



This document forms part of a series of publications that document field experience in HIV and AIDS. This work was undertaken by Robin Altaras, intern with UNHCR in Kibondo, Tanzania and Marian Schilperoord, Technical Officer HIV/AIDS, UNHCR, Geneva.

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**Other titles in the HIV/AIDS Field experience series:**

Assessment of HIV/AIDS Behaviour Change Communication Strategies employed by NGOs in Kakuma Refugee Camp, Kenya (December 2002)

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## **FOREWORD**

This UNHCR HIV/AIDS Field Experience on the “evaluation of the introduction of post exposure prophylaxis in the clinical management of rape survivors in Kibondo refugee camps, Tanzania” adds to a growing literature produced by UNHCR on how to implement HIV/AIDS interventions among refugee and other displaced population settings. HIV post exposure prophylaxis (PEP) for rape survivors is an essential intervention to be implemented from the onset of any humanitarian emergency. This Field Experience evaluates UNHCR’s and our partners’ experiences in implementing PEP: it describes how PEP was introduced to refugees in Kibondo, Tanzania; provides a methodology for monitoring and evaluating the intervention; and reports on lessons learned.

I hope that persons reading this document will be motivated not only to provide PEP to refugees and other displaced persons during humanitarian emergencies, but to ensure a system of monitoring and evaluation is put in place so that the effectiveness of such interventions can be documented. Finally, I encourage all organisations to document and disseminate their experiences in providing PEP in humanitarian emergencies – both what went right and what went wrong. In this way, we can all learn from one another, and most importantly, provide more effective HIV/AIDS interventions to refugees and other displaced populations.

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## ACRONYMS

AMO	Assistant Medical Officer
ARV / ART	Antiretroviral / Antiretroviral Therapy
AZT	Zidovudine
CO	Clinical Officer
CHW	Community Health Worker
CSB	Corn Soya Blend
DIC	Drop-in-Centre
FGD	Focus Group Discussion
HBC	Home-based Care
HIV/AIDS	Human Immunodeficiency Virus / Acquired Immune Deficiency Syndrome
HM	Health Manager
IEC	Information, Education and Communication
IAWG	Interagency Working Group on Reproductive Health in Refugee Situations
IRC	International Rescue Committee
MCH	Maternal and Child Health
M&E	Monitoring and Evaluation
NPEP	Non-occupational Post-Exposure Prophylaxis
PEP	Post-Exposure Prophylaxis
PHO	Public Health Officer
PMTCT	Prevention of Mother-to-Child Transmission
RH	Reproductive Health
RHO	Reproductive Health Officer
SGBV	Sexual and Gender-Based Violence
STI	Sexually Transmitted Infection
3TC	Lamivudine
UN	United Nations
UNFPA	United Nations Population Fund
UNHCR	United Nations High Commissioner for Refugees
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

## EXECUTIVE SUMMARY

Over the last ten years, much has been done to develop programming aimed at prevention and response to sexual and gender based violence (SGBV) among refugees and displaced populations. However, only recently have strides been made to address the troubling intersection of sexual violence, HIV/AIDS and forced displacement. Timely provision of post-exposure prophylaxis (PEP) following sexual assault may reduce the likelihood of HIV seroconversion. This report describes the experience of introducing PEP as a component of the post-rape care provided in five refugee camps in western Tanzania.

This evaluation used primarily qualitative methods to assess the service delivery, uptake, access, community involvement and training of clinical officers on the provision of PEP. Semi-structured interviews were conducted with medical and social service providers to assess front-line practice. Focus group discussions were held with refugee community leaders to assess knowledge of available post-rape medical services and the process of educating the community about PEP. Individual interviews were also conducted with survivors post rape to gather information on their experiences with PEP.

The project was conducted among a relatively stable population with well-established SGBV programmes and community structures enabling information dissemination. PEP was provided via weekly return visits to enable clinical follow-up, management of side effects and facilitate completion of the full 28-day regimen. This process appeared to offer added benefit for clients. However, staff experienced some gaps in ensuring timely return visits each week. Implementing staff successfully incorporated PEP follow-up into existing SGBV follow-up procedures and effectively used SGBV counsellors to help monitor compliance, provide ongoing support and follow up with survivors on how to correctly take the medicine.

Several important gaps and challenges were observed during the start-up process and initial months of implementation:

- *Insufficient clinical training prior to implementation* of both PEP and the overall clinical management of rape survivors. Areas of persistent confusion included indications for PEP (in relation to suspected cases where staff felt there was “no evidence of rape”); appropriate adult doses and how to substitute doses according to body weight.
- *Community awareness and education on what PEP is and who it is for.* There was significant confusion in the community as to how PEP differed from treatment for those who are HIV positive. This confusion led staff to believe that some clients might be “falsely reporting” rape in order to access services they perceived to be beneficial.
- *Systems for tracking and scheduling follow-up* to avoid missed doses and ensure weekly return.
- *Coordination between SGBV staff and voluntary counselling and testing staff* around issues of shared confidentiality of HIV test results and follow-up for repeat HIV testing.

The proportion of survivors reporting to the health facility within 72 hours increased sharply following the introduction of PEP. The increase in timely reporting likely reflected a combination of (i) added impetus for reporting due to the ability to reduce the likelihood of HIV transmission and (ii) increased awareness of the importance of early reporting as a result of intense community awareness campaigns. In the first year of implementation, of those who reported within the 72 hour window period, 94.8% elected to take PEP. Approximately 92% completed the regimen. The largest impediments to completion appeared to be due to logistic and psychosocial problems rather than intolerance of side effects.

Survivors, community leaders and SGBV counsellors all highlighted the significant role of HIV prevention post-rape in facilitating communication and negotiation with the survivor's partner or husband regarding the incident. Interviews with clients also suggested an overall sense of psychological relief as a benefit of taking PEP.

This report is organized by stages of implementation in order to facilitate its use as a step-by-step guide for future practice in this area. Based on the field experience documented in this report, specifically the highlighted gaps and challenges, special attention should be given to the following areas when initiating PEP provision for sexual assault among displaced populations:

- Presenting PEP to the community as an integrated component of post-rape care, and not a stand-alone programme.
- Devoting adequate time to training all key staff, defining terms, and anticipating questions and concerns prior to introducing the service to the community, particularly with a view towards averting potential confusion around the difference between HIV prevention post-rape and treatment for those who test HIV positive.
- Developing joint leadership and oversight between SGBV and clinical staff, ensuring the active involvement of clinical staff in education, training and supervision efforts.
- In this setting, weekly follow-up and provision of drugs appeared to provide clients with additional benefits; in less stable settings, a full provision of the 28 days treatment course may be more appropriate.

# 1. INTRODUCTION

People displaced by conflict may be at increased risk of acquiring HIV and other sexually transmitted infections (STIs). Population movements, interaction with militias or other combatants, general insecurity and social instability, conditions of poverty and economic disruption, and mass-scale sexual violence all contribute to creating a climate in which displaced populations are more vulnerable to HIV.

In the case of Burundian refugees in Tanzania, a vast number of women and girls experienced sexual violence during flight. Once settled in refugee camps in the host country, rape has proved an ongoing threat as women regularly move outside the camps to collect firewood or tend to agricultural plots, and as bandits persist in conducting raids on the peripheries of the camps, robbing and raping the most vulnerable in the population.

Over the last 10-15 years, a concerted effort has been undertaken to develop comprehensive programming towards preventing and responding to sexual and gender-based violence (SGBV) among conflict-affected populations. UNHCR's *Guidelines for Prevention and Response to Sexual and Gender-Based Violence against Refugees, Returnees and Internally Displaced Persons* were updated in 2003. Comprehensive guidelines for the *Clinical Management of Survivors of Rape* were developed by UNHCR and World Health Organization (WHO) in 2002 and updated in 2004. The latter document guides the development of essential post-rape medical services to be made available in refugee and displaced populations. These services include care of traumatic injuries, collection of forensic evidence, prevention of pregnancy, presumptive treatment for STIs, voluntary counselling and testing (VCT) for HIV and, in some settings, post-exposure prophylaxis (PEP) for HIV – a short course of antiretrovirals (ARVs) taken post-exposure to reduce the likelihood of HIV seroconversion.

Since 1996, ARV drugs have been routinely administered in developed countries following accidental occupational exposures (primarily in health care workers). In 1995, a Centers for Disease Control and Prevention (CDC) study demonstrated the efficacy of zidovudine (ZDV or AZT) use following occupational exposures, showing a 79% reduction in HIV infection. Several studies have also demonstrated the efficacy of ARVs in preventing mother-to-child transmission (PMTCT) even when ARVs are provided after birth, supporting the potential benefit of ARVs taken post-exposure. Yet little is known about the efficacy of PEP when used for other non-occupational exposures, including following sexual assault.

Based on the current evidence from occupational exposure and mother-to-child transmission studies, WHO has concluded that PEP provision is likely beneficial and should be recommended for survivors of rape.



## 2. BACKGROUND

In December 2003, a project for the provision of PEP as part of the clinical management of rape survivors was initiated in five refugee camps in Western Tanzania. SGBV services have been provided in these camps since 1994. Addressing potential exposure to HIV had been acknowledged as a missing component in an otherwise comprehensive package of post-rape services.

The project was developed in follow-up to recommendations made during the 2002 Interagency Working Group (IAWG) on Reproductive Health in Refugee Settings meeting where it was agreed that PEP should be made available post-rape. A proposal was submitted to the United Nations Population Fund (UNFPA) to support a project in the Kibondo refugee camps. UNFPA funded the provision of antiretroviral drugs and the training of clinical staff.

The draft treatment guidelines for the use of PEP as part of the clinical management of rape survivors were jointly drafted by UNHCR and UNFPA, based upon the United Nations (UN) PEP guidelines, guidelines developed in South Africa and the Médecins sans Frontières' guidelines, with technical support from WHO.

The Tanzanian refugee camps were selected as an appropriate site given the comprehensive and well-established HIV/AIDS and SGBV initiatives already in place.

The project was implemented as a collaborative effort between the overall coordinating agency, the United Nations High Commissioner for Refugees (UNHCR), UNFPA, and the implementing partner, the International Rescue Committee (IRC).

## **2.1 Rationale and Objectives**

Six months into the project, UNHCR undertook a process evaluation of the implementation of PEP in the SGBV programme. This initial assessment was important given that this was one of the first such programmes in a refugee setting and the need for careful monitoring and evaluation.

Specific objectives were to assess the service delivery, uptake, access, community involvement and training of clinical officers, as well as to review and refine the indicators for monitoring and evaluation.

Research was conducted with the dual intent of providing feedback to service providers to improve the current project, as well as with a view towards guiding the expansion of PEP provision to other displaced population settings. Findings from the evaluation were also applied in the revision of the clinical guidelines for post-rape survivors and towards improving tools for monitoring and evaluation of PEP provision.

## **2.2 Setting**

The Kibondo District in western Tanzania hosts five refugee camps, four (Mtendeli, Nduta, Kanembwa and Karago) of entirely Burundian population, and one small protection camp (Mkugwa) of approximately 1700 mixed population from Burundi, Congo, Rwanda, Madagascar, Zimbabwe, and Sudan.

Total population of the five camps was approximately 153,600 as of 1<sup>st</sup> of January 2004. However, repatriation began in earnest at the end of 2003 and the total population had dropped to 92,015 as of 1<sup>st</sup> of August 2004. The population of one camp in particular (Karago Camp) was reduced by almost two-thirds. Most of the current population has spent between 5 to 11 years in the camps. A map of the camp locations is included in Annex 1.

Since 2004, the health facilities in all five camps have been managed by the IRC. All health services are provided free-of-charge to the refugees, as well as to the local Tanzanian population. Roughly 10% of all health utilization is by the local community.

Each of the hospital compounds contains an SGBV service facility called a “Drop-in-Centre”, which is typically located in either the Maternal and Child Health (MCH) or Community Health buildings to protect against the identification or singling out of SGBV survivors.

Comprehensive SGBV services are provided within a multisectoral framework, in line with the local protocol developed in 2001 and the UNHCR SGBV Guidelines. In brief, the objectives are to both prevent and respond to all types of SGBV, including rape, attempted rape, sexual harassment, forced marriage, early marriage, and domestic violence. Prevention activities include sensitization and awareness creation in the community, such as holding social forums to discuss issues related to the leading SGBV incidents, and other

social and capacity building activities aimed at reducing SGBV incidence. Services provided in response to SGBV incidents include counselling, medical assistance, safe shelter, material support, legal support, and social reintegration. Ongoing follow-up and home visits are also conducted in accordance with the wishes of the survivor.

The incidence of reported sexual violence in and around the camps fluctuates in conjunction with changes in the security situation, including factors such as police force rotations and banditry. In 2003, the three IRC-managed facilities attended 85 rape survivors; in 2002 that number was 104. Across all five camps, a total of 123 survivors were seen in 2004.

HIV/AIDS prevalence in Tanzania is 7.8%. During four consecutive years, sentinel surveillance studies have been conducted in the Tanzanian camps, showing a prevalence of 2.4%. The four largest camps have long-standing VCT services. Those who test HIV positive are referred for follow-up counselling, supplemental feeding, medical and home-based care (HBC) when needed. A PMTCT programme was introduced in all camps in April 2003.

## 2.3 Methods

A process evaluation was conducted using primarily qualitative methods, along with some quantitative analysis of existing data and data abstracted from medical records and monitoring and evaluation forms. In the field, a phased approach to data collection was utilized, using data gathered to identify and develop additional areas for more detailed investigation with other individuals and groups.

The first phase of data collection consisted of **semi-structured key informant interviews** with health service providers and coordinating staff. A total of 22 individual interviews were conducted with the following camp-level staff (numbers interviewed are in parentheses):

- SGBV Officers or SGBV-in-charge (5)
- SGBV Clinical Focal Persons and other Clinical Officers (COs) or Assistant Medical Officers (AMOs) who had received specialized training on PEP or who were identified as regularly attending rape survivors (9)
- Voluntary Counselling and Testing (VCT) Focal Persons or Counsellors (4)
- Camp Health Managers (HM) or Clinical Officer-in-Charge (4)

Key informant interview guides are included in Annex 2.

In three of the camps, group discussions with SGBV supervisors, counsellors and Drop –in-centre assistants were also held and in one camp, an SGBV training course and an SGBV camp-level coordination meeting were observed. At the camp level, additional informal interviews and conversations were held with health administrators, community services focal persons, reproductive health officers (RHOs), MCH supervisors, STI focal persons, adolescent health focal persons, pharmacists, and other staff who played roles in the provision of SGBV or PEP services. At base, the Health Coordinator, the SGBV Programme

Manager, the Reproductive Health Manager, Protection Officers, and other staff also provided numerous inputs.

Available SGBV surveillance data were analyzed to assess trends pre- and post-PEP introduction, as well as any inter-camp variations. Field-level UNHCR and IRC programme documents were also reviewed. Health and SGBV facility observations were conducted to assess drug availability and storage, record-keeping systems, and referral pathways.

The second phase of data collection focused on assessing information, education and communication (IEC) campaigns; soliciting community knowledge and perspectives of the medical response to rape survivors (specifically PEP); and soliciting the experiences and opinions of clients who reported to the Drop-in-Centre and elected to take PEP.

**Focus Group Discussions (FGDs)** were conducted with two sets of **refugee community leaders** in four of the five camps:

- Block Leaders (3 FGDs)
- Women's Representatives/Assistant Block Leaders (3 FGDs)
- In one camp (Karago), a single FGD was conducted with a mixed group of block leaders and women's representatives.

The FGDs incorporated a participatory community mapping exercise to identify and describe rape incidence in and around the participants' community as well as the key actors, systems, and processes in place to respond to rape survivors. A sample FGD guide is provided in Annex 2. A **community transect** was also conducted in one camp (Nduta) to assess awareness about the medical response for rape survivors among various sectors of the community.

Finally, **individual interviews** were conducted with ten rape survivors who had taken **PEP**. All rape survivors who initiated PEP in Mtendeli, Nduta and Kanembwa camps between 1 May and 30 June 2004 were initially identified. Those below age 18 or deemed to be at risk, suffering ongoing trauma, sadness or other difficulties that might be exacerbated by participating in an interview were excluded. In one camp, a random sample was selected of the remaining women, and in two camps, all remaining women were invited to be interviewed.

Invited women were visited by a SGBV counsellor and asked if they would be interested in speaking with someone working with UNHCR, who would like to ask a few questions about her experiences taking PEP. A standard invitation letter with sample interview questions was supplied to the counsellor. If the woman agreed, the counsellor arranged a time for the interview in a quiet confidential place.

The final phase of investigation included **review of medical records** and **group meetings with key implementing staff**. The review of drop-in centre PEP-related records focused on gathering information from clinician's notes of post-rape medical exams, and assessing the completeness of records and the monitoring of follow-up. Group meetings with HMs, COs,

RHOs, MCH Supervisors, VCT Counsellors and SGBV Officers were held to discuss major points of observation across the camps, areas for continuous improvement, and next steps.

### **3. DESCRIPTION AND FINDINGS OF THE PEP PROJECT**

Findings from this evaluation are presented in two sections: (1) a description of how PEP provision was operationalized in this setting, including activities undertaken and challenges experienced in each phase of the post-rape care process; and (2) observed effects, including potential secondary impacts on survivors.

#### **3.1. Training of Clinical and Counselling Staff**

Training of clinicians, SGBV counsellors and other service providers was conducted in two phases: (1) an initial training attended by clinical focal persons from each of the camps, and (2) various training sessions at the individual camp level that were conducted by those who attended the first training.

##### ***Training Phase I***

The training was jointly facilitated by an Obstetrician -Gynaecologist from Muhimbili Medical Centre in Dar es Salaam and by the IRC SGBV Manager. PEP is available in Tanzania for health care workers in case of occupational exposure. PEP was entirely new for all of the training participants. Most reported that they had never heard of PEP before; one commented that she had seen it noted in the protocol for the Clinical Management of Rape Survivors but had not understood what it was prior to the training. One clinical officer reported:

*“Before I had no idea concerning PEP; so at the training, we studied how it worked, who is the survivor who should be given PEP, the medical interview before giving PEP, to make sure the one given PEP is the right one. Sometimes survivors come late (after 72 hours) so then we don’t give PEP. If they agree to an HIV test, and if it’s positive, we don’t give PEP.”*

One clinician commented that because the participants were of mixed clinical backgrounds (AMOs, COs, nurses), the training could not cover detailed information on the pharmacology of ARV drugs. Several clinicians commented that they did not understand how ARVs worked or how the evidence from PMTCT was applicable, and would have liked to receive more detailed information on these areas in the training.

##### ***Training Phase II***

Following the specialized training for SGBV focal persons, staff returned to their respective hospitals and began training other Clinical Officers, RHOs, PHOs, MCH supervisors, CHWs and SGBV staff. As reported by one of the camp training leaders, there were two primary objectives of these training sessions:

1. To equip service providers with the correct knowledge and skills to administer PEP
2. To develop refugee community awareness, including dissemination of standardized messages to avoid misunderstanding that PEP is HIV/AIDS treatment.

Many of the issues raised by staff during these training sessions pertained to the general response and clinical management of rape survivors. Examples of points of discussion recalled by one of the training leaders were:

- A case in which the survivor is a minor and doesn't want her parents to know about the incident.
- A case in which a woman is raped and doesn't want her husband to know.

During the staff training sessions, differences between what had been agreed to in the guidelines and what had been learned at the training were also discussed. The guidelines directed that a one-week supply should be provided when the client first presents and that the remaining 3- week supply be given at the one week follow-up visit. Prior to implementation, staff voiced concerns about the ability to monitor any problems and that the drugs might be sold. At the training it was concluded that it would be better to request that the client return weekly, to facilitate monitoring of side effects and adherence.

New staff learned about PEP via on-the-job training, during which SGBV issues and PEP are generally introduced. In addition, all rape cases were discussed in the daily morning hospital staff meetings, providing another opportunity for all staff to hear about the provision of PEP.

### ***Gaps and Challenges – Training***

- *Lack of training on overall clinical management of rape survivors.* While some of the camp health managers reported that all of their Clinical Officers are supposed to be trained on the clinical management of rape, in reality many Clinical Officers had not attended formal training and had very little, if any, prior experience attending rape survivors. Even for those who attended the specialized PEP training in November, the length and depth of this training was inadequate to cover the wide range of issues related to responding to rape survivors.
- *Lack of training on use of ARVs.* For all of the Clinical Officers and some of the health managers, this was the first time that they had heard about post-exposure prophylaxis (including for use following occupational exposure) and the first time they learned about ARVs and their use. In order to have a more thorough understanding of the appropriate use of ARVs and be better equipped to accurately respond to clients' and community members' questions, clinicians requested more comprehensive training encompassing basic pharmacology.
- *Lack of shared experience from PMTCT.* Despite the fact that PMTCT had been introduced 8 months prior, there was no overlap between clinical staff implementing the PMTCT programme and those selected to be trained on PEP provision.
- *Insufficient background information on PEP.* Clinicians were provided with very little background information on the known effectiveness of PEP. They had many questions in this area and requested that more detailed information be supplied on the existing evidence from occupational exposures and MTCT.
- *Small number of staff received expert training.* Only seven staff across all five camps attended the formal training on PEP. This was inadequate, particularly given the high rate of staff turnover and the fact that any Clinical Officers on night duty may attend a survivor.
- *PEP availability for health care staff in case of occupational exposure.* While IRC developed an initiative in April 2003 to make PEP available to all staff in case of occupational exposure, staff in some camps were apparently not made immediately aware of this or were not convinced of its accessibility until early 2004. This was seen as inequitable and was reported as a major concern for some staff.

### 3.2. Community Awareness and Education

As indicated above, a wide variety of health service providers were employed in the dissemination of information about PEP as a new component of the medical assistance available to rape survivors. SGBV staff routinely conducts sensitization activities in the community, going block to block to talk with people about SGBV prevention and what to do if an incident occurs. General SGBV education and awareness are also conducted on an ongoing basis during antenatal services, outpatient services, and at the health outposts/dispensaries that are located in other areas of the camps. Information was also shared in the schools and youth centres. In addition, two mass awareness efforts were undertaken in conjunction with World AIDS Day and 16 Days of Activism against Gender-based Violence, during which clinical staff spoke directly with the community about HIV prevention post-rape.

Finally, SGBV staff also engaged community leaders to help disseminate the message. Each of the camps have well-established camp leadership structures and highly engaged community leaders, including block leaders (typically men) and women's representatives or assistant block leaders (women, or in the case where the block leader is a woman, the assistant block leader will be a man). The introduction of any new service or activity involves meeting with the block leaders to solicit their input and facilitate the dissemination of messages to their constituents. In addition, religious leaders are also engaged to share education messages with the community.

In some camps an initial PEP awareness campaign and education of community leaders took place in November, shortly after the implementing organization learned that it would begin the PEP provision in December. Other community leaders reported that they first heard about PEP in December and January and some leaders reported learning about PEP for the first time in April and May 2004.

The community leaders demonstrated a high degree of awareness of the message that PEP is for the prevention of HIV and that, in order for it to be beneficial, the survivor must report to the hospital within 72 hours. All community leaders who participated in the FGDs reported knowledge of these two facts, with the exception of participants in Karago Camp. The high turnover of leadership due to ongoing repatriation meant that new leaders in Karago had not yet been trained by SGBV staff and were not aware of the existence of PEP as part of the medical response for rape survivors.

Staff and community leaders reported that in the initial months of PEP implementation there was significant confusion about whether PEP was preventive or curative. In response to this, implementing staff intensified their efforts in March and April to communicate clearly that PEP is not treatment for HIV. During FGDs this was repeatedly highlighted, as community leaders emphasized that they were *"told that PEP is not medicine for AIDS, but is only for prevention for those already affected."*



The community leaders reported that the following issues and questions about PEP were consistently raised when they first met with their communities:

- **The importance of advising women to try to inform their husbands of the incident.**  
*“Sometimes it happens that a woman is raped, and when she reaches home, she fears to explain to her husband, but they already meet for sexual intercourse and then wait until next day – they are asking if the man can also be given PEP.”*
- **Whether PEP can be used to treat AIDS / Response for those who are positive.**  
*Whether it is “really medicine which treats HIV/AIDS or if can get medicine for all the community.”*  
*“For someone who has already contracted HIV, is this medicine helpful for him?”*  
*“They think the drug is to treat HIV. They are wondering that if they have ARVs, they can prolong life.”*  
*“People who come and are found to be positive, why can’t they just give these drugs to them?”*  
*“Maybe somebody can be raped and found to be positive with the AIDS virus, they were asking how she can be assisted; even if there’s no treatment, what can be done to prolong life.”*
- **Process of repatriation and assistance available in Burundi.**  
*“Can a survivor travel with the drugs?”*  
*“What if something happens on the way, where can one get assistance?”*
- **Having sexual relations while taking PEP.**  
*“At first it was difficult to convince the men to not have marital relations during this whole period.”*  
*“The men discussed between themselves, this is no different, we must do this during the period of childbirth also.”*
- **Whether men can also benefit from medicine.**  
*“What about the man who has been attacked, even for men, they’re being raped”*

- **Effects after using PEP.**

The population of Mkugwa camp differs significantly from the other four camps. Much of the population is well-educated, from urban areas and highly informed, and because the population comprises a variety of different nationalities, the residents share with each other a diverse range of experiences. The residents here had understood clearly the difference between prophylaxis and long-term therapy, but raised some pointed questions, such as whether “in discordant couples who are using condoms, when the condom use fails, can the negative partner be given PEP?”

Eight of the ten clients interviewed reported that they had already heard something about PEP before they first came to the Drop-In Centre. One client reported that counsellors from SGBV came to her block and talked about PEP:

*“(We were told) that when we get problem of incident of rape, to come quickly here (to the drop in centre) without changing clothes so as to get that medicine of PEP. We were told that would not come beyond three days. We were also told that the medicine of PEP will help prevent HIV. Also, if we are quick to come, the medicine will keep the virus. If abused by a person with HIV, the virus will not have time to circulate in (the survivor’s) body. We were also told that beneficiaries of PEP are people who have been assaulted, but not those who have sexual intercourse willingly. Also, if one takes the medicine as prescribed by the doctor, it will be more effective.”*

To assess the variety of messages in the broader community, informal interviewing was conducted in various areas of Nduta camp. A variety of knowledge levels were observed. One male pastor reported no knowledge of anything related to SGBV or what should be done for someone who was raped. Three female *sungu-sungus* (refugee security persons) had high knowledge of the response for rape survivors and were familiar with PEP. Women interviewed near their homes in outlying areas quickly volunteered that a survivor should report “to the hospital” or “go to SGBV,” but they had very little idea about what kinds of assistance a survivor might receive when she reported. However, when prompted with examples of some problems a survivor might experience, some indicated some familiarity. Finally, women working in the market revealed quite high knowledge of the medical response for rape survivors. When prodded, they volunteered information on medicine for pregnancy, STIs, and HIV.

### **Gaps and Challenges – Community Awareness**

- *Prevention versus treatment for those who are positive.* The most fundamental challenge faced was in clearly explaining that PEP is for prevention only and cannot help someone who is already infected. The fact that ARVs were not entirely new to this population (PMTCT services had been in operation for 8 months prior to the introduction of PEP) did not seem to be a factor in community education. In the case of PMTCT, wide-scale community awareness was largely not conducted; the target population learned about PMTCT when they attended for antenatal care. (Antenatal care attendance is near 100% in these camps.) Because many survivors will not seek medical care post-rape, educating the entire community that a rape survivor can do something to prevent HIV if she reports quickly can provide extra impetus for reporting.
- *Insufficient planning and training before launching awareness campaigns.* Given a short start-up period, awareness campaigns with community leaders were quickly initiated, before staff themselves had an in-depth understanding of what was being introduced. Campaigns were hastily conducted and not always disseminating or reinforcing accurate information, leading to perceptions that PEP could be treatment for HIV. Similarly, inadequate time was devoted to formulating consistent first messages. For example, there was some confusion generated when local residents began talking about “P-E-P”, while refugees were educated about “PEP,” leading some clients to believe there were two different types of medicine they should receive. Of course, explaining “PEP” was made all the more challenging given that it was not feasible to effectively translate the words “post-exposure prophylaxis” into local languages.
- *Turnover of community leaders.* One camp lacked consistent community leadership due to the high rate of repatriation, hindering efforts to disseminate information to the community.

### **3.3. Offering PEP Post-Rape**

#### **Information and Counselling for Survivors**

##### ***Reporting to the Drop-In Centre***

Survivors typically report to the Drop-In Centre directly, or are escorted by a community member such as a block leader, a *sungu-sungu* or sometimes a family member or relative. In four of the five camps, a counsellor is on duty at the Drop-In Centre 24 hours a day, seven days a week to receive clients. In Mkugwa, given the small size of the camp population, the Drop-In Centre is staffed with a single Burundian counsellor. In this camp, survivors may report directly to the counsellor’s home, or the counsellor will be brought from her home if a client presents at the hospital during the night.

When a survivor presents, she will typically meet first with an SGBV counsellor, usually a Burundian refugee staff person. The survivor may also be accompanied to the police station near the entrance to the camp to receive the police form #3.

A clinical officer is immediately notified when a survivor presents at the Drop-In Centre. If it is during the day, the SGBV focal person will be sought out; if the focal person is not available, then another Clinical Officer who is able to attend rape survivors will be located. During the night, one Clinical Officer remains on duty in the hospital compound and this clinician will usually be the one to respond and provide the medical examination and care. However, the SGBV focal person is the only person who has access to the PEP drugs, which are kept in a locked box inside the Drop-In Centre, so during the night the focal person must nonetheless be brought from the staff compound (located just outside the camp) in order to dispense the drugs.

### ***Information and Counselling on PEP***

The Clinical Officer begins to provide care by providing reassurance and comfort to the survivor. The Clinical Officer then takes a history, conducts a general physical examination, a vaginal examination, and sends any collected specimens to the laboratory. A pregnancy assessment is conducted. The Clinical Officer will then proceed to explain what medicines are recommended to help the survivor, what options are available to her, and then prescribe and dispense the drugs directly to the client. Among the medicines that the Clinical Officer may discuss with the client are presumptive STI treatment, prevention of pregnancy and PEP.

As described by the practicing Clinical Officers, counselling on PEP typically includes discussion of what PEP is for, the side effects that may be experienced while taking PEP, and the importance of being tested for HIV.

Regarding the effectiveness of PEP, several Clinical Officers reported that they would typically tell the client something like *“we are not 100% sure if (HIV will be) prevented”* or *“I can’t say it’s 100%; (but) there is a possibility of protecting you.”*

Explaining that it was difficult to convey information about effectiveness, one clinician said, *“Even if you explain to them they don’t understand about it...you are only going to confuse him or her about it. When you explain, that person is depressed, not grasping information, even if you explain well, it is not sure she is going to capture the message. We try to explain to them, but in a shallow way.”*

But another said *“we say that we don’t know how many by percent, but that it has been observed that it can minimize the transmission of HIV – we don’t explain that it will prevent, but just minimize the risk.”* Some confusion around the concept of effectiveness was evident in interviews with clients. When asked what they were told about how well PEP would work, most survivors responded that they were told that if they took the medicine properly as directed, then it would be effective.

### ***Informed Consent***

While the protocol does not require a written consent, the project opted to obtain a written consent by the clinician prior to providing PEP. The consent form requires the client to

certify that she agrees to take the medicine called PEP and then to apply her signature or thumbprint. For survivors under the age of 18, a parent or guardian is required to consent for them. Some of the clinicians mentioned however that they do not see the need for a written consent noting that PEP is not different from other drugs a client elects or does not elect to take. Using a consent form might also raise ethical dilemmas that might occur when adolescent survivors do not wish to inform their parents or guardians.

### ***What Do Survivors Remember Being Told about PEP?***

When asked about what they were given medicine for when they came to the Drop-in - Centre, most clients interviewed talked about pregnancy, sexually transmitted infections and HIV/AIDS. However, there was more variation in the understanding and knowledge of what the specific medicine being called “PEP” was for.

Two clients did not clearly differentiate between the various types of medicines they were prescribed. They were (as were all the clients) clearly familiar with the word PEP, but they reported that they were told this medicine would solve all problems or all infections or “contaminations”. One said she thought taking PEP meant she would not get pregnant, not be contaminated with HIV, and prevent any kind of sexually transmitted infection.

Others had very specific recollections of what they were told about PEP:

*“(The doctor) told me that if the assailant contaminated me with HIV, that then HIV doesn’t grow. (The doctor) told me that the PEP kills the virus that the assailant had.”*

Another described that PEP was *“to kill the virus. To prevent me from AIDS.”* Another reported that: *“I believe that even though the person was HIV positive, the virus does not attack me.”*

*“I was told that the medicine is to help the virus stay in one place, not to circulate in the blood.”*

Nine of the ten survivors interviewed recollected being told about the possibility of experiencing certain side effects, such as nausea, vomiting, diarrhoea, fever, and abdominal pain, and noted that they had been told to return to the Drop-in-centre if they had any problems. Some survivors also reported that they were given behavioural advice, such as not to drink alcohol while taking the medicine and to not allow sexual intercourse. Some also reported that they were counselled on the importance of taking the medicine as prescribed.

*“I was told that I should be regular taking the medicine. Even if going on a trip, I should go with the medicine, so that I remember to take it.”*

Clearly a number of factors may influence client recall; the nature of the traumatic circumstances, the amount of previous information received, and a client’s level of education, all may contribute to both how a client understands and how well she remembers what the clinician told her about PEP. Given the small sample interviewed, it is impossible to draw any conclusions about the influence of these factors compared to the influence of any variations in clinician practice. However, it is worth noting that several survivors

reported having some prior knowledge about PEP and that what the clinician told them reinforced what they had already heard in the community.

### ***Special Circumstances***

One survivor who was interviewed was six months pregnant at the time of her assault. She described that the doctor asked her *“to report quickly whenever I see any special signs. But that if there are no special signs, if I am well, then to keep on taking the medicine.”* Clinicians reported some difficulty and frustration in counselling pregnant survivors. There is no clear guidance to offer survivors who are concerned about potential harmful effects PEP may have on their pregnancy.

### ***Gaps and Challenges – Information and Counselling for Survivors***

- *Providing accurate information about effectiveness.* Clinicians struggled to convey a simple, but accurate message about the effectiveness of PEP. Many reported making guesses about percentage effectiveness, instead of stating that we don't know how well it works, but that we believe it can be effective.
- *Necessity of written consent.* Although the draft guidelines made clear that written consent is not required for PEP provision, many staff felt strongly about receiving written consent from the client. The primary reason cited was that this medication differed from other drugs in that it could produce significant side effects and that the client should acknowledge she has been forewarned of these potential adverse events. Staff wanted legal protection and expressed some fear that if a client were to die while taking the medicine, that her family might take the clinician to court. Some clinicians did contend that written consent was not necessary, noting that PEP is not different from other drugs a client elects or does not elect to take.
- *Shortage of female Clinical Officers.* While the SGBV focal persons are all female, in some hospitals this individual is the sole female Clinical Officer in the camp. At most of the hospitals the shortage of female Clinical Officers means that survivors are often attended by a male clinician.

### **3.4. Assessing Baseline HIV Status**

The PEP treatment protocol stipulates that HIV testing should never be a prerequisite to PEP provision. At each step in the counselling and care process, SGBV staff and health providers may discuss with the client the possibility of having been exposed to HIV and the importance of being tested.

Clinical Officers described that they may advise the client to have an HIV test, explaining that if she is already HIV positive, taking PEP will not help her. Once clients have discussed HIV testing with the Clinical Officers and have expressed a willingness to be tested, they are referred for VCT.

Initially, clients who requested an HIV test were sent to a VCT counsellor located in a separate building in the hospital compound. However, after observing that low numbers

were actually going for testing and in light of concerns about confidentiality, staff revised this procedure. The SGBV programme makes a concerted effort to provide all services under one roof to avoid further disturbing the survivor or risking public exposure. To maintain confidentiality and avoid requiring the survivor to move about the hospital compound, SGBV staff decided to request that a VCT counsellor report to the Drop-In Centre to provide pre- and post-test counselling to the survivor in the Drop-In Centre facility. This procedure was inconsistently reported by staff however, indicating that increased communication still needs to be fostered between the SGBV staff, clinical officers and VCT Counsellors.

In one camp (Mkugwa), there were no VCT counsellors, so clients were referred and transported to Nduta Hospital (about 40 minutes driving distance away) to receive HIV counselling and testing.

In the client interviews, some survivors made clear that they understood the importance of having an HIV test in relation to taking PEP. When asked what the doctor told them about having an HIV test, one client reported:

*“The doctor told me that it is better if I can test before taking the medicine, because if it’s found I’m contaminated already with HIV, the medicine will not help. But if I have no problem, then the medicine will be able to help.”* Another affirmed that the doctor *“explained well that if the test shows I am already sick, then PEP will not help anything.”*

Another recalled being told:

*“The PEP medicine does not help in case the survivor is already positive. It is not good to take PEP medicine when already infected, because it might even shorten life.”*

Other clients mentioned the general importance of knowing one's health status:

*“Because if you are tested and found positive, you also get information on the conduct to follow in that circumstance to avoid spreading the HIV. You should have that test to know your health state and know how to behave in order not to spread or contaminate others.”*

One older woman demonstrated some confusion about what the baseline HIV test would indicate. She reported: *“I took the HIV test to see whether I was already contaminated by the perpetrator.”*

VCT with PEP clients follows the VCT protocol that is used for all VCT services. According to counsellors interviewed, the following topics are covered during pre-test counselling:

- What the client knows about HIV/AIDS
- What an HIV test means
- Factors contributing to HIV spread
- Modes of transmission of HIV; high-risk behaviour
- Risk reduction measures; safer sex
- Clinical features – how HIV presents, stages of illness
- Impact of HIV/AIDS, also stigma and discrimination
- Services available for those who test positive (supplementary feeding, Cotrimoxazole prophylaxis, follow-up counselling, treatment for opportunistic infections, and HBC if at a terminal stage).
- Discussion of how the survivor will cope if the result is positive and what the survivor will do if the result is negative.

Following pre-test counselling, rapid testing is done. There was some variation in consent procedures used for HIV testing. Some counsellors reported that oral consent was done, and that a client will sign only when she agrees for the results to be disclosed to a third person. But one described that the client would sign a consent form written in Kirundi signifying that she's ready to be tested.

Post-test counselling is done either the same day or the next day according to the wish of the client. The result is shared and follow-up is discussed. The counsellor stresses that even if the client has tested negative, it is not possible to know if she may have been recently infected and that it is therefore important for her to return in three months time in order to rule out HIV. The entire VCT process was reported to take anywhere from 45 minutes to three hours.



## ***Preventive Measures***

Counselling on risk reduction measures has proved especially critical for survivors who are married. Health providers, community members and clients all highlighted the tensions around the potential ramifications of sharing or not sharing the incident with one's husband.

One client reported that she was told that if her husband didn't use a condom, he could be contaminated from her. Her husband came with her for couples counselling and they discussed their options with the staff together. She described:

*"The staff gave him some condoms and asked him whether he would be able to wait having sexual intercourse until I finished the medicine. But once we got home, after a few days, he came back and said he was unable to continue (with abstinence). They offered condoms, and then he was using condoms."*

Another client recounted:

*"I came after some few days to get an HIV test because I was told that if I'm found positive it might be that I was already infected. I talked with my husband. I reported to my husband that the doctors advised me to not have sexual intercourse before I finished the medicine. My husband understood the situation and thanked me to have told him before he can have any affair with me. Because we had already tested together, when I go for the second time, we will go together to test together. He will also have the time to check whether the medicine has been effective or not."*

Those who did not elect to attend VCT services when they first presented, were advised to return the following day or in a few days time to meet with a VCT counsellor. Given the traumatic circumstances, the majority of clients did not opt for HIV testing the same day of the incident and instead returned to the Drop-In Centre for testing either the following day, after 2-3 days or at least within 1 week following the incident.

Survivors who accepted VCT and tested positive were provided with follow-up counselling by their VCT counsellor and were referred for clinical care, home-based care (HBC), supplemental feeding programmes, and to community support groups for people living with HIV/AIDS.

### **Gaps and Challenges – Baseline VCT**

- *Shared confidentiality of HIV test results.* Staff expressed frustration around the sharing of HIV results between the HIV counsellor and the attending clinician. Clinicians expected the results to be shared, contending that if a survivor is found to be HIV positive, this impacts the decision to provide PEP. But VCT counsellors were adamant about preserving client confidentiality.
- *Shortage of trained HIV/AIDS counsellors.* The above challenge would be diminished if more clinical officers were trained to provide VCT. The upside of this would be that it would reduce the number of people the survivor has to see, preserving confidentiality and clarifying follow-up. However staff pointed out that often the survivor may develop a better relationship with one care provider and that meeting with more than one person offers her a choice of provider.
- *Counselling on risk reduction measures for couples.* It was not being made clear for how long protective measures should be used. It was routinely noted that survivors were counseled on taking protective measures during the course of PEP therapy, but after the completion of PEP, the instructions were not clear. There appeared to be a disconnect between (a) what clients were told regarding when the possibility of HIV infection can be ruled out and the importance of repeat HIV testing (eg they are told to return in three months), and (b) when it is safe to discontinue abstinence or have unprotected sex.

### **3.5. Provision of Drugs, Management of Compliance and Side Effects, and Follow-up**

#### ***Provision of Drugs***

Adult survivors who elect to take PEP are prescribed bi-therapy for 28 days, consisting of 300 mg of zidovudine (AZT) and 150 mg of lamivudine (3TC), each to be taken twice daily. Survivors less than 40 kg are prescribed diminished doses according to body weight. For children less than 2 years of age or between 5-9 kg, it is recommended that PEP be provided in syrup form. However, the syrup was not available in this setting, and so clinical officers attempted to provide measured mg/kg body weight doses of crushed tablets.

The first dose is provided immediately in the Drop in Centre. A seven-day supply of each drug is then provided to the client in small plastic bags and she is requested to return to the Drop-In Centre in one week's time to collect a new supply of medicine.

As noted in the discussion of clinical officers training, the draft treatment guidelines originally stipulated that an initial one-week supply of drugs should be provided, with the remaining three-week supply provided at the one-week return visit. Concerned about compliance and usage of drugs, implementing staff revised this procedure to provide PEP via weekly return. Specific concerns noted by staff were an inability to monitor adherence after the first week,

inability to manage ongoing side effects, and the potential for the client to sell or share the drugs. This revised policy was also more consistent with the dispensing policies for other kinds of drugs in the camp hospitals.

During the course of this evaluation, it surfaced that many clinical officers in at least four of the camps were incorrectly prescribing AZT – providing 300 mg to be taken three times daily, instead of twice daily.<sup>1</sup> Though it's impossible to assess, this over-prescription may have led to experiencing increased side effects and it may also have factored into women's experiences in complying with the regimen. Many of the clients described that they were taking the medicine every eight hours and would wake early in the morning and late at night in order to take the tablets as directed. One client interviewed described how she was very careful to take the medicines at the right time and that she "wasn't going out" and was always staying in her house, so that she could take the medicine at the right time.

### ***When is PEP Indicated?***

Clinicians expressed a lack of confidence in determining who should and should not be offered PEP. They described several "gray areas" in which they weren't certain if PEP should be provided. For example, in a few of the camps, staff described how clients would come to the Drop-In Centre and report that they had been "ghost-raped" during the night. In one incident, a clinical officer reported that a client presented at the SGBV and said that when she woke in the morning, she "thought that she had been raped" during the night, describing how she felt physically and that a neighbor had seen someone coming from her house. The clinical officer reported that there was no indication that there had been an exchange of bodily fluids. Staff contended that some of these incidents were likely "false reporting" of rape in order to access a service perceived to be beneficial. Clinician practice appeared to vary in response. Some stated that they did not offer PEP, when "there was no evidence of rape," and clearly noted this in clinical records. Others always prescribed PEP.

*"(They) play sex with someone else and then take loophole and come to Drop-In Centre and say was raped, so can be provided PEP."*

*"Sometimes someone comes and reports being raped; we do a history and lab exam, but there is no evidence that she was raped, so we don't give PEP. We just do counselling and we send to VCT for test."*

*"(Some) pretend to cheat us that they have been raped...but we should provide (PEP), we're not there to say whether she was raped or not."*

*"Any woman can come and complain she is raped. Maybe she had sexual intercourse and then worried afterwards. But it is difficult to judge. We are not supposed to conclude as medical persons, we just give supportive investigation to support the survivor. But we can be cheated by the survivor."*

There is evidence that some HIV-positive women clearly hoped that this medicine might be able to help them. In one camp, a woman who was a PMTCT client reported to the Drop-In Centre. She declined VCT, but accepted PEP. However, when a VCT counsellor saw her

going to the Drop-In Centre one day, he and the SGBV Officer discussed her case. The VCT counsellor confirmed that she was HIV-positive and met with the client to discuss why she decided to take PEP. He reported that “in her mind, she thinks the drugs being given there are a cure for HIV.” After discussing with the counsellor, the client did not return to the Drop in Centre and only took PEP for one week. This incident also highlighted some of the challenges of shared confidentiality and breaches of confidentiality.

While PEP is an integrated part of the clinical management of rape and should therefore be provided to survivors from the local communities as well, this was not clear to some staff. In one camp it was reported that a survivor from the local community presented to the SGBV and knew about PEP; however, she was declined PEP by the attending clinician because the clinician believed that PEP was only to be provided to refugees. In the same camp, however, some non-refugee clients were offered and completed PEP.

### ***Management of Compliance***

In order to ascertain whether a client has been taking the tablets as prescribed, the clinical officer will typically ask how many pills the client has remaining and how many times per day she is taking the pills when the client presents at her weekly return visit.

Home visits are also a regular part of the SGBV strategy and activities. Follow-up visits to PEP clients are incorporated into these activities in order to monitor how survivors are doing overall, provide counselling, ensure compliance, review instructions on how to take the medicines, and discuss any other challenges or problems the client might be facing. One survivor reported that the “*counsellors were regularly visiting her and trying to remind her to take the medicine as prescribed.*” Some of the SGBV staff described that they would count the number of pills the client had remaining to help determine if she had been taking the tablets as directed.

When asked who helped them to take PEP, several of the clients interviewed reported that no one else helped them. Some clients described that their husbands helped them to remember the time to take the dose. One older woman reported that her niece “was reminding me to wake up and take it in the night.” Many of the clients interviewed were quite adamant about the personal importance of completing PEP, underscoring that this was motivation enough:

*“I forced myself to finish because I wanted to look for a strong life.”*

*“I was very careful; I was responsible for my health. I did not want to miss 1 hour, 1 day, to give a chance to HIV, because I did not know the health status of the assailant.”*

One woman traveled frequently outside the camp. She said that she never missed one day and that even when she traveled outside the camp, she took the medicine with her.

### ***Management of Side Effects***

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Clients are instructed to return to the Drop-In Centre if they experience any side effects or discomfort. Paracetamol is generally provided to manage complaints. Some clients were advised to take some food after taking the medicine. In some instances, clients were also given supplemental food rations. Fortified Corn Soya Blend (CSB) is regularly provided to postnatal clients, PMTCT clients, people living with HIV or AIDS and others with chronic illness via supplemental feeding programmes. It was suggested by staff that CSB rations also be routinely provided to clients taking PEP. Three of the clients interviewed had received CSB after experiencing side effects. They each reported that taking CSB eased some of the side effects and that the discomfort, loss of appetite, vomiting and nausea eventually subsided.

It is also worth noting that in some cases, reporting of side effects was confused by other maladies experienced at the same time. For example, a few had also presented with malaria at some point during the course of PEP and had difficulty differentiating between side effects due to PEP and discomfort and illness due to other factors.

### ***Follow-up***

Clients are asked to return each week to pick up another seven-day supply of PEP drugs, however there was variation across camps on when exactly clients were being told to report. In some cases, clients returned on the same day as they took their last pill in the morning, and in other cases they were instructed to come on the sixth day, with one full day's supply remaining.

For those who did not present at the Drop-in-Centre on the appointed day, a counsellor would attempt to locate the woman and remind her to come to collect the next week's supply. In a few cases, clients were not located in time as they had gone outside of the camp to conduct agricultural work or other activities. In some cases this led to a delay in provision and missed doses.

There are a few circumstances in which clinicians varied the follow-up plan. Clients who planned to repatriate were provided the full dose prior to repatriation. However, repatriating survivors were also generally encouraged to wait to repatriate if possible until after they completed PEP. Some clients and their families chose to delay repatriation for one to three weeks after discussing with the SGBV staff the importance of being able to manage side effects and provide support to the survivor. Similarly, Tanzanian clients from the local communities were sometimes provided with the full 28-day supply, particularly if they were coming from some distance away. However, these clients were still recommended to come for follow-up after some period of time, usually two weeks after the incident.

Universally, the ten interviewed survivors reported that it was not difficult to return each week to get a new supply of medicine. Of the clients interviewed, the walking distance from their homes to the Drop-in-Centre ranged from ten minutes to over one hour. One client said, *"It wasn't difficult, because it was like a rule to come on each first day."*

When asked a forced choice question about returning to the Drop-in-Centre to pick up a new supply of medicine, clients universally reported that they preferred to return to the Drop-in-Centre each week. When asked why, several cited the benefits of the ongoing counselling, additional services and continued reminders about how to take the medicine. (*“Because each day you come here, you get advice.”*) Three noted that they preferred to be given PEP weekly because otherwise they would have been concerned that they would not remember to consistently take the medicine.

*“It is better to come every week. Because if given once, I would have had some problems; I would have forgotten to take or maybe the place where I had put them (the pills).”*

As noted earlier in the discussion of the limitations of this evaluation, not enough is known about the challenges experienced by those who stopped taking PEP before completing the full regimen. SGBV staff may record any known reasons (record-keeping varied by camp) for dropping PEP, but a few cases were documented in which the survivor did not return to the Drop in Centre because she had traveled outside the camp, or the survivor was from the local population and did not return because of the distance.

### **Gaps and Challenges – Provision, Management and Follow-Up**

- *“Overloading clients with drugs.”* The majority of clinicians voiced concerns about the large number of drugs being prescribed simultaneously, and the attendant side effects and potential for poor compliance. The most efficient combinations of accompanying drugs were not available.
- *Unavailability of syrup.* The guidelines indicate that PEP should be provided as syrup for children less than two years of age or less than 5-9 kg. However, in the absence of syrup, clinicians lacked clear guidance on how best to treat these clients. In practice, clinicians crushed tablets, estimating the dose based on mg/kg body weight calculations. No one felt comfortable with this method.
- *Supervision of clinical service providers.* SGBV Focal Persons appeared to be left on their own without much supervision unless they reported problems. A few of the focal persons were quite inexperienced in providing post-rape care. Consistent supervision and periodic review of records may have helped to identify and correct the mistakes regarding dosages at an earlier point in time.
- *Determining when PEP is indicated.* Many challenges arose around distinguishing when PEP is and is not indicated. Some clinical officers struggled to balance what they felt was a responsible clinical assessment of risk with a non-judgmental response to women who they “were not convinced had been raped.” These specific challenges arose in part because of misconceptions about the benefit of PEP. Staff also struggled with issues related to consensual versus non-consensual sexual encounters.
- *Scheduling of follow-up to avoid missed doses.* Practice on the timing of weekly drug provision varied slightly by camp. In some camps, clients were asked to follow-up on the same day as they were taking their last dose in the morning, leaving little time for follow-up if the client didn’t show.
- *Tracking follow-up with clients.* Some camps kept quite fastidious records of who was due for follow-up and when, and what subsequent action was taken. However, this was not consistent across all the camps and in some camps there appeared to be no systematic approach. At one site, records did not make any note of a survivor returning to pick up a new supply, although staff attested that she had returned and completed PEP.

### 3.6. Repeat HIV Testing

Clients are recommended to return for repeat VCT at three months after the incident. Although the guidelines recommend that clients also return at six weeks time for repeat VCT, this procedure was not implemented by staff to maintain consistency with VCT protocols and testing methods already in use.

There was no consistent method employed for reminding clients to return at three months time. In some cases, SGBV counsellors were still continuing follow-up with the survivor, and would make a point to remind the client about the importance of having another HIV test. In other cases, the VCT counsellor might directly follow-up with the client. (VCT counsellors also make home visits in the community to follow-up with clients and conduct awareness and education activities.) Lastly, some clients may not have any further follow-up contact with a service provider and may (or may not) report for VCT on their own. For those who return, some report directly to the VCT counsellor (located in a separate building from SGBV) and others may report directly to the SGBV unit.

Most of the interviewed clients reported that they planned to return for the second HIV test. During the course of client interviews, several of the clients volunteered the precise date they were told to return for another HIV test. It was evident in their reporting how fixed the date was in many of their minds.

Clients who planned to repatriate were counseled to seek out a facility where they could receive follow-up HIV testing in Burundi. One chronic frustration expressed by staff was that they didn't know much about services available on the other side of the border. This made it difficult to counsel clients on what care they could expect to receive or where to go for those services.

#### **Gaps and Challenges – Repeat VCT**

- *Monitoring Return for Follow-up VCT.* One of the challenges resulting from high rates of repatriation is that it obscures other dynamics which may impact follow-up care. Repatriation was often the ready scapegoat for any observed breakdown in services. While there are clearly other factors affecting return for HIV testing, these were difficult to detect given the tracking and record-keeping of those who do and don't return for VCT at 3 months.
- *Coordination between VCT and SGBV staff.* Staff reported different understandings of whose responsibility it was to encourage clients to return at 3 months time. Some reported a hierarchy of responsibility in which the SGBV Officer, the clinical officers and the VCT counsellor were responsible for the overall case management of survivors. Others reported that either the VCT counsellor or the SGBV counsellor was individually responsible for follow-up.



## SECTION 4. OBSERVED EFFECTS

While it is not possible to assess the effectiveness of PEP in achieving the ultimate outcome of preventing HIV seroconversion, several potential effects and qualitative benefits of PEP provision were observed in this project.

Following the introduction of PEP, staff are under the impression that there is an increase in the number of survivors reporting to the Drop-in Centre. This could have been due to a combination of possible factors:

1. The additional benefit of HIV prevention as an impetus for reporting. One Block Leader reported that *“HIV response (to rape survivors) had been seen as a missing element...some women thought it was not worth going for services.”* Another said *“(PEP) assisted a lot. Even those who were trying to hide after being raped, now feel they can attend.”*
2. Confusion over the benefit of PEP and who PEP is indicated for (“false reporting” to seek HIV treatment)
3. An increase in actual rape incidence in conjunction with increased banditry and insecurity

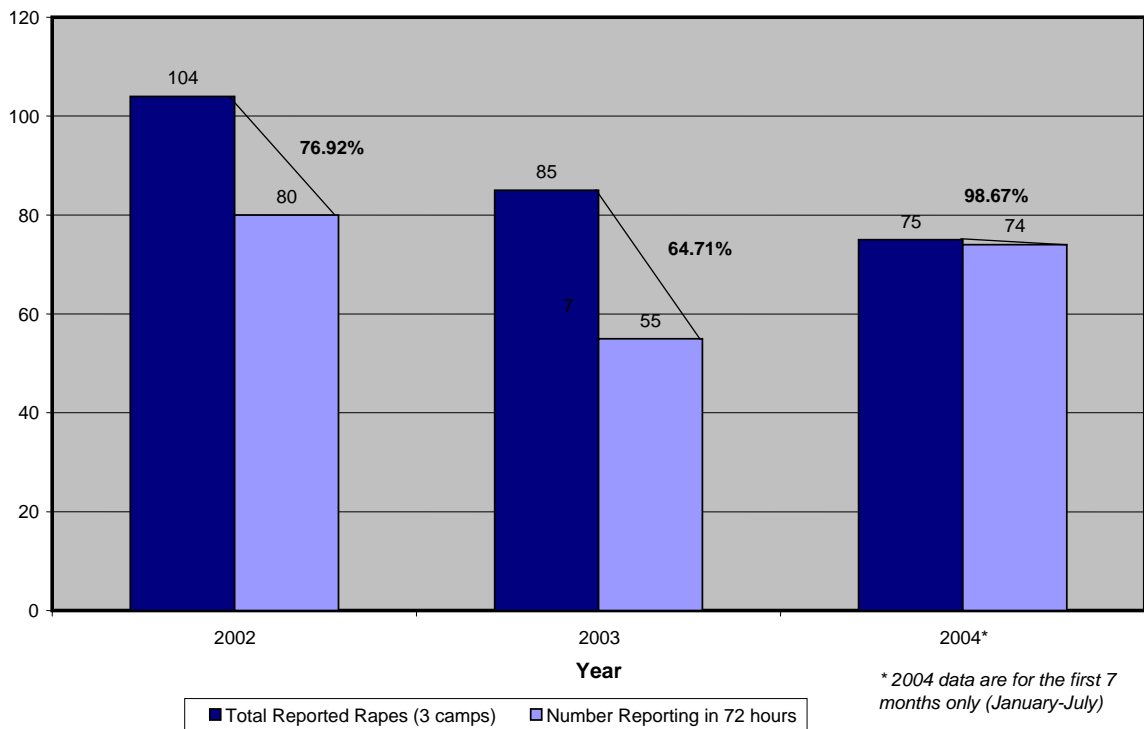
More significantly, the proportion of survivors reporting within 72 hours increased from the prior two years. Figure 1 shows the trend in those reporting within 3 days after the incident in Mtendeli, Nduta and Karago. In the first seven months of 2004, 98% of all survivors reporting came within 72 hours in these three camps. Over all five camps, 92.31% reported within 72 hours from January – December 2004.

Again, part of the increase in timely reporting may reflect a combination of:

1. the ability to do something to prevent HIV as an added impetus for early reporting, and
2. increased awareness of the importance of early reporting as a result of mass awareness efforts

The personal and social ramifications of being able to do something about HIV are clearly an important impetus for early reporting. One Block Leader in Mtendeli stated that survivors were motivated to report to the Drop-in Centre in order to get medical assistance *“that will make her husband confident that she is protected from AIDS. If there wasn’t any help, then he would divorce her.”* A survivor’s ability to demonstrate that, although she has been raped, she is able to do something to prevent HIV, appears to help facilitate increased openness and discussion of the incident with husbands or partners. As described by clients themselves, husbands in turn may provide support that enables completion of PEP.

**Figure 1. Three-year Trend in the Proportion Reporting within 72 Hours in Mtendeli, Nduta and Karago**



Data show a high acceptance of PEP therapy and initial VCT. The proportion of those who reported within 72 hours and accepted PEP is shown in Table 1.

During the period January – December 2004, ten survivors discontinued PEP and did not complete the full 28 day PEP regimen. Reasons for dropping PEP were spontaneous repatriation (2), distance from facility for Tanzanians (2), left the camp for more than 1 week (2), side effect (1), alcohol abuse (1), social problems(2). Although the numbers are too small to draw conclusions, it is worth emphasizing that the largest impediments to completion appeared to be due to logistic or psychosocial problems and not tolerance of side effects. In the same period, 49 survivors (53.8%) did present with side effects due to PEP, including nausea, tiredness and loss of appetite.

Finally, it is impossible to estimate the personal and psychological importance to the survivor of being able to take PEP following sexual assault. When asked what they thought would be the result of taking PEP, several of the survivors commented not only on the prevention of HIV, but one noted that *“it will result in a better life; that I will have a better life like others.”* Another stated that *“it is for me to protect my life. Because they told me that if we (survivors) present ourselves quickly at the Center, we won’t be contaminated.”* This sense of reassurance may also assist in the mental recovery and stability of the survivor. One survivor described that they (she and another woman were attacked at the same time) had been having nightmares after the incident: *“We still remember people running to us. That’s why I kept taking PEP,*

**Table 1. PEP Acceptance, VCT Acceptance and PEP Completion(Dec 2003 – June 2004)**

	Mtendeli	Nduta	Kanembwa	Karago	Mkugwa	TOTAL
Reported Rapes	50	23	21	7	3	104
Reported Rapes that were within 72 hours	50	23	16	5	2	96
<b>% Reported Rapes that were within 72 hours</b>	<b>100.00%</b>	<b>100.00%</b>	<b>76.19%</b>	<b>71.43%</b>	<b>66.67%</b>	<b>92.31%</b>
Number of survivors starting PEP	50	23	13	4	1	91
<b>% reporting within 72 hrs who took PEP</b>	<b>100.00%</b>	<b>100.00%</b>	<b>81.25%</b>	<b>80.00%</b>	<b>50.00%</b>	<b>94.79%</b>
Number of survivors who discontinued PEP	2	3	2	0	0	7
<b>% survivors starting PEP that completed PEP</b>	<b>96.00%</b>	<b>86.96%</b>	<b>84.61%</b>	<b>100.00%</b>	<b>100.00%</b>	<b>92.31%</b>
Number of survivors accepting VCT within 1 week**	41	22	15	4	1	83
<b>% survivors accepting** VCT within 1 week</b>	<b>82.00%</b>	<b>95.65%</b>	<b>71.43%</b>	<b>57.14%</b>	<b>33.33%</b>	<b>79.81%</b>

\*\*Disaggregated data were not available on the number of PEP eligible survivors or the number of survivors taking PEP who opted for VCT. Based on staff observations, the proportion accepting VCT among those taking PEP is considerably higher than acceptance among all survivors.

*because if I hadn't, I would be very concerned.*" Feeling that they are able to do something to prevent HIV may mean one less burden for survivors to carry.

## SECTION 5. MONITORING AND EVALUATION

Assessing the effectiveness of PEP provision is challenging. Regular evaluation must be conducted to measure whether PEP is being operationalized effectively. The introduction of PEP highlights the need for clear record-keeping to facilitate the follow-up and ongoing assistance provided to survivors and to enable staff to quickly assess gaps and breakdowns in the care process. While SGBV staff generally had records of follow-up activities, there were often no notes from clinical follow-up. Good records also facilitate the ability to conduct regular supervision, which can help to identify and correct errors or problems early on.

At the time of this evaluation, a system for formal monitoring and evaluation (M&E) of the introduction of PEP had not yet been put in place. A separate monitoring and evaluation form for PEP provision was developed to record key indicators related to PEP provision. These data can then be entered and tracked in a database to facilitate easy monitoring and assessment of service provision across the camps. A simple database was created in

Epilinfo for this purpose. The indicators and form to be used for monitoring and evaluation are provided in Annex 3.

In addition, staff knowledge, attitudes and practices should be periodically assessed to determine where additional training is needed and what elements of provider-client communication need to be strengthened.

## **SECTION 6. DISCUSSION**

Despite some initial setbacks, this project effectively integrated the provision of PEP into the medical response for rape survivors. Implementing staff were able to capitalize on the existence of well-established SGBV programmes and relatively stable populations, with strong liaisons between service providers, community leadership structures and groups mobilized on SGBV issues, as well as strong working relationships with implementing partners on community services. Many staff acknowledged that without these mechanisms it would have been impossible to implement this service.

Staff responded to challenges as they were encountered and demonstrated great resourcefulness and commitment to continually improving services. This section discusses some of the overarching challenges faced in implementation and makes recommendations for future programmes implemented in similar settings.

As with any new initiative, it is natural and necessary to place special emphasis on it at the outset. However, future efforts should pay careful attention to ensuring that the initiation of PEP provision is clearly defined as another component of post-rape care and, as such, is integrated into existing SGBV and clinical protocols and not presented to staff or community members as a stand-alone, parallel programme.

At the same time, efforts need to be made to ensure that existing HIV/AIDS groups are involved and aware of this service. Careful attention must be given to how PEP is initiated both as a component of SGBV service delivery and as an integrated element of overall HIV prevention efforts. While the Tanzanian camps have strong multisectoral networks addressing HIV/AIDS, for the most part these groups were not tapped to help disseminate or correct messages about post-rape HIV prevention versus treatment for those who are HIV positive.

Initial community awareness efforts were hindered by confusing messages and inadequate responses to community questions about how PEP differed from long-term HIV treatment regimens. Perceived inequities formed a fundamental barrier to clearly understanding the benefits of prophylaxis for rape survivors. Many members of the population had heard about ARVs and the availability of medicines to treat HIV elsewhere and questioned why medicine for HIV was only being provided for rape survivors. Some even suggested that health staff were “withholding” medicine. Staff reported that *“they (the community) think we have very few drugs and don’t want to give them out (to people other than rape survivors.)”* As one

community leader reported, “*They (people in the community) complain, why do only pregnant women and rape survivors get these medicines...why is there nothing for men?*” Other leaders requested that this “rare medicine” be made more available.

Obviously this barrier would be diminished in settings where ARV therapy for those who test HIV positive is also available. However, this project has demonstrated that it is feasible to provide PEP in the absence of complementary programmes for those who are HIV positive, and that there is a clear benefit to providing PEP post-rape. However, very careful attention needs to be given to how post-exposure prophylaxis is described and presented to the community and to educating staff about how best to respond to confusion and concerns regarding prevention versus long-term therapy.

### ***Preparation and Involvement of Clinical Staff***

The introduction of PEP provision raised many challenges in providing appropriate and respectful care to rape survivors and highlighted the need for expert training in this area. It is essential that clinical staff receive comprehensive training or refresher training on the clinical management of rape survivors prior to or in conjunction with introducing the additional component of PEP provision to post-rape services.

In addition, clinical staff must be more involved in education, training and supervision efforts. Implementation should be jointly led by a medical staff person in conjunction with SGBV staff who both have clearly defined roles and responsibilities. This leadership can in turn engender collaboration and communication between SGBV staff (social workers/counsellors) and clinical staff. It is essential therefore to ensure that a specific medical person can devote some time and attention to overseeing the introduction of new post-rape clinical services.

Finally, implementing agencies should ensure that PEP is available and in place for health care providers in case of occupational exposure. This is not only an essential step for staff morale and equity, but can also serve as an opportunity to ensure that staff understand the principles of PEP.

### ***Additional Concerns for Displaced Population Settings***

The experience in Karago camp, where a vast population movement was occurring, suggested some additional challenges of providing PEP among less stable populations. In less stable settings, particular emphasis should be placed on training clinicians to develop an appropriate follow-up plan. While weekly follow-up appeared to be beneficial in this setting, staff acknowledged the challenges in ensuring return. It may well be that longer-term provision of drugs is more appropriate in less stable settings.

In the refugee context, attention needs to be given to cross-border collaboration and supporting the development of comparable services in the country of origin. At the time of this evaluation, there was a tremendous amount of anxiety around repatriation in many of

the camps. Community members voiced concern about where they could expect to get services and assistance during and after return. The availability of SGBV and HIV/AIDS services on the other side of the border was reported to be minimal. Many community members are more concerned about starting and fostering the development of services in the country of return.

Collaborating refugee and local community service providers must give careful consideration upfront to how information is communicated, received and interpreted by both the refugee population as well as other surrounding communities.

Despite early challenges and setbacks, this project demonstrated the feasibility of providing PEP for sexual assault among a displaced population, and has suggested some potential secondary benefits to survivors.

## **SECTION 7. RECOMMENDATIONS FOR IMPROVING EXISTING SERVICES**

UNHCR and its implementing partners should consider the following actions towards improving the provision and monitoring of PEP and the overall clinical management of rape survivors in the Kibondo refugee camps.

### *Training*

- Ensure that all clinical officers responding to rape survivors attend a general training on the overall clinical management of rape survivors, with particular emphasis on how to provide non-judgmental care.
- Increase the numbers of clinical staff formally trained on PEP provision and the clinical management of rape survivors.
- Provide a refresher course or follow-up training for those who attended the initial training.
- Provide Clinical Officers with more information on the use and pharmacology of ARVs, and how the PEP regimen differs from therapy for those who are HIV positive.
- Train more Clinical Officers (specifically the SGBV focal persons) on providing HIV VCT, so that a single clinician is capable of providing all medical support to the survivor.
- Train SGBV counsellors carefully on the difference between offering advice versus counselling the survivor about her options, particularly in relation to negotiating relations with husbands/partners.

### ***Conducting Information, Education and Communication Campaigns***

- Provide more formal training seminars (conducted by medical personnel) to key community leaders on the medical response provided to rape survivors.

- Include medical personnel more regularly in the dissemination of messages to the community, particularly to new populations. Someone must be present who is equipped to accurately respond to questions.
- Develop talking points or recommended responses to key questions to ensure that all staff are consistently delivering the same message.
- Use the radio to disseminate a consistent and clear message about the medical response available for rape survivors, including PEP.
- Develop posters and other IEC materials to communicate what services are available and why a survivor should report quickly.
- Emphasize that in order to provide the best possible assistance, survivors should report *as soon as possible*, ideally within a few hours (not just within 72 hours).
- Where turnover of community leaders is high, focus awareness efforts on highly regular repetition of a few simple key messages to ensure that new staff and leaders have received essential basic messages (eg why a survivor should report to the Drop-in Centre quickly and what the components of the medical response provided to rape survivors, including PEP.)

### ***Counselling Survivors***

- Provide all clients with accurate information on the effectiveness of PEP (e.g. that the efficacy of PEP following sexual assault *is not known*, but that there is some evidence that it could be effective in reducing the risk of HIV infection.)
- Collectively reconsider the advantages and disadvantages of administering written consent for PEP. Written consent is not necessary for provision of PEP. If staff wish to require written consent, then the form should be provided in the client's language and the client should be offered a copy of what she has signed or thumb printed.
- Provide Clinical Officers with a checklist of points to be covered in PEP counselling to ensure that all key points of information are conveyed.
- Improve counselling on risk reduction and prevention measures, specifically on the importance of continuing with these measures until HIV and STI infection are excluded. The provider should communicate that the possibility of HIV transmission cannot be excluded until at least 3 months post potential exposure.
- Include discussion of being able to complete treatment as part of promoting informed consent. The client should make clear that she understands that she will have to take medications for 28 days. This should also include discussion of follow-up procedures, so that the clinician and the client can agree on a plan of follow-up that will be effective and enable her to complete the course.

### ***Providing PEP***

- Post the correct adult doses (per the treatment guidelines) on the wall of the medical examination room to ensure that mistakes are not made.
- Procure Combivir.
- Procure clear instructions for dosage for children.
- Always keep client records in a locked cabinet. If this is not currently possible, steps need to be taken to make it possible.

### ***Ensuring Appropriate Follow-up***

- Place more emphasis on training clinicians on how to collaboratively develop an appropriate follow-up plan that balances the needs of monitoring compliance and side effects with any unique challenges the client may face. As appropriate, the follow-up plan should be tailored to clients' special needs and clinicians should feel they have the discretion to provide a supply for a period longer than one week.
- Schedule return visits for the day prior to the client's last day's supply to ensure adequate time for follow-up if she does not present.
- Start individual medical record files for all rape survivors to ensure that clear clinical records are kept for each visit, facilitating clinicians' ability to monitor changes and follow-up.
- Use a standard clinical form for the recording of post-rape history, physical examination findings, laboratory investigations, treatments prescribed and follow-up plan.
- Ensure proper coordination and communication between VCT and SGBV staff and services around repeat HIV testing. Clarify staff roles and responsibilities for monitoring and encouraging follow-up. Ensure accurate and consistent documentation and systems for sharing follow-up information with the consent of the survivor.

### ***Monitoring and Evaluation***

- Strengthen supervision of clinical staff providing PEP. Someone should follow up and periodically review case notes to identify and correct ongoing problems.
- Use standard monitoring and evaluation forms to guide the introduction of PEP in the clinical management of rape (see Annex 3).



# Annex 1: Map of Kibondo Refugee Camps

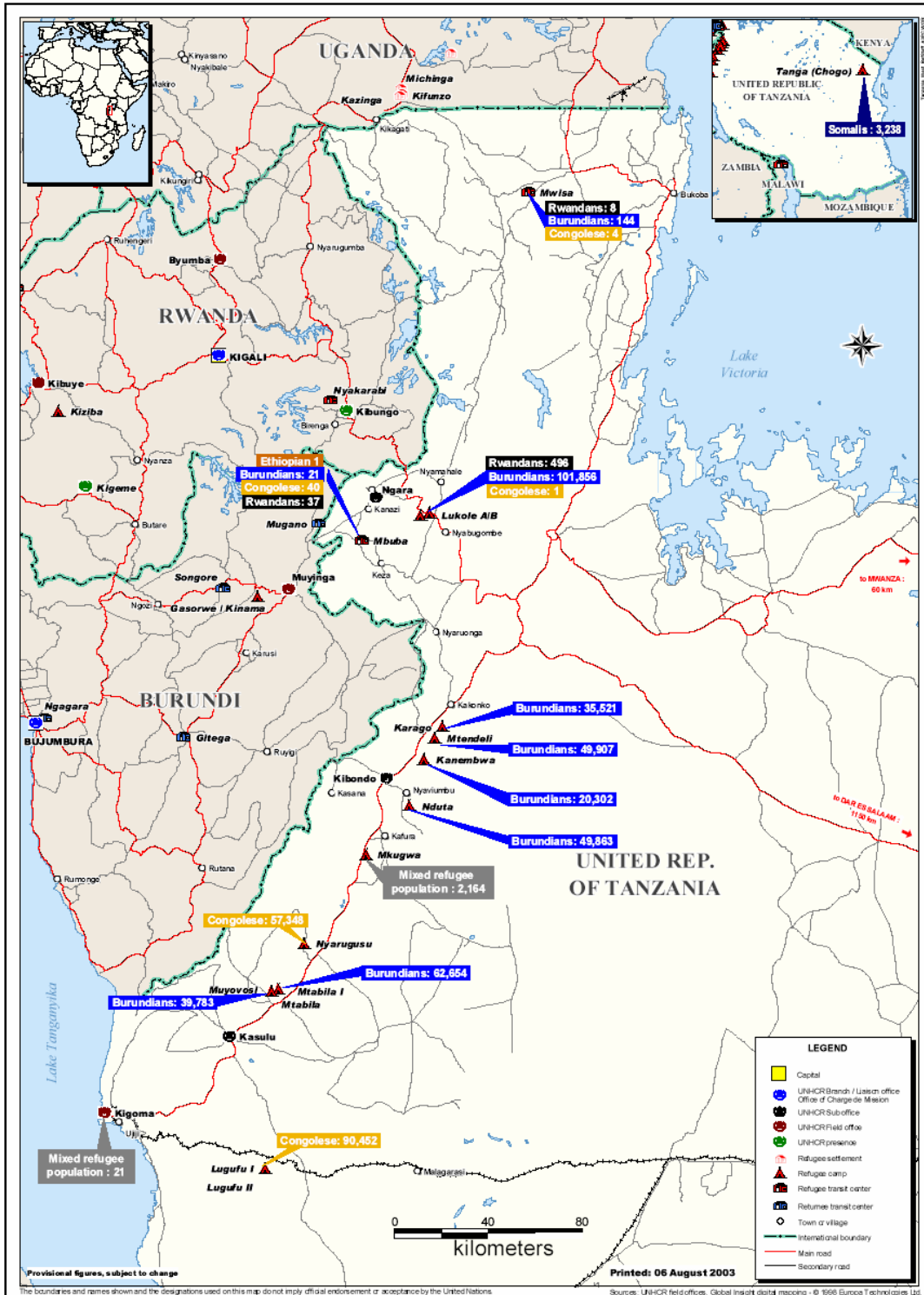


UNITED REPUBLIC OF TANZANIA

Refugee Statistics as of June 2003

GIMU / PGDS

Geographic Information and Mapping Unit  
Population and Geographic Data Section  
Email: mapinfo@unhcr.ch



## Annex 2: Data Collection Tools

### *Client Individual Interview Questionnaire*

#### Introduction

*Mwakeye / Mwiliwe. Ni amahoro?* (Greetings.) My name is \_\_\_\_\_. This is \_\_\_\_\_. She works in SGBV in xxx. She is here only to translate what you and I say in English and Kirundi.

I am a student from America. I am here working with UNHCR and IRC to learn about some of your experiences here in [Mtendeli / Nduta / Kanembwa].

I want to talk with women who have taken the medicine called PEP.

I would like to ask you some questions about your medical experiences and opinions about the services here in the DIC.

Examples of some questions I would like to ask you are:

- Where did you first learn about the medicine called PEP?
- What did the doctor tell you about PEP?
- Was taking PEP difficult?

What you choose to share with me will help me to make recommendations to improve services for women both here in [Mtendeli / Nduta / Kanembwa], as well as for other refugees elsewhere.

#### Consent

You do not have to talk with me if you do not want to. I cannot offer you anything for choosing to talk with me.

Whether or not you choose to talk with me will not have any affect on the services you receive here.

Anything you choose to share with me will be treated confidentially. That means that not only will we speak in private, but any answers you provide will remain private.

\_\_\_\_\_ has also agreed to confidentiality and can never repeat anything that is said here.

You do not have to tell me your name. Staff here are also not permitted to tell me your name. I have made up a special code that I will use on this form. [SHOW FORM]

As we talk, I will write down your responses.

The questions will take about 40 minutes. If you choose to talk with me, you do not have to answer every question.

If at any time you are uncomfortable or don't want to answer a question, just tell me, and we will stop the interview or move to another question.

#### Do you agree to answer some questions today?

[IF NO] I understand that you don't want to talk with me about PEP today. Thank you for your time.

[IF YES] *Urakoze cane.* Thank you for your willingness to talk with me. Do you have any questions before we get started?

## QUESTIONNAIRE

### SECTION I. SOCIODEMOGRAPHIC INFORMATION

Some of the questions that I ask you may be about information that you have already told staff here, but it is important that I hear directly from you. To begin, I have a few basic questions.

1. Can you please tell me your age?
2. Umaze igihe kingana iki hano mw-ikambi? (*About how long have you lived in the Camp?*)
3. Urubatse? (*Are you currently married?*)
4. Waraciye mw-ishule? (*Have you ever attended school?*)
5. Wageze mu mwaka wa kangaha? (*What was the highest level of schooling you completed?*)

### SECTION II. KNOWLEDGE ABOUT SGBV SERVICES AND PEP

Now I have some questions about when you first came here to the DIC.

6. When you first came here to the DIC, what services or assistance did you expect to receive? (PROBES: What kind of assistance did you hope to receive? Anything else? What type of medicine/medical assistance?)
7. Before you came to the DIC, had you ever heard about the medicine called PEP?
  - a. The first time you ever heard about PEP, who told you about it? (PROBE: Where did you here about it? Anyone/anywhere else?)
  - b. What did that person tell you about PEP? (PROBE: Is there anything else that you had heard about PEP before you first came here?)

[IF HASN'T ALREADY MENTIONED SEEING DOCTOR OR TAKING MEDICINE, ASK 8 and 9]

8. When you first came to the DIC, did you see a medical doctor?
9. Did the doctor give you any medicine?
10. What did the doctor give you medicine for? / Were you given any other medicines? (PROBE: For example, did you take any medicine...[READ a-d].)
  - a. so that you wouldn't get pregnant?
  - b. so that you wouldn't have a STI?
  - c. for any pain or discomfort?
  - d. for anything else?

[IF NO MENTION OF HIV / PEP, ASK: Did the doctor talk with you about the medicine called PEP?]

11. Overall, what do you remember most about what the doctor told you about the medicine called PEP? (IF NO RESPONSE: Did the doctor talk with you about HIV? What did he tell you about it?)
  - a. When the doctor talked about PEP with you, is there anything else that he or she told you about what it is for? [ASK: what else?; PROBE: Anything else?]
12. What did the doctor tell you about how effective PEP is? That is, what did the doctor tell you about how well this medicine would work (against HIV infection)?
13. Did the doctor mention any possible side effects from taking PEP, that is, did he talk with you about feeling some sickness from taking the medicine?
  - a. What types of sickness did the doctor mention? (PROBE: Anything else?)

14. What did you think would be the result of taking PEP? (PROBE: Anything else?)
15. When you first talked with the doctor, what did he or she tell you about having an HIV test? (PROBES: What did the doctor tell you about why you should have an HIV test? Anything else?)
- Did you also talk with someone else about having an HIV test? (PROBE: did a special counsellor talk with you about testing for HIV?)
16. At this first visit, what did you decide about having an HIV test? Did you decide to . . .
- to have the test right away,
  - to wait and come back for the test another time, or...[ASK Q16a-b]
  - to not have a test at all?
- 16a. When [did/do] you plan to come back for the test?
- 16b. Did you return for the test?
17. What was the main reason you decided [to have / not to have] an HIV test?
18. After leaving the DIC, did you talk about PEP with anyone else? (PROBE: For example, did you talk about PEP with ... [READ a-d]... )
- [your husband]?
  - someone in your family?
  - a friend or neighbor?
  - someone else in your community?
- 18a. What did you discuss with that person? (PROBE: What did that person tell you?)
- 18b. Did you receive any advice from any service provider about talking with (your husband / partner) about taking PEP? [IF YES: What did they advise you to do?]
19. Thinking about your experiences taking PEP and how you felt while taking PEP, how difficult was it to ... (READ a-e) ... [FOLLOW-UP: What made it difficult to \_\_\_\_\_?]
- Remember to take the medicines at the right times?
  - To take more than one type of medicine at the same time?
  - Tolerate the side effects or any sickness you felt from taking the medicine?
  - Find a safe place to keep your medicines?
  - Come back to the DIC to get more medicine each week?
20. Was there anything else that was difficult about taking PEP? (What else was difficult? What made it difficult...?)
21. Would you have preferred to return less frequently to the DIC, or did you not mind returning each week to the DIC? For example, if you were to choose, would you have preferred to receive the remainder of the medicine after one week, or would you have preferred as it was to come back to the DIC each week? (Follow-up: Why would you have preferred...?)
22. About how long does it take you to walk to the SGBV DIC?
23. Were you able to take PEP for all 28 days?
- Sometimes it may be hard to remember to take medicine or it is not convenient or it is difficult to take when you are not feeling well. Did you ever miss any days or doses of PEP? How many [days/doses]?
  - What was the main reason you missed a [few days/doses]? (PROBE: were there any other reasons?)
  - What was the main reason you stopped taking PEP? (PROBE: were there any other reasons?)
  - What helped you to complete the full course of PEP for 28 days? (PROBES: Did anyone help you to take PEP? Were there any other reasons?)
24. Did anyone ever suggest to you that you should share your medicine with someone else? (IF YES, ASK: Who? What did that person tell you?)

25. Did anyone ever suggest to you that you should sell your medicine? (IF YES, ASK: Who? What did that person tell you?)
26. *[Since you have completed taking PEP,]* do you plan to return for another HIV test? When do you plan to return?  
IF ALREADY CAME BACK FOR REPEAT TESTING, ASK:
  - a. What helped you to come back after 3 months? Did anyone help you to remember to come?
27. If a friend were to come to you and ask your advice on what she should do if she were to be raped, what would you tell her?
28. In your opinion, what if anything could be done to improve services for others who need this kind of assistance?

## **CLOSE**

That is the end of my questions. Thank you very much for your time and for sharing your experiences and opinions with me. What you have told me has been very helpful in understanding the experiences of women who take PEP. We have talked about many things today. I understand some of these things may be very difficult for you. If you have any questions or concerns, or you just want to talk with someone, there is always a counsellor here to help you at anytime.

29. Before we conclude, is there anything else you would like to tell me about the services you've received here?
30. Urafise ikibazo wifuza kumbaza? *(Do you have any questions that you would like to ask me?)*

Urakoze kandi kuganira na jewe. *(Thank you again for speaking with me.)*

## **Focus Group Discussion Guide**

### **Introduction**

[GREETINGS]. My name is \_\_\_. This is \_\_\_. She is here only to translate what we say in French and Kirundi.

I am a public health student in the United States. I am here with UNHCR to learn about your experiences responding to rape survivors, and specifically about providing the medicine called PEP. The outcome of this evaluation will be to make recommendations for how we can improve your services here, as well as to guide how services are provided to other refugees elsewhere.

Thank you for coming here today and thank you in advance for your patience. Because I do not speak Kirundi, we must all be patient and allow time for the translation.

Can we start by having each of you introduce yourselves – your name, what block you represent, and for how long you've lived here in [NAME OF CAMP]?

Before we begin, let us agree on how our discussion will take place. It is very important that you say candidly and completely what you think and feel about the topics raised in our conversation. There are no right or wrong opinions. Please speak freely. Please talk one-by-one and give everyone a chance to speak. Whatever you share with me will be treated confidentially. All information will be reported in a summarized way. Are we all agreed?

I also would like to ask your permission if I may tape-record our conversation. This is only because it is difficult for me to take good notes and speak with you at the same time. The tape will help me to remember what you have said here after we finish talking. I have this machine here. No one other than me will listen to this tape. Is it okay to use the tape recorder?

### **Warm-Up Activity / Introductory Questions**

1. I'm sure you have all had some kind of experience with sexual violence here in xxx – for example, perhaps you've assisted a survivor who sought out your help. Thinking about rape specifically, can we start our discussion by making a drawing of rape incidence here in xxx and around xxx?

### **Mapping Activity:**

Where does rape occur and in general, who does it happen to? Are there people who are more vulnerable than others? Who are the other people who are affected by rape? In general, who are the perpetrators? What groups or actors respond to rape incidents? Where will survivors go first to seek help? *Probe* : In xxx and around xxx? *Probe* : Are there any other groups or actors who work to prevent or respond to rape? (In the area of health, legal support, social support?)

### ***Transition Questions: Experience and Involvement with PEP IEC Campaigns***

2. What is the medical response to rape survivors? When they come to the DIC, what services will they receive?
3. Have you all heard of PEP? When was the first time you heard about PEP? (*Probe*: where? from who?)

Before the introduction of PEP, what were you told about what PEP is and who it is for? Who talked with you? (*Probe*: a clinical officer? SGBV staff?) What are the most important messages that you remember being told about PEP?

When you first heard that PEP would be offered, what did you think about it? (*Probes*: What questions or concerns did you have about PEP? Were your questions answered satisfactorily? What was confusing?)

How were you involved in sharing information about PEP? What were your experiences when you went to your blocks to explain about PEP?

- o When you went back to your blocks to tell them about PEP, how did they respond?
- o What questions or concerns did they have?
- o What did you find was challenging about explaining PEP?
- o How did you feel about the quantity of information you had to clearly explain this new service to them?

### ***Key Questions: Observed Outcomes***

4. If a rape survivor were to come to you today and say she is worried about HIV, what would you tell her?
5. In general, rape can often be underreported because of fear or stigma. In your opinion, what are the most important factors that help survivors to come and seek care at the DIC?
6. Since PEP was introduced, have you observed any changes in the reporting of rape to the DIC? (What changes are you seeing?)

### ***Closing Questions: How to Improve Information Campaigns***

7. In your opinion, how do you think the first information, education and communication campaigns could have been improved or done differently? Are there any groups here (refer to drawing) that were not sufficiently included? Who could have been more involved/done more?

What other ways or materials do you think would be useful to better communicate to the community what PEP is? What information should be included? What messages are the most important to communicate? The most difficult to communicate?

8. Finally, do you have any further suggestions for what could be done to improve PEP provision or other services for rape survivors?

Murakoze cane. Thank you for your time and for sharing your opinions. Do you have any questions that you would like to ask me?

## ***Semi-Structured Individual Interview Guides***

### **Introduction/Consent**

Thank you for taking the time to talk with me. As we discussed earlier, I am here working with UNHCR to document your experiences with PEP.

As you know, the implementation of PEP provision in the refugee setting is new and many people are very interested to learn about your experiences here.

The outcome of this evaluation will be to make recommendations for how to strengthen and monitor PEP provision here, as well as to produce a report that can be used as a guide for expanding PEP provision to other refugee or displaced persons settings.

I would like to ask you some questions about your experiences and opinions regarding the medical response for rape survivors and specifically about offering PEP [baseline and follow-up VCT]. Please share candidly and completely both the positive and negative aspects of your experience, so that we can learn both what has worked well and what have been the challenges of implementing PEP provision.

Whatever you share with me will be treated confidentially. All information will be presented in an anonymous or summarized way. Is it okay to proceed with the interview?

I also would like to ask your permission if I may tape-record our conversation. This is only because it is difficult for me to take good notes and speak with you at the same time. No one other than me will listen to this tape. Is it okay to use the tape recorder?

### **Questions for SGBV Officers**

First, I have some basic questions about your SGBV services:

1. Can you please describe what your role and responsibilities are? How long have you been working here in X camp?
2. At any given time, how many staff are typically here at the DIC?
3. Who are the other actors, community groups and leaders involved in SGBV activities in this camp?
4. What types of GBV are most commonly reported in your camp?
5. Regarding rape, what are some of the root causes of violent incidents? Who are the perpetrators of violent incidents in your camp?
6. Rape is typically underreported. Do you think that the majority of rape survivors in your camp come to the DIC or do you think that those coming to the DIC may actually represent a small portion of rapes committed in the camp?
7. Say I had been raped and came to the DIC in the middle of the night, what would happen to me first? (Then what...?) What is the interaction with the police? Would anything be different if I came during the day?
8. About how long would it take for all of the activities to occur? (How long are rape survivors typically here for?)
9. If someone had escorted me to the DIC, what would this person be asked to do once we arrived?

### **Medical Response**

1. About how long will a survivor have to wait before the clinical officer arrives?
2. During the medical examination, is anyone else present?
3. What are survivors told about what will happen to them during the medical exam?
4. What kinds of questions do rape survivors ask?
5. How is consent obtained? What are they told about their options? In your opinion, do clients understand the process of consent? What other steps are taken to ensure clients rights are promoted and protected?
6. Are there special protocols for counselling and consenting children?
7. How is follow-up conducted? Under what circumstances does this vary – according to protocol and in practice when has it varied?
8. How is VCT counselling incorporated into care? Is it always offered at first visit? Have any clients accepting PEP refused VCT at first visit?
9. Is anything different for repatriating refugees?
10. Have any Tanzanians been offered PEP? What has been different re VCT f/u, etc.?
11. What kinds of community awareness campaigns were conducted... prior to PEP introduction / after PEP introduction? (When, how many...?) How might the IEC needs be different in a refugee/displaced population setting with new arrivals or less stable population?

12. Based on your experience, what have you seen as the main challenges in introducing PEP provision? How common has this been? Would you say this has been a major or minor challenge?
  13. What do you think were the key enabling factors or essential elements for beginning to implement PEP provision here?
  14. When survivors have presented, do they know about PEP? Have any of them specifically mentioned or asked for PEP or medicine for HIV/AIDS? What did they say?
  15. Since beginning PEP, have you observed any changes in SGBV clients?
  16. Is there anything else you would like to share with me or do you have any questions for me?
- Thank you again for taking so much time to talk with me. I appreciate your candid responses. Before we conclude I have a few questions about records and protocols.
17. What are the different kinds of records that you keep? Who has access to the confidential records?
  18. What protocols or guidelines do you routinely use in the DIC? How are they used? Where are they kept?
  19. What charts or forms or tools do you use to track when someone is due for follow-up?

### **Questions for Clinical Officers**

First I'd like to ask some questions about any **training that you've received on PEP**.

1. What training sessions have you participated in related to both the overall clinical management of rape survivors and specifically on the provision of PEP? Could you describe the general content and activities of each of the training sessions? In the PEP training, what did you learn about that you felt was new or that you didn't have a lot of experience with?
2. In your opinion, what was the best or strongest aspect of the training? What areas were weak or could have been stronger? Was there a topic or area that you would have liked to learn more about or have additional training on?



### **Guidelines**

3. How has the PEP treatment protocol been most useful to you in your practice or when you are attending to a case? How does it help you guide your discussions with survivors?
4. What parts of the guidelines do you think could be strengthened?

Now I'd like to ask some questions specifically about the **medical care that is provided to rape survivors**.

5. How are you notified that a rape survivor needs your attention? How quickly are you able to report to DIC? During the night-time, how is this different?
6. Is anyone else ever present in the exam room during the medical examination?
7. When you first meet with a rape survivor, what do you talk with her about first? What kinds of questions do survivors ask?

### **Regarding PEP**

8. When survivors have presented, do they know about PEP? Have any of them specifically mentioned or asked for PEP or medicine for HIV/AIDS? What did they say?
9. What are they told about the other medicines they may be taking at the same time? What do you provide for ECP? / for presumptive STI treatment?
10. What do you tell them about the effectiveness of PEP?
11. How is VCT incorporated into post-rape care? Do you discuss having an HIV test? What do you say to the survivor about her risk? Does this differ from how things were done prior to introducing PEP and if so, how?
12. Is an HIV test always offered at first visit? Have you attended any clients who accepted PEP but did not want to have an HIV test at the first visit?
13. What do you tell a client who is already known to be HIV positive? Or who tests positive?
14. How is consent obtained? What are they told about their options? In your opinion, do clients understand the process of consent? What other steps are taken to ensure clients rights are promoted and protected?
15. Are there special protocols that you use for managing children or minors? For counselling and consenting children?
16. How is follow-up conducted? Under what circumstances does this procedure vary – both according to protocol and in practice when has it varied?
17. How is compliance monitored? Do you ask the client if she has completed the course? How do you ask whether she has missed any doses/days? How do you counsel a client who reports she has stopped taking PEP? If she has missed some days, do you discontinue PEP or do you continue with the remaining doses?
18. What side effects have clients reported? How common has this been? How are side effects managed?
19. How are procedures different for refugees who report they plan to repatriate?
20. Have any Tanzanians reported here and been offered PEP? What has been different regarding follow-up and VCT?
21. Based on your experience, what have you seen as the main challenges in PEP provision? How common has this been? Would you say this has been a major or minor challenge? [For cases suspected of 'false reporting', how have you advised them?]
22. Other than the treatment protocol, what other additional resource materials or information would find helpful in your practice? For training purposes?
23. Is there anything else you would like to share with me or do you have any questions for me?

### **Questions for VCT Focal Persons**

First I'd like to ask some questions about any special **training** that you've received related to PEP.

1. What training sessions have you participated in? Can you describe the content and activities of each of the training sessions?
2. What did you learn about that was new or that you didn't have a lot of experience with?
3. In your opinion, what was the best or strongest aspect of the training?
4. Are you familiar with the draft treatment guidelines for PEP? How do you think the guidelines could be strengthened?

Now I'd like to ask some questions specifically about **responding to rape survivors**.

5. How are you notified that a rape survivor needs your attention? How quickly are you able to report to the DIC? If a survivor reports during the night, how will this be different?
6. When you first meet with a rape survivor, what do you talk with her about first?
7. What do you tell survivors about . . .
  - a. their possible exposure to HIV? their potential level of risk?
  - b. why it's important to have an HIV test? (about why it's important to know their status in relation to taking PEP?)

- c. If her result will be positive, what do you tell her about what health services will be available to her?
8. When you counsel a rape survivor, what kinds of questions do survivors ask? What do you tell them?
9. Do you meet with survivors before or after they have been counseled about PEP?
10. How is consent obtained? What are they told about their options? In your opinion, do clients generally understand the notion and process of consent? Do they understand that the HIV test is offered as a choice? How do you know this?
11. What special protocols or procedures do you use for counselling children or minors?
12. Have any clients not wanted to have an HIV test at the first visit? Have any clients told the counsellor or clinical officer that they wanted to have a HIV test, and then changed their minds after meeting with the VCT counsellor?
13. Once the test has been administered, how long does it take for the results? Do you wait with the client for her results? How do you meet with the client to discuss results?
14. How do you plan for follow-up if the result is negative? / if the result is positive?
15. How is follow-up coordinated and conducted with DIC staff? Do you work with one specific counsellor for a given survivor?
16. Are clients returning for VCT at 6 weeks? At 3 months?
17. In your experience, what are the main reasons you've observed that clients do not return for repeat VCT?
18. How are HIV testing and follow-up procedures different for those who opt to repatriate?
19. For Tanzanians from the local population, what has been different related to VCT f/u?
20. Based on your experience, what have you seen as the main challenges in introducing PEP provision? How common has this been? Would you say this has been a major or minor challenge?
21. In your view, have awareness campaigns successfully communicated what PEP is? How could they be strengthened? What messages have not been clear or penetrated well?
22. Are there any other resource materials or information that you would find helpful to have in your practice?
23. Is there anything else you would like to share with me or do you have any questions for me?

#### **Additional Questions for Health Managers**

1. When did you first learn that [name of camp] would be a site for PEP provision for rape survivors? As Health Manager, how were you involved in the process of starting up the PEP?
2. Have you ever participated in any special training related to the provision of PEP – either for occupational exposures or in the case of sexual assault or training related to ARVs in general? (What was the content and activities of the training?) (Was PEP/ARVs something new or something that you didn't have a lot of experience with?)
3. Are you familiar with the content of the training that was provided to clinical officers on the provision of PEP? In your opinion, what was the best or strongest aspect of the training? What areas were weak or could have been stronger?
4. In your opinion, what is the most useful part of the PEP treatment guidelines?
5. How have medical personnel been involved in community awareness campaigns on the medical response to rape survivors (including PEP)?
6. Are all health care staff aware of PEP, what it is for and who it is for? How have staff been educated on PEP? How are new staff made aware of PEP?
7. Is PEP currently available to hospital staff in case of occupational exposure?
  - a. Do all staff know about the availability of PEP for themselves in case of occupational exposure? How have they been made aware of this?
  - b. What are the criteria for providing it?
  - c. Who counsels staff in case of occupational exposure?
  - d. Would such an incident be brought directly to your attention?
  - e. Has an occupational accident ever occurred for which PEP was provided?
8. Based on your experience, what have you seen as the main challenges in introducing PEP provision? How common has this been? Would you say this has been a major or minor challenge?
9. Currently, COs are administering written consent for the provision of PEP. Do you think written consent is necessary or do you think oral consent would be sufficient? Why?/What do you see as the benefits/disadvantages?
10. What process or procedure is in place for children who do not have a parent or guardian to provide consent? (Does the attending physician decide what is in the child's best interest? Does he or she consult with anyone else? Does this apply for both HIV testing and PEP provision?)

11. How are clinical staff supervised? How are cases reviewed, monitored? Who provides oversight/supervision of clinical officers attending rape survivors?
12. What are the differences in roles for Burundian and Tanzanian COs in relation to attending to rape survivors?
13. How have efforts been coordinated between VCT/HIV health services and SGBV health services? What have been the challenges? How could this relationship be strengthened?
14. What do you think were the key enabling factors or essential elements that helped to start implementing PEP here?
15. What do you think were the major barriers to starting PEP provision for rape survivors here?
16. Have you experienced any challenges with implementing PEP provision in relation to the local Tanzanian communities? (Probe: Because it is not national policy to provide PEP for rape survivors, how has this affected how services are provided? How has this affected information and awareness?)
17. What have you seen as the positive or negative secondary effects of starting to provide PEP for rape survivors? (For example, have you observed any possible impact on utilization, community awareness of HIV / rape, etc.?)
18. Based on your experience with providing PEP thus far, are there any parts of the draft treatment guidelines that you think could be strengthened?
19. What topics or areas do you think staff need more training on? What areas need more emphasis?
20. What are the limitations you face in making improvements? (adequate/appropriate staff?)
21. Other than the treatment protocol, what other additional resource materials or information related to PEP do you think would be helpful to have available to your staff? For training purposes?
22. Is there anything else you would like to share with me or do you have any questions for me?

### Annex 3: PEP Monitoring and Evaluation Data Form

**CODE NUMBER:** \_\_\_\_\_ **Date of Rape:** \_\_\_ / \_\_\_ / \_\_\_ **Time of Rape:** \_\_\_ . **Date of Exam:** \_\_\_ / \_\_\_ / \_\_\_ **Hour of Exam** \_\_\_ .  
 \_\_\_\_\_ (day/month/year) \_\_\_\_\_ (00 – 24 hours) \_\_\_\_\_ (day/month/year) \_\_\_\_\_ (00 – 24 hours)  
**Year of Birth:** \_\_\_ \_\_\_ \_\_\_ **Age:** \_\_\_ \_\_\_ **Sex of Survivor:** \_\_\_\_\_

**VISIT INFORMATION: FIRST VISIT AND FOLLOW-UP VISITS DURING WEEKS 1-3**

	First Visit	One Week Follow-up Visit	2nd Week Follow-up visit	3rd Week Follow-up Visit
<b>Date of Visit</b> (day/month/year)	___ / ___ / ___ ___	___ / ___ / ___ ___	___ / ___ / ___ ___	___ / ___ / ___ ___
<b>Is survivor Currently Pregnant?</b>	[ ] NOT Pregnant [ ] Pregnant	[ ] NOT Pregnant [ ] Pregnant	[ ] NOT Pregnant [ ] Pregnant	[ ] NOT Pregnant [ ] Pregnant
<b>Given Emergency Contraception?</b>	[ ] EC NOT given [ ] EC Given			
<b>Given STI Presumptive Treatment?</b>	[ ] STI treatment NOT Given [ ] STI treatment Given	[ ] STI treatment NOT Given [ ] STI treatment Given		
<b>HIV test done?</b>	[ ] NOT done [ ] Done, negative [ ] Done, positive [ ] Done, indeterminate	[ ] NOT done [ ] Done, negative [ ] Done, positive [ ] Done, indeterminate		
<b>Was Survivor Given PEP?</b>	[ ] PEP NOT given [ ] PEP Given	[ ] PEP NOT Given [ ] PEP Given	[ ] PEP NOT Given [ ] PEP Given	[ ] PEP NOT Given [ ] PEP Given

<b>PEP Adherence</b>		<input type="checkbox"/> Taken as prescribed <input type="checkbox"/> Missed days/doses ( <i>how many</i> ):____ <i>Reason Missed:</i> _____ <input type="checkbox"/> Stopped taking PEP <i>Reasons Given:</i> _____ _____ _____	<input type="checkbox"/> Taken as prescribed <input type="checkbox"/> Missed days/doses ( <i>how many</i> ):____ <i>Reason Missed:</i> _____ <input type="checkbox"/> Stopped taking PEP <i>Reasons Given:</i> _____ _____ _____	<input type="checkbox"/> Taken as prescribed <input type="checkbox"/> Missed days/doses ( <i>how many</i> ):____ <i>Reason Missed:</i> _____ — <input type="checkbox"/> Stopped taking PEP <i>Reasons Given:</i> _____ — _____ _____
Any <b>symptoms or possible side effects</b> of PEP reported?		<input type="checkbox"/> None <input type="checkbox"/> Nausea <input type="checkbox"/> Vomiting <input type="checkbox"/> Flu-like symptoms <input type="checkbox"/> Other: _____	<input type="checkbox"/> None <input type="checkbox"/> Nausea <input type="checkbox"/> Vomiting <input type="checkbox"/> Flu-like symptoms <input type="checkbox"/> Other: _____	<input type="checkbox"/> None <input type="checkbox"/> Nausea <input type="checkbox"/> Vomiting <input type="checkbox"/> Flu-like symptoms <input type="checkbox"/> Other: _____
Any <b>clinical signs of anaemia</b> ?	<input type="checkbox"/> None <input type="checkbox"/> Yes, describe:_____	<input type="checkbox"/> None <input type="checkbox"/> Yes, describe:_____	<input type="checkbox"/> None <input type="checkbox"/> Yes, describe:_____	<input type="checkbox"/> None <input type="checkbox"/> Yes, describe:_____

**VISIT INFORMATION: FOLLOW-UP VISITS POST-COMPLETION OF PEP**

	<b>6 Week Follow-up Visit</b>	<b>3 Month Follow-up Visit</b>
<b>Date of Visit</b> (day/month/year)	____ / ____ / _____	____ / ____ / _____

Is survivor <b>Currently Pregnant?</b>	<input type="checkbox"/> Not Pregnant <input type="checkbox"/> Pregnant	<input type="checkbox"/> Not Pregnant <input type="checkbox"/> Pregnant
<b>HIV test done?</b>	<input type="checkbox"/> Not done <input type="checkbox"/> Done, negative <input type="checkbox"/> Done, positive <input type="checkbox"/> Done, indeterminate	<input type="checkbox"/> Not done <input type="checkbox"/> Done, negative <input type="checkbox"/> Done, positive <input type="checkbox"/> Done, indeterminate
<b>PEP Adherence</b>	<input type="checkbox"/> PEP taken as prescribed during 4 <sup>th</sup> Week <input type="checkbox"/> Missed Days / Doses, ( <i>how many</i> ): _____ <i>Reason Missed:</i> _____ _____ <input type="checkbox"/> Stopped taking PEP <i>Reason Stopped:</i> _____ _____	
Any <b>symptoms or possible side effects</b> of PEP reported during final week of prophylaxis?	<input type="checkbox"/> None <input type="checkbox"/> Nausea <input type="checkbox"/> Vomiting <input type="checkbox"/> Flu-like symptoms <input type="checkbox"/> _____ ] Other: _____ _____	
Any <b>clinical signs of anaemia?</b>	<input type="checkbox"/> None <input type="checkbox"/> _____ ] Yes, describe: _____ _____	

**Other Information** (*Note Date*):

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