



A Hard Road

The experiences of mobile populations in accessing HIV/AIDS care and support services within the Greater Mekong Subregion countries of Cambodia, Laos, Vietnam and Thailand



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Executive Summary

- 1) This report investigates the everyday experience of mobile and migrant people as they try to access care and support services within the Greater Mekong Subregion (GMS) countries of Cambodia, Laos, Thailand and Vietnam. The goal of the study was to identify options for delivery of good quality, client-focused HIV/AIDS care and support services for marginalized mobile and mobility affected people living with HIV and AIDS in the GMS.
- 2) Migrant labour is economically important; both for the migrants themselves, their families, their home countries and for the countries which they migrate to. Some industries, particularly those which offer labour-intensive, low-paid jobs, rely on migrant labour.
- 3) Moving in search of income does not necessarily have to equate to vulnerability and marginalisation. But migrants who move across countries are often powerless in the face of employer and state control, plus language barriers. In Thailand, which is the primary receiving country for migrants in the whole of the GMS, approximately 1.5 million migrant workers are undocumented. This situation exists in part through unwillingness of employers to register workers, and in part because the Thai government has effectively imposed a ban on registration of any workers other than those who were registered in October 2001.
- 4) Additionally, all migrants (internal and external – see *Definitions*) are moving away from the areas that they know, their extended families and the traditional community coping mechanisms which often represent their only safety net in times of economic or health-related hardship. This can be particularly affecting when people are in need of HIV/AIDS care and support.
- 5) Some encouraging evidence emerged from Cambodia of longer-standing migrant populations beginning to build their own informal community networks, offering psychosocial support for people living with or affected by HIV/AIDS. It is of note that these networks are predominantly created by women.
- 6) Discouraging evidence emerged of a worrying prevalence of uninformed testing – primarily occurring within hospital or health care settings. There was also evidence from Vietnam of compulsory testing for those people believed to be intravenous drug users or sex workers.
- 7) Across all of the four GMS countries involved, participants reported limited provision of HIV/AIDS care and support services. Severe lack of the most basic health care resources were also reported; some health care providers

spoke of lacking beds, blankets and basic drugs . It is acknowledged that these service constraints affect everyone – mobile or not – but as stated previously mobility can increase a person’s vulnerability and marginalisation. This in turn leads to reduced access to those services which do exist.

- 8) A great deal of active health-seeking behaviour was reported. Despite severely limited funds, and despite the recognised constraints on what services are available, people are expending enormous amounts of time, effort and what little money they can afford on trying to find appropriate and effective health care. Word of mouth is considered one of the most valuable channels for determining whether a service is effective or not.
- 9) Experiences of informal charging within the public health sector are ongoing in Cambodia and Vietnam. While participants did not seem to make definitive quality judgements between private and public health care, they spoke of avoiding public health facilities as much as possible because of a fear of these informal charges. People spoke of being able to control what they spent on health care within the private sector, because charges can be clarified upfront.
- 10) The HIV/AIDS care and support needs of mobile and migrant people affect sending, receiving, transit and return communities (see *Definitions*). Thus any responses to these needs must incorporate each of these communities.
- 11) Several regional commitments to improving access to HIV/AIDS care and support for mobile people already exist. This report demonstrates that there is an urgent need to narrow the gap between the theory of these documents and the lived experience of the research participants.

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Grateful thanks are due to:

The many migrants and mobility-affected people who were willing to share their knowledge and personal experience of attempting to access health care and support services – and to offer their suggestions for how these services could be improved.

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Gill Fletcher who pulled together the entire team as well as the report.

Last, but not least, thanks must go to the many staff, volunteers and expatriate assistants linked to the CARE offices of Cambodia, Laos, Thailand and Vietnam. They took the additional work which this project represents in their stride, and spent much time and energy on making the research a successful one.

Definitions

Greater Mekong Subregion (GMS)

In 1992, the Asian Development Bank (ADB) assisted the countries of Cambodia, Lao People's Democratic Republic, Myanmar, Thailand and Vietnam, plus Yunnan Province in the People's Republic of China, to enter into a programme of “subregional economic cooperation, designed to enhance economic relations among the countries.”

According to ADB: “The programme has contributed to the development of infrastructure to enable the development and sharing of the resource base, and promote the freer flow of goods and people in the subregion. It has also led to the international recognition of the subregion as a growth area.”(ADB, 2003)

Mobile people

Those who move temporarily, seasonally or permanently (those who move permanently are also called ‘migrants’, see below). Mobility can be undertaken voluntarily – albeit often for reasons of survival, rather than genuine ‘choice’ – or involuntarily, as is the case with people who are trafficked.

Migrants

Those who take up permanent or long-term residence in a site away from where they might call ‘home’. Migrants can be external – moving from country to country – or internal – moving from ‘home’ to another site within the same country.

People affected by mobility

Those who feel the impacts of mobility, including but not restricted to people who are themselves mobile. People affected by mobility can be directly linked to mobile people – for example partners, children, other family members – or they may be part of a community which: is a destination site for mobile people; is a ‘sending’ community which mobile people leave from; or a ‘transit’ community, which mobile people pass through.

The mobility and migration definitions listed above are based on those developed by UNAIDS (UNAIDS 2001) and the UN Regional Taskforce on Mobile Populations and HIV Vulnerability (UN Regional Taskforce, 2001).

Introduction

It is estimated that there are now more than 6.6 million migrants living and working outside of their country of citizenship in South East Asia. Up to half of these migrants are believed to be undocumented (*Evans, 2003*). Numbers of internal migrants are not consistently recorded, but in the Cambodian border province of Koh Kong 31.2% of the population has lived in the province for just five years or less (*Royal Government of Cambodia, 1998*).

Whatever their documentation status, it is generally accepted that the vast majority of migrants leave their homes, their families and their known support networks in search of income and an escape from poverty (*ASEAN, 2001*). For a few, the dream comes true. Others remain in poverty, and must face racial discrimination, exploitation (facilitated by fear of ‘the authorities’, plus the need to provide survival income for other family members), and distancing from traditional community and public care and support mechanisms. Women and female child migrants are likely to face additional exploitation and discrimination because of their gender.

Being documented should bring guarantees of freedom from discrimination, and of access to services. Yet it has been reported that, in practice, documentation brings with it a high level of State or employer control and diminished personal rights without ensuring access to health care or other social services.

Mobile and migrant people have been stereotyped as “driving” HIV epidemics¹, but there is increasing awareness that mobility should be viewed more effectively as part of a complex system of socio-economic determinants which reduce people’s options, and leave them more vulnerable to risk – including the risk of HIV infection. People who migrate are the human face of an economically driven system which incorporates sending or source communities, transit communities, destination or receiving communities, and return communities (which may not be the same as sending communities). All of these communities are affected by socio-economic changes which often expose vulnerabilities and which can undermine previously existing coping strategies and safeguards against risk.

Strategies for prevention of HIV infection, and for mitigating the impact of infection, must be identified and responded to within all of these communities. It is hoped that this research will contribute to such vital work.

¹ Similar stereotyping has affected sex workers and men who have sex with men, often leading to state-supported discrimination and vilification against individuals who are already heavily marginalized and discriminated against within many societies.

Taking A Rights-Based Approach

It was the UN which formally brought rights based approaches or RBA onto the world stage in 1998, when the-then Secretary-General stated:

“A rights-based approach to development describes situations not simply in terms of human needs, or of developmental requirements, but in terms of society’s obligations to respond to the inalienable rights of individuals. It empowers people to demand justice as a right, not as a charity, and gives communities a moral basis from which to claim international assistance where needed.” (report of the Secretary-General, UN 1998, cited in Patterson, 2002, p4).

HIV/AIDS is widely accepted as an area in which a RBA is essential if people, communities and states are to be empowered and enabled to both prevent infection and to develop appropriate and effective care and support mechanisms. Yet human rights are often overlooked in respect of people infected with, and affected by, HIV/AIDS. Migrant people or communities affected by mobility can be doubly disadvantaged. The Universal Declaration of Human Rights contains several Articles which are routinely broken in respect of migrant and mobility affected people. These include:

Article 2

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 6

Everyone has the right to recognition everywhere as a person before the law.

Article 7

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 13

1. Everyone has the right to freedom of movement and residence within the borders of each State.
2. Everyone has the right to leave any country, including his [*sic*] own, and to return to his [*sic*] country.

Other international treaties of particular relevance in regard to HIV, mobility and human rights include the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention of the Elimination of all forms of Discrimination Against Women (CEDAW) and the Convention on the Rights of the Child (CRC).

CARE recognises and supports the ethics behind such treaties, and through its development work aims to close the gaps between such ideals and the day-to-day reality for the most vulnerable and marginalized people. CARE's mission is to facilitate lasting change by strengthening capacity for self-help, influencing policy decisions at all levels, providing economic opportunity, and addressing discrimination in all its forms. In support of this mission CARE is moving towards adopting and integrating a rights based approach in all program spheres. CARE wishes to work in mutually accountable partnerships that help people claim and access the basic conditions that support their efforts to live with dignity and develop their full potential as human beings (*CARE, 2002*).

Section 1:

Research Overview

This qualitative and participatory research project was driven by a desire to investigate the everyday experience of mobile and migrant people as they try to access care and support services within four countries in the GMS. The fact that these people are already in need of greater access to HIV/AIDS services is already acknowledged at a macro level; the Association of South East Asian Nations (ASEAN) has adopted the objective of including access to appropriate HIV/AIDS “*care, treatment and information for mobile populations*” in its current work programme (ASEAN, 2001).

This is an attempt to further micro-level understanding of the factors that affect access to care and support for mobile and mobility-affected people living with HIV/AIDS in Thailand, Cambodia, Vietnam and Laos PDR. CARE’s country offices in Cambodia, Vietnam and Laos carried out field-based research while the CARE Thailand/Raks Thai Foundation (previously known as CARE Thailand) commissioned a situational review, in recognition of Thailand’s particular role within the region as a major destination country for large numbers of economic migrants.

1.1 Study Goal

The goal of the study was to:

Identify options for delivery of good quality, client-focused HIV/AIDS care and support services for marginalized mobile and mobility affected people living with HIV and AIDS in the GMS.

This goal is in line with both the *ASEAN Work Programme on HIV/AIDS II (2002-2005)* and the *Strategy on Mobility and HIV Vulnerability Reduction in the Greater Mekong Subregion 2002-2004*, developed by the UN Regional Taskforce on Mobile Populations and HIV Vulnerability.

1.2 Study Outputs

Research findings will enable CARE country offices within the whole GMS to develop a mobility response framework, built upon models for providing quality accessible HIV/AIDS care and support in all communities affected by mobility. This will allow CARE’s country offices to provide quality care for mobile populations and, equally importantly, to advocate for greater collaboration between government and policy makers, private sector partners, other NGOs and partners, other gatekeepers to care, and people living with HIV/AIDS. CARE believes that any such collaborations

must be underpinned by an acceptance of the rights of mobile people, and an acknowledgement that freedom of movement should be protected.

1.3 Research Topics

It was agreed that the research within each country would follow the same basic superstructure, covering five broad topic areas:

- Where do people go for health care services?
- Why do they go there?
- Which services are available?
- What are their perceptions of the quality of those services which are available?
- What would an ideal service look like? What suggestions for service improvement could participants offer?

1.4 Methodologies

Within the study right based framework and overall research topics, a range of potential methods was determined by the research teams from all countries. These included individual interviews, focus group discussions, the use of participatory tools such as mapping, and literature reviews. The selection of specific methodologies was taken in each country in a participatory fashion, while at the same time, considering issues of confidentiality and appropriateness.

Site sampling in each country was purposive, based upon both discussions with research partners and access to potential research participants willing to discuss confidential issues around HIV/AIDS, with the most frequently selected sites being existing CARE project sites. Within sites, sampling was purposive, snowball or both, which allowed the researchers the most potential for reaching participant key informants able to represent a range of views about care and support for those living with and affected by HIV/AIDS. It is acknowledged that this sampling methodology does not provide information that can be generalised to all populations. However, through capitalising and building upon existing relationships with partners and participants, so that sensitive topics can be discussed, such sampling methods have been shown to provide information characterised by high internal validity. This validity was cross checked through including the researched as well as the researchers as full participants in both research and analysis and through triangulation of information from various sources or research participants and various methods.

The majority of information contained in this report was collected through individual interviews and focus group discussions. In recognition of best research practice, individual interviews were held where there was an expressed or implied need for confidentiality plus a desire to collect highly personalised, experiential data. Focus group discussions were held to facilitate expression of a range of opinions on less sensitive topic areas.

In Vietnam, researchers also provided carers with disposable cameras to assist them in constructing the stories of their own lives and the recording of their oral histories. These techniques were felt to be particularly valuable in terms of enabling research participants to take control of their own narrative.

In addition, each country office undertook a desk review of relevant laws and literature relating to mobile people. This information provides important context within which to place the experiences of the research participants, and is considered an important part of the research findings.

The design, implementation and analysis of this research was informed by a rights-based approach (see *Taking a Rights-Based Approach*) focusing on eight core human rights which all States should respect, promote and fulfil:

- Health
- Participation
- Confidentiality
- Dignity
- Freedom from discrimination
- Information
- Privacy
- Autonomy

CARE recognises that this list does not in any way reflect the full complexity of international and national human rights writings and thought. But these eight rights were selected as the framework on which this research was built for reasons of scale, practicality, and in-country context (which in some instances made wider reference to international human rights potentially damaging for CARE's programmes, community partners and staff).



A CARE Cambodia researcher interviews a research participant.

1.5 Limitations

- **Inability to include data from Myanmar**
Ideally, this research would have been carried out with the participation of CARE Myanmar to reflect the major role which Myanmar plays in migration within the GMS. Funding restrictions in relation to Myanmar made this impossible.
- **Practical difficulties in implementing a research across different countries**
The structure of the research was designed with input from all participating CARE country offices; however the implementation of the research was guided by in-country experience and practical considerations. This strengthened the research at a country-by-country level, however it does mean that there are occasional differences in the type of data collected from country to country.
- **Potential of bias in the sampling frame**
Due to the sensitive nature of the topics under discussion – including HIV, AIDS, undocumented migration and the on the ground realities of provision and planning HIV/AIDS care and support services, (as opposed to the theory of such service provision and planning) – researchers identified potential

participants from among people already known to CARE staff. This purposive sampling facilitated discussion through building on existing trust relationships. However it is acknowledged that this may have affected the research results; those involved should have had greater knowledge and awareness of those services which might be available to them through their connection to CARE. Additionally, many of the interviewees are, in the normal course of events, also providers of care and support services as implemented by CARE. In some instances, the interviewees should themselves have been interviewees.

- **Reluctance of some health service providers to offer an opinion**
Despite the trust relationships already established between CARE and research participants, both public and private sector service providers were reported as being wary of possible repercussions from involvement in the research. In the public sector, this centred on fears of supervisor reactions; in the private sector, fears were mainly expressed about possible future sector regulation and about the need for secrecy arising from the fact that many private sector providers are moon-lighting from the public sector. This resulted in many of the private sector participants offering simple “yes” or “no” answers to questions and being unwilling to respond to probes for more information.
- **Participants’ absolute right to privacy regarding their HIV status**
The right to privacy – and specifically the right to privacy regarding one’s medical history, including one’s HIV status – was recognised throughout this research. Thus some participants identified themselves as HIV-positive but others chose not to reveal their status. Therefore it cannot be assumed that the experiences reported herein relate exclusively to services aimed at people who have AIDS-related illnesses. However CARE believes that the research presents a valid picture of the challenges facing chronically ill people, and particularly those people who are or have been mobile or are affected by mobility (see *Definitions*). The inclusion of opinions of service providers and service managers on treatment of people living with HIV/AIDS helps to provide a fuller picture.
- **The research highlights themes, NOT absolutes**
This is qualitative research, and as such attempts to describe and explain the experiences of participants as well as to highlight some common themes in experiences within and across countries. The experiences reported should not be generalised to represent the definitive experience of all mobile and mobility affected people within the countries involved. However CARE believes that the results are transferable; providing authentic information which can inform future site specific research and service development.
- **All participants were free to refuse or withdraw consent at any time – however perceived power balances may have prevented this**
CARE acknowledges that, despite implementation of ethical practice and considerable efforts being made to ensure that informed consent was given or that people felt genuinely able to refuse to take part in the research, this may

have been affected by perceived power imbalances between CARE project staff and project clients. All possible steps were taken to reduce this possibility.

- **Language**

As with all intercultural research, the issue of language (and the limitations of translation) must be acknowledged. While the research questions were finalised in national languages and research was conducted by national staff, the initial research design discussions and the research results consensus workshop were held in English. Additionally, final data analysis was conducted in English (enabling expatriate staff to provide analysis support to national staff). However all attempts have been made to ensure that the results presented here provide an accurate reflection of the national language data.

Above and beyond all of these limitations, the CARE country offices had to contend with a series of events or country-specific controls which increased the challenge of research implementation:

Cambodia

The research took place in the aftermath of a breakdown in Thai/Cambodian diplomatic relations, arising from an attack on the Thai Embassy in Phnom Penh. Borders were closed, and mobile populations within the research sites were left to cope with increased vulnerability and reduced income. The results from Cambodia should be read with this in mind; however it is believed that the experiences reported provide an accurate picture of the pre-border closure experience of those mobile and migrant people interviewed.

Laos

For the research to take place, approval had to be given by three national institutions (Ministry of Health, Committee for the Control of AIDS Bureau, Institute of Medical Science). Permission also had to be sought from local authorities in the research sites, and a local authority representative had to be involved in all interviews. CARE does not wish to suggest that this representative was anything but an enthusiastic and committed researcher. However it is highly probable that the mere presence of a known local authority representative compromised data collection among largely undocumented (or, in the case of sex workers, officially illegal) mobility-affected communities and chronically ill people in those communities.

Both Laos research sites are believed to attract internally mobile sex workers. However a crackdown on sex work was launched to mark International Women's Day in Laos. This occurred during data collection.

The current low prevalence in Laos (just 0.05% of adults are currently HIV positive, according to the HIV Sentinel Surveillance figures, 2002) made it difficult to identify, contact and win the trust of HIV positive people.

Large numbers of agricultural workers were expected to return to Laos from working in Thailand in June, but the harvest dragged on and the workers were delayed. The research timetable could not accommodate this, so the experiences of these workers could not be included in this research.

Local officials were frightened of being interviewed, due to a recent misunderstanding which had resulted after involvement of other officials in a TV broadcast. At a village level, leaders tended to deny that their communities were involved in mobility and migration. This was despite other evidence to the contrary.

Thailand

Initially, the plan was for Raks Thai Foundation staff to interview migrant workers and to incorporate their opinions into results from Thailand. However this proved too difficult, and therefore Thailand's contribution to this report is in providing an important contextual analysis of the country's responses to migration and to HIV/AIDS. Two key reasons prevented Thailand's more active participation in the research with participants:

- Migrant workers in Thailand faced a crackdown just prior to implementation of the research project. Such crackdowns occur twice a year, just before migrant registration dates. Migrant workers experience increased fear and vulnerability at these times, affecting willingness to talk about their situation or to identify themselves in any way. Additionally, migrant workers from Cambodia would have been affected by the Thai/Cambodia border dispute (see *Cambodia*, above).

The timing of the research project was not ideal; migrants to Thailand often return home for New Year (which falls in April for most of the GMS) and for the rice planting season (which usually takes place in June). This, combined with particularly heavy work pressures on Foundation staff, prevented any interviews being carried out with migrants.

Vietnam

Bar owners, hotel owners and others who effectively control access to sex workers within the research sites were wary of involvement in the project, making it difficult for CARE Vietnam to approach the women.

The research was instigated in the wake of Vietnam's New Year holiday. Many health service managers were unavailable either due to extended holiday or increased work commitment arising from having been away from work for the New Year.

CARE Vietnam wished to ensure that the experience and views of HIV positive people who also use injecting drugs were included in this research. In reality, however, this meant that individual interviews had to take place within a TB Unit where HIV positive people are kept under guard. The guards insisted on being present while the interviews were held.

1.6 Study Sites

Cambodia

This study was implemented in two sites: Poipet, a commune of Banteay Meanchey province, in north western Cambodia; and Koh Kong Province, in the south west of the country. These sites mark the major transit points for migrants to Thailand, and both are also destination sites for internal migrants. CARE Cambodia implements HIV/AIDS prevention and care work in both sites.

Poipet commune lies on the Thai-Cambodian border at the border crossing to the Thai town of Aranyaprathet. The Poipet border crossing offers the most direct overland route to the Angkor temples in Siem Reap, and is the primary route for goods and produce to move between the two countries.

The Angkor temple complex is a huge tourist attraction, and foreign backpackers often make the overland trip from Thailand to Cambodia via Poipet. But for an estimated 500,000 Thais a year (*CARE Cambodia 2002*), gambling is the major cross-border draw. Poipet town is home to several large casinos – which are illegal in Thailand. The enormous increase in commerce generated by the casinos, and a general view of Poipet as a high-turnover town offering employment and economic opportunities, has had the knock-on effect of attracting many Cambodians to migrate to Poipet for both the short- and the long-term. A large sex work industry has developed to cater for the almost exclusively male gambling clientele, and in response to large numbers of male migrants in Poipet.

Koh Kong province was designated the second legal land border crossing with Thailand in 1998. Previously an area of high logging activity, Koh Kong had seen a slight economic downturn since the government issued a ban on logging in Cambodia. (This ban is, however, believed to be regularly flouted.) The province is now home to large numbers of men employed within the fishing industry; high numbers of military and police officers, due to Koh Kong's strategic position; and male and female small traders and business people – many of whom are believed to cross regularly to Thailand. Koh Kong also has one large casino, which employs a significant number of workers – many of whom are internal migrants. Additional internal migrants can be found in the province's large sex industry, which has developed primarily in response to the numbers of male migrants in the area, specifically from the logging and fishing industries and from the uniformed services. Almost one third of Koh Kong's population (31.2%; *Royal Government of Cambodia, 1998*) has lived in the province for less than five years.

It must be noted that, when the interviews for this research were carried out, the borders between Cambodia and Thailand were closed at both Poipet and Koh Kong. This resulted from riots in Phnom Penh on January 29th 2003, when the Thai Embassy was attacked. Khmer vendors could no longer travel to work in Thai markets, and the high Cambodian/Thai through-traffic which brought trade to both Koh Kong and Poipet came to an abrupt halt. The closure severely affected many vulnerable families

in Koh Kong and Poipet. Among the most vulnerable were families facing compounded debt incurred by paying medical costs caring for a person with AIDS-



related illnesses.

Baklong Health Centre, Koh Kong Province, Cambodia.

Laos

The research was carried out in Vientiane Municipality and Bokeo Province - two of eight Lao provinces sharing a border with Thailand. These sites were chosen for two reasons: anecdotal reports regarding incidence of mobility/migration and of people known or believed to be HIV-positive in the area; and the existence of CARE services in both sites, thus facilitating research implementation.

Vientiane Municipality, which has a population of 633,100 inhabitants (*National Statistics Center, 2002*), faces Nong Khai Province in Thailand. Vientiane Municipality is reported as having the second highest official record of HIV prevalence in Laos; the cumulative number was 285 as of April 2003 (NCCAB, 2003). Vientiane Municipality also records high STI prevalence: 34.8% for chlamydia and 13.6% for gonorrhoea (*NCCAB, 2002*).

Vientiane Municipality is joined to Thailand by the Friendship Bridge, opened in 1994 as part of the government's move away from an isolationist policy. Today, the bridge is the busiest international checkpoint in Laos. An estimated 1,000 people cross the bridge daily. At present, no monitoring system exists to keep count of the numbers of people returning via immigration check points in Laos. The Municipality also plays a role as a migration receiving community. Vientiane Municipality is the foreign investment centre of Laos, and young people move from other provinces to work in Municipality factories. CARE Laos currently operates a reproductive health project within 10 garment factories in one Municipality district. Young women who move to work in the growing numbers of bars, nightclubs, karaoke shops and small drink shops within Vientiane comprise a second, significant, internally mobile population. It is understood that some of these women engage in casual sex work, although officially sex work is illegal in Laos. Street-based sex workers are also increasingly visible in Vientiane. Again, many of these women are believed to be internal migrants.

The second research site, Bokeo Province, is one of the northern mountainous provinces of Laos. It has a population of 137,200 (*National Statistics Centre, 2002*). Bokeo shares its border with Thailand's Chiang Rai Province; the Mekong River serves as the boundary. According to the Provincial Committee for the Control of AIDS Bureau (PCCAB), the number of people travelling to Thailand for work has dropped considerably over the past 6-7 years. The reason given is an increase in work commitments within Laos (*Bokeo PCCAB, 2003*). However it is recognized that people still cross the border to work in Thailand, especially those who have family members living there. Statistics gathered from four of Bokeo's border districts show around 250 undocumented seasonal workers travel annually from these areas to Thailand. Further, statistics from the Bokeo border crossing collected between June 2002 and July 2003 show that around 18 000 Bokeo residents crossed legally into Thailand during this period. Chiang Rai Province reported Thailand's highest HIV prevalence rate in 1995, and is still one of the most significantly AIDS-affected provinces in the whole of Thailand. In Bokeo, as of April 2003, the official cumulative number of people known to be HIV-positive was 71 (*NCCAB, 2003*).

In recent years, the province has begun to develop a role as a mobility receiving community, as well as a sending one. The number of entertainment establishments is rising - for example Huay Xai township, site of an international Laos-Thailand border crossing - had just one nightclub in 1996. In 2002, the township had six nightclubs plus one karaoke bar and several small drink shops have arisen so far. Numbers of guesthouses and hotels have also increased from a few to about 20 (*Bokeo PCCAB, 2002 and personal communication*). This increase in entertainment industry sites has led to a recognised increase in internal migration of young women from surrounding rural areas. In response to perceived increasing need for HIV information, CARE Laos operates the STD/HIV/AIDS Reduction Project (SHARP) in Huay Xai, Tonpheung and Paktha districts of Bokeo Province working with sex workers, out-of-school youth, and housewives.

Vietnam

The study was conducted in Quang Ninh province, where CARE Vietnam is currently implementing a project entitled *Confronting AIDS in the Workplace*. The project focuses on encouraging and enabling businesses to take responsibility for HIV prevention, care and support both within workplaces and within the communities in which workers live.

Quang Ninh Province, located in northern Vietnam and bordering with China, has almost 1.1 million inhabitants. The Vietnamese Government considers Quang Ninh a core component of the Northern Economic Triangle, which also includes Hanoi and Hai Phong. Quang Ninh is an industrial and a tourist centre known particularly for coal, cement and steel industries while its key tourist attraction is Ha Long Bay, recognised as a UNESCO world heritage site. The perceived economic gains from industrialisation and tourism have resulted in a high influx of internal migrants to Quang Ninh. They work primarily in the coal mines, the cement and steel factories, and in industries related to tourism such as motorbike-taxi driver or unofficial guide.

The province also has one of the highest rates of intravenous drug users in the country combined with a growing problem of STD/HIV infection and rising numbers of people believed to have AIDS-related illnesses. According to the Provincial AIDS Standing Bureau, around 6,000 HIV positive cases have been officially recorded in the province. Nearly half of these cases are also recorded as having died from AIDS or having developing AIDS-related illnesses². Permanent or temporarily mobile populations who move to Quang Ninh are among those who have been affected by HIV/AIDS.

² Quang Ninh Provincial AIDS Standing Bureau, 2003



Map of research sites

Stick pins mark research sites.

1.7 Profiles of Participants

It was agreed that each of the countries involved in the research should seek participants from three broad target groups:

- Mobility-affected communities and specifically chronically ill people in those communities³
- Service providers in both private and public arenas
- Care and support service managers/gatekeepers

While it was generally agreed that the primary focus should be on the experiences of mobile and mobility-affected people (and, therefore, on ensuring that mobile and mobility-affected people were the primary participants in this research), the views of smaller numbers of service providers and service managers / gatekeepers were also sought to assist in building a holistic picture of care and support within the research sites. The final participant breakdown follows:

HIV-positive people

A total of 143 mobile people participated in this study, and 35 voluntarily identified themselves as HIV-positive. The majority of these were female (see *Gender Dimensions of Care and Support*). It is likely that many other participants are also HIV-positive, but either do not know their status or did not choose to reveal their status to researchers.

In **Cambodia**, a total of 25 people chose to identify themselves to interviewers as HIV-positive. The majority (19) were women. Interviewers reported that men were more reluctant to be interviewed and also seemed less willing to reveal their HIV status. Most of the women were widows, whose husbands had died in the past three years (generally from AIDS). Many women reported that their husbands had been soldiers, truck drivers or fishermen – all highly mobile occupations. Most of the women had at least two children, and those whose husbands had died reported that most of the family's assets had gone on buying health care for the husband. Some participants were in good health; others were suffering mild through to serious AIDS-related illnesses.

In **Laos**, 3 women revealed their status. All of the women had been married; all had children. In one case, the woman's husband had died and her husband's parents no longer wanted her to live with them. The woman had returned to live with her parents. In the second case, the woman was married to a Thai man and had two sons. After one son died from AIDS, the husband told the woman to leave Thailand and return to Laos. He kept their second son with him. The third woman who revealed her status is a farmer with one son. She still lives with her husband and son.

³ "Chronically ill people" includes those who have AIDS-related illnesses. However for reasons of personal rights it was agreed that participants should not be required to reveal their HIV status. Those participants referred to as HIV-positive in this report voluntarily revealed their status.

In **Vietnam**, 5 men and 2 women were open about their positive status. All of the men are former injecting drug users, and some of the participants had to be interviewed while kept under guard within the public TB Unit in Quang Ninh Province under the Vietnam government's 'social evils' campaign (see *Laws and Policies on HIV/AIDS*).

External Migrants

Participants who had undertaken or been affected by external migration were found in both Cambodia and Laos. **Vietnam's** migrants were all internal (*see below*).

Many of the participants from **Cambodia** were both external and internal migrants. They initially moved across Cambodia in search of economic opportunity (*see below*), but for many the travelling continued. Either they or their close family members had travelled between Cambodia and Thailand in search of work. This work was reported to be primarily agriculturally-based manual labour, although some participants had sold food at markets on both sides of the border. However most of the women were markedly less mobile than their children or husbands, as is common in most Khmer families.

Widowed participants who spoke about their dead husband's occupation reported truck driving and fishing as jobs involving external mobility. However the majority of the truck driving reported was internal. Fishing took place exclusively on Thai boats leaving from Thai ports.

In **Laos**, a total of 25 external migration returnees participated in the research. These returnees were aged between 18 and 35; 13 were male, 12 female. Some were married and were supporting families. The last year of schooling was given as between Primary School Year 4 and Secondary School Year 4.

All of the external migrant returnees involved in this research stated that, in Laos, they are farmers. However while in Thailand they worked at jobs including fishermen (males only), factory work (male and female), housemaids (female only), work in restaurants and bars (primarily female) or in petrol stations and on farms (male and female). Destinations in Thailand included Chaing Rai, Chaing Mai, Bangkok, Samut Sakorn, Trang, Ranong and Surin.

The returnees reported that they decided on where to go dependent on existing connections to friends working in the same areas, or through information obtained through informal networks among migrant workers. Most said that they travel to Thailand after the harvest (October-December) and come back home for planting season (May-July).

As Thai and Laotian are considered basically dialects of the same language, albeit with different scripts, it is comparatively easy for Lao migrants to exist undetected in Thailand. Lao migrants travelling to Thailand are reportedly often mistaken for Isan people from Northeast Thailand.

Internal Migrants

In **Cambodia**, the majority of the HIV-positive people who participated in the research had moved across Cambodia to their current location within the past 5 years. A few were long-term residents of 10 years or more. Most migrants reported that they had moved in search of economic opportunities – however a few reported that they had moved to escape AIDS-related discrimination. One male participant had even moved specifically to access AIDS care (see *Health-Seeking Behaviour*). Primary occupations for mobile men were truck driving, sea fishing and becoming a soldier. For the women, the most common occupations within Cambodia were selling cakes or noodles and tailoring. Both genders reported having worked as manual labourers, within Cambodia and Thailand (see *External Migrants*).

In Laos and Vietnam, research participants included young women who have moved within their own country to either sell sex or to work in the entertainment industry (which, for many women, also involves selling sex).

Sex work is illegal in **Laos**, but the recognised increase in numbers of nightclubs, bars, small drink shops and karaoke shops in urban areas strongly indicates an increase in sex work within such areas and an increase in internal migration of young women. (Little, if anything, seems to be known about the existence of male sex workers in Laos.) An estimated 50% of women working in the entertainment industry in Vientiane Municipality are believed to have migrated from northern provinces (*MoLSW and UNICEF, 2002*).

The 58 women working in the entertainment/sex industries who participated in this research came from a wide area. Those women working in Bokeo tended to come from the neighbouring Northern provinces and were Lowland and Midland Lao. The women working in Vientiane reported that they came from northern, central and southern Laos, but were predominantly Lowland Lao. Decisions on destination seemed to primarily result from the previous experience of friends, or from information obtained via an informal migrants' network. Most of the women reported needing money to support their parents and families. Others had left home after family problems – particularly with stepfathers – or after being separated from husbands. The women who participated in this research were aged 16-26, and had left school at between Primary School Year 2 and Secondary School Year 5. The illegal status of sex work puts all of these women in a highly vulnerable and marginalized position within Lao society.

The precarious position of these women involved in sex/entertainment industries is replicated in **Vietnam**, where sex work is not only illegal but is considered a 'social evil' (see *Laws and Policies on HIV/AIDS*). Of the 7 women who participated in this research, the majority were working in karaoke shops, cafes and bars. They sold sex to patrons of these establishments. The primary reason reported for involvement in sex work was to repay debts incurred by themselves or their families. The women reported that they migrated to avoid being stigmatised as sex workers in their own communities; and because they perceived greater economic opportunities within their destination community.

CARE Vietnam also collaborated with two other ‘groups’ of internal migrants for this research; intravenous drug users and truck drivers. Ten male drug users with an average age of 25 agreed to participate; all live with members of their extended family in Quang Ninh. Their marital status was not recorded. The men’s migration was two-fold; the men moved from their original family homes to Quang Ninh from neighbouring districts or provinces in search of economic opportunities, and they now move in and out of the area chasing income – often as motorcycle-taxi drivers. These participants reported having had either primary or secondary level educations.

The 8 truck drivers who participated were all male. They work for large distribution companies, and regularly travel from Quang Ninh to provincial towns in northern and central Vietnam.

Health Care Providers

The research involved both public and private health care practitioners, in recognition of the important roles played by both health sectors. In **Cambodia**, the research targeted all public health facilities within the research sites. Public hospital and health centre in- and out-patient doctors, plus nurses, were interviewed. Practitioners from one public STI clinic in each site were also included. Care was taken not just to interview staff with a good reputation; a wide range of attitude was sought. Within the private sector, the research targeted one laboratory offering HIV testing, pharmacies and private clinics. These facilities were identified by HIV-positive participants as places at which treatment is sought. The pharmacy staff involved in the research diagnose and distribute drugs (including ARVs); the private clinic staff who participated have contact with patients. Cambodia’s research also included the participation of 3 Kru Khmers (traditional healers). Again, the Kru Khmers involved in the research had been identified as “preferred service providers” by HIV-positive people. It is not uncommon for Kru Khmer to claim to be able to cure AIDS (or to be perceived as being able to cure AIDS). People go to Kru Khmer for a wide range of services, including provision of natural medicines, fortune telling and to buy good luck charms.

Six of the seven health care providers who participated in the research in **Laos** were employed in a public health care setting. However most of them also generate extra income by working in private clinics out of working hours.

The health care providers involved in the research in **Vietnam** included female community members who are supported by CARE Vietnam to provide home-based care, and staff employed in public health services.

The 8 community care-givers who participated are all married women, related to people who are HIV-positive. Many of the women are self-employed, or employed by local coal mining factories. Some are official members of the Commune Women’s Union. These women provide some palliative care but, due to lack of resources, focus on providing psychosocial support for HIV-positive people. They also attend funerals of people who have died of AIDS-related illnesses and, where possible, assist in

referring people with AIDS-related illnesses to appropriate public health services. The women also facilitate access to voluntary counselling and testing for those people who express a desire to know their status.

A total of 6 public health care nurses and doctors also participated in the research. No private sector health practitioners were interviewed. In Vietnam, prevention, care and support for HIV/AIDS remains the task of the public sector. There is a very limited response from the private sector. There are no AIDS clinic within private hospitals and health centres. In Quang Ninh, where the research was carried out, a coal mining company has received training in development of an AIDS prevention and placement of care and support policy for workers. However none of the company's health staff was trained in care and support for AIDS patients. Vietnam's pharmaceutical industry has produced a large amount of ARV drugs, but this is primarily for export. Those ARVs left in country are priced beyond the reach of most HIV-positive people.

Service Managers / Gatekeepers

Each country identified a slightly different service manager/gatekeeper profile. In **Cambodia**, the focus fell on Buddhist and Muslim religious leaders in recognition of the key role they can play in facilitating access to, and encouraging provision of, care and support for people affected by AIDS. Within each site, researchers identified one wat and one mosque within areas with high mobile population density. The senior monk and senior cleric within each religious institution were interviewed. One additional, lower level religious representative was also interviewed at each site.

Three levels of service managers / gatekeepers participated in the research in **Laos** - village leaders, senior government officials and 'mama sans', or entertainment establishment owners. Village leaders play a key role in monitoring and controlling both external and internal migration; they are required to collect regular reports on numbers of village occupants, and absences or additions are noted. Further, village leaders have the power to enforce what appears to be a semi-official fine on undocumented migrants who return to Laos. These returnees pay their village committees fines reported as ranging from 25,000 Kip (about US\$2.5) to 100,000 Kip (about US\$10). The amount levied varies from village to village, but even at the top end the fines are minimal in comparison to possible earnings from working in Thailand. These earnings are reported as ranging from 3,000-5,000 Baht a month (about US\$71-119). A total of 8 village leaders took part in this research; all are male.

Two senior government officials agreed to be interviewed – Director of the National Committee for the Control of AIDS Bureau (female) , and the Deputy Director of the Department Of Labour and Social Welfare in Bokeo Province (male).

The entertainment establishment owners interviewed – commonly known as 'mama sans' – were female. They run karaoke shops, bars, and restaurants. These women employ large numbers of young women, many of whom are believed to sell sex. In some instances, it is believed that there is a degree of debt bondage which keeps the women under the close control of their 'owners'. This means some are obliged to

continue working at an establishment until the money they have borrowed from the owners is repaid.

One representative of the Provincial Health Department was interviewed in **Vietnam**. The representative, a woman, is responsible for overseeing provincial public health HIV activities including prevention, care and support programmes and policy implementation.

Participant Breakdown per Country

Table 1: Cambodian participants

Koh Kong

Mobile people

People who voluntarily disclosed their status as HIV+ 13 (9 female, 4 male)

Health care providers

Private sector (pharmacy, private clinic) 7 (No gender breakdown)

Public sector (public hospital, STI clinic, health centre) 10 (4 male, 6 female)

Kru Khmer (traditional healers) 2 (All male)

Gatekeepers

Religious leaders (head monks, monks, Imans) 5 (Male)

Poipet

Mobile people

People who voluntarily disclosed their status as HIV+ 12 (2 male, 10 female)

Health care providers

Private sector (pharmacy, private clinic) 7 (No gender breakdown)

Public sector (public hospital, STI clinic, health centre) 3 (2 male, 1 female)

Kru Khmer (traditional healer) 1 (Male)

Gatekeepers

Religious leaders (head monks, monks, Imans) 5 (All male)

Table 2: Laotian participants

Vientiane Municipality

Mobile people

Sex workers 34 (All female)

Returnees 19 (11 male, 8 female)

Health care providers

Public (some with unofficial private work on the side) 4 (all female)

Service managers / Gatekeepers

Director of National Committee for the Control of AIDS Bureau (NCCAB) 1 (Male)

Deputy Director of Labor Department. 1 (Male)

Immigration Police 1 (Male)

Village leaders 3 (All male)

Entertainment establishment owners/Mama-sans 3 (All female)

Bokeo Province

Mobile people

Sex workers 24 (All female)

Returnees 6 (2 male, 4 female)

<i>People who voluntarily disclosed their status as HIV+</i>	3	(All female)
Health care providers		
<i>Private</i>	1	(Male)
<i>Public</i>	2	(Both male)
Service Managers / Gatekeepers		
<i>Deputy Director of Dept of Labor & Social Welfare</i>	1	(Male)
<i>Village leaders</i>	5	(All male)
<i>Entertainment establishment owners/Mama Sans</i>	3	(All female)

Table 3: Vietnamese participants

Mobile people		
<i>People who voluntarily disclosed their status as HIV+</i>	7	(5 male, 2 female)
<i>Intravenous drug users</i>	10	(All male)
<i>Sex workers</i>	7	(All female)
<i>Truck drivers</i>	8	(All male)
Service providers		
<i>Public health care providers (nurses and doctors)</i>	6	(4 female, 2 male)
<i>Volunteer community caregivers (including one mother of an HIV-positive woman)</i>	8	(All female)
Service Manager		
<i>Provincial Health Dept representative</i>	1	(Female)

Section 2: The Regional Context

Extensive documentation already exists on patterns of mobility and migration, and on mobility and HIV vulnerability, within the GMS (*Chantavanich, 2000; Evans, 2003; UN Regional Taskforce on Mobile Populations and HIV Vulnerability, 2001; UNDP South East Asia HIV and Development Programme, 2002 et al*). This section will not attempt to reprise existing literature, but to serve as a pointer to the key regional agreements on mobility and its relationship to HIV vulnerability and AIDS care and support.

Perhaps the core regional agreement is the *Strategy on Mobility and HIV Vulnerability Reduction in the Greater Mekong Subregion, 2002-2004* (*UN Regional Taskforce on Mobile Populations and HIV Vulnerability, 2001*).

The Strategy, signed up to by the governments of Cambodia, Lao PDR, Myanmar, Thailand, Vietnam and China on September 5, 2001 (*UNDP South East Asia HIV and Development Programme, 2002*), identified Priority Action areas for the whole of the region. One such Priority Action was: “Provide HIV/AIDS care and support services to mobile populations, to mitigate the physical, emotional, social and economic impacts of the disease.”

Actions outlined included:

The strengthening of health care systems “to ensure adequate health coverage for HIV-associated conditions, STIs, and other sexual health needs of mobile and host populations”

and

Commissioning of special projects “to strengthen the capacity of family and communities in low resource environments to provide appropriate HIV care and support, and ensure sustainable human development in both source and destination communities”

The Strategy is underlined by a raft of previous agreements. It is particularly worth noting that the Sixth ASEAN Summit in December 1998 called on ASEAN members to “make sure our people are assured of adequate medical care and access to essential medicines”.

2.1 Thailand's Role

Thailand is estimated to have as many as 2 million migrant workers within its borders⁴. The vast majority of these workers (nearly 80%) are believed to be from Myanmar. The remaining 20% are split almost evenly between Cambodia and Laos (*Bangkok Post*, 2003; *Office of the Administrative Commission on Irregular Migrant Workers*, 2001; *Evans*, 2003). It is no coincidence that these sending countries all experience high levels of poverty and, in the case of Myanmar and Cambodia, have faced years of political upheaval and civil unrest.

Migrant workers are vital to Thailand's labour-intensive industries, which generally offer very basic wages alongside tough working conditions and hold little attraction for Thai workers (*CARE Thailand/Raks Thai Foundation*, 1999). When migrant worker crackdowns took place following the 1997 Thai economic recession the rice milling, fisheries, pig farming, rubber growing and shipping industries all experienced severe labour shortages (*CARE Thailand/Raks Thai Foundation*, 1999). But migrant workers in Thailand face a tough time. They are legally supposed to be registered by their employers, but since October 2001 the State has operated an effective ban on registration. Today, just 480,000 of Thailand's estimated 2 million migrant workers is currently documented (*Office of The Administrative Commission on Irregular Migrant Workers*, 2002). That's less than one in four.

Rights supposedly inherent in registration include the right to minimum wage and basic employment conditions, plus access to the State's subsidised public health system where per visit costs are pinned at 30 baht (less than US\$1). Not being documented removes any possibility of workers accessing the limited protection which registration is supposed to afford them. They are also blocked from accessing affordable public health systems and must therefore either go without care or access the more expensive private sector.

However registration is no guarantee of rights. Anecdotal evidence collected by CARE Thailand/Raks Thai Foundation and the *Bangkok Post* (*July 8, 2003*) shows that many of those employers whose workers are registered keep hold of the workers' registration documentation as a form of control. Thus these workers are left without health coverage and are just as vulnerable to on-the-spot arrest and repatriation as non-documented workers. For employers who are less than scrupulous, migrant workers represent a highly pliable workforce; any requests for basic wages or decent working conditions can be met with a threat of the worker being turned over to the authorities as undocumented. Many migrant workers refuse to leave their site of employment, for fear of arrest.

⁴ While Thais themselves do migrate, it seems that their preferred destination countries lie primarily outside of the GMS. Countries which report the highest numbers of Thai migrant workers include Taiwan, Japan and Saudi Arabia. Additionally, when the Foreign Ministry embarked on a campaign to export 210,000 workers in 1998, the focus fell outside the GMS. (*Scalabrini Migration Center, Asian Migration Atlas 2000*).

Ironically, it was recognition of the need for migrant workers that is credited with leading Thailand to introduce its first migrant workers' registration scheme in 1996. Since that time, Thai employers have been legally bound to register their migrant workers and pay a 4,450 baht registration fee (about US\$100). Employers who do not register workers are liable to be fined. Introduction of the registration scheme and fines for not registering workers did not dissuade employers from choosing not to document the vast majority of migrant employees – thereby avoiding paying the registration fee, and avoiding having to worry that workers with legal status might feel free to try and obtain minimum wages and basic employment conditions. But at least employers who relied on migrant workers and who did not want to break the law were able to register their migrant staff. This is no longer the case.

The last open registration took place in September 2001. While those who managed to register at that time are allowed to re-register every six months, no new registrations are being issued. Between October 2001 and October 2002, the number of registered workers dropped by 88,000 – just over 15%. Either employers have stopped re-registering these workers, or the workers have moved on (perhaps returning home), or they have failed to negotiate the re-registration procedure.

Re-registration must take place at the local authority office where the migrant first registered. Failure to re-register means loss of registration – as does failure to notify the migration authorities of any job change within a week of leaving the original job. Migrants who do not re-register lose their health coverage – even though the full cost of this coverage is paid in the registration fee instalment made at the start of each registration year⁵.

For those workers who are eligible to re-register, and who manage to do so, there is a yearly compulsory health check. In the past, some provinces were found to have included a compulsory HIV test in the examination (*CARE Thailand/Raks Thai Foundation, 1999*). There is no evidence to suggest that this is still occurring. If any woman is found to be pregnant during the registration health check, her employer will be told. If the offer of employment is withdrawn, the woman will be repatriated. Just a couple of years ago, women found to be pregnant at the compulsory health check were automatically repatriated.

Children born in Thailand to either documented or undocumented migrant workers do not receive a birth certificate, thus becoming stateless. They are, officially, entitled to attend Thai primary school. It has been reported that few attend, “due to ignorance of the local authorities, schools being ill-prepared, limitations of the government education budget, natural fear of the illegal workers, and the lifestyle of the displaced children, in addition to the barriers of language and culture” (*Koetsawang, 2001*).

⁵ The fee is paid in two instalments. The first, made in September, covers the health insurance. The second instalment, payable on re-registration, covers registration process expenses, and a contribution to the Ministry of the Interior's Repatriation Fund for the return of undocumented migrants caught in Thailand.

Some Thai provinces translate basic information to assist migrant workers in understanding the registration and re-registration process. Others don't. And those provinces which do show a greater awareness of the needs of migrant workers are often unable to carry out proactive preventative health work because of lack of available funds.

These are all structural constraints on the health and well-being of migrant workers in Thailand. But that's not the end of the story. Further evidence of migrant workers' vulnerability appeared in *The Bangkok Post* editions of May 26 and May 27, 2003. On May 26, the English-language newspaper reported that six undocumented Myanmar migrant workers had been beaten, shot and their bodies burnt. The following day, the paper reported that the deaths "may be intended as a lesson for other illegal workers" from those in control of trafficking rings. May 27 also saw the Post carry a front page story on armed teenage gangs, who attack migrant workers to extort money – and to vent their racist feelings towards migrants.

The threat to migrant workers' lives and rights is not just from outside of the State. In April 2002, the BBC reported that Myanmar and Thailand had agreed on a plan to repatriate more than 500,000 Burmese illegal immigrants resident in Thailand. As part of the deal, the Burmese workers would all be screened for HIV. Those testing positive would be separated from the other workers and sent home as part of a "special" repatriation. Adverse international publicity erupted as a result of the agreement, and no formal policy on mandatory testing of returnees has ever been established between the two countries. However there are reports of returnees being literally "dumped" back over the border into Myanmar, regardless of their state of health and regardless of concerns about exposing individuals to threats of force by Myanmar officials. Additionally, there have been sporadic reports of compulsory testing of HIV returnees ordered by Myanmar officials following repatriation.

2.2 The Legal Framework for Mobile People and HIV/AIDS

Cambodia

The *Law on HIV/AIDS Response and Prevention* was passed by the National Assembly and became law in mid 2002. This progressive piece of legislation was enacted to provide a legal framework for HIV/AIDS prevention and care and support within Cambodia. Articles 7 and 8 are relevant to cross border mobility and state that the government will provide HIV/AIDS education documents at international border crossings and provide education seminars for all Khmer labourers, diplomatic and government officers before departing to work overseas. Article 26 states that the government will ensure basic health care free of charge for people living with HIV/AIDS and Article 27 states that the government will enhance participation of community and religious groups in care and support for people living with HIV/AIDS. The law prohibits discrimination in employment, education and access to health care and sets out penalties for discrimination including fines and imprisonment.

Laos

In response to HIV/AIDS/STIs, the *National HIV/AIDS/STD Policy* (2001) was developed following the universal principles of non-discrimination; a multi-sectoral, integrated approach; voluntary approaches to testing, including informed consent, confidentiality, counselling and service referral; empowerment of individuals to protect themselves and others; and promotion of gender equity. The policy incorporates the following priority areas:

Prevention of infection, including measures for the general population, groups particularly vulnerable to HIV/AIDS/STIs, promotion of condoms, reduction of mother-to-child transmission of HIV, STI control, a focus on injecting drug use, and blood safety.

Care and support for people living with HIV/AIDS including universal precautions, counseling and testing, care and support for infected and affected people.

Mitigating the adverse impact of HIV/AIDS through organizing a multi-sectoral, integrated and coordinated response, surveillance, research, and capacity building.

Measures for personnel dealing with HIV/AIDS, including regular physical check ups/blood testing in case of needle sticks or other high risk medical accidents and universal precaution training.

Following the 2001 UNGASS recommendations, the National Committee for the Control of AIDS Bureau and the Ministry of Health worked to develop the *National Strategic Plan 2002 – 2005*. The plan, which incorporates a care and support strategy for people living with HIV/AIDS, is now being implemented. The plan includes cooperation with international agencies to make sure that ARVs are available. Medecins Sans Frontieres, which has run a pilot project to provide free medical care to people living with HIV/AIDS in Savannakhet Province since July 2001, should begin to provide ARV treatment in early October 2003.

In terms of migration, the Lao and Thai governments are attempting to collaborate on issues including the labour and sexual exploitation experienced by many Lao migrant workers in Thailand. The governments signed a Memorandum of Understanding (MoU) in October 2002, but the main purpose of the MoU was to reduce undocumented migration. The rationale was that this would enable protection of the rights of documented Lao migrant workers. The MoU indicated that documented Lao migrant workers should be treated as Thai national workers in terms of welfare. Following this, government representatives from both countries held an informal meeting at Nong Khai (a Lao province bordering Thailand) in February 2003. Both sides agreed that, in order to make collaboration more effective, a working agreement needed to be formulated and signed by both governments. When this report was written, it appeared that no further progress had been made.

To date, Thailand has simply expelled undocumented Lao workers found in Thailand. Most of these undocumented workers are believed to have been victims of sexual violence and trafficking. No formal repatriation arrangements exist.

The Lao Ministry of Labour and Social Welfare is currently planning to work in collaboration with the Ministry of Health to introduce mandatory HIV screening for those workers expatriated from, or voluntarily returning from, Thailand. Anyone found to be HIV positive would be provided with counselling for prevention and care (*Department of Labour and Social Welfare, personal communication*). During the course of this research, one village leader referred to a Bokeo Provincial Regulation which he claimed prohibited “all people living in the province from going to work in Thailand”.

Thailand

Thailand published its National Plan for the Prevention and Control of HIV/AIDS in 1997. The National Plan includes a State commitment to provision of prevention and relevant health services, but does not guarantee or provide for any legal protection of the rights and confidentiality of HIV-positive people. However it is widely held that such provision would have been unnecessary, due to Thailand’s written Constitution and State recognition of human rights. The Constitution, which was promulgated in 1997, stipulates that “The human dignity, right and liberty of the people shall be protected” and enshrines in law a citizen’s right to legal recourse. Additional protection for broad human rights was provided in 2001, when Thailand’s National Human Rights Commission began to function. The Commission was established by the 1999 National Human Rights Commission Act as a result of Article 199-200 of the Constitution. While neither the Constitution nor the Human Rights Commission has a specific HIV/AIDS remit, both mechanisms should theoretically enable HIV-positive Thai citizens to access the services outlined under the National Plan.

In terms of specific policies relating to HIV/AIDS, Thailand is notable within the GMS for a policy on prevention of transmission from mother-to-child, introduced in 2000. Under the policy, the Ministry of Health stated that all pregnant women should be provided with voluntary counselling and testing for HIV. Those who are positive are offered zidovudine and infants born to HIV-infected mothers are given zidovudine, infant feeding formula, and clinical care (*Ministry of Public Health of Thailand and US Centers for Disease Control and Prevention, quoted on Global Strategies for HIV Prevention, 2003*).

Documented migrants working in Thailand are entitled in law to access the public health care system on presentation of a registration card, and the Ministry of Education has a policy of allowing migrants and stateless children to attend public primary schools. Employers found to be using unregistered migrant labour face five years’ imprisonment and/or a 50,000 baht fine for violating the Immigration Act (*Scalabrini Migration Center, Asia Migration Atlas 2000*). Under the Immigration Act, migrant workers are officially considered illegal aliens, allowed to work provided they register and then re-register every six months.

Vietnam

Over past ten years, a number of policies on HIV/AIDS have been developed and implemented in Vietnam. In general, the approach taken is one of containment and control. People who are HIV-positive or who develop AIDS-related illnesses are often linked with the ‘social evils’ of sex work and intravenous drug use, and therefore are perceived to be in need of enforced re-education and ‘treatment’ in government centres instead of care and support. This can be clearly seen in *Prevention and Control of AIDS: Government Directive No. 52-CT/TW* (11 March 1995). The Directive calls on all levels of the Party to strengthen HIV/AIDS control through promoting a healthy, clean and faithful lifestyle and abstinence from drug abuse and prostitution. This decree links HIV-AIDS prevention to Vietnam’s “social evils” campaign to wipe out prostitution and drug use. According to the Ministry of Health, almost 65 % of Vietnam’s officially recorded total of HIV-positive people are identified as intravenous drug users; 20% are sex workers. As a result of this Directive, sex workers and drug user are detained in “re-education” camps. The camps do not provide care and support for those with AIDS-related illnesses.

In June 2000, the Prime Minister of Vietnam issued *Decision No. 61/2002/QĐ/TTg* to establish the National Committee for the Prevention of AIDS, Drugs and Prostitution (NCADP). The committee assists the Prime Minister in directing and co-ordinating AIDS and ‘socially evil’ drugs use and sex work prevention and control.

The social evils approach leads to stigmatisation and discrimination, isolating HIV-positive people from their families and communities and preventing them from seeking and receiving appropriate treatment, care and support services. HIV/AIDS workers face several dilemmas. Because sex workers and drug users are unlawful citizens, it is very difficult to reach them with education and information about HIV/AIDS. Many have ‘gone underground’ to avoid re-education or treatment centres. The issues of needle exchange and condom distribution continue to be sensitive. Moreover associating HIV/AIDS with ‘anti-social behaviour’ is also misleading and fails to communicate to the majority of the population that they too are vulnerable to HIV infection through their own behaviour or that of their sexual partners.

Given the high proportion of IDUs among the HIV-positive population in Vietnam, the law surrounding narcotics and drug use also affects HIV/AIDS programs. Narcotics are forbidden and the State has the power to enact regulations on compulsory treatment of drug addiction and other dangerous social diseases. Implementation of this article is covered primarily by the *Law on Narcotic Drug Prevention and Suppression*. This law is somewhat coercive and restrictive in nature and views drug abuse primarily as an individual criminal offence rather than a public health or social issue. It calls for compulsory two- year incarceration of drug abusers and makes no reference to the care and support needs of HIV-positive IDUs within the centres.

This is despite the 1995 *Ordinance on the Prevention and Control of Human Immuno Deficiency Virus and Acquired Immuno-Deficiency Syndrome (HIV/AIDS)*, which

states that administrations at all levels should organize and advocate for the physical and psychological health of people living with HIV/AIDS. However, the implementation of these guidelines has been limited. To date there has been no extensive research on the experience of HIV-positive people within the health care system. Nor has there been any comprehensive assessment of providers' capacity in the area of HIV/AIDS care and support service provision.

But there are some signs of change. In March 2001, the NCADP launched *Directions for Work of HIV/AIDS Prevention and Control for the Period of 2001-2005*. The Directions have three general objectives: 1) to limit the rate of HIV/AIDS infection amongst the general population; 2) to prolong the onset of AIDS; and 3) to mitigate the socio-economic impact of the HIV/AIDS epidemic⁶. And the Government of Vietnam's 2002 report to UNGASS acknowledged limited access to care and support within the country – including limited access to ARVs. Recent receipt of a Global Fund grant of more than US\$12million for enhanced care and support services should increase service provision and access. Plans for the implementation of the grant-funded programme are still being developed.

2.3 CARE in the Greater Mekong Subregion

CARE International has responded to the HIV/AIDS epidemic in South East Asia since its outset, primarily with prevention programs but increasingly though exploring ways to provide care and support. The needs of mobile people are already recognised and responded to within each of the country offices involved in this research – it is hoped that the results of this research will assist CARE's country offices in further developing their work. Existing work with mobile populations includes:

CARE **Thailand**/Raks Thai Foundation has extensive prevention experience among migrant Cambodian, Burmese and Thai seafarers, port workers, seafood processors and sex workers in southern and eastern Thailand. The Foundation is increasingly moving towards care and support and in 2002 completed a participatory study to identify indicators of well being among Thai people living with HIV/AIDS, carried out in partnership with the Centre for New Life Friends, New Life Friendship, Alden House and Power of Life.

In **Cambodia**, CARE is working with mobility-affected people living with HIV/AIDS in Koh Kong and Banteay Meanchey provinces to provide home based care and support and facilitate Buddhist spiritual support and guidance.

In **Vietnam** CARE works with multi-national company Timberland as well as with Chambers of Commerce to improve care and support and prevention efforts within factories. Many factory workers are internal migrants.

⁶ Included in *Vietnam's National HIV/AIDS Program: HIV/AIDS Country Profiles*, National AIDS Standing Bureau of Vietnam, 2001.

Section 3: Participants' Views

Research participants spent hours sharing their thoughts, feelings and beliefs with interviewers. While the research produced some country-specific results, there was also extensive agreement on issues across Cambodia, Laos and Vietnam. A great deal of time, money and energy was expended on trying to access health care, and five main themes emerged regarding reasons for health-seeking behaviour. These can be defined as restrictions on freedom of choice, cost, confidentiality, convenience and word-of-mouth recommendation.

Additionally, participants in each country were asked for their perceptions on the difference between private and public health services. Here, participants from Laos were generally of the opinion that public services in Laos were equal in quality to private services available in Thailand. In Cambodia and Vietnam, what emerged was a sense that private services were not necessarily seen as better than public ones, but that there was general agreement that using public services would inevitably result in facing hidden costs.

3.1 Health-Seeking Behaviour

The vast majority of those mobile and mobility-affected people who participated in this research expend time, energy and as much money as they can find on seeking health care. Active health-seeking choices are made, and participants are strongly motivated to find the services which they perceive as offering the best possible care:

“I go to P... Clinic about twice a month for medical check up, because I am afraid of diseases... Before, I went to get treatments from two other private clinics and one public hospital, but I did not get satisfaction from the services, until I found the P... Clinic.” Sex worker, Laos

The majority of participants in all three countries reported that pharmacies or unlicensed drug sellers were their first stop for self-medicated health care – primarily because of the lower costs involved, but also often because of convenience. Beyond pharmacies or unlicensed drug sellers, choice of health care provider was reported as being affected by four main interlinking factors; a desire for confidentiality, convenience, word of mouth on quality and – again - cost.

All of this is no doubt also true of non-mobile people; however those who move from place to place are frequently more constrained in their health-seeking options. Sometimes this constraint is simply due to lack local knowledge about what services are available; how to access them; and what costs will be involved. But other, more

structural constraints affecting the ability of mobile and mobility-affected people to make autonomous, informed choices regarding health care were documented.

Restrictions on Freedom of Choice

The health-seeking behaviour of undocumented external migrants was reported as being heavily influenced by the need to remain “invisible” to avoid unwanted attention from the authorities. Thus even when reciprocal health care arrangements are made – for example between Laos and Thailand, which allows documented Laos migrants to access Thai public health systems – the benefits of these arrangements are inaccessible to undocumented migrants.

Remaining undocumented is often not a personal “choice”; it is believed that the majority of Laos external migrants remain undocumented because employers do not wish to pay the relatively high registration fee of 4,450 Baht (about US\$106) per person⁷. The registration system in Thailand is also reported to be complex, and increasingly hard to access (see *The Regional Context*). But being undocumented increases the sense of vulnerability experienced by external migrants, and means they must pay more for medical care:

“When I got sick, I sought treatment from [private] clinics. Because, going to the clinic, a doctor doesn’t ask for ID card. But at the public health centre, they ask... Although costs charged by the clinic are more expensive, I prefer to go there when I am sick. Medical staff don’t know I am Lao. So I was treated like one of Thais.” Externally mobile returnee, Laos.

“When working in Thailand, it depends on employers. Some employers help share some medical costs, but some do not. When we go to healthcare services in Thailand, they may ask for ID card. Because we don’t have that ID card, our medical costs may be more expensive.” Externally mobile returnee, Laos

In Vietnam, which operates its own internal migration control system, those who do not have the appropriate paperwork are also effectively excluded from access to many public health services. In particular, they cannot access exemption schemes which are intended to protect the right to health care for the poorest people:

“Only people who possess the hospital waiver card [a card which enables poor people to access fee exemption schemes] can get health services free. I don’t have a fee waiver card and my HIV-positive daughter-in-law... is not registered here. She cannot go back and she cannot get a card here.” Female caregiver, Vietnam.

Vietnam has institutionalised discrimination against people who inject drugs and against sex workers through its “social evils” campaign (see *Laws and Policies on HIV/AIDS*). Thus for many such men and women, the first contact with health

⁷ This registration fee should be borne by the employer; however it is likely that many employers pass the cost on to workers as a form of “bond”, to be worked off.

services related to HIV/AIDS was reported to arise from arrest followed by mandatory blood testing (see *Experiences of Care and Support*). In such circumstances, human rights including the right to autonomy, privacy, confidentiality, and health freedom from discrimination remain theoretical concepts which are ignored in practice.

People known to be intravenous drug users will not be issued with legal internal migration documents. Employed and documented migrant workers are provided with health insurance cover from the Vietnam Health Insurance Company; this cover includes basic medicines and first aid. But even workers holding an insurance card spoke of needing to pay to avoid a long wait for treatment:

"For instance, if you have money and I've got health insurance, doctors will examine you first, not me. All hospitals are the same, so are private health services." Truck driver, Vietnam

For the sex workers who participated in this research, their rights to health care, and to make their own health-seeking decisions, were controlled not just by the State:

"If I get headaches, common flu, then the [establishment] owner gives me medicine to treat it. If the sickness is severe, then the owner may or may not take us somewhere else to get it treated. It is up to the owner." Sex worker, Vietnam

".....whether I go to a hospital or a health clinic to treat my illnesses depends upon the owner's discretion. The health centre is familiar with the owner." Sex worker, Vietnam

"If girls are having health problems I take them to the clinic." Mama San, Laos.

The Vietnamese women who participated in this study explained that such close control was exercised to prevent women from running away, which would represent the loss of an "asset" to the business owner. This is not something only experienced by sex workers who have travelled for work, but is a reminder of the myriad human rights abuses which face so many sex workers every day of their lives – often tacitly justified by "moral" judgements.

Cost

For those people who participated in the research and who had greater degrees of autonomy (within the constraints of lack of information related to health options), health-seeking behaviour seemed to be largely dictated by poverty and the cost involved in seeking health care. This is true of many populations, not just those who are mobile or affected by mobility, but migration brings with it financial costs (usually in the form of loans to enable travel and finding a new home in the destination site). Social costs are also high – mobile people must survive away from the extended family networks which might otherwise find ways of assisting them

financially. Additionally, mobile people do not often have access to land and therefore cannot grow small crops of rice or vegetables to help sustain their families. For those mobile families who do manage to hold land, the onset of chronic illness usually forces its sale – exposing the whole family to a cycle of poverty. A father of three told Cambodian researchers:

“An NGO gave land to us, but when I was severely ill I sold it. Now I take care of it for the owner for two years.”

Q: So after two years where will you go?

“I don’t know. Maybe we will stay on the side of the street.” HIV-positive man, Cambodia

The preference for pharmacies or unlicensed drug sellers as the first stop for self-medicated health care was repeatedly put down to the fact that at such facilities people can control the cost – they buy what they can afford. Additionally, the widespread availability of drug sellers reduces the opportunity costs of having to stop work and travel bigger distances to access care:

“The service from the pharmacy is not bad. It is near, fast, inexpensive and my illness was cured.” Externally mobile returnee, Laos.

Q: Why did you decide to go to the pharmacy at the market for treatment?

“It’s near my house and I don’t know anywhere else.” HIV-positive woman, Cambodia

But if symptoms persist, or illnesses recur, further decisions must be made on which health services to access next. However according to one participant, the drive to move beyond self-medication only take place when the ill person retains hope:

“He doesn’t go to any other service... He only goes to buy medicine... he believes he is going to die anyway so why bother?” caregiver, Vietnam

Even if a person retains enough hope to attempt to access more health care, there was a uniform acceptance that all health care needs to be paid for. Despite the formal existence of health cost exemption schemes in Cambodia, Vietnam and Laos, in practice these schemes are often difficult to access. There was a uniform perception that the more you can pay the better the service you will receive – within both the public and private sectors. Research participants from Cambodia, Laos and Vietnam spoke of the balancing act they must strike between need for health care, desire to access what they perceived to be the best services possible (often based on word-of-mouth recommendations), and entrenched poverty:

Q: If I have money, I expect to be cured. I want to receive serum⁸, but I don’t have money.” HIV-positive woman, Cambodia.

⁸ Intravenous drips are a popular treatment in Cambodia, and are seen as an effective and appropriate medical response for anything from a cold to AIDS-related illnesses. Anecdotal

"I went to the hospital because... medical costs are not so expensive." Sex worker, Laos.

"He is really worried. He really wants to receive treatment but can't because of our financial conditions. We have no money for treatment or medicines. It is just something we have to tolerate" Mother of a man with AIDS-related illness, Vietnam

The reality of poverty preventing sick people from being able to access health care which could at least alleviate their suffering and, at best, increase their life expectancy was recognised by the health services manager interviewed in Vietnam:

"Upon discovery that they have been infected with HIV, the vast majority of PLHA stay at home to self- treat their symptoms because they do not have enough money to pay for the health care services in the hospitals." Health service manager, Vietnam

As another participant explained:

"Truthfully, in order to get good health care at the hospital, you first need to have money. To smooth everything out there, you have to negotiate with doctors. For nurses to give you better services, one needs money to pay for all the services". HIV-positive truck driver, Vietnam.

Confidentiality

Fear of being identified as someone who is HIV-positive led one person to shun all medical treatment, according to his caregiver:

"He sought treatment at home because he didn't want anyone to know about his illness." Family member and caregiver of person with AIDS-related illnesses, Vietnam

A similar reluctance to be revealed as HIV-positive was reported from Cambodia:

*Q: Did the pharmacy tell you what disease you had?
"No, because I didn't let them check." HIV-positive woman, Cambodia*

Confidentiality was of particular concern to the sex workers who participated in this research. They reported that their health-seeking choices were strongly influenced by their fear of identification as a sex worker and the resultant discrimination. Several examples of such discrimination were documented, including the following example from Laos:

reports suggest that different serum sellers introduce substances including amphetamines and steroids, to make their serums appear more effective in giving energy and boosting strength.

*“One girl went to a hospital, but medical staff treated her with no respect when she was known to have gonorrhoea although she was not yet married.”
Entertainment establishment owner, Laos*

Most said they preferred to use pharmacies or private health care providers for treatment of any symptoms which they perceived to be related to sexual activity. There was a strong perception among the women – and other participants - that confidentiality was less likely to be respected within the public system than within individual businesses offering private health care. The public health system is known to request far more personal and identifying details from its patients, and has a shared communication network:

“I advised my friend to go to the hospital, but she would not, because she thought many people would know her.” Sex worker, Laos

“Girls working here prefer to seek treatment from clinics or pharmacies. They do not dare go to a hospital, as they are embarrassed of the medical check-up.” Beer shop owner, Laos

In Vietnam, the reported confidentiality concerns of public health service users differed greatly from the views of health care providers. The providers thought that people with AIDS-related illnesses chose public services because they were staffed by skilled, warm and competent staff who could be trusted and relied on for support:

“ The health clinic’s personnel are trained in HIV/AIDS care and support. Therefore, people with HIV do not need to be afraid or hesitant because they know they trust the personnel and it will be confidential.” Health care provider, Vietnam

Convenience

As stated previously, pharmacies and unlicensed drug sellers are popular as a first stop for health because of the controlled cost involved, and because such facilities exist in even the smallest villages. For many of the Laos participants, convenience when moving beyond self-medication often involved a trip to Thailand. They reported that Thai private health care services were closer to their border province homes than Laos services. There did not appear to be any widespread perception that Thai health services were better than those available in Laos:

“... people prefer to go for treatment in Thailand, as it is nearer than services in Laos. For example, if we go to the Thai hospital it’s only 7-8 km away after crossing the Mekong River. But, if we go to the district hospital, it is about 28km from here, and the road is not in a good shape.” Externally mobile returnee, Laos

“I heard that someone went to get treatment from the friendship hospital in Vientiane. It was OK. The medical staff were good. But it is too far to get to the hospital in Vientiane. That’s why villagers here prefer going to Phonphisai

*Hospital [Thailand], as it is very near, just across the Mekong River. ”
Externally mobile returnee, Laos*

One Laotian woman, who now has AIDS-related TB, reported that she has to travel to the provincial hospital every week for medication; the round trip takes her a day, and her travel cost is about 200 Baht (US\$5, approx) every time.

Word-of-Mouth

Within the boundaries of confidentiality, convenience and cost, participants spoke of being guided towards specific services or treatments because of word-of-mouth recommendations. Some reported recommendations involved “cures”; others involved non-medical staff offering vital medical information to HIV-positive people.

“...someone was cured by that medicine, they told me. Then I bought the same as them.” HIV-positive woman, Cambodia

“I spent a lot of money on medicine. I want to be cured soon. I was told that this disease will be cured after 100 times of injection.” HIV-positive woman, Cambodia

“Mrs X of the family health club of the Women’s Union told me about having medicines that prevent the disease being passed from mother to child.” HIV-positive woman, Vietnam

One Cambodian participant reported that he had moved to Poipet on the strength of reports about Poipet offering better access to services related to HIV/AIDS:

“I know there is a Kru Khmer [traditional healer] here...In Thailand I heard that one women is selling medicine for AIDS...Khmer radio broadcast that other Asian countries have medicine to treat AIDS.” HIV-positive man, Cambodia

Several examples of unfounded rumours were also reported in Cambodia, for example:

“It is usually said that if someone goes to receive service from an NGO, it will make them die sooner. They also say be careful when you eat CARE’s cake – so when they give it to me I dare not eat it.” HIV-positive woman, Cambodia

But in information sharing, as in much else, mobile populations are likely to be disadvantaged. Newcomers to an area will have far fewer contacts, far fewer people to trust and therefore limited access to informal information networks. However evidence from Cambodia suggests that mobile populations are forming their own communities which provide vital psychosocial care and support and no doubt also act as health care information sharing networks (see *Experiences of Care and Support*).

Public or Private?

The issue of whether to choose public or private health care providers did not seem to centre on perceptions of private services offering higher quality services. This was particularly true in Laos where, despite the concerns regarding confidentiality voiced by the Laos sex workers, several of the other Lao participants had a high opinion of the quality of public health services (see *Experiences of Care and Support*). They did not report any major barriers to choosing public health care services other than distance and convenience, as outlined above. However it must be borne in mind that a government representative had to be involved in all data collection in Laos (see *Limitations*).

“At the provincial hospital, medical staff took care of me very well. They came and asked me if I was getting better. Even though the provincial hospital is not perfect, medical staff there listened to me very carefully and gave me a lot of moral support and good advice. In contrast, I went to Chiang Saen hospital in Thailand, medical staff there did not give me as good care as the provincial hospital [in Laos] did with me.” Woman with AIDS-related illnesses, Laos

Among the participants from Cambodia and Vietnam, the main perception was that using public health services would involve having to face unofficial (and, therefore, impossible to budget for) requests for money from nurses and doctors. This led the majority of participants in Cambodia and Vietnam to seek private health care – where charges are clearly delineated – before accessing public health care. This was despite the fact that in some instances, public health care was seen as actually of better quality than private health care:

“When we go and seek treatment at the specialist [public] hospital it’s because we trust them. A physical examination at the hospital is best.” Sex worker, Vietnam

Public hospitals were generally perceived as places to go when a patient is suffering from severe or terminal illness. In Vietnam, participants reported that people prefer to die at home – but this option is not practically available to mobile people who are away from home and who have no one to care for them.

3.2 Experiences of Care and Support

In general, the HIV-positive participants had very low expectations of the level of medical care they could access or of the information and advice they could expect to receive from medical staff.

“The private hospital only examines, they don’t give advice.” HIV-positive woman, Cambodia

Most spoke of seeking relief of symptoms or medical help with finding the energy to keep working and, therefore, to survive from day to day in the face of mounting

medical costs⁹. This lack of expectation was particularly true of the women interviewed (see *Gender Dimension of Care and Support*):

“I hope to get better and be able to walk and eat; to have enough medicine to stop getting a fever in the night time.” HIV-positive woman, Cambodia.

In both Cambodia and Laos, reference was made to the fact that expensive drugs do exist to treat (or ‘cure’) AIDS. While they may not have known the term, participants were undoubtedly referring to anti-retroviral drugs. Health care providers in Cambodia also spoke of selling ARVs, albeit without the appropriate prescribing regimen (see *Service Provider Perspectives*). But even assuming these drugs were properly prescribed and suitable follow-up provided, the cost involved would be well out of the reach of the study participants.

The HIV-positive people who participated in this research looked to health care services for provision of drugs and treatment, but clearly only expected to receive day-to-day practical health care and psychosocial support from their families, their friends and, in some instances, from the broader communities within which they lived.

In terms of provision of drugs and treatment, very few positive experiences were reported from Cambodia or Vietnam. Participants spoke of dismissive attitudes and active discrimination from health service staff, of treatment delays, of unnecessary and (ineffective) drug provision.

Voluntary Counselling and Testing (VCT)

Perhaps the most striking information collected related to experiences of HIV testing. Voluntary counselling and testing (VCT) is internationally recognised as an important link between HIV/AIDS prevention interventions, and as an entry point to HIV/AIDS care and support services (UNAIDS 2002). Mandatory testing is actively discouraged, both from the point of view of personal liberties and the recognised negative effects which mandatory testing can have on the person tested and on their friends, partners, families and communities.

But in Cambodia, Laos and Vietnam, participants reported incidents of being tested for HIV without being asked to provide informed consent. In Cambodia and Laos, health care providers confirmed that testing was frequently carried out on patients believed to be showing signs of AIDS-related illnesses without the patient’s knowledge or consent. The test results were often not passed on to the patients, but were used for statistical purposes as well as to inform medical decision-making, without the involvement of the patient. In some instances, the immediate answer seemed to be to stop offering any treatment and to return the patient to her or his family.

⁹ IV drips which have had steroids or amphetamines added would certainly provide such a (short-term) lift; see *Health-Seeking Behaviour*.

“We test people who we think may be infected, and we send the results to the provincial hospital and PCCAB [Provincial Committee for the Control of AIDS Bureau] for data collection.” Public hospital health care provider, Laos

“In this hospital, when there are patients that the doctors treat for a long time who don’t seem to be getting any better, they take a blood test for AIDS [sic] without telling the patients themselves. If the result is positive, they just call the families of AIDS patients to take the patients back home. The hospital has done this for a long time.” Public hospital health care provider, Cambodia

Generally, we don’t ask the patient’s permission [to test for HIV]. We just test for AIDS [sic] secretly without informing the patient, so we don’t have to wonder for ourselves if they have AIDS or not.” Public hospital health care provider, Cambodia

The concept of uninformed testing must be attractive to health care providers who are often struggling to cope with chronic illnesses they do not understand (see *Service Provider Perspective*). But the above examples infringe many rights. In addition, testing is only genuinely useful to the person tested when it provides an entry point to a comprehensive package of care and support. Without such ongoing care and support it is easy for testing to turn into an instrument of discrimination, as seen in Vietnam. Mobile and mobility-affected people may be particularly vulnerable to such discrimination, because of their identification as a group at “high risk” of infection:

“Those who come back from working in Thailand should be tested for HIV.” Public hospital health care provider, Laos.

“We warn the villagers under our administration, as we know that those who go to work in Thailand bring in diseases.” Village leader, Laos.

In Vietnam, factory workers reported that they were required to take an annual health check-up which included a general physical examination and the collection of blood and urine samples. It is generally understood that these samples were collected to test for STIs, HIV and drug use. However, no information was provided on the purpose of the tests and no informed consent was obtained.

“The time s/he¹⁰ took my blood s/he didn’t explain anything to me. After testing positive for HIV, s/he invited me to come into a private room. S/he started to explain to me about the blood test to calm me down. Then s/he informed me that I was HIV infected. S/he didn’t give me the results on paper.” HIV-positive man, Vietnam.

One man, who is HIV-positive and an intravenous drug user, spoke of leaving his job because he was afraid of what would happen if he took the routine health check:

10 Vietnamese pronouns do not mark gender differences.

“...I worked in the coal mines. When I was working I found out I was infected and quit of my own accord. At that time, the company was about to do a routine physical examination and I was still using drugs, so I didn’t want anyone to know about my drug habit.” HIV-positive man, Vietnam

Other workers reported that they had undergone blood testing during the job recruitment process but did not receive an adequate explanation about the purpose or implications of the tests. Additionally, some of the men who participated in this research had previously been in the army. They reported that army recruits were given a mandatory HIV test.

Participants who had undergone testing without giving informed consent also reported instances in which doctors informed other family members of a positive test result before telling the infected person. No permission had previously been sought regarding the possible sharing of the test result. There were also several reports of repeated tests being carried out, with conflicting results:

“The first time the test was positive but negative in the second time, and negative again at the third time. After several tests, I know I am positive.” Intravenous drug user, Vietnam

Most of the Vietnamese research participants who were sex workers or intravenous drug users reported that they were required to take what, in practice, were mandatory HIV tests. The results of these tests were then often shared among health care workers and leaked out to other community members without the HIV-positive person’s consent.

“My husband was a drug user and he was arrested. I tried to get him out of prison. When I was three months pregnant I discovered he was HIV positive. He did not tell me. (X’s) aunt told me because she knew the doctor who did the test.” Woman who is HIV-positive, Vietnam

The sharing of test results with family members was also reported in Cambodia:

“Sometimes I tell their relatives. Tell or not tell the patient, that depends on the clients themselves. I ask them before testing if they want me to tell them they are HIV-positive.” Private clinic health care provider, Cambodia

And in Laos, a village leader revealed that he knew a person’s HIV status but her family didn’t. It was not clear whether or not the woman herself knew her status:

“I know Ms xxx is HIV-positive... She goes to the provincial hospital for medical care. Her family members are taking care of her very well. The provincial hospital has not yet told her family members about her HIV status.” Village leader, Laos

However Cambodia also provided an example of a family member assuming she had the right to have her husband’s blood tested, and that she should be told the results:

“I often had his blood tested and the doctors said they could not disclose about this disease to the patient’s family; something to do with emotion.” HIV-positive woman, Cambodia

This attitude is completely in keeping with Cambodian and (SE Asian) cultural norms, in which the individual is perceived to be far less important than the family or broader societal groupings. Such communal cultures often struggle with more individualist concepts, such as the rights of one person taking precedence to the rights of the group.

Only a few of the participants who had undergone HIV testing reported the provision of some form of pre- and post-test counselling; this “counselling” appeared in the main to consist of verbal information on how to prevent further transmission following a positive test. Many health care providers reported that they either completely lacked, or lacked confidence in, counselling skills (see *Service Provider Perspectives*). This also became clear through the way in which some providers explained their decision not to tell people if they had a positive HIV test. As one participant remarked:

“...if we find the client is HIV-positive, we will not tell them the truth. The person will be terrified and will want to commit suicide immediately.” Public health centre service provider, Cambodia

This sense of disaster following a positive HIV test was possibly increased by what appeared to be a general perception that being HIV-positive left people with no hope, and no possibility of continuing to live healthily for many years. No reports were made of follow-up appointments being made for people who were found to be HIV-positive, nor of written information materials being provided - assuming the client had the relevant literacy skills to understand such information. One Cambodian woman, who has lower level literacy skills, told researchers that her HIV-test result was “the plus sign”. The researcher probed:

Q: What does plus sign mean?

“They don’t tell you that! I saw plus sign and the red drawing...”

Q: A red drawing as well? But they didn’t tell you they saw any disease?

“No.”

HIV-positive woman, Cambodia.

One Lao health care provider reported that she knew of five migrant people who had undergone HIV tests and discovered they were HIV-positive while in Thailand, but had returned to Laos for “treatment of common flu”.

Health Provider Attitudes

Participants in Cambodia and Vietnam generally perceived that they would have a better reception from private sector staff than from those in the public sector. Examples were provided of instances in which public health service staff reacted negatively to, or displayed fear of, people who are HIV-positive:

“...when I was in [public] hospital, one of the staff spat near me.” HIV-positive woman, Cambodia

“...this Monday, Mrs O – a nurse on the ward – was very scared of my friends and didn’t even greet or talk to them. So they didn’t greet her. It was as if she didn’t want to do her job with us.” HIV-positive man, Vietnam.

“The attitudes of surrounding people are that they are kind of afraid. Once, a nurse from the city came to take my blood. After that he was scared of my group, had a frowned face, he had no sympathy, which made me very sad.” HIV-positive man, Vietnam

One Cambodian woman spoke positively of the outcome of her hospital stay, but followed up with another story of fear affecting the work of public health care providers:

“I feel satisfied with the care at the [public] hospital, I am better. But some staff don’t want to take the [IV] needle out of my hand because they are afraid of being infected. So I just try to take it out myself.” HIV-positive woman, Cambodia

It is possible that such attitudes arise in part from lack of knowledge, fear of their own infection and frustration at not being able to ‘cure’ HIV-positive people on behalf of the medical service providers, rather than from an intrinsically judgemental response to HIV-positive people. This seems to be borne out in part by the providers’ own opinions (see *Service Provider Perspective*). However many HIV-positive participants were convinced that such attitudes arise from public health sector staff being primarily concerned with eliciting unofficial payments, and not with providing care and treatment.

The picture from Laos was slightly different, with several participants presenting a positive picture of the attitudes of health care staff and of services provided – but as stated previously, this information should be considered in the light of a government employee being involved in all interviews (see *Limitations*). One sex worker, referring to public health services, stated:

“Medical staff listen to me” Sex worker, Laos

And another explained why she went to public health services by stating:

“I thought the medical staff would keep confidential about my matter.” Sex worker, Laos

One Lao sex worker, who appeared to expect discrimination because of the societal stigma associated with her line of work, was pleasantly surprised:

“The [public sector] doctor is very good, even if he knows we are sex workers.” Sex worker, Laos

But another sex worker clearly stated her preference for private clinics, despite the presence of a local authority representative during the interview:

“I feel more comfortable going to private clinics than public hospitals, as medical staff at the clinic are respectful. Good advice and faster services are provided.” Sex worker, Laos

Psychosocial Support

There was a general recognition that medical services operated from within a purely “scientific medical” paradigm. HIV-positive people looked to their families (and particularly their female spouses or relatives) for any sort of nursing care. Vietnamese participants reported that the burden of care fell mainly on mothers of HIV-positive people; in Cambodia, wives were reported as primary carers (see *Gender Dimension of Care and Support*).

Additional psychosocial support was reported as coming from other HIV-positive people, and to some extent from the broader community.

“When I was sick, I didn’t seek treatment anywhere. I just stayed at home, took herbs to lessen my fever...At that time, my friend also became infected and he regularly came to talk.” HIV-positive man, Vietnam

“Occasionally, I have moments of happiness. I can’t feel sad all the time. The time when I am happy are when I am with my HIV-positive friends to talk...” male intravenous drug user, Vietnam

In Cambodia some of the participants – who were living in probably the most clearly definable migrant communities to be involved in the research - reported that they had received considerable emotional support from those living nearby. This suggests encouraging evidence of mobile communities developing their own reciprocal coping mechanisms, despite all the pressures which mobile communities face and despite the fact that most people are likely to have lived in these communities for a few years at most:

“My neighbours pity me because I am kind. If I have food or sweets, I share with them. We share with each other. So when I got ill they came to visit me. For the money, we cannot lend each other because we are all poor.” HIV-positive woman, Cambodia

“There are many who give me support. They do not only stand and look, they gather if I get fever in the night-time. They massage me and stay with me until morning. Then I can go to the hospital.” HIV-positive woman, Cambodia

However Cambodian researchers noted that evidence of such support was offered primarily by women; additionally, the support given was generally provided by female members of the community (see *Gender Dimensions of Care and Support*).

The picture of psychosocial support being available within mobile communities was not universal, however. Some participants reported that they had received greater understanding from within their source communities than within their destination communities:

“No one helps me here. They are disgusted with this disease. In my home village they are very helpful, some gave me food while some even gave me bags of herbal medicine.” HIV-positive man, Cambodia.

For example, when my husband died they [neighbours] helped during the funeral. Now I feel I’m mentally stronger because of their help.” HIV-positive woman, Cambodia

Services Reported as Available

A limited range of health care services were mentioned as available by health care recipients and health care providers during the course of this research. These services fall well short of the WHO/UNAIDS recommended essential care and support services for people living with HIV/AIDS (see Table 4). It must be remembered that the table is not intended to provide an overview of the services which are officially available throughout each country. However the fact that both service providers and people who are HIV-positive speak of such limited service options being available serves as a useful reminder that there are often gaps between the theory of service provision and the on-the-ground practice.

Table 4: Services reported as ‘available’ or ‘received’

WHO/UNAIDS recommended essential care & support services for PLHA	Reported as ‘available’ (health care providers) or ‘received’ (HIV-positive participants)		
	Cambodia	Laos	Vietnam
Psychosocial support	✓	✓	✓
	Limited availability within health care services; primarily provided within communities / families / friends / other HIV+ people		
VCT	✓	✓ (very limited)	✓
	However the testing carried out is, in practice, often not ‘voluntary’; and generally involves little client-centred, problem-solving counselling ¹¹		
Palliative: Pain management	✓	✓	✓
Palliative: Anorexia			
Palliative: Weight loss			
Palliative: Malaise			
Palliative: Fever	✓	✓	
Palliative: Weakness			
Palliative: Brain impairment			
OI: Pneumonia		✓	
OI: Diarrhoea	✓	✓	✓
OI: TB	✓		✓
OI: Oral thrush			
Nutritional care			
STI Rx and care	✓	✓	✓
FP services	✓	✓	✓
PMTCT			✓
			Unable to describe treatment regime or drugs used
Co-trimoxizole			
Universal precautions			✓
			Over-interpreted with pregnant women

Gender Dimension of Care & Support

As stated in the previous section, the responsibility for nursing and caring for husbands, sons, daughters and siblings diagnosed as HIV-positive (plus, no doubt, for

¹¹ ‘Counselling’ is a concept which often sits at odds with more communal societies, where the expectation is that ‘higher level’ medical staff will give advice and direct people towards the ‘right’ choice.

any children of HIV-positive parents) fell on women. This is entirely in keeping with societal norms, in which women's role is to "serve". It is a role often adopted unquestioningly by the women:

"When my younger sister found out she tried to blame me, blaming my party habits for this disease – but she really loves me. She told me later that she was not going to get married but stay home and look after me, but I advised her she had to get married." Male intravenous drug user, Vietnam.

In Cambodia, this phenomenon primarily manifested itself through women caring for their HIV-positive husbands and accessing as wide a range of health care as possible (with attendant costs) only to find that when they themselves manifested AIDS-related illnesses all of the family's savings and assets had been spent on care for the husband:

"Yes, this house is ours – but since my husband's illness the house has been in pawn. Now the moneylender tells me the house is no longer mine. Now the interest is equal to the borrowed money. My children won't have anything after I have died." HIV-positive woman, Cambodia

"Before I had this disease, my income was great. But my income was cut short when I succumbed to this disease... when my husband was alive he could find firewood with his own ox-cart, but when his disease was profound we sold both cows and ox-cart for his treatment." HIV-positive woman, Cambodia

In Laos, a woman who had nursed her husband through his AIDS-related death was then banished from her place within his family home when her husband's parents told her to return to her own parents' home. A second woman who had migrated to Thailand and married a Thai man was told by him to return to Laos after she found out she was HIV positive. The couple's son, whose illness prompted the woman to take an HIV test, remained with the father in Thailand.

It must also be noted that of the 35 participants who chose to identify themselves as HIV-positive, the majority (24 out of 35, or 68.5%) were female. In Cambodia, the country with the highest number of HIV-positive participants, just over three-quarters of those participants were female (19 out of 25, or 76%) and most of these were widows whose husbands are believed to have died of AIDS-related illnesses.

In Laos, a country with low official HIV prevalence, it is the experience of CARE Laos staff that those people who are HIV-positive are extremely wary of revealing their status. However the 3 participants who did voluntarily reveal their status were all female, and 2 were widows whose husbands had died of AIDS-related illnesses.

The picture was slightly different in Vietnam, no doubt reflecting the fact that intravenous drug use is identified as the primary route of HIV transmission in the country – and it is accepted that men are more likely to be intravenous drug users than women. Of the 7 participants who revealed their HIV-positive status, 5 were male and 2 were female.

For Cambodia and Laos, it appears that the gender discrepancy in HIV-positive participants arises from two sources. Firstly, transmission is more likely to occur from men to women than vice-versa within heterosexual sexual relationships. Men have on average more sex partners which increases their own risk of transmission, and physiologically male-to-female transmission is twice as efficient as female-to-male (UNAIDS, 2000). Thus if a female participant were infected as a result of unprotected sex with her long-term male partner, that partner would be more likely to die of AIDS-related illnesses first as he would have been infected for longer. Secondly, the Cambodian research found that HIV-positive women were generally more willing to speak about their status than men.

“If someone asks me if I have AIDS, I tell them the truth. I never think of embarrassment.” HIV-positive woman, Cambodia

“It’s OK to tell. I want the younger generation to understand.” HIV-positive woman, Cambodia

“I say I have some diseases, but not AIDS because I am afraid of losing face... if someone has AIDS, they are considered a wicked person.” HIV-positive man, Cambodia

There were some exceptions to this trend – one man reported that he had told friends living nearby, while some women reported they had not disclosed their status for fear of discrimination – but the gender difference in willingness to tell was a dominant theme through the interviews with all of the Cambodian HIV-positive people. Additionally, the female participants reported greater experience of support from their communities. It could be speculated that this support was in some way linked to the women’s openness with those around them; however it may also be that many of the male participants still had a living female partner or a female relative who would care for him and, therefore, might not be seen as so in need of support from other women in the community.

In Vietnam, the research also unveiled disturbing stories of HIV-positive, pregnant women and their experience of health care services, including lack of medical advice regarding mother-to-child transmission:

“My mother-in-law advised me to abort the baby as it would not be normal, but my husband did not allow me because he hoped that the baby would be normal. When the foetus was five months, Mrs X – head of the Women’s Union – told me about having medicines that prevents the disease from being infected from mother to child. I went to XX hospital and the doctor told me I had to wait and they would call me. I waited, the foetus was six months and still they said nothing; seven months and still they said nothing. I went back to the hospital again, the doctor said I had to buy the medicine... it cost so much, 200,000vnd per day¹².” HIV-positive woman, Vietnam.

¹² Approximately US\$1.5 per day.

It was reported that HIV-positive women in Vietnam are isolated from other pregnant women when delivering their babies. They must deliver in a room which is designated for positive women, despite the fact that correct and careful infection control procedures would make such isolation unnecessary. Furthermore, another HIV-positive woman explained that her in-laws tried to pressure her to give up her baby for other family members to raise as she was “not safe or fit to raise a child”.

3.3 Service Provider Perspectives

Health care providers reported limited knowledge of the range of care and support services available for HIV-positive people. For instance, in Vietnam some providers talked about services and treatment to prevent mother-to-child transmission but they could not describe or list the treatment regime or drugs used. Shortages of the most basic drugs and equipment were reported in Cambodia, Laos and Thailand (see *Visualising ‘Ideal’ Services*). Public sector staff in Cambodia and Laos expressed a need for more training and greater skills development to help them cope. Comments regarding lack of counselling skills, or lack of skills in managing interpersonal relationships with HIV-positive clients or clients with advanced AIDS-related illnesses, were common:

“For me, I have not learned counselling skills. I can’t converse with those who have AIDS.” Public hospital health care provider, Cambodia

“With the very limited resources we have, we are able only to treat diarrhoea, malaria, dengue fever and the common flu. The drug revolving fund here is very limited. For people with AIDS-related illnesses, we treat symptomatically – for example if they have diarrhoea we give them rehydration fluid, if they have a fever, we give Paracetamol. We do not give any counselling, as we do not know how to do it... We need more technical support – in particular, when we face an AIDS case, what and how we are supposed to do.” Public sector health care provider, Laos.

Some health care providers expressed feelings of helplessness and frustration at not being able to do more for clients, and about being constrained by poor working conditions and lack of resources.

“My room usually has the door closed. If patients come, please tell them to knock on the door. It’s hot and I need to talk to patients inside, so I close the door. Tell people ‘don’t go home if you see my door is closed. Don’t be afraid.’ But we don’t have anywhere for them to wait; it’s very difficult”.
Public STI clinic staff, Cambodia

One member of staff from a Cambodian public sector health clinic reported how difficult it was to cope when people in the final stages of AIDS-related illnesses were taken to the centre and left to die. Clinics have no resources for funerals, and the

participant clearly expressed anger and a feeling of being trapped in such circumstances.

In Vietnam, however, public health care providers appeared to believe that HIV-positive people received good quality care which was “free of charge”, confidential and readily accessible. There were only two voices of dissent; one from the health service manager interviewed for this report (see *Health-Seeking Behaviour and Service Managers and Gatekeepers*), and one from a provider who stated:

“It is harder for people living with HIV to access health services than other people because they are poor, have low self-esteem and difficult circumstances.” Health care provider, Vietnam

The following quotes from other service providers should be read bearing in mind the reported experience of HIV-positive people in Vietnam – including HIV testing which, in practice, is mandatory; discriminatory attitudes from health care staff; lack of information on services available; lack of a real alternative to public health care and, above all, the need to make informal payments within public health care systems (see *Experiences of Care and Support*):

“In any circumstances, people living with HIV/AIDS are able to access local services, management and information. Because of this they are not facing any difficulties accessing health care services.” Health care service provider, Vietnam

“At the community health service, they know that HIV prevention workers already know about their situation – they do not feel shy and when they are told of their HIV status they can understand well. According to Vietnamese law, these workers are responsible for keeping information secret, so PLHA can definitely trust them.” Health care provider, Vietnam

“I believe the service is good because if it wasn’t then why would people come? If people come here for an examination, then I think our service is good.” Health care service provider, Vietnam

In terms of private health service providers, the motivator in deciding which services to offer was, hardly surprisingly, reported as a purely business-based one – often with little link to good practice. This was particularly noticeable when the private practitioners spoke of the sale of ARVs:

“Before I used to sell [ARV drugs] but nobody bought them so I turned back. After that there was one customer, a brothel owner who came to buy, and I told him I could order it if he needed it.” Pharmacy staff, Cambodia

“I ...sell a pack of it containing 2 cans for \$100. The Indian-made medicine is \$40-50.” Private laboratory staff, Cambodia.

It was reported from Laos that private practitioners will often verify the patient's capacity to pay before providing this consultation/ treatment. However information from private health providers was hard to come by. Cambodia's researchers reported extreme difficulties in interviewing private health providers. Although all of the private health providers interviewed had consented to do so, most offered no information beyond "yes" or "no" answers (see *Limitations*).

Three traditional healers – Kru Khmer – were interviewed as part of the Cambodian research. Kru Khmer treatments can range from prescription and provision of traditional medicines, to fortune telling and the preparation of charms to bring good fortune. All three of the Kru Khmer who participated in this research reported that they had treated many patients who they believed to be HIV-positive and with AIDS-related illnesses. One of the Kru reported having strong referral links with local "modern" doctors:

"Before I can treat them, I tell them to go to the hospital first. Sometimes I can treat and sometimes the doctor can treat. In short, we refer patients to each other." Kru Khmer, Cambodia

The other two appeared to operate much more independently of the formal medical sector. They both reported their main role in AIDS care as providing symptomatic relief for ulcers and diarrhoea associated with AIDS. One of these, however, claimed that he could also cure AIDS:

"I could cure 70-80 out of 100 people. However, some are untreatable and become weaker and weaker and some only come for two days.

Q: You said you could cure 70-80% of patients. How are they cured? Do you cure the entire virus in the body, or what?

I have many pictures of cured patients here. Some are recovered and healthy. It was entirely cured... although you take the drug here or at home, you must take for 60 days or more, then I guarantee it will be cured entirely." Kru Khmer, Cambodia

3.4 Service Managers' and Gatekeepers' Perspective

Each of the country offices involved in this research interpreted the broad target group heading of "service managers/gatekeepers" differently. In Cambodia, the decision was taken to interview religious leaders because of the key role they can play in supporting and enabling effective, community-based care and support for people affected by AIDS.

In Laos, interviews were carried out with village leaders (who are expected to record and control undocumented migration to Thailand), entertainment establishment owners (who often control the movement of women employed in their establishments) two local authority representatives and one national AIDS authority representative.

In Vietnam, researchers interviewed one key employee at provincial health department level.

In **Cambodia**, the religious leaders had mixed responses to issues of care and support for people believed to have AIDS-related illnesses. Those who felt care and support was not anything to do with them offered comments including:

“Monks are usually busy, so there is little time to devote to people with AIDS.” Monk, Koh Kong

One monk was well aware of the problems that AIDS brings for communities, but also felt that responding to these problems was not part of his role. It was not clear why:

Q: If there are a lot of people with AIDS, will there be any problems?

“It’s difficult to live together in the community. It’s difficult to look after the infants or children. So there will be transmission from mothers to infants who don’t know anything. As I know AIDS can be transmitted from mothers to infants if the mother has AIDS.”

Q: So what is the role that the monk can play to help them?

“I can’t play any role.” Monk, Cambodia

One participant felt that care and support was primarily the responsibility of the government, or of NGOs such as CARE:

“Yesterday an AIDS patient was brought here, but I sent him back to... our government hospital. I didn’t follow what happened then. I don’t have an association to help patients in this pagoda.” First Deputy Monk, Cambodia

In fact, the same monk was deeply upset when the CARE Cambodia staff member told him that his pagoda was believed to be able to help people with AIDS-related illnesses, through a lay support association. He appeared to think that the pagoda had no care and support role to play:

Q: Some health workers told me this pagoda has an association.

“This pagoda has an association! I want to meet someone who said that kind of thing. It’s not true! That’s why I’ve seen that AIDS patients rejected from the hospital come to this pagoda. I think if CARE has a support service for AIDS patients those patients shouldn’t be abandoned like this. Every district has its own hospital and also CARE. If the government can’t handle those patients, they can contact CARE for help, not just throw them away like cats or dogs.”

Q: Don’t we need money to go to the hospital?

(silence) *“Last year I sent an old man to the district hospital but he was rejected.”*

Q: Does this pagoda help AIDS patients?

“This pagoda doesn’t get any help from anyone, I was amazed at some health workers saying that my pagoda had an association. I should call them and ask them about this...” First Deputy Monk, Cambodia

But this attitude was not universal. A few participants believed that the pagoda has an important role to play in supporting people with HIV and people who have AIDS-related illnesses or are affected by AIDS:

“When the AIDS patient died in this pagoda, we suspected that his wife may have contracted AIDS from her husband. So we as monks collect money from each monk to help her.” Monk, Cambodia

“In the past, there were some prostitutes who knew they had HIV and attempted to commit suicide. Those girls came to meet me. I counselled them, gave them my medicine and watered them¹³. After that they seemed more courageous and didn’t want to commit suicide again.” Monk, Cambodia

One religious leader honestly admitted that he is scared of being infected if he interacts normally with people who are HIV-positive:

Q: If an AIDS patient prepares food would you eat it?

“No I am frightened of infection. I fear that scabs or blood drop into meals or food.” Imam, Koh Kong

This Imam asked CARE staff for advice and information regarding routes of infection, and prevention of infection. Two of the monks who participated in the research requested training in HIV/AIDS care and support. They wanted their pagodas to take a more active role in prevention and caring for people with AIDS-related illnesses in the community:

“I want an NGO to train monks to make a visit to AIDS patients at the hospital or the house, like a home visit. They have this in other places, but in Koh Kong, we don’t have. I want to use my role as a monk to visit AIDS patients although some people may see this as an absurdity. But monks must have sympathy toward everyone.” Monk, Cambodia

“Does your NGO or other NGOs have any training programs about AIDS for monks? Because over here all the monks are eager to know about AIDS. When people have problems, they ask the monks to go to their houses to give Buddhist chants. So every monk should know about this disease to be able to help people and make them aware. This would help them to be careful and prevent continuously.” Monk, Cambodia

¹³ Watering (*Jut tuk*) is a popular Buddhist ceremony in Cambodia. A monk sprinkles water over the afflicted person while chanting Buddhist precepts and good wishes tailored to the ailment. Watering is commonly used for lingering illnesses and psychosocial problems, like depression. It is believed to be efficacious where other medicine has failed or as an adjunct to other treatment.

In **Laos**, village leaders were aware of the existence of AIDS in their communities and offered generally compassionate views towards people believed to have AIDS-related illnesses.

“We campaign for our villagers not to discriminate against people with HIV/AIDS.” Village leader, Laos

“Mrs got AIDS from her first husband... I see her living as normal as any other. I do not see any discrimination against her. She is treated like other people in the village.” Village leader, Laos

“Now, there is one woman with AIDS. She got the disease from her husband. She is quite sick, her husband has died. I observe that other people treat her like general people.” Deputy village leader, Laos

However HIV infection and AIDS were primarily characterised as linked to migration:

“In our village there were two people known to be HIV-positive. One who went to work in Thailand was sick, and died of AIDS finally... They migrated to work in Thailand for years...we warn the villagers under our administration, as we know that those who go to work in Thailand bring in diseases.” Village leader, Laos

“Many people coming from Thailand have been infected with AIDS.” Village leader, Laos

There is an inherent danger of stigma and discrimination against mobile people in such an approach, although it is understandable that people attempt to make sense of what they see as a ‘new’ disease affecting their communities. This link may already be leading to greater control on migration, according to one participant:

“Khan Theung [senior authorities] advise that those who go to work in Thailand may bring in diseases from Thailand, so we try to prevent that movement.” Village leader, Laos.

In addition, the desire to ‘make sense’ of HIV/AIDS often equates to a desire to identify the cause of infection. Although it is almost impossible to identify the point at which the virus moves from one body to another, people with HIV often find themselves subject to wide ranging assumptions regarding the ‘morality’ of their sexual behaviour or their lifestyle. One of the Laos village leaders provided a clear demonstration of this tendency when he recounted the following tale:

“Regarding people with AIDS, one I know is Ms Tan [there is a clear implication here that the woman concerned is unmarried]... We use this example to campaign that this is a result from sex work.” Village leader, Laos

Another village leader told interviewers:

“In this village, we do not allow Sao Dink [bar girls] to rent a house or stay here, because they are the cause of social evil – drugs and prostitution. And the district governor lives in this village, so we have to pay more attention to this kind of issue by cracking down on commercial sex work and drug use among sex workers.” Village leader, Laos

The entertainment establishment owners interviewed all spoke of trying to encourage their female workers to use medical services, but reported that the women themselves preferred to self-medicate and to avoid hospitals (see *Health-Seeking Behaviour*).

The provincial Deputy Director of the Department of Labour and Social Welfare interviewed for this report spoke of his department’s desire to prevent economic migration through development of income generating alternatives:

“Our policy is to support work in the province – traditional chicken raising, mushroom growing, pig farming, tree planting, handicrafts and so on. All of these we want to do, but the plan has not yet been financially supported.” Deputy Director, Dept of Labour and Social Welfare, male, Laos

3.5 Visualising ‘Ideal’ Services

Participants offered a wide range of practical suggestions for improving care and support services for people affected by HIV/AIDS. None of the suggestions listed below should be beyond reach. However any desire to instigate new or improved services should be balanced against the frequently reported lack of basic health care essentials including clean water, beds and medication.

The main improvement ideas from each participant group are summarised below.

Mobile Populations

(including HIV-positive people)

- Lower costs, and an end to unofficial charging in the public sector (although this was not an issue for the Laos participants)
- Access to reliable, impartial, easy-to-understand information to help HIV-positive people make their own decisions on health-seeking choices, and specifically:
 - Clear referral advice on appropriate services available in the private, public and NGO sector, how to access such services and what costs might be involved
 - Advice on self-medication for common opportunistic infections (including advice on the appropriate use of traditional medicines)
 - More information from health care providers before treatments are initiated
- An end to testing for HIV without informed consent
- Greater provision of, and access to, drugs and treatments, and specifically:

- Greater technical and financial support for home-based care, including training for home carers and access to clear, practical information on caring for people with AIDS-related illnesses
- Access to drugs which can keep AIDS-related illnesses at bay (the participants did not use the term anti-retrovirals, but the researchers believe this is what was being referred to)
- More client-focused services, which should include:
 - More provision of community-based services, thereby reducing the current high costs in terms of time, energy and travel expenses experienced by chronically or seriously ill people trying to access health care services
 - Services whose opening hours are guided by patient need, not staff preference
 - Better trained staff (and higher numbers of staff trained in issues relating to care and support of HIV-positive people and people with AIDS-related illnesses)
 - Less discrimination and a more compassionate approach from health care providers (particularly for HIV-positive people who sell sex or inject drugs, or who have done so in the past)
 - Greater confidentiality (including provision of genuinely private counselling areas)
 - Access to either female medical staff, or female attendants, for female patients
 - Effective feedback systems, which actively seek and respond to the knowledge and opinions of service users
- More counselling and emotional support services, including:
 - Access to self-support groups for HIV-positive people
 - Better counselling linked to testing, plus clear explanation of HIV-test results, and practical advice on what health care options are available following an HIV test

Health Care Providers

- More training in and/or information on:
 - How to care for people who have AIDS-related illnesses, including what medicines or treatments may be effective for AIDS-related illnesses
 - What public, private and NGO services are available for people with HIV/AIDS, what referral links exist and/or how to establish referral links
 - Counselling
- Greater provision of services for people affected by HIV/AIDS, and specifically:
 - Home-based care (seen as a service to be provided by health care staff in collaboration with community-based carers)
 - Counselling
 - Specialist AIDS-care centres

- More resources (from government and from NGOs and INGOs), specifically:
 - More HIV testing facilities and equipment
 - Basic supplies, including beds, blankets, patient record sheets, syringes, condoms, and medication for skin diseases, TB and diarrhoea
 - Provision of basic OI and palliative care medication kits to enable home care
 - Provision of genuinely private spaces for counselling of HIV-positive people, and for general patient examination
 - Genuinely private rooms for STI diagnosis and treatment
- Greater coordination between health care management systems at national, provincial and district levels

Service Managers and Gatekeepers

The diverse sampling of service managers and gatekeepers in each country makes it difficult to generalise this information. However some interesting ideas arose from within different participant groups.

Religious Leaders, Cambodia

- More information for community carers and community leaders (including religious leaders) on how to care for people with AIDS-related illnesses

Village Leaders, Laos

- Provision of village-based treatment options, including:
 - Free or reduced price dispensaries
 - Care and support for people with AIDS-related illnesses (type of care and support not specified)
- Support groups and income generating schemes for people affected by HIV/AIDS
- Greater provision of basic resources at a district or provincial hospital level (shortages reported included clean water, basic equipment, trained staff, medicines)

Entertainment Establishment Owners, Laos

- Client-friendly STI services, specifically:
 - Guaranteed confidentiality
 - A private examination and treatment room
 - Services provided by female staff
 - An end to health care provider discrimination against women believed to be sex workers

Conclusion

In many ways, this report could almost not be about migration. The stories contained herein could equally have been told by people across the GMS who have never left their home village but are affected by HIV/AIDS. They are sadly familiar stories of...

- lack of suitable services for people with AIDS-related illnesses;
- HIV testing without informed consent;
- enormous debts being run up in search of health care;
- health care providers struggling to deal with AIDS-related medical conditions and psycho-social needs they know little about, and for which they are ill-prepared and under-resourced.

Yet for many of the HIV-positive people who participated in this research, their vulnerability and marginalisation has been magnified through the lens of migration. Poverty has been compounded by debts incurred during moving home, and through migrants either being distanced from, or having to sell off, farm land which might otherwise offer them a subsistence existence. Isolation has been increased by lack of access to extended families or to traditional community coping mechanisms. And for women whose mobility ends with involvement in sex work, this isolation is compounded still further by heavy societal stigmatisation of sex workers. Health-seeking behaviour has been skewed by lack of local knowledge, and by limited access to local information networks. Undocumented migrants are left vulnerable to exploitation, and with little recourse to protection in law.

The answer is not to curb migration. As Catrin Evans reports (2003), “UNAIDS stresses that being mobile in and of itself is not a risk factor for HIV infection. Indeed, freedom to move in pursuit of livelihood opportunities is an important freedom.” Additionally, Thailand’s experience with crackdowns on migrants leading to labour shortages shows that migrants are a key part of a country’s socio-economic web. Thus what needs to be developed are responses which address and reduce the ways in which mobility and migration can increase people’s vulnerability and marginalisation. An important part of this must be to ensure access to care and support services is widely available to all people affected by HIV/AIDS.

Within the GMS, there already exist many laudable agreements and declarations aimed at reducing the vulnerability of people affected by mobility, and at increasing access to care and support services. This report shows that the current experiences of people affected by mobility fall way short of those agreements and declarations. The challenge now is how to narrow those gaps.

Recommendations

- The team recommends that researchers exploring issues around HIV/AIDS as well as community development test the use of rights and rights based approaches in conducting studies. Defining and using a rights based framework to conduct research was both an effective tool for exploration and analysis of issues, but also a useful means of learning about rights and rights based approaches. This applied to both programme staff and programme participants or beneficiaries.
- This research recognises that people have a right to be mobile but found that mobility tended to put in jeopardy rights around care and support, both for those who are mobile, as well as the population at large, as the health issues of mobile people affect the health of the entire population. Therefore we conclude that strategies must be developed to increase the safety of mobility and reduce related marginalisation and vulnerability, which exacerbate HIV/AIDS related vulnerability. Such strategies need to include provision of information about mobile people's rights, including clarification of the steps people can take to realize their rights within existing rules/policies; targeting programmes to sending, receiving and transit communities; paying special attention to gender issues; and including succession planning in such programmes.
- The UNDP GMS mobility and ASEAN initiatives should be revisited and used as tools to clearly identify policies and practices that are both consistent with and contrary to pre-agreed regional statements, policies and guidelines. Identification of such policies and practices would enable advocacy efforts to focus on ensuring the enforcement of existing consistent policies, as well as promotion of the development and adoption of supportive policies that are consistent with these regional initiatives that promote the rights of mobile and mobility affected people living with and affected by HIV/AIDS.
- Source and destination service providers, both private and public, should be facilitated and supported to develop links and to learn methods of effectively working with mobile people. Simple to use referral systems that rely on user rather than facility based records need to be developed. Joint capacity building could be provided, focusing on promotion of such referrals, increased sensitisation of service providers to the needs and rights of mobile people, and building service provider care and support clinical and psychosocial skills.
- Mobility and mobility affected people should be enabled and encouraged to participate in planning, monitoring and evaluation services. In practice this will take different forms in different countries, but a valuable example exists in Thailand where volunteers who are members of mobile communities assist

CARE Thailand/Raks Thai Foundation staff in reaching vulnerable and marginalized migrants.

- Existing national and international policies, which state that all HIV testing should be confidential, and/or accompanied by informed consent, and include pre-/post-test counselling need to be put into practice.
- HIV testing should be a link and entry point to a basic package of care and support and prevention services as defined by each country.
- Women should have the option of being cared for by female service providers or of having a woman attendant present during medical consultations.
- Sex worker programmes/policies need to include safe mobility strategies as well as strategies to address issues that increase sex worker vulnerability and contribute to violations of their rights.
- National and regional programmes and policies need to incorporate drug use / harm reduction strategies among mobile populations and take steps towards eliminating related human rights violations related to drug use.
- Care and support services must not be developed in isolation from other services but rather part of a continuum that includes prevention, access to treatment where possible and efforts to increase resilience to the impacts of HIV/AIDS. Lack of access to livelihoods or savings/remittance services also affects care and support.
- Establish strategic linkages and coordination between organizations that address mobility such as the International Organisation for Migration and International Labour Organisation and international NGOs addressing HIV/AIDS and mobility so that issues of care and support are addressed in a coordinated and comprehensive fashion.

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