



**Pact**



# HIV/AIDS Communication Mapping of IEC Materials for PLWHA<sub>s</sub> in Cambodia



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**in collaboration with**

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Our sincerest gratitude is extended to the Pfizer Foundation for funding this project that will have valuable impact on providing guidance for future IEC materials and the effect these materials will have on the lives of People Living with HIV/AIDS in Cambodia.

## List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retro Viral Treatment
BCC	Behavior Change Communication
CAA	Children Affected by AIDS
CPN+	Cambodia People Living with HIV/AIDS Network
FHI	Family Health International
GO	Governmental Organization
HACC	HIV/AIDS Coordinating Committee
HIV	Human Immunodeficiency Virus
IDA	Indra Devi Association
IEC	Information Education and Communication
KHANA	Khmer HIV/AIDS NGO Alliance
MoH	Ministry of Health
NAA	National AIDS Authority
NCHADS	National Centre for HIV/AIDS, Dermatology and STD's
NGO	Non-Governmental Organization
OI	Opportunistic Infection
PLWHA	People Living With HIV/AIDS
STD	Sexually Transmitted Disease
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
VCT	Voluntary Counseling and Testing

## *Executive Summary*

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The goal of this communication mapping exercise was to assess the Information Education and Communication (IEC) materials available for People Living with HIV/AIDS (PLWHAs) in Cambodia. For this exercise, Pact Cambodia chose to partner with 2 local organizations that have vested interest in HIV/AIDS material development: Cambodia People Living with HIV/AIDS Network (CPN+) is 4,000 members strong and growing, and the HIV/AIDS Coordinating Committee (HACC) is a network of over 90 local and international NGOs and GOs working in the HIV/AIDS sector. These partnerships provided an excellent cross section of experts in the field and brought first hand experiences of PLWHA to the table.

Over the course of two months, the team met with 30 NGOs and GOs and 5 focus groups comprised of PLWHAs and home care providers totaling 99 individuals. As part of the communication mapping exercise, the team collected 133 different types of IEC and BCC materials in Cambodia. Of the material collected, 89% (107 national, 57 international) IEC materials focused on prevention and 11% (9 national, 10 international) focused on care and support for PLWHAs.

We learned that there are no IEC materials being designed by PLWHAs and for PLWHAs and there is only limited materials dealing with care and support for PLWHAs. The fact that there are 164,000 people currently living with HIV/AIDS in Cambodia, and that over the next decade there will be an average of 20,000 new cases each year, the need for PLWHA services is great.<sup>1</sup>

The results from the focus groups and meetings revealed a common thread. PLWHAs and home care workers have a high demand for IEC materials. They expressed a need to develop materials that portray PLWHAs as normal, healthy, happy, attractive and productive individuals. This was a resounding design demand for all PLWHA literature and not just IEC materials that address issues of discrimination. PLWHAs expressed that there are too many materials that depict PLWHAs as emaciated even though most PLWHAs live healthy lives for many years after sero-conversion.

PLWHAs and caregivers want booklets that are half the size of a sheet of A4 paper and no longer than 10 pages. These booklets would become part of a series of materials for PLWHAs that deal with one topic or sub-topic at a time. The team learned that excessive information was often overwhelming and confusing to the reader. The demand for the particular size for the publication was very important since the user could carry it discreetly in their pocket or bag thus avoiding being targets of discrimination for possessing HIV/AIDS materials.

Many people, including members of the home care support teams and PLWHA support leaders, are illiterate or semi-literate. Therefore, to make the information accessible to all, it needs to have high quality pictures that are supported by a limited amount of text. Repeatedly, PLWHAs stated that they equated real photographs with real life situations that were plausible, rather than hand drawings or cartoons which were less likely to be perceived as real or believable. If people can relate to the individuals in the photographs, the messages will be taken seriously by PLWHAs and will be more likely accepted and followed.

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1 Cambodia 2002 sentinel survey

There are HIV/AIDS books and flipcharts developed by other organizations for home care workers that require training to properly deliver the information to the end user. The team suggests focusing on developing materials that reduce the need for a “gatekeeper” to IEC materials and ensures that the IEC materials are user friendly thus requiring little or minimal training. To provide the end-user support, it would also be advisable to include relevant phone numbers and addresses of clinics, hospitals, support groups, etc. where people can access more information and seek support.

The most pressing issue for PLWHAs was self-care. Self-care is a low-cost, easy, effective way that PLWHAs can maintain their physical and mental well-being. This is especially important in a poor country like Cambodia where the majority of PLWHAs may not have access to medicine or healthcare due to poor infrastructure or lack of money. There are presently less than 1,000 PLWHAs receiving free antiretroviral (ARV) treatment from NGO programs and mostly distributed at major hospitals in Phnom Penh such as the programs of Medicines Du Monde (MDM), Medicines Sans Frontiers (MSF France and Belgium) Center of Hope and ESTHER. The government hopes to increase this number. Until then, most PLWHAs will never have access to these drugs, but need to find alternate and equally life saving ways to live with HIV/AIDS.

The request for information on self-care was followed by a request for information about traditional medicine, treatment for OIs and other complications, information about ART, discrimination and stigma reduction.

It is critical to involve PLWHAs in the entire development and distribution process so that the materials accurately reflect and meet their needs. It is the goal of the project to empower as many PLWHAs as possible and encourage them to take an active role in seeking out information and sharing it with others. CPN+ and HACC are the most logical points of distribution as they each have a large membership through which materials can be developed, tested and disseminated quickly and efficiently.

This report is useful for any organization developing IEC and BCC materials for PLWHAs. It provides some useful guidelines for material development that will help increase the accessibility of materials for PLWHAs in Cambodia.

## Chapter 1: Introduction

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### 1.1 Background

Cambodia has the highest HIV/AIDS prevalence rate in Asia relative to its population. In 2002, the estimated HIV+ population of Cambodia topped 164,000. More than 94,000 have died from AIDS since the beginning of the epidemic in 1991. Adult prevalence rate is 2.6% of the general population between the ages of 15-49. That translates into roughly 3% of the adult male and 2% of the adult female population.

Many local organizations implement HIV/AIDS prevention programs but few work with PLWHAs. There is a growing number of PLWHAs with 15,750 documented cases out of the 164,000 estimated and a dire need to provide them with services that will improve their quality of life. This severe need is exemplified by one of the leading PLWHA support group networks of more than 4,000 members, CPN+, that does not have any health literacy materials developed by and for their members.

The goal of the Pact/Pfizer project is to strengthen HIV/AIDS communication and education materials targeting people living with HIV/AIDS and their caregivers. Pact will bring together local and international experts in the HIV/AIDS sector with media and health literacy experts to create a new package of materials appropriately designed for and by PLWHAs and their caregivers.

### 1.2 Implementing Partners (see annex 1)

Pact selected The Cambodian People Living with HIV/AIDS Network (CPN+) and The HIV/AIDS Coordinating Committee (HACC) as the main partners for the Pact/Pfizer Project: "Optimizing Communication Strategies and Materials for Persons Living with HIV/AIDS and their Caregivers" because of their wide network and outreach through which more than 10,000 PLWHAs or individuals working with population affected by HIV/AIDS can be reached easily. In order to accomplish the proposed project activities, Pact provides sub-grants and technical assistance to these partners.

### 1.3 Communication Mapping Team

The team consisted of Ms Keo Keang, Ms. Renana Keynes, Mr. Kurt MacLeod from Pact Cambodia, Mr. Heng Sambath and Mr. Meas Ramo from CPN+ and Mr. Sun Yura from HACC.

### 1.4 Goal

The overall goal of the communication mapping exercise was to find out what materials have been/are being developed for PLWHAs; and to make recommendations about future IEC material development.

## 1.5 Objectives

The main purpose of the communication mapping exercise was to accomplish the following:

- Communication mapping of existing HIV/AIDS programs in Cambodia with a focus on on-going health literacy/IEC materials being used by implementing organizations that focus specifically on the needs of PLWHAs and caregivers.
- Analysis of communication mapping findings.
- To identify the major communication gaps in both content and communication techniques and determine how the Pact/Pfizer Foundation project can best fill these gaps to meet the needs of PLWHAs and caregivers.
- To identify entry points for PLWHA IEC materials in existing campaigns to best leverage on-going efforts.

## Chapter 2

# Communication Mapping Process and Methods

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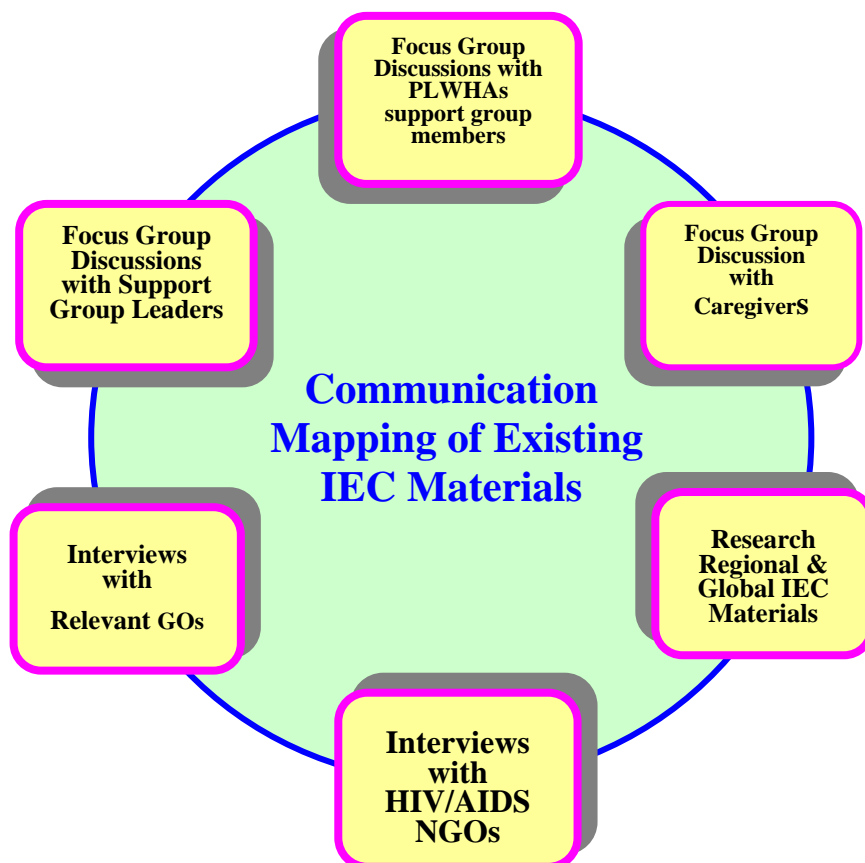
### 2.1 Process

In order to achieve the goal, the team met with 30 NGOs and GOs (see annex 2) and PLWHA support group leaders to learn about the types of IEC materials they are using, distributing and producing. A total of 99 individuals were interviewed. The project wanted to put into place a process of IEC material development for and by PLWHAs and their caregivers that included a number of steps that allowed PLWHAs, caregivers and key stake holders (NGOs and GOs) to participate in the assessment, share their experiences in developing and using IEC materials and to define their needs (see annex 3).

### 2.2 Methods

In order to carry out of this assessment, Pact, CPN+ and HACC established clear methods for gathering and analyzing IEC materials (see annex 4). This included developing “tools” for the interviews with NGOs and GOs (see annex 5), Conducting focus group discussions with PLWHAs, care givers and PLWHA support groups leaders (see annex 6), collecting HIV/AIDS materials and HIV/AIDS IEC material analysis.

### Communication mapping methodology



### **2.2.1 Interviews with NGOs and GOs**

**GOAL:** To meet with organizations that are currently working on HIV/AIDS issues and learn from their experiences in producing and distributing IEC materials, look for future partners/collaborators and ensure that the team doesn't duplicate what has/is already being done.

The team established a list of NGOs and GOs working in areas of HIV/AIDS education, care and support. The team met with 30 organizations and IEC/BCC specialist to collect samples of materials they developed and/or distribute about HIV/AIDS and healthcare and in particular those materials developed for PLWHAs. The meetings provided an opportunity to ask questions about their IEC material development.

### **2.2.2 Focus Group Discussions**

**GOAL:** To hear directly from PLWHAs and HIV/AIDS NGOs, and PLWHA support group leaders about their experiences, needs and ideas for future IEC material development.

CPN+ used 2 of their 11 support groups in Phnom Penh as their focus groups for the IEC discussions. They chose these two groups due to the strength of their counseling/peer education and home based care services, as well as their strong outreach to the community. HACC selected 22 members of their network that deal with IEC production and care and support of PLWHA.

### **2.2.3 HIV/AIDS IEC Materials Analysis**

**GOAL:** To assess the IEC materials currently available for PLWHAs for content, design and accessibility to PLWAHs.

Throughout the communication mapping process, samples of IEC materials were collected for further analysis. A database was designed to catalogue the materials and provide a quick reference for the team as to what materials are available. The team established an evaluation tool (see annex 6) to analyze the different materials. The materials were divided into the following categories: Content, Target Audience, Type of Material, Language, Organization(s) involved in material development, and Method of Distribution. This database proved to be useful in enabling the team to look at what is available and where we should concentrate our material development.

This is the beginning of one of the most comprehensive database libraries of HIV/AIDS IEC materials in Cambodia and will be handed over to HACC to manage at the end of the project. It will also be linked with RACHA, Medicam and the MoH—if possible—all of which have health material related databases.

### **2.2.4 IEC Advisory Committee**

Due to the complexity of designing appropriate IEC Materials, it was decided to invite a team of experts in the field of HIV/AIDS to serve as an advisory body. It is composed of specialists within some of the organizations interviewed, as well as PLWHAs (see annex 7). Since the material created will be made available to any group or organization, it is important that a cross-section of voices be heard and their suggestions incorporated into the final design. Their input and feedback throughout the material development process will enable the project to create a better end product.

## Chapter 3

# HIV/AIDS IEC Materials Analysis

Of the thirty organizations working in HIV/AIDS issues that were interviewed, 25 were based in Phnom Penh and 5 in Battambang. While all of them use IEC and BCC materials to deal with healthcare, HIV/AIDS education, prevention, care, support and discrimination issues, half of the organizations interviewed relied on other NGOs for their materials and distributed these materials through their network. Only 5 NGOs produced materials for PLWHAs. During the meetings, the team collected samples of IEC materials that each organization was producing and/or distributing and discussed the pros and cons of each type.

Of the materials collected, there were 164 (107 national, 57 international) IEC materials on Prevention and 19 (9 national, 10 international) on care and support. There are 35 local and international institutions that produced the 107 Cambodian based HIV/AIDS prevention IEC materials and 7 institutions that produced the 9 care and support IEC materials. The most common type of materials was brochures, with the dominant language being Khmer, followed by English and then Vietnamese.

### 3.1 Material Analysis

The following is a list of the types of IEC materials that are currently being produced /used by the NGOs and GOs that the team interviewed and their analysis.

Types of Materials	Interviewees Analysis	
	Pros	Cons
T-shirt	<ul style="list-style-type: none"> <li>everyone likes them because they are provided free</li> <li>attractive</li> <li>high visibility (mobile education)</li> </ul>	<ul style="list-style-type: none"> <li>can only contain a short message</li> <li>expensive</li> <li>usually event based and not message based</li> </ul>
Radio	<ul style="list-style-type: none"> <li>good out reach</li> <li>appeals to illiterate population</li> <li>easy to understand</li> </ul>	<ul style="list-style-type: none"> <li>mid to high cost</li> <li>may not cover all regions</li> <li>not everyone listens to or can afford a radio</li> </ul>
TV	<ul style="list-style-type: none"> <li>good out reach</li> <li>appeals to illiterate population</li> <li>easy to understand</li> </ul>	<ul style="list-style-type: none"> <li>high cost</li> <li>may not cover all regions</li> <li>not everyone watches or can afford a TV</li> </ul>
Booklets/Books	<ul style="list-style-type: none"> <li>can contain large amounts of information</li> <li>mid price range</li> <li>portable</li> <li>long lasting</li> <li>clear message if contains clear illustrations &amp; concise text</li> </ul>	<ul style="list-style-type: none"> <li>difficult to understand for low literate population (remote and rural areas) unless picture based</li> <li>if too big, cumbersome and can cause discrimination</li> <li>manuals are mostly useful for literate caregivers and PLWHA if not too long</li> </ul>
Posters/Calendar/ Stickers	<ul style="list-style-type: none"> <li>popular</li> <li>mid price range</li> <li>eye catching</li> </ul>	<ul style="list-style-type: none"> <li>limited information</li> <li>if the picture is unclear, message will be lost</li> </ul>

	<ul style="list-style-type: none"> <li>• appeals to low literacy population</li> <li>• long lasting</li> <li>• highly visible: home, clinics, businesses, public places, high risk locations</li> <li>• calendar is useful even after the year is finished if the information is valid and informative.</li> <li>• effective for all populations</li> </ul>	<ul style="list-style-type: none"> <li>• poster may not be placed in an appropriate location – not visible</li> <li>• calendars are only for 1 year (limited lifetime)</li> </ul>
Poster Story/Flip-chart/Games	<ul style="list-style-type: none"> <li>• good for low literate population</li> <li>• able to get a lot of information across and can reinforce message with a small poster</li> <li>• no words on poster to detract from the message</li> </ul>	<ul style="list-style-type: none"> <li>• not large outreach</li> <li>• requires a facilitator to relay the messages</li> <li>• often not provided to beneficiary</li> <li>• difficult to transport</li> <li>• requires time to provide message</li> <li>• more expensive to produce</li> <li>• time consuming to train educators</li> </ul>
CD(karaoke)/DVD & Videos Spot	<ul style="list-style-type: none"> <li>• realistic, easy to relate to</li> <li>• appeals to low literate population</li> <li>• effective training and educational materials</li> <li>• long lasting</li> </ul>	<ul style="list-style-type: none"> <li>• expensive to produce</li> <li>• requires audio/visual equipment</li> <li>• requires electricity</li> <li>• difficult to distribute to entire population</li> <li>• may be misunderstood</li> </ul>
Training Materials	<ul style="list-style-type: none"> <li>• highly informative</li> </ul>	<ul style="list-style-type: none"> <li>• may have too much text for some audiences (many of the some issues as for poster/story/flipchart).</li> <li>• expensive to produce and train facilitators</li> <li>• required facilitator to relay the messages</li> </ul>

**Note:** Theater was not assessed since in is experiential and not material based.

### 3.2 Results from the Interviews:

The team learned that some provincial organizations produce their own IEC materials, but many more rely on materials produced in Phnom Penh by national and international agencies and government bodies. It is important to note that these materials tend to be general enough to address national issues yet they may not address issues specific to a particular province or community (ie. ethnic groups, commercial sex workers in the casino industry, transportation drivers, etc.).

Based on the interviews, the team learned that FHI, World Vision, Action IEC, CHED and NCHADS are the only organizations creating IEC materials specifically for PLWHA. To date, there is nothing being developed by PLWHAs themselves. Of the publications available, the team found that hand drawn pictures aren't as effective as real pictures because PLWHAs don't think they are real situations but rather fabricated stories.

Some organizations discovered that material release can be stalled because it needs to be approved through the proper channels, so it is imperative to bring the appropriate authorities on board early in the development process to help ensure swift approval.

Since Cambodia is not a reading-oriented culture, even literate people tend not to read books with excessive text. The interviewees' also found that some IEC materials assumed a high literacy rate among home care team members, even though some of them may also be illiterate, especially in the rural villages. According to a report on The Assessment of Functional Literacy Levels of the Adult Population in Cambodia, 37.1% of the adult population, (15 years and older) are literate. Of that, only 24.7% are capable of "self-learning", and within this group only 20.7% are women. Therefore, when designing future IEC materials, it will be important to ensure that materials be designed to meet the needs of an illiterate and semi-literate population in order to reach the majority of the people.

Other recommendations included: having a place on posters, booklets, and pamphlets for relevant phone numbers, for example information about VCT centers, clinics, and hospitals.

Some of the information gaps identified included: information on self-care, ARVs, OI treatment, VCTs, nutrition, schooling for CAA, discrimination, care for children after the death of parents, and community support.

Many NGOs and GOs distribute materials through training sessions; others disseminate materials without training recipients about how to use the materials. This results in some materials not being clearly understood or used to their fullest potential. Aside from informal interviews, most IEC materials have not been evaluated for their effectiveness or monitored for their use. Usually this is due to lack of human and financial resources and time constraints. Ideally, each of the IEC materials developed should be monitored and evaluated to determine whether or not changes in the materials need to be made in order to be more effective.

Many of the NGOs and GOs the team interviewed were enthusiastic about the development of new IEC materials, interested in participating in the development process and were looking forward to receiving the final product.

### **3.3 Results from Focus Groups**

The team identified three target groups for the focus group discussions (FGD) in Phnom Penh: PLWHA group members, PLWHA group leaders, and caregivers/NGOs workers. Of the five FGD conducted, three were conducted by CPN+ with PLWHA group members and leaders while two were conducted by HACC with caregivers and NGOs workers. Sixty-nine (69) participants attended the FGD: 35 PLWHA group members, 11 PLWHA group leaders, and 23 caregivers/NGOs workers. All the participants joined actively in the discussions, shared their ideas/experiences and provided recommendations to the assessment team.

#### ***3.3.1 PLWHA focus group discussions***

##### ***Type of materials***

The results from the focus group discussions illustrated that the most common types of IEC materials received by PLWHAs were: brochures, booklets, and posters that tend to focus on HIV/AIDS prevention and STD education. The three kinds of materials that were the most useful were booklets, calendars and t-shirts.

##### ***Availability of Materials***

Of the 35 PLWHAs who participated in the focus group discussions, 62% saw some type of IEC material at home care centers and during visits by home care workers only 25% received materials that they could keep.

*“I was trained by home care teams about self care but I didn’t receive any care materials. I think that it will be helpful if they could provide me with some care materials because I cannot remember all that I learnt from the home care teams. If I could bring materials home, it will help me remember what I am supposed to do to take care myself and also teach my children how to learn how to take care of me.”<sup>1</sup>*

### **Traditional Medicine**

91% of PLWHAs are interested in learning how to use traditional medicines properly. They would find it useful if the care materials used real pictures of traditional medicines and featured stories of people who have had positive experiences using them. The group said that many PLWHAs are strongly influenced by rumors and misinformation they obtained from other people. Many of them had visited “Krukhmer” (traditional healers) because of rumors that they could cure HIV/AIDS. They spent a lot of money buying medicine from “Krukhmers”. Some of the traditional medicine had caused harmful side effects such as allergies, headaches, diarrhea, difficulty sleeping, swelling, loss of appetite, and ultimately lost wages due to the deterioration in their health.

*“I heard people say that the traditional medicines can cure HIV/AIDS related conditions such as diarrhea, skin problems, mouth infections but I don't know how to use them. One day my friend received training from a home care worker and got a copy of the World Vision’s “Home Care Book”. It mentions how to use traditional medicines, but I am still not confident myself in using them.”*

*“My wife and I decided to buy traditional medicine from the “Krukhmer” because we heard that the traditional medicine he had made can cure HIV/AIDS. We took the medicine and we almost died. My body became swollen; I had allergies, headaches and could not sleep. My wife became even more ill, she could not even walk or eat so we decided to stop taking that medicine and met with a home care team. After more than two months of support from the home care team I feel better, but my wife is no longer with me.”*

### **Format of IEC Materials**

60% of the group said that they could not read books but they could understand if the care material contained pictures. All PLWHAs expressed an interest in learning more about how to take care themselves. Those PLWHAs who had received training and had access to care materials have improved their overall health. Many of them were familiar with and liked the format of the “Home Care Book” created by World Vision.

*“I have seen both HIV/AIDS materials with drawings of PLWHA and real pictures of PLWHA. When I look at the material with drawing, I wonder if the story is real or just made up. Some materials make me felt afraid and hopeless because at the end of the stories, the people living with HIV/AIDS die in difficult situations.”*

The PLWHA focus group would like a series of booklets with limited text and colorful pictures showing PLWHAs living healthy, positive lives. They want to get away from the

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<sup>1</sup> The paragraphs in italics are statements from PLWHAs.

stereotype that all people living with HIV/AIDS are skinny, sad, and hopeless. There are many inspirational stories in Cambodia that could be incorporated into the materials and used to emphasize each topic (See Annex 8).

### **3.3.2 PLWHA Support Group Leaders**

The 11 PLWHA support group leaders that attended the focus group discussion stated that the most common types of IEC materials they received were: brochures, booklets, and posters, which focused on HIV/AIDS prevention and STDs education. They received those materials through home care teams, HACC, CPN+, training sessions and meetings. These materials included phone numbers which are very useful for those who wanted to access health services or learn more about them. Unfortunately, not many support group leaders living in rural areas had access to those materials.

As well as facilitating support group meetings, these leaders also provide education and counseling to their members, distribute medicine and bring PLWHAs to the hospice/hospital. Because the support group leaders themselves often lack knowledge, skills and understanding about HIV/AIDS, they are ill equipped to counsel their members on the progress/stages of the disease, hygiene, nutrition, medicine and other medical issues.

They reported that most of their members have never received any kind of care materials and there is a real lack of knowledge and understanding about HIV/AIDS and how to take care of themselves. Many of their members are likely to seek quick cures using a variety of traditional and western medicines without proper advice. The group is interested in learning how to use traditional medicines properly because some of their members have been victims of traditional healers. Many of their members had visited “Krukmer” and the medicines they prescribed had caused harmful side effects such as allergies, headaches, diarrhea, difficulty sleeping, swelling, loss of appetite, and as a result lost weight.

### **3.3.3 Caregiver/NGOs workers**

90% of the caregivers and NGOs workers who attended the focus group discussions shared similar problems accessing IEC materials for PLWHAs as the other FGs. The materials that they used/distributed to their target groups included: posters, stickers, leaflets, video spots, radio spots, booklets and flipcharts. Most of the materials focused on HIV/AIDS prevention, education, STDs and reproductive health. Of the 22 organizations represented in the focus group discussions, eight produced IEC materials that concentrated mainly on prevention and two of those produced literature on care. Most of the participants confirmed that they need more IEC materials about care for their target group but are unable to do so due to lack of resources (human and financial). The materials they received from others organizations were mainly used by an educator and caregivers—‘gatekeepers’—and not available for direct distribution to PLWHAs.

*“We cannot provide “care” materials to PLWHAs when they came to our health center and/or during home visits because we have only one copy of the World Vision home care book and calendar.”*

The groups also recognized that due to the growing numbers of PLWHAs in the country there is a strong need for materials dealing with care and support to improve their quality of their lives. This is especially true for those who live in rural areas since they have even less access to quality care services and IEC materials. FHI is leading the way in producing IEC materials that address a large range of topics from self-care to discrimination for PLWHAs.

Another concern raised was the method in which IEC materials are distributed. Typically, they are distributed through trainings, publishing campaigns, health care centers and home care visits. Materials are often distributed without adequate training and some NGOs workers and caregivers do not have a clear understanding of the materials or its purpose. Therefore, if IEC materials are going to be developed for use by home care workers and NGOs, it should be either self explanatory or there needs to be appropriate training to ensure that it is understood and administered correctly.

Discrimination was also highlighted as another pressing issue, which tends to be multi-fold. Some PLWHA have low self esteem and feel that they are not worthy of receiving proper care, treatment and support. Therefore it is important to address this form of discrimination to boost their self worth and encourage them to advocate for their rights. As long as PLWHAs feel the threat of discrimination, they will be less likely to seek the care they need to be strong healthy and productive members of their families and communities. Another area of discrimination that needs to be addressed is within the PLWHAs family and the community at large. These target groups need to be educated about the disease and taught compassion and understanding in order to reduce the negative stigma about HIV/AIDS.

*"We cannot say our IEC materials are very useful because until now discrimination is still everywhere and many PLWHAs still do not take good care of themselves. We will try to learn from our past experiences and improve our IEC material."*

The group recommended developing a booklet similar in size to the World Vision "Home Care Book". They stated that size is important because a large book can lead to discrimination since people want to be able to carry it with them without drawing attention to the book. If it contains too much information, it may be overwhelming to the reader, especially if they are not literate. The images need to be colorful, portray attractive people and supported by minimal text. They also suggested a 12-page calendar with photographs and colorful images.

## Chapter 4

# Recommendations and Conclusions

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### 4.1 Recommendations

Based on the feedback from the interviews with NGOs/GOs and the focus group discussions, there are several gaps that need addressing for developing IEC materials by and for PLWHAs. While this project will not be able to address all of the issues raised, we will focus on those issues of the highest priority. The team will review the most effective types of materials in order to accelerate the development and production process. It will also be important to invite the NAA and/or appropriate authorities on-board early in order to avoid delaying the production.

#### 4.1.1 Target Audience

PLWHAs and their Caregivers are the target audience, since there are so little materials available for these groups.

#### 4.1.2 Types of Material and Content

All of the focus groups shared similar recommendations: the need for IEC materials that are accessible, user friendly and positive. They all agreed on a series of booklets that address only one topic or sub-topic at a time. It should be no longer than 10 pages per booklet, and half the size of a sheet of A4. The team discovered that people want positive, attractive, and real images of PLWHAs. People can relate better to photographs of real people and are more likely to take the message seriously. FHI did an assessment entitled “Findings of Self Care Needs Assessment for PLWHA” that revealed that many PLWHAs have a low literacy level, while usually one member of the household will be able to read. Therefore, the pictures need to be clear enough to illustrate what the topic is and writing should be kept to a minimum. The following is a prioritized list of IEC materials that all the focus groups would like to see developed:

1. Self-Care: This is a low cost, easy and effective way in which PLWHAs can best take care of themselves to maintain or regain their physical and mental well being. This is particularly important in poor countries like Cambodia, where medical care is often expensive for the poor and inaccessible to people who live in the countryside. Sub-topics include:
  - a) proper nutrition
  - b) personal hygiene
  - c) home hygiene
  - d) enjoying safe sex
  - e) exercise/sport
  - f) emotional and mental support from family, friends and their community
- 2.a. Proper use of traditional medicine
- b. Symptoms and Treatment for OIs and other complications, using both western and traditional treatments:

- tuberculosis
- Cryptococcal Infection
- Candidiasis (thrush)
- Sarcoxic sarcoma
- dandruff like skin problem
- numbness
- cryptosporidiosis
- headaches
- Toxoplasmosis
- Pneumocystis carinii pneumonia
- Mycobacterium avium complex
- Cytomegalovirus
- Histoplasmosis
- insomnia
- nausea

*Note: that only traditional treatments that have been approved by WHO and the Ministry of Health should be included.*

#### 3.a. Information about ART

This would be more technical in nature, since it has to deal with issues that couldn't be illustrated solely with photographs. Presumably, it would also be targeting a more literate population, since they are most likely to be the ones who would have the resources to seek out and pay for this treatment.

#### 3.b. Discrimination and Stigma Reduction

To be targeted to the community at large with some solid solutions

4. Pre and post-natal care
5. Future planning for the children of PLWHAs.
6. Support Services - such as: VCTs, hospitals, health clinics, and pagodas, as well as services available through HACC, CPN+, etc.

#### **4.1.3 Distribution/Training**

Since the goal is to produce IEC materials that are highly accessible for PLWHAs, the end user should be able to understand the materials without any prior training. Both CPN+ and HACC could serve as major distributor's centers for the materials. They should be made available to NGOs, hospitals, clinics, VCTs, support groups, and brothels where previously little or no information exists. To begin with, 10,000 copies of each booklet would be printed and distributed through this network. CPN+ has a network of 4,000+ members, HACC has 90 members who would receive a minimum of 50 copies each plus a surplus of 1,500 to be distributed as the need arises.

#### **4.1.4 IEC Specialist**

Pact will hire an IEC specialist for the next phase of the project. Of the IEC production organizations that have experience working on IEC materials for PLWHAs, ACTION IEC is producing some creative and effective materials. They have the capacity to provide an

IEC specialist and produce high quality materials. Since they have worked with FHI on similar materials and understand the issues, if there is a need to bring in design expertise, it would be faster to work with them than with another group due to their extensive experience.

#### ***4.1.5 Sustainable Database of IEC Materials***

Once the initial data has been entered into the newly established database, it should be turned over to HACC to maintain and continue to be updated after providing adequate training. This would provide the entire HIV/AIDS network with the most comprehensive collection of materials produced about HIV/AIDS accessible through a search engine. Materials from other countries could be included. The database could be useful in avoiding duplication of materials and provide new ideas from other countries. It should also be linked with the Ministry of Health, RACHA and Medicam's websites if possible.

#### ***4.1.6 Research Global and Regional IEC/BCC Materials***

There are many global and regional materials that have been very effective. The project should examine the possibility of using these materials with adjustments to the Cambodian context. HACC should establish a library with these resources available for future reference.

#### ***4.1.7 Involvement of PLWHA in Material Development and Distribution***

A parallel goal of the process is to involve PLWHAs and build their capacity in material development. This is being accomplished by partnering with CPN+ to shape and create the IEC materials. To ensure that the materials are speaking to the target audience, PLWHAs should be involved throughout the process, from focus group discussions, material development, testing the effectiveness materials, to sitting on the advisory committee and distributing the end product. This will result in a product that is designed by and for PLWHA, a first of its kind in Cambodia.

## **4.2 Conclusions**

With the mounting HIV/AIDS crisis in Cambodia, the communication mapping exercise confirms that there is a real need for some well-developed educational materials targeting PLWHAs and their caregivers. This was further reinforced by the feedback from the focus groups. There is an abundance of material available that deals with prevention, (89%) but very little about how to live positively with HIV/AIDS (11%). While NCHADS, FHI and World Vision have created in-depth manuals dealing with care and support, some of these materials tend to rely extensively on text as the medium. As learned from this mapping, PLWHAs—both literate and illiterate—prefer photographs supported by simple and concise text. The most effective materials were those that were highly realistic and depict active people in their messages.

IEC best practices will be used the development of the IEC identified by the PLWHAs and the team. Several possible areas of IEC material development were identified, and the high priority topics were prioritized as follows:

1. Self-Care:
  - a) proper nutrition
  - b) personal hygiene
  - c) home hygiene

- d) enjoying safe sex
  - e) exercise/sport
  - f) emotional and mental support from family, friends and their community
- 2a. Proper use of traditional medicine
- 2b. Symptoms and Treatment for OI and other complications, using both western and traditional treatments:
- a) tuberculosis
  - b) Cryptococcal Infection
  - c) Candidiasis (thrush)
  - d) Sarcoxic sarcoma
  - e) dandruff like skin problem
  - f) numbness
  - g) cryptosporidiosis
  - h) headaches
  - i) Toxoplasmosis
  - j) Pneumocystis carinii pneumonia
  - k) Mycobacterium avium complex
  - l) Cytomegalovirus
  - m) Histoplasmosis
  - n) insomnia
  - o) nausea
- 3a. Information about ART
- 3b. Discrimination and Stigma Reduction

The suggested format for IEC materials was very specific: a slim booklet, half the size of an A4 paper, with no more than 10 pages addressing one topic or sub-topic at a time. The size was an important issue since PLWHAs and Caregivers would like the material to be discreet without mentioning HIV/AIDS on the outside, and small enough to fit in their bag to avoid drawing attention to the material or their HIV/AIDS status. Stigmatization and discrimination are among the greatest obstacles for PLWHAs so the material needs to be sensitively designed.

There also needs to be a space on the back of the material where important contact numbers can be included. As previously stated, these may include clinics, hospitals, NGOs, GOs, CPN+ and HACC. A blank space may also be useful for a home care worker or NGO to write their contact information.

The IEC that is available tends to stereotype PLWHAs as weak, sad, near death, and non-productive. While this may be true for some of the infected population, there are many PLWHAs who are working, healthy and well integrated into their community. Since PLWHAs interviewed identified a direct correlation between IEC/BCC materials, positive behavior modification and reducing discrimination, well-developed materials for both PLWHAs and caregivers, should also improve the quality of lives for PLWHAs. It is important that PLWHA are portrayed in a “normal” way so as not to further stigmatize them but to weave them into the fabric of Cambodian society. By creating materials for PLWHAS that addresses their everyday concerns related to HIV/AIDS they will be able to live productive and healthy lives with their families and within their community.

# Annexes

## **Annex 1: Implementing Partners – CPN+ and HACC**

### **1) Cambodia People Living with HIV/AIDS Network**

CPN+ is a new national organization that has organized 24 PLWHA Support Groups, 11 of which are located in Phnom Penh and 13 in the provinces of Battambang, Banteay Meanchey, Prey Veng, Takeo, Kampong Thom and Kompong Cham. CPN+'s goal is to provide broader national support to its members. Member services include:

- General health education for PLWHAs,
- Education on the use of the antiretroviral drugs,
- Education on medications and care for opportunistic infections,
- Education and training on basic palliative care and support for PLWHAs,
- Training of Support Group Leaders for home-based care approaches.
- Advocacy

CPN+ mobilizes PLWHAs to join support groups that provide mutual support and address advocacy issues related to PLWHAs. CPN+ staff builds the capacity of Support Group Facilitators to lead the groups and empower PLWHAs. Currently CPN+ has a membership of 4,000. To date, CPN+ has provided this outreach and support in the absence of any educational materials, or a strategic approach to networking and further scaling up. It is an understatement to suggest that the CPN+ network has an important role to provide health literacy related materials to PLWHAs and their caregivers. Additionally, with the technical support from Pact and the other collaborating partners, this is a sound and strategic investment for the Pfizer Foundation HIV/AIDS Health Literacy Program.

### **2) HIV/AIDS Coordinating Committee**

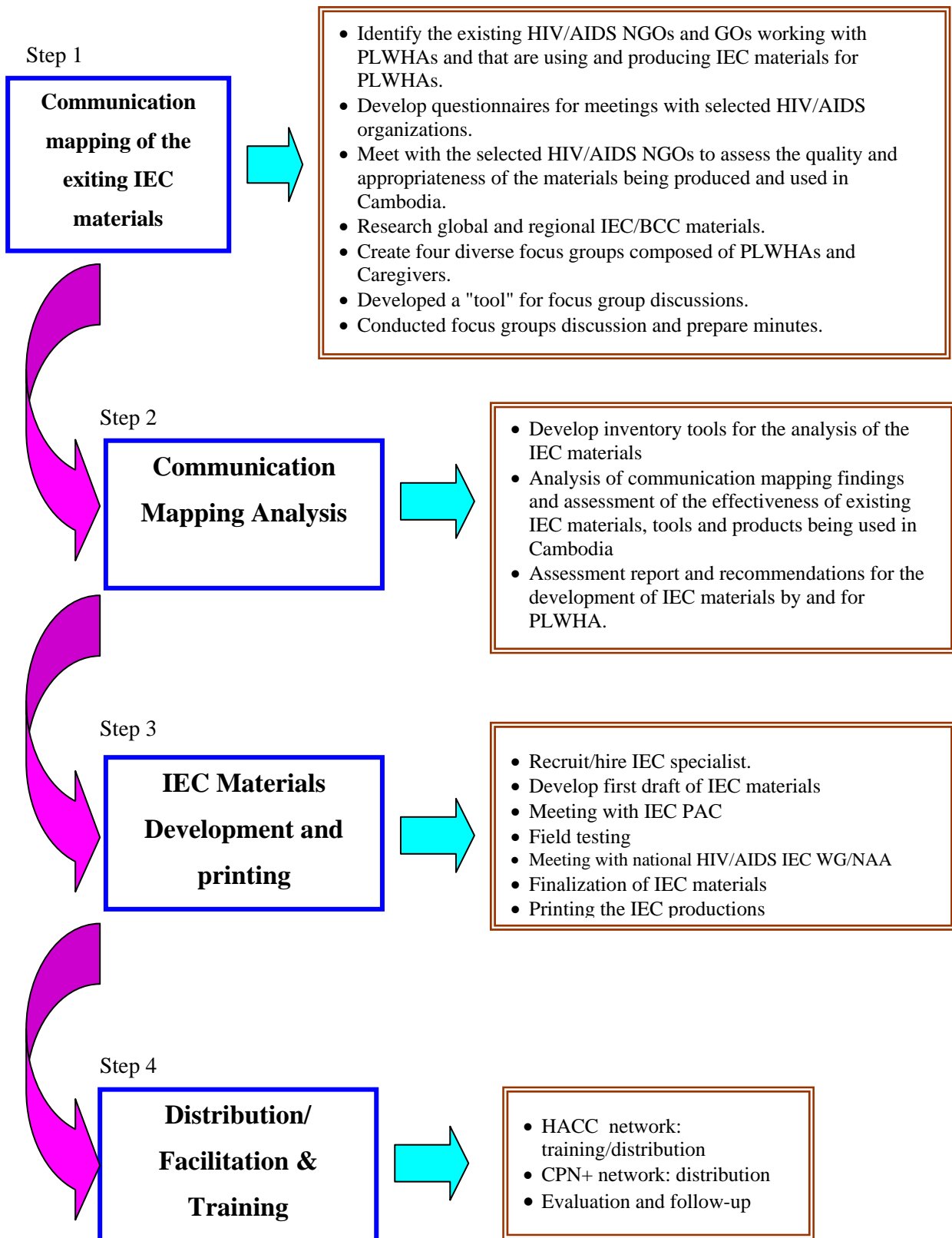
HACC is a coalition of over ninety international and local NGOs working on HIV/AIDS issues. Its mandate is to coordinate all NGOs working in the HIV/AIDS sector to ensure efficient use of limited resources. HACC maintains an excellent relationship with the government whereby the government recognizes it as the principle contact umbrella organization for the NGO HIV/AIDS sector.

Because HACC represents such a large network of NGOs working on HIV/AIDS issues, they provide the program with the potential for broad outreach and far-ranging scale-up. This will increase the probability that the program will have a significant national impact for PLWHAs and caregivers.

Annex 2: List of NGOs and GOs interviewed

<b>Organization</b>	<b>Contact Name</b>	<b>Phone</b>
Action	Mr. Cedric Jancloes	012 803 670, 023 212 944
CARAM	Ms. Tep Mony – Program Director	023 218 065, 012 847 976
CARE	Kim Green	023 215 267, 012 908 526
CHEC	Ms. Kasem Kolnary/ Si Sotha	023 217 030, 012 945 077
CHED	Lok Vichet	023 884 842
CWDA	Putheareth Ken	023 210 449
CWPD	Ms. Chou Bun Eng	
FHI	Pratin Dharmarak	023 211 914, 012 804 292
FHI	Bous Savy – BCC specialist	012 775 377, 023 211 914
Friends	Dr. Sok Supon – HIV Coordinator	023 426 748
GIPA	Mr. Alex Marcelino	012 847 784, 012 767 084
HAGAR	Ms. Kheiv Rany	023 217 478
HOPE	Dr. Sok Phan	023 211 524, 011 874201
IDA	Ms. Pan Sopheap	012 841 372
KHANA	Mr. Choub Chamreun	023 211 505
MARYKNOLL	Father Jim Noonan	023 425 018
NAA	Dr. Tia Phalla	012 900 091
NCHADS	Hut Kuntha Pirum	012 855 955, 011 707 677
NYEMO	Dr. Ky Kanary	023 213 160, 012 800 815
Policy Project	Misha Coleman	023 218 656, 012 903 413
RACH	Kim Hourn Kouy – IEC/Marketing	023 219 340, 011 972 920
RACH	Dr Ouk Vong Vathiny – Executive Director	023 219 340, 012 720 022
RACHA	Maia Smith – IEC Advisor	023 213 724, 012 802 123
SC(UK)	Mr. Lindsay Daines	023 216 222
UNAIDS	Geeta Sethi	023 219 340, 0012 990 645
UNESCO	Fabrice Laurentin	023 426 726, 012 804 654
Vithy Chivit	Mr. Hout Totem	023 308 090, 012 864 193
Battambang		
BFD	Mr. Heng Monychenda – Exec. Dir.	053 370 041, 016 881 521
BWAP	Ms. Ing Siv Heng	052 952 150, 016 530 236
CVD	Mr. Mounh Sarath	053 952 198, 016 952 198
KRDA	Mr. Dim Samedy – Exec. Dir.	012 920 029, 053 370 097
HURIPRUDA	Mr. Im Loum – Exec. Dir.	012 530 525, 053 952 583

Annex 3: Process of the Development of IEC Materials



#### **Annex 4: Questionnaire for Interview**

Organization: _____
Contact Person: _____
Phone Numbers: _____
Address: _____
Email Address: _____

#### **Questions for Meetings:**

1. What type of IEC/BCC materials are you using for PLWHA? Pamphlets, books, radio, broadcast, etc.
2. Who developed the materials? How were they developed? Who is the target audience?
3. What are you using the material for, and have they been evaluated and updated?
4. Does it include useful phone numbers, where applicable, addresses?
5. Are you currently using prevention materials with PLWHA?
6. What is the cost of production/distribution?
7. How is it distributed and have you determined the outreach?
8. What difficulties do you see with the current distribution?
9. How does the literature deal with discrimination?
10. Where are the gaps in Cambodia for materials that focus on PLWHA?

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Notes:

Date:

## **Annex 5: Questionnaire for Focus Group Discussion**

### **Tools for Focus Group Discussion**

#### **Objectives:**

- To have better understanding on the current type of IEC/BCC materials developed and used by PLWHAs and Caregivers.
- To collect and determine information needed for PLWHAs/Caregivers
- To get commend/see which IEC/BCC materials are effective for PLWHAs and their caregivers.

#### **Schedule for meeting**

##### **1) HACC (meeting with HIV/AIDS NGOs and Caregivers)**

- Welcome and self introduction
- Project presentation (HACC/PACT/Pfizer project)
- Objectives of the meeting
- Reporting from each participant about the current types of IEC materials produced/used by their caregivers/partners.
- Discussion on the current types of IEC materials used by caregivers
- Recommendations/suggestions to the development of the IEC materials for PLWHAs and their Caregivers.
- Other business and what is next?

#### **Questions for discussion:**

1. What type of IEC/BCC materials are you using for PLWHA? Pamphlets, books, radio, broadcast, etc.
2. How is it distributed and have you determined the outreach?
3. What difficulties do you see with the current distribution?
4. How does the IEC/BCC deal with care and discrimination?
5. Have they been evaluated and updated?
6. What types of information do you need for improving care of PLWHAs?

##### **2) CPN+ (meeting with Support group leaders and PLWHAs)**

- Welcome and self introduction
- Project presentation (CPN+/PACT/Pfizer project)
- Objectives of the meeting
- Discussion on the current types of IEC materials used by PLWHAs
- Recommendations/suggestions to the development of the IEC materials for PLWHAs and their Caregivers.
- Other business and what is next?

#### **Questions for discussion:**

1. What type of IEC/BCC materials are you using? Pamphlets, books, radio, broadcast, etc.
2. Who developed the materials? Where do you get it/ how do you get it?
- 3) Does it include useful phone numbers, where applicable, addresses?
- 4) Is it useful for you? Why?
- 5) How does the IEC/BCC deal with care and discrimination?
- 6) What types of IEC/BCC materials is good/effective?
- 7) What type of information do you need for your self-care?

## Annex 6: Database Inventory of HIV/AIDS IEC Material

# HIV/AIDS IEC Material Inventory

ID Number: 004

Material Title: HIV/AIDS-IEC Material Database

Content

Prevention  Care and Support  Reference Material  PLWHA

Material Type

Brochure  Sticker  TV Spot  Postcard  
 Booklet  Poster  Radio Spot  Banner  
 Book  Flip Chart  Magazine  Training manual  
 DVD / CD / VHS  T-Shirt  Comic Book  Other

Target Audience

PLWHA  Sex worker  Children  Youth  
 Care giver  Military / Police  Men  Families  
 Home based care  Garment worker  Women  General Population

Language

Khmer  Vietnamese  English

Developed by

World Vision  CVD  PATH  UNESCO  
 Action  RACHA  UNICEF  MoEYS  
 HURIPRUDA  CIDA  UNAIDS  ADB  
 RACH  PSI  MSF  Oxfam  
 NAA  AusAID  KWCD  SC (UK)  
 CARAM  Moj  PSAD  Policy project  
 Redd Bama  USG  Mary Knoll  CDA  
 MoMPC  KHEMA  Homeland  TTA  
 CWPD  CARE  CHED  NPC  
 KHANA  USAID  HACC  Friends  
 FHI  MH  East-West Management Institute  
 Commonwealth Department of Health, Housing and Community Service

Distribution Method

Training  Peer education  Events  Hospital / Clinic  
 Home care worker  Counseling  Public distribution (TV, Radio)

Analysis

0  Color 3  Sound Quality 0  Message / Content 0  Black and White  
 6  Size 0  Drawings 0  Writing Quality 0  Methodology  
 7  Photographs  Other: XXX  Other: \_\_\_\_\_

## Annex 7: IEC Advisory Committee

### List of IEC Advisory Committee

Contact Person	Position	Organization	Phone and e-mail
Ms. Dy Many	UNV/GIPA advocate	GIPA	
Miss. Bou Savy	BCC Officer	FHI	012 755 377
Ms. Maia Smith	IEC Advisor	RACHA	012 802 123
Mr. Pen Chantra	Media Coordinator	World Vision	011 945 204
Ms. Um Sophep	Program Officer	Policy Project	023 210 656
Ms. Tep Mony	Program Director	CARAM Cambodia	012 847 976
Dr. Sin Kim San	Advocacy and IEC	NAA	012 840854
Mr. San Sothy	BCC Officer	NCHADS	
Mr. Hout Totem	Director	VC	012 864 193
Dr. Sok Sophal	HIV/AIDS Coordinator	FRIENDS	023 426748
Mr. Sok Sothea	Program Officer	RHAC	012 720 022
Mr. Cedric Jancloes	Advisor	ACTION IEC	012 803 760 023 212 944

The advisory committee terms of reference are as follows:

1. Provide technical support for the development of IEC materials.
2. Inform HACC and CPN+ about new IEC materials currently being developed.
3. Attend IEC meetings as required.
4. Feedback and recommendations about proposed materials throughout the IEC material development process.

### **Annex 8: Case of Positive Lives of PLWHAs**

During the field assessment, the team found an HIV positive widow with four children who has known her HIV status since 1994. She is health and lives with her children.

*“I have known that I am HIV+ since 1994. My husband died in 1999. I felt hopeless and I didn’t want other people to know about my status because I was afraid they would look down on my family and me. I wanted to die, but my children and my family (my parent’s in-law, sister and brother in-law, and my nieces) encouraged me not to give up and to live for them. I try my best to take care myself by doing normal things like continuing to buy vegetables/fruit to sell at the market, planting vegetables around the house, communicating with others and keeping my home clean. With the advice from my home care team who I visit with regularly, I take my medicine on time, and eat healthy food. My goal is to live happily with my children and find ways to prepare for their future until my day arrives.”*

This case illustrates that People Living with HIV can live long and healthy lives and gain additional strength when their families support them and they also try to take care and supported themselves.

Another important element of this woman’s life is that she has a positive attitude who has a clear will to live and is strongly committed to making things happen for their family, children and herself. The largest obstacles to PLWHAs like this are they have difficulty to achieve their goal because of they lack knowledge, skills and opportunities to do so. Developing IEC materials by and for PLWHAs are important to bridging this gap in knowledge.