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CITIZEN MONITORING FINAL REPORT—VIETNAM

AUGUST 2010

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EXECUTIVE SUMMARY

Vietnam faces a concentrated HIV epidemic, with the highest seroprevalence rates among injecting drug users (IDUs), female sex workers (FSWs), and men who have sex with men (MSM). As of December 31, 2009, there were 160,019 reported HIV cases and 44,050 deaths due to AIDS-related illnesses. In 2009, there were 15,713 newly-reported HIV cases and 2,010 AIDS-related deaths.¹ One of the greatest challenges to fighting the HIV epidemic in Vietnam is pervasive stigma and discrimination. Without addressing stigma and discrimination, people will continue to be inhibited from seeking HIV prevention, care, treatment, and support services; and caregivers will be reluctant to deliver support openly.

For 10 years, Futures Group under the POLICY Project and now under the USAID | Health Policy Initiative, Task Order 1, has been among the most vocal advocates in Vietnam for responding to HIV with a rights-based approach—embracing the Greater Involvement of People Living with AIDS (GIPA) principle and involving civil society in policy development and implementation, transparent governance, and accountability. Community members are beginning to emerge as meaningful participants in the fight against HIV, as evidenced by the inclusion of people living with HIV (PLHIV) and vulnerable populations in policy advocacy, development, and implementation and monitoring. Their collective efforts have enabled them to attract donors and leverage resources to increase access to clean needles and syringes, substitution therapy, home-based and community care, and antiretroviral treatment (ART).

From citizen surveillance committees in Peru and legal clinics in Vietnam to human rights monitoring in Cambodia, the evidence is growing to support the benefits of actively engaging affected communities and other key stakeholders in monitoring quality of HIV services and progress in reducing stigma and discrimination. The citizen monitoring concept originated from various participatory monitoring approaches that enhanced the capacity of local organizations to observe, gather, and analyze evidence and advocate for a specific concern. In some cases, these local organizations were supported by international or national researchers who assisted them in understanding the data. In citizen monitoring, groups employ successful advocacy methods by using evidence to influence decisionmakers and opinion leaders to make positive changes. Citizen monitoring is especially important for most-at-risk populations and other disenfranchised groups that are often under- or inadequately represented in policy decisionmaking.

The goal in Vietnam was to pilot a process to build the capacity of PLHIV networks to carry out participatory monitoring activities to further evidence-based policy advocacy and dialogue. With the project's technical support, the Vietnam Network of Positive People (VNP+) implemented the activity, which included developing the processes for data gathering, analysis, and capacity building of its members in monitoring. Similar to other participatory approaches, the *process* is a “product” in and of itself, aimed at empowering people to use evidence to advocate for improvements in HIV services, including reducing stigma- and discrimination-related practices. In addition to identifying lessons learned for further refining the citizen monitoring approach, the objectives of the pilot were to

- Broaden the meaningful participation of civil society, especially vulnerable groups;
- Support the government and HIV service providers to fulfill policy commitments and meet their HIV/AIDS program targets; and
- Facilitate access to HIV services for PLHIV and most-at-risk populations (FSWs, IDUs, MSM).
- Provide VNP+ with the skills to develop ongoing evidence-based advocacy

¹ Socialist Republic of Vietnam. 2010. Declaration of Commitment on HIV and AIDS adopted at the 26th United Nations General Assembly Special Session in June 2001 (UNGASS), Reporting Period January 2008–December 2009. Hanoi: Socialist Republic of Vietnam.

The Health Policy Initiative developed the approach for HIV-related citizen monitoring and then helped the VNP+, as well as other local nongovernmental organizations (NGOs)—Vietnam Civil Society Platform on HIV/AIDS and Center for Counseling on Policy and Law on Health and HIV/AIDS—design and implement a pilot of the citizen monitoring approach in Vietnam. The activity focused on building the capacity of PLHIV networks to carry out participatory monitoring activities as citizen monitors to further evidence-based policy advocacy and dialogue. From July–October 2009, VNP+ collected 1,102 questionnaires from 514 participants on stigma and discrimination in healthcare settings and access to high-quality ART. This six-month pilot project was designed to develop the capacities of the national network of PLHIV in project management, data collection and analysis, and development of evidence-based advocacy messages.

Evidence collected by the VNP+ citizen monitors showed a perceived decline in stigma and discrimination in healthcare settings by PLHIV and vulnerable groups, improvement in the attitudes of health providers toward positive patients, and reduction of stigma- and discrimination-related practices in healthcare settings during a four-month period. Most participants reported having free access to antiretrovirals and some HIV services. Of the participants responding, the reported adherence rate was high at 96 percent, and CD4 counts improved substantially since the start of treatment.

At the same time, there are still visible signs of stigmatizing attitudes and behavior toward HIV-positive patients; for example, many participants feel that health workers avoid them (52%); look down on them (37%); and are colder toward them than with other patients (44%). Participants also expressed concern about confidentiality; almost 40 percent of participants found that their files are marked with their HIV status or risk behavior. Fifty-eight percent of patients expressed concern about the qualifications and competence of their healthcare providers.

Key stakeholders found the results compelling and recommended expansion beyond the pilot phase, including fine tuning the data collection tools and further strengthening local capacity in data analysis. Additionally, stakeholders recommended that the results of citizen monitoring be linked with qualitative appreciation of stigma and discrimination indicators as well as triangulation with the perceptions of providers on quality of care in healthcare settings.

Results

- With the knowledge and skills acquired through trainings and technical assistance, a core group of 50 VNP+ members was able to successfully lead the citizen monitoring activity.
- The Health Policy Initiative’s support enabled VNP+ to analyze the results and use this evidence to develop an advocacy agenda.
- Lessons learned from the pilot Citizen Monitoring in Vietnam helped to improve the processes of empowerment, tool design, and analysis by PLHIV networks so that the pilot could be replicated in another setting (next phase in Mali)

Key Lessons learned

- Building the capacity of a national PLHIV network in research protocol is possible.
- Involving networks of PLHIV in all aspects of the activity is crucial to successful participatory monitoring. Training and practice on using the data collection tools is important.
- Indicators and tools should be based on the national situation, policies, and programs but adapted to be consistent with global indicators for quality of care and stigma and discrimination. Feedback from potential participants should be elicited.

- Data collection instruments should correspond to the capacities of the national NGOs so they can be fully involved in data analysis and subsequent development of the advocacy agenda.
- Local research institutions should be involved when necessary to facilitate dialogue between implementers and researchers to foster a greater understanding of the relevant HIV quality of care and stigma and discrimination issues.
- Triangulation with qualitative appreciation of PLHIV, with surveys of health providers, and with community-level stigma indicators (i.e. Demographic Health Surveys) would add greater depth to the results of this study and would facilitate advancement of stigma research.

ABBREVIATIONS

05 Center	centers for female sex workers
06 Center	centers for drug users
AIDS	acquired immune deficiency syndrome
ARV	Antiretroviral
ART	Antiretroviral treatment
CCLPH	Center for Counseling on Laws and Policies on Health and HIV/AIDS
CITI	Collaborative Institutional Training Initiative
FSW	female sex worker
GIPA	Greater Involvement of People Living with HIV/AIDS
ICRW	International Center for Research on Women
IDU	injecting drug user
IRB	Institutional Review Board
ISDS	Institute of Social Development Studies
HIV	human immunodeficiency virus
MSM	men who have sex with men
NGO	nongovernmental organization
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	people living with HIV
UNAIDS	Joint United Nations Program on HIV/AIDS
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nation's Children's Fund
USAID	United States Agency for International Development
VAAC	Vietnam Administration for HIV/AIDS Prevention and Control
VCSPA	Vietnam Civil Society Platform on HIV/AIDS
VND	Vietnamese dong
VNP+	Vietnamese Network of People Living with HIV
WHO	World Health Organization

I. BACKGROUND AND COUNTRY CONTEXT

Vietnam faces a concentrated HIV epidemic, with the highest seroprevalence rates among injecting drug users (IDUs), female sex workers (FSWs), and men who have sex with men (MSM). Although the HIV epidemic has spread to all provinces, geographically it is concentrated in large metropolitan areas where groups of IDUs, FSWs, and MSM are significant. The general adult HIV prevalence estimate remains low at 0.44 percent; however, in the IDU, FSW, and MSM populations, prevalence rates are much higher (see Table 1).² Currently, the number of adults and children living with HIV is estimated to be 290,000. As of December 31, 2009, there were 160,019 reported HIV cases and 44,050 deaths due to AIDS-related illnesses. In 2009, there were 15,713 newly-reported HIV cases and 2,010 AIDS-related deaths.³

Table 1: HIV Prevalence Rates Among Specific Populations

Injecting drug users	23%
Female sex workers	4%
Men who have sex with men	9%

In March 2004, the government of the Socialist Republic of Vietnam released the *National Strategic Plan on HIV/AIDS Prevention for 2004–2010 with a Vision to 2020*. The strategy provides the framework for a comprehensive national response to the epidemic, calling for mobilization of government, party, and community-level organizations across multiple sectors. Citizen monitoring supports the government’s vision to fight stigma and discrimination of people living with HIV (PLHIV), increasing access to HIV services, including comprehensive harm reduction, and perfecting monitoring and evaluation of the HIV/AIDS prevention and control program.

By far, one of the greatest challenges to fighting the HIV epidemic in Vietnam is pervasive stigma and discrimination. HIV-positive children are continuing to be denied entry into school; workers living with HIV are being removed from their positions; and PLHIV are being shunned by their families and communities after disclosing their HIV status. In Vietnam, prostitution and drugs are viewed as “social evils against the moral and traditional customs and habits of the nation.”⁴ Only 25.6 percent of MSM are reached by prevention programs, and less than one-quarter of PLHIV in these risk groups are aware of their HIV status.⁵ Without addressing stigma and discrimination, people will continue to be inhibited from seeking HIV prevention, care, treatment, and support services; and caregivers will be reluctant to deliver support openly.

II. EVOLUTION OF CITIZEN MONITORING: FOCUS ON VIETNAM

Over the past 10 years, under the POLICY Project and the USAID | Health Policy Initiative, Task Order 1, PLHIV networks have contributed greatly to the development of citizen monitoring methods and tools. From citizen surveillance committees in Peru and legal clinics in Vietnam to human rights monitoring in Cambodia, the evidence is growing to support the benefits of actively engaging affected communities and other key stakeholders in monitoring the quality of HIV services and progress in reducing stigma and discrimination.

² Ministry of Health and United Nations Program on HIV/AIDS (UNAIDS). 2009. Vietnam HIV/AIDS Estimates and Projections 2007–2012. Geneva: UNAIDS.

³ Socialist Republic of Vietnam. 2010. Declaration of Commitment on HIV and AIDS adopted at the 26th United Nations General Assembly Special Session in June 2001 (UNGASS), Reporting Period January 2008–December 2009. Hanoi: Socialist Republic of Vietnam.

⁴ International Center for Research on Women. 2004. Understanding HIV and AIDS-related Stigma and Discrimination in Vietnam. Washington, DC: ICRW.

⁵ Results from the HIV/STI Integrated Biological and Behavioral Surveillance (IBBS) in Vietnam 2005–2006, Ministry of Health.

In early 2000, the Vietnamese government and key national and international stakeholders recognized the need to change their approach to fighting the HIV epidemic. Under the POLICY Project, Futures Group was among the most vocal advocates for moving to a rights-based approach, embracing principles of the Greater Involvement of People Living with HIV/AIDS (GIPA) and involving civil society in policy development and implementation, transparent governance, and accountability. As a result of these and complementary efforts, the legal, social, and policy environment in Vietnam has been substantially improved. The ruling Communist Party issued Directive # 54 recognizing HIV/AIDS as not only a health but also a socio-economic development issue and called for social mobilization, involvement of vulnerable groups in the HIV/AIDS response, and removing stigma and discrimination as barriers to high-quality prevention, care, treatment and support.

The development and ultimate passing of the HIV/AIDS Law in 2006 marked the emergence of community members, including PLHIV self-help groups, as welcome participants in the fight against HIV. Because of their effective campaigning, the National Assembly passed the Law on HIV/AIDS Prevention and Control with a rights-based approach that included non-discrimination and equal rights of PLHIV, free access to treatment, harm reduction, and participation of PLHIV. Additionally, the government has enacted multiple decrees, including the Decree on Local Democracy that allows broader and more meaningful civil society participation in policy and program implementation and monitoring. With a strong legal framework that supports advocacy and monitoring activities, the PLHIV movement has been significantly strengthened:

- The National Network of Positive People now has more than 10,000 members, inclusive of IDUs, FSWs, and MSM.
- VNP+, a network of 150 self help groups and alliances based in Hanoi was officially recognized by the Government of Vietnam in 2009.
- Vulnerable population groups and local nongovernmental organizations (NGOs) established the Vietnam Civil Society Platform on HIV/AIDS (VCSPA) to serve as a powerful advocate for PLHIV and vulnerable populations in policy advocacy, development, and implementation and monitoring.

The government's inclusion of PLHIV and vulnerable populations has enabled them to leverage a broader base of funding including the Global Fund, World Bank, PEPFAR, and others, for clean needles and syringes, substitution therapy, home-based and community care, and antiretroviral treatment (ART).

III. THE CITIZEN MONITORING APPROACH IN VIETNAM

Goals and Objectives

With the burgeoning strength of PLHIV groups, including VNP+ in monitoring and advocacy, VNP+ requested support from the Health Policy Initiative to pilot the HIV-related citizen monitoring approach. The goal was to pilot a process to build the capacity of networks of people living with HIV to carry out participatory monitoring activities to further evidence-based policy advocacy and dialogue. With the project's technical support, VNP+ implemented the activity, which included developing the processes for data collection, analysis, and capacity building of its members in monitoring. Similar to other participatory approaches, the *process* is a "product" in and of itself, aimed at empowering people to use evidence to advocate for improvements in HIV services, including reducing stigma- and discrimination-related practices. In addition to identifying lessons learned for further refining the citizen monitoring approach, the objectives of the pilot were to

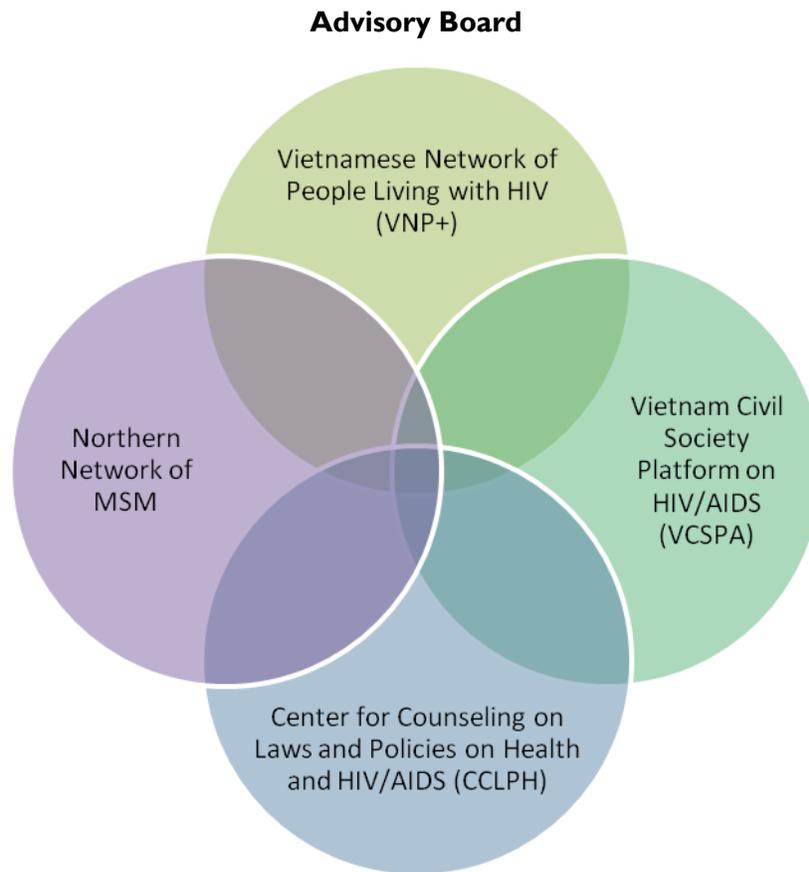
- Broaden the meaningful participation of civil society, especially vulnerable groups;

- Support the government and HIV service providers to fulfill policy commitments and meet their HIV/AIDS program targets;
- Provide VNP+ with the skills to develop ongoing evidence-based advocacy; and
- Facilitate access to HIV services for PLHIV and most-at-risk populations (FSWs, IDUs, MSM).

The Citizen Monitoring process includes: (1) forming the Citizen Monitoring team, (2) identifying areas of interest or importance for the group, (3) agreeing on indicators, (4) developing data collection and data entry tools, (5) data collection and data entry, (6) analysis, (7) developing the advocacy agenda and plan, and (8) dissemination and dialogue. In Vietnam, HPI completed the pilot process through step 7 and launched the process for step 8.

Formation of the Citizen Monitoring Team

Based on its experience in working with civil society networks to promote rights-based approaches and GIPA principles, the Health Policy Initiative established an Advisory Board to guide the citizen monitoring activity in Vietnam.



Founding members of the Advisory Board included VNP+, VCSPA, the Center for Counseling on Laws and Policies on Health and HIV/AIDS (CCLPH), the Northern Network of MSM, and the Health Policy Initiative. VNP+ is an official, government-recognized NGO, and its mandate is to conduct HIV information and communication campaigns and promote research on prevention, care, and treatment. VCSPA is a partner in monitoring implementation of the National HIV/AIDS Program and focuses on the reduction of stigma and discrimination and the meaningful involvement of PLHIV. CCLPH, an active

partner of the Health Policy Initiative, works with PLHIV networks in establishing and running legal clinics in five focus provinces of the President’s Emergency Plan for AIDS Relief (PEPFAR). The Northern Network of MSM includes MSM self-help groups in several provinces and works to advocate for the rights of MSM, reduce stigma and discrimination, promote access to healthcare, and strengthen knowledge and skills on sexually transmitted infections, HIV prevention, and safe sexual behavior. The Advisory Board was active during inception of the citizen monitoring activity, advising on selection of the HIV-related areas to be monitored and development of the monitoring tools.

Selection of Focus Areas

In selecting the areas, the Advisory Board reviewed the legal framework in Vietnam, the drivers of stigma and discrimination, and factors affecting access to HIV services. The board ultimately chose to monitor stigma and discrimination and access to ART. The provisions within the legal framework are clear and include prohibition of stigma and discrimination against PLHIV and the provision of antiretrovirals (ARVs) free of charge.

Identification of and Agreement on Indicators

Based on discussions with VNP+ and the Advisory Board, Dr. Khuat Thi Hai Oanh from the Institute of Social Development Studies (ISDS) and co-chair of the VCSPA, Mr. Tran Tien Duc, Country Director of the Health Policy Initiative/Vietnam—with assistance from the project’s technical advisors—drafted an initial list of indicators and questions. The Advisory Board approved the questions in December 2008 and presented them to representatives of vulnerable groups during an inception workshop in Hanoi in January 2009. Participants included PLHIV (VNP+), MSM (Northern Network of MSM), IDUs (VCSPA-supported drug user group), and sex workers (VCSPA-supported FSW group). VNP+ and the Health Policy Initiative team incorporated the participants’ comments and finalized the questionnaires/data collection tools. The questions were grouped around these indicators:

- Access to high-quality HIV services, particularly treatment, for vulnerable groups such as IDUs
- Stigma and discrimination barriers and practices
- Violations of the rights of PLHIV identified by the HIV/AIDS Law
- Implementation of GIPA principles
- Treatment targets set by the National HIV/AIDS Program and PEPFAR
- Global indicators on stigma and discrimination

Design and Implementation of Data Collection and Data Entry Tools

The Advisory Board chose to monitor, over a four-month period, the perceptions of PLHIV and other vulnerable groups about stigma and discrimination in healthcare settings and access to high-quality ART. Some key questions included the following:

Stigma and Discrimination

- What are the most common manifestations of stigma and discrimination in health care settings?
- What are stigma drivers and facilitators?
- Are there any perceived changes over time?

Access to ART

- How accessible is ART?
- What factors affect access to ART?
- Are patients counseled on an ARV regimen?

Monitoring ART

- What factors affect adherence to ARV continuation?
- Are there any changes over time?

VNP+ and the Health Policy Initiative finalized four questionnaires:

1. **Participant demographic information**—26 questions on educational level, income, marital status, perceived sexual and drug use behavior, and experience with 05/06 detention centers.
2. **Experience in healthcare settings**—57 questions about type of facilities, type of treatment, waiting time, attitudes of health personnel and their behavior and interaction with patients, and feelings of being stigmatized and discriminated.
3. **Access to ART**—30 questions on treatment start date, CD4 count, facility, barriers and difficulties to accessing treatment, and counseling and treatment preparation.
4. **Monitoring ART**—33 questions on CD4 status throughout the course of treatment, payment for lab tests, and healthcare provider attitudes and interactions with patients.

The Health Policy Initiative obtained IRB (Institutional Review Board) approval for the citizen monitoring activity from the Institute for Social Development Studies (ISDS) (NIH IRB #00006747) in Vietnam in April 2009, and from the Health Media Lab's Institutional Review Board in United States (NIH IRB #00001211) in May 2009. Also in May 2009, VNP+ obtained Federalwide Assurance from the Office for Human Research Protections, and VNP+ members and Health Policy Initiative/Vietnam staff completed the web-based training program in human research subjects protections sponsored by the Collaborative Institutional Training Initiative (CITI). This is an important achievement in human research in Vietnam, as this was the first time an organization representing HIV-positive people participated in this type of training. The entire process from developing and finalizing the tools to receiving IRB approval and CITI certification took eight months.

VNP+ identified data collectors from their network. These data collectors participated in a general orientation and training in January and an intensive training in June, which covered the goal and objectives of citizen monitoring, the questionnaires, data collection procedures, and data editing and consistency checks. During the training, which was carried out by HPI staff and consultants, the data collectors participated in group discussions and role plays to facilitate understanding of the questionnaires. The data entry personnel and Senior Monitors from HPI and VNP+ also participated in the training.

During the four months, additional groups of PLHIV showed enthusiasm for citizen monitoring and joined the effort. VNP+ also trained the monitors from these groups in proper form completion, form checking, and submission processes. All together, 20 VNP+ members participated in regular monitoring activities including training, data collection, monthly meetings, and initial data analysis.

Data collection

VNP+ network members worked together to prepare a list of 514 participants willing to participate in the citizen monitoring activity. To maintain anonymity, VNP+ assigned each participant a unique identifier. Names and identifiers were secured in a locked file cabinet by VNP+ with the signed Informed Consent forms. Only the VNP+ project manager had access to the file cabinet.

Group leaders, trained in citizen monitoring, provided the questionnaires to their participants monthly. Participants completed the questionnaires after returning from a health check-up. Monitors reviewed the questionnaires for completeness and then forwarded the questionnaires to the Senior Monitor at VNP+ for a final check. Participants received \$2 for every completed questionnaire, and group leaders received \$1

for every correctly completed questionnaire to cover personal costs related to completing and turning in the questionnaire. Twenty-eight people refused to accept any payment for their participation and worked as volunteers during the activity.

Data entry and analysis

The Health Policy Initiative created an easy-to-use data entry tool for each questionnaire in Microsoft Access and trained four persons from VNP+ in data entry.

Two data entry clerks entered each questionnaire into Microsoft Access and checked for errors and inconsistencies. The data were then exported into Stata, followed by coding of the open-ended questions of more than 1,000 questionnaires and merging of the files. Initial data entry took three months to complete.

The Health Policy Initiative ran frequency tables for each question and discussed the results and trends with VNP+. The project subsequently cleaned and validated the data and developed a preliminary analysis. Health Policy Initiative experts conducted three sessions with VNP+ members to review the data. Each result was reviewed for consistency and relevance within the country context. Reasons for expected and unexpected results were discussed and results were triangulated with existing country data. Data trends were identified and further analysis was performed, including disaggregation by gender, age, and risk factors.

IV. RESULTS

Questionnaire I: Participant Profile

The majority of the participants were female, between 25 and 34 years old, had completed secondary or higher education, were married or had been married, were heterosexual, and had lower income than the average. Yearly per capita income in Vietnam was \$1,052 in 2009,⁶ and 26 percent of participants generated this amount or more. Table 2 provides a summary profile of participants. Note that two participants stated that they were HIV negative. Their questionnaires were kept as part of the analysis since they did answer questions related to healthcare settings.

Table 2: Participant Profile

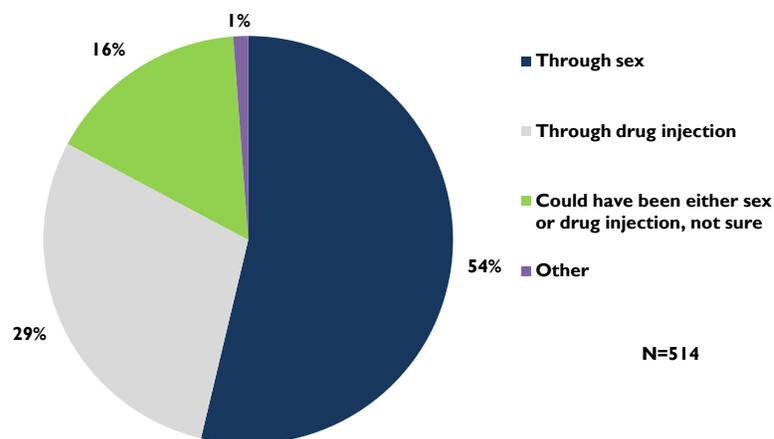
Participant Profile (N=514)			
Gender		Age	
Female	69.67%	15–24	6.80%
Male	29.21%	25–34	72.74%
		35–44	17.68%
		>45	2.13%
Education (Highest grade completed)			
Less than secondary		8.56%	
Some secondary		17.12%	
Completed secondary		33.46%	
Completed post secondary		40.86%	

⁶ U.S. Department of State. <http://www.state.gov/r/pa/ei/bgn/4130.htm> accessed June 2, 2010.

Marital Status	
Married	38.91%
Never married	32.3%
Remarried	20.43%
Not remarried	8.17%
Missing	0.19%
Yearly Income	
Less than 5,844,000 VND (less than \$300)	16.15%
Between 5,844,000 and 9,744,000 VND (Between \$300 and \$480)	38.33%
Between 9,744,000 and 19,500,000 VND (Between \$480 and \$1,020)	19.26%
More than 19,500,000 VND (More than \$1,020)	25.88%

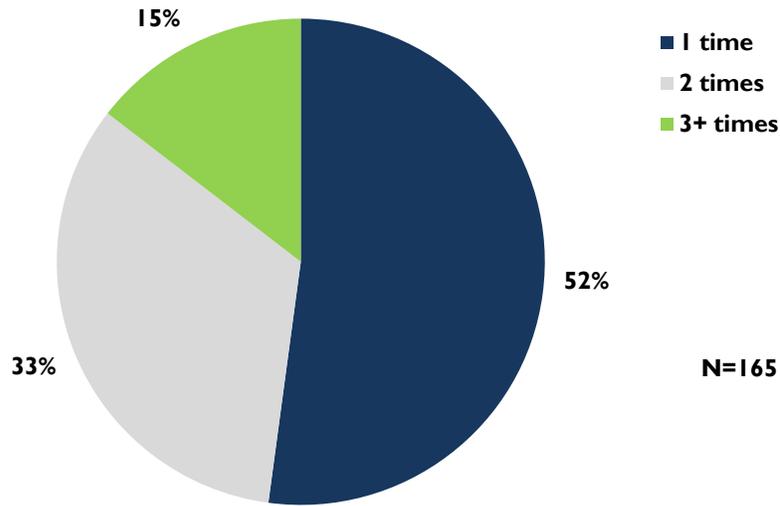
As previously mentioned, the HIV epidemic in Vietnam is concentrated among IDUs, FSWs, and MSM. Fifty-two percent of participants had at one point in their lives injected drugs. Five percent reported having exchanged sex for money or gifts, and 3 percent reported having sex with someone of the same sex. Half of the participants stated they had become infected with HIV through sex, and a third of participants through injecting drug use. Approximately 1/6 of participants reported that the transmission could have been through either sexual activity or injecting drug use. Figure 1 shows the reported method of HIV infection.

Figure 1: Method of HIV Transmission



In Vietnam, prostitution and drugs are highly stigmatized, and people involved with commercial sex work or drugs are deemed as needing rehabilitation. Sex workers and drug users are sent to 05/06 detention centers for “re-education” on morals. A 05 Center is a residential center for FSWs, and a 06 Center is a residential center for IDUs. These most-at-risk populations live in the residential center for 2–5 years, while they are rehabilitated and “re-educated.” These centers are endorsed by the government, and re-education is compulsory. Thirty-two percent (165 participants) of participants reported spending time in either a 05 or 06 detention center. Figure 2 shows the number of times participants attended a detention center; 48 percent of those who had attended a center did so more than two times. 68% who attended a center lived there for more than 12 months. Twenty-five percent spent 6–12 months, and 7 percent spent less than 6 months at a detention center.

Figure 2: Number of Times Attended a 05/06 Detention Center



Questionnaire 2: Experience in Healthcare Setting

Eighty-nine percent of participants had attended a public hospital or public clinic to receive HIV-related care. This questionnaire aimed to identify the most common forms of stigmatizing and discriminatory behaviors and attitudes experienced or perceived by the participant; identify drivers and facilitators of these behaviors and attitudes; and identify any changes over time. Discriminatory behavior refers to actions taken by healthcare staff due to the patients' seropositive status and not based on the medical need of an HIV-positive person. This can include making HIV-positive patients wait longer than others, marking files or medical records to identify them as HIV positive, wearing gloves when it is not medically necessary, and demanding payment for services that are legally free. Table 3 presents results regarding potentially discriminatory behavior.

Table 3. Potentially Discriminatory Behavior

Waiting Time		
Do you think your waiting time in the facility was longer or shorter than the waiting time for other patients?	Longer than others	5%
	Shorter than others	13%
	Same as others	75%
	Don't know	8%
Marked Items		
During the time you were in the facility, were any of the following items used for or by you marked as HIV or risk behavior? (Percent of respondents who responded yes)	Patient file or medical register	40%
	Test indication slip	37%
	Treatment or prescription slip	32%
	Hospital gown	9%
	Hospital bed	7%
	Hospital utensils or instruments	8%
	Door of the room	2%

Medically Unnecessary Use of Protection		
During the time you were in the facility, did the health care workers wear gloves when they were just talking with you?	All/most	25%
	Some	21%
	Few/none	54%
Unnecessary Payment		
What was the total amount of money which you/your family had to pay to the health facility as official fees?	Nothing	33%
	< 500,000 VND	46%
	> 500,000 VND	13%
	> 1 million VND	5%
	Don't know	3%
What was the total amount of money you/your family spent to buy drugs and/or other items used for treatment in addition to official payment?	Nothing	24%
	< 500,000 VND	39%
	> 500,000 VND	16%
	> 1 million VND	12%
	Don't know	9%

In addition to experiencing stigmatizing and discriminatory behavior from healthcare staff, patients could have perceived stigmatizing and discriminatory attitudes on behalf of the staff. Overall, participants in the survey reported both positive and negative experiences in health care settings (see Table 4). The most common forms of stigma and discrimination included wearing gloves when it was not medically necessary, marking medical records to explicitly reveal HIV-positive status, and making patients feel that they were not welcome back to the facility.

Table 4: Stigmatizing and Discriminatory Attitudes

Interactions with Facility, Health Workers, and Other Patients	Percent of Respondents Agreeing with Statement
The health workers showed a caring attitude toward me	84%
The health workers avoided me, did not want to look at me	52%
The health workers seemed to look down at me or judge me for my condition	37%
The health workers spoke respectfully with me	65%
The health workers were generally colder to me than to other patients	46%
The health workers were generally no more angry with me than with other patients	52%
The health workers were generally no more demanding with me than with other patients	45%
Some of the health workers made me feel that they found me disgusting	35%
Some of the health workers were too curious about my personal life	40%
The health workers were generally ruder to me than to other patients	26%
My health care workers were just as qualified and competent as the health care workers that attended other patients	92%
My health care workers talked to others about me or talked loudly so others could hear	26%
My health care workers made me feel welcome to come back if I need to	82%

The other patients seemed to fear me or avoid me	46%
The health care workers knew or thought I have HIV	72%
The health care workers knew or thought I use drugs	35%
The health care workers knew or thought I sell sex for money	22%
The health care workers knew or thought I have same-sex sex	23%

To identify drivers and facilitators of stigmatizing and discriminatory behavior, participants were asked about visible signs at the time of visit, such as a skin problem (rash, lesion, ulcer, etc), visible tattoo, visible injecting marks, obvious weight loss or wasting, and/or cough or problem breathing. Table 4 shows reported visible signs. Overall, the majority of participants reported not having visible signs when they attended the health center.

Table 5: Drivers of Stigma and Discrimination

At the time you came to seek service in that facility, did you show any of the following signs? (N=74)		
	Yes (%)	No (%)
Skin problems (rash, lesion, ulcer, etc.)	29.73	70.27
Visible tattoo(s)	14.86	85.14
Visible injecting mark(s)	6.76	93.24
Obvious weight loss or wasting	27.03	72.97
Cough or problem breathing	21.62	78.38

Questionnaire 3: Experience Accessing ART

This section presents results related to participants' experience in accessing ART and the quality of HIV-related treatment services. The questionnaires aimed to answer the following questions:

- How accessible is free ART?
- What factors affect access to ART?

Table 6: Help with Application for ART

When you applied for ARV treatment, from whom did you receive help or support? (N=514)		
	Yes (%)	No (%)
Health worker	63.42	36.58
PLHIV group	65.37	34.63
Individual living with HIV	77.24	22.76
Staff of a social organization or NGO	27.63	72.37
Family member	28.4	71.6
Anyone else	53.11	46.89

One aspect that could affect access is the application process; it could be difficult to complete without help, and the health staff could exhibit negative attitudes and behaviors toward the patient filling it out. For example, the paperwork may be dense, lengthy, and incomprehensible unless the patient has some

assistance filling it out. The majority of participants received help from an individual (see Table 5). Figure 3 shows participants' perception of the difficulty of filling out the application. Nearly two-thirds of participants described the application process as "somewhat easy."

Figure 3: Difficulty Level of ART Application

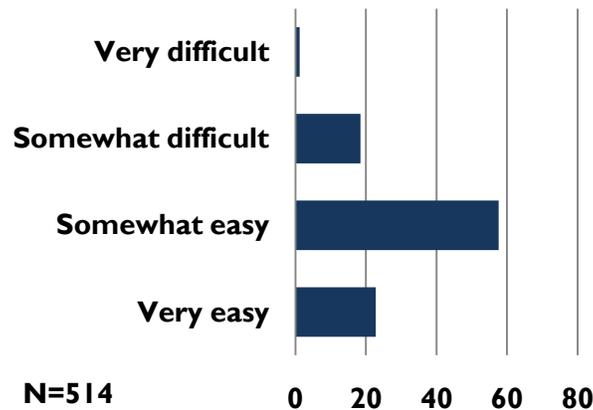
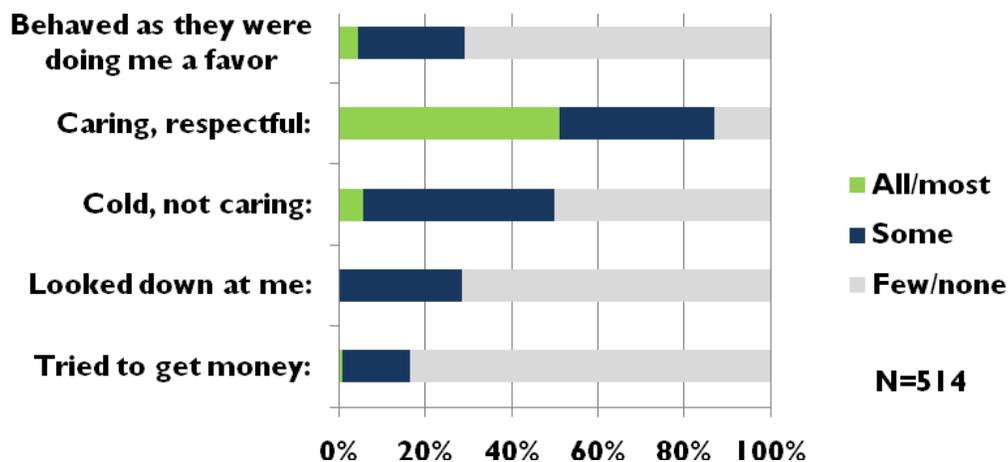


Figure 4 illustrates the respondents' perception of healthcare staff attitudes and behavior during the application process for ART. It shows that more than 51 percent of respondents thought all or most of the staff (represented by the light blue bar) showed a caring and respectful attitude during the application process. It also shows that the majority of respondents thought few or none of the staff (shown by the dark blue bar) expressed a negative attitude.

Figure 4: Staff Attitude and Behavior during Application Process



Several questions tried to address components of quality in HIV-related treatment. The results shown in this section are related to counseling services provided by the healthcare staff. Nearly all participants (94%) received counseling at the facility before starting ART. Table 6 shows that most participants also

spoke with someone about how to take ARVs and the possible side effects. This may be a reflection of the support members of VPN+ provide each other, and results may be biased because many of the participants are VPN+ members or have a relationship with them. They were also able to rely on this network when ART was started.

Table 7: Discussed ARVs

Since you applied for ART but before you started treatment, whom have you talked with about ARVs— for example, how to take them, how they work, what kind of side effects you might experience?			
	Yes (%)	No (%)	Don't know/Don't remember (%)
Facility staff	74.51	22.89	2.59
PLHIV in facility	47.30	48.81	3.46
PLHIV group	76.24	20.95	2.81
Person living with HIV	54.43	38.44	7.12

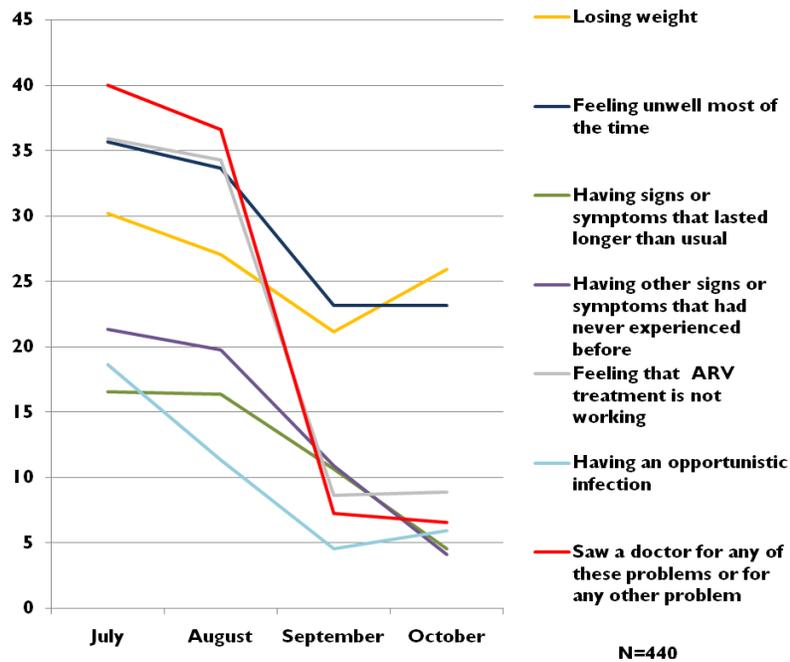
Questionnaire 4: Monitoring ART

In general, the participants who were on ART claimed good adherence; 96 percent stated they had taken their pills “yesterday.” Asking whether a patient has taken his medication yesterday is a good proxy for adherence. This section presents information on factors that could challenge or discourage a patient to discontinue ART. Some examples include the following:

- Patient seems to be getting progressively weaker regardless of treatment.
- Patient does not see doctor for ART.
- Patient does not meet with anyone to talk about ART at time of service.
- Patient has to pay or is coerced to pay for treatment that is supposed to be free.

Figure 5 shows participants’ perception of their health over a four-month period from July–October 2009; they believed it to have improved. For example, in July, 21 percent of participants on ART stated that they had experienced symptoms in the past month they had never experienced before. However, by October, only 4 percent of participants said they experienced symptoms that they had never experienced before. The proportion of participants who thought their treatment was not working also dropped from 36 percent in July to 9 percent in October.

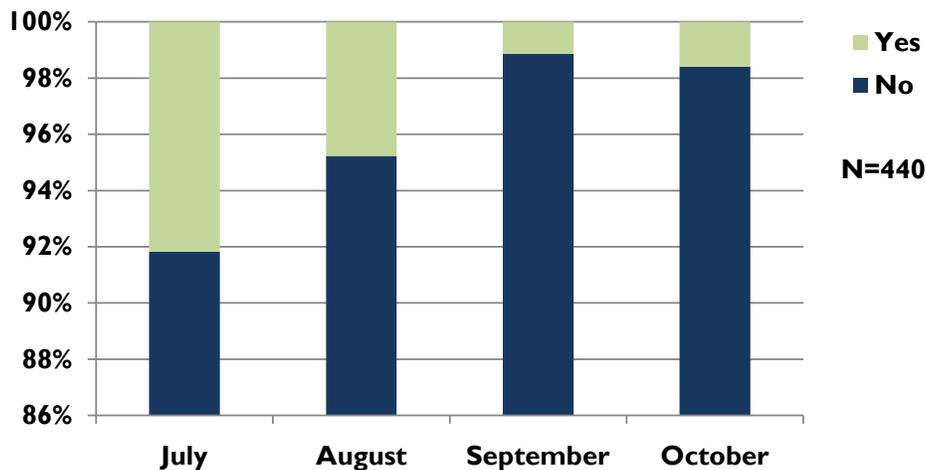
Figure 5: Patient's Perception of Their Health over Four-Month Period



More than four-fifths of respondents stated that they had seen a doctor when they picked up their ARVs each month, and about 60 percent were examined by a doctor and 61 percent received an explanation by the doctor about their state of health. One-third of participants felt that the doctor's attitude was caring, and 69 percent felt the doctor's attitude was normal. However, more than half of participants were not asked by their doctor if they had questions and/or also did not receive answers to their questions.

Finally, one last aspect that could affect continuation of ART is an unwarranted fee. In Vietnam, regulations state that HIV-positive patients should not be charged for treatment. The proportion of participants that reported not paying a fee for treatment increased over the four-month period (see Figure 6).

Figure 6: Fee for ARV Treatment



V. DISCUSSION

Although the goal of the citizen monitoring activity in Vietnam was to pilot a process for building the capacity of networks of PLHIV to carry out participatory monitoring activities for policy advocacy and dialogue, a discussion of the resultant data and limitations is important.

First, this was not a randomized controlled trial. Respondents were members of self-help groups in Hanoi, and, prior to participating in the citizen monitoring activity, they received training on issues such as GIPA, advocacy, human rights, and HIV treatment through these groups. Therefore, they are not representative of the overall profile of PLHIV in Vietnam or even in Hanoi. Second, the complexity of the questionnaires, including the number and interpretation of questions, introduced multiple data interpretations that made analysis difficult. At best, the team was able to infer results and comment on trends. The questionnaire itself may have increased participants' awareness of issues related to stigma and discrimination, resulting in different responses than would have normally been expected. Although the results provide clear indications of problem areas, they should be validated by other means. Third, the time elapsed between monthly health check-up and completion of questionnaires varied among participants, potentially affecting respondents' ability to accurately recall the visit. Finally, the four-month period over which participants completed questionnaires is relatively short to assess real change over time, but one can infer trends and identify challenges.

VNP+ and the Health Policy Initiative encountered several challenges in piloting the process for enhancing the capacity of VNP+ to monitor HIV activities. Health Policy Initiative staff provided technical support throughout the activity—most intensely in the data collection and data entry phases. The data entry phase revealed that the relative complexity of the questionnaire hindered the capacity of VNP+ to perform simple monitoring or begin independently developing an advocacy agenda based on the results. In addition, because the questionnaires were relatively complex, data analysis was performed primarily by Health Policy Initiative staff rather than VNP+ members, which distanced participants from the process.

Toward the end of the data collection period, the Health Policy Initiative's office in Vietnam closed. As a result, ongoing technical support to VNP+ was provided via email, conference calls, and chats. The Health Policy Initiative enabled a small number of VNP+ members to “reconnect” to the data through lively discussions around validating the results and emails. Nevertheless, this method was less than ideal as the discussions were complicated by distance and the need for translation.

Despite these challenges, VNP+ was able to use the results of the data collection to draft an advocacy agenda (below). Although the data was not clean enough to be definitive, the preparation for and implementation of the stakeholder dissemination workshop provided for meaningful participation by the broader VNP+ membership. By eventually sharing these results with providers and comparing quality and stigma surveys in health facilities it may be easier to facilitate access to care for PLHIV and most at risk populations.

Drafting of the VNP+ Advocacy Agenda

In preparation for the stakeholders meeting, VNP+, with assistance from Health Policy Initiative representatives, reviewed the data and drafted an advocacy agenda based on the data:

- **Acknowledge positive steps for improving the quality of health services for PLHIV.**
- **Continue to encourage effective stigma reduction efforts.** The data showed a decrease in perceived stigma and discrimination toward PLHIV in healthcare facilities over a four-month time period. The findings are consistent with other studies in Vietnam, which show declining stigma in the healthcare setting, potentially reducing a key barrier to care for PLHIV.

- **Give special care and attention to PLHIV with a history of substance use.** Twenty-one percent of respondents reported substance use within the previous 12 months and a significant proportion indicated dissatisfaction with the healthcare system at multiple levels. Despite these factors, ARV adherence was 96 percent.
- **PLHIV networks should be expanded throughout Vietnam.** These networks are vital to improving adherence, overcoming stigma, and improving the patient-provider relationship. Although there are likely multiple factors contributing to the good adherence rates observed, the VNP+ network of support groups undoubtedly played a positive role in improving members' knowledge of HIV, enhancing their ability to manage the complexity and side effects of ART, and helping them navigate the healthcare system.
- **Expand access to ARVs to slow the progression of HIV and improve the quality of life for PLHIV.** There was a substantial increase of CD4 count among participants since the start of treatment. With a stronger immune system and fewer HIV-related illnesses, participants reported improved perceptions of health.
- **Continue to improve provider-patient interaction and communication.** Practices in the healthcare setting identified as needing improvement include education of providers in universal precautions, patient-provider communication skills, and ceasing the practice of visibly marking patients' files and charging patients for HIV services.
- **Reinforce stigma and discrimination reduction efforts and improve enforcement of existing policies and regulations.**
- **Take action to remove barriers to treatment, including addressing stigma and discrimination in the healthcare setting and reducing financial barriers that restrict access.**
- **Advocate for increased priority of treatment services in detention centers.** A significant percentage of participants have spent time in 05/06 detention centers and/or prisons. As HIV treatment is not available in detention centers or prisons in Vietnam, it is highly unlikely that these patients are taking ARVs while living in these centers. Although Vietnam is suffering from human resource and budgetary constraints, effective HIV prevention, care, and treatment is feasible in detention centers and prisons. The concentration of HIV in vulnerable groups makes it even more important to prioritize HIV services in detention settings.

Public Review of the Citizen Monitoring Activity

On April 9, 2010, a half-day stakeholder dissemination workshop was held at the Press Club in Hanoi Vietnam (see Annex A). Preliminary findings of the citizen monitoring activity were presented to stakeholders to elicit their feedback, identify issues for advocacy, and obtain support for extending the activity beyond its pilot phase. Participants included representatives from USAID, UNAIDS, the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), Pact, and other international organizations, as well as various Vietnamese NGOs. The organizers received regrets from the Ministry of Health (Vietnam Administration for HIV/AIDS Prevention and Control—VAAC, Department for Health Legislation, and Administration for Curative Treatment and Hanoi Center for HIV/AIDS Prevention and Control).

Mr. Do Dang Dong, Chief Coordinator of VNP+, opened the meeting. He highlighted the VNP+ and associate groups' progressive ownership of the process of designing and implementing the activity. Per Mr. Dong, "The project helped to strengthen the capacity of VNP+ and civil society groups in monitoring the implementation of legal documents, especially provisions related to human rights, stigma and discrimination, and quality of care for vulnerable groups." Mr. Dong underlined the importance of the

Health Policy Initiative's technical assistance and expressed sincere thanks to PEPFAR and USAID for their valuable support.

On behalf of VNP+ and the Health Policy Initiative, Mr. Tran Tien Duc gave an overview of citizen monitoring, focusing on Vietnam. Mr. Duc introduced the process of designing and developing the tools, and the crucial role of positive and vulnerable groups in this process. He also highlighted the attention paid to protecting the participants with good research methods and skills training provided by VNP+ and the Health Policy Initiative. Mr. Duc shared the major findings of the pilot activity and his thoughts on how to improve the activity. He noted, for example, that triangulation with some qualitative exploration of specific issues and with a survey of health professionals views on quality of services and stigma and discrimination would undoubtedly provide a more complete picture of the situation.

In the discussion, participants validated the results and offered expert opinions.

- Ms. Thanh from the Milk Flower self-help group confirmed that among 54 members in their group, 20 were chosen for participation based on their education level. She confirmed that all participants signed consent forms and that all questionnaires were reviewed for completion prior to being sent to VNP+ for data entry.
- Ms. Thanh confirmed that patients in Dong Da Hospital paid more than 1 million VND for lab tests. Lab tests were paid by the ART program only when patients had CD4 counts that were less than 200, and they were added to the waiting list for treatment.
- Also, according to Ms. Thanh, positive patients preferred public facilities because patients are able to access free services.
- Ms. Hai from the Pigeons self-help group confirmed that its members had to pay for regular lab tests to get ARVs.
- The country representative of UNAIDS, Eammon Murphy, commended VNP+ and the Health Policy Initiative for this innovative activity and expressed hope that the findings would be shared with all stakeholders after finalization of the report. The findings will contribute to the reduction of stigma and discrimination in healthcare settings and improvement of quality of care for HIV-positive patients.
- Ms. Ngo Minh Trang, USAID Cognizant Officer for the Health Policy Initiative/Vietnam, commended VNP+, the Health Policy Initiative, and Futures Group for the excellent results of this pilot initiative. Findings of the citizen monitoring activity are in line with other studies on stigma and discrimination in Vietnam, which documented the reduction of stigma and discrimination in general and in healthcare settings in particular. She agreed with suggestions made in the presentation by Tran Tien Duc on the need to add a qualitative component to the project and to compare findings on stigma and discrimination in healthcare settings from the patients' perspective with those from the providers' perspective. Ms. Trang supported the idea of extending the activity beyond the pilot phase and expanding citizen monitoring to other groups (not only members of VNP+) and other cities/provinces. Ms. Trang suggested that VNP+ approach VAAC again and other health institutions to present and discuss findings of the activity and to develop policy agenda based on the evidence provided by this and other studies.
- UNICEF and WHO representatives expressed appreciation for the activity findings and supported adding a qualitative component. They also supported making the tools simpler and easier for collection and analysis.
- Ms. Van from CARE international found the findings promising. She greatly appreciates the concept of citizen monitoring when participants monitor and assess the services themselves. Ms. Van also supports adding a qualitative component to the activity.

All discussants recommended that the findings be disseminated at other forums (e.g., the HIV/AIDS Technical Working Group, where all stakeholders working on HIV/AIDS programs in Vietnam hold a bi-monthly meeting).

VI. NEXT STEPS

Based on results of the stakeholders' dissemination workshop, VNP+ will develop a more complete advocacy agenda, focusing on strengthening stigma and discrimination education with health providers, improving stigma and discrimination policies and regulations in healthcare settings, and setting up mechanisms for dialogue among VNP+, self-help groups, and healthcare management to reduce stigma and discrimination and improve quality of care. Additionally, VNP+ will convene a meeting with the Ministry of Health (VVAAC, Department for Health Legislation, Administration for Curative Treatment and Hanoi Center for HIV/AIDS Prevention and Control) to review the results and discuss next steps.

VII. RESULTS AND KEY LESSONS LEARNED

Results

- With the knowledge and skills acquired through trainings and technical assistance, a core group of 50 VNP+ members was able to successfully lead the citizen monitoring activity.
- The Health Policy Initiative's support enabled VNP+ to analyze the results and use this evidence to develop an advocacy agenda.
- Lessons learned from the pilot Citizen Monitoring in Vietnam helped improve the processes of empowerment, tool design, and analysis by PLHIV networks, so that the pilot could be replicated in other countries (Mali).

Key Lessons learned

- Building the capacity of a national PLHIV network in research protocol is possible.
- Involving networks of PLHIV in all aspects of the activity is crucial to successful participatory monitoring. Training and practice on using the data collection tools is important.
- Indicators and tools should be in line with global and national indicators for quality of care and stigma and discrimination but adapted based on the national situation, policies, and programs. Feedback from potential participants should be elicited.
- Data collection instruments should be simple so that national NGOs can be fully involved in data analysis and subsequent development of the advocacy agenda.
- Local research institutions should be involved when necessary to facilitate dialogue between implementers and researchers to foster a greater understanding of the relevant HIV quality of care and stigma and discrimination issues.
- Triangulation with qualitative appreciation of PLHIV, with surveys of health providers, and with community-level stigma indicators (i.e. Demographic Health Surveys) would add greater depth to the results of this study and would facilitate advancement of stigma research.

ANNEX A. AGENDA OF STAKEHOLDER MEETING

Agenda Stakeholder Meeting April 9, 2010

Time	Content	Responsible person
8h30 - 9h00	Registration	
9h00 - 09h10	Introduction of the workshop objectives and participants	Do Dang Dong, VNP+
9h10 - 10h25	Overview of the Citizen Monitoring Project, design, data collection, analysis, findings and recommendations	Trần Tiến Đức (Futures Group consultant) Pham Hung Quoc (VNP+)
10h25 - 10h40	Tea break	
10h40 - 11h30	Q&A and discussion	Dong, Quoc and Tran Tien Duc
11h30 - 12h00	Wrap up	Dong and Tran Tien Duc
12h00 - 13h00	Lunch	

Participants

No	Name	Organization
1	Nguyễn Thanh Vân	Tình Thân group
2	Vũ Thanh Liễu	Sức Trẻ group
3	Nguyễn Hải Anh	Ban Mai group
4	Đào Phương Thanh	Hoa Sữa group
5	Phan Phương Quý	Nơi Bình Yên group
6	Nguyễn Văn Kiên	Ước Mơ Xanh group
7	Chu Thị Thanh	Về Nhà group
8	Nguyễn Hữu Tuấn	Gạch Đầu Dòng group
9	Nguyễn Thị Hải	Bồ Câu group
10	Cam Tuấn Dũng	Long Biên group
11	Nguyễn Sơn Minh	Niềm Tin Xanh group
12	Nguyễn Văn Dũng	Thông Xanh group
13	Võ Công Thành	Thông Xanh group
14	Lại Minh Hồng	Mặt trời của bé group
15	Phạm Thanh Huyền	Gia Đình group
16	Lưu Quang Thắng	Cho Bận cho tôi group
17	Vũ Phương Lan	Hoa Hương Dương group
18	Lê Mạnh Hưng	Sắc Màu Nhân Ái group
19	Nguyễn Diệu Hằng	Ước Mơ Xanh group
20	Nguyễn Thị Nguyệt	Hoa Đồng Nội group
21	Đặng Thị Lê Trâm	Policy law advisory center about health care

22	Earmon Murphy	UNAIDS
23	Ngô Minh Trang	USAID
24	Nguyễn Thanh Vân	CARE
25	Nguyễn Thu Nga	WHO
26	Ms. Hiền	UNICEF
27	Yasmine Refaat	UNODC
28	Nguyễn Sơn Minh	VCSPA
29	Nguyễn Hoàng Điệp	O2 Television

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