the impact made by the HCT in the 5 villages in which they operate, compared with the remaining 2 villages. The

leaders from the 5 villages visited by the HCTs noted that the HCT takes care of PLHA, but more importantly, have taught and encouraged the community to care and support the patients.

*"They are helping us to help each other. I thank the gods that they have come to our village"*  
[Village Headman, Ko Koh]

The community leaders emphasised that the HCT activities converge with other community-level support activities, and help to relieve some of the burden of the community, improve health and reduce discrimination against PLHA.

*"Their education work they do is important for the health of our village. The patients are waiting (for the HCT). Before, we felt that people with AIDS were evil and deserved to die. Now we talk together, sit together, play cards together"*  
[Village Headman, Ko Koh]

It was clear that the HCT had also had a significant impact on knowledge and understanding of HIV/AIDS, especially modes of transmission.

*"Before the home care team visited our village we knew nothing about HIV/AIDS. Thanks to them, people now know about prevention. They have also learnt about sanitation and how to take care of themselves"*

[Village Association Leader, Ko Koh]

*"Before the home care team came we did not even dare to approach people with AIDS. Now we can touch them, hold them, eat with them and help to feed them"*

[Village Headman, Ko Koh]

This latter comment provoked a barrage of questions from the 4 leaders from the 2 villages which were not visited by the HCT. These four men seemed genuinely surprised that people

could touch and eat with PLHA, and wanted to know about methods of transmission. The impact of the HCT's HIV/AIDS education programme was clearly demonstrated when the leaders from the 5 villages visited by the HCT provided the answers themselves.

It should be noted that, in addition to their Home Care Team, KRDA have a Prevention Team operating in the area, who may (also) have been responsible for educating the community. In order to avoid duplication of effort, KRDA are in the process of combining their Care and Prevention Programmes.

The community leaders suggested appointing volunteers to act as liaison persons in each village, to provide a nodal link with the HCT. These volunteers would need to be trained and would require a little financial support. The leaders felt that, with adequate resources and support, a system of volunteers would be key to reaching all PLHA in rural areas.

## 6.4 Volunteers

*The team has recruited 4 Volunteers, two of whom are themselves HIV+. The Volunteers receive a stipend of \$15 per month (compared with \$12 in Phnom Penh). As the Volunteers live in the community, they have established close links with the patients and play a major role in providing counselling and support to PLHA, their families and*

*caregivers. As in Phnom Penh, the Volunteers are becoming a major source of referral of patients.*

There is apparently no shortage of volunteers willing to work alongside the HCT, but the number that can be recruited is limited by the financial resources available in the NGO grants to support them.

## 6.5 Access/coverage

*It is clear that one HCT is limited in its ability to reach the majority of PLHA. Moug Russey District, covering an area of some 1000 sq km,*

*has 13 communes, and the HCT presently works in 9 of these. The team visits patients in 21 villages, but they are unable to cover the*

*remaining 88 villages in the area. Although some villages are quite accessible, many are distant (up to 20 km) and the road conditions are often poor. Travelling to these (even in the dry season) can take 40-50 minutes. During the rains, access is often impossible.*

It is estimated that up to 25% of allocated patient contact time is spent travelling to visit patients. Transport costs are correspondingly high and the team spends over \$120 per month on travel (compared with \$80 per team in Phnom Penh).

Because of the time spent on travel, the

maximum patient caseload of 60 is lower than in Phnom Penh at 80. It is estimated that the number of visits over the operating period averages at 154 per month.

An extremely rough estimate of coverage of the district by the HCT can be made if we assume an even spread of PLHA throughout the villages of the district. The HCT visits 21 (i.e. 19%) of the 109 villages. If, as in Phnom Penh, the HCT reaches between 50-80% of the clients in the areas they visit, this indicates that the team will only provide 10 -15% coverage in the district.

# 7 EXPANSION OF THE HOME CARE PROGRAMME

The forthcoming MoH/NCHADS Strategic Plan for HIV/AIDS Prevention & Care has, as one of its strategic goals, the extension and expansion of the Home-based Care programme nation-wide. The findings of this evaluation strongly support such an expansion.

As the report has indicated earlier, it is clear that the programme in Phnom Penh, and the pilot initiative in Battambang are having a significant impact on quality of life of PLHA and their families, on reducing discrimination and improving prevention, and on addressing some of the needs of the poorest and most vulnerable members of society.

Extending and expanding the programme raises a number of key questions:

1. what are the key components of Home Care provision which need to be in place for an expanded programme to be successful?
2. can the model used in Phnom Penh (and the Battambang pilot) simply be replicated

in rural areas, or are there alternative models which may be more suitable?

3. how should the expansion be phased, and where should it begin?
4. which institutions and/or organisations are best placed to implement the expanded programme?
5. what mechanisms should be in place to co-ordinate and manage the expanded programme?
6. which institutions and/or organisations are best placed to provide technical support?
7. what will be the costs involved in expansion?

*and of course:*

8. are there sustainable sources of financial support available to resource the programme?

This section of the report will address the first two questions, and will attempt to provide some insights into the remainder.

## 7.1 Key Components

*Section 5 of this report reviewed the inputs and processes involved in establishing and maintaining the existing Home Care programme. It will be useful to summarise here the key compo-*

*nents of the programme which have contributed to its success, and which should ideally be incorporated in its expansion. These include:*

- **A well-resourced and supportive Home Care Network** programme and local NGOs who participate in the programme
- **The establishment of strong partnerships between MoH and NGOs**
  - between KHANA and their partner NGOs who support the Home Care teams
  - between the Home Care Teams and the Health Centres at which they are based
- **Selective team formation and composition**
  - between the Home Care Teams and leaders of the communities in which they work
- **Expansion and integration of volunteers into the programme**
  - between the government and NGO Home Care Team members who implement the programme
- **Close linkages with the community, increasing community involvement and ownership**
- **Appropriate initial and ongoing training**
- **The provision of adequate technical and financial resources and support**
- **Ongoing reviews, monitoring and evaluation**
- **The establishment of a supportive system of medical and management supervision**

These partnerships have enabled scarce resources to be shared, and have ensured that the comparative advantages of each of the players have been effectively utilised.

***Lesson learned: partnerships have enabled scarce resources to be shared, and have ensured that the comparative advantages of each of the players have been effectively utilised.***

Basing the HCTs in MoH Health Centres has assisted in convergence with the public health system, and has gone some way to promote a sense of shared ownership of the programme between MoH and NGOs. More equitable sharing of financial responsibilities and commitments between government and NGOs will further enhance shared ownership. However, the implications of transferring (at least some of) the responsibility of financial support from KHANA and the NGOs to MoH has not been evaluated.

Partnerships between the home care programme and referral hospitals in Phnom Penh have been less successful. It will be important to establish and maintain good links

Each of these will be briefly reviewed in the sections below:

#### **7.1.1 | The establishment of strong partnerships**

This evaluation has noted that good partnerships exist at a number of levels in the Home Care programme:

- between MoH/NCHADS, KHANA and the international NGOs who support the

between the home care programme and referral hospitals and health centres in the Provinces.

### 7.1.2 | **Selective team formation and composition**

Findings from this evaluation indicate that the selection of the right personnel and achieving the right mix of skills and experience in the HCTs is critical to successful team working.

Combining staff with medical backgrounds and those with experience in AIDS prevention and counselling in the Home Care Teams has been instrumental in providing a comprehensive service to PLHA and their families. It has also fostered cross-learning and improved understanding between the MoH and NGO staff. Using a process of competitive selection has ensured that the right staff with the right attitudes are recruited onto the teams.

### 7.1.3 | **Expansion and integration of volunteers into the programme**

This evaluation found that Volunteers are increasingly fulfilling a number of important roles in the Home Care Programme:

- They are proving to be the major source of referral of new patients
- They often occupy positions of trust within the community and are well placed to facilitate good access to local authorities, pagodas, phum leaders, etc.
- They are well placed to develop links other community level initiatives, such as micro-credit and food distribution programmes

- They are well placed to identify and facilitate placements of orphans within the community
- They often have good relationships with traditional healers, and are in a good position to help break down the mutual mistrust which sometimes exists between traditional healers and orthodox medical practitioners

**It is recommended that Volunteer involvement is expanded and strengthened and that Volunteers begin to assume most of the social support responsibilities of home care provision, in addition to many of the non-patient-related activities**

### 7.1.4 | **Close linkages with the community, increasing community involvement and ownership**

During a participatory review of the Home Care programme the Home Care Teams identified the support from community leaders as the most important factor contributing to the successful implementation of their work. This was reiterated during discussions held with HCTs during this evaluation.

***Lesson learned: support from community leaders is an important factor contributing to the successful implementation of the work of the HCTs***

In addition to helping to ensure support from local authorities, establishing close linkages with the community is important in accessing existing community-based welfare initiatives and in mobilising community resources to support programme activities.

### 7.1.5 | **Appropriate initial and ongoing training**

On recruitment, very few of the HCT staff were familiar with the key aspects (clinical, psychological, social and educational) of home care provision. Initial training, including community placement, in the essential aspects of home care was therefore essential preparation for work in the HCTs. In addition, during the two years of the programme, KHANA has supported and/or provided up to five further orientations and updates for the home care staff. These training sessions have been in response to identified needs to update or provide new skills.

The evaluation team believes that adequate and appropriate initial training, supplemented by responsive, preferably on-the-job, refresher training are key components to maintain professionalism of home care provision.

### 7.1.6 | **Provision of adequate technical and financial resources and support**

Since the WHO pilot period, technical and financial support has been provided to the participating local NGOs and government team members by KHANA with support from MoH and the AIDS Alliance, while World Vision and Maryknoll have supported their own HCTs, both with donor support. This support has resulted in increased capacity of the NGOs to manage their Home Care Teams, and of both MoH and NGO staff of the HCTs to manage their work programmes. This evaluation recognises the importance of this support and emphasises that it will be an essential component in the expanded programme. It will be important to identify the

appropriate mechanism to ensure continuous financial support to the home care programme.

There are some indications that a number of donors are expressing interest in supporting the home care programme. This would provide an excellent opportunity to trial a sub-sector-wide approach of donor support to a health programme and the evaluation recommends that this approach should be explored.

**It is recommended that donors explore the possibility of trialing a sub-sector-wide approach to funding the Home Care Programme in Cambodia.**

### 7.1.7 | **Ongoing reviews, monitoring and evaluation**

Participatory and external reviews, monitoring and evaluation are essential components of any programme, and especially an evolving programme. This evaluation notes that the many reviews and evaluations have helped shape and improve the Home Care programme. It is to the credit of those involved in managing its implementation that they have demonstrated flexibility and responsiveness in modifying the programme to accommodate evaluation findings.

***Lesson learned: participatory reviews and responsive management have played an important role in helping to shape and guide the home care programme.***

Developing and establishing a participatory review system, which monitors both process

and impact, and includes appropriate indicators, will be an essential component of an expanded home care programme. Identifying appropriate technical resources will be a necessary first step in establishing an impact monitoring system.

**7.1.8 | Establishment of a supportive system of medical and management supervision**

Good supervision has been shown to be a key factor in the provision of quality services, and yet is often the missing link in service delivery programmes. The findings of this evaluation demonstrate the importance of, and demand for a supportive supervisory system to address the management and medical needs of the providers of home-based care.

A supportive supervisory structure will be particularly important in the rural areas where long distances between centres and villages are likely to result in greater isolation of home care providers from resource centres

**7.1.9 | A well-resourced and supportive Home Care Network**

The evaluation notes that the establishment and maintenance of the Home Care Network in Phnom Penh has been critical in helping to ensure co-ordination of support, improve linkages and assist the programme to better meet the increasing demands for improved care and support at low cost.

The establishment of similar Home Care Networks at Provincial level will be beneficial to help manage and co-ordinate the expansion of home care activities in the provinces. They are likely to play an important part in co-ordinating activities, avoiding duplication and ensuring co-ordination of technical support and training, establishing and maintaining links with other initiatives and institutions and facilitating monitoring of process, outputs and impact.

**7.2 Expansion Models**

*Although the home care model described in this report works efficiently and cost-effectively in Phnom Penh, there are dangers in simply transferring the model wholesale to the Provinces. The previous section highlighted the key components which contribute to the success of the model, and which should be replicated in the expansion.*

However, one major difference between Phnom Penh and most of the Provinces, is the large distance between villages, health centres and hospitals, and between the villages them-

selves. As shown by the Battambang pilot, using professional HCTs with the same cadres of staff as in Phnom Penh to visit patients in outlying villages is neither efficient nor cost-effective. It is estimated (see section 6.6 of this report) that the existing model in Battambang is only providing between 10-15% coverage in the district.

Furthermore, cost estimates discussed earlier in the report (section 4.4.3) indicate that the cost of providing services in rural areas using

this model can be significantly higher than the cost of providing similar services in urban areas.

It is clear that HIV infection is well-established and has reached the general population in every province<sup>39</sup>. Given the current prevalence rate, it is estimated that a typical Operational District (O.D.) will have between 1000-2000 PLHA. Using the present Battambang pilot/Phnom Penh model, where the rural HCT has a patient load of 60 per month, this would indicate that between 10-25 HCTs per O.D. would be necessary to give the degree of coverage presently provided in Phnom Penh. Given the limited infrastructure and human resources in the provinces, and the uncertainty of financial support, it is unlikely that this approach will be feasible.

There are a number of alternative partnership and funding options for expansion of the programme to the provinces. Based on the findings of this evaluation, four possibilities are suggested below:

### **Option 1**

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Adapt and scale up the existing model to selected provinces, maintaining the current key components:

- Home Care Team structure consisting of government nurses, NGO staff and community volunteers.
- co-ordination by a representative network group, through the Provincial AIDS Office
- funding through NGOs with donor support
- external Technical Assistance to co-ordinate the network

Based on lessons learned from the rural pilot, the adaptation could conceivably involve:

- A 4-person District-level Home Care Team based at the Referral Hospital (Operational District Level) rather than Health Centre (Commune Level)
- The District-level HCT liases directly with 2 person Commune HCTs based at each Health Centre
- Commune HCTs liase with Village Home Care Volunteers (1 or 2 per village), who will become the grass-roots providers of home-based care.

It is estimated that the above adaptations to the rural environment will enable up to 1,500 patients to be visited per O.D, an average of 3 times a month, at a programme cost of between \$50-70,000 a year.

### **Option 2**

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The model outlined above would be employed, but all funding would be provided through the government, rather than through NGOs. It should be noted that whilst this option is entirely possible, it has not yet been tried. It is likely that external Technical Assistance would still be required to co-ordinate the Network and provide training to Home Care staff.

### **Option 3**

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Again, use the above model, but with government funding the government component, whilst the NGO component is funded from non-government sources. Again, while this mechanism is possible, it has not been tested.

<sup>39</sup> Consensus workshop on HIV/AIDS in Cambodia, Phnom Penh, 1999 op.cit.

#### Option 4

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Although the evaluation has shown that government/NGO partnerships are key to the success of this approach, ministries other than the Ministry of Health (for example the Ministry of Women's & Veterans' Affairs) could be involved to a greater or lesser extent. It is likely that there would still be a requirement for external technical assistance.

A key evaluation recommendation for the existing urban Home Care Network to become an independently resourced group should also apply to future Provincial Home Care Networks, however funded. The Provincial AIDS Office (PAO) is well placed to host the Network, perhaps with joint coordinators from the PAO itself and an NGO. It is reasonable to assume that technical support will be required from both NCHADS and perhaps an external source, such as KHANA, to ensure that Provincial Networks are well established and resourced. In addition, it is likely that Provincial Home Care Networks will need technical assistance to enable them to respond to the training needs of the home care staff, and in establishing effective referral and monitoring systems.

The options outlined above all draw on the key components reviewed in the previous section of this report, namely:

- **good partnerships (between MoH, NGOs/CBOs and possibly other ministries)**
- **selective team formation and composition**
- **expansion and integration of volunteers (who are now likely to be the primary providers of home-based care)**
- **closer community participation (the home care programme is now located within the community, fostering greater ownership and involvement)**
- **supportive supervisory system (operating at three levels, and converging with the existing MoH supervisory system)**

- **a supportive home care network (drawing on resources of key partners throughout the province).**

It should be reiterated that if this model is to operate effectively, it is important that the other key components outlined in the previous section are also put in place. These include:

- **appropriate initial and ongoing training**
- **adequate technical and financial resources and support**
- **ongoing reviews, monitoring and evaluation**

These are only a few of a number of possible options for consideration. The costs associated with these models will need to be carefully estimated. However, it is likely that they will be significantly less than those associated with simply replicating the present model throughout the O.D.

The evaluation team recommends that the cost-benefits of these, and other models, should be examined. Given the diversity of resources and capacities of various players in different Provinces it would be wrong to be prescriptive at this stage. It may be that different models are needed for different Provinces, and that the existing Phnom Penh model would operate effectively in urban centres in other Provinces.

**It is recommended that NCHADS and partners examine the cost-benefits of different models for expansion. Different models may be needed for different locations.**

**It is recommended that NCHADS and partners ensure that key components are included when expanding the programme to the Provinces**

## Phasing the Expansion

7.3

*A key lesson learned by the evaluation about setting up the existing home care programme was the importance of careful planning to ensure that the key components were in place. This included developing appropriate systems and procedures, establishing effective partnerships, creating awareness and fostering ownership at each stage. The time taken to do this should not be underestimated.*

In order to ensure that these elements are in place at Provincial level, and given the limitations on human and financial resources, it is

suggested that the planned expansion takes place in several phases over the coming years.

It might be appropriate to limit the expansion, at least initially, to the Provinces which have operation systems for Voluntary Counselling & Testing (VCT). At present this includes Battambang, Siem Reap, Kompong Cham and Kompong Som. This will facilitate integration of the programme into existing networks. It may also be appropriate to begin in Accelerated Development Districts (ADDs) which have operational Health Centres.

## Roles and Responsibilities of Programme Partners

7.4

*For an expanded model to be effective, several key institutional and structural questions need to be addressed:-*

- 1. which institutions and/or organisations are best placed to implement the expanded programme?**
- 2. what mechanisms should be put in place to co-ordinate and manage the expanded programme?**
- 3. which institutions and/or organisations are best placed to provide technical support?**

As Government/NGO partnerships have proved so successful in implementing the existing programme, this evaluation recommends continuing these partnerships in implementing the expansion. There are sensitive issues related to funding and control of funds which will need to be addressed as and when potential funding sources become clearer.

It would be wrong to be prescriptive in identifying institutions to manage and co-ordinate the expansion, and in any case, this is beyond the scope of the evaluation. However, it is clear that MoH/NCHADS are extremely well placed to manage and co-ordinate the expansion through existing MoH structures. In some Provinces the PAOs will be able to co-ordinate the Home Care Networks which will play an important role in providing support to the programme. In some Provinces, other mechanisms, such as PAC/PAS may be better placed to perform this role.

**It is recommended that MoH/NCHADS takes the main co-ordinating role in expanding the Home Care Programme in Cambodia.**

With regard to support, KHANA has been proactive and effective in providing both technical and financial support to the existing

programme. KHANA and other organisations, such as World Vision will need to make internal decisions on whether they wish to increase their support as the programme expands to the provinces. As the programme goes to scale, it is clear that other organisations and institutions, perhaps drawn both from government and NGO sectors will be needed to provide financial and technical resources. Sharing resources between many partners has helped and will continue to help to reduce costs and improve coverage. The Multi-sectoral Unit of NCHADS is well-placed to identify and co-ordinate government partnerships, while KHANA is perhaps best placed to identify and co-ordinate NGO partnerships.

If it is decided that KHANA should be involved in the expansion programme, then it is recommended that the Alliance should increase

its financial support to KHANA for prevention, care and support activities, while maintaining its present level of technical support.

**It is recommended that the Alliance should increase its financial support to KHANA for prevention, care and support activities, while maintaining its present level of technical support.**

Given that strong government/NGO partnerships have contributed significantly towards the success of the Cambodia Home Care Programme, it is recommended that the Alliance considers using this model elsewhere.

**It is recommended that the Alliance considers using the Cambodian Home Care Model in other AIDS care programmes that they support.**

# 8 SUMMARY OF KEY COMPONENTS, LESSONS LEARNED AND RECOMMENDATIONS

*This section provides a summary of the key components of the home care programme, together with lessons learned and recommendations for improving the programme in Phnom Penh and expanding the programme into the Provinces.*

## **Key Components of the Home Care Model**

**8.1**

- A well-resourced and supportive Home Care Network
- Strong government/NGO partnerships
- Selective team formation and composition
- Integration of volunteers into the programme
- Close linkages with the community, increasing community involvement and ownership
- Appropriate initial and ongoing training
- The provision of adequate technical and financial resources and support
- Ongoing reviews, monitoring and evaluation
- The establishment of a supportive system of supervision

## **Lessons Learned**

**8.2**

- Home Care Network Group Meetings provide valuable feedback, co-ordination and support to the HCTs and are an important component of the home care programme
- A competitive selection procedure for HCTs to ensure the right staff with the right set of attitudes towards PLHA is important to ensure quality home care provision

- Achieving the right balance of skills, experience and gender within a team and fostering team support and collaboration are important inputs in setting up the home care programme
- Comprehensive training for the HCTs, using participatory approaches where appropriate, is essential preparation for initiating a home care programme
- Supportive supervision is a key component of the home care programme and is highly valued by the home care teams
- Volunteers play a number of important roles in the home care programme and are likely to be a key component in the expansion programme
- Strong NGO/government partnerships have enabled scarce resources to be shared, and have ensured that the comparative advantages of each of the players have been effectively utilised
- Support from community leaders is an important factor contributing to the successful implementation of the work of the HCTs
- Participatory reviews and responsive management have played an important role in helping to shape and guide the home care programme.

## 8.3 Recommendations

### Home Care Network

*It is recommended that:*

- The Home Care Network group becomes an autonomous unit with its own resources and financial support in order to ensure co-ordination of technical support, improve links with other initiatives and facilitate monitoring.
- The Municipal Health Department AIDS Office begins to assume responsibility for co-ordinating the Home Care Network in Phnom Penh
- Because of its capacity and present involvement in the programme, KHANA is approached to provide technical and financial support to facilitate the expansion and relocation of the Home Care Network Group
- The HCNG seeks technical support to facilitate the process of establishing an impact monitoring system for the home care programme, including developing appropriate indicators
- The Home Care Network Group addresses the concerns of HCTs related to health and safety at work
- organisations wishing to provide home-based care are federated to the Home Care Network
- CENAT is included in the list of collaborating institutions of the Home Care Network
- a representative from the Home Care Network Group is invited to be on the HIV/TB working group chaired by NCHADS
- HCNG identifies and supports Community Liaison Officers to improve and expand links between HCTs and community-based welfare and support activities

## Home Care Activities

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*It is recommended that:*

- The Home Care Network Group initiates a review process to clarify and agree strategic priorities for home care activities and to rationalise the roles and responsibilities of the home care teams
- Home Care Teams (HCTs) should only provide money to PLHA against specific criteria which are agreed in consultation with the Home Care Network
- The Home Care Network Group reviews with the HCTs the system of monitoring and reporting patient numbers and team activities
- MoH includes drugs used in Home Care Kits in the Essential Drugs list
- Central Medical Stores initiates steps to provide drugs for Home Care Kits through Health Centres
- Home Care Network Group reviews the criteria and rationalises the process of prescribing medicines to patients.
- The Home Care Network Group reviews the criteria for home care provision of prophylactic Bactrim to HIV patients in Cambodia, ensuring that there are clear guidelines for selection and monitoring of patients.

## Referrals, Supervision and Training

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*It is recommended that:*

- The HCNG strengthens the hospital referral system by reinstating the system of attaching each of the HCTs to one of the main referral hospitals in Phnom Penh. The designated hospital would then assume responsibility for medical supervision and facilitate referrals for their partner HCTs
- Home-based Care activities are further integrated into the programme of work of Health

Centres in Phnom Penh and Referral Hospitals in the Provinces

- Referral hospitals provide supportive supervision to attached HCTs. Supervisors must be resourced and trained in facilitative supervision
- The Home Care Network identifies and resources a pool of supervisors from government and NGOs to provide facilitative supervision to the HCTs
- The Home Care Network Group reviews and strengthens the system of record keeping, planning and prioritising visits to patients
- The Home Care Network implements a schedule of ongoing refresher training and orientations to deal with emerging issues facing HCTs. KHANA, NGOs, MoH and other ministries could act as resources with funding and support through the Home Care Network
- The draft training pack used in initial training is updated and developed into a training resource pack for use when the home care programme is expanded
- The AIDS Care Handbook is translated into English and 1000 copies are printed for distribution to NGOs/IOs
- Pictures from the Home Care Stories are incorporated into a flipchart for teaching purposes by organisations working in the field of AIDS care.
- Module on "Managing Client Expectations" is included as part of the ongoing counselling training provided to HCTs

## Volunteer Expansion

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*It is recommended that:*

- The Home Care Teams expand and strengthen Volunteer involvement in the home care programme in Phnom Penh and the Provinces

- The maximum number of Volunteers per team is increased from five to ten and Volunteers are encouraged not to work more than 10 days per month
- Volunteers begin to assume more of the social support responsibilities of home care provision, in addition to many of the non-patient-related activities
- The HCTs review and upgrade the skills of the Volunteers, to enable some to provide basic counselling to PLHA and to support peer counselling by PLHA
- MoH/NCHADS and partners consider establishing Home Care Networks at Provincial level. These are likely to play an important part in co-ordinating activities, avoiding duplication and ensuring co-ordination of technical support and training, establishing and maintaining links with other initiatives and institutions and facilitating monitoring of process, outputs and impact.
- Donors explore the possibility of trialing a sub-sector-wide approach to funding the home care programme in Cambodia

### **Programme Expansion**

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*It is recommended that:*

- NCHADS and partners examine the cost-benefits of different models for expansion. Different models may be needed for different locations
- NCHADS and partners ensure that key components of the home care model are incorporated when expanding the programme to the Provinces.
- MoH/NCHADS takes the main co-ordinating role in expanding the home care programme in Cambodia
- The Alliance increases its financial support to KHANA for prevention, care and support activities, while maintaining its present level of technical support
- The Alliance considers using the Cambodian Home Care Model in other AIDS care programmes that they support.

# APPENDICES

# APPENDIX I

## **1a**      **Questions for Patients and Families** (to be asked by neutral interviewer)

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**Name of team that visits this family:**  
**Interview number:**

***Introduce interviewer and explain the purpose of the interview.  
Ask permission from the patient & family before proceeding.***

Age of patient \_\_\_\_\_

Sex of patient \_\_\_\_\_

### **Introductory questions**

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**1.** How did you first hear about the Home Care Team? (*tick one*)

- in hospital
- at the health centre
- at home
- from a neighbour
- at a phum meeting
- at the pagoda
- other (.....)

**2.** a) How soon after you heard about the Home Care Team did you first meet them?

b) How long ago was this?

**3.** Where did you first meet the Home Care Team? (*tick one*)

- in hospital
- at the health centre
- at your home
- at a phum meeting
- other (.....)

4. a) How often do they visit you each week? (*tick one*)

- less than once
- once
- twice
- more than twice
- whenever necessary

b) How do you feel about the frequency of visits? (*tick one*)

- too often
- not often enough
- about right

c) How often would you like to be visited by the Team?

#### **Referral**

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5. a) Has the Home Care Team ever taken or sent the patient to a health centre, a hospital or a testing centre? YES / NO (*circle one*)

If YES:

b) When was the last time:

c) Which facility was the patient sent or taken to?

d) Who accompanied the patient?

e) What were the good things which happened during the visit?

f) What were the not-so-good things which happened during the visit?

g) What difference (if any) did the Home Care Team make to how the patient was treated during the visit?

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#### **Questions specifically to the patient**

#### **Impact**

---

6. a) Have you been diagnosed as HIV+? YES / NO (*circle one*)

If YES:

b) When were you diagnosed as HIV+?

**7. What effect has the Home Care Team had on the following:**

- a) your understanding of HIV/AIDS
- b) your general well-being and physical health
- c) the number of visits you make to hospital
- d) the time you spend in hospital
- e) the time it takes to get medicines at the hospital
- f) the time and money you spend on traditional healers
- g) the way you are treated by your family
- h) the way you are treated by the local community
- i) the way you look after yourself (e.g. nutrition, hygiene)
- j) your sexual behaviour
- k) how much you feel in control of your own life
- l) your outlook (attitude about the future)
- m) your plans for the future of your dependants (if relevant)
- n) your comfort in sharing information about your HIV status with others

**8. If you didn't have Home Care support, how might things be different (if at all)?**

.....

**Questions to the family/caregiver** (If the patient is living alone, go to Qu 11)

**Impact**

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**9. What effect has the Home Care team had on the following:**

- a) your understanding of HIV/AIDS
- b) the time you spend on care of the patient in the home
- c) the amount of money you spend on care of the patient in the home
- d) the time you spend accessing clinics, hospitals or pharmacies
- e) the amount of money you spend accessing clinics, hospitals or pharmacies
- f) the time and money you spend accessing traditional healers
- g) how able you are to provide care
- h) how you prevent transmission of HIV
- i) how the community behaves towards your family
- j) how you cope overall with the situation of having a person living in the family with HIV/AIDS

**10.** If you didn't have Home Care support, how might things be different (if at all)?

### Children

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**11.** Are there any children in the family? YES / NO (*circle one*)

If YES:

Since the patient became sick, how has this affected the lives of the children?

- a) Have they had to start working? YES / NO (*circle one*)
- b) Have they had to provide care or take up other major additional household duties? YES / NO (*circle one*)
- c) Have they had to leave school? YES / NO (*circle one*)
- d) Have they had to go without things (e.g. food, clothes, books?) YES / NO (*circle one*)
- e) Have they had to leave the home or live in another household? YES / NO (*circle one*)

**12.** Has participating in the home care programme resulted in any changes for the children in the household? YES / NO (*circle one*)

If YES:

What changes?

### Income

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**13.** a) Has the patient had a decrease in earnings due to illness? YES / NO (*circle one*)

If YES:

- b) Can you estimate how much per week?
- c) What difference (if any) has home care team support made here?

**14.** a) Since the patient was diagnosed as HIV+, have family earnings dropped as a result? YES / NO (*circle one*)

If YES:

- b) Can you estimate how much per week?
- c) What difference (if any) has home care team support made here?

15. a) Since the patient was diagnosed as HIV+, have you received any financial support from others (e.g. NGOs) to help with expenses?  
YES / NO (*circle one*)

If YES:

- b) Can you estimate how much per week?  
c) What difference (if any) has home care team support made here?

*If there is a caregiver outside the family, e.g. a neighbour, ask Qu 16*

16. a) Have the caregiver(s) had a change in earnings due to the demands of care? YES / NO (*circle one*)

If YES:

- b) Can you estimate how much per week?  
c) What difference (if any) has home care team support made here?

#### **Expenditure**

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17. Can you estimate how much money you spent per week on medicines, traditional healers and clinic visits when you were sick, but before the home care team began visits?

18. Can you estimate how much money you spend per week on medicines and clinic visits since the home care team began visits?

19. Do the home care visits save you money or cost you more money?

How much money per week?

20. Do the home care visits save you time or cost you more time?

How much time per week?

#### **Home Care Support**

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21. a) Does the Home Care Team use the home care kit?  
YES / NO (*circle one*)

If YES:

- b) What items have you been given from the kit?

- c) Are there other things that you **really** need that you don't receive from the kit?

22. What other material and financial support does the Home Care Team provide to the patient & the family?
23. What other support does the Home Care Team provide?
24. Has the Home Care Team ever mobilised support from community leaders, neighbours, monks, etc. to help you?  
YES / NO / DON'T KNOW (*circle one*)
25. Has the Home Care Team ever put you in touch with local support groups? YES / NO (*circle one*)
26. Has the Home Care Team ever helped you to get support from other programmes? (e.g. food aid, micro-credit, specialised social or medical care) YES / NO (*circle one*)
27. Do you know where the Home Care Team comes from?
28. What are the most valuable things (if any) about home care visits to you and your family?
29. Would you recommend, or have you ever recommended, the Home Care Team to another family? YES / NO (*circle one*)
30. What suggestions do you have on how home care visits and teams can be improved?

***Thank the patient and family for their time and co-operation.***

**1b**

**Interview Guide for Phum Leaders, Monks, other Local Authority and Community Leaders** (to be asked by neutral interviewer)

Home Care team Number .....

Name .....

Type of community leader .....

Village/Pagoda .....

**1.** Do you know about the Home Care Team who visit people with chronic/ illnesses in your area? YES/NO (*circle one*) (If NO, terminate the interview)

**2.** Do you know what work the Home Care Team does?

**3.** Does the work that they do fit in with or disturb other community activities?

**4.** Have you ever put a family in contact with the Home Care Team?  
YES/NO (*circle one*)

If YES:

How many families?

**5.** How did you first hear about the Home Care Team?

**6.** How often do you meet with the Home care Team?

**7.** What effect do you think the Home Care Team has on community awareness and understanding of HIV/AIDS (including how to prevent HIV infection)?

**8.** What difference (if any) do you think the Home Care Team has on the attitudes & behaviour of people in the community towards people with HIV/AIDS?

- 9.** What difference (if any) do you think the Home Care Team has on community mobilisation to support people living with HIV/AIDS?
  
- 10.** Does everyone in your community who has HIV/AIDS have access to the home-care teams? (Do you know people in your community who have HIV/AIDS but are not visited by the Home Care Teams?)
  
- 11.** How do you feel about the work that the Home Care Team does for patients and families of people living with HIV/AIDS (ask for examples)
  
- 12.** How do you feel about the work that the Home Care Team does for other members of the community (ask for examples)
  
- 13.** Do you have any suggestions on how the work of the Home Care Team can be improved?

## **1c** Questions for Home Care Teams: Semi-structured Interview Guide

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### **Inputs**

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- Describe the range of Home Care activities, both patient-related and non-patient related.
- Describe how you conduct Home Care visits (frequency, duration, approach, activities, contact persons)
- Is there the right balance between material support to patient & family/ Psychosocial and spiritual support to patient & family / Medical care of patient
- Volunteer involvement - how well is it working? Should it be expanded?
- Medical care of patient - the contents, appropriateness and adequacy of home care kit; adequacy of medical knowledge; knowledge of TB/DOTS
- Linkages with, and support from, other programmes (food aid, micro-credit, etc)

### **Process**

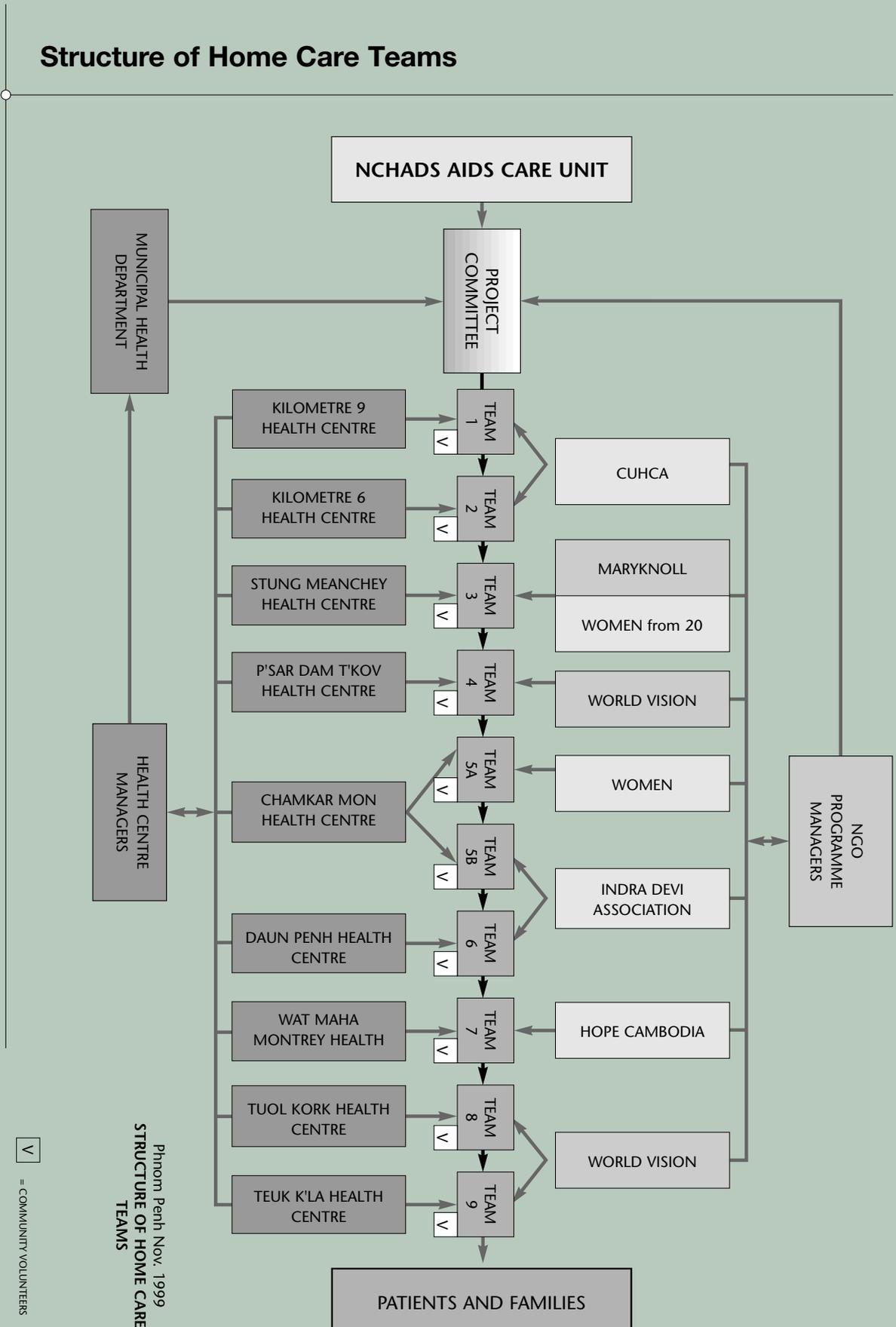
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- Team selection - what was the process?; Was there value in this?
- Training - initial and on-the-job; need for further training?
- Monitoring and reporting - process; usefulness, problems encountered
- Supervision - process; usefulness, problems
- What is the process of identifying families for home care visits? Is this effective? Where do the referrals come from?
- What is the process of arranging visits? Are there any problems of identifying & responding to needs
- Record keeping - process; usefulness, problems
- How well are partnerships working? (NGO/Gov) (HCTs/medical facilities)
- Referral system - referral of patients to programme by health centres, hospitals & community; referral by programme to health centres & hospitals. How well are these working? What can be done to improve the system?

- What are your estimates of access & coverage of the programme?
- Involvement of PLHA - is this successful?
- Involvement with traditional healers - what issues are involved?
- Home Care for non-HIV patients - is this important? how prevalent is this?
- What are the major problems you encounter in your work?
- What things are important in helping you do your job well?
- What do you think is the major impact of the home care programme?
- What are your suggestions for improvement of the programme?
- What lessons have you learned which will help to plan for expanding the programme?

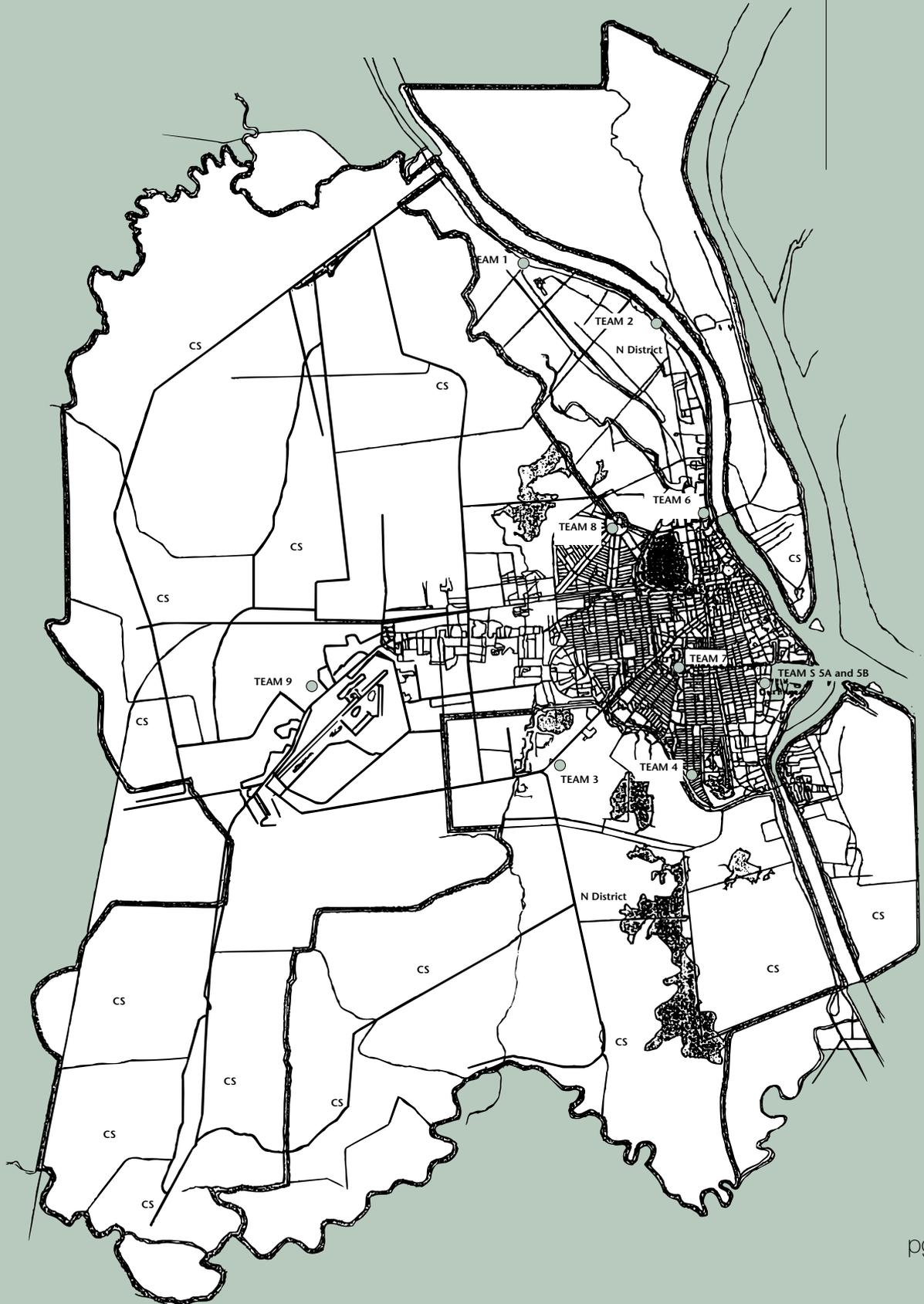
# APPENDIX II

## Structure of Home Care Teams



# APPENDIX III

## Location of Home Care Teams in Phnom Penh



# APPENDIX IV

## Roles and Responsibilities of Home Care Partners

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### Home Care Teams

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- Identify patients to be visited
- Receive referrals from community leaders, testing and counselling centres, health centres, hospitals, neighbours, other patients, monks
- Conduct home care visits to patients and families
  - conduct assessments of physical needs of patient
  - conduct assessments of emotional and social needs of patient and family
  - show families and patients how to manage symptoms
  - prescribe medicine from the home care kit
  - help patients & families to understand about the illness
  - give information about HIV/AIDS
  - provide financial and material support, e.g. transportation costs to hospital; food and soap powder
  - provide spiritual and psychological help to patient & family
  - respond to observed special needs, e.g. pregnancy, unsafe housing, children as carers, evidence of discrimination from community
  - record main points of visit including medication given
- Refer (and if necessary accompany) patients to hospital, testing centre, clinic, other NGOs
- Conduct IEC sessions on HIV/AIDS with local community, schools, factories, pagodas
- Meet regularly with community leaders, monks, health workers, traditional healers
- Support, train and manage a team of 5 Community Volunteers
- Provide placements to others wanting to experience Home Care in practice (government nurses; NGOs; donors)
- Act as an advocate for PLHA and their families
- Facilitate groups for PLHA
- Help patients to plan for the future, including orphan care

## **Team Co-ordinators**

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- Provide day-to-day supervision of team activities
- Produce monthly reports on HCT activities
- Represent team at monthly meetings
- Select and support 5 community volunteers
- Delegate responsibilities within the team
- Ensure home care kits are maintained
- Act as a focal point for communication between HCT and Home Care Co-ordinator, NGO, KHANA, etc

## **Home Care Co-ordinator**

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- Provide overall coordination of Home Care Network in Phnom Penh
- Support Team Coordinators and chair monthly Team Coordinator Meeting
- Summarise HCT monthly reports and present at monthly Home Care Meeting.
- Chair and produce minutes for monthly HC Meetings. Ensure important issues are raised and discussed
- Write monthly schedule for supervision and medical consultation; inform supervisors and record feedback
- Perform monthly supervisory visits to Teams
- Act as a link between Home Care activities in Phnom Penh and other provinces
- Procure, record and distribute Home Care Kit materials
- Act as key informant on Home Care for PWA

## **KHANA NGO Partners with HCTs (4 NGOs with 7 teams)**

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- Develop project proposal based on community needs assessment
- Select team of 3 full-time NGO staff, 2 half-time government staff
- Provide overall management of Home Care activities, including programme budget, monitoring and evaluation
- Ensure Team Coordinator produces accurate monthly reports

- Represent NGO at monthly Home Care Meeting, and participate in problem solving and Home Care development
- Participate in team /clinical supervision and help maintain quality standards of Home Care
- Provide quarterly programme and financial reports to KHANA

### **Health Centres (9)**

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- Provide 2 half-time staff for HCT
- Keep up to date with HCT activities and promote appropriate use of the service
- Represent Health Centre Managers at monthly Home Care Meetings, and participate in problem solving and Home Care development
- Participate in team /clinical supervision and help maintain quality standards of Home Care

### **Municipal Health Department**

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- Disburse Government HCT member salaries
- Keep up to date with HCT activities and promote appropriate use of the service
- Represent Municipal Health Department at monthly Home Care Meeting and participate in problem solving and Home Care development
- Participate in team /clinical supervision and help maintain quality standards of Home Care

### **Hospitals & Testing Centres**

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- Refer patients as appropriate
- Receive referrals from HCT
- Participate in clinical supervision of HCTs

## **KHANA**

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- Support appropriate capacity building activities of partner NGOs
- Provide technical support to partner NGOs (care & support, project design, community needs assessment, participatory review, developing indicators, behaviour change communication, external relations, finance & management) through workshops, office & field visits.
- Provide funds for partner NGOs with HCTs and disburse on quarterly basis
- Facilitate exchange visits with other partner NGOs
- Participate in monthly Home Care meetings

## **World Vision (3 teams)**

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- Fund and manage their Home Care Teams
- Select 3 teams of 3 full-time NGO staff, 2 half-time government staff and 5 volunteers
- Provide overall management of Home Care Team activities, including programme budget, monitoring and evaluation
- Ensure Team Co-ordinator produces accurate monthly reports
- Represent NGO at monthly Home Care Meeting, and participate in problem solving and Home Care development
- Participate in team /clinical supervision and help maintain quality standards of Home Care

# APPENDIX V

## **KHANA Technical Support**

In addition to monitoring the work of partner NGOs to check progress against agreed workplans and budgets, Khana provides both technical support and organisational capacity building. Khana employs different mechanisms for providing technical support to partners. These include:

- One-to-one programme-related field visits for direct observation of work, to assist staff to discuss any difficulties in implementation and help them to find appropriate solutions. Home Care Teams receive on average 2 field visits from Khana programme staff per quarter.
- One-to-one finance-related field visits to build capacity in financial management are carried out on average twice per year by Khana finance and admin staff.
- Collective technical support through regular workshops. In 1999, Home Care staff participated in a total of 3 workshops including Basic or Advanced Counselling; Community Management of HIV; Appropriate Prescribing and Physiotherapy for Pain Relief. Workshops to build organisational capacity included Project Review and Project Design.
- NGO exchange visits whereby Khana supports staff from one project to visit and work with staff from another. In relation to Home Care, this has been a particularly useful strategy for helping the staff from the pilot projects in Battambang build technical capacity.
- Participation in supervision of the Phnom Penh Home Care Network. The Khana Programme Officer for Care and Support visits different Home Care Teams once a month to provide clinical and managerial guidance to Home Care staff.
- Participation in Home Care Network monthly coordination meetings, providing ongoing advice and guidance on addressing problems as they arise.
- Sharing lessons learned through adaptation, translation and dissemination of relevant materials from the Alliance and other organisations, and through Khana documenting and sharing local experience. For example, the Khana booklet on appropriate prescribing of medications often used in home care, the quarterly information-sharing newsletter Bo Krohom (Red Ribbon), and a pack of commonly asked questions and answers on HIV prevention have been widely distributed.
- Supporting partners to participate in and share their work with wider forums at conferences and on study tours. For example, Khana assisted three NGO partners to have abstracts accepted for the global conference on AIDS this year.
- Khana itself receives on-going technical support from the Alliance in the form of international and local consultants and 2 resident advisors - one specifically building capacity in care and support.

Khana is currently expanding it's own capacity to provide technical support by training other local providers and creating a resource pool of specialised skills.

# APPENDIX VI

## List of Key Informants Interviewed During the Evaluation

Dr Nhep Angkeabos	Director, Chamcarmon Health Centre
Dr Jeffrey Ashley	Health & Population Director, USAID
Dr Nhek Bunchhup	Vice Director DoH, Battambang
Dr Chhe Bunthou	STD/AIDS Programme Manager, MHD
Ms Lucy Carter	Clinical Management Advisor, SSC
Mr Lang Chanthol	Home Care Team Co-ordinator, Phnom Penh
Dr Chantha Chak	Project Management Specialist, USAID
Dr Hak Chanrouern	(HIV) Physician, Medicin B, Calmette Hospital
Ms Khun Chantha	Home Care Team Co-ordinator, Phnom Penh
Dr Janet Cornwall	TB/HIV Specialist, Servants
Mr Mony Dara	Home Care Team Co-ordinator, Phnom Penh
Ms Dominique Dumoulins	Home Care Specialist, WHO
Dr Bernard Fabre-Teste	Public Health/Epidemiologist, French Co-operation
Ms Michelle Fontana	Representative, MSF, Battambang
Mr Philippe Girault	BCI/Evaluation Officer, FHI/Impact
Mr Peter Godwin	World Bank Advisor to NCHADS
Dr Mam Bun Heng	Secretary of State, MoH
Dr Nong Kanara	Head of AIDS Care Unit, NCHADS
Mr Yee Kimleng	Home Care Team Co-ordinator, Phnom Penh
Dr Lo Veasna Kiri	Deputy Director, Dept of Planning, MoH
Ms Men Kosal	Home Care Team Co-ordinator, Moug Russey
Dr Hor Bun Leng	Deputy Director NCHADS
Ms Fabienne Lopez	Formerly WHO AIDS Care
Ms Nhim Mala	Home Care Team Co-ordinator, Phnom Penh
Mr Geoff Manthey	CTA, UNAIDS, Cambodia
Mr Chea Mongkol	Home Care Team Co-ordinator
Dr Kong Bun Navy	Physician, HIV/AIDS Dept, Centre of Hope
Dr Song Ngak	Technical Officer, FHI/Impact
Fr Jim Noonan	Manager Maryknoll HIV Programme
Dr Sok Phan	Physician, Centre of Hope Sihanouk Hospital
Dr Bill Piggott	Representative, WHO Cambodia
Dr Phouy Sona Roth	AIDS Specialist, Battambang Provincial Hospital
Dr Sour Salan	Deputy Director, Municipal Health Department
Ms. Hou Samy	Home Care Team Co-ordinator, Phnom Penh
Dr Chhim Sarath	KHANA
Mr Chea Sarith	President, WOMEN
Ms Kim Saroeun	Home Care Team Co-ordinator, Phnom Penh
Dr Meas Sarun	NGO Coordinator, MHD
Ms Son Seda	Home Care Team Co-ordinator, Phnom Penh
Dr Hy Seilarith	Director, Daun Penh Health Centre
Ms Tilly Sellers	Technical Advisor, International HIV/AIDS Alliance
Dr Chhin Senya	Head of Infectious Disease Ward, Norodom Sihanouk Hospital

Dr Oum Sopheap	Project Manager, World Vision
Ms Pan Sopheap	Home Care Team Co-ordinator, Phnom Penh
Mr Uy Chhan Sothy	HIV/AIDS Coordinator, Indradevi Association
Dr Samreth Sovannarith	Home Care Coordinator, AIDSCare Unit, NCHADS
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# APPENDIX VII

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