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RESEARCH AND EVALUATION REPORT

Task Shifting in HIV/AIDS Service Delivery:

An Exploratory Study of Expert Patients in Uganda

NOVEMBER 2011

This research report was prepared by University Research Co., LLC (URC) and Initiatives Inc. for review by the United States Agency for International Development (USAID). It was authored by Lauren Crigler, Dan Wendo, and Anya Guyer of Initiatives Inc. and Juliana Nabwire of URC. The expert patient study in Uganda was funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and carried out under the USAID Health Care Improvement Project, which is made possible by the generous support of the American people through USAID.

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Abbreviations

AIDS	Acquired immune deficiency syndrome
ANC	Antenatal care
ART	Antiretroviral therapy
EP	Expert patient
EPI	Expanded Program on Immunization
HCI	USAID Health Care Improvement Project
HCT	HIV counseling and testing
HIV	Human immunodeficiency virus
MSF	Médecins sans Frontières
NGO	Non-governmental organization
PLHA	Persons living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission
PSI	Population Services International
QI	Quality improvement
STI	Sexually transmitted infection
TB	Tuberculosis
URC	University Research Co., LLC
VCT	Voluntary counseling and testing
WHO	World Health Organization

EXECUTIVE SUMMARY

According to the World Health Organization (WHO), the world needs more than four million more doctors, nurses, and midwives than are currently available. Health worker shortages are particularly severe in sub-Saharan Africa and Asia. In 2006, WHO listed Uganda as one of 57 countries with a "critical shortage" of health workers (WHO 2006). As a developing country, Uganda has both limited resources and an increased demand for health services created by the chronic care required to maintain antiretroviral therapy (ART) for people living with HIV/AIDS (PLHA) among other issues. Over the past several years in Uganda, many health facilities have adopted strategies to shift some facility and community-based tasks to "expert patients", clients who are recruited and trained to provide support services for other clients in facilities and in communities.

Although several non-government organizations (NGOs) and public health systems have integrated expert patients into HIV/AIDS care and support using a variety of models, there is a lack of knowledge about how and how well they contribute to improving access to and the quality of health care. Among the significant gaps in the current literature, limited documentation and robust evidence exist about the range of tasks expert patients perform; how they are recruited, trained and supervised; and how communities are involved in the selection and use of expert patients. This study examines these issues from the Ugandan context to improve understanding of current practices and perceptions, and asks three main research questions:

i. How are expert patients being used?
ii. What organizational support is provided to expert patients?
iii. What are the perceptions of actors most closely affected by the use of expert patients?

The USAID Health Care Improvement Project (HCI) carried out a qualitative study in May 2011 at six health facilities that were using expert patients in a variety of tasks within the facility and at the community level. The assessment used a descriptive qualitative study methodology with semi-structured questionnaires to gather information from Ministry of Health officials at the district and national levels, site managers of the HIV service providing clinics, clients, expert patients, and community members. A total of 61 interviews were conducted.

Evidence gathered in this study showed that shifting tasks to expert patients in these facilities and communities was successful and that there was strong enthusiasm among all stakeholders. Facility staff, clients, and communities, as well as expert patients themselves, all benefited: clients waited less and had a friendly ear, health workers were able to hand off some responsibilities, and expert patients strengthened relationships with coworkers and communities. This study did not evaluate the performance of expert patients, however, and cannot speak to the quality of the work they do.

Sites began to shift tasks to expert patients as a way to address the growing numbers of HIV clients crowding clinics and waiting for hours to be seen. Some PLHAs were recruited, others volunteered, and communities were occasionally consulted in the selection process. Tasks shifted to expert patients at the facility included preventive health education, filing and data maintenance, crowd management, treatment adherence education and health education, and client assessment during triage. In communities, expert patients followed up with HIV clients, did health education and supported care in the homes. The different stakeholder interviewed expressed satisfaction with the performance of the expert patients on these tasks.

Policies or training guidelines on expert patients did not exist, and organizational processes varied greatly from site to site, which created some confusion about the role among stakeholders. NGOs provided the large part of initial training and materials and clinical staff at sites coached and provided ongoing training in multiple sessions based on emerging areas of need. Supervision and performance monitoring differed site to site but was usually done by site managers or clinical staff. Nonetheless,

expert patients reported meeting frequently with supervisors and receiving coaching and help with problems when they needed it. All expert patients received free drugs and medical care; some received payments in cash, per diem, or travel reimbursements. When asked which incentives were most important, expert patients selected payment over medical care. Financial incentives do not seem to be the main motivator, however, as all expert patients were highly engaged and said the most satisfying part of the job was helping others who suffered from the same disease.

Most expert patients and many clients reported that the stigma of HIV was lessening. It is unclear if this is partly due to the involvement of expert patients or if it is due to other causes. Nevertheless, one clear message from clients was that expert patients were helpful to them with their example of positive living.

The success of shifting tasks to HIV-positive patients in these sites was clear to all parties. Expert patients helped to alleviate long waits for clients and overloaded health workers. They also had skills and special experience that helped make them successful as patient counselors and community spokespersons. Site managers, NGOs, communities and clinical staff all played some role in the success of expert patients, and this broad based engagement could be part of its success. Still, there was an absence of policies, standardized curricula, and operational guidelines for the use of PLHA to deliver services in facilities and communities. As the use of expert patients increases and spreads, it is important that measures are taken to support consistency and ensure quality standards. It is also important that decision makers consider the sustainability of such a program before it is adopted on a larger scale.

Drawing on these findings, the study investigators recommend that the Government of Uganda **develop a national policy framework** that clearly defines the expert patient role and tasks in the facility and community as well as the enabling environment required for the success of such a program. A **broad range of stakeholders should be involved in this process**, including expert patients and communities, and in keeping with WHO's task shifting recommendations, it **should begin with an analysis that will provide information on the current gaps** in service provision, the extent that task shifting is already taking place, and the existing human resources quality assurance mechanisms. It is also recommended that this **process be piloted first** and that resources are available in order to sustain it once it is implemented fully.

A national policy framework should include policies and clear guidance on the organizational support that a new cadre of worker requires, including:

- **Role definition** to clarify what tasks expert patients should and could perform.
- **Recruitment** criteria and guidance about the recruitment process.
- **Standardized training** that is based on a clearly defined expert patient role and which is harmonized between government programs and private organizations, and across sites within certain programs.
- **Supervision and monitoring** that will ensure that expert patients are performing to standard and to enable expert patients to take on more complex tasks with confidence.
- **Incentives** balanced to include financial and non-financial rewards.

As countries like Uganda struggle with a scarcity of human resources and look for affordable solutions, one of the biggest challenges will be to ensure that scaling up expert patient programs does not undermine the needs-based approach that facilities in this study were using. Additional research is needed to look at different methods sites can use to support expert patients that are both flexible and encourage participation from all members of the health care team, communities, and clients. Additional research should also be conducted to determine the cost-effectiveness of shifting tasks to PLHA and incorporating them into service provision teams.

I. BACKGROUND

According to the World Health Organization (WHO), the world needs more than four million more doctors, nurses, and midwives than are currently available. Health worker shortages are particularly severe in sub-Saharan Africa and Asia. In 2006, WHO listed Uganda as one of 57 countries with a "critical shortage" of health workers (WHO 2006). As a developing country, Uganda has both limited resources and an increased demand for health services created by the chronic care required to maintain antiretroviral therapy (ART) for people living with HIV/AIDS (PLHA) among other issues. Most Ugandans receive health care through the public system; however, in 2009 approximately 47 percent of approved positions in public health facilities were vacant (Uganda Ministry of Health 2005). Other countries in the region and those in similar socioeconomic situations face comparable shortages.

Some of the gap between the number of qualified health professionals needed and the number working in the health sector is due to limited supply. Many developing country health education systems do not train enough new health workers to meet demand. Other reasons for the gap include migration of qualified professionals to other countries for advanced training or better career opportunities, attrition of staff due to their own poor health, urban bias among health professionals who prefer to live in population centers, and competition from private sector (both for- and not-for-profit) organizations able to offer better salary and benefit packages.

In response to these human resource challenges, the WHO has proposed a model of "task shifting" to rapidly strengthen and expand the health workforce in order to increase access to HIV and other health services (WHO 2008). Task shifting is defined as the rational redistribution of tasks among health workforce teams making more efficient use of the human resources available. In this model, selected tasks are transferred from one level of health professionals to another (e.g., allowing senior nurses to prescribe instead of only physicians) or from health professionals to lay workers or volunteers (e.g., letting community members conduct child growth monitoring instead of nurses).

Task shifting is of particular importance in addressing the current shortages of health workers in countries like Uganda that have high HIV infection rates. It offers a framework for expanding the human resource pool; further, when tasks are shifted to people drawn from the local community and patient population, the process can also serve to build bridges between the health facility and the community, to create local jobs and to offer new opportunities for vulnerable populations (WHO 2007).

According to WHO's task shifting guidelines, community health workers, including people living with HIV/AIDS, can safely and effectively provide specific HIV services both in the facility and the community. However, to ensure that shifting tasks from one cadre to another is effective, systems to support workers in their new tasks must be strengthened as well. Clearly defined roles and associated competency levels, standards for recruitment, training and evaluation, strengthened supervision, and appropriate incentive structures provide a framework to make task shifting successful (WHO 2008).

Over the past several years in Uganda, many health facilities have piloted shifting some facility and community-based tasks to HIV-infected clients. Existing clients are recruited and trained to provide support services for other clients in facilities and in communities. Lay clients engaged in this way are referred to as "expert patients." The term was first used in the United Kingdom to describe individuals who were well educated about their own chronic diseases (e.g., diabetes, heart disease or mental illness) who participated in decision making about their own care and who could, as a result, provide support to others with the same disease (United Kingdom Department of Health 2001).

In the Ugandan context, and for the purpose of this research, expert patients are PLHA who have been trained to deliver one or more HIV services but who are not certified or categorized formally within the recognized health system.

A. Study Questions

Although several non-government organizations (NGOs) and public health systems have integrated expert patients into HIV/AIDS care and support using a variety of models, there is a lack of knowledge about how and how well they contribute to improving access to and the quality of health care. Annex 1 provides a summary of existing literature on shifting HIV-related tasks to expert patients and to similar lay health workers.

Among the significant gaps in the current literature, limited documentation and little strong evidence exist about the range of tasks expert patients perform; how they are their recruited, trained and supervised; and how communities are involved in the selection and use of expert patients. The perceptions of expert patients and those with whom they interact have also not been studied adequately. This study examines these issues in the Ugandan context to improve understanding of current practices and perceptions and asks three main research questions:

i. How are expert patients being used?
ii. What organizational support is provided to expert patients?
iii. What are the perceptions of actors most closely affected by the use of expert patients?

II. METHODOLOGY

In this descriptive, qualitative study, key groups of respondents, including expert patients, clinical staff, clients, community members, Ministry of Health representatives, and other key informants, were interviewed using semi-structured questionnaires.

A. Site Selection and Characteristics

Six sites were selected from a sampling frame of 29 sites participating in improvement collaboratives supported by the USAID Health Care Improvement Project (HCI) that were known to be utilizing expert patients (EPs) at facilities or in communities. To ensure good representation of certain characteristics such as geographic distribution, numbers of expert patients working, tasks assigned, and whether government supported or NGO supported, site managers completed pre-assessment questionnaires. The final sample of six sites included four government facilities (three hospitals and one health center) and two hospitals run by faith-based organizations. Two sites each were located in the West Nile and Central regions; the other two were in the Southwest and Western regions.

Facilities were informed in advance about the purpose and time of the assessment to ensure they were willing and prepared to participate. At each site, respondents were identified based on their positions and experience with expert patients. Clinic staff were selected in advance by site managers that had been working at the site for over three months. Community members were also identified in advance by site managers and asked to meet the interviewers at the facility. All other site level respondents were selected based on availability and convenience. District Health Officers and other key stakeholders were interviewed as possible. As detailed in Table 1, in total, 61 people were interviewed.

B. Data Collection Instruments

The assessment team used six semi-structured interviews for key stakeholders. In addition, expert patients completed a survey to measure their workplace engagement that is adapted from Gallup's Q12 which seeks to understand concepts of empowerment and responsibility to affect change (Wellins et al. 2007; Gallup 1993-1998).

Instruments and data entry forms were developed by HCI staff and consultants and were field tested for validity and comprehensibility at Holy Cross Hospital in Kampala which was not among the facilities selected for the assessment. They were slightly modified to ensure comprehensibility. Annex 2 has a complete package of all tools.

Table 1: Respondents, Data Collection Tools, and Numbers Interviewed

Respondent	Tool	Content	Numbers Interviewed
Site manager	Semi-structured questionnaire	Policies and processes, roles and responsibilities of EPs, perceptions and relations of health workers to EPs, supervision	1 per site 6 total
Health workers who interact with EPs	Semi-structured questionnaire	Roles and responsibilities, perceptions of and relations with EPs	2 per site 12 total
Expert patients	Semi-structured questionnaire Engagement Survey	Roles and responsibilities, skills and knowledge, motivational factors, perceptions of their role, relations with others Attitudes and beliefs regarding work, environment and empowerment	2 per site 12 total
Clients	Semi-structured questionnaire	Perceptions of, relations with EPs	2 per site 12 total
Community members	Semi-structured questionnaire	Perceptions of community members toward EPs working in the community, comfort and satisfaction with EP services	2 per site 12 total
Ministry of health officials and other key informants	Semi-structured questionnaire	Policies and processes pertaining to EP role including recruitment, training and support of EPs. Acceptability of role, perceptions of success or lack thereof	7 total

Responses were recorded verbatim on paper during the interviews and subsequently entered into Survey Monkey software when data collection teams had access to the Internet. Data were extracted and analyzed thematically in Microsoft Excel. Each question in each data collection instrument was categorized according to the three key question areas. Responses were coded and analyzed thematically.

C. The Data Collection Team

A four-person team composed of HCI Uganda staff and consultants (see Annex 3) collected data in May 2011. The lead consultant (D.W.) trained the data collectors with an orientation on the study's background and deliverables, discussions of each tool, a review of techniques for interviewing and brainstorming on other issues that might have been overlooked in the design. The data collectors also practiced translations into local languages. To maintain consistency, the lead consultant interviewed senior national and district ministry of health officials and site managers. He also supported interviews of clinical staff as needed. A single interviewer conducted all expert patient interviews; another team member conducted client and clinical staff interviews. A third person interviewed all community members in five sites, while at the sixth site, other team members also conducted these interviews.

D. Ethical Considerations

The study protocol was reviewed by the University Research Co., LLC (URC) Institutional Review Board and approved before it was submitted to the Uganda National Council of Science and Technology for registration and approval. The council reviewed and approved the protocol and provided a clearance letter for the URC team.

All data collection was conducted confidentially and anonymously; no personal identifiers (names, identification cards) were collected during the course of the interviews. Expert patients, clients and members of the community were assured that their interview would not have any effect on treatment, medicines or services. Every effort was made to ensure that interviews were held in private.

Health workers were assured that their participation or non-participation would have no impact on their roles and would not be used to evaluate them. Health workers were not coerced or offered any incentives to participate in the study. Likewise, EP participation or non-participation did not have any effect on their future roles at the facilities. Care was taken to minimize the disruption caused to scheduled patient care or to operations at the study sites.

The interviewers obtained informed consent (Annex 4) before the start of each interview and provided opportunities for interviewees to ask questions or opt out of the interview at any time. During transcription, any personal identifiers including names were erased. The Survey Monkey database was password protected; only researchers with approval from HCI had access to it.

III. FINDINGS

A. Background Information

All sites visited provided comprehensive HIV services including HIV counseling and testing (HCT), prevention of mother-to-child transmission (PMTCT) for pregnant women and ART. Some of the facilities also offered home-based care, spiritual counseling and male involvement programs. The five hospitals offered HIV/AIDS services in designated clinics or dedicated certain days each week providing for HIV care only. At the level IV health center, HIV/AIDS services were integrated into a larger package of services offered daily.

All sites visited had used expert patients for at least one year, and averaged 18 per site. Twelve expert patients were interviewed; ten had been working in their role as an expert patient for more than three years. More than half worked in both the facility and community while slightly fewer than half worked in either the community or the facility. One site used expert patients exclusively for community services. Five of those interviewed worked daily (five days per week) and six worked two days per week. Nine of the twelve claimed to work at least seven hours during a workday. Two thirds of the expert patients interviewed were women.

B. The Expert Patient Role

When expert patients were asked what made them want to work as an expert patient, all 12 answered that they wanted to help educate others and provide support to others suffering with HIV/AIDS. "*I accepted my HIV+ status and wanted to help others cope with HIV and come out of stigma. I also wanted to help myself to prevent stress at home, wanted my children to know that being HIV+ is not the end of the world and learn how to live with HIV. I also wanted to help care takers and the community on taking care of the sick*." And another stated, "*I wanted to educate others that life must continue with HIV. I also wanted to help others to be like me. I wanted to take care of myself and also advise others to prevent risky behaviors and unplanned pregnancies.*" And still a third, "*I wanted to create an environment where clients can access treatment and improve relations between health workers and clients*."

All site managers cited two key reasons for creating EP positions: long client waiting time and staff shortages. Four emphasized the overwhelming workload of clinical staff and one noted that because they were already patients, expert patients knew how the clinic operated. One site manager commented that creating an EP program was similar to taking a peer support program "to scale."

Clinic staff members also cited heavy workloads as the main reason for creating EP positions and were asked to comment on whether certain tasks they had been doing previously had been shifted to expert patients. Eleven of the 12 clinical staff interviewed agreed to the following statement: "tasks that used to be your responsibility had been shifted to expert patients." When asked why they believed the tasks had been shifted the most common answer was to relieve overall staff workloads. A majority also cited relieving staff of certain tasks so they could focus on others and provide more timely service to clients. When asked, "In your opinion, are the expert patients useful in improving the delivery of care in this

health facility or community," all responded positively. Yet when asked if there were other tasks that expert patients could perform to decrease the burden further, only 42 percent said yes. Suggestions included, "*The EPs could be trained on more technical work like patient assessment,*" and "*…could be educated more so that they can provide teaching to other PLHA*."

Ministry officials all felt that shifting tasks to expert patients arose primarily because HIV had become a chronic disease requiring prolonged follow-up and care and the need for patients to be involved in their own care and maintenance. They said that tasks that could be delegated to expert patients included clinical assessments for referrals, disclosure, triaging, filing and registration, counseling and talks on prevention and adherence. Ministry officials viewed this as part of promoting the "meaningful involvement of PLHA." They also confirmed that since there was no policy guiding the work of expert patients, they were, by default, allowed at all levels of health care in Uganda. Each institution engaged EPs as it saw fit, and expert patients were working from at all levels of the health system. Responses from Ministry of Health officials and the WHO interviewee were similarly consistent: All six interviewees said that shifting some tasks to expert patients was necessary and a good practice. Their reasons: expert patients are highly motivated; they provide much needed support to an overstretched health service delivery system; and as they are members of the community themselves, and they work well with HIV infected clients.

According to one central Ministry of Health official, "*HIV has become a chronic disease requiring prolonged follow up and care*." He went on to explain that extending the lives of PLHA survivors has also heavily increased the workload of health care professionals. "*HIV caused high attrition of health workers themselves with no feasible program for replacement*." He continued to say, "[Expert Patients] *provide numbers, are able to reach more people, and bring life to the care as the PLHA identify with the EPs*."

Tasks expert patients perform

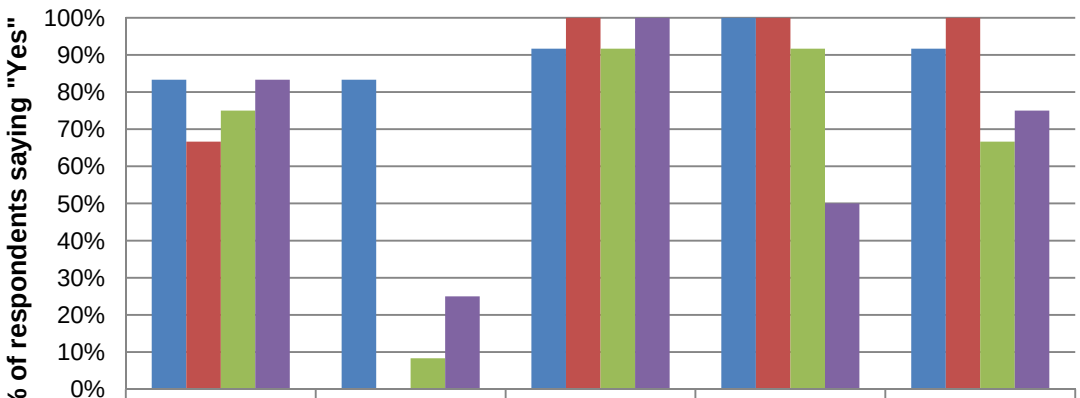
With a few key exceptions, there was broad agreement about the tasks expert patients performed at facilities. As shown in Figure 1, most community members and expert patients themselves said that EPs maintain data and files and that EP tasks include preventive health education, treatment adherence education to clients, and patient assessment (registration, anthropometric measurements, and triage of patients in queues). Most expert patients reported that they also provided laboratory assistance, although no one else reported this role. Expert patients mentioned other tasks, including scheduling visits, managing crowds, and registering clients.

EP tasks in the community include making referrals and providing counseling to other PLHA. More than half of expert patients also reported involvement in treatment adherence, bedside care and making referrals among patients at the facility. Several also reported delivering medicines in the community (see Figure 2).

As seen in Figure 2, there were some discrepancies in the other respondents' understanding of EPs' work in the community. Although there was general agreement that most were involved in referring clients and providing counseling to other PLHA, clinic staff were less aware of their work in bedside care and delivering medicines. Site managers also did not seem fully aware that EPs provided bedside care in the community but did report that some EPs were involved in tracking clients for follow up. Community members also reported that EPs provided health education.

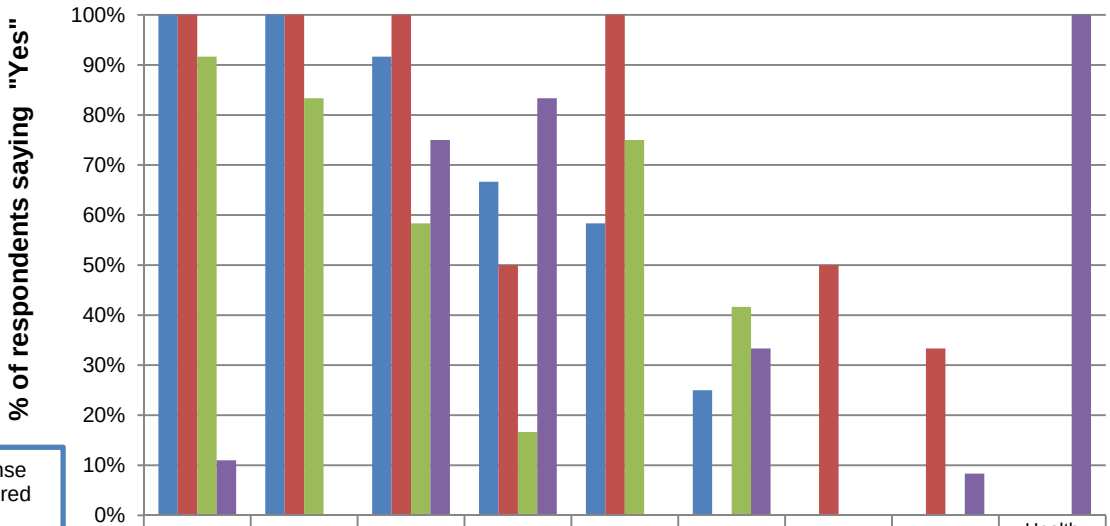
Nine expert patients interviewed claimed to work seven or more hours per day, and five of them worked a five-day week. Six others said they worked only two days per week.

Figure 1. Key Tasks Performed by Expert Patients in Facilities, by Type of Respondent



	Patient Assessment/ Triage	Laboratory Assistance	Preventive health education	Filing and data maintenance	Treatment adherence education to clients
Expert Patient (n=12)	83%	83%	92%	100%	92%
Site Manager (n=6)	67%	0%	100%	100%	100%
Clinic Staff (n=12)	75%	8%	92%	92%	67%
Community Member (n=12)	83%	25%	100%	50%	75%

Figure 2: Key Tasks Performed by Expert Patients in Communities, by Type of Respondent



* this response was not offered to all respondents

	Identify & refer patients	Counsel other PLHAs*	Treatment adherence follow-up	Bedside care	Identify & refer at facility*	Deliver supplies & medicines to clients	Trace clients lost to follow-up*	Other*	Health educ. in the community *
Expert Patient (n=12)	100%	100%	92%	67%	58%	25%	0%	0%	0%
Site Manager (n=6)	100%	100%	100%	50%	100%	0%	50%	33%	0%
Clinic Staff (n=12)	92%	83%	58%	17%	75%	42%	0%	0%	0%
Community Member (n=12)	11%	0%	75%	83%	0%	33%	0%	8%	100%

C. Organizational Support for Expert Patients

Policies and guidelines

Despite the many tasks in facilities and in communities, few formal guidelines or policies exist. However, some managers said they had developed their own guidelines with support from NGOs. Ministry officials also confirmed that there were no recruitment guidelines or training curricula. Interviewees simply stated those expert patients were engaged according to the needs and abilities of each facility.

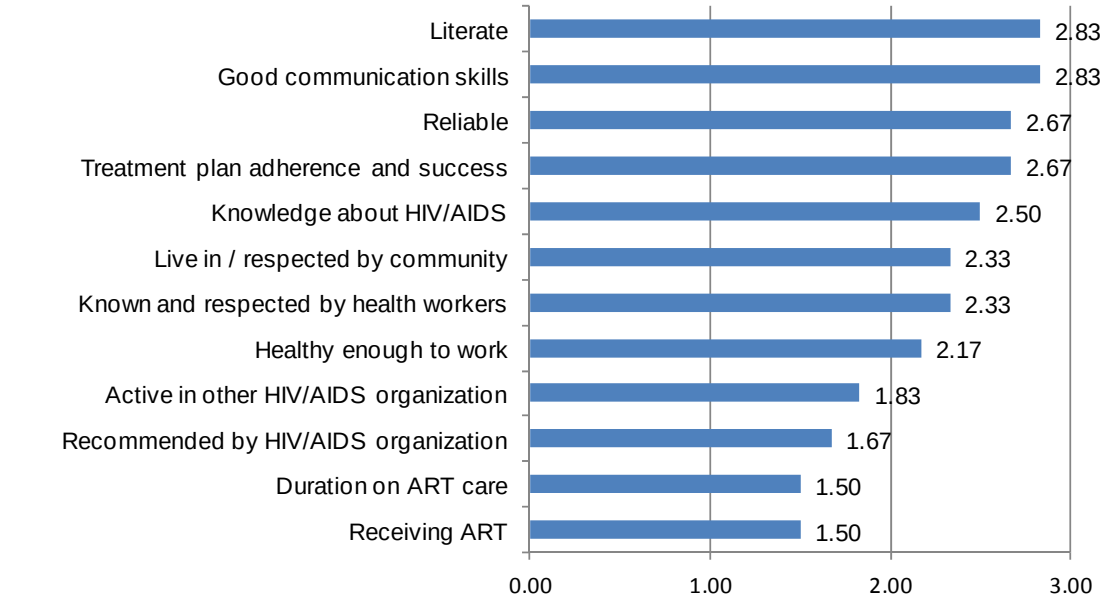
Recruitment and selection of expert patients

Expert patients were asked how they were recruited into their positions. Most responded that the facility managers, clinical staff, or the HIV/AIDS NGO supporting their site had approached them. About one third indicated that they had volunteered. In one instance, an announcement was made publicly in the community during an outreach session. Half of the sites reported involving the community in identifying expert patients, and in one instance, the local council chair helped identify a candidate.

When asked if some clients refused to accept the position, a few site managers said that some clients wanted to be paid, others did not want to disclose their status, while others declined saying they would become too sickly.

The six site managers interviewed were asked to rate 12 selection criteria when recruiting and selecting expert patients. As shown in Figure 3, literacy, communication skills, reliability, and treatment adherence were deemed the most important selection factors.

Figure 3: Importance of Factors in Selecting Expert Patients According to Site Managers



Training of expert patients

Initial training for expert patients training generally included adherence, health education, and patient confidentiality, as well as referral, community health education and community treatment follow-up. A few sites managers reported training in infection prevention and bedside care in the community. All sites agreed that no training was provided in laboratory assistance or in quality improvement.

When asked what continuing training EPs received, managers indicated that in addition to topics listed above, EPs were trained in clinic registration, triage, file maintenance, client data, patient assessment, health education, infection prevention, and safety and patient confidentiality. Other courses mentioned including family planning for HIV clients, PMTCT and the new PMTCT policy and nutrition assessment. Infection prevention and safety were taught with respect to TB and HIV co-infection, medical waste management, nutrition assessment, and ART side effects.

NGOs provided almost all initial training for EPs with a few courses offered by the Ministry of Health. Health workers trained EPs on the job, however, in topics such as, adherence, infection prevention, patient assessment, registration, and triage. The longest training courses were for home-based bedside care and health education, with almost half of expert patients reporting training of four days or more in these topics. Other topics were more likely to be addressed in shorter single sessions or through multiple short sessions conducted over time.

Expert patients were asked if they felt capable of performing their tasks following the training they received. Ten answered yes; two said no. When asked to explain their responses, they referred to skills they had not been trained in, such as pediatric counseling. As suggestions for improvement, one responded that she would like to learn how to prescribe simple medicines in the community, as "*this is something that patients ask us to do because the clinic remains closed during the weekend*." Another said that it would "*Bring expert patients together to share experiences and identify where improvement is needed*."

> *"We need refresher trainings because there is new information and also HIV care has changed, we need to be updated."*
>
> -Expert Patient

Incentives for expert patients

All expert patients reported receiving access to medicines and medical care when unwell. Most also reported receiving uniforms, transportation allowance, and meal vouchers while on duty at the facility. Some mentioned direct payment, tote bags, identification cards, bicycle maintenance and Internet access. Non-financial benefits included: recognition from facilities, clients, and communities; the satisfaction of seeing patients improve; improving their own knowledge about HIV; the opportunity to interact with health workers; and, in one case, a chance to travel to Nairobi to share experiences with representatives from other countries.

Almost all managers cited access to medicines and medical care as an incentive, and four stated that payment was provided. When asked for details, managers responded: "[NGO] *used to provide payment and* [NGO] *used to provide tea and snacks…*" and, "*Payment is only* [provided] *for four at the health facility. The majority is not paid*." One manager cited per diem for work in communities: "*The EPs are treated the same as the health workers if they are out doing home visits. They get the same per diems*."

When expert patients were asked to select a single most important incentive, four answered that transportation allowance was most important and four others, direct payment. Three expert patients chose access to medical care.

> "*Yes I receive support from my supervisor. The supervisor checks my work daily and when a problem is identified, my supervisor calls me to discuss the problem and also give feedback when improvement is seen. For example one time a patient lost his number and I told him to look for the file number before coming to me. The patient went away without a number. I was then called by my supervisor and asked me not to send patients without their numbers.*"
>
> -Expert Patient

Supervision of expert patients

All expert patients reported meeting with their supervisors at least monthly. A third met with them daily or weekly. EPs were not, however, asked specifically who were their supervisors.

According to site managers, either they or other facility staff supervised expert patients in facilities. In

communities, PLHA group leaders and adherence officers also supervised expert patients at work.

Expert patients received performance feedback from clinic staff, during discussions at monthly EP meetings and from the EP group chairperson. Some facilities had special days for continuing training and used that opportunity for coaching.

Although only two of the managers indicated that performance targets were set for EPs, EPs reported several ways they received feedback on their work performance and quality. Almost all said that they agreed on targets for tasks with their supervisors and that they received feedback at regular team meetings. Half claimed to receive feedback on the spot from their supervisor, and five expert patients described one-on-one pre-planned meetings with their supervisors. Many examples of feedback and coaching were given: "*Yes, when a gap is identified, for example while in the community, I call my supervisor to explain the problem, he invites me to discuss the issue to identify a solution*"; and, "*Yes, I discuss with my supervisor and when the target is not achieved we identify ways to improve*."

Most sites nevertheless reported that there was no system in place to monitor EP performance. Those that did reported periodic monitoring with checklists, group discussions, and monthly or quarterly reports.

Engagement of expert patients

Expert patients in this study reported a high level of engagement with their work. All expert patients surveyed agreed that their work was both important and understood by the community to be important. They reported getting support and recognition from the community and having adequate opportunities for professional development, though a small minority disagreed. In addition, only two in 12 disagreed with the following statement: "Suggestions made by EPs on how to improve the work are usually accepted," and three disagreed with "I have the freedom to make changes in the way I do my work" and, "I participate in decisions about how services are provided within our facility/community." The greatest disagreement came with the statement: "I can openly disagree with the leadership if I don't agree with him or her."

The concern most commonly expressed by EPs was in response to the statement, "I have the tools I need to do my job well." One third of the respondents disagreed, indicating they felt resource constraints in doing their jobs. Additionally, three reported they were sometimes afraid to ask for help when they had questions about responsibilities. Two reported they were not always confident about their capacity to resolve difficulties, and one felt that he or she did not have the knowledge and skills to meet expectations.

D. Perspectives Regarding the Expert Patient Role

Expert patient perspective

> "*Helping others to live healthier lives.*"
>
> -Expert Patient

Expert patients were asked, "What do you find satisfying in your role as an expert patient?" Two thirds of responses focused on the satisfaction they got by supporting other clients to be healthy by getting them tested for HIV or getting them treatment and helping them adhere to it. In addition to seeing their clients do well, collaboration and teamwork with health professionals and clients were key components in EP job satisfaction. Answers showed an emphasis on enjoying teamwork and creating closer linkages between health workers and clients. One expert patient stated, "[It is satisfying] *working well with health workers and when they respect and talk to us properly. I am also known by health workers and this makes me happy*." And another, "*I used to be an ordinary client but now I am recognized as an EP. Good relations with health workers also make me happy*."

Expert patients recognized their role in reducing the workload of health workers and improving service efficiency and effectiveness. More than half made comments such as: "*My work helps reduce the workload*

of health workers. For example, returning files to the storage boxes ease their work. This cannot be done by the health workers who at the same time are expected to attend to us,"; "*During health education sessions with clients, I encourage clients to keep clinic appointments. This helps reduce defaulters and prevents crowding the clinic on other clinic days when defaulters return*,"; and "*Recording client information helps the monitoring and evaluation department. More clients are seen every day, and those who used to fear have started treatment. More clients are seen and health workers are no longer rude. Waiting time has been reduced*."

When asked the opposite question, "What do you find least satisfying in your role as an expert patient?" half of the EPs reported feeling dissatisfied when clients did not follow their recommendations for protecting their health. One expert patient said, "*When patients stop treatment and report back very sick, this shows that I did not do my job very well*." In contrast to responses to reasons for satisfaction, one third of expert patients surveyed mentioned problems with transport allowances or payments to enable them to attend to their responsibilities. Other reasons for dissatisfaction mentioned by some EPs included problems at the clinic such as stock outs, lack of teamwork, and being treated differently by clients than health workers.

Nearly all EPs reported that health workers appreciate their work and treat them well by listening to their suggestions, actively learning from them, and taking care of them when they felt sick. Only three examples of negative treatment from health workers were cited. Two referred to instances where health workers would preferentially wish to provide the service so that they could get informal payment from clients: "*Sometimes when health workers are going for follow up they do not want expert clients to be involved because there is money in the activity*." And a second mentioned that health workers "*reduce our salary*." EPs also feel clients generally treat them well and emphasize the importance of sharing: "*Clients take me as an example, they comfort me, we share ideas and we are socially together*"; "*Sharing their problems with me*"; and "*Share knowledge, ask questions, friendly to us*." EPs are also discouraged when clients fail to follow their advice: Most categorized "clients failing to follow advice" as negative treatment. Despite this overall positive assessment, half also reported abusive language from clients.

Expert patients were also asked how communities treated them. Again, all 12 felt their community treated them well, "*I am the president in my community, my children give me respect and do want to see people talking about me, and the community recognizes and respects me.*" Some negative examples also surfaced, "*The community thinks that we lie about our HIV status in order to receive money and other benefits. They say HIV has made me proud, I am lying about my HIV status in order to receive free things, and they want to see me suffering*."

When expert patients were asked about the difficulties they encountered at work, more than half cited their clients' failure to adhere to treatment or other advice was a major difficulty, while half mentioned the lack of payment.

> "*We receive no payment for our work, thus we cannot afford basic needs like soap*."
>
> -Expert Patient

This question was followed by another open-ended question: "What do you do when you encounter problems or barriers?" Almost half responded that they had no solutions or recourse in dealing with the difficulties they faced, particularly in relation to salaries and transportation allowances. One expert patient stated, "*Salaries are low, this makes me hate the job and think of doing business. I do not want to do this because I want to help others.*" Another stated, "*Work is too much and we travel long distances to come to work. [Our] payment is not enough to look after our children. [Patients] not following instructions.*"

Finally, answers to the open-ended question "What would help you do a better job as an expert patient?" also reflected their interest in remuneration for their work and in doing their work well as 10 of the 12 mentioned either salary or allowances while seven mentioned additional training, despite broad agreement to an earlier question about capability to do their jobs well.

Site manager perspective

Site managers were generally positive about EP performance and supported the use and sometimes the expansion of the EP role, citing reduced workloads, better peer support, and strengthened facility-community linkages. They pointed out, "*Clients prefer the expert patients to the staff,*" and that expert patients are effective at peer education and support: "*Clients felt that staff that are not PLHA do not understand their views, particularly on adherence*." A third reported that clients "*want to emulate what the EPs are doing and want to come out of stigma like the EPs*."

Five sites also reported that expert patients sometimes 'go overboard' or are 'too enthusiastic' about their responsibilities. Other problems mentioned included expert patients demanding more compensation for their work, EPs breaching patient confidentiality, and instances of interpersonal issues among EPs and other clients. Three site managers also reported that clients may not fully trust the quality of care and information provided by the EPs, although none reported clients avoiding the facility because of the EPs or insisting on seeing a professional staff member instead of an EP. The site managers all said that problems with the EPs were resolved through a combination of individual and group discussions, counseling and meetings.

When asked how to improve the performance of the EP, all six site managers suggested additional training. Several also mentioned payment for EPs and improved monitoring of their performance.

Client perspective

The large majority of clients interviewed felt that services had improved with the use of expert patients. Three-fourths of the clients reported trusting expert patients and feeling very comfortable confiding in them. There were some concerns about how EPs spoke with patients, including one who reported, "*They despise and shout at patients*." Another commented, "*They need more basic training to improve the way they handle patients*." On the whole, however, the feedback from clients was positive about their experiences with EPs.

> "*EPs are also like us, they have the disease. They are easy for me to interact with, and they talk the truth.*"
>
> -Client

Clinical staff perspective

All clinical staff surveyed reported that expert patients were useful in improving delivery of care with almost all selecting "very helpful" when describing the contributions of expert patients. Further, when asked to rate their level of satisfaction with EP performance of 11 specific tasks in both the facility and in the community, none of them reported being "not at all" satisfied with any aspect of the expert patients' work, and the majority were "very satisfied" with how the EPs carried out their tasks. Especially positive were ratings regarding expert patients' performance in treatment adherence follow-up in the community, delivering supplies and medicines to clients, identifying and referring from the community, and preventive health education, all of which rated a "very helpful" rating from almost all of the clinical staff interviewed. When asked how to strengthen EP performance, suggestions included additional training and strengthened supervision. Several commented that good performance depended upon close supervision, having working guides or protocols to follow, and being accompanied by health workers while conducting visits.

> "*EPs could be educated more so that they can better provide teachings to other PLHAs.*"
>
> -Clinical Staff

Community member perspective

Almost all of the community members interviewed indicated that expert patients were highly trusted by the community and that the community was very satisfied with

> "*They have told us the truth about HIV. They are trusted.*"
>
> -Community Member

the work they do: Expert patients maintained confidentiality, and people felt comfortable talking with them and learning from them. All community members felt expert patients were very useful in improving service delivery through counseling, their ability to link community members to health workers, and the support they provided for people living with stigma. Three-fourths of the respondents also mentioned that expert patients were "very competent" in carrying out their assigned tasks; however, only four of the 12 community members thought the expert patients were well trained, and most thought that they needed additional skills as well as updates and refresher courses on their existing skills.

> "*The community does not discriminate [against] me. The local leaders say that I make their work easier when I educate people about HIV/AIDS. However, sometimes the community laughs at me saying that 'I am infected' but because I am an expert patient, I do not mind it anymore.*"
>
> -Expert Patient

Regarding stigma

EPs were asked if clients, health workers or community members treated them differently because of their HIV status. The question was intended to explore the EP's perspectives of others with whom they interact, and highlight any issues specifically related to their HIV status. One quarter of EPs say that both health workers and community members treat them differently.

One expert patient volunteered, "*They used to discriminate [against] us. HIV was seen as the worst disease, which has ever come on earth, they used to talk bad about us and not to eat together with us. When I fell sick, people thought I was going to die and wanted to grab my land; they thought I was going to die, moreover they were not my relatives*."

But other examples of different treatment were very positive: "*Health workers take me as an important person. They appreciate me and when I am tired or sick, they ask me to rest.*" And, "*Clients want to associate with me because I understand their situation*."

EPs were also asked, "To your knowledge, has anybody expressed feelings of fear of touching you / things that you touch?" Five answered positively. However, responses suggest that stigma has lessened: "*In my community people used to point at me during weddings or funerals. I used to sit alone and people feared touching me and when I used a cup they would throw it away. Because of this I used to shun gatherings. Now, such things are not happening*." And another example, "*One time I feel sick and my sister separated my items. I did not take this important because I had been told at hospital that such things happen. When she learnt that she could not catch HIV from sharing, this stopped*." Another EP said, "*It used to happen those days but not anymore*."

IV. DISCUSSION

It is clear from this study that shifting tasks to expert patients in both facilities and communities is considered by all key stakeholders to be successful. However, organizational support for expert patients was not systematic but driven by the needs and resources of each site. There is variation in the role of the expert patient – some perform functions in facilities, others in communities, and most in both – and there is some confusion regarding what their role actually is. EPs believe they play a role in laboratory services, but no one else mentions it; EPs go beyond what they are asked to do and are criticized; and communities ask for services that are not part of their role and for which they have not been trained. EP recruitment varied by site, by need, and by NGO support.

Training, like recruitment, was provided by whatever means available, with NGOs playing the largest role in initial training, and on-site health workers providing a majority of the continuing training. Although EPs agreed they felt capable of performing the tasks they'd been assigned, they felt they could do better with training to learn new skills and to update those they had. Clients, community members,

clinical staff and ministry officials also felt that EPs needed more training, suggesting that with additional training, EPs could perform more complex tasks thus further reduce the workforce burden.

The work and their mission motivated expert patients; they took it personally if patients did not follow their guidance. Relationships they developed with facility staff and communities by using their intimate knowledge of the disease to help others were important. Their engagement was high in all areas, despite feeling resource constraints and the inability to solve some problems on their own. They also want to be paid, either directly or with a transportation allowance, and several voiced frustration that they could not do their jobs if they could not reach communities.

Despite the lack of payment, facility staff, clients, and communities supported expert patients with supervision, coaching, and recognition. Supervision was not systematic and, like recruitment and training, depended upon who is available to supervise. Nevertheless, and perhaps because all parties benefited if EPs were successful, they received more attention and guidance than many professional health workers receive. Still, there was broad support that with more and more consistent training and supervision, they could offer a broader range of tasks, and perform better than professional health workers, who cannot know the disease as intimately.

Interestingly, most expert patients and many clients reported that the HIV stigma was lessening. It is unclear if this is partly due to the involvement of expert patients or if it is due to other causes. Nevertheless, one clear message from clients was that expert patients were helpful to them with their example of positive living.

A. Program Sustainability

Some site managers and Ministry officials voiced concern about how that would affect the sustainability of the EP program. The HIV/AIDS clinics at the sites were initiated with significant support from several international and NGO partners, including Baylor and Makerere Universities, PSI, PACE, MSF-France, Alliance Uganda, and NuLife Uganda. This support was clearly visible in the delivery of training, the development of some guidelines, and in the payments and per diems mentioned at some sites. These partners are currently scaling back their support as part of the handover to Ugandan institutions.

B. Study Limitations

This study did not attempt to evaluate the performance of expert patients conducting their tasks, and therefore cannot comment on the quality of services provided by expert patients.

Due to the small sample size of each type of respondent, findings should not be generalized to facilities or expert patients beyond the study area. Respondents were identified based on their positions and experience with expert patients. Clinic staff were selected in advance by site managers from among staff that had been working at the site for over three months. Community members were also identified in advance by site managers and asked to meet the interviewers at the facility. All other site level respondents were selected based on availability and convenience, so it is possible that bias was introduced through this selection process.

Interviews were not audio-recorded, but recorded and transcribed by hand after the interviews. Survey Monkey was used to enter responses and data were then exported into Excel where they were analyzed using three pre-determined themes. This could have biased the reading of the data to those pre-determined themes and left other thematic areas uncovered.

V. CONCLUSIONS AND RECOMMENDATIONS

The results of this study show that the use of PLHA as expert patients in both facility and community services has been successful for these sites. From communities to Ministry of Health officials, there is enthusiasm about expert patients' ability to reduce workload on health facility staff, communicate with clients suffering as they do, and build stronger bridges to communities. Facility staff, clients, communities, and the expert patients themselves were seen to all benefit: clients waited less and had a friendly ear, health workers were able to hand off some responsibilities, and expert patients strengthened relationships with coworkers and communities.

The success of shifting tasks to HIV-positive patients in these sites was clear to all parties. Although the quality of their clinical tasks was not evaluated, expert patients helped to alleviate long waits for clients and overloaded health workers. They also offered skills and special experience that helped make them successful as patient counselors and community spokespersons. Site managers, NGOs, communities, and clinical staff all played some role in the success of expert patients, and this broad based engagement could be part of its success. Still, there was an absence of policies, standardized curricula, and operational guidelines for the use of PLHA to deliver services in facilities and communities. As the use of EPs increases and spreads, it is important that measures are taken to support consistency and ensure quality standards.

It is also important that decision makers consider the sustainability of such a program before it is adopted on a larger scale. As current international and NGO partners pull back from supporting these sites, Expert Patients, facility managers, health workers, and community members are wondering what the impact will be on improved processes and services. Programs such as this, if not sustained over time, can bring disappointment and a lack of credibility to health services attempting to reach clients.

The study investigators recommend that Uganda:

Develop a national policy framework that clearly defines the EP role and tasks in the facility and community as well as the enabling environment required for the success of such a program.

This framework should include policies and clear guidance on the organizational support that a new cadre of worker requires, including:

1. **Clearly defined EP role** describing tasks expert patients should and could perform, which should include details such as who will perform what tasks and where, the number of hours or days per week, and who supervises the expert patients. In addition, other policies and guidelines should be based on the definition of the EP role, especially in recruitment, training, and the design of a balanced incentive structure.
2. **Define recruitment** criteria and guidance about the recruitment process, such as how to engage the community from the beginning.
3. **Standardize training** that is based on a clearly defined EP role and which is harmonized between government programs and private organizations, and across sites within certain programs. At the time of data collection, the Integrated Management of Adolescent and Adult Illnesses Program was trying to harmonize the EP training implemented by various NGOs.
4. **Create guidelines for supervision and monitoring** that leverage and build on the enthusiasm seen at these study sites to ensure that EPs are performing to standard and to enable expert patients to take on more complex tasks with confidence.
5. **Develop a balanced incentives** approach to include financial and non-financial rewards. Although EPs are clearly motivated by a desire to help others that suffer with their disease, they also made it clear that they wanted financial incentives, either in the form of direct payment or as transportation funds. Free access to medical care and medicines was recognized as a benefit, but a

balanced incentive approach that includes financial and non-financial incentives would ensure sustainability.

Involve a broad range of stakeholders in this process, including expert patients and communities.

Begin with an analysis of current gaps in service provision, the extent that task shifting is already taking place, and the existing human resources and quality assurance mechanisms, in keeping with WHO's task-shifting recommendations.

Pilot this process first and provide resources be made available to sustain the process once it is implemented fully.

A. Additional Areas for Research

As countries like Uganda struggle with a scarcity of human resources and look for affordable solutions, one of the biggest challenges will be to ensure that frameworks for scaling up EP programs do not undermine the needs-based approach that facilities in this study were using. Additional research should be done to look at different methods sites can use to support the use of EPs that are both flexible and encourage full-site participation. Although this study shows that EPs can be very useful, it did not look at the quality of the clinical tasks EPs completed, and therefore, additional research should be done in this area before broad implementation of EP programs. Additional research should also be conducted to determine the cost effectiveness of shifting tasks to PLHA and incorporating them into service provision teams.

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VII. ANNEXES

Annex 1: Summary of Literature on Task-shifting to PLHA

Study	Setting	Role of PLHA in task shifting	Patient status	Findings	Remarks
Reach Out Mbuya HIV AIDS Initiative http://www.reachoutmbuya.org/communitysupport.html (accessed 19 April 2010)	Kampala, Uganda	Reach-Out volunteers –Visit clients in their homes. Notify doctors in emergencies, suggest clients for program, and generally create a support system.	Majority clients, but also include some non-client volunteers.	The findings suggest that PLHA working alongside health workers and nurses can provide excellent AIDS care. Survival, ART response and adherence were excellent.	Volunteers not limited to PLHA, Unable to attribute the effects on workloads or outcomes to the work of PLHA
Expanding the Role of Networks of People Living with HIV/AIDS in Uganda Project, International HIV/AIDS Alliance in Uganda International HIV/AIDS Alliance in Uganda. 2007 Annual Report accessed at: http://www.aidsalliance.org/includes/Publication/Uganda_Annual_Report_2007.pdf	14 districts of Uganda	Network support agents Integrated into the formal health care delivery system and participating in delivery of general HIV education and awareness, HCT, ART and PMTCT.	Individuals openly living with HIV seconded by PLHA groups	Viewed by health workers as an important resource in reducing HIV/AIDS stigma and discrimination, increased uptake of services in health facilities as a result of network support agents' participation	Findings largely reliant on individual cases
Peer health workers and AIDS care in Rakai, Uganda: a mixed methods process evaluation of a cluster-randomized trial. Arem H, Nakyanjo N, Kagaayi J, Mulamba J, Laks R, Nakigozi G, Serwadda D, Quinn T, Gray R, Bollinger R, Reynolds S, Chang L. 5th IAS Conference on HIV Pathogenesis, Treatment and Prevention, Cape Town, 2009. Abstract CDD100.	Rakai, Uganda	Peer Health Worker cadre address adherence and clinical problems	Composed of PLHA taking ART and demonstrate good ART adherence for at least 6 months	Improved organization in the clinic, greater access to medical support, and increased confidentiality. Demonstrated success in building rapport with patients. Clinic staff strongly agreed that the PLHWA improved the care of patients, and 86% strongly agreed or agreed that the PLHWA had made their own jobs easier.	Strong research, methodology, No clear mention of what the peer workers do, Does not address task-shifting in objective manner, Limited to a localized setting of 50 villages
Adherence Support Workers: A Way to Address Human Resource Constraints	Five selected ART sites in Zambia	Adherence support workers mostly (PLHA), often on		Marked shift of workload from health care workers to adherence	Adherence support workers not limited to

in Antiretroviral Treatment Programs in the Public Health Setting in Zambia. Torpey KE, Kabaso ME, Mutale LN, Kamanga MK, Mwango AJ, Simpungwe J, Suzuki C, Mukadi YD. *PLoS ONE* 2008, 3(5): e2204.		ART. Provide adherence counseling and expected to participate in consultations and meetings as part of the ART Team. Conduct community visits to track down patients and provide support to improve adherence.		support workers. Quality of adherence counseling by adherence support workers comparable to health care workers. Reduced waiting times for adherence counseling. Loss to follow-up rates of new clients declined from 15% to 0%.	PLHA. Small clinic based settings, No indication of how task shifting occurred
Use of task-shifting to rapidly scale-up HIV treatment services: experiences from Lusaka, Zambia. Morris MB, Tambatamba C, Chi BH, Mwango A, Chi HF, et al. *BMC Health Serv Res.* 2009;9:1–9.	Lusaka, Zambia	Peer educators - Main role in adherence counseling and health education for patients. Perform administrative and basic clinical duties.	HIV status - not a requirement, but nearly all candidates are HIV-infected patients who may or may not be on ART	Description of the policies and procedures in task-shifting	No data on health care processes or clinical endpoints, Wide scale implementation, Use of PLHA part of larger process of task shifting

Annex 2: Data Collection Tools

2.1 Site Manager Interview

Interviewer name: _____

Date of Interview: _____

PURPOSE OF STUDY

Thank you for taking the time to speak with me today.

The purpose of our discussion today is to understand the processes for task shifting to expert patients, including what has worked and where opportunities for improvement exist.

Definition of expert patients (EPs): *Expert patients are people living with HIV who have received some form of training to perform HIV service delivery tasks,* ***but are not certified or categorized formally within the recognized health system****. The purpose of this survey is to understand how EPs support HIV/ AIDS services in this facility and/or community.*

Our findings will help inform how best to implement human resource policies and processes that support the effective and consistent inclusion of EPs into facilities providing HIV/AIDS services.

Specifically, our objectives are the following:

- *To describe task shifting to EPs and the extent of their integration into the health system.*
- *To examine existing policies pertaining to EPs and their recruitment, training, supervision and support in the health system and the community.*
- *To explore the perceptions of the role of EPs among various stakeholders (including health workers, communities and EPs themselves) and existing relations among stakeholders in the context of the EP role.*

Here are a few details about this interview before we begin.

- *We do not record names of individuals or sites. All data will be coded and your participation is anonymous.*
- *There are no right or wrong answers. We want to learn about your EP program and your insights about it, positive or negative.*
- *I do not have a vested interest in anything that is said during this interview. I work for Initiatives Inc., an independent contractor.*
- *This interview will last approximately 60 minutes.*

Do you have any questions, before we start?

Do I have your permission to start? _____ (Note the response and time and sign)

I first would like to learn some background information about your facility:

1. I'd like to confirm that this site is: (circle as applicable):

   a. Government health center 1
   b. Government hosp 2
   c. NGO 3

2. What is the HIV service type* (circle as applicable):

   a. vertical 1
   b. integrated 2

3. What is the staff type at this facility (circle as applicable):

   a. all dedicated 1
   b. all integrated 2
   c. mixed (some dedicated some integrated) 3

4. What kinds of HIV/AIDS services does this facility provide?

	(Circle Yes (1) or No (0) as appropriate)	
	Yes	No
a. ART monitoring	1	0
b. Opportunistic infections	1	0
c. STI	1	0
d. Drug disbursement	1	0
e. Adherence management	1	0
f. ART counseling	1	0
g. Psychosocial counseling	1	0
h. Other 1	1	0
i. Other 2	1	0

5. How many EPs are engaged at this site? (If EPs work at different sites, list where they work most of the time).

Category	**Number**
a. How many are community-based only	
b. How many are facility-/clinic- based only	
c. How many work in both facility and community	
d. Other	
e. Other	
Total	

* Definitions: 1) Service Type – Vertical sites are sites that provide only HIV/AIDS services (VCT, PMTCT, and/or ART); Integrated sites are sites that provide HIV/AIDS services as part of a larger package of health care. 2) Staff Type at Site: dedicated refers to sites in which the staff who provide HIV/AIDS services provide no other health services (only HIV/AIDS services); integrated refers sites in which the staff that provide HIV/AIDS services provide other health services as well, and mixed refers to sites in which some staff may be dedicated to HIV/AIDS services while others provide both HIV/AIDS and other services.

6. How long have expert patient(s) supported work in this facility? (check one only)
   - ☐ less than one month
   - ☐ 1–3 months
   - ☐ 3 months to 1 year
   - ☐ 1–2 years
   - ☐ more than 2 years

7. Did any of the following factors influence the decision to add EPs at your facility?

FACTORS	YES	NO
a. Facility meeting where we noticed a need	☐	☐
b. Existing service bottlenecks	☐	☐
c. Staff shortages	☐	☐
d. Patient assessments not always done	☐	☐
e. High number of clients defaulting on ART	☐	☐

7.1 What other factors influenced the decision to add EPs at your facility?

ROLE DEFINITION:

8. Do you have written policies regarding the **role** of EPs?
   a. yes
   b. no
   c. do not know

   8.1 If yes, can I see a copy to review?

      a. copy present
      b. copy not present

9. What are the key tasks of the EPs?

TASK	Yes	No
Patient Assessment		
a. Laboratory assistance		
b. Preventive health education		
c. Filing and data maintenance		
d. Treatment adherence education to clients		
Community and Home Outreach		
e. Delivering supplies and medicines to clients		
f. Bedside care		
g. Treatment adherence follow up		
h. identifying and referring at facility		
i. identifying and referring from the community		
j. counseling of other PLHA		
Others Specified Below		
k.		
l.		
m.		
n.		

10. Are there other tasks you think the EPs could be doing that would benefit the facility?
    a. yes
    b. no
    a. If yes, what are they?
11. How are roles and responsibilities of EPs communicated to them? (check all that apply)
        a. at the training sessions
        b. by their supervisors at the sites where they are assigned
        c. in the community where they are recruited
        d. during orientation sessions
        e. other, specify.....

RECRUITMENT

12. How important are the following factors in deciding whom to recruit as EPs? (score as: very, a little, not at all)

	Factors	Very much	A little	Not at all
a.	Knowledge about HIV/AIDS			
b.	Receiving ART			
c.	Treatment plan adherence and success			
d.	Good communication skills			
e.	Known and respected by health workers			
f.	Healthy enough to work			
g.	Reliable			
h.	Active in other HIV/AIDS organization			
i.	Recommended by HIV/AIDS organization			
j.	Live in/respected by community			
k.	Literate			
l.	Other, specify factors considered			

13. Is the community involved in the recruitment of EPs? (Check one only).
    ☐ yes
    ☐ no (jump to Question 15)
    ☐ do not know
14. Give examples of how the members of the community where the facility is situated are involved in the recruitment of EPs. (check all that apply)
    a. Ministry of health officials announce the positions in the community
       If so, how?
    b. The health facility officials announce the position in the community
       If so, how?
    c. Community vets and forwards the names of shortlisted EPs to the facility manager
    d. Community members sit on the interview panel for EPs
    e. Your facility consults community only after they have nominated the EPs
    f. Other, specify
       …….....…….

15. Are [other] HIV/AIDs NGOs involved in recruiting EPs? (check one only)
    - ☐ yes
    - ☐ no (jump to Question 17)
    - ☐ do not know
16. Give examples of how HIV/AIDs NGOs are involved in the recruitment of EPs.(check all that apply)
    - ☐ Announcements of the opportunity done by NGOs
    - ☐ Agencies identify EP candidates from the clients in the facilities they support
    - ☐ Shortlisting of EP candidates done by the NGOs
    - ☐ NGOs participate on EP interview panels
    - ☐ Ministry of health and clinics inform NGOs of EPs identified
    - ☐ NGOs not involved in recruitment at all (if applicable, check this one only)
    - ☐ Other, specify ……
17. Who asks the client to take on the EP role? (Circle all that apply)
    - ☐ site manager
    - ☐ health worker
    - ☐ member of the community
    - ☐ other, describe.....
18. How do you use task or role descriptions in selection? (check all that apply)
    - ☐ Read out to the prospective applicant so they decide
    - ☐ Used when seeking opinion of referees
    - ☐ Not used at all
19. Have any patients refused to take on the role of EP? (Circle that applies)
    - ☐ yes
    - ☐ no
    - ☐ don't know
20. What issues would make a client refuse to take up an EP role?
    a. Travel too difficult
    b. Had other work
    c. Caring for children or family
    d. Needed to earn money
    e. Don't know
    f. Other, specify

    ……
21. How the EP learned about the goals and values of the facility

    21.1 What is done to involve the EP in the facility's goals and values? (check all that apply)

    - ☐ EPs invited to attend goal and value development meetings
    - ☐ Publications of the facility goals and values issued to EPs on recruitment
    - ☐ Goals and values of facility discussed with EPs as part of the orientation process
    - ☐ EPs not formally informed of the goals and values of the facility
    - ☐ Other, specify .....……

21.2 How are EPs involved in celebrations of facility accomplishments (i.e. milestones or progress achievements?)

- ☐ EPs attend regular progress review meetings
- ☐ EPs usually oriented on how to communicate achievements to the community
- ☐ EPs not involved at all in progress review discussions
- ☐ Other, specify.....

TRAINING

22. Do EPs receive training before starting work?
    a. yes
    b. no (jump to Question 15)
    c. don't know

23. What training do the EPs receive **before** starting their work?

	Kind of Training	**YES, Training Conducted**	**No, Training Not Conducted**	**Don't know whether training was conducted**
a.	Registration	☐	☐	☐
b.	Triage	☐	☐	☐
c.	Patient Assessment	☐	☐	☐
d.	Laboratory assistance	☐	☐	☐
e.	Health education	☐	☐	☐
f.	Filing and data maintenance	☐	☐	☐
g.	Adherence	☐	☐	☐
	Community outreach	☐	☐	☐
h.	Delivery of supplies or medicines	☐	☐	☐
i.	Bedside care	☐	☐	☐
j.	Treatment follow-up	☐	☐	☐
k.	Identify and refer[†]	☐	☐	☐
l.	Health Education	☐	☐	☐
m.	Quality	☐	☐	☐
n.	Safety	☐	☐	☐
o.	Patient confidentiality	☐	☐	☐
p.	Other	☐	☐	☐

24. If training was provided, who developed and supplied the materials to train the EPs?
    (Probe whether there is a curriculum; who developed the curriculum; how were the ministry of health and partners involved in its design?)

[†] Children without caregivers, pregnant women

25. What training opportunities do EPs receive **on the job** after starting work?

	Kind of Training	**YES, Training Conducted**	**No, Training Not Conducted**	**Don't know whether training was conducted**
a.	Registration	☐	☐	☐
b.	Triage	☐	☐	☐
c.	Patient assessment	☐	☐	☐
d.	Laboratory assistance	☐	☐	☐
e.	Health education	☐	☐	☐
f.	Filing and data maintenance	☐	☐	☐
g.	Adherence	☐	☐	☐
	Community outreach	☐	☐	☐
h.	Delivery of supplies or medicines	☐	☐	☐
i.	Bedside care	☐	☐	☐
j.	Treatment follow-up	☐	☐	☐
k.	Identify and refer[‡]	☐	☐	☐
l.	Health Education	☐	☐	☐
m.	Quality	☐	☐	☐
n.	Safety	☐	☐	☐
o.	Patient confidentiality	☐	☐	☐
p.	Other	☐	☐	☐

26. Are you satisfied with the training of the EP(s)?
    i. yes
    ii. no
    iii. satisfied with some of the training but not all
    iv. no opinion
    v. other, specify.....

27. What suggestions would you give to improve training?

SUPERVISION OF EXPERT PATIENTS

28. Who is responsible for supervising the EP's work? (check one only)
    a. the nurses at the facility
    b. the clinical officer at the facility
    c. the health facility/site manager
    d. NGO officials
    e. do not know
    f. other, specify ……

[‡] Children without caregivers, pregnant women

29. How are EPs' questions about the work they do answered by their supervisors? (check all that apply)
    a. answered on the spot by the supervisor
    b. answered by the head of the facility
    c. written answers circulated to the EPs
    d. do not know
    e. other, specify.....
30. Briefly describe some of the problems the EPs have experienced during their work.
31. How is the EP supported when problems occur?(check all that apply)
    a. The clinic manager supports the EP.
    b. The NGO sponsoring the activities provides support.
    c. The communities around the clinic provide support.
    d. Other, specify.....
32. How does the EP receive coaching and feedback? (circle all that apply)
    a. facility team meetings
    b. supervisor
    c. one-on-one meetings
    d. quality improvement team meetings
    e. other, specify……..……..……
33. How often does coaching or feedback occur?
    a. weekly
    b. once a month
    c. every quarter
    d. half yearly
    e. rarely
    f. other, specify……

PERFORMANCE EVALUATION

34. How is the EP's work evaluated?
    (Probe: Please describe the process if one exists. Indicate if any criteria are used.)
35. Does the EP have performance targets?
    ☐ yes
    ☐ no (jump to Question 37)
    ☐ do not know

36. If they have targets, can you please describe what those targets are?

37. How are the targets monitored and reported?
    a. weekly
    b. monthly
    c. quarterly
    d. semi-annually
    e. other, specify…….

REWARDS AND RECOGNITION

38. Is there any incentive for achieving or overachieving targets
    - ☐ yes
    - ☐ no (jump to Question 40)
    - ☐ do not know
39. What incentives are EPs given to do their work? (circle all that apply)
    a. payment
    b. uniforms
    c. tote bag
    d. access to medicines and medical care
    e. meals or meal vouchers
    f. transportation allowance
    g. community recognition
    h. facility recognition
    i. other, specify……..…….
40. Are Expert Patients included on quality improvement teams?
    a. yes
    b. no (jump to Question 42)
    c. do not know
41. If yes, what is the process?
    (Probes: what quality improvement training do EPs receive? What kind of feedback do EPs receive?)
42. How do community-based EPs refer clients to the facility or to other appropriate facilities?
43. What kind of data are collected by the EP?
    (Probe: How is this information collected? Once information is collected, what is done with it? How is information incorporated into facility reports?)
44. What kinds of supplies do EPs typically need to conduct their tasks?
45. How do EPs secure supplies or materials used in their tasks? (circle all that apply).
    a. EPs have been trained in the supply management chain and can order from the health facility.
    b. The health facility manager decides what to give the EPs.
    c. A community member confirms supply needs before an EPs can requisition them.
    d. other, specify…….

PERCEPTIONS

46. Feelings about having EPs at the facility
    46.1 In your opinion, what are the main advantages of having EPs in the facility?
    46.2 What are the main disadvantages or challenges of having EPs in the facility?
47. What are some of the positive responses from clients about the EPs?
    a. Clients feel the EPs are very helpful.
    b. Clients verbally appreciate the work of EPs.
    c. Clients feel the waiting time in facilities has been reduced.
    d. other, specify.....
48. What are some of the negative responses from clients about EP? (circle all that apply)
    a. Clients insist on being seen by qualified staff.
    b. Clients avoid or stop coming to the clinic.
    c. Clients change facilities to avoid EPs.

d. other, specify…….

49. What are some of the positive responses from health workers about the EPs?
    a. Health workers are very supportive and encourage EPs.
    b. Health workers verbally appreciate the EPs' work.
    c. Health workers now have enough time for other activities.
    d. other, specify.....
50. What are some of the negative responses from health workers about EPs?
    a. EPs us abusive/rude language.
    b. Health workers do not appreciate EPs.
    c. Health workers repeat activities done by EPs.
    d. other, specify……
51. Have you or the facility experienced any problems since the EPs were introduced?
    a. yes
    b. no (If no, jump to Question 53)
52. What problems have you experienced from having EPs working at the facility?
    52.1 List problems seen or heard about EPs:

    52.2 How did you resolve the problem(s)?
53. Have you received any positive comments about having EPs working at the facility?
    a. yes
    b. no (jump to Question 55)
54. If yes, list the positive comments:.
55. Do you have any suggestions for how the EP's role could be improved?
56. What are the reasons that EPs may choose to stop working at the facility? (circle all that apply)
    a. dissatisfaction with work conditions
    b. lack of legal protection at work
    c. lack of incentives/payment for work
    d. too much work, cannot cope
    e. disrespected by clients
    f. avoided by clients when they realize EPs are also living with HIV
    g. EPs do not feel respected by health workers
    h. other, specify
    ……

Finally, I have some specific questions about staff and client numbers.

57. Ask to see the monthly report to gather information on the total number of clients seen for the three months prior to this assessment.

Service	**January '11**	**February '11**	**March '11**
HIV ART			
HIV Non-ART			

58. How many people are assigned at this location to support ART services?

Cadre	Number of planned positions	Number of filled positions	No. of Staff providing HIV/AIDS Services Full-time all days/week	No. of Staff providing HIV/AIDS Services Part-time Some days/week
Medical Officers				
Clinical Officers				
Nurses/Midwives				
Nursing Assistants				
Lab Technicians				
Counselors				
Social Workers				
Pharmacists				
Pharmacist 's Assistant				
Expert Patients				
Other 1				
Other 2				

2.2 Clinical Staff Interview

Interviewer name: _____

Date of Interview: _____

PURPOSE OF STUDY

Thank you for taking the time to speak with me today.

The purpose of our discussion today is to understand the processes for task shifting to expert patients, including what has worked and where opportunities for improvement exist.

Definition of expert patients (EPs): *Expert patients are people living with HIV who have received some form of training to perform HIV service delivery tasks,* ***but are not certified or categorized formally within the recognized health system****. The purpose of this survey is to understand how EPs support HIV/ AIDS services in this facility and/or community.*

Our findings will help inform how best to implement human resource policies and processes that support the effective and consistent inclusion of EPs into facilities providing HIV/AIDS services.

Specifically, our objectives are the following:

- *To describe task shifting to EPs and the extent of their integration into the health system.*
- *To examine existing policies pertaining to EPs and their recruitment, training, supervision and support in the health system and the community.*
- *To explore the perceptions of the role of EPs among various stakeholders (including health workers, communities and EPs themselves) and existing relations among stakeholders in the context of the EP role.*

Here are a few details about this interview before we begin.

- *We do not record names of individuals or sites. All data will be coded and your participation is anonymous.*
- *There are no right or wrong answers. We want to learn about your EP program and your insights about it, positive or negative.*
- *I do not have a vested interest in anything that is said during this interview. I work for Initiatives Inc., an independent contractor.*
- *This interview will last approximately 60 minutes.*

Do you have any questions, before we start?

Do I have your permission to start? _____ (Note the response and time and sign)

1. Have any tasks that used to be your responsibility been shifted to EPs?
   a. yes
   b. no (jump to Question 4)
   c. do not know

2. I have a list of tasks I'd like to read to you. For each of the tasks I'd like to know whether it has been shifted from your responsibility to the EP, and if so, your level of satisfaction with the way the tasks are accomplished by EPs (mark as appropriate).

TASK	**Shifted? Yes or No**	**Level of Satisfaction (tick as appropriate)**			**Comments**
	Y or N	**Very**	**Somewhat**	**Not At ALL**	
a. Patient assessment					
b. Laboratory assistance					
c. Preventive health education					
d. Filing and data maintenance					
e. Treatment adherence education for clients					
Community and Home Outreach					
f. Delivering supplies and medicines to clients					
g. Bedside care					
h. Treatment adherence follow up					
i. identifying and referring at facility					
j. identifying and referring from the community					
k. counseling other PLHA					
others, please specify:					
l.					
m.					
n.					
o.					

3. Why do you think these tasks were shifted to EPs?
   a. heavy workloads on clinic staff
   b. to relieve staff for more technical work
   c. to ensure timely attendance to clients
   d. EPs live in communities of clients
   e. EPs trusted by the clients
   f. other, specify ……

4. Are there other tasks you think the EPs could do that could benefit the facility or community?
   a. yes
   b. no

   4.1 If yes, what are they?

5. In your opinion, are the EPs useful in improving the delivery of care in this health facility or the community?
   a. yes
   b. no
   c. don't know

   5.1 If yes, give examples:

6. In your opinion, how trustworthy are the EPs with private client information?
   a. very trustworthy
   b. somewhat trustworthy
   c. not trustworthy at all

   6.1 Please give examples to explain your response.

7. In your opinion, are EPs helpful in reducing the workload of health workers?
   a. very helpful
   b. somewhat helpful
   c. not helpful at all

   7.1 Please give examples to explain your response to the previous question.

8. How do other health workers respond to EPs?

   8.1 Examples of **positive** responses:

   8.2 Examples of **negative** responses:

9. What are some of the positive responses from clients about the EP? (circle all that apply)
   a. Clients feel the EPs are very helpful.
   b. Clients verbally appreciate the work of EPs.
   c. Clients feel the waiting time in facilities has decreased.
   d. other, specify.....

10. What are some of the negative responses from clients about EPs? (circle all that apply)
    a. Clients insist on being seen by qualified staff.
    b. Clients avoid or stop coming to the clinic.
    c. Clients change facilities to avoid EPs.
    d. other, specify …….

11. What problems or concerns do you see with having EPs working in your facility?
    (Probe: What do you think caused the problem/concern? What has been done to address the problem? How could your concern be addressed?)

12. What are the benefits of having EPs work at this facility?

2.3 Expert Patient Interview

Interviewer name: _____

Date of Interview: _____

PURPOSE OF STUDY

Thank you for taking the time to speak with me today.

The purpose of our discussion today is to understand the processes for task shifting to expert patients, including what has worked and where opportunities for improvement exist.

Definition of expert patients (EPs): *Expert patients are people living with HIV who have received some form of training to perform HIV service delivery tasks,* ***but are not certified or categorized formally within the recognized health system****. The purpose of this survey is to understand how EPs support HIV/AIDS services in this facility and/or community.*

Our findings will help inform how best to implement human resource policies and processes that support the effective and consistent inclusion of EPs into facilities providing HIV/AIDS services.

Specifically, our objectives are the following:

- *To describe task shifting to EPs and the extent of their integration into the health system.*
- *To examine existing policies pertaining to EPs and their recruitment, training, supervision and support in the health system and the community.*
- *To explore the perceptions of the role of EPs among various stakeholders (including health workers, communities and EPs themselves) and existing relations among stakeholders in the context of the EP role.*

Here are a few details about this interview before we begin.

- *We do not record names of individuals or sites. All data will be coded and your participation is anonymous.*
- *There are no right or wrong answers. We want to learn about your EP program and your insights about it, positive or negative.*
- *I do not have a vested interest in anything that is said during this interview. I work for Initiatives Inc., an independent contractor.*
- *This interview will last approximately 60 minutes.*

Do you have any questions, before we start?

Do I have your permission to start? _____ (Note the response and time and sign)

1. How long have you been an EP?
   a. less than 1 month
   b. 1–3 months
   c. 3 months to 1 year
   d. 1– 2 years
   e. more than 2 years
   e. other, specify ……...……

2. Where do you perform your duties as an EP most of the time?
   a. in the community
   b. in the health facility
   c. other, specify ……..

3. How often do you work as an EP?
   a. daily (5 days a week)
   b. 3-4 days in a week
   c. 2 days a week
   d. 1 day in a week
   e. other, specify ……

   3.1 How many hours per day on average do you work?

4. How did you become an EP?
   a. nominated by community
   b. nominated by an HIV/AIDS service organization
   c. asked by the facility manager
   d. asked by health facility nurse or clinical staff member who has been seeing me on follow-up
   e. volunteered to do the community work
   f. other, specify ……..…….

5. What made you want to be an EP? (Probe: What attracted you to the role?)

6. What tasks do you perform in your role as an EP? (Read and Tick all tasks mentioned)

	Activity / Tasks	**Yes**	**No**
a.	Registration at facility	☐	☐
b.	Prioritizing patients for care (triage)	☐	☐
c.	Patient assessment	☐	☐
d.	Assisting in laboratory	☐	☐
e.	Health education	☐	☐
f.	Filing and data maintenance	☐	☐
g.	Follow-up for ART adherence	☐	☐
	Community Outreach	☐	☐
h.	Deliver supplies or medicines	☐	☐
i.	Bedside care	☐	☐
j.	Treatment follow-up	☐	☐
k.	Identify and refer: orphans and vulnerable children and pregnant women	☐	☐
l.	Health education (nutrition, hygiene, malaria prevention, ANC, EPI)	☐	☐
m.	Other, specify	☐	☐

6.1 Who asked you to perform these tasks?
   a. the by community
   b. the HIV/AIDS service organization
   c. the facility manager
   d. health facility clinical staff who have been seeing me on follow-up.
   e. other, specify ……..……

7. Why do you think you were asked to do these particular tasks? (check all that apply)
   a. I have been a long-term client at this facility.
   b. I have been adhering to treatment and appointment schedules.
   c. I am quick to follow instructions.
   d. I have attended several training forums in the community.
   e. This task will enable quick delivery of services to those coming for care.
   f. Other, specify ……

How the new role and responsibilities are explained to the EP

8. Who explained your roles and responsibilities to you when you began working here?
   8.1 List the roles and responsibilities explained.

   8.2 What information did you receive about the goals of this clinic and how your work supports the goals?

9. Describe any training you received **BEFORE** starting work as an EP at this facility.

If the EP was trained, use this form to record answers. Enter ***Trainer #*** in center box, and the **Duration #** in the right hand box. Choose from the options in the following table. If more than one trainer, indicate the numbers.

	Training Topics	**Trainer #**	**Duration #**
a.	Registration of patients		
b.	Triage (care of very sick clients arriving at facility)		
c.	Patient assessment		
d.	Laboratory assistance		
e.	Health education		
f.	Filing and data maintenance		
g.	Adherence		
	Community Outreach		
h.	Deliver supplies or medicines		
i.	Bedside care		
j.	Treatment follow-up		
k.	Identify and refer: orphans and vulnerable children and pregnant women		
l.	Health education (nutrition, hygiene, malaria prevention, ANC, EPI)		
m.	Health education		
n.	Quality		
o.	Infection prevention safety		
p.	Patient confidentiality		
q.	Other		

Trainer #:

1. NGOs
2. ministry of health officials
3. health worker
4. other, specify in box)

Duration #

1. less than 1 hour
2. 1–3 hours
3. 1 day
4. 1 day to 1 week
5. 1 week to 1 month
6. multiple short sessions
7. no training
8. other

10. What kind of on-the-job training did you receive **AFTER** you started working?

	Training Topics	**Trainer #**	**Duration #**
a.	Registration		
b.	Triage (care of very sick clients arriving at facility)		
c.	Patient assessment		
d.	Laboratory assistance		
e.	Health education		
f.	Filing and data maintenance		
g.	Adherence		
h.	Report writing		
	Community Outreach		
i.	Delivery of supplies or medicines		
j.	Bedside care		
k.	Treatment follow-up		
l.	Identify and refer: orphans and vulnerable children and pregnant women		
m.	Health education (nutrition, hygiene, malaria prevention, ANC, EPI)		
n.	Quality		
o.	Infection prevention Safety		
p.	Patient confidentiality		
q.	Counseling		
r.	Other		

Trainer #:

1. NGOs
2. ministry of health officials
3. health worker
4. other, specify in box

Duration #

1. less than 1 hour
2. 1– 3 hours
3. 1 day
4. 1 day to 1 week
5. 1 week to 1 month
6. multiple short sessions
7. no training
8. other

11. Did you feel capable of performing EP tasks following the training you received?
    a. yes
    b. no
    c. some but not all
    d. don't know

    11.1 Why? (Explain)

12. How would you improve the training you received? (provide examples)

13. What benefits or incentives do you receive for being an EP? (read and check all that apply)
    a. payment
    b. uniforms
    c. tote bag
    d. access to medicines and medical care
    e. meals or meal vouchers
    f. transportation allowance
    g. community recognition
    h. facility recognition
    i. other, specify ……
    13.1 From the above list, which benefit or incentive do you consider the MOST important as a motivation for being an EP?

14. What do you find satisfying in your role as an EP?
    14.1 What do you find least satisfying in your role as an EP?

15. Do you have a supervisor?
    a. yes
    b. no (jump to Question 19)

16. How often do you meet with your supervisor?
    a. weekly
    b. every two weeks
    c. monthly
    d. quarterly
    e. other, specify ……..

How supervision is carried out.

17. Does your supervisor ever observe you performing your duties?
    a. yes
    b. no
    c. do not know

    17.1 Are you provided with a chance to ask questions?
        a. yes
        b. no

    17.2 Are your questions answered?
        a. yes
        b. no

    17.3 If no, are your questions referred elsewhere for explanations? (Probe if feedback is received.)

18. In discussions with your supervisor, do you settle on targets to be achieved?
    a. yes
    b. no (jump to Question 19)
    18.1 If yes, describe them.

19. How do you get feedback on your work performance and quality? (check all that apply)
    a. on the spot from the supervisor
    b. at regular facility team meetings
    c. from my supervisor as necessary

d. one-on-one meetings with supervisor at pre-planned meetings
e. quality improvement team meetings
f. in a private room, one-to-one, the same day
g. feedback is never given
h. other, specify ……

20. If your performance is not satisfactory, do you receive coaching on how to improve? (Probe: describe the process)

21. If you work in the community, does the community give you feedback?
    21.1 If yes, please describe the process

22. Are you a member of the quality improvement team?
    a. yes
    b. no (jump to Question 24)

23. If yes, what is your role on the quality improvement team? (Probe: what do you do as a member of the team? How do you participate?)

24. What are some of the **positive** (good) ways that the other health workers have treated you?
    a. Health workers are very supportive and encouraging.
    b. Health workers verbally appreciate our roles and work.
    c. Health workers say they now have enough time for other activities.
    d. Other, specify.....

25. What are some of the **negative** (bad) ways the other health workers have treated you?
    a. Sometimes health workers use abusive language.
    b. Health workers are at times rude to the EPs.
    c. Health workers do not appreciate the work the EPs do.
    d. Health workers do not trust our work and repeat work we have done.
    e. no negative treatment
    f. Other, specify ……

    25.1 What are some of the **positive** (good) ways that the other clients have treated you?
    a. openly appreciate our work
    b. recognize and trust our work
    c. other ……

    25.1 What are some of the **negative** (bad) ways the other clients have treated you?
    a. Patients fail to follow the EP's instructions.
    b. Some clients discriminate and do not want to identify with the EPs.
    c. Clients refuse to talk with the EPs.
    d. Clients use abusive language with EPs.
    e. Other.....

26. Have you faced any kind of verbal abuse from a co-worker due to your HIV status?
    a. yes
    b. no (jump to Question 28)

    26.1 If yes, please give examples.

27. To your knowledge, has anybody expressed fear of touching you/things that you touch?
    a. yes
    b. no (jump to Question 29)
    27.1 If yes, please give examples.

28. Have you ever felt that you are being treated differently due to your HIV status?

Treated differently by	**a. Yes**	**b. No**
Health workers		
Clients		
Community members		

    28.1 If yes to any, please give examples.

29. How does the work you do help the facility?
    (Probe: examples of how your work has improved services at this facility)

30. What difficulties do you encounter in working? (Probes: lack of support from health system? client does not adhere to treatment, client becomes sick or dies? any other challenges you have encountered? Please give an example.)

31. What do you do when you encounter problems or barriers?

32. Does your community know that you are an EP?
    a. yes
    b. no
    c. don't know

33. How are you treated in the community in your EP role?
    (Probe: what are some positive or negative examples of how the community treats you?

34. I am going to ask you some questions concerning your perceptions of your working conditions. The questions are aimed at determining if the conditions are supportive and lead to good performance. For each question, you can respond by choosing one of the following:
    1. Agree | 2. Disagree | 3. Do not know

Belief in work and organization	**Agree**	**Disagree**	**Don't Know**
I believe that what I do at work is important.			
The community understands that what I do is important.			
Belief in ability to succeed			
I have the knowledge and skills to meet the expectations placed on me.			
When I have questions about my responsibilities, I am sometimes afraid to ask for help.			
I have the support I need from the facility/community to do my job well.			
When I'm faced with a difficult situation, I'm confident that I can resolve it.			
I have the tools I need to do my job well.			
Relations with the health system			
I work closely with other health workers to solve problems.			

	Belief in work and organization	Agree	Disagree	Don't Know
	The people that I work with know that I work hard.			
	I have a close friend at the facility/community with whom I can share my ideas or problems.			
	I can openly disagree with the leadership.			
Relations with the community				
	I work closely with the community to solve problems.			
	When I need support, the community members are there for me.			
	I know which community members to rely on when I face challenges.			
Professional advancement				
	I have enough opportunities to learn and grow in my work.			
	I receive feedback about my work.			
	I believe if I do my work well I will have more opportunities.			
Support and recognition				
	The community praises me when I do a good job.			
	The community openly listens to my opinions and ideas.			
	I believe that if I do my job well, the community will recognize me.			
Influence in decision making				
	Suggestions made by EPs on how to improve their work are usually accepted.			
	I participate in decisions about how services are provided in our facility/community.			
	I have the freedom to make changes in the way I do my work.			

What would help you do a better job as an EP? (Probe: What other types of support do you feel you need to do a better job? further training? closer supervision? a clearly defined role? support from the community?)

2.4 Client Interview

Interviewer name: _____

Date of Interview: _____

PURPOSE OF STUDY

Thank you for taking the time to speak with me today.

The purpose of our discussion today is to understand the processes for task shifting to expert patients, including what has worked and where opportunities for improvement exist. Our findings will help inform how best to implement human resource policies and processes that support the effective and consistent inclusion of expert patients into facilities providing HIV/AIDS services.

Specifically, our objectives are the following:

- *To describe the process of task shifting to expert patients and the extent of their integration into the health system.*
- *To examine existing policies pertaining to expert patients and their recruitment, training, supervision and support in the health system and the community.*
- *To explore perceptions of the role of expert patients among various stakeholders (including health workers, communities and expert patients themselves) and existing relations among stakeholders in the context of the expert patient role.*

Here are a few details about this interview before we begin.

- *We do not record names of individuals or sites. All data will be coded and your participation is anonymous.*
- *There are no right or wrong answers. We want to learn about your expert patient program and your insights about it, positive or negative.*
- *I do not have a vested interest in anything that is said during this interview. I work for Initiatives Inc., an independent contractor.*
- *This interview will last approximately 60 minutes.*

Do you have any questions, before we start?

Do I have your permission to start? _____ (Note the response and time and sign)

Find out if these clients have been served by an EP in this clinic. Be sure they understand what an EP is.

1. What services have you received from the EP in the clinic today? (circle all that apply)

   a. patient assessment
   b. registration at the facility
   c. prioritizing and directing patients for urgent care
   d. laboratory assistance
   e. health education at the facility
   f. filing and data maintenance at the facility
   g. follow-up for ART adherence
   h. other, specify ……..

2. How satisfied were you with the EP performing the service you received today? (check as appropriate)

TASK	**Level of Satisfaction**			**Comments**
	Very	**Somewhat**	**Not At ALL**	
a. patient assessment				
b. registration at the facility				
c. prioritizing and directing patients for urgent care				
d. laboratory assistance				
e. health education at the facility				
f. filing and data maintenance at the facility				
g. follow-up for ART adherence				
h. other, specify				

3. How comfortable are you confiding in the EPs? (mark as appropriate)
   a. very
   b. somewhat
   c. not at all

   3.1 Why do you feel this way?

4. In your opinion how have the services offered at this facility changed since EPs started working there? (consider clients for 6 months or more)
   a. are better
   b. are worse
   c. no change at all
   d. other, specify …….

5. What have you heard other clients say about the services they have received from EPs working in this facility? (Probe: example of what has been said about EPs)

   5.1 **Positive** things that may have been said about EPs working in this facility:

   5.2 **Negative** things that may have been said about EPs working in this facility:

6. How have you seen health workers treat EPs in this facility?

   6.1 **Positive** ways health workers have treated EPs at this facility:

   6.2 **Negative** ways health workers have treated EPs at this facility:

7. Have you faced any kind of verbal abuse from a health provider due to your HIV+ status?
   a. yes
   b. no (jump to Question 9)
   7.1 If yes, how long ago was that…….

8. If yes, what kind of abuse?
   a. ridicule
   b. insults
   c. blame
   d. other, specify……

9. Have you noticed any difference in the way you are treated at this facility since EPs started working here?
   a. yes
   b. no (jump to Question 11)

   9.1 If yes, give examples.

10. In your opinion, have you ever had less satisfying care from a health provider (doctor, nurse or clinical officer) because of your HIV+ status?
   a. yes
   b. no
   10.1 If yes, give examples.

11. Have you ever decided not to use the services of this health facility or have you chosen not to come to the facility because you are HIV+ and fear of discrimination?
   a. yes
   b. no (jump to Question 13)

12. If yes, has having EPs at this facility lessened this fear?
   a. yes
   b. no

13. To your knowledge, has anybody expressed fear of touching you/things that you touch?
   a. yes
   b. no (jump to Question 15)

14. If yes, do you notice any differences since EPs have started working at the facility?
   14.1 Please give examples.

15. Are there additional tasks/responsibilities that EPs could do at the clinic?
   15.1 If yes, please give examples.

16. Are there some tasks that EPs should not do?

   16.1 If yes, please give examples.

   16.2 Were you involved in identifying EPs?

   16.3 Were you satisfied with the way EPs were recruited for this facility?

2.5 Community Member Interview

Interviewer name: _____

Date of Interview: _____

PURPOSE OF STUDY

Thank you for taking the time to speak with me today.

The purpose of our discussion today is to understand the processes for task shifting to expert patients, including what has worked and where opportunities for improvement exist. Our findings will help inform how best to implement human resource policies and processes that support the effective and consistent inclusion of expert patients into facilities providing HIV/AIDS services.

Specifically, our objectives are the following:

- *To describe the process of task shifting to expert patients and the extent of their integration into the health system.*
- *To examine existing policies pertaining to expert patients and their recruitment, training, supervision and support in the health system and the community.*
- *To explore perceptions of the role of expert patients among various stakeholders (including health workers, communities and expert patients themselves) and existing relations among stakeholders in the context of the expert patient role.*

Here are a few details about this interview before we begin.

- *We do not record names of individuals or sites. All data will be coded and your participation is anonymous.*
- *There are no right or wrong answers. We want to learn about your expert patient program and your insights about it, positive or negative.*
- *I do not have a vested interest in anything that is said during this interview. I work for Initiatives Inc., an independent contractor.*
- *This interview will last approximately 60 minutes.*

Do you have any questions, before we start?

Do I have your permission to start? _____ (Note the response and time and sign)

Important Note: Be careful here not to name any individual EPs in this community when providing examples. Also be sure that community members understand what an EP is before conducting the interview.

1. Briefly describe your leadership role in this community?

2. What have the EPs been doing in the facility and in the community? (tick as appropriate)

	FACILITY Activities / Tasks	**Tick**		**COMMUNITY Activities/ Tasks**	**Tick**
a.	Registration at the facility		b.	Delivering supplies or medicines in the community	
c.	Prioritizing and directing patients for urgent care		d.	Bedside care at home	
e.	Patient assessment		f.	Treatment follow-up	
g.	Assisting in the laboratory		h.	Identification and referral of others including orphans and vulnerable children and pregnant women	
i.	Health education (nutrition, hygiene, malaria prevention, ANC, EPI)		j.	Health education in communities	
k.	Filing and data maintenance at facility		l.	Health education (Nutrition, Hygiene, malaria prevention, ANC, EPI)	
m.	Follow-up for ART adherence		n.	Counseling	
p.	Other, specify		q.	Other	

3. Did your community have a part in identifying and selecting the EPs? (tick as appropriate)

Where EPs work	**Yes**	**No**
Community		
Health Facility		

4. If the community had a part in identifying EPs,

   4.1 Explain how the community identified them.

   4.2 List the criteria the community used to identify them.

5. Have community members had concerns about having an HIV+ person delivering services?
   a. yes
   b. no
   c. do not know

   5.1 If yes, please give examples.

6. What level of trust do people have in the EPs who deliver services?
   a. highly trusted
   b. somewhat trusted
   c. not trusted at all

   6.1 Why do you feel that way? (give examples)

7. How would you rate satisfaction with the services EPs provide?
   a. very satisfied
   b. somewhat satisfied
   c. not at all satisfied
   7.1 Why do you feel that way? (give examples)

8. Do you feel the EPs are well trained to deliver these services?
   a. yes
   b. no
   c. not at all
   8.1 Why do you feel that way? (give examples)

9. In your opinion, how useful are the EPs in improving the delivery of care?
   a. very useful
   b. somewhat useful
   c. not useful
   9.1 Why do you feel that way? (Give examples)

How services were delivered before EPs

10. Were you able to receive these services before the EP started delivering services in your community?

   a. yes
   b. no
   10.1 If yes, how did you receive these services before the EP began working in your community?

11. In your opinion, what has changed with the introduction of the EPs?

   11.1 Is it easier to access care in the community?

   11.2 Do you feel supported now that the EP is working in your community?

      a. yes
      b. no
      c. do not know

   11.3 Why do you feel that way? (Explain)

   11.4 If stigma against HIV/AIDs patients was present in your community before the introduction of the EP, has it now decreased?

      a. yes
      b. no
      c. do not know

   11.5 Why do you feel that way? (give examples)

12. In your opinion, how competent are the EPs in carrying out their assigned tasks?

    a. Very competent, expertly
    b. Somewhat competent
    c. Not competent at all
    d Other, specify ……

    12.1 Why do you feel this way? (explain)

13. How do people in the community who are not patients treat the EPs?
    a. with respect
    b. badly (give examples)
    c. other, specify ……..

14. How do clients treat the EPs in this community?
    a. with respect
    b. badly
    c. other, specify

    14.1 Please give examples.

15. What problems have been reported regarding EPs providing services in this community?

    15.1 Give examples of problems.

    15.2 Why do you think the problems exist?

    15.3 How have the problems been addressed?

    15.4 How could the situations be improved?

16. How do EPs communicate with community leaders? (check all that apply)
    a. In organized meetings
    b. One-on-one
    c. In learning sessions
    d. At treatment club updates
    e. Other, specify

17. How do the EPs raise community HIV program issues with the facility?
    a. EPs report issues to their supervising clinic officials
    b. EPs raise the issues with the health facility management team at meetings
    c. Issues are reported to the clinic manager
    d. EPs raise the issues with the supporting NGOs
    e. Other, specify ……..

18. How do EPs share facility information with the community?
    a. organize community meetings
    b. share information with community leaders who then share info with the community
    c. visit households to share information
    d. other, specify_____

19. Does the community provide the EP with recognition or incentives?
    a. yes
    b. no
    c. do not know

20. If yes, describe the incentives or recognition.

21. Does the community provide the EP with feedback about the work he or she is doing?
    a. yes
    b. no
    c. do not know

22. Who gives the feedback from the community to the EPs? (list all groups or individuals who provide feedback)

23. How often is feedback given?
    a. weekly
    b. every two weeks
    c. monthly
    d. quarterly
    e. other, specify ……..

24. Does the community share this feedback with the facility?
    a. yes
    b. no
    c. do not know

    24.1 If yes, how do they share the feedback with the facility? (Probe: please give an example)

    24.2 If no, do they share feedback with anybody at all? (Probe for the institutions involved)

25. What suggestions can you offer that would help EPs do a better job in the community?

2.6 Ministry Of Health Officials

(For interviewing district, regional and national officials)

Interviewer name: _____

MOH Official Position _____

1. What are your thoughts on shifting some roles and tasks of trained health personnel to EPs?
   - Is it necessary, or is it a good practice?
   - Why do you feel that way?

2. What are some of these tasks in HIV care that could be shifted to the EPs?

3. What are your thoughts about the quality of work EPs do?
   - Are you confident in the EPs ability to do the tasks?
   - How satisfied are you with the way the tasks are completed?

4. In your opinion, are EPs useful in improving the delivery of care?
   - Please explain why you feel that way.

5. What is the ministry of health's policy (guidance) on the participation of EPs in the delivery of health services, particularly for HIV care and support?
   - Is there any written circular or guidelines on EPs? List them.

6. At what level of health care does government policy allow EPs to provide care? (Probe for the different levels of health care in Uganda from level I–V, regional and national referral: list them)

7. Kindly indicate the activities that the EPs perform at each level.
   (Probe and use the table below for activities mentioned by level)

Level of Health Care	**Activities Sanctioned for EP** (indicate the # of the activity)	**Types of Care**
Community (level I)		a. Patient assessment b. Laboratory assistance c. Preventive health education d. Filing and data maintenance e. Treatment adherence education f. Community/home outreach g. Delivering supplies or medicines h. Bedside care i. Treatment follow-up j. Identifying and referring k. Counseling of other PLHA l. Safety training in health clinics
Health Center (level II)		
Health Center (level III)		
Sub district (level IV)		
District Hospital (level V)		
Regional referral hospital (level VI)		
National referral hospital		

8. How are the EPs identified and selected for the services they provide?
   - Are there any officially approved/authorized processes to be followed? State them if they exist.
   - How are the positions announced and by whom?
   - Do they undergo formal interviews and who interviews them?

9. What are the qualities or characteristics used in identifying EPs? (circle all that apply)
   a. knowledge about HIV/AIDS
   b. receiving ART
   c. treatment plan adherence and success
   d. good communication skills
   e. known and respected by health workers
   f. healthy enough to work
   g. reliable
   h. active in/recommended by HIV/AIDS organization
   i. lives in/respected by community
   j. literate (is there a desired education or background?)
   k. other, specify……..

10. Are the following also involved in the selection of the EPs? (yes or no)
   a. communities? _____ (Give examples of how involved if yes)
   b. HIV/AIDs organizations_____ (Give examples of how involved if yes).
   c. Others, specify …….

11. Do EPs receive training when they are recruited?
   a. yes
   b. no
   c. don't know
   (If no or don't know then jump to Question 15)

12. If training is provided, what materials are used to train the EPs?
   - Are the programs formal training programs with curriculum provided by the government?
   - What is the ministry of health's involvement and participation in EP training?
   - What is the ministry's role if other partner agencies provide training materials?
   - What job aids are provided to support EP training?

13. Are you satisfied with the quality of the training?
   a. yes
   b. no
   c. I do not have an opinion (jump to question 15)

14. What suggestions would you give to improve the training of EPs?

15. Are the EPs supervised at the various levels at which they operate?
    - If so, please explain how it happens at each level.

16. Does the Ministry of Health provide partners and facilities managers with feedback about the work of EPs in their facilities?
    - Who gives feedback and how often is feedback given?
    - Is this feedback shared with the EPs?

17. Does the Ministry of Health have any kind of policy for providing incentives to EPs?
    a. yes
    b. no

18. What is the Ministry's policy on incentives for EPs? (circle all that apply)
    a. payment
    b. uniforms
    c. tote bag
    d. access to medicines and medical care
    e. meals or meal vouchers
    f. transportation allowance
    g. community recognition
    h. facility recognition
    i. other**,** specify

19. How do certified trained health workers respond to EPs?
    - Have there been examples of bad responses to EPs by health workers?

20. Do you think that EPs benefit the health system in your district (or mention appropriate level for the interviewee)?
    - If so how? …….

21. What are some of the problems that EPs face?
    - What kind of problems have been observed or mentioned?
    - What could have caused the problems?
    - How could that kind of problem be resolved?

22. Do you have any suggestions for how the EP role could be improved?
    - What are some policy and professional regulatory guidelines that need addressing to improve the participation and roles of EPs?

2.7 NGO Officials

(For interviewing officials of NGOs that support EPs in HIV programs)

Interviewer name: _____

Date of Interview: _____

PURPOSE OF STUDY

Thank you for taking the time to speak with me today.

The purpose of our discussion today is to understand the processes for task shifting to expert patients, including what has worked and where opportunities for improvement exist. Our findings will help inform how best to implement human resource policies and processes that support the effective and consistent inclusion of expert patients into facilities providing HIV/AIDS services.

Specifically, our objectives are the following:

- *To describe the process of task shifting to expert patients and the extent of their integration into the health system.*
- *To examine existing policies pertaining to expert patients and their recruitment, training, supervision and support in the health system and the community.*
- *To explore perceptions of the role of expert patients among various stakeholders (including health workers, communities and expert patients themselves) and existing relations among stakeholders in the context of the expert patient role.*

Here are a few details about this interview before we begin.

- *We do not record names of individuals or sites. All data will be coded and your participation is anonymous.*
- *There are no right or wrong answers. We want to learn about your expert patient program and your insights about it, positive or negative.*
- *I do not have a vested interest in anything that is said during this interview. I work for Initiatives Inc., an independent contractor.*
- *This interview will last approximately 60 minutes.*

Do you have any questions, before we start?

Do I have your permission to start? _____ (Note the response and time and sign)

Recruitment

1. What factors influenced the decision of your NGO to support EPs?

2. Did your NGO seek any guidance from the Ministry of Health before supporting EP activities?
   a. yes
   b. no

   2.1 If yes, what guidance was sought?

   (Probe: did you seek authorization? was guidance given on recruitment of EPs?)

3. Are there any officially approved or authorized processes to be followed in recruiting EPs? (Probe: what is the process if it exists?)

4. Was your NGO involved in the recruitment of the EPs?
   a. yes
   b. no (jump to Question 6)
   c. do not know (jump to Question 6)

   4.1 If yes, what was your involvement in the recruitment process? (circle all that apply)
      a. announcements of the opportunity done by the NGO
      b. NGO identified EP candidates from clients in the facilities supported
      c. Shortlisting of EP candidates
      d. participated on EP interview panels
      e. other, specify ……..

5. What were the criteria for identifying a potential EP?

Roles and Responsibilities

6. Briefly describe the EP's roles in your program

7. Are these roles discussed with the EPs
   a. yes
   b. no

   7.1 If yes, then at what stage are they discussed with the EPs? (circle all that apply)
      a. on advertising for the position
      b. at one-to-one discussion with potential EPs to convince them
      c. at training before the EP starts work
      d. during supervision while working.
      e. other, specify

         ……

Training

8. Is your NGO involved in training EPs?
   a. yes
   b. no

8.1 If yes, in what stage or phase of training does your NGO participate?

a. initial training on recruitment
b. during supervision and follow up
c. special on-the-job training sessions
d. other, specify ……

9. How frequently does your NGO participate in EP training?§

	Kind of training	**Frequency at initial stage**	**Frequency after starting work**
a.	Registration		
b.	Triage		
c.	Patient Assessment		
d.	Laboratory assistance		
e.	Health education		
f.	Filing and data maintenance		
g.	Adherence		
	Community Outreach		
h.	Delivery of supplies or medicines		
i.	Bedside care		
j.	Treatment follow-up		
k.	Identify and refer: orphans and vulnerable children and pregnant women		
l.	Health education		
m.	Quality		
n.	Safety		
o.	Patient confidentiality		
p.	Other		

Frequency Key: – 1: less than an hour, 2: 1–3 hours, 3: one day, 4: 1 day to 1 week, 5: 1 one week to 1month , 6: multiple short sessions, 7: no training, 8: other

10. Is there a standardized curriculum for training EPs?

a. yes
b. no

10.1 If yes, how was it developed? (circle the most appropriate)

a. by the Ministry of Health
b. by our NGO
c. by a consortium of NGOs working in the HIV program
d. by NGOs and the ministry of health
e. other, specify.....

11. Are training materials (handouts, pamphlets, etc) available at EP training sessions?

a. yes
b. no

§ Use the frequency key

11.1 If yes, who provides them?

a. partner organizations
b. ministry of health
c. other, specify ……

Feedback/supervision

12. In your opinion, are EPs useful in improving the delivery of care in health facilities?

12.1 Please explain why you feel this way.

13. Are EPs supervised at different sites/levels? (e.g., at facilities, by the Ministry of Health or by NGOs)?
131. If so, please explain how supervision is done at the different levels in your program

14. Who is responsible for supervising the work of EPs in your program?
a. nurses at the facility
b. clinical officer at the facility
c. health facility/site manager
d. NGO program officials
e. other, specify ……

15. Does your NGO participate in maintaining the quality of services performed by EPs?
a. yes
b. no (jump to Question 17)

16. Briefly indicate how the NGO assures that the quality of services performed by EPs is maintained.

17. Does the EP receive coaching and feedback from NGO staff?
a. yes
b. no
c. don't know

17.1 If yes, how does the EP receive coaching and/or feedback?
a. facility team meetings
b. supervisor
c. one-on-one meetings
d. quality improvement team meetings
e. never occurs
f. other, specify……..……..……..

17.2 How often are coaching and/or feedback offered?
a. weekly
b. monthly
c. quarterly
d. semi-annually
e. rarely
f. other, specify

18. Briefly describe how questions that EPs may have are answered by NGO staff.

Incentives

19. Are EPs offered incentives for the work they do?
    a. yes
    b. no
    c. do not know

20. Briefly describe any incentives EPs are given to do their work

21. What do you see as the major advantages of using EPs in facilities (list)

22. What are the major disadvantages of using EPs in facilities?

23. What have been some of the challenges that the NGO has faced working with EPs?

24. In your opinion, how does working with EPs contribute to the sustainability of NGO HIV programs?

Annex 3: Data Collection Team and Schedule

Data Collection Team

	Team Member	Respondents Interviewed
1.	Dan Wendo	Ministry of Health, All district health officers, WHO Officials, Site Managers- all sites Clinical staff – Kangulumira, Arua, Bwera
2.	Juliana Nabwire	Clients – All sites Clinical Staff – most of the sites Community - Bwera
3.	Mabel Namwabira	Expert Patients- All Sites Community – Kangulumira
4.	Jennifer Kabasinguzi	Community – All sites (except Bwera) Clients - Kangulumira

Final Schedule

Date (2011)	Item
Monday: May 2	Meeting and training
Tuesday: May 3	Testing tools
Wednesday: May 4	Make changes and print tools, team meeting
Thursday: May 5	Talk to MOH, WHO
Friday: May 6	Talk to partners; plan for next week's travel and pack materials
Sunday: May 8	**Travel**
Monday : May 9	Arua
Tuesday: May 10	Nebbi
Wednesday: May 11	**Travel**
Thursday: May 12	Mengo
Friday: May 13	Kangulumira
Sunday: May 15	**Travel**
Monday : May 16	Ishaka
Tuesday: May 17	**Travel**
Wednesday: May 18	Bwera
Thursday: May 19	**Travel to Kampala**
Friday: May 20	Wrap up

Annex 4: Informed Consent Script Sample

Interviewer name: _____

Date of Interview: _____

PURPOSE OF STUDY

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- *This interview will last approximately 60 minutes.*

Do you have any questions, before we start?

Do I have your permission to start? _____ (Note the response and time and sign)

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