INFORMATION NOTE ON HIV TESTING FOR RESETTLEMENT APPLICANTS

EXECUTIVE SUMMARY

The United Nations High Commissioner for Refugees interviewed 29 physicians who perform HIV testing for resettlement applicants in an African country (hereafter referred to as Country X) in July 2005. The findings of this qualitative research were subsequently reported to UNHCR Headquarters and shared with the resettlement countries concerned. This information note highlights the salient findings and recommendations of that initial research. In addition, UNHCR consulted with a number of other offices in Africa and Asia where major resettlement activities take place and found that parallels can be drawn to the findings of this study. Hence, this information note is indicative of what may be occurring in other countries regarding the procedure of pre- and post HIV test consultations. Recommendations include:

1. Counselling duties should be transferred to professional counselling services: Doctors lack the resources to provide proper counselling on the nature of HIV and the various measures that can be taken to prevent its spread. Some physicians complained of lack of time and/or training, while others asserted counselling was unnecessary. The overwhelming majority of doctors interviewed for this study were providing either inadequate counselling or none at all.

2. Professional and confidential translators should be provided: Currently, patients who do not speak English provide their own translators who are usually family members or friends. Doctors complained that translators provided by the applicants are unprofessional, unaccountable and may not be accurately conveying information. Since translators are usually family members or friends of the patient, doctors were concerned, given the stigmatisation of HIV in Africa, that translators provided by the applicants compromise doctor-patient confidentiality by revealing the patient's status to his/her family.

3. Applicants and doctors should be informed of resettlement criteria: Applicants must be informed that only for certain countries may HIV-positive status be an obstacle to resettlement. All of the panel physicians who were interviewed in Country X expressed confusion as to what medical conditions will result in the possible denial of a visa. Doctors told stories of patients disappearing or committing suicide after testing positive for HIV due to an erroneous assumption that their resettlement application would be automatically rejected.

4. HIV-positive applicants should receive care and treatment while awaiting resettlement: Even though resettlement applicants have the right to medical care while in Country X, xenophobia and scarce resources make it difficult for resettlement applicants to receive care and treatment. The vast majority of the doctors interviewed offered to provide treatment, including antiretroviral medications. A consensus emerged that it would be far more efficient for resettlement countries to allow them to do so while the applicants awaited resettlement. This would maintain the applicants' health and avoid the expense of intensive treatment to reverse the decline in health caused by HIV after their arrival in the country of resettlement.

5. Procedural safeguards should be enacted to ensure follow-up consultations: Every panel physician who was interviewed in Country X complained of patients neglecting to return for post-test counselling. Post-test counselling ensures that applicants are familiar with the disease and the measures that can be taken to avoid spreading it. Doctors agreed that the resettlement process would function more efficiently if a release, in the form of a signed affidavit, that the patient had undergone post-test counselling, were required before a visa could be granted. While some countries currently require a similar procedure, the applicable forms should be modified to ensure

that they contain more detailed information and should be translated into the various languages spoken by the majority of resettlement applicants.

In conclusion, given the consistency of the feedback from the 29 physicians in Country X combined with similar issues reported in other countries and regions on this issue, a larger multi-country study using qualitative and quantitative methodologies is warranted.

INTRODUCTION

The recommendations in this quantitative survey are the result of a joint study commissioned by the Office of the United Nations High Commissioner for Refugees (UNCR) in Country X and the Centre for the Study of AIDS in Africa (CSA), an HIV/AIDS and human rights policy group. The study was conducted from 29 June to 30 July 2005.

The study's main goal was to gather feedback from the physicians in Country X who perform HIV testing for resettlement applicants and make recommendations to improve the HIV counselling and reporting process.

The recommendations contained in this report have been formulated with special attention to confidentiality, expediency and efficiency of the HIV testing and reporting process. These recommendations aim to improve the testing process by making it fairer and more confidential to applicants and less burdensome for both doctors and clients. Furthermore, the recommendations of the report do not impose an undue financial or administrative burden on resettlement countries.

METHODOLOGY

Twenty-nine panel physicians were interviewed on the HIV testing process using a semi-structured questionnaire[1]. Approximately seventy-five percent of the interviews used to compile the report were conducted by means of a personal visit to the physician's office. The rest were conducted by telephone due to time constraints and a limited budget for travel expenses. Personal visits allowed for evaluation of factors such as office and reception layout, nonverbal communication by the doctors and staff, and the general atmosphere that is experienced by resettlement applicants visiting a given doctor. These factors, while not expressed in a purely verbal interview, are important in the counselling process: a friendly and open office will put an applicant at ease and allow the doctor to elicit all the information necessary to properly carry out counselling and testing, while an intimidating environment will encourage applicants to withhold potentially important details.

After the doctors were interviewed, their responses were collated and examined. A general consensus emerged on certain issues. This consensus was then translated into the recommendations contained in the report.

CASE STUDIES AND RECOMMENDATIONS

CASE STUDIES ON COUNSELLING DUTIES

Doctor A (Country X): *"I don't have the time to counsel all my patients. There are always people in the waiting room, and when I get a patient for an HIV test, I have to just take the blood, send it off to the lab, and tell them I'll call them soon. It really isn't fair, but we're just not set up for that kind of thing here."*

Doctor B (Country X): *"Counselling has become obsolete. AIDS has been around for 20 years and everyone knows about it by now. The mystery is disappearing. I pretty much ask the standard 'have*

[1] Based on "Human Rights and Ethical Guidelines on HIV: A Manual for Medical Practitioners", South African Medical Association, July 2005 (www.samedical.org).

you ever been to the hospital' kind of questions, and leave the rest to the media and other groups that are supposed to teach about AIDS."

Doctor C (Country X): *"I don't do the counselling here; I wouldn't even know where to begin. There is an in-house counselling service here at the hospital, and I send all the patients there before I get them to sign the consent form. After the test, and when I bring them back to get their results, I send them back to the service for post-test counselling. They [the counselling service] have experience and training dealing with people's reactions to being told they're HIV positive. I just take care of the medical procedures. That is my job."*

Doctor D (Country X): *"It takes about 40 minutes to properly counsel someone about HIV. You are supposed to ask them about whether they've been exposed and tell them all about condoms, abstinence, nutrition, good health and prevention. I can't do all that here. Many of these patients [resettlement cases] don't even speak English. Besides, I only get them for about ten minutes – just long enough to draw some blood to send to the lab."*

Doctor E (Country X): *"We don't have the time or training [to do counselling]. I operate pretty much on a 'need to know' basis. If there isn't something that I feel is an imminent threat, I just send the sample to the lab."*

Doctor F (Country X): *"Counselling isn't my job. I don't chat with people about prevention or their behaviour or their feelings."*

RECOMMENDATION ONE:

Counselling duties should be transferred to professional counselling services

Doctors lack the expertise and time to provide proper counselling on the nature of HIV and the various measures that can be taken to prevent its spread as well as the measures to provide support, care and treatment for those who are HIV positive. While physician opinions ranged from an assertion that counselling is unnecessary because *"everyone knows about AIDS and how not to get it"* to the simple explanation that *"I'm not trained as a counsellor, and I don't have the time to properly counsel all my patients,"* the overwhelming majority of doctors interviewed for this study were providing either inadequate counselling or no counselling at all.

In order to solve this problem, countries could utilise professional counselling services provided by non-governmental and charitable organisations. Some doctors are able to provide counselling through specialised services based at their particular hospital or clinic. When doctors have no such service, pre- and post-test counselling should be performed by a local specialised service that has been approved by the resettlement country.

CASE STUDIES ON PROFESSIONAL AND CONFIDENTIAL TRANSLATORS

Doctor A (Country X): *"What am I supposed to do when the translator is a family member or friend? I can't give those people [the translators] the result in cases where a patient turns out to be HIV-positive! I find myself sitting across from sixteen-year-old girls that have brought their father in as a translator and thinking, 'If I tell this guy that his daughter is HIV-positive, he is going to kick her out on the street.' What am I supposed to do in that situation?"*

Doctor B (Country X): *"As long as the patient seems to understand and they sign the [consent] form, I draw the blood and go on with the test. I don't speak French or Arabic or whatever some of the refugees from Ethiopia and other places are speaking, so I'm stuck with the translator they bring in. Some of these translators don't speak English any better than the patient. I never know if they're getting the message across or not."*

Doctor C (Country X): *"I don't know if the patients really understand [the consent form and testing process] or not. Most of my refugee patients for the past few years have been from Ethiopia, Congo, or the Sudan. Almost none speak English, but they'd sign anything to get a visa. For all I know, their translators might be saying 'sign the form or you don't go [to the resettlement country].' I'm forced to work with these translators because of language problems, but I try to make sure that the patients understand what HIV is and how not to spread it, and I try to avoid giving results to family members. I have no way of telling whether I succeed."*

RECOMMENDATION TWO:

Professional and confidential translators should be provided

Currently, patients who do not speak English provide their own translators. These translators are usually family members or friends. There is widespread concern among physicians that these translators are not properly conveying messages to patients. The doctors complained that translators provided by the applicants are unprofessional and unaccountable. Furthermore, many doctors worry that their patients are not receiving all information material to their decision to undergo the test. Most importantly, given the stigma attached to HIV in many African societies, doctors were concerned that translators provided by the applicants compromised doctor-patient confidentiality by requiring the doctor to reveal the patient's HIV status to the translator. When patients are forced to use family members or friends as translators, and the doctor has no way of communicating the patient's HIV status but through the translator, it is almost certain that the patient's family will learn of his/her HIV status.

In order to solve this problem, resettlement countries should consider providing professional and confidential translators for testing and counselling sessions. To facilitate these services and the applicant's understanding of testing information, UNHCR could assist resettlement countries with the translation of existing information and consent forms and distribute these translations to doctors to be used on a voluntary basis. Every panel physician interviewed in Country X stated that they would use translated forms if they were made available.

CASE STUDIES ON RESETTLEMENT CRITERIA:

Doctor A (Country X): *"I recently had a large family from Ethiopia come in for testing. There were probably about eight or nine of them, and only the mother turned out to be HIV-positive. I called her back in to tell her about the result and asked her to come back for reconfirmation testing the following week. About a month later, after I'd been calling for quite a while, one of the other family members told me that she'd killed herself after she found out [she was HIV-positive]. They said that she wanted them to be able to go [to the country of resettlement], and they couldn't since she was HIV-positive. I'm not sure about the requirements, but I think her visa would still have been granted [despite her HIV status]. There was no reason for her to die, but these patients will do anything to get their families there [to the resettlement country]."*

Doctor B (Country X): *"They [applicants] aren't rejected if they're HIV-positive? No one has ever told us that, and I just assumed that the test was required because being positive would mean that a visa wouldn't be granted."*

Doctor C (Country X): *"I had a family of seven come in a few months ago. The son, I think he was about 20, was HIV-positive. I called to tell them that I needed to talk to him, and I've never heard back from the family. It is pretty typical for people to just disappear once they learn one of them is positive. They're all under the impression that having an HIV-positive family member will result in automatic rejection. Worse yet, some think that they'll be kicked out of the country where they await resettlement and sent back to the countries from which they fled."*

Doctor D (Country X): *"The bureaucracy that we have to deal with makes the process really difficult. I usually have no idea who to submit my findings to or what class of visa I should specify on these*

forms. It would really help us if we could tell the patients exactly where they stand, since the all-consuming concern for these people [the applicants] is whether or not they'll actually get to go [to the resettlement country]."

Doctor E: *"I have a huge problem getting people to come back for their results. When I call and tell people that I need to see them again, they assume they are positive and disappear on me because they think they'll be denied."*

RECOMMENDATION THREE:

Applicants and doctors should be informed of resettlement criteria

Applicants must be informed that for only certain resettlement countries HIV-positive status may bar resettlement. All of the panel physicians interviewed in Country X expressed confusion as to what medical conditions will result in the denial of a visa. Doctors told stories of patients disappearing or committing suicide after testing positive for HIV due to an erroneous assumption that their resettlement application would be automatically rejected.

In order to solve this problem, the doctors suggested that the countries make their resettlement criteria clear from the beginning of the process. Doctors should be provided information as to what specific medical conditions will bar or delay resettlement, and applicants should be informed both through pre- and post-test counselling, and through individual caseworkers employed by the resettlement country.

CASE STUDIES ON HIV TREATMENT WHILE PENDING RESETTLEMENT:

Doctor A (Country X): *"We refer anyone who is HIV-positive to the local government hospitals for treatment, but they don't ever end up getting it. The medical system here is so overloaded that we can't even treat all the citizens of the country with HIV. I can guarantee that foreign refugees are being turned away."*

Doctor B (Country X): *"Are you kidding? Sure, they have a right to treatment. So do all the people in the country. That doesn't mean that they're actually getting it. The system is just too crowded and there isn't enough funding to treat everyone."*

Doctor C (Country X)*: "I could easily refer the patients to a private clinic for treatment, but they haven't got the money to pay. If they even make it into a clinic, it is going to be at the government hospital. They won't get treatment there, the hospitals are overloaded and there is a real bias against foreigners."*

Doctor D (Country X): *"The patients who are HIV-positive absolutely need treatment. If we were able to get these people on a triple cocktail [a combination of three types of antiretroviral drugs that has been found most effective in treating HIV to lower to viral load within a patient's body] immediately, they wouldn't start showing signs of AIDS like severe weight loss and [opportunistic] infections. Instead, they waste away during the time they have to wait to go [to the resettlement country], and when they finally get to go some of them are in advanced stages of AIDS. What makes the whole thing worse is that, once they get there, the healthcare system there is going to be stuck giving them intensive treatment. It is all very traumatic for the patient, and very wasteful."*

Doctor E (Country X): *"The patients who turn out HIV-positive really need ARVs [antiretroviral drug treatments] immediately. If we let their viral load get higher and higher, the disease is more likely to take hold in anyone else who is exposed."*

RECOMMENDATION FOUR:

HIV-positive applicants should be treated while awaiting resettlement

Even though resettlement applicants have the right to medical care while in Country X, xenophobia and scarce resources make it difficult for refugees to receive treatment. Applicants awaiting resettlement often live in poor conditions, with inadequate access to nutrition and risk exposure to a variety of health hazards. For HIV-positive applicants, these conditions accelerate weight loss and may lead to opportunistic infections that seriously impair the applicant's health.

There was consensus among the doctors that it would be far more efficient for the resettlement countries to provide treatment for applicants awaiting resettlement. Under current conditions, AIDS becomes advanced in many applicants while they await resettlement. Intensive antiretroviral and antibiotic therapies are needed upon arrival in the resettlement country to lower the applicant's viral load, fight opportunistic infections and stimulate weight gain. This intensive therapy is extremely expensive and burdensome for the State, and extremely traumatic for the patient. If resettlement countries sponsored treatment for HIV positive applicants awaiting resettlement, the time and expense of intensive treatment could be significantly reduced.

CASE STUDIES ON FOLLOWUP CONSULTATION PROCEDURES:

Doctor A (Country X): *"We get a lot of disappearing acts. A big part of the problem is that refugees think their application will be denied if they are HIV-positive. When I call them to tell them they need to come back in, they assume the worst and we never hear back from them. If I could tell them that they're not necessarily going to be denied, but that they won't get to go [to the resettlement country] unless they come back to get their results and be counselled, I have no doubt that they'd come in for further tests and counselling."*

Doctor B (Country X): *"You have to realize that the most important thing – the only important thing – for these people [applicants] is that they get that visa. If getting it were dependent on their returning for post-test counselling, they would do so."*

Doctor C (Country X): *"I've never understood why the countries don't require some kind of doctor's release. They [the resettlement country authorities] send the patients to us for the testing, but they don't have any procedure in place to make sure that they are properly counselled after getting their results on how not to spread HIV."*

Doctor D (Country X): *"I think one of the main problems is that refugees simply don't have the money to get back to my office. Many are living in the outlying areas around [the city] and they just can't afford the taxi fares to return. If the countries that require these tests really want to refugees to know about their HIV status, they should provide the resources for them to return for counselling, and they should require me to certify that I've seen them again and counselled them on prevention."*

Doctor E (Country X): *"We aren't supposed to reveal results to people over the phone, but I sometimes find that I have no choice. When I call some of the patients back and tell them that they need to come in for counselling, I either never hear from them again, or they just tell me that they can't. At the end of the day, I usually reckon that its better for them to at least know their result, even if I have to give it over the phone with no counselling."*

Doctor F (Country X): *"We have [HIV] positive patients disappear on us all the time. Some are in denial, others assume that their result means they aren't going to get to go [to the resettlement country]."*

RECOMMENDATION FIVE:

Procedural safeguards should be enacted to ensure follow-up consultations

Every panel physician who was interviewed in Country X complained of patients neglecting to return for post-test counselling. Post-test counselling ensures that applicants are familiar with the disease and the measures that can be taken to avoid spreading it.

Almost all doctors were of the opinion that the resettlement process would function more efficiently if a doctor's release, in the form of a signed affidavit, in English and the main languages spoken by refugees, indicating that the patient had undergone post-test counselling was required before a resettlement visa could be granted.

CONCLUSION

This quantitative study is not intended to be representative of the situation in all of Country X; rather, this quantitative report provides an indication of what may be occurring in Country X. Given the consistency of the feedback from the 29 physicians in Country X combined with similar issues reported in other countries and regions on this issue, a larger multi-country study using qualitative and quantitative methodologies is warranted.