Health Action AIDS

PHR

Physicians for Human Rights

NIGERIA

Access to Health Care for People Living with HIV and AIDS

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A Report by Physicians for Human Rights
in coordination with
Futures Group International/POLICY Project and
Center for the Right to Health

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PHYSICIANS FOR HUMAN RIGHTS

Physicians for Human Rights (PHR) mobilizes health professionals to advance health, dignity, and justice and promotes the right to health for all.

Since 1986, PHR members have worked to stop torture, disappearances, and political killings by governments and opposition groups and to investigate and expose violations, including: deaths, injuries, and trauma inflicted on civilians during conflicts; suffering and deprivation, including denial of access to health care caused by ethnic and racial discrimination; mental and physical anguish inflicted on women by abuse; exploitation of children in labor practices; loss of life or limb from landmines and other indiscriminate weapons; harsh methods of incarceration in prisons and detention centers; and poor health stemming from vast inequalities in societies.

PHR's Health Action AIDS campaign works to engage the US health professional community in international advocacy and education to stop the global AIDS pandemic. The project's objectives include: organizing a large-scale education initiative to raise awareness in the health professions and mobilize support for a comprehensive AIDS strategy; urging the US government to increase its financial commitments to the Global Fund to Fight AIDS, Tuberculosis and Malaria; providing up-to-date research on the connection between human rights and AIDS; and developing opportunities for health professionals in the US to support AIDS activists around the world.

As one of the original steering committee members of the International Campaign to Ban Landmines, PHR shared the 1997 Nobel Peace Prize.

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MAP OF NIGERIA

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The report was prepared for production by Ms. Ayotte and Caitriona Palmer.

GLOSSARY OF TERMS AND ACRONYMS

AIDS: Acquired Immunodeficiency Syndrome
ARV: Antiretroviral drugs
FCT: Federal Capital Territory
HIV: Human Immunodeficiency Virus
LGA: Local Government Area
NACA: National Action Committee on AIDS
NGO: Non-governmental Organization
PCA: Presidential Commission on AIDS
PHR: Physicians for Human Rights
PLWA: Person/people living with HIV/AIDS
STD: Sexually transmitted disease

I. EXECUTIVE SUMMARY

Purpose of Study

The HIV pandemic is perhaps the greatest health and human rights issue of our time. Worldwide, an estimated 40 million people are currently infected with HIV, the virus that causes AIDS. With an estimated 3.6 million people with HIV/AIDS, Nigeria is home to 1 out of every 11 people with HIV/AIDS worldwide.[1] The HIV prevalence among adults in Nigeria has increased from 1.8% in 1991 to an estimated 5.4% in 2003.[2] Unofficial estimates range as high as 10%, which represents 4 to 6 million people infected.[3] Many people living with AIDS in Nigeria may face discriminatory behavior in the health sector. This study is the first population-based assessment of discrimination against people living with HIV/AIDS (PLWA) in the health sector of a country.

Stigma and discrimination are critical factors in the spread of HIV/AIDS. Discrimination undermines efforts to provide effective prevention education, diagnosis, and treatment, thereby blocking efforts to reverse trends in the pandemic. It also robs people affected by this life-threatening illness of the fundamental respect for their dignity and their right to health. [4] Health care professionals face enormous challenges in addressing this problem in society and within the health sector.

Nigerian health professionals are part of a society in the early phases of a comprehensive approach to prevention, treatment and care of HIV and AIDS that often attaches stigma and moral judgment to HIV/AIDS. The prevalence, character of, and factors contributing to the discriminatory practices of Nigerian health care professionals towards PLWA are, however, largely undocumented.

To address this lack of knowledge, Physicians for Human Rights (PHR), the Policy Project Nigeria and the Center for the Right to Health (CRH), conducted two surveys. The first, a survey of a representative sample of health professionals in four sites in Nigeria, and the second, a convenience sample of people living with HIV/AIDS in those four states and in Lagos and Abuja. These findings were supplemented by a survey of directors within the facilities where the health professional surveys were conducted and individual interviews with key informants including national and state policymakers, NGO representatives, and officers of international agencies.

Methods of Investigation & Participant Characteristics

The team conducted the health care professional study in four states: Abia, Gombe, Kano and Oyo. These sites were selected by dividing the country's six geopolitical zones into two sections — north and south — in order to capture geographical and other differences and then randomly selecting two of three zones from each section. Within the four selected zones, using health care facility lists compiled by Nigeria's Federal Ministry of Health[5], the team identified states that have a tertiary care institution and randomly selected one of these states from each zone.

To obtain a representative sample of health care professionals in these states, the team determined the numbers of health care professionals in each state and proportionally sampled doctors, nurses and midwives from the tertiary facility and systematically selected public and private secondary and primary health care facilities in the four states. Fifty-four percent of the health care professionals were sampled from tertiary care facilities. Eligible facilities were those included in

[1] UNAIDS. *2004 Report on Global AIDS Epidemic*. Geneva, Switzerland 2004:190.

[2] Id., UNAIDS. 2004:190. Data based on sentinal survey of pregnant women in antenatal clinics.

[3] See National Intelligence Council (NIC). *The Next Wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India, and China*. 2002:9.

[4] United Nations. *Nigeria: Common Country Assessment*. 2001:148.; *Economic Social and Cultural Rights: the rights of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Report of the Special Rapporteur, Paul Hunt, submitted in accordance with Commission resolution 2002/31 E/CN.4/2003/58, para 68. Oluduru O. "Legal Issues Raised by HIV/AIDS." *HIV/AIDS and Human Rights: Role of the Judiciary*. Lagos (Nigeria): Center for the Right to Health; 2001:28.

[5] Nigeria Federal Ministry of Health. *Health Facilities Data Base in Nigeria*; 2000. Abuja (Nigeria): Federal Ministry of Health.

the Federal Government database and operational at the time of the survey.

In each health care facility, the team randomly sampled from all doctors, nurses and midwives to acquire information about professional knowledge, attitudes and behavior. The team determined the sample size based on local activists' estimates that approximately 10% of clinicians exhibit discriminatory behavior and attitudes. Eligible professionals were physicians or certified nurses or midwives working in positions with direct patient contact. The 1,021 professionals surveyed were predominantly female (67%) with a mean age of 36. Fifty-four percent were nurses, 32% were physicians and 13% were certified midwives. This sampling strategy was designed to represent the attitudes and experiences of the nearly 4,500 health care professionals in the four study states who serve a combined population of approximately 17.8 million people.

The team interviewed PLWA in the four states where it conducted the health care professional survey: Abia, Gombe, Kano and Oyo and also in Abuja and Lagos. The study team interviewed PLWA in order to gain insight into the nature and range of experiences of discrimination within the health sector. The information gathered from PLWA was also used to evaluate the findings of the health care professional surveys. PLWA living in the catchments areas of the health facilities were referred to the study through support groups.

In order to ensure that there were no ethical breaches including disclosures of status without consent in the process of conducting the study, the team recruited PLWA through support groups rather than randomly. Due to the small number of identified PLWA in the areas where health professionals were surveyed and to difficulties in accessing them, some PLWA were recruited through support groups in Lagos and Abuja. While the sampling strategy for PLWA may not permit generalization of the PLWA survey findings, it is useful in contrasting the reality of individual PLWA experiences with patterns of discrimination identified in the health care professional survey.

Approximately half of PLWA who responded to the survey were male (53%). Participating PLWA had a mean age of 32. Forty-two percent were single and 40% were married. The mean number of years of education completed by respondents was 12. Most participants in the PLWA survey were not employed full time. Of those who reported not being employed full time, 41% indicated that no jobs are available, 22% blamed poor health, and 20% reported being dismissed for reasons related to their HIV status.

Overview of Findings and Conclusions

While some degree of discriminatory attitudes and unethical behaviors against PLWA is likely to exist in virtually every health care system in the world, this study suggests that much of the documented discriminatory behaviors and attitudes may be related to the health professional's fear of becoming infected or of infecting other patients in the health facility. This major concern among health professionals is likely be linked to a lack of knowledge and information about HIV and AIDS and to the insufficient supplies of materials needed to prevent transmission in the health care setting and to treat patients effectively.

Limited Resources

The study findings confirm[6] that many health care professionals in the four Nigerian study states work in facilities that have limited resources and that lack sufficient supplies of medications, equipment, and materials needed for practice of safe health care including gloves. A majority of health care providers surveyed have not received sufficient training on HIV and AIDS prevention and treatment and have limited access to current information about HIV and AIDS. Seventy-two percent of health care professionals surveyed said they practice universal precautions in all cases. Of those who did not do so in all cases, 65% indicated that this was due to lack of materials. Respondents to both surveys indicate that the cost of health care is a significant barrier: PLWA in this study identified the lack of financial resources as the greatest obstacle to accessing health care. Participants in the health care professional survey also identified patients' lack of financial resources as one of the most significant obstacles to effective treatment of infections/conditions related to HIV and the second most significant obstacle to accessing health care.

Ethical Obligations

The findings of the health care provider survey further suggest that most Nigerian health care providers in the areas surveyed comply with their professional ethical obligations and do not deny care or treatment to people living with HIV and AIDS. The majority of PLWA interviewed reported no negative interactions with the health care sector - especially noteworthy given the resource constraints metnioned above. However, a considerable number of health care professionals reported

[6] United Nations. *Nigeria: Common Country Assessment*. 2001.

engaging in behavior that is discriminatory towards PLWA and/or unethical. Ten percent of professionals reported refusing to care for an HIV/AIDS patient, and 10% indicated that they had refused an HIV/AIDS patient admission to a hospital. Sixty-five percent reported that they had observed other health care professionals refusing to care for an HIV/AIDS patient and 40% reported that they observed others refusing an HIV/AIDS patient admission to a hospital.

Health care professionals also reported engaging in practices that are against international and Nigerian codes of professional ethics including testing without consent and disclosure of confidential medical information without permission.[7] Over 50% of health care professionals surveyed reported that they obtained informed consent of patients for HIV tests half the time or less. Fourteen percent indicated that they never obtained informed consent for HIV tests. Nearly half (49%) of PLWA surveyed stated that they did not know that they were being tested for HIV and 67% indicated that no one explained the HIV test to them prior to their being tested. Disclosure of confidential patient information without permission was also reported by participants in the health professional survey. Thirty-eight percent stated that they had revealed such information to a patient's family member without consent, and 12% indicated that they had disclosed such information to someone who is not a family member of a patient.

Stigma and Discrimination

Given the stigma associated with HIV/AIDS in Nigeria, these attitudes and unethical behaviors by health care providers, including those who hold discriminatory attitudes towards people with HIV/AIDS likely have an enormous impact on an individual's life and his or her ability to survive. Moreover, these practices are corrosive to the health sector as they taint all members of the health professions, erode trust in their practitioners, and may well dissuade individuals with HIV from seeking health care. They also represent missed opportunities for prevention, positive living education, and treatment thereby undermining Nigeria's concerted national efforts to address the HIV/AIDS epidemic including the important ongoing efforts to reduce the spread of HIV in Nigeria.

The stigma associated with HIV/AIDS and reinforced even within the health sector likely contributes to the spread of HIV/AIDS in Nigeria. Discouraged by stigma from seeking out their status, people may unknowingly infect their sexual partners. Stigma may also inhibit people from seeking information about prevention of transmission that could prevent them from being infected or infecting others.[8] Fear of stigma may also cause PLWA to engage in unsafe behaviors in an effort to hide their status from others.

Discrimination that occurs within the health sector may have devastating social and personal consequences. The discriminatory practices documented in this study violate international principles of medical ethics and may also serve to legitimize other forms of discrimination toward people living with HIV/AIDS. PLWA in Nigeria have been found to be subject to discrimination and stigmatization in the work place, and by family and communities. They may be evicted from their homes, be denied inheritance rights, lose their jobs or be passed over for promotion, and be shunned by their families and communities.[9] Twenty-four percent of respondents to the PLWA survey indicated that their current sexual partners were not aware of their HIV status. One PLWA reported his experiences since making his HIV status known as negative, declaring:

> *Let me tell you people, you want us to disclose our status! Do you know what that means! It results in a death sentence. I regret ever having succumbed to that lie of accepting publicly my status.*

Improvement of the education of health care professionals on HIV and AIDS and the provision of sufficient materials for prevention, treatment, and care is therefore likely to go a long way towards eliminating discriminatory and unethical behavior by health professionals. However, as is it probable that some of the discriminatory and unethical behavior by some professionals is rooted in prejudice, anti-discrimination policies must also be instituted and enforced and mechanisms established through which those experiencing such behavior can seek redress.

[7] World Medical Association. *International Code of Medical Ethics (as amended 1983).* Available at: http://www.wma.net/e/policy/17-a_e.html. Accessed April 4, 2003; Medical and Dental Council of Nigeria. *Rules of Professional Conduct for Medical and Dental Practitioners in Nigeria.* 1995.

[8] United Nations. *Nigeria: Common Country Assessment*. 2001:148; *Economic Social and Cultural Rights: the rights of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Report of the Special Rapporteur, Paul Hunt, submitted in accordance with Commission resolution 2002/31 E/CN.4/2003/58, para 68. Oluduru O. "Legal Issues Raised by HIV/AIDS." *HIV/AIDS and Human Rights: Role of the Judiciary*. Lagos (Nigeria): Center for the Right to Health; 2001:28.

[9] Center for the Right to Health. *Human Rights and HIV/AIDS: Experiences of People Living with HIV/AIDS in Nigeria*. Lagos (Nigeria): Center for the Right to Health; 2001.

Summary of Findings

As stated above, the findings of the health care provider survey suggest that, despite resource limitations and lack of access to training and information on HIV/AIDS, most Nigerian health care providers in the surveyed states reported behaving in compliance with their professional ethical obligations. Moreover, Nigerian health professionals are a part of a society in the early phase of a comprehensive and determined approach to prevention and treatment of HIV and AIDS.

As has been documented in other countries during the early phases of their concerted response to HIV/AIDS,[10] however, this study suggests that a considerable number of Nigerian health care professionals engage in discriminatory practices against and have discriminatory attitudes toward people who have, or are suspected to have, HIV/AIDS. This includes refusal to care for or admit PLWA reported by 10% of respondents and observed by 65% and 40% of providers respectively. This study suggests that much of the discriminatory behaviors and attitudes documented in this study may be addressed by several interventions, including improvement of education of health care professionals on HIV and AIDS and provision of sufficient materials for prevention, treatment and care.

Testing patients without informed consent appears to be a common practice, one that precludes an informed decision by the patient and, given the stigma associated with HIV/AIDS in Nigeria, can have an enormous impact on an individual's life and their ability to survive. Additionally, testing without consent is generally performed without any counseling of the individual regarding how they can protect themselves from infection, and if infected, protect others from infection and live healthy lives with HIV. This is a missed opportunity for prevention and positive living education can undermine ongoing efforts to reduce the spread of HIV.

The study findings also provide information on misconceptions regarding appropriate treatment and care for PLWA. Fear of becoming infected appears to be a major concern among health professionals, and is likely to be responsible for discriminatory attitudes and behaviors among many professionals. Another common perception among health practitioners is that treatment of HIV/AIDS and related conditions is a waste of precious resources. Although these attitudes may relate to resource limitation including the lack of materials to enable practice of universal precautions and other factors,[11] the effects of such attitudes on patient care are abundantly clear. Although the study does not indicate the extent to which discrimination against people with HIV/AIDS may differ from those with other conditions or diseases, the extraordinary health consequences and social stigma associated with HIV/AIDS discrimination warrant urgent and effective remediation.

Informed Consent and Confidentiality

Over half of professionals reported that they obtained informed consent of patients for 50% or less of HIV tests they ordered including 14% who indicated that they never obtained informed consent for HIV tests. Fifty-one percent of health care professionals reported that, regardless of consent, routine HIV testing of all patients scheduled for surgery always took place at their facilities and 50% reported such routine HIV testing of all women attending antenatal care clinics. Three quarters of health care professionals agreed that there are circumstances where it is appropriate to test a patient for HIV without his/her knowledge or consent.

Most respondents to the PLWA survey reported being informed of their HIV status in the past three years. Approximately half of them (49%) stated that they did not know that they were being tested for HIV. Eighteen percent of PLWA reported that it was their idea to be tested while 45% stated that the test was the idea of the health worker. The majority (64%) indicated that the reason they were tested was that they were sick all the time. Other top reasons for testing included: partner or spouse testing HIV positive (16%), to know status (9%) and routine testing for blood donation (4%) or antenatal care (4%). Most, (92%) reported that they were not asked to sign a consent form for the HIV test, and 67% indicated that no one explained the HIV test to them prior to the test.

[10] Richter M. *Nature and Extent of Discrimination against PLWAs in South Africa: Interviews and a study of AIDS Law Project client files 1993-2001.* Johannesburg: Aids Law Project;2001.; UNAIDS. India: HIV and AIDS-related Discrimination, Stigmatization, and Denial. Geneva, Switzerland;2001.; Danziger R. "Discrimination against people with HIV and AIDS in Poland." *British Medical Journal.* 1994;308:1145-1147.; Tirelli U, Accurso V, Spina M, Vaccher E. "HIV and discrimination." *British Medical Journal.* 1991;303:582.; Link RN, Feingold AR, Charap MH, Freeman K, Shelov SP. "Concerns of Medical and Pediatric House Officers About Acquiring AIDS from Their Patients." *American Journal of Public Health.* 1988;78(4):455-459.; Bermingham S, Kippax S. "HIV-related discrimination: a survey of New South Wales general practitioners." *Australian and New Zealand Journal of Public Health.* 1998;22(1):92-97.

[11] PHR. *Unsafe Health Care and the HIV/AIDS Pandemic: Testimony of Holly Burkhalter.* Available at: http://www.phrusa.org/campaigns/aids/release080103.html. Accessed on 5 November, 2003.

About a quarter (24%) of respondents to the PLWA survey indicated that their current sexual partners were not aware of their HIV status. Five percent reported that a doctor revealed their HIV status to someone without their permission. Four percent reported that a nurse revealed their HIV status to someone without their permission and 3% reported that a laboratory technician did this. Seven percent reported being shunned by their family or by their community.

Individual interviews with PLWA provided additional insight into the problem of being tested for HIV without informed consent. As a result of no informed consent for testing and breaches of confidentiality, some PLWA have suffered severe consequences of social stigma. Respondent Y related the following:

I was pregnant and very sickly so was taken to the hospital when HIV test was done without my knowledge. The result was given to my husband who went home and told my children not to have anything to do with me. They should not eat or drink with me or have anything to do with me. This went on until we both received counseling after he was discovered to be positive also.

Treatment and Care

Forty-eight percent of professionals expressed their belief that a person with HIV/AIDS cannot be treated effectively in their facility. Twelve percent of professionals expressed agreement with the statement that treatment of opportunistic infections in HIV/AIDS patients wastes resources, and 7% agreed that treating someone with HIV/AIDS is a waste of precious resources.

E, a PLWA in his 30s, indicated that the lack of medication in public hospitals may be the reason he had been refused care.

I have stopped going to the federal medical centers when I am sick, because once I went there they refused to let me be seen by the doctor saying I have HIV and that it cannot be cured so there is no need for them to take me into the hospital and waste the little medicine they have for people who can't be cured.

Among health care professionals, the three most important concerns about treating HIV/AIDS patients were fear of becoming contaminated (81%), contamination of facility, materials or instruments (17%), and not having materials needed to treat (10%). Indeed, based on reports collected during the facility survey, protective materials and other supplies and utilities were not always available. Seventy-three percent of respondents reported that universal precautions were always practiced. Of those not reporting consistent use of universal precautions, 65% cited lack of materials as the reason. Ninety percent of health care professionals agreed that staff and health care professionals should be informed when a patient is HIV positive so they can protect themselves. M, a participant in the PLWA survey reported his experience, "A nurse was attending to me and I told her I was HIV positive and immediately she went and started putting on gloves [rather than applying universal precautions and using gloves for every patient]."

Respondents to the PLWA survey indicated that special and unnecessary precautions used by medical personnel when they are seen at a health facility included the use of extra gloves or protective gear (61%), charging them more than other patients (26%), and separating them from other patients (11%). They indicated that the main obstacles faced by PLWA in trying to access health care are lack of financial means (73%), fear of being stigmatized (45%), and a lack of knowledge of having the disease (33%).

Y, a woman in her mid 30s, described the special precautions taken by medical staff when she was in the hospital to deliver her baby. According to her:

I was treated badly at the hospital, they separated my bed from others when I wanted to deliver my baby. They also asked my people (family) to come and wash the bed-sheet after soaking it. They do not bathe the baby and if they do, they use gloves.

At times, this distancing by medical personnel was in direct opposition to medical orders. According to B, a woman in her late 20s:

When I was admitted before I had miscarriage, the doctor told the nurses not to allow me to move around, he said they should give me the bed pan if I wanted to ease myself. The nurses refused and asked me "Don't you have legs? Go to the toilet." When they want to give me drugs they keep a distance as if touching me will infect them.

Eleven percent of PLWA participating in the study reported being refused medical care. Seventeen percent of respondents observed others being refused medical care. Being refused admission to a hospital was reported by 6% of participants. Twelve percent

observed an HIV positive patient being refused admission to a hospital. Public, government-run facilities were the sites of most of these refusals (74%). Nine percent reported that their confidential information had been given to their family member by medical personnel and 10% observed this happening to another PLWA. Eight percent stated that their confidential information had been revealed to a non-family member by a health care worker and 7% reported seeing this happen to another PLWA. Verbal mistreatment by a health care worker was reported by 8% of respondents and observed by 10%.

Staff of both private and public facilities reported cases of PLWA being refused admission. T, a woman in her late 20s, was refused care in a public facility.

> *I was refused care in the general hospital. The nurse just told me to go and find a private hospital because they do not attend to HIV people. She said she wanted to let me know so I do not waste my time.*

P, in her 40s, reported her experiences in trying to access care in private hospitals.

> *I was taken to about 8 private hospitals where I was rejected each time just by looking at my appearance. I was eventually taken back home for treatment by my brother*

In addition to refusal to care or admit and breaches of confidentiality described above, fewer than one percent of professionals reported verbally mistreating an HIV/AIDS patient and 23% of respondents reported seeing others verbally mistreat HIV/AIDS patients. Thirty-eight percent of professionals reported giving confidential information to a patient's family member without the patient's consent, and 50% had observed this behavior. Twelve percent of professionals reported giving confidential information to a person not related to a patient without consent and 22% had observed this behavior. These are probably underestimates as health care professionals are likely not to have reported their own unethical or discriminatory behavior.

Health Care Professional and PLWA Attitudes About HIV/AIDS and Discrimination

In addition to reporting discriminatory behaviors, health care professionals held beliefs and attitudes towards PLWA that likely contributed to discriminatory behavior towards and bad consequences for PLWA. Thirty-nine percent of professionals reported that it is possible to determine a person's HIV status by looking at him or her. Over half (57%) of professionals agreed that people with HIV/AIDS should be on a separate ward in a hospital or clinic, and 23% agreed that they could refuse to treat an HIV/AIDS patient to protect themselves and their family.

Most health care professionals expressed support of human rights. A vast majority reported agreement with many statements that supported women's rights and the rights of PLWA. Over 90% of respondents agreed that: there should be legal protections for the rights of women (98%); there should be legal protections for the rights of people with HIV/AIDS (96%); women should have inheritance rights (95%); more should be done to protect women and girls from having sex when they don't want to (93%); and women with HIV/AIDS should have inheritance rights (90%). Ninety percent agreed that women and girls need more education about their right to refuse sex. Over eighty percent of respondents indicated agreement with a woman's right to refuse sex if a man refuses to use a condom (83%). Furthermore, 84% of participants believed that any woman has the right to refuse sex.

Despite these findings that suggest a high level of recognition of human rights among participants, 82% agreed with mandatory premarital HIV testing of men and of women. Sixty-six percent indicated that a good wife obeys her husband even if she disagrees, and 57% agreed that it is a wife's obligation to have sex with her husband even if she does not want to. Twenty percent stated that many of those who contracted HIV/AIDS had immoral behavior and deserved the disease. Thirteen percent indicated that women (not men) are responsible for the transmission of most heterosexual HIV cases and 6% of health care professionals surveyed indicated that a man has the right to beat his wife if she disobeys him.

PLWA also overwhelmingly expressed support for human rights. Over 90% of respondents to the PLWA survey agreed that there should be legal protections for the rights of people living with HIV/AIDS (96%), that there should be legal protections for the rights of women (96%), more should be done to protect women and girls from having sex when they don't want to (90%), and that women and girls need more education about their rights to refuse sex (90%). Sixty-six percent of respondents, however, indicated that women should have to be tested for HIV before getting married.

Sixty-five percent of PLWA believed that a good wife obeys her husband even if she disagrees and 46% agreed that it is a wife's obligation to have sex with her husband even if she does not want to. One quarter of respondents to the PLWA survey indicated agreement with the statement that women are responsible for spreading most heterosexual cases of HIV/AIDS. Sixteen percent of PLWA agreed that a person's HIV status can be determined by his/her appearance. Nine percent agreed that many of those who contracted HIV/AIDS had immoral behavior and deserved the disease.

Conclusions

Most health care professionals in the four states where the study was conducted appear to be providing care to PLWA and to complying with their ethical responsibilities despite the lack of sufficient materials needed for treatment and prevention. A considerable minority, however, reported engaging in discriminatory and/or unethical behavior including denial of care, refusal of admission to hospital, testing for HIV without consent and disclosing confidential medical information without permission. Such behaviors in Nigeria's health sector must be addressed if the pandemic is to be reversed. Also at stake are the health and well-being of PLWA and the credibility and integrity of health practitioners and the health system as a whole. There are numerous challenges to dealing with HIV/AIDS in Nigeria effectively. Many health care professionals and policymakers are working actively to overcome obstacles but this study demonstrates that much work remains. These recommendations have been developed based on the findings of the study and in consultation with key stakeholders.

Recommendations[12]

President Olusegun Obasanjo's recent signature into force of the Government's new HIV/AIDS Policy[13] and a stated government commitment to pass legislation protecting PLWA from discrimination are promising steps taken by Nigeria's government. In moving forward to implement the new National HIV/AIDS Policy, the relevant key stakeholders should take the following steps.

Nigeria's Federal Government should:

- Provide sufficient supplies of protective materials for practice of universal precautions including the provision of gloves and disposable syringes to all health facilities under Federal Ministry of Health control.
- Develop logistical systems to ensure adequate supplies of protective materials.
- Provide sufficient supplies of drugs including ARVs (for post exposure prophylaxis and treatment), antibiotics and other drugs needed for treatment and prevention of HIV/AIDS and related conditions to all health facilities under Federal Ministry of Health control. Make these drugs available to patients at a reasonable cost, and reduce the cost of diagnostic tests and care related to HIV/AIDS.
- Provide free post exposure prophylaxis and treatment including ARVs for health care professionals who become infected with HIV because of exposure at work.
- Develop and implement programs to educate health care professionals and all staff in health facilities about HIV/AIDS including modes of transmission and universal precautions, ethics, and treatment and care. Involve PLWA in preparation of these programs.
- Stop all mandatory HIV testing in Federal institutions and develop effective monitoring and enforcement mechanisms.
- Ensure that all testing for HIV is voluntary, confidential, and includes informed consent and pre and post-test counseling. Utilize public education and media campaigns to encourage people to be tested for HIV.
- Develop, promulgate and enforce HIV/AIDS testing and treatment policies within health institutions under Federal Ministry of Health (FMOH) control that guarantee non-discrimination against PLWA. Ensure the input of PLWA in these processes.
- Work with state governments and the private sector to ensure development and promulgation and enforcement of HIV/AIDS testing and treatment policies within health institutions not under FMOH control that conform to international standards of

[12] These recommendations have been developed based on the findings of the study and in consultation with key stakeholders. As appropriate, they have been repeated within the body of the report where they are placed in text boxes following the relevant sections to illustrate their source.

[13] Federal Government of Nigeria. National HIV/AIDS Policy. Abuja: 2003. HIV/AIDS Impact on Education Clearinghouse. Available at: http://iiep.tomoye.com/ev_en.php?ID=4239_201&ID2=DO_TOPIC. Accessed July 18, 2006.

medical ethics and guarantee non-discrimination against PLWA. Ensure the input of PLWA in these processes.

- Work with health care professionals, PLWA support groups and NGOs to develop referral systems to support services for people testing positive for HIV in facilities under Federal Ministry of Health control.
- Engage in a thorough review of laws and the constitution and enact legal and constitutional reform to ensure legal protection of PLWA in all sectors. PLWA must be represented in this process.
- Engage in a thorough review of laws and the constitution and enact legal and constitutional reform to ensure legal protection of women in all sectors in order to reduce the effects of gender on vulnerability to HIV infection.
- Ensure that policies, laws and regulations related to HIV/AIDS prevention treatment and care are consistent with and enable health care professionals to act in keeping with the latest scientific understanding of HIV/AIDS.
- Educate the general public about patients' rights including processes for reporting discrimination and/or unethical behavior by health care professionals.

National Action Committee on AIDS:
As the national multi-sectoral coordinating body on HIV/AIDS, NACA should:

- Assist in the thorough review of laws and the constitution and enactment of legal and constitutional reform to ensure legal protection of PLWA in all sectors, and ensure that PLWA are represented in this process.
- Create a task force that includes representatives of the relevant government bodies, professional associations and PLWA groups to address discrimination in the health care sector. Work with State Action Committees on AIDS to have such task forces at the State level.
- Support efforts to ensure that all health care professionals are educated about HIV and AIDS.
- Vigorously continue to pursue its aims and objectives.

States and Local Government Areas should:

- Work with the Federal Ministry of Health and PLWA to develop, promulgate and enforce HIV/AIDS testing and treatment policies within health institutions under their control that conform to the Nigerian code of medical ethics and that guarantee non-discrimination against PLWA.
- Work with private institutions and practitioners in the State/ LGA to ensure the development, promulgation and enforcement of HIV/AIDS testing and treatment policies within private health institutions that conform to the Nigerian code of medical ethics and that guarantee non-discrimination against PLWA.
- Stop mandatory HIV testing in institutions under their control and develop effective monitoring and enforcement mechanisms. Encourage voluntary and confidential testing for HIV and AIDS.
- Work with health care professionals, PLWA support groups and NGOs to develop referral systems for people testing positive for HIV in facilities under their control.

The Medical and Dental Council and the Nursing and Midwifery Council of Nigeria should:

- Review complaints systems to ensure that cases of unethical behavior by physicians, nurses and midwives are reviewed, and that physicians meet their obligation to report unethical behavior by peers.
- Engage in (continuing) education of physicians, nurses and midwives on matters of professional ethics. Make these courses affordable and available to health care professionals at their facilities to enable participation.
- Require all physicians, nurses and midwives to take courses on HIV and ethics as part of their continuing education licensing renewal requirement, and advocate and work for health care professional access to such courses.
- Work with the Federal Ministry of Health to develop and implement programs to educate health care professionals and all staff in health facilities about HIV/AIDS including modes of transmission and universal precautions, human rights, ethics, and treatment and care. Involve PLWA in preparation of these programs.
- Work with National and State Action Committees on AIDS to create task forces that include representatives of the relevant government bodies, other professional associations, and PLWA groups to address discrimination in the health care sector.
- Encourage the integration of education about HIV and AIDS in formal medical and nursing education, which

includes formal instruction in professional ethics and specific concerns that relate to HIV and AIDS.

- Encourage health care professionals to know their HIV status and to support their HIV positive colleagues.
- Advocate for provision of free post exposure prophylaxis and treatment including ARVs for health care providers who become infected with HIV because of exposure at work.

Health care facility managers should:

- Develop, promulgate and enforce HIV/AIDS testing and treatment policies within their facilities that conform to Nigerian medical ethics and guarantee non-discrimination against PLWA.
- Encourage official recognition of members of staff that treat patients in an ethical and non-discriminatory manner and provide incentive to meet these standards.
- Engage in ongoing education of facility staff on these policies. Such programs may need to address attitudes and cultural beliefs.
- Establish mechanisms for reporting and investigation of unethical and/or discriminatory behavior by staff.

Health care professionals should:

- Uphold standards of medical practice that are consistent with Nigerian codes of medical ethics.
- Ensure that the dignity of all patients is respected, even those with terminal and/or infectious illnesses, including HIV/AIDS.
- Obtain educational information for effective diagnosis and treatment of HIV/AIDS.
- Work for conditions that will improve the lives of individual PLWA and communities at risk.
- Work with PLWA support groups, NGOs, and the Ministry of Health to develop referral system for people testing positive in facilities where they work.

People living with HIV and AIDS and their associations should:

- Work with the Federal and State Ministries of Health, LGAs and health care professionals to develop, promulgate and enforce HIV/AIDS testing and treatment policies within health institutions that conform to the Nigerian code of medical ethics and that guarantee non-discrimination against PLWA.
- Work with the Federal and State Ministries of Health, LGAs, civil society and health care professionals to develop and provide educational programs to health care professionals about the rights of PLWA.
- Engage in education of PLWA about their rights within the health care system.
- Support efforts of PLWA who have experienced discriminatory and unethical behavior by health care professionals to bring complaints to the appropriate bodies including the Medical and Dental Council of Nigeria, the Nursing and Midwifery Council of Nigeria, and the Human Rights Commission.

Non governmental and civil society organizations should:

- Work with Federal and State Ministries of Health, LGAs, health care professionals, and PLWA to develop, promulgate and enforce HIV/AIDS testing and treatment policies within health institutions that conform to the Nigerian code of medical ethics and that guarantee non-discrimination against PLWA.
- Engage in education of the population about HIV and AIDS, the rights of PLWA and the rights of people in the health care system.
- Support efforts of PLWA who have experienced discriminatory and unethical behavior by health care professionals to bring complaints to the appropriate bodies including the Medical and Dental Council of Nigeria, the Nursing and Midwifery Council of Nigeria, and the Human Rights Commission.

International donors should:

- Provide materials and technical assistance to professional associations for efforts to educate health professionals and the public about HIV/AIDS and ethics of the medical profession.
- Provide material and technical assistance for efforts to review and reform law and policy, including ensuring legal protection of PLWA.
- Provide material and logistical support to ensure that all health facilities have sufficient and consistent supplies of materials needed for HIV/AIDS treatment and prevention, including for implementation of universal precautions.
- Support the Global Fund to Fight AIDS, Tuberculosis and Malaria.

II. BACKGROUND

Population and Geography

Nigeria borders Benin to the West, Niger to the North, Chad to the Northeast, Cameroon to the Southeast and the Atlantic Ocean to the South. It is approximately 923,768 sq km – similar in size to twice the state of California.[14]

Nigeria is home to the largest population in Africa,[15] and at the time of publication, approximately 131,500,000 people were living in the 36 states and Federal Capital Territory of Nigeria.[16] The states are divided into six geopolitical zones. In addition to the federal and state governments, there are 774 Local Government Areas (LGA). The Federal Capital Territory is the location of the federal government. The capital is Abuja, and Lagos is the largest city and center of commercial activity. [17]

There are over 300 ethno-linguistic groups in Nigeria.[18] The main groups include the Hausa in North, Ibo in East and Yoruba in West. The country's South is mainly Christian and the North primarily Muslim.

Historical Overview

Modern Nigeria was established and became a formal colony of Britain[19] in 1914 until gaining its independence in 1960.[20] In 1967, the Eastern region of the newly independent country seceded and declared itself the Republic of Biafra.[21] The ensuing Biafran Civil War resulted in over one million deaths before its end in 1970.[22]

In 1983, a military coup ousted the civilian government of Shehu Shagari, in office since 1979,[23] and installed Muhammad Buhari as ruler.[24] Another coup, which brought General Ibrahim Babangida to power, followed in 1985. The Buhari and Babangida years were ones of economic decline and growing political instability.[25] Elections in 1993 resulted in a victory for Moshood Abiola, but were annulled by the military and Sani Abacha declared himself president.[26] Abiola was later charged with treason for declaring himself winner of the 1993 election.[27]

Abacha's regime was marked by human rights abuses, which included the 1995 hanging of nine political activists including writer Ken Saro-Wiwa.[28] This event triggered international outcry and led to Nigeria's suspension from the Commonwealth.[29] In 1998 Abacha died suddenly under suspicious circumstances and was replaced by General Abdulsalam Abubakar.[30] An election was held and a new constitution released in 1999, marking the end of military rule with Olusegun Obasanjo's victory. [31]

[14] CIA World Factbook. Available at: http://www.odci.gov/cia/publications/factbook/geos/ni.html. Accessed November 5, 2003.

[15] United Nations. *Nigeria: Common Country Assessment*. 2001:4.; Falola T. *Culture and Customs of Nigeria.* Westport and London: Greenwood Press; 2001:1.

[16] United Nations Population Fund (UNFPA). *State of the World Population*. New York; 2005.

[17] CIA World Factbook. Available at: http://www.odci.gov/cia/publications/factbook/geos/ni.html. Accessed May 23, 2006.

[18] United Nations. *Nigeria: Common Country Assessment*. 2001.

[19] Falola T. *Culture and Customs of Nigeria.* Westport and London: Greenwood Press; 2001:1.

[20] Nelson HD (Ed.). *Nigeria a Country Study*. Washington DC: The American University; 1982:45.

[21] Id., Nelson HD (Ed.). 1982:56.; Falola T. *Culture and Customs of Nigeria.* Westport and London: Greenwood Press; 2001:21.

[22] Nelson HD (Ed.). *Nigeria a Country Study*. Washington DC: The American University; 1982:60.

[23] Falola T. *Culture and Customs of Nigeria.* Westport and London: Greenwood Press; 2001:22-3.

[24] Id., Falola T. 2001:23.

[25] Id., Falola T. 2001:23.

[26] Osaghae EE. *Nigeria Since Independence: Crippled Giant.* Indiana University Press;1998:273.; Falola T. *Culture and Customs of Nigeria.* Westport and London: Greenwood Press; 2001:23.

[27] Id., Osaghae EE. 1998:298.

[28] Id., Osaghae EE. 1998:304.

[29] Id., Osaghae EE. 1998:305.

[30] Falola T. *The History of Nigeria.* Westport and London: Greenwood Press; 1999:204.

[31] Falola T. *Culture and Customs of Nigeria.* Westport and London: Greenwood Press; 2001:24.

Health Care in Nigeria

Responsibility for health care in Nigeria is split between the different levels of government. The Federal government is responsible for establishing policy objectives, training health professionals, coordinating activities, and for the building and operation of Federal medical centers and teaching hospitals. The States are responsible for the secondary health facilities and for providing funding to the Local Government Areas (LGAs), which are responsible for primary health care centers.[32] In addition to government-run public facilities, there are also private health facilities, most of which are secondary level facilities.[33] Many Nigerians do not go to government facilities first[34] but rather seek health care from traditional healers, patent medicine stores, lay consultants and private medical practices and facilities owned and managed by faith-based organizations.

The health care system in Nigeria is inadequately funded and understaffed, and suffers from material scarcity and inadequacy of infrastructure which may contribute to overall discriminatory behavior.[35] The blood transfusion system is inadequate and [36] access to quality health care is limited.[37] There are regional disparities in education, health status, poverty level, and other aspects of human development.[38] As in other countries, Nigeria's health professionals "are poorly paid and work long hours with shortages of equipment in obsolete facilities."[39] This contributes to the "brain drain" phenomenon of young educated people leaving the country in search of better opportunity.[40]

Health indices have been getting worse.[41] As with all health data in Nigeria, there are issues of data quality.[42] In the 1990s, trends in health status including child mortality seemed to be getting worse.[43] Nigeria's healthy life expectancy has declined from 50 years in 1994 to 43 years in 2005. The increasing prevalence of HIV/AIDS has significantly contributed to this decline.[44] Recent estimates of Nigeria's maternal mortality ratio (MMR), 800/100,000 live births, suggest that it is among the highest in the world.[45] This total estimate may obscure an even higher MMR in rural areas.[46] The data used to produce this estimate originates from health facilities and may underestimate the number of deaths that occur in communities. This data may also not be reported appropriately.[47]

Antenatal care and delivery assistance are accessible mainly in urban areas and in the southern part of the country.[48] According to UNAIDS,[49] the infant mortality rate for 1995 – 2000 was 88 deaths per 1,000 live births. About 58% of all deliveries in Nigeria take place at the home, however, in the north, approximately 90% of births occur in the home; of assisted births, midwifes and nursed attend 42% deliveries, doctors oversee 8% and traditional birth attendants assist 20% of births (1999).[50] Reproductive health issues for adolescents

[32] DFID Health Systems Resource Centre. Nigeria Country Health Briefing Paper. 2000. Available at: http://www.healthsystemsrc.org/publications/Country_health/Nigeria.pdf. Accessed November 5, 2003.

[33] Federal Ministry of Health Database.

[34] Federal Ministry of Health. National HIV/AIDS & Reproductive Survey 2003. Abuja, Nigeria.

[35] United Nations. *Nigeria: Common Country Assessment*. 2001:xix:114.; Hargreaves S. "Time to right the wrongs: improving basic health care in Nigeria." *The Lancet*. 2002;359(9322):2030-5.; Federal Office of Statistics. Core Welfare Indicators Questionnaire Survey. 2001. Benue State.

[36] United Nations. *Nigeria: Common Country Assessment*. 2001:xxii.

[37] Id., United Nations. 2001:12.

[38] Id., United Nations. 2001:13.

[39] *Economic Social and Cultural Rights: the rights of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Report of the Special Rapporteur, Paul Hunt, submitted in accordance with Commission resolution 2002/31 E/CN.4/2003/58, para 9.

[40] United Nations. *Nigeria: Common Country Assessment*. 2001:18.

[41] Id., United Nations. 2001:12.

[42] Id., United Nations. 2001:18.

[43] Id., United Nations. 2001:100.

[44] United Nations Children's Fund. *State of the World's Children report*. New York, NY; 1996.; World Health Organization. *Nigeria. Selected Health Indicators*. Available at: http://www.who.int/country/nga/en. Accessed March 31, 2003.

[45] UNFPA, *State of the Worlds Population 200*5. Available at: http://www.unfpa.org/swp/2005/english/ch1/index.htm. Accessed June 22, 2006.

[46] Macdonagh S. Evaluation of DFID Development Assistance: Gender Equality and Women's Empowerment. Department for International Development. March 2005:29. Available at: http://www.dfid.gov.uk/aboutdfid/performance/files/wp8.pdf. Accessed July 18, 2006.; DFID. Reducing Maternal Deaths: Evidence and Action. December 2005:14. Available at: http://www. dfid.gov.uk/pubs/files/maternal-health-progress-report.pdf. Accessed July 18, 2006.

[47] United Nations, *Nigeria: Common Country Assessment*. 2001:108.

[48] CRLP. *Women of the World: Laws and Policies Affecting their Reproductive Rights. Anglophone Africa*. 2001:78.

[49] UNAIDS, Epidemiological Factsheet, 2002 Update.

include low use of contraception, having more than one sexual partner, and teenage pregnancy.[51]

In spite of poor data quality and the tendency of many to self-medicate or seek traditional healing and avoid health facilities,[52] incidence of sexually-transmitted disease (STD) is believed to be high.[53] The syndromic approach to management of STDs is not applied everywhere and the drugs necessary for treatment are not always available. Nigeria's population lacks knowledge about STDs.[54] The Federal Ministry of Health HIV/Syphilis Survey notes the overall high occurrence of STDs (10.2%) among young people aged 10-19.[55] This survey also showed that 64.7% of persons with STDs across Nigeria's six geopolitical zones were women.[56]

Financing of Health Care in Nigeria

Health care in Nigeria is largely financed by user fees. Field studies by the World Bank estimate that Nigerian households pay roughly 45% of total health expenditures in the country.[57] The Federal Government subsidizes staff salaries in federal facilities, which usually account for more than 65% of recurrent expenditure in the health service[58]. In non-federal facilities, staff salaries are paid through the funds allocated by the Federal Government to the LGAs. However, since LGAs receive "block allocations" or one pool of money from which to finance all of their projects, this funding is often insufficient for covering salaries or purchasing prescription drugs[59]. As a result, the cost of medication, tests, hospital beds and facilities used by patients during their visits is expected to be borne by them.[60] Nigeria's budgetary allocation to health has remained lower than that recommended by WHO,[61] and in most years it has fallen to 5% of GDP and 3.2 % of total government expenditure.[62]

WHO estimates that public expenditure in Nigeria accounts for 25.5% of the total expenditure on health in Nigeria for the year.[63] It also estimates that 74.5% of funds spent on health come from non-public sources. The World Bank poverty assessment for 1996 estimated that households in Nigeria pay roughly 45% of total health expenditures.[64] The rest of funding comes from bilateral and multilateral assistance.[65]

Recent attempts to introduce a national health insurance scheme have not yet been successful at assisting those most at need.[66] The current plan favors the employed, as entrance into the scheme requires a percentage of an employee's salary be deducted and compulsory contributions by employers.[67] This system has been met with skepticism.[68]

[50] CRLP. *Women of the World: Laws and Policies Affecting their Reproductive Rights. Anglophone Africa*. 2001:78.

[51] United Nations, *Nigeria: Common Country Assessment*. 2001:106.

[52] Id., United Nations. 2001:109.

[53] Id., United Nations. 2001:xix.

[54] Id., United Nations. 2001:109.

[55] Department of Public Health. *2000 HIV/Syphilis and STD Survey*, 40 (This finding is considered an indication of early sexual exposure with little or no knowledge of protective measures against STDs by these young age groups of the population).

[56] Department of Public Health. *2000 HIV/Syphilis and STD Survey*, 40 (Reasoning that this might be due to certain biological factors as well as a possible greater utilization of health facilities for STDs by females. Note that the latter assumption does not seem to be consistent with other sources, which show that women – especially in the northern states - have less access to health care.)

[57] World Bank. *Nigeria: Poverty in the Midst of Plenty. The Challenge of Growth with Inclusion*. A World Bank Poverty Assessment. May 1996.

[58] Shaw RP and Elmendorf AE. *Better Health in Africa - Experience and Lessons Learned. Development in Practice series.* Washington, D.C.: World Bank; 1994.

[59] United Nations Population Fund. "UNFPA and Government Decentralization: A Study of Country Experiences." Evaluation FINDINGS: 30. UNFP Office of Oversight and Evaluation. June, 2000. Available at: http://www.unfpa.org/monitoring/pdf/n-issue30.pdf. Accessed July 13, 2006; Khemani S. *Local Government Accountability for Health Service Delivery in Nigeria*. Development Research Group, The World Bank. June 2005. Available at: http://siteresources. worldbank.org /INTPUBSERV/Resources/Khemani.Local.Gov.Acc.Nigeria_JAE_accepted. June.2005.pdf. Accessed July 13, 2006.

[60] Federal Ministry of Health. Department of Planning and Research. *Health in Nigeria: 1996–2000*.

[61] Id., Federal Ministry of Health, Department of Planning and Research. *Health in Nigeria: 1996-2000*.

[62] WHO. *World Health Report 2006 – Working Together for Health*, Geneva, Switzerland; 2006.

[63] Id., WHO.2006.

[64] World Bank. *Nigeria: Poverty in the Midst of Plenty. The Challenge of Growth with Inclusion*. A World Bank Poverty Assessment. May 1996.

[65] Federal Ministry of Health. Department of Planning and Research. *Health in Nigeria: 1996–2000*.

[66] Peterson K. and Obileye O. *Access to Drugs for HIV/AIDS And Related Opportunistic Infections in Nigeria.* POLICY Project/Nigeria. September, 2002:33-4.

[67] National Health Insurance Decree no. 35, Laws of the Federation of Nigeria, 1999.

[68] Katibi IA, Akande AA, Akande TM, "Awareness and Attitude of Medical Practitioners in Ilorin towards the National Health Insurance Scheme." *Sahel Medical Journal*. January – March 2003;6.

The Federally driven national health insurance scheme has also been met with resentment by some states that have implemented different health financing programs by their governments.

Medical Training in Nigeria

HIV/AIDS has been incorporated into the curriculum for medical education for both medicine and nursing since 1988 and is addressed as part of the usual basic sciences and clinical courses rather than separately.[69] Most recent graduates of medicine should have enough knowledge to provide some form of care for PLWA. Those who graduated in the 1980s are unlikely to have had formal HIV/AIDS instruction during training, and would have to rely on various sources of information, including journals, seminars, internet, and continued medical education for knowledge on HIV/AIDS.

In 1990 the Medical and Dental Council of Nigeria, decided that continued medical education was important and developed a policy that doctors are required to take a number of units of continued medical education in order to obtain and maintain registration to practice within Nigeria. The current regulation requires a minimum of 36 credits every two years to be eligible for continued licensing. A doctor who is below 65 years of age must obtain a minimum of 12 - 24 credits each year to meet the continuing professional education requirement.[70] The implementation of this policy has, however, been hindered by the logistics needed to implement and enforce it.[71] Very few doctors register with the council on a regular basis and the council has very little ability to carry out checks to ascertain up-to-date registration of practicing doctors.[72]

While HIV/AIDS is now taught formally in medical and nursing schools, medical ethics are not. An understanding of ethical obligations is expected to be cultivated during training and maintained through association with peers and teachers. While this may lead to an internalizing of ethics, many physicians lack formal and practical knowledge of these standards. It is, therefore, likely that in the absence of formal medical ethics education, health professionals may act upon beliefs in ways that may conflict with their ethical obligations.

HIV/AIDS in Nigeria

History of HIV/AIDS in Nigeria[73]

The first case of AIDS in Nigeria was reported in 1986.[74] There were some initial efforts to address HIV/AIDS in the late 1980s, but these were insufficiently funded and did not result in public awareness. Governmental lack of attention to HIV/AIDS was likely a result of political instability, lack of political will and lack of awareness. However, the absence of reliable data, a lack of funding, the lack of participation of PLWA, and the inadequacy of the legal system to address developments likely contributed to insufficient advocacy and awareness raising, leading to a public perception that HIV/AIDS was not important. [75] In 1997, the popular musician Fela Anikulapo Kuti died, and his family's public announcement that the cause of his death was AIDS became an important step towards the raising of public awareness of HIV/AIDS in Nigeria.

In 1999, with the election of President Olusegun Obasanjo, Nigeria emerged from approximately 20 years of military dictatorship in which almost no governmental attention or funding was directed at addressing HIV/AIDS.[76] In that same year, Obasanjo formed the Presidential Commission on AIDS (PCA) that included ministers from different sectors. This was also a period of increased efforts by local NGOs. In 2001 the government approved an HIV/AIDS emergency plan that would guide national action on HIV/AIDS until a broader national policy could be elaborated.[77] The current government's multi-sectoral response to HIV/AIDS

[69] United Nations Educational, Scientific and Cultural Organization. UNESCO and the Education Sector's Response to HIV/AIDS Prevention in Nigeria. UNESCO, 2003. Available at: http://portal.unesco.org/en/ev.php-URL_ID=13532&URL_ DO=DO_ TOPIC&URL_SECTION=201.html. Accessed July 19, 2006.

[70] Medical and Dental Council of Nigeria. Available at: http://www.mdcn.org/cme.htm. Accessed on April 12, 2004.

[71] Interview with National Medical Association President, Professor Wole Atoyebi. Medical Nigeria. July 2005. Available at: http://medicalnigeria.net/Interview%20with%20NMA%20President.htm. Accessed July 19, 2006.

[72] Id., Interview with National Medical Association President, July 2005.

[73] All of the historical information is from: United Nations. *Nigeria: Common Country Assessment*. 2001:149.

[74] Federal Ministry of Health: National Action Committee on AIDS. *Situation Analysis Report on STD/HIV/AIDS in Nigeria*. March 2000. Available at: http://www.nigeria-aids.org/situation.cfm.

[75] Id., Federal Ministry of Health: National Action Committee on AIDS. 2000.

[76] United Nations. *Nigeria: Common Country Assessment*. 2001.

[77] Id., United Nations. 2001:150.

is coordinated by the National Action Committee on AIDS (NACA). NACA includes representatives of the government, NGOs, the private sector and PLWA. The formation of similar State and Local Government Action Committees is ongoing. In the summer of 2003, President Obasanjo signed the new National HIV/AIDS Policy.[78] The policy formalizes a multi-sectoral approach to addressing HIV and AIDS and commits the government to providing equitable care and support for persons affected by HIV/AIDS.[79] Prevention of Mother to Child Transmission (MTCT) is being piloted in 6 sites and ARV provision is piloted in 25 sites in the country with plans to scale up both programs.[80]

HIV/AIDS in Nigeria Today

With an estimated 3.6 million people with HIV/AIDS, Nigeria is home to 1 of every 11 of the 40 million people with HIV/AIDS worldwide.[81] The HIV prevalence among adults in Nigeria has increased from 1.8% in 1991 to an estimated 5.4% in 2003.[82] Unofficial estimates range as high as 10 %, which represents 4 to 6 million people infected.[83] Prevalence ranges from 2% to 14.9% in the country's 36 states and Federal Capital Territory.[84] According to official estimates, Nigeria faced 200,000 new infections in 2002 and approximately 310,000 people died from AIDS related deaths in 2004.[85] These numbers are projected to increase each year.

Nigeria has been listed as one of the populous 'next wave' countries where HIV prevalence is expected to explode if action is not taken.[86] These populous countries are all in the early-to-mid-stage of the epidemic, together they comprise over 40% of the world's population and, according to the National Intelligence Council (NIC), do not show sufficient sustained governmental commitment to combating the epidemic.[87] According to NIC estimates, by 2010 Nigeria is expected to have as many as 10 to 15 million HIV positive people, which will constitute about roughly 18 – 26 % of the adult population.[88]

There are geographic differences in prevalence,[89] which ranges from 2% to 14.9% in the country's 36 states and Federal Capital Territory.[90] Adolescents and young adults in their 20s are most affected by HIV/AIDS and have little access to reproductive health services and to information.[91] Prevalence for girls and young women aged 15-24 is higher than for males in that age group[92].

Most (over 80%) of HIV infections in Nigeria are believed to be transmitted sexually.[93] Other modes of transmission relevant to the epidemic in Nigeria include mother to child transmission, and unsafe blood transfusions. Intravenous drug use appears to be on the rise in Nigeria, and may contribute to unsafe sex. It is not yet believed to be a significant contributing factor to the HIV/AIDS epidemic in Nigeria.[94]

Poor health as a result of malnutrition, limited health care, and other infectious diseases such as TB may contribute to the rapid progression and spread of HIV.[95] High prevalence of infections of the reproductive tract, and sexually-transmitted diseases (STD) may contribute to the spread of HIV.[96] Often, people are co-

[78] IRIN. *"NIGERIA: Obasanjo launches new HIV/AIDS policy."* LAGOS, August 5, 2003. Available at: http://www.plusnews.org/AIDSreport.asp?ReportID=2350&SelectRegion=West_Africa. Accessed November 5, 2003.

[79] The Federal Government of Nigeria. The National HIV/AIDS Policy, NACA.

[80] Federal Ministry of Health. National STI and HIV/AIDS Control Programme.

[81] UNAIDS. *2004* Report on the Global AIDS Epidemic. Geneva, Switzerland:2004.

[82] UNAIDS. *2004 Report on the Global AIDS Epidemic*. Geneva, Switzerland:2004. Data based on sentinal survey of pregnant women in antenatal clinics.

[83] S*ee* National Intelligence Council (NIC). *The Next Wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India, and China*. 2002:9.

[84] Federal Ministry of Health, *A Technical Report: The 2001 National HIV/Syphilis Sentinel Survey among Pregnant Women attending Ante-natal Clinics in Nigeria*. 2001.

[85] *Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections: 2002 Update*. Available at: http://www.unaids.org/hivaidsinfo/statistics/fact_sheets/pdfs/Nigeria_en.pdf. Accessed October 9, 2002.; UNAIDS. 2004 Report on the Global AIDS Epidemic, Geneva, Switzerland: 2004.

[86] S*ee* National Intelligence Council (NIC), *The Next Wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India, and China*. 2002.

[87] Id., NIC. 2002:7.

[88] Id., NIC. 2002:10.

[89] United Nations. *Nigeria: Common Country Assessment*. 2001:143.

[90] Federal Ministry of Health. *A Technical Report: The 2001 National HIV/Syphilis Sentinel Survey among Pregnant Women attending Ante-natal Clinics in Nigeria*. 2001.

[91] United Nations. *Nigeria: Common Country Assessment*. 2001:xxii,142.

[92] In the range of 4.35-5.89% for girls in 1999, as compared to boys, 1.68-3.35%. Id., United Nations. 2001:xxii,142.

[93] Id., United Nations. 2001:145.

[94] Id., United Nations. 2001:125-6.

[95] *See* National Intelligence Council (NIC), *The Next Wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India, and China*. 2002:11. (Regarding Ethiopia.)

[96] Id., NIC 2002:6.; Department of Public Health. *2000 HIV/Syphilis and STD Survey. 2000:*40.

infected with HIV and other conditions. Other factors likely contributing to HIV in Nigeria include the lack of blood product safety,[97] drug use and associated behaviors,[98] and traditional practices.[99] Current challenges to addressing HIV/AIDS in Nigeria include funding constraints; a lack of trained personnel; the absence of a reliable data collection system; the lack of knowledge in the general population; the low status of women, and the stigma attached to HIV/AIDS.[100]

Status of Women

Throughout Sub-Saharan Africa, women make up the majority of those infected with HIV/AIDS.[101] They are often blamed as a source of infection[102] and, if infected, may be accused of being promiscuous or immoral.[103]

The vulnerability of women to HIV infection is in part due to biological factors. Other factors contributing to women's vulnerability may be related to poverty, responsibility for extended family, and their lack of power to control the terms of sex within their relationships. Women who lack economic opportunities may be dependent on men for livelihood. As such, they may fear a loss of livelihood or physical violence[104]. These fears may reduce a woman's ability to determine the terms of sexual interaction.[105] According to an expert group convened by the UN Division for the Advancement of Women, the World Health Organization (WHO) and UNAIDS in 2000, "Women's unequal access to economic resources and their economic dependence on men means that they are often unable to negotiate safe sex. This occurs at a number of levels. Many women are forced to resort to exchanging sex for survival, as men provide them with necessary goods (such as income, shelter, school fees) in return for sexual access on a one-off, short- or long-term basis. Others may be forced to resort to different forms of sex work in order to survive."[106] The experts also pointed out that, "because of women's general lack of autonomy over decisions concerning their bodies and health, HIV testing of women may be undertaken without their informed consent. This compromises their rights especially those to health care and life, and can threaten their physical and emotional security."[107]

The expert group concluded that, "A gendered understanding of HIV/AIDS suggests that it is women's and girls' relative lack of power over their bodies and their sexual lives, supported and reinforced by their social and economic inequality, that makes them vulnerable in contracting and living with HIV/AIDS. Any effective response to the epidemic has to address these interrelated levels of gender inequality, as well as the global inequalities that frame them." [108]

Often linked to their limited access to higher education, women are underrepresented in the formal sector[109] and poorly represented in the professional and political arenas.[110] This may have repercussions for all women, for example, lack of women doctors may lead to under-utilization of certain health services by women.[111] This lower status of women may, in part, be due to lack of attention to gender issues.[112]

The power imbalance between women and men in Nigeria[113] has cultural and legal roots. Women in Nigeria may be denied inheritance rights. In some communities they are forced into early marriage.[114] Harmful

[97] United Nations. *Nigeria: Common Country Assessment.* 2001:145.

[98] Id., United Nations. 2001:123-140,145.

[99] Id., United Nations. 2001:145. See below for more detail.

[100] USAID Brief and Federal Ministry of Health: National Action Committee on AIDS. *Situation Analysis Report on STD/HIV/AIDS in Nigeria.* 2000. Available at: http://www.nigeria-aids.org/situation.cfm).

[101] UNAIDS. Report on the Global HIV/AIDS Epidemic, July 2002. Barcelona Report. Abuja: 2002;25-26. Available at: http://www.unaids.org/barcelona/presskit/factsheets/FSssafrica_en.htm. Accessed July 19, 2006.

[102] United Nations Division for the Advancement of Women, WHO, UNAIDS. *"The HIV/AIDS Pandemic and its gender implications: Report of the Expert Group Meeting Windhoek, Namibia 13-17 2000."* 2000:13.

[103] Id., United Nations Division for the Advancement of Women, WHO, UNAIDS. 2000:13.

[104] For information on domestic violence in Nigeria, see Center for Reproductive Law and Policy. *Women of the World: Laws and Policies.* New York; 2001:85.

[105] Gupta G.R. "How Men's Power over women fuels the HIV Epidemic." *British Medical Journal.* 2002;324: 183-184.

[106] United Nations Division for the Advancement of Women, WHO, UNAIDS. *"The HIV/AIDS Pandemic and its gender implications: Report of the Expert Group Meeting Windhoek, Namibia 13-17 2000."* 2000:15.

[107] Id., United Nations Division for the Advancement of Women, WHO, UNAIDS. 2000:14.

[108] Id., United Nations Division for the Advancement of Women, WHO, UNAIDS. 2000:9.

[109] Tashjian VB. "Nigeria: Women Building on the Past." in *Women's Rights, A Global View.* London and Westport: Greenwood Press. 2001.

[110] United Nations. Nigeria*: Common Country Assessment.* 2001:35.

[111] Id., United Nations. 2001:109.

[112] Id., United Nations. 2001:13.

[113] Id., United Nations. 2001:110.

traditional practices that exist in Nigeria include female genital cutting,[115] wife inheritance and polygamy, and blood letting and traditional surgeries with non-sterile instruments.[116] Gender-based violence is also common.[117] There are still laws on the books that are discriminatory against women.[118] The status of women in Nigeria likely contributes to the fact that women in Nigeria make up the majority of HIV infections.[119]

Nigeria has three distinct types of marriages according to customary law, Islamic and civil law. One half of the women marry by the age of 16; in the north, however, more than 50% of girls marry between 12 and 15 years of age.[120] In general, boys marry at a much older age than girls. In 1999 the median age for a first marriage for girls was about 15 years.[121] Under customary law and practices women's rights to acquire and inherit land are constrained while varying significantly among different states, religions and tribes.

Status of PLWA in Nigeria

People Living with HIV/AIDS (PLWA) in Nigeria have been found to be subject to discrimination and stigmatization in the work place,[122] as well as by family and communities.[123] They may be evicted from their homes and shunned in the streets.[124] Although President Obasanjo's government has shown leadership on HIV/AIDS, there is still little legal protection for the human rights of people living with HIV/AIDS (PLWA) in Nigeria. Nigerian health professionals, as members of their society, are influenced by the stigma and moral judgement associated with HIV/AIDS.[125] Ideally these health professionals should "play an indispensable role in the promotion and protection of the right to health."[126] However, PLWA may also face discrimination from those employed in the health care sector.[127] According to one policy maker, in Nigeria, there is a "tendency even for health workers to treat HIV patients differently from other patients."

Discriminatory or unethical behavior against PLWA, as documented in other countries,[128] may create an atmosphere that interferes with effective prevention and treatment by discouraging individuals from being tested or seeking information on how to protect themselves and others from HIV/AIDS.[129] Denial of health care to PLWA because of their HIV status is discrimination.[130] Furthermore, discriminatory practices and violations of international principles of medical ethics may serve to legitimize the other forms of discrimination against PLWA discussed above.

[114] Id., United Nations. 2001:13.

[115] Id., United Nations. 2001:xix,110.

[116] Id., United Nations. 2001:xxii.

[117] Id., United Nations. 2001:110.

[118] Id., United Nations. 2001:36.

[119] Id., United Nations. 2001:148.

[120] Tashjian VB. "Nigeria: Women Building on the Past." in *Women's Rights, A Global View*. London and Westport: Greenwood Press. 2001:162.

[121] United Nations. *Nigeria: Common Country Assessment*. 2001:xix.

[122] Center for the Right to Health. *Human Rights and HIV/AIDS: Experiences of People Living with HIV/AIDS in Nigeria*. Lagos, Nigeria; 2001:9-10;23-30.

[123] Id., Center for the Right to Health. 2001:10-11;31-39.; Alubo O, Zwandor A, Jolayemi T, Omudo E. "Acceptance and Stigmatization of PLWA in Nigeria." *AIDS Care*. 2002; 14(1):117-126.

[124] Center for the Right to Health. *Human Rights and HIV/AIDS: Experiences of People Living with HIV/AIDS in Nigeria*. Lagos, Nigeria; 2001.

[125] Alubo O, Zwandor A, Jolayemi T, Omudo E. *"Acceptance and Stigmatization of PLWA in Nigeria." AIDS Care.* 2002;14(1):117-126.

[126] Economic Social and Cultural Rights*: the rights of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Report of the Special Rapporteur, Paul Hunt, submitted in accordance with Commission resolution 2002/31 E/CN.4/2003/58, para 95.

[127] Center for the Right to Health. *Human Rights and HIV/AIDS: Experiences of People Living with HIV/AIDS in Nigeria*. Lagos, Nigeria; 2001.

[128] UNAIDS. *India: HIV and AIDS-related Discrimination, Stigmatization, and Denial*. Geneva, Switzerland;2001.; Danziger R. "Discrimination against people with HIV and AIDS in Poland." *British Medical Journal*. 1994;308:1145-1147.; Tirelli U, Accurso V, Spina M, Vaccher E. "HIV and "discrimination"." *British Medical Journal*. 1991;303:582.; Devroey D, Van Casteren V, Sasse A, Wallyn S. "Non-consented HIV testing by Belgian general practitioners." *AIDS*. 2003;17(4):641-642.; Richter M. *Nature and Extent of Discrimination against PLWAs in South Africa: Interviews and a study of AIDS Law Project client files 1993-2001*. Johannesburg: Aids Law Project;2001.; ICRW. *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia*. ICRW, Washington D.C.: 2003.

[129] Mann J, Gostin L, Gruskin S, Brennan T, Lazzarini Z, Fineberg HV. *Health and Human Rights*. 1994; 1(1):6-23.; Integrated Regional Information Networks. *Nigeria: Antiretroviral scheme draws poor response.*2002. Available at: http://www.irinnews.org/AIDSreport.asp?ReportID=1331&SelectRegion=West_Africa&SelectCountry=NIGERIA. Accessed April 3, 2003.; Parker R, Aggleton P. *HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action*. Population Council; 2002.

[130] UNAIDS. *Factsheet: An overview of HIV/AIDS-related stigma and discrimination*. Available at: www.unaids.org. See Commission on Human Rights Resolutions, 1999/49 and 2001/51.

Stigma and HIV and AIDS

The stigma associated with HIV/AIDS is also an important contributory factor to the spread of HIV/AIDS. Discouraged by stigma from seeking out their status, people may unknowingly infect their sexual partners. Those individuals who are HIV positive may engage in unsafe behaviors in an effort to hide their status from others. Stigma may also inhibit people from seeking information about prevention of transmission that could prevent them from being infected or infecting others.[131]

According to one key Nigerian policy maker on HIV and AIDS interviewed by PHR, "The greatest problem is the issue of stigma - it drives the engine of response... moralization associated with modes of transmission... discourages people from getting tested and from disclosing." As the UN Special Rapporteur on the Right to Health describes the role of stigma: "Stigma associated with HIV/AIDS builds upon and reinforces prejudices related to gender, poverty, sexuality, race and other factors. Fears related to illness and death; the association of HIV with sex workers, men having sex with men and injecting drug use; and beliefs that attribute moral fault to people living with HIV/AIDS all contribute to the impact of stigma and often give rise to intolerance and discrimination. Stigma and discrimination against people living with HIV/AIDS affects the spread and impact of the disease in several crucial ways. For example, fear of being identified with HIV/AIDS stops people from seeking voluntary counseling and testing, which are vital to prevention, care, and treatment efforts."[132] One NGO officer working in Nigeria concluded, "stigma is there and people don't come forward."

Effects of HIV/AIDS on Nigeria's Economy

Nigeria is largely an agricultural state,[133] but is also rich in natural resources – particularly oil, which is found primarily in the Delta region.[134] Not withstanding, poverty is wide spread,[135] especially among female-headed households.[136] Much of the country's wealth is spent on servicing Nigeria's debt.[137]

HIV/AIDS has significant economic impact in Nigeria.[138] HIV/AIDS places a burden on the health sector. The cost of care and treatment is high and more people need services as prevalence of the disease increases.[139] Effects on education include the need for expansion of educational curricula to address HIV/AIDS, the loss of teachers to HIV and increased work burden of those remaining. Children, disproportionately girls, may be withdrawn from school to care for relatives or because low family income results in the inability to afford school fees.[140]

Households bear the brunt of the cost of medical care and medications. Many family members who fall ill lose their ability to earn income. Most often women have to care for those who are ill and may have to forgo their education or work outside the home.

Following the death of a family member, the family must bear funeral and burial costs and incur a loss of income for time spent away from their employment. Employers are also affected when employees take time off work because of AIDS related illness or to care for sick family members or attend funerals.

[131] United Nations. *Nigeria: Common Country Assessment*. 2001:148.; *Economic Social and Cultural Rights: the rights of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Report of the Special Rapporteur, Paul Hunt, submitted in accordance with Commission resolution 2002/31 E/CN.4/2003/58, para 68.; Oluduru O. "Legal Issues Raised by HIV/AIDS." in *HIV/AIDS and Human Rights: Role of the Judiciary*. Lagos (Nigeria): Center for the Right to Health; 2001:28.

[132] *Economic Social and Cultural Rights: the rights of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Report of the Special Rapporteur, Paul Hunt, submitted in accordance with Commission resolution 2002/31 E/CN.4/2003/58, para 68.

[133] Falola T. *The History of Nigeria*. London and Westport: Greenwood Press; 1999:8.

[134] Falola, T. *Culture and Customs of Nigeria*. London and Westport: Greenwood Press; 2001:9.

[135] United Nations. *Nigeria: Common Country Assessment. 2001*:xv.

[136] Id., United Nations. 2001:xvi.

[137] Id., United Nations. 2001:9.

[138] Bollinger L, Stover J, Nwaorgu O. *The Economic Impact of AIDS in Nigeria*. The Futures Group International; 1999:4-5.

[139] Id., Bollinger L, Stover J, Nwaorgu O. 1999:6.

[140] Id., Bollinger L, Stover J, Nwaorgu O. 1999:8.

III. ASSESSMENT OF DISCRIMINATORY CLINICIAN ATTITUDES AND PRACTICES TOWARD PATIENTS WITH HIV/AIDS IN NIGERIA

Anecdotal information suggests that health care professionals in Nigeria may engage in discrimination against and stigmatization of PLWA.[141] The prevalence, character of, and factors contributing to these practices are, however, largely unknown. To address this lack of knowledge, PHR, the Policy Project Nigeria and the CRH conducted two surveys: a survey of health professionals in four states in Nigeria and a survey of people living with HIV/AIDS in those four states and in Lagos and Abuja. The study was designed to answer three research questions: 1) Are there discriminatory practices in the health sector that affect the health and well-being of people with HIV/AIDS in Nigeria? 2) How receptive are health workers and institutions to treating people with HIV/AIDS? and 3) What underlying factors may contribute to any discriminatory practices? The study was intended to inform ongoing policy discussions and development of effective interventions.

A. HEALTH CARE PROFESSIONAL SURVEY

Methods

Sampling

At the time of the study, approximately 120,000,000 people were living in the 36 states and one territory of Nigeria.[142] The team conducted the health care professional study in four states: Abia, Gombe, Kano and Oyo. These sites were selected by dividing the country's six geopolitical zones into two sections - north and south- in order to capture geographical and other differences and then randomly selecting two of three zones from each section. Within the four selected zones, using health care facility lists compiled by Nigeria's Federal Ministry of Health,[143] the team identified states that have a tertiary care institution and randomly selected one of these states from each zone. To obtain a representative sample of health care professionals, the team determined the number of health care professionals in each state and proportionally sampled doctors, nurses and midwives from the tertiary facility and systematically selected public and private secondary and primary health care facilities in the four states. Fifty- four percent of the health care professionals were sampled from tertiary care facilities. Eligible facilities were those included in the Federal Government database[144] that were operational at the time of the survey. In each health care facility, the team systematically sampled from all doctors, nurses, and midwives to acquire information about professional knowledge, attitudes, and behavior. Eligible professionals were physicians, certified nurses, or midwives working in positions with direct patient contact. Data on the number of health care professionals was derived from Federal Ministry of Health data, which indicated that these four states have a total of nearly 4,500 health care professionals who serve a population of approximately 17.8 million people. [145] In order to determine an appropriate sample size for this study, the team estimated a prevalence of discrimination and set a desired margin of error. The team assumed a prevalence of discrimination of 10%, based on local activists' estimates that 10% of clinicians exhibit discriminatory behavior and attitudes, a margin of error of +/- .01% and a 90% confidence (10% significance) level. The sample size required given these constraints was 301 health care professionals. However, the sample design included several levels of clustering, and the team therefore assumed a design effect of 3 and thus the sample size needed was calculated to be approximately 1,000. The team sampled a total of 1,021 health care providers in proportion to population size of doctors, nurses and midwives.

[141] Alubo O, Zwandor A, Jolayemi T, Omudo E. "Acceptance and Stigmatization of PLWA in Nigeria." *AIDS Care*. 2002;14(1):117-126.; Adelekan ML, Jolayemi SO, Ndom RJE, Adegboye J, Babatunde S, Tunde-Ayimode M, Yussuff O, Makanjuola, AB. "Caring for People with AIDS in a Nigerian Teaching Hospital: Staff attitudes and knowledge." *AIDS Care*. 1995;7(Supp 1):S63-72.

[142] United Nations Population Fund (UNFPA). *State of the World Population.* New York; 2002.

[143] Nigeria Federal Ministry of Health. *Health Facilities Data Base in Nigeria*; 2000.

[144] Id., Nigeria Federal Ministry of Health. 2000.

[145] Federal Ministry of Health, Dept of Research Planning and Statistics: Nigeria Health Profile 1996.

Survey Questionnaire

The 104-item health care professional survey included questions on respondent demographics, practices regarding informed consent, testing, disclosure of HIV status, treatment and care of HIV/AIDS patients, and attitudes and beliefs about treatment and care of HIV/AIDS patients.

Treatment and care practices of HIV/AIDS patients were assessed using Likert-type scales (e.g. always, most of the time, sometimes, rarely, never). Attitudes and beliefs were assessed by a response of "agree" or "disagree" with statements regarding testing, treatment and care of HIV/AIDS patients.

Using a separate 103-item survey instrument, the team obtained information about each facility's capacity, resources, and policies from the person in charge of the facility. Of the 163 facilities sampled, 20 were no longer operational, contact could not be established after two attempts at the time of sampling in 10, and fifteen were not eligible.

The questionnaires were written and interviews conducted in English. Seven regional, human rights, and medical experts reviewed the questionnaires for content validity. The instruments were pilot-tested among 20 participants in Lagos and suggestions regarding clarity and cultural appropriateness were incorporated.

Interviewers

After completing an intensive training program, 24 Nigerian interviewers conducted the survey interviews. Interviewer training consisted of five days of classroom teaching and role-play followed by several days of field observation and ongoing supervision by PHR and Nigerian researchers.

All interviews were conducted over five weeks in October and November, 2002. Interviews lasted approximately 20-30 minutes and were conducted in the most private setting possible within each health care facility. All questionnaires were reviewed for completeness and for correctness of recording after the interview by the interviewers themselves, by the Nigerian research team leaders, and by PHR field supervisors at the end of each day.

Definitions

In the surveys, informed consent was defined as ensuring that a patient who is competent to make decisions is informed and consulted about his or her care. Respondents were informed that this included the responsibility of the clinician to let the patient know about any procedure or medical decision, reasonable alternatives to it, and the risks, benefits, uncertainties, and possible consequences related to each alternative. The clinician must carry out the discussion in layperson's terms, assess the patient's understanding along the way, and ensure that the patient understands the information and consents to it voluntarily. [146] Universal precautions were defined as the use of protective barriers such as gloves, gowns, aprons, masks, or protective eyewear, which can reduce the risk of exposure to potentially infective materials, at all times regardless of a patient's HIV or other status. [147]

Human Subjects Protections

This study was reviewed and approved by an independent ethics review board (ERB) of individuals with expertise in clinical medicine, public health, bioethics, and international HIV/AIDS and human rights research developed for this research project by PHR. In reviewing the research, the ERB was guided by the relevant provisions of Title 45 of the US Code of Federal Regulations,[148] and complied with the Declaration of Helsinki, as revised in 2000.[149] The study was also reviewed for ethical and cultural appropriateness by a panel convened in Nigeria by the Policy Project. In addition, permission for the study was granted by the Nigerian Federal Ministry of Health, State and local government authorities, and facility directors. There were no limitations placed on movement or surveying. Verbal informed consent was obtained from all participants, their names were not recorded, and only minimal identifying information was taken in order to preserve the anonymity of their responses. Participants did not receive any compensation.

Statistical Analysis

The data were analyzed using STATA 7.[150] To control for clustering and design effect, the sample was weighted

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[146] Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. New York, NY: Oxford University Press; 1989:67-119.

[147] Centers for Disease Control. *Universal Precautions for the Prevention of Transmission of HIV and other bloodborne infections*. 1987. Available at: http://www.cdc.gov/ncidod/hip/Blood/UNIVERSA.HTM. Accessed on April 3, 2003.

[148] United States Department of Health and Human Services. Title 45 CFR Part 46 Protection of Human Subjects. Available at: http://ohsr.od.nih.gov/ mpa/45cfr46.php3. Accessed April 4, 2003.

[149] World Medical Association. *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects*. 5th rev ed. Edinburgh, Scotland: World Medical Association;2000.

[150] STATA 7.0 (Intercooled) for Windows. College Station, Tex: STATA Corp; (2002)

by the number of states selected with a tertiary facility from each of six selected geopolitical zones, the number of local government areas per location, the number of facilities selected from each local government area, and the response rate in each location. Since the objective was to describe health care professional practices and attitudes towards people with HIV/AIDS, rather than to conduct comparisons between professionals or explore associations between professional characteristics and different outcomes, the team did not conduct comparative statistical analyses.

Results

Characteristics of Facilities

Eighty-two percent of the facilities surveyed were private. Over half of the facilities were general hospitals (54%) and 23% were primary health centers.

Eighty- four percent of facility directors reported not having anti-retroviral medications (ARVs) in their facility. Moreover, the availability of other medications and dietary supplements was limited and protective materials and other supplies and utilities were not always available. Fifty-nine percent of respondents reported that diagnostic testing was available at their facilities (Table 1). Of the 118 eligible facilities where contact was established, 111 participated in the study (78% of operational facilities).

> Nigeria's Federal Government should provide sufficient supplies of protective materials for practice of universal precautions including the provision of gloves and disposable syringes to all health facilities under Federal Ministry of Health control.

Characteristics of Respondents

Of the 1,103 health care professionals sampled, 23 were not eligible, five were not available after two attempts at the time of sampling, eight were interrupted during the course of the interview, and 46 refused to participate. Consequently, 1,021 professionals participated in the study (93% response rate).

Sociodemographic Characteristics

Professionals were predominantly female (67%) with a mean (SE) age of 36 (.026) (Table 2). Fifty- six percent were nurses, 31% were physicians and 12% were certified midwives (Table 2). Fifty-four percent of the health care professionals were sampled from public tertiary care facilities.

TABLE 1: Characteristics of 111 Participating Facilities

FACILITY CHARACTERISTICS	NO. (%)*†
Facility funding N=109	
Private	89 (82)
Public	20 (18)
Type of facility N=101	
General hospital	56 (54)
Primary health center	24 (23)
Maternity	9 (9)
% of month with adequate supply mean (SD)	
Anti-malarials N=109	93 (21)
Antibiotics N=109	86 (27)
Intravenous fluids N=109	86 (31)
Anti-tuberculosis drugs N=106	41 (43)
Condoms N=102	41 (47)
Anti-retrovirals N=104	12 (27)
% of month with adequate supply, mean (SD)	
Sterile syringes N=108	90 (27)
Sterile gloves N=108	84 (31)
Proper disposal of blood contaminated products N=105	82 (27)
Record keeping ability N=109	78 (29)
Sterilization capabilities N=109	77 (33)
Telephone service N=107	62 (42)
Running water N=108	60 (41)
Refrigeration N=109	58 (39)
Private counseling space N=104	58 (43)
Electricity N=108	54 (30)
Laboratory with HIV testing capability N=101	34 (45)
HIV diagnostic testing available at facility N=107	
None	44 (41)
Samples sent out to other lab	35 (33)
ELISA	21 (20)
Western blot analysis	9 (8)

* Values are number (percent) unless stated otherwise
† Doctor, nurse, or midwife

HIV/AIDS Training

Most professionals reported having some training on HIV/AIDS (Table 2). Current literature (69%), conferences (56%), and courses as a student (52%) were most frequently reported by professionals as the sources of this training. Seven percent reported having no training on HIV/AIDS at all. When asked about the adequacy of their training relating to HIV/AIDS, a majority of profes-

TABLE 2: Demographic Characteristics Among 1,021 Health Care Professional Respondents

RESPONDENT CHARACTERISTICS	NO. (%)*†
Gender N= 1018	
Female	683 (67)
Male	335 (33)
Age (years), mean (SE) (range) N=1010	36 (.78) (20-67)
Profession N=997	
Nurse	540 (56)
Doctor	324 (31)
Midwife	133 (12)
Types of training received on HIV/AIDS N=1019‡	
Review of current literature/journals	698 (69)
Conferences on HIV/AIDS	568 (56)
Courses as a nursing /medical student	532 (52)
Books	512 (50)
Continuing nursing/medical education	487 (48)
Internet updates	115 (11)
No training	75 (7)

* Values are number (percent) unless stated otherwise
† Doctor, nurse, or midwife
‡ May list more than one. Not weighted

sionals indicated that their training on the following was adequate: recognizing signs and symptoms (86%); strategies for individual and community prevention (68%); counseling of HIV/AIDS patients (67%); health consequences of discrimination (59%); ethical and legal obligations of health care professionals (54%); and treatment of HIV/AIDS and related conditions (51%). Only 30%, however, reported that their training on HIV/AIDS and health policy in Nigeria was adequate. The utility of this purely subjective self-report of adequacy of training is limited by the lack of any basis for comparison, but it does provide an indication of the level of satisfaction that providers had regarding their own education on HIV/AIDS.

The Federal Government of Nigeria should develop and implement programs to educate health care professionals and all staff in health facilities about HIV/AIDS including modes of transmission and universal precautions, ethics, and treatment and care. PLWA should be consulted in preparation of these programs.

Testing and Consent

Practices

Seventeen percent of surveyed health care professionals reported that their facility had a written HIV testing policy (Table 3). Respondents indicated that the policies included requirements for informed consent (58%); pre-test counseling (53%); post-test counseling (52%) and post-test referral (29%).

Even when facility policies against testing without consent existed, health care professional concerns about safety are likely to have affected adherence. One physician, when asked about whether there is a written policy on HIV testing at her facility, stated: *"there was a written policy; the situation on the ground has overcome the written policy because everyone is afraid."*

- The Federal Government of Nigeria should stop all mandatory HIV testing in Federal institutions and develop effective monitoring and enforcement mechanisms.
- The Federal Government of Nigeria should ensure that all testing for HIV is voluntary and confidential and includes informed consent and pre and post test counseling.

When asked about how often they obtained informed consent from patients prior to conducting an HIV test, over half of professionals reported obtaining informed consent of patients for half of the HIV tests they ordered or less. Of these who reported obtaining informed consent 0- 50% of the time, 27% indicated that they never obtained informed consent for HIV tests (Table 3).

Fifty four percent of respondents reported that, regardless of consent, routine HIV testing of all patients scheduled for surgery always took place at their facilities, and 50% reported such routine HIV testing of all women attending antenatal care clinics.

Attitudes

Ninety percent of professionals agreed that staff and health care professionals should be informed when a patient is HIV positive so they can protect themselves (Figure 1). Over three quarters of health care professionals surveyed (78%) agreed that there are circumstances where it is appropriate to test a patient without his/her knowledge or permission. Forty-one percent of professionals thought that the charts or beds of HIV patients should be marked so that health facility workers know the patient's status.

TABLE 3: HIV/AIDS Testing and Consent Practices

SURVEY ITEM AND RESPONSES	NO.(%)*†
Is there a written HIV testing policy at facility N=1012	
Yes	201 (17)
No	376 (39)
Don't know	435 (43)
What is included in the written HIV testing policy at facility N=230 ‡	
Informed Consent	133 (58)
Pre-test counseling	122 (53)
Post-test counseling	119 (52)
Post-test referral	66 (29)
Guidelines for testing/treatment	51 (22)
Don't Know	11 (5)
Percentage of cases where obtain informed consent of the patient for HIV test, N=632	
0	88 (14)
1-10	99 (16)
11-20	32 (5)
21-30	21 (3)
31-40	25 (4)
41-50	61 (10)
51-60	38 (6)
61-70	20 (3)
71-80	44 (7)
81-90	44 (7)
91-99	17 (3)
100	143 (23)
How often is there routine HIV testing of patients scheduled for routine surgery regardless of consent N=1015	
No surgery at facility	44 (3)
Always	522 (54)
Most of the time	98 (10)
Sometimes	156 (14)
Rarely	64 (6)
Never	32 (3)
Don't know	99 (10)
How often is there routine HIV testing of women attending antenatal care clinics regardless of consent N=1002	
No antenatal care clinics at facility	27 (2)
Always	503 (50)
Most of the time	48 (5)
Sometimes	116 (12)
Rarely	78 (8)
Never	63 (6)
Don't know	167 (17)

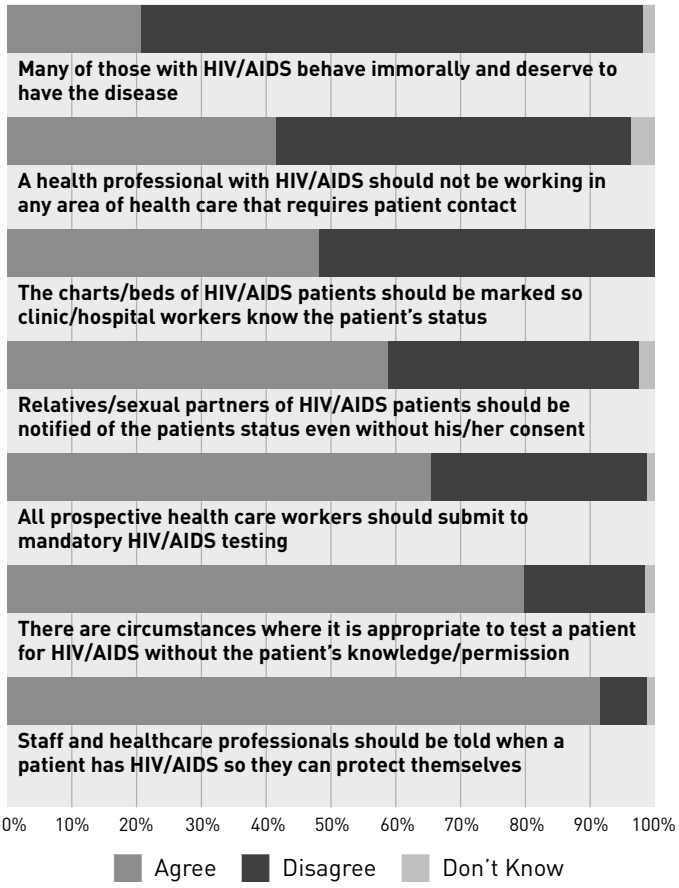
* Values are number (percent) unless stated otherwise
† Doctor, nurse, or midwife
‡ May list more than one. Not weighted

Sixty-four percent of respondents to the health care provider survey agreed with mandatory pre-employment testing of health care workers (Figure 1). Forty percent believed that health care professionals with HIV/AIDS should not be working in any area of the health professions that requires patient contact. Fifteen percent of professionals thought it was permissible to dismiss an HIV positive health professional from his/her job or ask them to resign, and 29% agreed that the employer and coworkers of someone with HIV/AIDS should be informed of the person's status even if he/she doesn't agree.

Fifty-seven percent believed that relatives and sexual partners of HIV/AIDS patients should be notified of their status even without their consent. Fifty-seven percent of respondents indicated that there are circumstances where it is appropriate to not reveal a person's HIV status to him/her. Forty percent of health care professionals reported that it is possible to determine a person's HIV status by looking at him or her.

- The Federal Government of Nigeria should develop, promulgate and enforce HIV/AIDS testing and treatment policies within health institutions under Federal Ministry of Health (FMOH) control that guarantee non-discrimination against PLWA and should ensure the input of PLWA in these processes.
- The Federal Government of Nigeria should work with state governments and the private sector to ensure development and promulgation and enforcement of HIV/AIDS testing and treatment policies within health institutions not under FMOH control that conform to international standards of medical ethics and guarantee non-discrimination against PLWA and should ensure the input of PLWA in these processes.

FIGURE 1: Health Care Professional attitudes and beliefs about HIV testing, consent and disclosure



Treatment and Care

Practices

The most common ways that professionals reported discovering that their patients were HIV positive included: HIV test (78%); nature of patient's presenting illness (60%); and patient's physical appearance (15%). The main reasons respondents gave for testing patients for HIV were: suspicion of AIDS related illness (64%); routine preoperative (32%) or prenatal (25%) testing; to know the HIV status of all their patients (27%); and patient appearance (19%) (Table 4).

Among health care professionals, the three most important concerns about treating HIV/AIDS patients were fear of becoming contaminated (81%), contamination of facility, materials or instruments (17%), and not having materials needed to treat (10%) (Table 4). Indeed, based on reports collected during the facility survey, protective materials and other supplies and utilities were not always available in the facilities. Seventy-two percent of respondents reported that universal precautions were always practiced. Lack of materials - reported by 65% of professionals not reporting consistent practice of universal precautions - was the main reason for not practicing universal precautions (Table 4). M, a nurse, stated that *"The stigma is still there. I do not know what the government can do about it at the state level. Some things we need to do our work, like protective gloves, should be provided."*

- Nigeria's Federal Government should provide sufficient supplies of drugs including ARVs, post exposure prophylaxis, antibiotics and other drugs needed for treatment and prevention of HIV/AIDS and related conditions to all health facilities under Federal Ministry of Health control and make these drugs available to patients at a reasonable cost.
- The government should provide free post exposure prophylaxis and treatment including ARVs for health care professionals who become infected with HIV because of exposure at work.

The lack of materials for protection of health personnel was also cited by policymakers. According to one:

> *Health care delivery system shortcomings contribute to discrimination. If the facilities aren't sufficient, [health care professionals] may be forced to take discriminatory action...There is a lack of protection for health care professionals — not enough gloves, no post exposure prophylaxis policies in most hospitals.*

Another policymaker agreed, stating *"Most hospitals don't have protective supplies. There is no incentive for health care professionals to risk infection..."*

Nine percent of professionals reported refusing to care for an HIV/AIDS patient, and 9% indicated that they had refused an HIV/AIDS patient admission to a hospital (Table 5). Sixty-six percent had observed other health care professionals refusing to care for an HIV/AIDS patient and 43% observed others refusing an HIV/AIDS patient admission to a hospital. While less than one percent of professionals reported verbally mistreating an HIV/AIDS patient, 27% of respondents reported seeing others verbally mistreat HIV/AIDS patients.

TABLE 4: HIV/AIDS Treatment and Care Practices

SURVEY ITEM AND RESPONSES	NO.(%)*†
Ways that professionals reported discovering that their patients were HIV positive N=1013 ‡	
HIV Serology Test	791 (78)
Assume By Patient Illness	606 (60)
Can Tell By Looking	151 (15)
Told by patient	37 (4)
Main reasons for testing patients for HIV N= 986 ‡	
Suspected AIDS-related illness	627 (64)
Routine pre-operative testing	315 (32)
To know the HIV status of all my patients	263 (27)
Routine ante-natal screening/MTCT	247 (25)
Because of patient's appearance	185 (19)
Prevent spread	105 (11)
Protect self/family/other patients/other health personnel	95 (10)
Request by the individual patient	88 (9)
Most important concerns or fears about treating HIV/AIDS patients N=1018 ‡	
Fear of becoming contaminated	825 (81)
Contamination of materials/facility/ instruments	177 (17)
No particular concerns	114 (11)
Don't have materials needed to treat	104 (10)
Fear of virus spread	70 (7)
Don't know how to treat/counsel	59 (6)
Personal/professional stigma by association	57 (6)
Don't have materials needed to protect self/others	52 (5)
How often Universal Precautions practiced. N=1014	
Always	737 (72)
Most of the time	162 (15)
Sometimes	90 (10)
Rarely	14 (2)
Never	8 (1)
Don't know	3 (1)
Reasons Universal Precautions not always used. N= 287	
Lack of materials	187 (65)
No need to practice universal precautions all the time	35 (12)
Don't know	12 (4)
Emergency	10 (3)
Protective measures taken when patient is known or suspected HIV + N=1018 ‡	
Extra gloves/protective gear	825 (81)
Separated from other patients	177 (17)
Be careful	114 (11)
Wash/sterilize after	104 (10)
None; treated like any other patient	70 (7)
Use different instruments/dispose of instruments used	59 (6)
Invasive procedures are not performed	57 (6)
HIV status clearly marked on chart or file	52 (5)

* Values are number (percent) unless stated otherwise

† Doctor, nurse, or midwife

‡ May list more than one. Not weighted

Thirty-eight percent of professionals reported giving confidential information to a patient's family member without the patient's consent, and 53% had observed this behavior. Twelve percent of professionals reported giving confidential information to a person not related to a patient without consent and 22% had observed this behavior.

Attitudes

To prevent discrimination by health care professionals against HIV/AIDS patients, most participants (87%) indicated that health care professionals who engage in discriminatory practices should be educated and counseled. M, a nurse, stated that her attitude toward PLWA has changed *"before my training as counselor I refused to care, but now I know better."* Health facility policies against discrimination were cited as solutions by 19% of professionals, and stronger laws against discrimination were suggested by 11% (Table 5). According to one policymaker, "what is needed is not sanctions rather education/discussion for all levels of workers." However, he pointed out that there is no legal framework underlying the system and stated that to address discrimination in the health care sector, there must be a "core instrument to fall back on while fashioning out any efforts at redress."

Ninety-five percent of respondents agreed that the quality of life of HIV/AIDS patients can be improved with counseling. Ninety-four percent indicated that medications to treat opportunistic infections may prolong an HIV positive person's life (Figure 2). Over half (59%) of professionals agreed that people with HIV/AIDS should be on a separate ward in a hospital or clinic. Forty-eight

TABLE 5: Assessment of Practices Toward Patients with HIV/AIDS

SURVEY ITEM AND RESPONSES	NO.(%)*†
Have refused to care for an HIV/AIDS patient N=1017	
Yes	103 (9)
No	904 (90)
Don't know	10 (1)
Have refused an HIV/AIDS patient admission to a hospital N=1018	
Yes	97 (9)
No	911 (90)
Don't know	10 (1)
Have observed others refusing to care for an HIV/AIDS patient N= 1018	
Yes	657 (66)
No	343 (32)
Don't know	18 (2)
Have observed others refuse an HIV/AIDS patient admission to a hospital N=1016	
Yes	413 (43)
No	583 (56)
Don't know	20 (2)
Have verbally mistreated an HIV/AIDS patient N=1015	
Yes	6 (.39)
No	1,002 (99)
Don't know	7 (1)
Have observed others verbally mistreat an HIV/AIDS patient N=1018	
Yes	236 (27)
No	767 (71)
Don't know	15 (2)
Have given confidential information to a family member N=1016	
Yes	367 (38)
No	643 (61)
Don't know	6 (1)
Have observed others give confidential information to a family member N=1016	
Yes	507 (53)
No	490 (44)
Don't know	19 (3)
Have given confidential information to a non-family member N=1016	
Yes	128 (12)
No	883 (87)
Don't know	5 (1)
Have observed others give confidential information to a non-family member N=1014	
Yes	223 (22)
No	773 (76)
Don't know	18 (2)
What should be done to prevent discrimination against PLWA by healthcare providers N= 1014 ‡	
Education/ counsel/advise of health personnel	884 (87)
Policies at health facilities against discrimination	195 (19)
Stronger laws against discrimination	114 (11)
Punishment of health personnel if they discriminate	69 (7)
Protective materials/separate materials, -wards, facilities for HIV positive	42 (4)

* Values are number (percent)
† Doctor, nurse, or midwife
‡ May list more than one. Not weighted

percent of participants expressed their belief that a person with HIV/AIDS cannot be treated effectively in their facility.

Forty percent of health care professionals reported that it is possible to determine a person's HIV status by looking at him or her, and 21% agreed that they could refuse to treat an HIV/AIDS patient to protect themselves and their family. Twelve percent expressed agreement with the statement that treatment of opportunistic infections in HIV/AIDS patients wastes resources, and 8% agreed that treating someone with HIV/AIDS is a waste of precious resources.

The assumption that an individual may contract HIV through sex and/or immoral behavior appears to exist within the health care sector as well, and may affect access to care and disclosure. The role that moral assumptions play in stigma and discrimination was also cited by key policymakers. According to one, many HIV positive people have problems because of "moralization associated with modes of transmission… [which] discourages people from getting tested and from disclosing [their status]."

FIGURE 2: Provider beliefs regarding treatment and care of HIV/AIDS

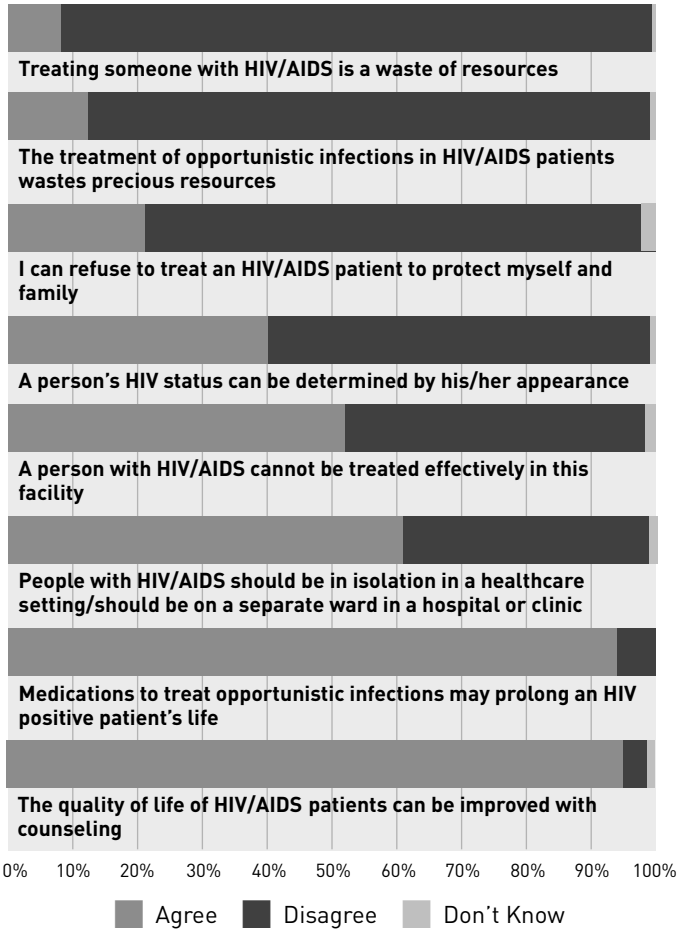


FIGURE 3: Provider attitudes about women and PLWA

Women's Rights

Most health care professionals reported agreement with a majority of statements that supported women's rights (Figure 3). Over 90% of respondents agreed that: there should be legal protections for the rights of women (98%); there should be legal protections for the rights of people with HIV/AIDS (96%); women should have inheritance rights (95%); more should be done to protect women and girls from having sex when they don't want to (93%); and women with HIV/AIDS should have inheritance rights (90%). Ninety percent agreed that women and girls need more education about their right to refuse sex. Over eighty percent of respondents indicated agreement with a woman's right to refuse sex if a man refuses to use a condom (83%). Furthermore, 84% of participants believed that any woman has the right to refuse sex.

Despite these findings that suggest a high level of recognition of women's rights among participants, 82%

TABLE 6: Health Care Provider Assessment of Obstacles to Health Care for PLWA

SURVEY ITEM AND RESPONSES	NO.(%)*†
Most significant obstacle to the effective treatment of infections/conditions related to AIDS N=1003	
Patient's inability to pay	476 (48)
Availability of medications for opportunistic infections	114 (12)
Most significant obstacle to HIV/AIDS patients obtaining access to health services in your area N= 1008	
Fear of being stigmatized	458 (48)
Lack of financial means	326 (32)

* Values are number (percent) unless stated otherwise
† Doctor, nurse, or midwife

agreed with mandatory premarital HIV testing of men and women. Sixty-six percent indicated that a good wife obeys her husband even if she disagrees, and 57% agreed that it is a wife's obligation to have sex with her husband even if she does not want to. Twenty percent of respondents to the health care professional survey agreed that many of those who have HIV/AIDS behaved immorally and deserve the disease. Thirteen percent indicated that women (not men) are responsible for the transmission of most heterosexual HIV cases, and 6% of health care professionals surveyed indicated that a man has the right to beat his wife if she disobeys him.

Health care professionals cited patients' lack of resources as a concern. Forty percent of professionals indicated that the patient's inability to pay was the most significant obstacle to effective treatment of infections/conditions related to HIV, whereas 12% cited the lack of availability of medications for opportunistic infections as the most significant obstacle. According to 48% of respondents the most significant obstacle to HIV/AIDS patients obtaining access to health services is the fear of being stigmatized, followed by lack of financial means, 32% (Table 6). Patients may also have to bear the brunt of a lack of resources in a facility. T, a nurse, indicated that *"when there is lack of materials, we ask patients to buy the materials."*

Health Care Professionals should:

- Uphold standards of medical practice that are consistent with Nigerian codes of medical ethics.
- Ensure that the dignity of all patients is respected, even those with terminal and/or infectious illnesses, including HIV/AIDS.
- Obtain educational information for effective diagnosis and treatment of HIV/AIDS.
- Work for conditions that will improve the lives of individual PLWA and communities at risk.

B. SURVEY OF PEOPLE LIVING WITH HIV/AIDS

Methods

Sampling

At the time of the study, an estimated 3.5 million people were living with HIV/AIDS (PLWA) in the 36 states and Federal Capital Territory of Nigeria.[151] The team interviewed PLWA in the four states where the team conducted the health care professional survey: Abia, Gombe, Kano and Oyo as well as in Lagos and Abuja. In order to ensure that there were no ethical breaches including disclosures of status without consent in the process of conducting the study, the team recruited PLWA through support groups rather than randomly. Due to the small number of identified PLWA in the catchment areas of facilities where health professionals were interviewed, some PLWA were recruited through support groups in Lagos and Abuja.

Survey Questionnaire

The 122-item PLWA survey included questions on respondent demographics, experiences regarding informed consent, testing, and disclosure, treatment and care, and attitudes and beliefs about treatment and care.

Treatment and care practices of HIV/AIDS patients were assessed using Likert-type scales (e.g. always, most of the time, sometimes, rarely, never). Attitudes and beliefs were assessed by a response of "agree" or "disagree" with statements regarding testing, treatment and care of HIV/AIDS patients and perceptions of gender roles and women's rights.

The PLWA survey instrument included four open-ended questions in order to obtain more detailed

[151] UNAIDS. *Report on the Global HIV/AIDS Epidemic*. Geneva, Switzerland: 2002.

descriptions from participants about any discrimination or ill-treatment that they have experienced in the health care sector. Although most participants did not report experiences of abuse, the experiences of ill-treatment reported by different respondents from different sites often had similarities.

English was used for both the surveys and the interviews. Seven regional, human rights, and medical experts reviewed the questionnaires for content validity. The instruments were pilot tested among 10 participants in Lagos, and suggestions regarding clarity and cultural appropriateness were incorporated.

Interviewers

After completing an intensive training program, six of the 24 Nigerian interviewers were selected by the PHR supervisors to conduct both health care professional and PLWA interviews. These individuals were selected based on their performance during the training and experience in and comfort with working with PLWA. The additional interviewer training consisted of classroom teaching and role-play followed by several days of field observation and ongoing supervision by PHR and Nigerian researchers.

Because of the difficulty of arranging them, PLWA interviews were conducted in October and November 2002, and in May 2003. Interviews lasted approximately 20-30 minutes and were conducted in the most private setting possible. All questionnaires were reviewed for completeness and for correctness of recording after the interview by the interviewers themselves, by the Nigerian research team leaders, and in 2002, by PHR field supervisors at the end of each day.

Human Subjects Protections

This study was reviewed and approved by an independent ethics review board (ERB) with expertise in clinical medicine, public health, bioethics, and international HIV/AIDS and human rights research. In reviewing the research, the ERB was guided by the relevant provisions of Title 45 of the US Code of Federal Regulations,[152] and complied with the Declaration of Helsinki, as revised in 2000.[153] The study was also reviewed for ethical and cultural appropriateness by a panel convened in Nigeria by the Policy Project. There were no limitations placed on movement or surveying. Verbal informed consent was obtained from all participants, their names were not recorded, and only minimal identifying information was taken in order to preserve the anonymity of their responses. Participants received money to cover their transport costs.

Statistical Analysis

The data were analyzed using STATA 7.[154] Since the objective was to describe the experiences of people with HIV/AIDS in their interactions with the health care sector, rather than to conduct comparisons between PLWA or explore associations between PLWA characteristics and different outcomes, the team did not conduct comparative statistical analyses.

Results

Characteristics of Respondents

Sociodemographic Characteristics

Approximately half of PLWA who responded to the survey were men (53%). PLWA ranged in age from 17-60 with a mean (SD) age of 32 (8.6) (Table 7). Forty-two percent were single and 40% were married. The mean (SD) number of years of education completed by respondents was 12 (4). Fifty percent of respondents reported completing secondary education, 36% reported completing tertiary education and 14% reported completing primary education. Most participants were not employed full-time. Thirty-one percent reported engaging in casual work and 28% reported being unemployed. Twenty-four percent of respondents were self-employed and 11% were students. Of those who reported not being employed full-time, 41% indicated that no jobs are available, 22% blamed poor health, and 20% reported being dismissed for reasons related to their HIV status. The mean (SE) total monthly income from all sources reported by participants was 11,442 (914) Naira (~$83).

The sources of information about HIV/AIDS most commonly reported by PLWA were radio (69%), television (53%), newspapers (39%) and magazines (22%). Twenty percent reported a health care worker as a source of information about HIV/AIDS. These sources of information may not always be accurate. B, stated that his doctor "lie(d) to me that HIV is from sleeping around with everybody. But I have not slept around. I was told at [my support group] that HIV can come through injection …."

[152] United States Department of Health and Human Services. Title 45 CFR Part 46 Protection of Human Subjects. Available at: http://ohsr.od.nih.gov/ mpa/45cfr46.php3. Accessed April 4, 2003.

[153] World Medical Association. *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects*. 5th rev ed. Edinburgh, Scotland: World Medical Association;2000.

[154] STATA 7.0 (Intercooled) for Windows. College Station, Tex: STATA Corp; (2002).

TABLE 7: Demographic Characteristics Among 227 Respondents to PLWA Survey

SURVEY ITEM AND RESPONSES	NO. (%)*
Gender N=226	
Male	119 (53)
Female	107 (47)
Age (years), mean ± SD (range) N=225	32± 8.6 (17-60)
Marital status N=225	
Single	95 (42)
Married	91 (40)
Widowed due to HIV/AIDS	19 (8)
Widowed	11 (5)
Number of years of school completed, mean ± SD (range) N=225	12± 4 (0-20)
Highest level of education completed N=218	
Secondary	109 (50)
Tertiary	79 (36)
Primary	30 (14)
Employment status N=213	
Casual worker	66 (31)
Unemployed	59 (28)
Self employed	51 (24)
Student	23 (11)
Housewife	12 (6)
Reason unemployed N=59	
No job available	24 (41)
Poor health	13 (22)
Dismissed related to HIV status	12 (20)
No money for own business	3 (5)
Total income in Naira per month (all sources), mean ± SE (range) N=182	11,442 ± 914 (0-80,000)
What are your sources of information about HIV /AIDS N=223	
Radio	153 (69)
Television	118 (53)
Newspaper	88 (39)
NGO	79 (35)
Magazine	48 (22)
Health care worker	44 (20)
Book	18 (8)
Friend	14 (6)
Clergy	13 (6)

* Values are number (percent) unless stated otherwise

Testing and Consent

Most respondents reported being informed of their HIV status in the past three years (Table 8); forty-five percent in 2002, 22% in 2001 and 11% in 2000. The location where respondents' reported first being tested for and diagnosed with HIV varied. Forty-one percent were first diagnosed at a general hospital, 22% at a teaching hospital and 20% at a private hospital. The majority (64%) indicated that the reason they were tested was that they were sick all the time. Other reasons for testing included: partner or spouse testing HIV positive (16%), to know status (9%) and routine testing for blood donation (4%) or antenatal (4%). Approximately half of respondents (49%) stated that they did not know that they were being tested for HIV. Only 18% reported that it was their idea to be tested. Forty-five percent stated that the test was the idea of the health worker. Sixty-four percent of respondents found out about their test result from a doctor, 10% (23/226) from a nurse or a lab technician and 6% from a family member.

Most (92%) reported that they were not asked to sign a consent form for the HIV test, and 67% indicated that no one explained the HIV test to them prior to the test. Of those that reported receiving post-test counseling, 72% were counseled about the meaning of being HIV positive, 63% were counseled about safer sex, 59% were counseled about how to cope at home, and 58% received information about where to go for help and advice (Table 8).

The government and health professionals should work with PLWA support groups, health care professionals and NGOs to develop a referral system for people testing HIV positive in health care facilities.

Disclosure of HIV Status

PLWA reported experiences of unauthorized disclosure of their HIV status by health professionals, often with adverse consequences including disclosures within the health care setting. According to N: *"The nurses inform others without the consent of the patient. Even cleaners are told about the patient's status."*

S, a woman in her late 20s, also indicated that the treatment she received in the hospital changed for the worse after her HIV status became known to the staff. *"One time I went to the hospital because I was very sick, I was treated nicely until one nurse went in and talked to the doctor, thereafter all their attitude to me suddenly changed and I was made to wait till every*

TABLE 8: HIV/AIDS Testing: Informed Consent & Counseling

SURVEY ITEM AND RESPONSES	NO. (%)*†
Year informed of HIV status N=225	
1990-1999	32 (14)
2000	24 (11)
2001	50 (22)
2002	101 (45)
2003	18 (8)
Where first tested/diagnosed for HIV N=227	
General Hospital	94 (41)
Teaching hospital	49 (22)
Private hospital	46 (20)
Private lab	17 (7)
Health Center	10 (4)
Reason tested N=227	
Sick all the time	146 (64)
Spouse/partner tested positive	37 (16)
To know status	21 (9)
Blood donation	10 (4)
Antenatal	10 (4)
Worried about a sexual contact	5 (2)
Tested unknowingly	5 (2)
Hospital admission	4 (2)
Don't know	4 (2)
Did you know you were being tested for HIV N=227	
No	112 (49)
Yes	113 (50)
Don't know	2 (1)
Whose idea was it for you to be tested N=227	
Doctor/ health worker	102 (45)
Mine	40 (18)
Didn't know was being tested	28 (12)
Family	26 (11)
Spouse/partner	14 (6)
Employer	6 (3)
Friend	2 (1)
How did you first find out about your HIV test result N=226	
Doctor	145 (64)
Nurse	23 (10)
Laboratory technician	23 (10)
Family	13 (6)
Opened results myself	8 (4)
NGO worker	4 (2)
Were you asked to sign a consent form for the HIV test N=225	
No	207 (92)
Yes	16 (7)
Don't know	2 (1)
Who explained the HIV test to you before the test N=227	
No one	151 (67)
Doctor	48 (21)
Nurse	8 (4)
Family	6 (3)
Receive post- test counseling about	
The meaning of being HIV positive N=203	146 (72)
Safe sex N=199	125 (63)
How to cope at home N=199	118 (59)
Where to go for help/information/ advice N=199	115 (58)
No post-test counseling N=200	49 (25)

* Values are number (percent) unless stated otherwise

patient was seen before they saw me, and when I confronted the nurse, she said I was even lucky the doctor agreed to see me and that if it was her that was the doctor she will not see me because they do not see HIV patients."

PLWA reported that disclosures without consent by healthcare professionals to their family members had negative consequences. Y told the following story: *"I was pregnant and very sickly so was taken to the hospital when HIV test was done without my knowledge. The result was given to my husband who went home and told my children not to have anything to do with me. They should not eat or drink with me or have anything to do with me. This went on until we both received counseling after he was discovered to be positive also."*

Participants in the PLWA survey also provided details about unauthorized health care professional disclosures to non-family members outside the health

care system. T stated that her neighbor, *"who by virtue of her profession as a nurse in the hospital [where] I was diagnosed, took it upon herself to be informing other neighbors to be on their guards against us."* Another participant, G, reported that *"A nurse actually told and wrote my employers to stop paying me because I would die in about two days."*

Family and Social Interactions

About a quarter (24%) of respondents indicated that their current sexual partners were not aware of their HIV status. Half stated that their current partners knew they were HIV positive, and 26% reported not having any current sexual partners. (Table 9) M reported his negative experiences with family and community since making his HIV positive status known and declared:

TABLE 9: Family Social and Personal Interactions of PLWA

SURVEY ITEM AND RESPONSES	NO. (%)*
Are your current sexual partners aware of your HIV status N= 226	
No	55 (24)
Yes	113 (50)
No current sexual partners	58 (26)
Has anyone notified anyone of your status without your permission N=226	
No	143 (63)
Don't know	54 (24)
Doctor	12 (5)
Friend	9 (4)
Nurse	8 (4)
Who notified your sexual partner of your status without your permission N=151	
No one	126 (83)
Doctor	14 (9)
Nurse	4 (3)
Relative	3 (2)
Consequences of others knowing your HIV status N=223 †	
Nothing	177 (80)
Shunned by family	16 (7)
Shunned by community	15 (7)
Not hired for job	6 (3)
Fired from job	5 (2)
Lost home	5 (2)

* Values are number (percent)
† May list more than one

> *Let me tell you people, you want us to disclose our status! Do you know what that means! It results in a death sentence. I regret ever having succumbed to that lie of accepting publicly my status.*

The fear of rejection by family and friends may prevent PLWA from disclosing their status to others, including sexual partners. This dilemma was reported by M, a woman in her early 20s.

> *When I'm having fun I try to tell my boyfriend to use condoms but he will not agree. He does not like to use condom and he does not know that I am positive. I am afraid to tell him because he will leave me. He promised to marry me.*

D reported that she has not had "any sexual partners since I tested positive to HIV. But before, I had a boyfriend and I don't know if he was the one that infected me." She further stated that "presently I have a man asking my hand in marriage and I have not told him that I am HIV positive."

Five percent of PLWA reported that a doctor revealed their status to someone without their permission. Four percent reported that a nurse did and 3% a laboratory technician. Most (80%) reported no consequences from others knowing their HIV status. Seven percent, however, reported being shunned by their family or by their community.

J explained what happened after a doctor's unauthorized disclosure of her status to her husband:

> *I knew my status before my husband. The doctor told him without my permission and when he also tested positive, he beat me and refused to talk to me or eat what I cooked for him. But I think now I know he was the one who gave me HIV.*

Access to Health Care

Eleven percent of participants reported being refused medical care. The majority were refused care in a public facility (71%). Nurses were most often reported as refusing care (67%) and doctors were reported to have refused care by 43% of respondents. Seventeen percent of respondents observed others being refused medical care. Again, the majority of these observed refusals were in a public facility (84%). Most observed refusals of care were by doctors (63%) and nurses (54%).

R, in his 50s, indicated his belief that refusal to care for PLWA is widespread in the public sector:

TABLE 10: PLWA Experiences of Refusal of Medical Care

SURVEY ITEM AND RESPONSES	NO. (%)*
Have you ever been refused medical care	
No	200 (89)
Yes	25 (11)
Where N=21	
Maternity	1 (5)
Primary health center	1 (5)
General hospital	12 (57)
Teaching hospital	2 (10)
Federal medical center	2 (10)
Specialized facility	2 (10)
Don't know	1 (5)
Facility type N=21	
Public	15 (71)
Private	5 (24)
Don't know	1 (5)
Refused by N=21 †	
No one	1 (5)
Doctor	9 (43)
Nurse	14 (67)
Support staff	2 (10)
Have you ever observed anyone being refused medical care N=225	
No	181 (80)
Yes	38 (17)
Don't know	6 (3)
Where N=36	
Maternity	4 (11)
Primary health center	3 (8)
General hospital	22 (61)
Teaching hospital	5 (14)
Federal medical center	2 (6)
Specialized facility	1 (3)
Don't know	3 (8)
Facility type N=37	
Public	31 (84)
Private	5 (14)
Don't know	2 (5)
Refused by N=35 †	
Doctor	22 (63)
Nurse	19 (54)
Support staff	4 (11)

* Values are number (percent)
† May list more than one

Most public hospitals owned by government always do not want to take care of any HIV positive patients. This is really common with general hospitals. However, the situation was the same with teaching hospitals until the anti-retroviral drugs came to them; thereafter they grudgingly attended to us.

T, a woman in her late 20s was refused care in a public facility, "I was refused care in the general hospital. The nurse just told me to go and find a private hospital because they do not attend to HIV people. She said she wanted to let me know so I do not waste my time."

S, in his 50s, reported that he was told he wouldn't be treated

at the teaching hospital where I was first diagnosed with HIV. After post-test counseling my doctor referred me to a non-governmental organization and warned me sternly never to come to the teaching hospital again that I would not receive any more treatment from him.

E, a PLWA in his 30s, indicated that the lack of medication in public hospitals may be the reason he has been refused care.

I have stopped going to the federal medical centers when I am sick, because once I went there they refused to let me be seen by the doctor saying I have HIV and that it cannot be cured so there is no need for them to take me into the hospital and waste the little medicine they have for people who can't be cured.

M's story suggests that this refusal to care can have dire consequences:

I went and booked at some place for Cesarean section so as to have my baby, but after booking, the doctor and nurses refused to get me into the theatre for the Cesarean section and instead just left me there in the bed before I was forced to leave and eventually I lost the child.

Being refused admission to a hospital was reported by 6% of participants. The hospitals where respondents were refused admission were mostly public facilities (82%). Doctors were most often reported as refusing admission (55%) and nurses were reported to have refused admission by 45% of respondents. Twelve percent observed an HIV positive patient being refused admission to a hospital. Public facilities were the sites of most of these refusals (74%). Most observed refusals

TABLE 11: Refusal of Admission to a Hospital

SURVEY ITEM AND RESPONSES	NO. (%)*
Have you ever been refused admission to a hospital N=225	
No	211 (94)
Yes	14 (6)
Where N=12	
General hospital	10 (83)
Federal medical center	1 (8)
Specialized facility	1 (8)
Facility type N=11	
Public	9 (82)
Private	2 (18)
Refused by N=11†	
Doctor	6 (55)
Nurse	5 (45)
Support staff	1 (9)
Have you ever observed an HIV positive patient being refused admission to a hospital N=224	
No	191 (85)
Yes	26 (12)
Don't know	7 (3)
Where N=24	
Primary health center	1 (4)
General hospital	15 (63)
Teaching hospital	2 (8)
Federal medical center	1 (4)
Specialized facility	1 (4)
Don't know	4 (17)
Facility type N=23	
Public	17 (74)
Private	3 (13)
Don't know	3 (13)
Refused by N=22 †	
Doctor	14 (64)
Nurse	11 (50)
Support staff	2 (9)

* Values are number (percent)
† May list more than one

were by doctors (64%) and nurses (50%).

In some cases refusal to admit leaves an HIV positive patient with few choices and increased health care costs. N, in her 30s, reported that,

> *After my HIV test result came out positive, the hospital I was attending my antenatal classes suggested that I should find another hospital to go and deliver my baby because they do not have enough materials to take care of HIV people. I went to a private hospital where my baby was born. I paid 50,000 Naira (~$377) there.*

Some PLWA indicated that they were refused admission to health care facilities with the claim that there was no room for them or that there were not sufficient staff to care for them. T, a man in his 40s, reported *"I was refused admission because I was positive. People who came after me were admitted even though the nurse said the bed spaces were filled."* Y, a woman in her 30s, stated that *"Once I was sick and went to the general hospital and they refused to take me in, saying that there was no bed, but I knew there was."* W, a man in his 40s, stated that *"I went to the hospital the nurse refused to admit me saying that she was the only one on duty and she cannot manage an HIV positive person alone."*

Refusal to admit because of HIV status was reported both at public and private facilities. The doctor who refused to admit F apparently lacked basic knowledge about modes of transmission. She stated:

> *I was refused medical attention in the hospital, a general hospital, because of ignorance of the doctors and nurses. The doctor said that if I spit out he may contact the disease. I was humiliated and left the hospital.*

Refusal to care for PLWA exists in the private sector as well as in the public. P, in her 40s, reported her experiences in trying to access care in private hospitals.

> *I was taken to about 8 private hospitals where I was rejected each time just by looking at my appearance. I was eventually taken back home for treatment by my brother.*

Nine percent reported that their confidential information had been given to their family member by medical personnel and 10% observed this happening to another PLWA. Eight percent stated that their confidential information had been revealed to a non-family member by a health care worker and 7% reported seeing this happen to another PLWA. Verbal mistreatment by a health care worker was reported by 8% of respondents and observed by 10%.

TABLE 12: PLWA Experiences of Breaches of Confidentiality and Verbal Mistreatment

SURVEY ITEM AND RESPONSES	NO. (%)*
Has anyone given your confidential information to your family member N=223	
No	167 (75)
Yes	21 (9)
Don't know	35 (16)
Where N=21	
Primary health center	3 (14)
General hospital	6 (29)
Teaching hospital	6 (29)
Federal medical center	1 (5)
Specialized facility	3 (14)
Don't know	2 (10)
Facility type N=20	
Public	12 (60)
Private	7 (35)
Don't know	1 (5)
Refused by N=19 †	
No one	2 (11)
Doctor	7 (37)
Nurse	6 (32)
Support staff	6 (32)
Have you observed anyone giving a PLWA confidential information to his/her family member N=225	
No	188 (84)
Yes	23 (10)
Don't know	14 (6)
Where N=21	
Maternity	1 (5)
Primary health center	2 (10)
General hospital	10 (48)
Teaching hospital	6 (29)
Federal medical center	2 (10)
Don't know	3 (14)
Facility type N=21	
Public	16 (76)
Private	4 (19)
Don't know	2 (10)
Refused by N=21†	
No one	2 (10)
Doctor	9 (43)
Nurse	12 (57)
Support staff	6 (29)
Has anyone given your confidential information to a non-family member N=225	
No	165 (73)
Yes	17 (8)
Don't know	43 (19)
Where N=13	
Primary health center	1 (8)
General hospital	8 (62)
Teaching hospital	3 (23)
Federal medical center	1 (8)
Facility type N=13	
Public	12 (92)
Private	1 (8)
Refused by N=13 †	
Doctor	4 (31)
Nurse	6 (46)
Support staff	6 (46)
Have you observed anyone giving a PLWA confidential information to someone who is not his/her family member N=225	
No	195 (87)
Yes	16 (7)
Don't know	14 (6)
Where N=14	
Primary health center	2 (14)
General hospital	9 (64)
Teaching hospital	3 (21)
Federal medical center	2 (14)
Specialized facility	1 (7)
Facility type N=14	
Public	11 (79)
Private	4 (29)
Refused by N=13 †	
Doctor	2 (15)
Nurse	10 (77)
Support staff	3 (23)
Has anyone verbally mistreated you N=225	
No	207 (92)
Yes	17 (8)
Don't know	1 (←1)
Where N=14	
Primary health center	1 (7)
General hospital	6 (43)
Teaching hospital	1 (7)
Federal medical center	1 (7)
Specialized facility	4 (29)
Don't know	1 (7)
Facility type N=13	
Public	10 (77)
Private	2 (15)
Don't know	1 (8)
Refused by N=14 †	
No one	1 (7)
Doctor	4 (29)
Nurse	7 (50)
Support staff	1 (1)
Have you observed an HIV/AIDS patient being verbally mistreated N=224	
No	199 (89)
Yes	23 (10)
Don't know	2 (1)
Where N=19	
Primary health center	2 (11)
General hospital	8 (42)
Specialized facility	8 (42)
Don't know	1 (5)
Facility type N=17	
Public	13 (76)
Private	3 (18)
Don't know	1 (6)
Refused by N=17†	
No one	2 (12)
Doctor	3 (18)
Nurse	11 (65)
Support staff	3 (18)

* Values are number (percent) unless stated otherwise

† May list more than one

TABLE 13: Other Stigmatizing Behavior of Health Care Professionals

SURVEY ITEM AND RESPONSES	NO. (%)*
Special precautions observed used by hospital/ clinic staff when seen at health facility N=223 †	
Extra gloves/protective gear	137 (61)
Charged more than other patients	57 (26)
None, treated like other patients	29 (13)
Separated from other patient	25 (11)
Don't know	14 (6)
HIV status clearly marked on chart/file	12 (5)
Not seen in hospital / clinic	9 (4)
Invasive procedures not performed	2 (1)

* Values are number (percent)
† May list more than one

Other Stigmatizing Behavior of Health Care Professionals

Respondents indicated that unnecessary and wasteful precautions used by medical personnel when they are seen at a health facility included the use of extra gloves or protective gear (61%), charging them more than other patients (26%), and separating them from other patients (11%). Thirteen percent of respondents reported that they are treated like any other patient.

PLWA were specifically asked about any experiences of being treated disrespectfully by medical personnel because of their HIV status. Participants reported that health care professionals engaged in a number of types of behavior that they considered disrespectful including avoiding being near them and the use of additional precautions in their care:

M, a man in his 40s, reported that health care professionals avoided being near him. *"I was admitted for diarrhea in the Military Hospital and the nurse would not enter the ward to give me drugs instead she would start shouting from afar."*

His experiences were mirrored by A, a man in his late 20s, who related the following incident:

> *When I was sick in the hospital the nurses refused to come into the room where I was. If they want to give me my pills, they just put them on the table instead of putting it into my palms for the fear that they may catch the disease if they touch me.*

X, a woman in her 30s also reported experiencing such treatment when she was in the hospital:

> *The nurses use degrading words, calling me names. I had put some water in a can and put it in the ward fridge but the doctor went and wrote my name boldly on the can. When they give me my pills they do so with gloves standing far from me.*

Y, a woman in her mid 30s, reported similar behavior by medical staff when she was in the hospital to deliver her baby. According to her:

> *I was treated badly at the hospital; they separated my bed from others when I wanted to deliver my baby. They also asked my people (family) to come and wash the bed sheet after soaking it. They do not bathe the baby and if they do, they use gloves.*

At times, this distancing by medical personnel was in direct contravention of medical orders. According to B, a woman in her late 20s:

> *When I was admitted before I had miscarriage, the doctor told the nurses not to allow me to move around, he said they should give me the bed pan if I wanted to ease myself. The nurses refused and asked me "Don't you have legs? Go to the toilet." When they want to give me drugs they keep a distance as if touching me will infect them.*

The use of additional precautions by medical personnel in provision of care was reported by a majority of respondents in the survey and was detailed by several of them:

"Nurses are scared to attend to me. Some of them tore newspapers to give me drugs," stated N, a man in his 30s. M, a man in his 20s, reported a similar experience *"A nurse was attending to me and I told her I was HIV positive and immediately she went and started putting on gloves."*

In D's case, even though she was not made to leave the hospital, the treatment she received amounted to refusal to care. After sustaining a deep cut at work, she was taken to the hospital. According to her:

> *Unfortunately the nurse I met knew that I was HIV positive; she refused to touch my wound and gave me the bandage to stop the bleeding myself. This attitude aroused suspicion among the other nurses. She did not tell them my status to my knowledge but I knew they suspected I was positive. I felt very bad. I have not been to that hospital again.*

According to one program director interviewed by PHR, most people who participate in his program report that often health care staff they encountered are

TABLE 14: PLWA Assessment of Obstacles to Access to Care and Prevention

SURVEY ITEM AND RESPONSES	NO. (%)*†
What is/are the most important obstacle that people with HIV/AIDS face in trying to access health services N=222 ‡	
Lack of financial means	161 (73)
Fear of being stigmatized	101 (45)
Lack of knowledge of having the disease	73 (33)
Fear of discrimination by clinical/ non clinical health personnel	33 (15)
Don't know	18 (8)
Difficulty getting to the health facility	15 (7)
Belief they won't get health care that will help	10 (5)
Main factor contributing to the spread of HIV/AIDS in your community N=220	
Heterosexual sex	145 (66)
Don't know	25 (11)
Transfusions with blood products	9 (4)
Poverty	9 (4)
Prostitution	8 (4)
What is/are the main obstacle to preventing HIV infection in your community N=224 ‡	
Lack of public education	154 (69)
Unprotected sexual intercourse	133 (59)
Stigma	75 (33)
Don't know	27 (12)
Lack of medical treatment	21 (9)
Low social status	9 (4)

* Values are number (percent)
† Doctor, nurse, or midwife
‡ May list more than one

unfriendly when they get to know the patient's HIV status. They also report experiencing hostility and being sent to other facilities for care.

Obstacles to Accessing Health Care

Respondents indicated that the main obstacles faced by PLWA in trying to access health care are lack of financial means (73%), fear of being stigmatized (45%), and a lack of knowledge of having the disease (33%) (Table 14).

As indicated above, the lack of financial means was most often cited by respondents to the PLWA survey as an obstacle for PLWA trying to access health services. According to W, *"the cost for laboratory test should be reduced. This is what discourages people from going to the hospital regularly for check up."* This was reiterated by K, *"the cost of the drugs and test are on the expensive side and should be reviewed downwards for easy affordability. Drugs such as anti-tuberculosis should be free in Kano, like it is free in other states."*

Fifteen percent of respondents reported that fear of discrimination by health personnel is an obstacle to accessing health care. O, a woman in her 40s related her feelings about being discriminated against by health care professionals:

> *When I had severe diarrhea and was almost at the point of death, I was taken to a private hospital close to where I live and the nurse refused to touch me and I was referred to the teaching hospital. I really felt very bad and wished I were dead. Deep inside I wanted to transfer the virus to those nurses especially one of them who went on talking about how she can never get the virus, because she does not go near people with the virus with a "ten feet pole."*

Obstacles to Prevention

Heterosexual sex was cited by most respondents (66%) as the major factor contributing to the spread of HIV/AIDS in their community. One of the main obstacles to prevention of HIV infection identified by respondents was lack of public education (69%) (Table 14).

O, a PLWA, stated that the need for education went beyond health care workers. According to him,

> *There is need for public enlightenment so that the community know that they can live with PLWA comfortably without contacting the virus. Government workers should be enlightened so that they should stop victimizing PLWA. I am a [government worker] and on various occasions my HIV status have been sought. Thanks to my [support group affiliated] doctor who did not reveal it to them. I would have been sacked by now!! [government employees who travel] need to be counseled most importantly because they are always travelling … and end up engaging in immoral behaviors. Help to train support group members and PLWA to become counselors so they can offer such services to other PLWA.*

The need for public education was also raised by J, a nurse. He stated that *"Government should educate the chiefs and school children. Most of them believe it doesn't exist. Government should provide facilities to educate people here."*

Other obstacles to prevention of HIV infection cited by PLWA were unprotected sexual intercourse (59%) and stigma (33%).

Obstacles to Diagnosis and Treatment

People not choosing to get tested (63%), lack of awareness of HIV/AIDS signs and symptoms (33%), and lack of HIV testing capabilities (15%) were cited as the main obstacles to diagnosing HIV (Table 15). Respondents stated that the main obstacles to treatment of infections related to HIV/AIDS were the patient's inability to pay (53%), the availability of medications (34%) and attitudes of clinical staff (16%).

V, a PLWA, explained why she has been unable to access anti-retrovirals (ARVs), *"we are forced to do a CD4 count test before taking anti-retrovirals and I can't afford to do the test."*

R, in his 40s, stated:

> *The attitude of some nurses and health workers to HIV positive people can make them want to spread the HIV especially to the health workers. Thank God the nurse who refused me admission is now HIV positive and is in our support group.*

Some discriminatory behaviors of health personnel reported by PLWA were more subtle than those reported above. C, a man in his 40s stated that he was made to wait for care because of his status: *"If I go to the hospital I am always attended to last even if I came to the hospital first."* J, a man in his 50s, indicated that: *"On announcing the result [of my HIV test], the doctor started talking with me with his backside, he faced the window."*

Even participants in government sponsored ARV distribution pilot programs reported experiencing disrespectful treatment by health care professionals working in the ARV distribution sites. According to M, a woman in her late 20s,*"At the ARV collection centers, the doctors and nurses are very rude and shout at us as if we are not humans."* B, in his 30s, stated that he *"went to collect ARV but was ignored for more than three hours."*

When asked about what concerns they believed doctors and nurses have in treating HIV/AIDS patients, 75% of respondents stated their belief that fear of becoming infected was a concern of health personnel. Other concerns included contamination of materials, facility or instruments (30%), wasting resources on people who will die (17%), and personal or professional stigma by association (14%) (Table 15).

TABLE 15: PLWA Assessment of Obstacles to Diagnosis and Treatment

SURVEY ITEM AND RESPONSES	NO. (%)*
What are the main obstacles to diagnosing (testing for) HIV in your community N=224†	
People do not choose to get tested	140 (63)
People unaware of HIV/AIDS signs and symptoms	74 (33)
Don't know	42 (19)
Lack of HIV testing capabilities	34 (15)
Cost/poverty	21 (9)
What are the main obstacles in treating infections/ conditions related to AIDS N=224 †	
Patient's inability to pay	119 (53)
Availability of medications	77 (34)
Don't know	69 (31)
Attitudes of clinical staff	36 (16)
Availability of diagnostic testing	29 (13)
What concerns do you believe doctors & nurses have in treating HIV/AIDS patients N=224 †	
Fear of becoming infected	169 (75)
Contamination of materials/facility/ instruments	68 (30)
Waste of resources because they will die	38 (17)
Personal/professional stigma by association	32 (14)
No particular concerns	27 (12)
Don't know	24 (11)
Stigma to clinic/facility	18 (8)
Don't have materials to protect self/others	15 (7)
Don't have materials needed to treat	13 (6)
Don't know how to treat	10 (4)
Don't know how to protect self/others	6 (3)

* Values are number (percent)
† May list more than one

Respondents suggested that health care workers' treatment of PLWA would be improved by clinicians knowing their own HIV status.

S indicated her belief that *"Every doctor and nurse should be made to do the HIV test. They do not know their status and that's why they discriminate."* T, in her 40s, agreed,

> *I think people working in the health field should be made to compulsorily take the HIV test so that they can know what it feels like to be positive. Many of them discriminate and stigmatize whereas they do not even know their status.*

Medications

Approximately half (48%) of respondents stated that they were currently taking anti-retroviral drugs (ARVs) (Table 16). Seventy-nine percent stated that they had received counseling or support services for HIV or a related condition and 75% reported having taken antibiotics for HIV or a related condition. The mean (SE) monthly cost of drugs currently taken for HIV/AIDS was 5,511 (801) Naira (~$42). Twenty percent of respondents indicated that they were able to afford a monthly supply of ARVs and 38% reported being able to afford a monthly supply of antibiotics. Most participants (69%) stated that they paid for their own medications. Thirty-eight percent reported that family paid for their medication, 15% indicated that their medication was paid for by an NGO or voluntary organization, and 10% said that their friends paid for their medication.

People living with HIV and AIDS and their associations should:

- Work with the Federal and State Ministries of Health, LGAs and health care professionals to develop, promulgate and enforce HIV/AIDS testing and treatment policies within health institutions that conform to the Nigerian code medical ethics and that guarantee non-discrimination against PLWA.
- Work with the Federal and State Ministries of Health, LGAs, civil society and health care professionals to develop and provide educational programs to health care professionals about the rights of PLWA.
- Engage in education of PLWA about their rights within the health care system.
- Support efforts of PLWA who have experienced discriminatory and unethical behavior by health care professionals to bring complaints to the appropriate bodies including the Medical and Dental Council of Nigeria, the Nursing and Midwifery Council of Nigeria, and the Human Rights Commission.

Opinions

Opinions about Testing and Disclosure

Forty-six percent of respondents agreed that people should be tested compulsorily for HIV/AIDS (Figure 4). The vast majority disagreed with the statements that post-test (95%) and pre-test (83%) counseling are not

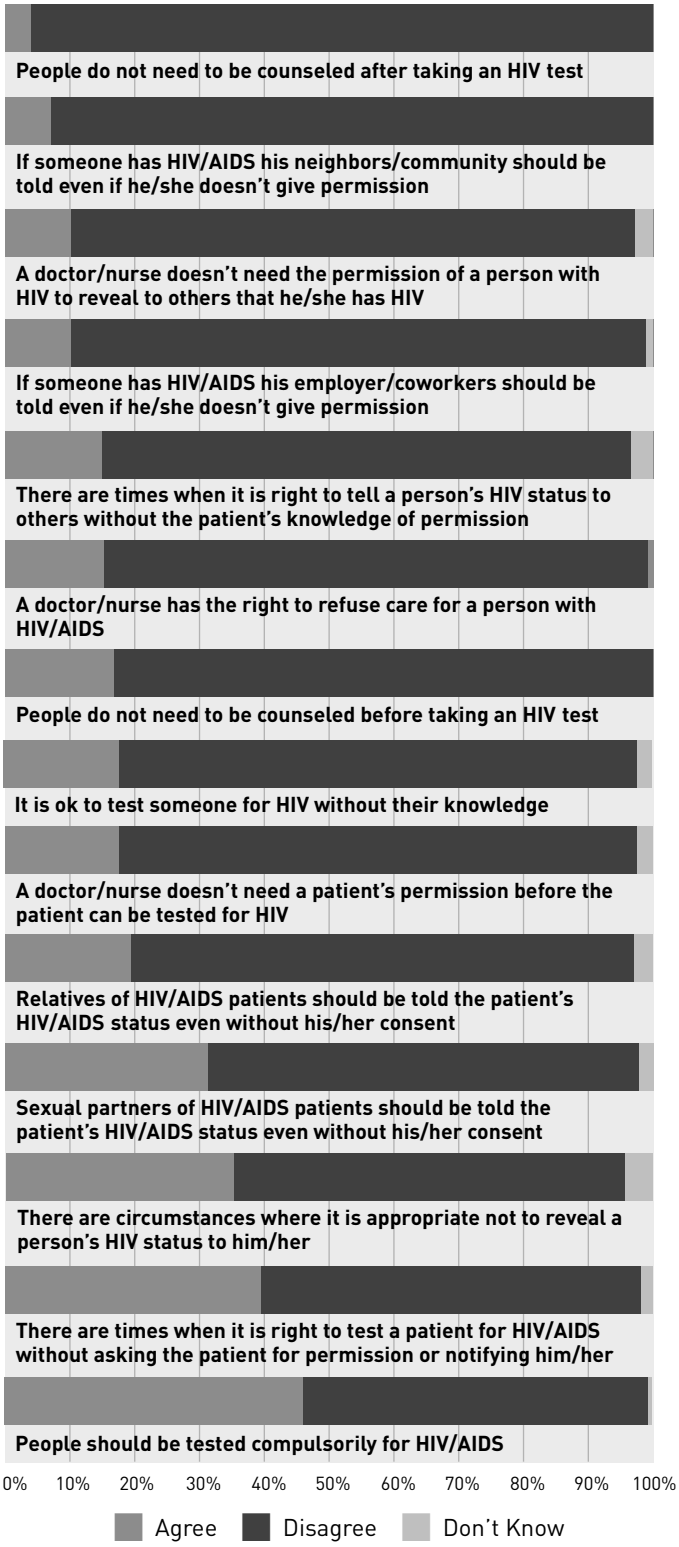
TABLE 16: HIV/AIDS Treatment Practices and Costs

SURVEY ITEM AND RESPONSES	NO. (%)*
Currently taking ARVs for HIV or HIV-related condition N=223	
No	104 (47)
Yes	108 (48)
Don't know	11 (5)
Ever take ARVs for HIV or HIV-related condition N=215	
No	97 (45)
Yes	105 (49)
Don't know	13 (6)
Ever take antibiotics for HIV or HIV-related condition N=224	
No	45 (20)
Yes	169 (75)
Don't know	10 (4)
Ever received counseling/support services for HIV or HIV-related condition N=222	
No	44 (20)
Yes	176 (79)
Don't know	2 (1)
Ever received nutritional supplements for HIV or HIV-related condition N=206	
No	59 (29)
Yes	128 (62)
Don't know	19 (9)
Ever received traditional or herbal treatment f or HIV or HIV-related condition N=220	
No	111 (50)
Yes	108 (49)
Don't know	1 (<1)
Can afford monthly supply of	
Nutritional supplements N=220	87 (40)
Antibiotics N=221	85 (38)
Traditional/herbal supplements N=172	42 (24)
Anti-retrovirals N=218	44 (20)
Monthly cost in Naira of drugs currently using for HIV/AIDS N=193	
mean ± SE (range)	5,511 ± 801 (0-104,400)
Who pays for your medications N=222 †	
Self	149 (67)
Family	84 (38)
Voluntary or NGO	33 (15)
Friends	22 (10)

* Values are number (percent)

† May list more than one

FIGURE 4: PLWA opinions about HIV testing, consent and disclosure



necessary. Ninety-two percent did not agree that if someone has HIV/AIDS his/her neighbors/community should be told even if he/she does not give permission, 89% opposed the statement that if someone has HIV/AIDS his/her employer/coworkers should be told even if she/he does not give permission, and 88% disagreed with the statement that a doctor or nurse does not need the permission of a person with HIV/AIDS to reveal his/her status to others. Thirty-nine percent indicated agreement with the statement that there are times when it is correct to test a patient for HIV/AIDS without asking the patient for permission or notifying him/her.

Opinions about PLWA and the Health Care Sector

Over 90% of respondents disagreed with the statements that it is OK for health facilities to refuse to care for patients with HIV/AIDS (97%), that it is OK to fire an employee with HIV/AIDS or ask him/her to resign (94%), and that it is OK to fire a health professional with HIV/AIDS or ask him/her to resign (93%) (Figure 5). Eighty-four percent expressed disagreement with the opinions that people with HIV/AIDS should not be employed in the health field, that the charts/beds of HIV/AIDS patients should be marked so that clinic/hospital workers know the patient's status, and that people with HIV/AIDS should be on a separate ward in a hospital or clinic. Half of respondents indicated agreement with the statement that all prospective health workers should have mandatory testing for HIV.

Opinions about PLWA and Women's Rights

Over 90% of respondents agreed that there should be legal protections for the rights of people living with HIV/AIDS (96%), that there should be legal protections for the rights of women (96%), more should be done to protect women and girls from having sex when they don't want to (90%), and that women and girls need more education about their rights to refuse sex (90%) (Figure 6). Eighty-seven percent believed that a woman has the right to refuse sex if a man refuses to use a condom, and 80% indicated that any woman has the right to refuse sex. Sixty-six percent of respondents, however, indicated that women should have to be tested for HIV before getting married, 65% believed that a good wife obeys her husband even if she disagrees and 46% agreed that it is a wife's obligation to have sex with her husband even if she does not want to.

Women's inability to negotiate the terms of sex is one factor that may contribute to their vulnerability to

FIGURE 5: Opinions of PLWA regarding HIV/AIDS and the heath care sector

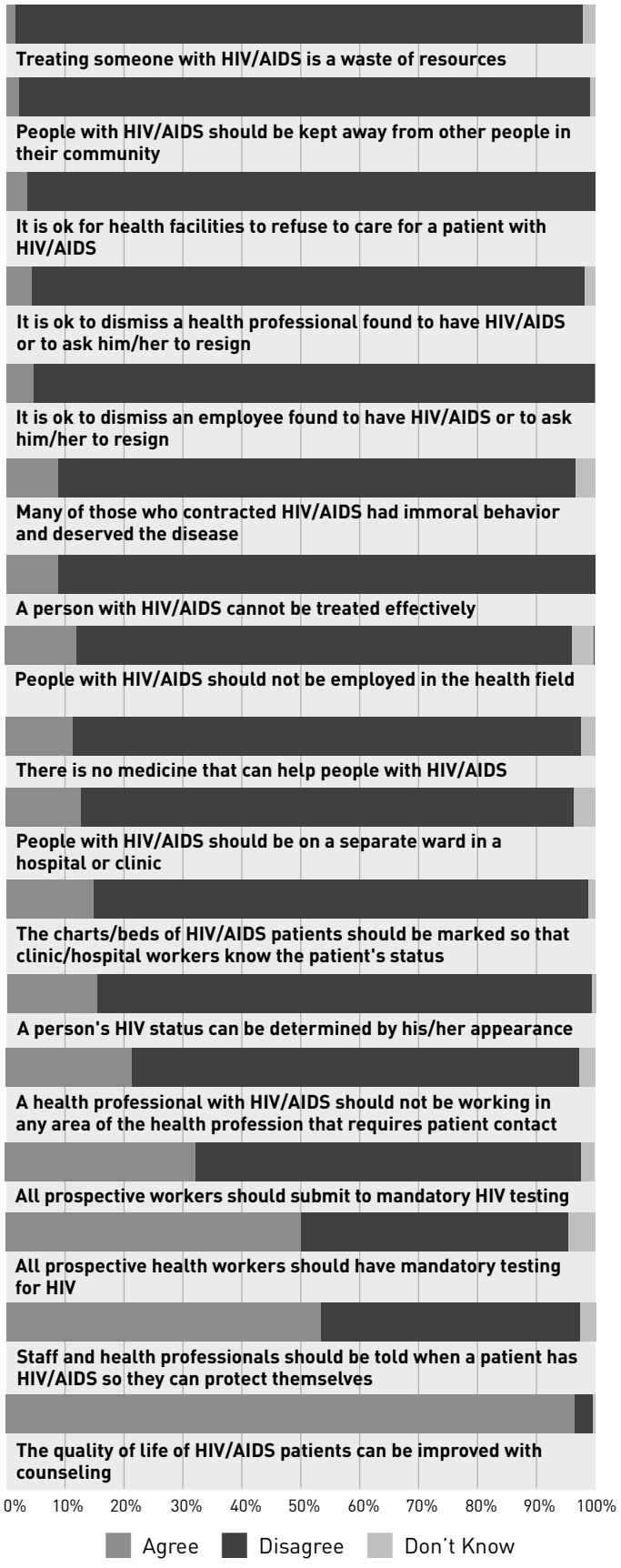


FIGURE 6: PLWA opinions about the rights of women and PLWA

HIV infection.[155] The lack of access to information and education may also contribute to women's vulnerability. According to one midwife:

> *"The culture doesn't permit their wives to come out to learn how to protect themselves so most remain ignorant."*

One quarter of respondents to the PLWA survey indicated agreement with the statement that women are responsible for spreading most heterosexual cases of HIV/AIDS. One HIV positive woman participating in the survey reported being blamed for bringing HIV into the family and losing her children after her husband's death. *"It is my husband's family; they do not speak to me saying that I killed their brother. I was thrown out of the house and my children were taken to his mother. I do not have any family again."* This form of discrimination against women who are HIV positive has been documented in Nigeria and elsewhere[156] and may be one reason why women do not disclose their HIV status.

Some PLWA also reported rejection by family and community members. G, in her early 20s, told the researcher about how she was affected by the treatment she received when her sister found out about her status:

> *"Before I contracted the virus, I was staying with my sister peacefully and happily. After I was confirmed positive for HIV, my sister started avoiding me, she will not sit with me, use the same toilet I use, touch me and would not even answer when I greet her. It really made me feel bad and I had to return to [this town]."*

Several women who participated in the PLWA survey reported experiencing rejection by their husbands. A, stated that *"My oga (husband) sent me out of the house after he found out I was positive. He is also positive and knew before me."*

Nine percent of PLWA agreed that many of those who contracted HIV/AIDS had immoral behavior and deserved the disease. The societal association of immorality and sex with HIV/AIDS may also affect the treatment an HIV positive woman receives. F, told of her experiences with her friends:

> *When one of my former friends knew that I was positive she told the others and they started calling me prostitute and would not allow me use the general toilet or bathroom because they were afraid they would contact it.*

F, a rape survivor in her early 20s, indicated that the doctor who tested her for HIV asked her questions that she found embarrassing.

> *For example, am I a prostitute? Do I sell in a bar? Do I live in a brothel? This kind of orientation fuels the basis for why people like me who innocently got infected not out of willful sexual intercourse, but forced sex (rape) to never want to identify ourselves for the fact that people will tag us as immoral and that we deserve the disease.*

C. LIMITATIONS

The health care professional study was conducted in four States in Nigeria with a total population of 17 million.[157] It is possible that these sites, though chosen at random from states with tertiary care facilities, may differ significantly from others in terms of resources and training provided to health care professionals. Although the findings of this study cannot be generalized to Nigeria as a whole, it is likely that, depending on resources and training available to the health care sector, the level of discriminatory behavior may be higher or lower in other parts of the country. The team sampled health care professionals randomly in the four states studied and believe that the findings documented in this report likely represent practices in these states. According to Ministry of Health data these four states have a total of nearly 4,500 health care professionals who serve a population of approximately 17.8 million people. [158]

[155] Gupta GR. "How Men's Power Over Women Fuels the HIV Epidemic: It limits Women's Ability to Control Sexual Interactions." *British Medical Journal.* 2002;324:183-184.; Andreef JL. "The Power Imbalance between Men and Women and its Effects on the Rampant Spread of HIV/AIDS among Women." *Human Rights Brief.* 2001;9:1. Available at: http://www.wcl.american.edu/hrbrief/09/1hiv.cfm. Accessed April 3, 2003.; Tallis V. *Gender and HIV/AIDS Overview Report 2002.* Available at: http://www.ids.ac.uk/bridge/reports/CEP-HIV-report.pdf. Accessed April 3, 2003.; United Nations Division for the Advancement of Women, WHO, UNAIDS. *"The HIV/AIDS Pandemic and its gender implications: Report of the Expert Group Meeting Windhoek, Namibia 13-17 2000."* 2000:13.EGM/HIV-AIDS/2000/Rep.1.

[156] Id., United Nations Division for the Advancement of Women, WHO, UNAIDS. 2000:13.; Center for the Right to Health. *Human Rights and HIV/AIDS: Experiences of People Living with HIV/AIDS in Nigeria.* Lagos, Nigeria; 2001:31-2.

[157] Federal Ministry of Health. *A Technical Report: The 2001 National HIV/Syphilis Sentinel Survey among Pregnant Women attending Ante-natal Clinics in Nigeria.* 2001.

[158] Federal Ministry of Health, Department of Research Planning and Statistics: Nigeria Health Profile 1996.

Two other limitations of the study concerning health professionals should be noted. First, it does not differentiate attitudes by profession, e.g., doctors, nurses, midwives. Second, it does not correlate attitudes with availability of protective equipment and supplies or training so we were not able to determine how likely these factors account for discriminatory attitudes.

In order to ensure that there were no ethical breaches including un-consented disclosures of status in the process of conducting the study, the team recruited PLWA through support groups rather than randomly. As such, PLWA participating in the study likely differ significantly from other PLWA in Nigeria because of their membership in a support group. Additionally, since only PLWA agreeing to be interviewed were approached, it is likely that they differ even from PLWA who are members of support groups.

As previously mentioned, the PLWA sampling frame was not randomized and, therefore, the findings of the PLWA survey cannot be generalized. All of the PLWA who were surveyed were approached through support/service organizations. Such individuals are likely to have greater access to information and may be more empowered and as such better able to achieve respect for their rights. Their connection to support group networks also is likely to reduce and/or mitigate possible negative experiences in the health care sector. The PLWA that we surveyed may be healthier than the average PLWA and have fewer interactions with the health care system. With fewer outward signs of HIV infection or AIDS their infection/disease status may have been less apparent to health care facility staff and the data from this study would be less likely to identify discriminatory behavior. It is also possible that the PLWA who experienced discrimination in the health care system may have elected to participate in order to share their experiences. There may also be PLWA who suffered from stigmatization and discrimination more generally and thus came to join support groups and/or agreed to participate in a study about these issues. If this is the case, the data from the PLWA study would likely overestimate the occurrence of discriminatory behavior by health care providers and others.

The quantitative and qualitative data from the PLWA survey should, therefore, be viewed as indicative of the experiences of at least a subsection of the PLWA population in Nigeria rather than as applicable to all PLWA or even all PLWA who belong to a support group. PLWA were surveyed in order to gain insight into the nature and range of experiences of discrimination within the health sector and to evaluate the findings of the health care professional surveys.

The apparent discrepancy between health care professional reported and observed behavior is likely due to participants under-reporting their own unethical behavior. The discrepancy may also result from over-reporting of observed discriminatory behavior or from health care professionals within the same institution having observed the same incidents. All quotes by policy–makers, clinicians, and PLWA should be viewed as illustrative of the study findings rather than as representative of any of the above groups or as interpretations of the data of the qualitative studies.

While this study focused on HIV/AIDS, it is possible that health care professionals also engage in inappropriate behavior toward, or breached the confidentiality of, people with other conditions. The health care system in Nigeria is under-funded and suffers from fundamental problems including material scarcity and inadequacies in infrastructure which may contribute to this behavior overall.[159] The team did not specifically ask clinicians to compare their treatment of PLWA with that of other patients nor did the study ask PLWA about experiences with the health care system prior to their HIV diagnosis. Even if health care professionals engage in breaches of confidentiality and other inappropriate behavior toward patients with other conditions, however, it is likely that the consequences of such actions may be worse for PLWA than for patients with other conditions. PLWA responses to the open ended questions, however, suggest that the treatment they reportedly received after their PLWA status became known to medical personnel was different and worse than the treatment they received before. As detailed above, intentional discrimination against people with specific HIV (or other health related) status represents a serious breach of medical ethics and human rights and must therefore be addressed specifically in that light in addition to any action that may be taken to improve access to and quality of health services over all.

Despite efforts to ensure privacy, the lack of privacy or concern about job status may have resulted in an under-reporting of discriminatory behavior and/or an over-reporting of 'correct' practices or attitudes by health care professionals. Although interviewers were careful to explain that there would be no material gain

[159] United Nations. *Nigeria: Common Country Assessment*. 2001; Hargreaves S. "Time to right the wrongs: improving basic health care in Nigeria." *Lancet*. 2002;359(9322):2030-5.; Nigeria Federal Office of Statistics. *Core Welfare Indicators Questionnaire Survey, Benue State*. Nigeria; 2001.

or penalty to the respondent from participation in the study, the responses may have been inaccurate if PLWA or health care professional respondents judged it in their material or political interest to exaggerate or conceal certain behaviors.

The team found that a vast majority of health care professionals in the four Nigerian states surveyed appeared to treat PLWA in compliance with their professional ethical obligations. However, the study also identified a considerable level of discriminatory and unethical behavior by health professionals in these four states toward patients with HIV or AIDS that warrants urgent and effective remedial interventions. The most common forms of discrimination by health care professionals in this study include, denial of care, breach of confidentiality and HIV testing without consent. These findings of the health care professional survey were supported by data collected from PLWA about their experiences, which were mostly positive but included a number of reports of unethical and discriminatory behavior towards them. The health care professional study identifies four factors that may contribute to this behavior: lack of correct information and education about HIV/AIDS and prevention of infection, lack of protective materials needed for the practice of universal precautions, lack of materials needed to care for and treat HIV/AIDS patients, and prevailing attitudes about people living with HIV/AIDS. This study suggests that adequately addressing these discriminatory practices and attitudes requires targeted education and provision of adequate resources to health care providers combined with instituting and enforcing anti-discrimination policies at health facilities.

IV. APPLICATION OF RELEVANT LAW AND INTERNATIONAL STANDARDS OF MEDICAL ETHICS

This study documents the existence of discriminatory behavior and attitudes toward HIV/AIDS patients among health care professionals in the surveyed states. The findings suggest that Nigeria should examine whether it is meeting its obligations to protect the right of PLWA under international human rights law.

International Human Rights Law

Numerous international and regional human rights instruments, to which Nigeria is a party,[160] protect the rights of PLWA. These include:[161]

- The African Charter on Human and People's rights[162] (African Charter)
- Convention on Elimination of All forms of Discrimination against Women[163] (CEDAW)
- Convention on the Rights of the Child[164] (CRC)
- International Convention on Elimination of All Forms of Racial Discrimination[165] (CERD)
- International Covenant on Economic, Social and Cultural Rights[166] (ICESCR)
- International Covenant on Civil and Political Rights[167] (ICCPR)

Of these, only the African charter and the CRC have been incorporated into the domestic law of Nigeria.[168] Nigeria is also a signatory to the Universal Declaration of Human Rights.[169]

The above instruments set out Nigeria's obligations to protect the rights of PLWA including the right to life,[170] the right to education,[171] the right to marry and found a family,[172] the right to non-discrimination,[173] the right to share in the benefits of scientific advancements,[174] the right to privacy[175] and the right to freedom of association.[176]

Several of the instruments to which Nigeria is a party include the right to health.[177]

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[160] *For the Record 2002: The UN Human Rights System*. Available at: http://www.hri.ca/fortherecord2002/vol2/nigeria.htm. Accessed March 31, 2003.

[161] International Covenant on Economic, Social and Cultural Rights. 21 G.A. Res. 2200 (XXI), UN GAOR, Supp. (No. 16) 49, UN Doc A (6316) 1966.; International Covenant on Civil and Political Rights, United Nations G.A. Res. 2200a (XXI), UN GAOR, 21st Sess., Supp. no 16., UN Doc A/6316 (1967).; Convention on the Elimination of all Forms of Discrimination against Women, adopted Dec 18, 1979, G.A. Res 34/180 UN GAOR 34th Sess. Supp No. 46. UN Doc A/34/46 (1976).; Convention on the Rights of the Child, adopted Nov 20 1989, GA Res. 44/25, annex, UN GAOR 44th Sess., Supp No. 49. UN Doc A/44/49 (1989).

[162] African [Banjul] Charter on Human and People's Rights, adopted June 27, 1981, OAU Doc CAB/LEG/67/3 rev.5, 21 I.L.M. 58 (1982), *entered into force* Oct. 21 1986. Available at: http://www.africaninstitute.org/html/african_charter.html. Accessed June 2, 2003.

[163] Convention on the Elimination of all Forms of Discrimination against Women (CEDAW), adopted Dec 18, 1979, G.A. Res 34/180 UN GAOR 34th Sess. Supp No. 46. UN Doc A/34/46 (1976). Ratified 13 June, 1985.

[164] Convention on the Rights of the Child (CRC), adopted Nov 20 1989, GA Res. 44/25, annex, UN GAOR 44th Sess., Supp No. 49. UN Doc A/44/49 (1989). Ratified 19 April, 1991.

[165] Acceded 16 October, 1967.

[166] International Covenant on Economic, Social and Cultural Rights (ICESCR), 21 G.A. Res. 2200 (XXI), UN GAOR, Supp. (No. 16) 49, UN Doc A (6316) 1966. Acceded 29 July, 1993.

[167] International Covenant on Civil and Political Rights (ICCPR), United Nations G.A. Res. 2200a (XXI), UN GAOR, 21st Sess., Supp. no 16., UN Doc A/6316 (1967). Acceded 29 July, 1993.

[168] Oluduru O. "Legal Issues Raised by HIV/AIDS" in *HIV/AIDS and Human Rights: Role of the Judiciary*. Lagos, Nigeria: Center for the Right to Health; 2001:29.; United Nations. *Nigeria: Common Country Assessment*. 2001:26. And communication by Nigerian Human Rights Commission.

[169] *Universal Declaration of Human Rights*, G.A. res. 217A (III), U.N. Doc A/810 at 71 (1948).

[170] ICCPR, Article 6.

[171] African Charter, Article 17.

[172] ICCPR, Article 23.

[173] African Charter, Article 2.

[174] ICESCR, Article 15.

[175] ICCPR, Article 17.

[176] African Charter, Articles 10 & 11.

[177] Article 5 (e) (iv) of CERD; Articles 11(1)(f) and 12 of CEDAW; Article 24 of the CRC; Article 16 of the African Charter; Article 12 of CESCR.

The right to health, was first elaborated in the International Covenant on Economic, Social and Cultural Rights. Article 12 states:

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;

(b) The improvement of all aspects of environmental and industrial hygiene;

(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;

(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.[178]

In 2000, the Committee on Economic Social and Cultural Rights (ESCR Committee), responsible for the interpretation and monitoring of the Covenant on Economic Social and Cultural Rights, published General Comment 14 on the Right to the Highest Attainable Standard of Health.[179] The ESCR Committee determined that fulfillment of the right to health means that access to health services must not be limited based on discrimination on a prohibited ground[180] including HIV status.[181]

In General Comment 14, the ESCR Committee also set out the core obligations of a State party to protect the right to health which include ensuring "the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups,"[182] the provision of essential drugs "as from time to time defined by WHO's Action Programme on Essential Drugs," [183] and ensuring "equitable distribution of all health facilities, goods and services."[184] In addition to these and other core obligations, the Committee also set out "obligations of comparable priority" [185] including a State Party's obligation "to take measures to prevent, treat and control epidemic and endemic diseases;"[186] "to provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them;"[187] and "to provide appropriate training for health personnel, including education on health and human rights."[188]

The committee also stated in General Comment 14 that "Any person or group who is a victim of a violation of the right to health should have access to effective judicial or other appropriate remedies at both national and international levels."[189] As a State Party, Nigeria is bound by the Provisions of the ICESCR and the authoritative interpretations of the ESCR Committee. This study finds that some PLWA have been excluded from access to health care because of their HIV status and that, at this time, PLWA have no access to judicial or other remedial processes to address this. The data further suggest that inadequate education of health personnel about HIV/AIDS along with a lack of protective and treatment materials likely contribute to these behaviors by health professionals. It is, therefore, likely that Nigeria has not met its core obligations to fulfill and protect the right to health.

Domestic Law

Nigeria's 1999 constitution[190] includes civil and political rights as well as economic social and cultural rights. Although rights included in both categories are limited, under the constitution, civil and political rights are legally binding, whereas social and cultural rights are not.[191] Social and cultural rights are listed in Chapter 2 of the constitution entitled "Fundamental Objectives and Directive Principles of State Policy"[192] This Chapter states that the State social order is founded on ideals of

[178] International Covenant on Economic, Social and Cultural Rights 21 G.A. Res. 2200 (XXI), UN GAOR, Supp. (No. 16) 49, UN Doc A (6316) 1966. Article 12.

[179] General Comment 14. Available at: http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4,+CESCR+General+comment+14.En?OpenDocument

[180] Id., 12(2)(i).

[181] Id., 18.

[182] Id., 43(1).

[183] Id., 43(4).

[184] Id., 43(5).

[185] Id., 44.

[186] Id., 44(3).

[187] Id., 44(4).

[188] Id., 44(5).

[189] Id., 59.

[190] *Constitution of the Federal Republic of Nigeria 1999*. Available at: http://www.nigeria-law.org/ConstitutionOfTheFederalRepublicOfNigeria.htm. Accessed March 31, 2003.

[191] United Nations. *Nigeria: Common Country Assessment*. 2001.; Constitution of the Federal Republic of Nigeria. Section 6(6)(c).

freedom, equality and justice. [193] It includes the state's responsibility to ensure the right to seek employment, adequate medical and health facilities for all persons:[194] educational opportunities, [195] protection of environment[196] and culture.[197] As stated above, the rights included in this section of the constitution are not legally enforceable. As section 6(6)(c) of the Constitution states:

> *The judicial powers vested in accordance with the foregoing provisions of this section -*
>
> *.....(c) shall not except as otherwise provided by this Constitution, extend to any issue or question as to whether any act of omission by any authority or person or as to whether any law or any judicial decision is in conformity with the Fundamental Objectives and Directive Principles of State Policy set out in Chapter II of this Constitution;198*

Chapter 4 of the Constitution is entitled "Fundamental Rights."[199] This chapter includes the right to life[200], right to be free of torture[201], right to personal liberty[202], due process[203], privacy[204], freedom of thought, conscience and religion,[205] freedom of expression,[206] freedom of assembly[207], freedom of movement,[208]and the right to property.[209] The justiceability of these rights is established within the Chapter itself which states, *"Any person who alleges that any of the provisions of this Chapter has been, is being or likely to be contravened in any State in relation to him may apply to a High Court in that State for redress."* [210] Chapter 4 also sets out the right to be free from discrimination on the basis of "particular community, ethnic group, place of origin, sex, religion or political opinion."[211] For this section to apply to the cases of discrimination alleged in this report would likely require a legal finding that HIV positive status makes an individual a part of a "particular community" protected by this section of the constitution.

Nigeria's legal system comprises English common law, statutory law, Islamic law, and tribal customary law.[212] Despite the incorporation of provisions of human rights provisions in the 1999 Constitution,[213] there are currently no laws under which those experiencing discrimination due to HIV status can seek redress in Nigeria.[214] This lack of access to effective judicial remedies in Nigeria for the discriminatory behaviors documented in this report represents a violation of the rights of PLWA under international human rights law.

International Principles of Medical Ethics and Nigerian Codes of Conduct

International principles of medical ethics and Nigerian codes of conduct clearly provide for patient autonomy, that is the right to informed consent, and confidentiality of patient information. In addition to representing violations of human rights, the denial of treatment and breaches of informed consent[215] and confidentiality detailed in this report, contravene international principles of medical ethics and Nigerian health professional codes of conduct.[216] The Rules of Professional Conduct for Medical

[192] *Constitution of the Federal Republic of Nigeria 1999*. Chapter 2.

[193] Id., Chapter 2 (17).(1).

[194] Id., Chapter 2 (17).(1)(d).

[195] Id., Chapter 2 (18).

[196] Id., Chapter 2 (20).

[197] Id., Chapter 2 (21).

[198] Id., Section 6 (6)(c).

[199] Id., Chapter 4.

[200] Id., Chapter 4 (33).

[201] Id., Chapter 4 (34).

[202] Id., Chapter 4 (35).

[203] Id., Chapter 4 (36).

[204] Chapter 4 (37) protects and guarantees "The Privacy of citizens, their homes, correspondence, telephone conversations, and telegraphic communications."

[205] *Constitution of the Federal Republic of Nigeria 1999*. Chapter 4 (38).

[206] Id., Chapter 4 (39).

[207] Id., Chapter 4 (40).

[208] Id., Chapter 4 (41).

[209] Id., Chapter 4 (43).

[210] Id., Chapter 4 (46).(1).

[211] Id., Chapter 4 (42)(1).

[212] CRLP. *Women of the World: Laws and Policies Affecting their Reproductive Rights - Anglophone Africa*. 2001:74.

[213] *Constitution of the Federal Republic of Nigeria 1999*. Available at: http://www.nigeria-law.org/ConstitutionOfTheFederalRepublicOfNigeria.htm. Accessed March 31, 2003.

[214] Center for the Right to Health. *Human Rights and HIV/AIDS: Experiences of People Living with HIV/AIDS in Nigeria*. Lagos (Nigeria): Center for the Right to Health; 2001.

[215] "Informed consent" includes the following conditions: ensuring patient competence for decision making, adequate disclosure of relevant information, ensuring the patient understands the information provided, that consent is voluntary, and that the patient authorizes the test or procedure in question.

[216] Medical and Dental Council of Nigeria, *Rules of Professional Conduct for Medical and Dental Practitioners in Nigeria*, 1995.

and Dental Practitioners in Nigeria (the Rules) state that, "A doctor shall preserve absolute secrecy on all he knows about his patient even after the patient has died, because of the confidence entrusted to him."[217] The binding rules also state that "Practitioners...must always obtain consent of the patient or the competent relatives...before embarking on any special treatment procedures with determinable risks."[218] The discriminatory practices documented by this study, their ethical implications and potential adverse medical and social consequences, therefore, should be studied further.

According to the Rules, the Medical and Dental Council of Nigeria enforces the rules and "A registered practitioner shall be guilty of professional misconduct if, after the investigation of an allegation and a trial during which he is given all opportunity to defend his actions and conduct, the Medical and Dental Practitioners' Disciplinary Tribunal rules that he has contravened any or all of the rules in this code of conduct.... The Council may impose penalties for the infringement of these desirable standards...in any of the following ways: (a) admonishing or reprimanding the practitioner; (b) suspending the practitioner from practice as a medical practitioner for a period not exceeding six months; (c) striking the practitioner's name off the relevant register, either permanently or for a determined period."[219]

Currently, individuals may report such violations to the appropriate Nigerian professional bodies[220], but the stigma attached to HIV/AIDS and cultural disinclination to pursue such claims are likely to have contributed to no such claims being filed with the Medical and Dental Council to date.[221] Additionally, such claims will not directly lead to any benefit to the claimant and this lack of direct benefit may further discourage claims. Medical practitioners also have a duty under the Rules to report any unethical conduct by their peers to the Council.[222] According to the rules, "every Doctor or Dentist must be his brother's keeper, with regard to the observance and indeed the enforcement of the rules and regulations which guide the profession. Doctors and dentists should expose without fear or favor, before the Medical and Dental Council of Nigeria either directly or through the Nigerian Medical Association, any corrupt, dishonest, unprofessional or criminal act or omission on the part of any Doctor or Dentist."[223] There is no indication that this may have happened in the case of the breaches documented in this study. At the time of publication, no specific medical ethics principles on HIV and AIDS have been articulated by the Medical and Dental Council of Nigeria.

Medical and Dental Council and the Nursing and Midwifery Council should:

- Review complaints system to ensure that cases of unethical behavior by physicians are reviewed, and that health care professionals meet their obligation to report unethical behavior by peers.
- Engage in (continuing) education of health care professionals on matters of professional ethics and make these courses affordable and available to health care professionals at their facilities to enable participation.
- Require all health care professionals to take courses on HIV and ethics as part of their continuing education medical licensing renewal requirement.
- Work with the Federal Ministry of Health and other key stakeholders to develop and implement programs to educate health care professionals and all staff in health facilities about HIV/AIDS including modes of transmission and universal precautions, ethics, and treatment and care and involve PLWA in preparation of these programs.
- Work with National and State Action Committees on AIDS to create task forces together with the relevant government bodies, other professional associations, and PLWA groups to address discrimination in the health care sector.
- Encourage the integration of education about HIV and AIDS in formal medical and nursing education, which includes formal instruction in professional ethics and specific concerns that relate to HIV and AIDS.

[217] "Duties of Doctors to the Sick" *Rules of professional conduct for medical and dental practitioners in Nigeria- revised edition 1995*. See also section 19.

[218] Id., *Rules of professional conduct*. 1995: 5(1).

[219] Id., *Rules of professional conduct*. 1995: 9.

[220] The Registrar, Medical and Dental Council of Nigeria, Federal Secretariat, Ikoyi, Lagos; The Registrar, Nursing and Midwifery Council of Nigeria, 8 Bank Anthony Way, Ikeja, Lagos.

[221] Conversation with Registrar of the Medical and Dental Council.

[222] *Rules of professional conduct for medical and dental practitioners in Nigeria- revised edition 1995*. 5(e).

[223] Id., *Rules of professional conduct*. 1995: 8.

Although the right to health is set out in human rights treaties[224] to which Nigeria is a party, and is incorporated in the Nigerian constitution,[225] individuals who have been deprived of this right as described in this report have no legal recourse in Nigeria.[226] Appeal to the appropriate professional body to report a breach of ethics is unlikely to relieve an individual of the stigma and in fact may subject him or her to further exposure.

[224] International Covenant on Economic, Social and Cultural Rights, 21 G.A. Res. 2200 (XXI), UN GAOR, Supp. (No. 16) 49, UN Doc A (6316) 1966; Convention on the Rights of the Child adopted Nov 20 1989, GA Res. 44/25, annex, UN GAOR 44th Sess., Supp No. 49. UN Doc A/44/49 (1989).

[225] *Constitution of the Federal Republic of Nigeria 1999*. Available at http://www.nigeria-law.org/ConstitutionOfTheFederalRepublicOfNigeria.htm. Accessed March 31, 2003.

[226] Center for the Right to Health. Human Rights and HIV/AIDS: Experiences of People Living with HIV/AIDS in Nigeria. Lagos (Nigeria): Center for the Right to Health; 2001.

V. CONCLUSIONS

The findings of the health care provider survey suggest that most Nigerian health care providers in the areas surveyed comply with their professional ethical obligations and do not deny care or treatment to people living with HIV and AIDS. This is supported by the majority of PLWA interviewed who reported no negative interactions with the health care sector. It is especially noteworthy given that most health care professionals in Nigeria work in facilities that have limited resources, and most have received insufficient training about HIV and AIDS treatment and care and have limited access to current information. Moreover, Nigerian health professionals are a part of a society in the early phase of a comprehensive and determined approach to HIV and AIDS.

Health care facility managers should encourage official recognition of members of staff that treat patients in an ethical and non-discriminatory manner.

Discrimination

As has been documented in other countries during the early phases of their concerted response to HIV/AIDS,[227] this study suggests that the number of Nigerian health care professionals who engage in discriminatory practices against and have discriminatory attitudes toward people who have, or are suspected to have, HIV/AIDS is high enough to have a destructive impact on people living with AIDS in Nigeria and on Nigeria's efforts to prevent the spread of the virus and care and treat those who have HIV. This study also suggests that much of the discriminatory behaviors and attitudes may be addressed by several interventions, including improvement of education of health care professionals on HIV and AIDS (including more communication from peers who do not engage in discriminatory behavior) and provision of sufficient materials for prevention, treatment and care.

The study findings suggest that three factors beyond inculcation of discriminatory attitudes in society may contribute to discriminatory behavior by health care professionals against people with HIV/AIDS. The first is lack of knowledge about HIV/AIDS. For example, it is of concern that, even among trained health professionals, 59% agreed that PLWA should be on a separate ward and 40% believed that a person's HIV status can be determined by his or her appearance. Although many of the participants in the study believed that their training on HIV/AIDS was adequate and most indicated that current literature was a source of their education, their responses to these questions signify that their familiarity with current research may be inadequate. These findings are supported by the study team's qualitative interviews with policymakers in Nigeria. According to one, *"Discrimination and stigma are around in the health care system. The [discriminatory] practice evolves from the secretive nature of the disease. [Health care professionals] live in milieu that has negligible understanding of the disease. Many [health care professionals] are learning on the job and have no formal training on HIV. Most have no opportunity to have continuing education or retraining on HIV and lack access to current information about HIV and AIDS."*

The vast majority of professionals expressed an interest in additional information and suggested education as a way to address discriminatory behaviors by their colleagues. An immediate investment to ensure the education of all existing clinical staff about HIV/AIDS, including modes of transmission, universal precautions and the rights of PLWA would likely reduce the number of discriminatory practices towards PLWA and may improve these patients' care and access to

[227]Richter M. *Nature and Extent of Discrimination against PLWAs in South Africa: Interviews and a study of AIDS Law Project client files 1993-2001*. AIDS Law Project, Johannesburg:2001.; *UNAIDS. India: HIV and AIDS-related Discrimination, Stigmatization, and Denial*. Geneva, Switzerland;2001.; Danziger R. "Discrimination against people with HIV and AIDS in Poland." *British Medical Journal*. 1994;308:1145-1147.; Tirelli U, Accurso V, Spina M, Vaccher E. "HIV and discrimination." *British Medical Journal*. 1991;303:582.; Link RN, Feingold AR, Charap MH, Freeman K, Shelov SP. "Concerns of Medical and Pediatric House Officers About Acquiring AIDS from Their Patients." *American Journal of Public Health*. 1988;78(4):455-459.; Bermingham S, Kippax S. "HIV-related discrimination: a survey of New South Wales general practitioners." *Australian and New Zealand Journal of Public Health*. 1998;22(1):92-97.

health services. This assertion is supported by previous studies that demonstrate the effect of HIV/AIDS education of nurses and other health workers on their attitudes and behavior towards HIV positive patients in Nigeria and elsewhere.[228] These studies also suggest that education about scientific matters may not be sufficient to achieve change in practice and that educational programs may also need to address attitudes and cultural beliefs.

Health care facility managers should:

- Develop, promulgate and enforce HIV/AIDS testing and treatment policies within their facilities that conform to Nigerian medical ethics and guarantee non-discrimination against PLWA.
- Engage in ongoing education of facility staff on these policies. Such programs may need to address attitudes and cultural beliefs.
- Establish mechanisms for reporting and investigation of unethical and/or discriminatory behavior by staff.

Lack of Materials

The second and third factors identified in this study that contribute to discrimination against people with HIV by health providers are the lack of protective and other materials needed to treat and prevent the spread of HIV and related conditions. While the issue of access to affordable anti-retroviral treatment is the subject of much debate in Nigeria,[229] many of the facilities did not even have sufficient stocks of basic antibiotics to treat opportunistic infections.[230] The lack of protective materials, documented in the health facility survey and cited also by professionals as the main reason for not applying universal precautions, contributes to discriminatory behavior in two ways. First, professionals lacking adequate protection quite reasonably appear to fear transmission of the virus from PLWA and this fear may lead to discriminatory behavior.[231] Second, a lack of resources may likely result in differential treatment practices that could contribute to the stigmatization of PLWA.

Testing and Informed Consent

The considerable number of health care professionals in the surveyed areas who reported engaging in breaches of confidentiality and testing for HIV without informed consent are in contravention of international principles of medical ethics,[232] and have also breached the Nigerian physician code of conduct to which all licensed physicians in Nigeria must adhere.[233] These ethical breaches are likely to have especially serious consequences in Nigeria as is suggested by testimonies of PLWA including those participating in this study.[234]

The Right to Health

Numerous international human rights instruments, to which Nigeria is a party, [235] obligate the government to protect the rights of PLWA.[236] The right to health is set

[228] Uwakwe, CBU. "Systematized HIV/AIDS Education for Student Nurses at the University of Ibadan, Nigeria: Impact on knowledge, attitudes and compliance with universal precautions." *Journal of Advanced Nursing*. 2000;32(2):416-424.; McCann TV, Sharkey RJ. "Educational intervention with international nurses and changes in knowledge, attitudes and willingness to provide care to patients with HIV/AIDS." *Journal of Advanced Nursing*. 1998;27(2):267-73.; Ezedinachi EN, Ross MW, Meremiku M, Essien EJ, Edem CB, Ekure E, Ita O. "The impact of an intervention to change health workers' HIV/AIDS attitudes and knowledge in Nigeria: a controlled trial." *Public Health*. 2002;116(2):106-12.

[229] Integrated Regional Information Networks. *Nigeria: Antiretroviral scheme draws poor response*. 2002. Available at: http://www.irinnews.org/AIDSreport.asp?ReportID=1331&SelectRegion=West_Africa&SelectCountry=NIGERIA. Accessed April 3, 2003.; Akanni O. "Problems dog Nigeria's ARV Programme." *Access Alert newsletter*. 2002. Available at: http://www.nigeria-aids.org/MsgRead.cfm?ID=591. Accessed on April 3, 2003.

[230] For more on availability of drugs see Peterson K & Obileye O. *Access to Drugs for HIV/AIDS and Related Opportunistic Infections in Nigeria* 2002. Policy Project. Available at: http://www.dec.org/pdf_docs/PNACR139.pdf. Accessed November 5, 2003

[231] Bermingham S, Kippax S. "HIV-related discrimination: a survey of New South Wales general practitioners." *Australian and New Zealand Journal of Public Health*. 1998;22(1):92-97.; Essien EJ, Ross MW, Ezedinachi ENU, Meremikwu M. "Cross-national HIV infection control practices and Fear of AIDS: a comparison between Nigeria and the USA." *International Journal of STD & AIDS*. 1997;8:764-771.; Link RN, Feingold AR, Charap MH, Freeman K, Shelov SP. "Concerns of Medical and Pediatric House Officers About Acquiring AIDS from Their Patients." *American Journal of Public Health*. 1988;78(4):455-459.

[232] World Medical Association. *International Code of Medical Ethics (as amended 1983)*. Available at: http://www.wma.net/e/policy/17-a_e.html. Accessed April 4, 2003.

[233] Medical and Dental Council of Nigeria. *Rules of Professional Conduct for Medical and Dental Practitioners in Nigeria* 1995.

[234] Center for the Right to Health. *Human Rights and HIV/AIDS: Experiences of People Living with HIV/AIDS in Nigeria*. Lagos (Nigeria): Center for the Right to Health; 2001.

[235] For the Record 2002: The United Nations Human Rights System. Available at: http://www.hri.ca/fortherecord2002/vol2/nigeria.htm. Accessed March 31, 2003.

[236] International Covenant on Economic, Social and Cultural Rights, 21 G.A. Res. 2200 (XXI), UN GAOR, Supp. (No. 16) 49, UN Doc A (6316) 1966.; International Covenant on Civil and Political Rights, United Nations G.A. Res. 2200a (XXI), UN GAOR, 21st Sess., Supp. no 16., UN

out in these human rights treaties,[237] and is incorporated in the Nigerian constitution. [238] Nigeria's core obligations under this right include ensuring non-discrimination in access to health facilities, the provision of essential drugs, and the provision of appropriate training to health personnel.[239] The interventions suggested above are, therefore, consistent with Nigeria's own commitment to respect for the right to health - a commitment that recognizes the importance of international assistance and support for countries with limited resources. Individuals who have been deprived of this right, however, have no legal recourse in Nigeria.[240]

The marginalization of certain groups and their increased risk for infection with HIV in Nigeria[241] must also be considered in light of this study. Misconceptions such as the belief that women are responsible for the transmission of most heterosexual HIV cases, expressed by 13% of respondents, should be taken into account when developing education and training programs for professionals and the public. Nigerian health professionals are members of their society, one in which stigma and moral judgment are still attached to HIV/AIDS.[242] Twenty percent of respondents to the health care professional survey agreed that many of those who have HIV/AIDS behaved immorally and deserve the disease. As such, it is likely that education of professionals and provisions of sufficient materials for protection and treatment, while contributing to improved care for PLWA, will require accompanying governmental and facility policies and monitoring to reduce discriminatory practices in the health care sector.

Non-governmental and civil society organizations should

- Work together with Federal and State Ministries of Health, LGAs, health care professionals, and PLWA to develop, promulgate and enforce HIV/AIDS testing and treatment policies within health institutions that conform to the Nigerian code medical ethics and that guarantee non-discrimination against PLWA.
- Engage in education of the population about HIV and AIDS, the rights of PLWA and the rights of people in the health care system.
- Support efforts of PLWA who have experienced discriminatory and unethical behavior by health care professionals to bring complaints to the appropriate bodies including the Medical and Dental Council of Nigeria, the Nursing and Midwifery Council of Nigeria, and the Human Rights Commission.

Addressing Poverty

Additionally, poverty, another structural factor that contributes to and may result from infection with HIV or AIDS, must be addressed as part of a comprehensive response to the pandemic. In this study, both health professionals and PLWA indicated that the ability to pay for medications was a critical factor and that they should work together to find a solution for more affordable medications. In fact, PLWA in the study identified the lack of financial resources as the greatest obstacle to accessing health care. Participants in the health care professional survey also identified patients' lack of financial resources as one of the most significant obstacles to effective treatment of infections/conditions related to HIV and the second most significant obstacle to accessing health care. Even those PLWA who qualified for participation in ARV trials described the burden of the cost of tests related to monitoring of ARV treatment as potentially prohibitive as did clinicians and program managers in the private and public sectors.

Such an investment in the health care sector is likely

Doc A/6316 (1967).; Convention on the Elimination of all Forms of Discrimination against Women, adopted Dec 18, 1979, G.A. Res 34/180 UN GAOR 34th Sess. Supp No. 46. UN Doc A/34/46 (1976).; Convention on the Rights of the Child adopted Nov 20 1989, GA Res. 44/25, annex, UN GAOR 44th Sess., Supp No. 49. UN Doc A/44/49 (1989).

[237] International Covenant on Economic, Social and Cultural Rights, 21 G.A. Res. 2200 (XXI), UN GAOR, Supp. (No. 16) 49, UN Doc A (6316) 1966.; Convention on the Rights of the Child adopted Nov 20 1989, GA Res. 44/25, annex, UN GAOR 44th Sess., Supp No. 49. UN Doc A/44/49 (1989).

[238] *Constitution of the Federal Republic of Nigeria* 1999. Available at: http://www.nigeria-law.org/ConstitutionOfTheFederalRepublicOfNigeria.htm. Accessed March 31, 2003

[239] International Covenant on Economic, Social and Cultural Rights, 21 G.A. Res. 2200 (XXI), UN GAOR, Supp. (No. 16) 49, UN Doc A (6316) 1966.; Committee on Economic Social and Cultural Rights. *General Comment No. 14: The right to the highest attainable standard of health (Art. 12).* 2000. Available at: http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4,+CESCR+General+comment+14.En?OpenDocumen. Accessed April 4, 2003.

[240] Center for the Right to Health. *Human Rights and HIV/AIDS: Experiences of People Living with HIV/AIDS in Nigeria.* Lagos (Nigeria): Center for the Right to Health; 2001. See section on legal standards below for more detail.

[241] UNAIDS. *Report on the Global HIV/AIDS Epidemic.* Geneva, Switzerland: 2002.

[242] Alubo O, Zwandor A, Jolayemi T, Omudo E. "Acceptance and Stigmatization of PLWA in Nigeria." AIDS Care. 2002;14(1):117-126.

to increase the capacity of practitioners to participate in current HIV/AIDS treatment and prevention programs and may expand the absorptive capacity of the system to engage in additional programs as treatment access is expanded. In addition to their role in treatment, health care professionals can contribute to prevention efforts both within the health care setting as well as through education and counseling of their patients and in their communities. By modeling appropriate behavior towards PLWA, health care providers may also help to reduce stigma thereby encouraging people to access information that they need in order to protect themselves and others from HIV infection.

International donors should:

- Provide material and technical assistance to professional associations for efforts to educate health professionals and the public about HIV/AIDS and ethics of the medical profession.
- Provide material and technical assistance for efforts to review and reform law and policy.
- Provide material and logistical support to ensure that all health facilities have sufficient and consistent supplies of materials needed for treatment and prevention, self healthcare including universal.
- Support the Global Fund to Fight AIDS, Tuberculosis and Malaria.

APPENDIX A: Survey Instruments

Nigeria Health Care Provider HIV/AIDS Survey
October, 2002

I am working with the Policy Project, the Center for the Right to Health and Physicians for Human Rights. I would like to speak to you about health care for people living with HIV/AIDS in Nigeria. We are gathering information from doctors and nurses in Nigeria to help inform policy for HIV/AIDS patients. There will be no direct benefit to you or this health care facility, however, we hope to improve policies overall. We have randomly selected health facilities and providers in an effort to identify possible concerns and problems. This is a confidential survey and we will not reveal the identity of any participants. This interview will take approximately 30 minutes. I will ask you a series of questions. If you do not understand a question, please ask me to explain it to you. If a question makes you uncomfortable, you may choose to skip the question. Do I have your permission to begin? Do you have any questions before we begin?

0. Consent given (circle one): CNST
No _____0
Yes_____1

1. Location Code _____ (1, 2, 3…) LCD
2. Interviewer ID _____ (1, 2, 3…) ICD
3. Respondent code _____ (1-2000) RCD
4. Date _____ (day) _____ (month), 2002 DATE
5a. Health Facility Code _____ (1, 2, 3…) HFC
5b. Participation Outcome: [Circle ONE] OUTC
Eligible/Survey Complete = 1
Not Eligible = 2
Not Available (2 visits) = 3
Refusal = 4a=Lack Time; 4b=Fear Reprisal; 4c=Opposed to Study; 4d=Other (specify)
Unable to Complete = 5a=Interrupted; 5b=Emotional; 5c=Safety; 5d=Other (specify)
Not Eligible, respondent is the same person who provided answers to the Facilities form = 6

SEX
6. Gender Female _____1
Male _____2

7. *What is your age*? _____years AGE

8. *What is your Profession, specialty, title, the number of years that you have practiced in your profession and the number of years that you have practiced at this facility?*

Profession	Specialty	Title/ position in	# Years Experience	# years at this facility
			_____	_____
Doctor _____1	Midwife_____1	Administrator ___1		
Nurse _____2	Community Nurse_2	General Director _2	YEXP	YFAC
Midwife _____3	General Nurse ___3	Medical Director _3		
	Surgical Nurse ___4	Owner _____4		
PRO	OB GYN _____5	Manager _____5		
	Surgeon _____6	Staff _____6		
	Internal medicine 7	Resident _____7		
	Pediatrics _____8	ADMP		
	General practitioner 9			

Other (specify)__10
SPEC

9. *In the past year, estimate the number of patients you see, on average, EACH MONTH.* _____ TPTN

10. *In the past year, estimate the number of HIV/AIDS patients you see, on average, EACH MONTH.* _____
APTN

Diagnosis of HIV/AIDS

11 *What are the most common ways that you find out a patient is HIV positive?* (DO NOT READ; circle **all** that apply) DHIV

Told by patient _____1
Chart/paperwork _____2
Told by others _____3
Can tell by looking _____4
Assume by patient illness _____5
HIV serology test _____6
Other (specify) _____7
Don't Know _____88

12. What diagnostic tests are available for HIV at your facility? (READ ALL CHOICES; circle **all** that apply)
HIVT

None _____0
Western blot analysis _____1
ELISA _____2
Antigen testing (levels) _____3
Rapid antigen _____4
Samples sent out to other lab _____5
Don't Know _____88

13. *In this facility, how often are patients who are scheduled for routine surgery routinely tested for HIV?* (READ ALL CHOICES; circle **one**) FHIV

No surgery and/other procedures at this facility _____0
Always _____1
Most of the time _____2
Sometimes _____3
Rarely _____4
Never _____5
Don't Know _____88

14. In this facility, *how often are women attending antenatal care clinics routinely tested for HIV?* (READ ALL CHOICES ;circle **one**) FAT

No antenatal care clinics at this facility _____0
Always _____1
Most of the time _____2
Sometimes _____3
Rarely _____4
Never _____5
Don't know _____88

15. *Estimate the average number of HIV tests that you ordered in a month* _____MHIV

16. *Estimate the total number of HIV tests that you ordered in the past **twelve** months* _____YHIV

17. *List THE TOP 3 REASONS why YOU test individuals for HIV* (DO NOT READ; circle **three** only) RTST

Suspected AIDS-related illness _____1
Routine preoperative testing _____*2*
Routine antenatal screening _____3
To know the HIV status of all my patients _____4
Request by the individual patient _____5

Request by a non-clinical third party such as for employment/military service _____6
At the request of patient's family _____7
Because of patient's appearance _____8
Other (specify): _____9
Other (specify): _____10
I do not test for HIV _____11

18. *Is there a written HIV testing policy at this facility*? (circle **one**) POL

No _____0 [GO to Q20]
Yes _____1 [GO to Q19]
Don't Know _____88 [GO to Q20]

RESEARCHER, PLEASE READ STATEMENT:

I will now ask you questions about informed consent, for the purpose of this study, "informed consent" means that a patient who is competent to make decisions is informed and consulted about his/her care. The clinician must let the patient know about any procedure or other medical decisions and about any reasonable alternatives to it. The clinician must also tell the patient about the risks, benefits, uncertainties, and possible consequences related to each alternative. The health care provider must ensure that the patient understands the information and that the patient gives consent to it voluntarily. The discussion should be carried out in layperson's terms and the patient's understanding should be assessed along the way.

19. *What is included in the written HIV policy at this facility?* (READ ALL CHOICES; circle **all** that apply) POLS

Informed consent _____1
Pre-testing counseling _____2
Post-test counseling _____3
Post-test referral _____4
Other (specify) _____5
Other (specify) _____6
Don't know_____88

20.*In practice how often do you obtain informed consent for procedures and tests?* (READ ALL CHOICES; Circle **one**) IF

Always _____1
Most of the time _____2
Sometimes _____3
Rarely _____4
Never _____5
Don't Know _____88

21a. *What do you do if a patient refuses to take an HIV test?* (DO NOT READ; circle **all** that apply) PREF

Patient is refused treatment _____1
Patient is referred to another physician/dept in this facility ____2
Patient is referred to another facility _____3
The patient is tested for HIV anyway _____4
Patient is treated but with increased precautions _____5
Other (Specify) _____6
Not aware of patient refusals _____7
Prefer not to answer _____8
Don't Know _____88

21b. a *Does this facility have written guidelines for treatment of HIV &/or related conditions*?

FGT
No _____0
Yes _____1
Don't Know _____2

I will now ask you some questions about your clinical experience - There are no correct or wrong answers for these questions. We are interested only in your best estimates.

22. *To the best of your knowledge, has the Nigerian Medical/Nursing Association provided professional guidelines on the treatment of HIV/AIDS patients?* (circle **one**) GUID

Yes _____1
No _____0
Don't Know _____88

23. *To the best of your knowledge, what percentage of all procedures in this facility are performed with the informed consent of the patient?* NIC

_____%
Don't Know _____DK

24. *To the best of your knowledge, what percentage of all HIV tests in this facility are performed with the informed consent of the patient?* FIC _____%

HIV tests are not performed at this facility __NT
Don't know _____DK

25. *When ordering an HIV test, in what percentage of cases do YOU obtain informed consent of the patient in your clinical practice?* HTIC _____%

I test without consent _____NC
Don't Know _____DK

Counselling and Referrals:

26. *How often do you counsel individuals BEFORE they are tested for HIV?* (READ ALL CHOICES; circle **one**) FBTC

Always _____1 [GO To Q28]
Most of the time _____2 [GO To Q27]
Sometimes _____3 [GO To Q27]
Rarely _____4 [GO To Q27]
Never _____5 [GO To Q27]
Don't Know _____88 [GO To Q28]

27. *Please state the main reason why you do NOT counsel patients BEFORE an HIV test is done?* (DO NOT READ; circle **one**) NBTC

Services not available _____1 [GO TO Q30]
Services available, but clinicians do not refer _____2 [GO To Q28]
Services available and clinicians refer, but patients do not go __3 [GO To Q28]
Other (specify)_____4 [GO To Q28]
Don't know _____88 [GO To Q28]

28. *How often are individuals counseled AFTER taking an HIV test and receiving a positive result?* (READ ALL CHOICES ;circle **one**) FCPT

Always _____1 [GO To Q30]
Most of the time _____2 [GO To Q29]
Sometimes _____3 [GO To Q29]
Rarely _____4 [GO To Q29]
Never _____5 [GO To Q29]
Don't Know _____88 [GO To Q30]

29. *Please state the main reason why counseling is NOT performed AFTER all positive HIV tests at your facility?* (DO NOT READ; circle **one**) RNCP

Services not available _____1
Services available, but clinicians do not refer _____2
Services available and clinicians refer, but patients do not go __3
Other (specify) _____4
Don't know _____88

30 *How often do you refer patients with HIV/AIDS to support groups, or other assistance organizations outside of this facility?* (READ ALL CHOICES; circle **one**) REFR

Always _____1 [GO To Q32]
Most of the time _____2 [GO To Q31]

Sometimes _____3 [GO To Q31]
Rarely _____4 [GO To Q31]
Never _____5 [GO To Q31]
Refer to social services in facility__6 [GO To Q32]
Do not know of available services__88 [GO To Q32]

31. *Why are patients not always referred?* (DO NOT READ; circle **all** that apply) NREF

Not aware of service providers in this area _____1
I know that there are no service providers in this area _____2
Service providers available, but clinicians do not refer_____3
Clinicians refer to service providers, but patients do not go ___4
Other (specify) _____5
Don't Know _____88

HIV/AIDS Treatment Practices:

32. *How Often are "universal precautions" practiced in this facility? By "universal precautions" I mean the use of protective barriers such as gloves, gowns, aprons, masks, or protective eyewear, which can reduce the risk of exposure to potentially infective materials at all times regardless of a patient's HIV or other status.*
(READ ALL CHOICES; circle **one**) VERP

Always _____1 [GO TO Q34]
Most of the time _____2 [GO TO Q33]
Sometimes _____3 [GO TO Q33]
Rarely _____4 [GO TO Q33]
Never _____5 [GO TO Q33]
Don't Know _____88 [GO TO Q34]

33. *Why are universal precautions not always practiced?* (DO NOT READ; circle **one**) VER2

Lack of materials _____1
No need to practice universal precautions all the time 2
Patients do not want the practice _____3
Other (specify) _____4
Don't know _____88

34. *To protect yourself and others, what other measures do you or the facility take when a patient is known or thought to be HIV positive?* (DO NOT READ; circle **all** that apply)
PREC

Extra gloves/protective gear _____1
Invasive procedures are not performed_____2
HIV status clearly marked on chart or file_____3
Separated from other patients _____4
None; they are treated like any other patient _____5
We do not admit/treat people who are HIV positive __6
Other (specify) _____7

35. *In the communities you serve, what primary factor do YOU think is contributing to the spread of HIV/AIDS?*
(DO NOT READ; circle **all** that apply) CFAC

Heterosexual sex _____1
Homosexual sex _____2
Prostitution _____3
Injection drug use _____4
Mother to child transmission _____5
Transfusions with blood products _____6
Sinful/inappropriate/immoral behavior ____7
Other (specify) _____8
Don't Know _____88

36. *In the communities you serve, what is the most important obstacle to preventing HIV infection?* (DO NOT READ; circle **one** only) BARP

Lack of public education _____ 1
Unprotected sexual intercourse _____ 2
Lack of medical treatment _____ 3
Lack of HIV testing capabilities _____ 4
Inability of women to protect themselves from HIV infected spouse ___ 5
Other (specify) _____ 6
Don't Know _____ 88

37. *In the communities you serve, what is the most important obstacle to accurately diagnosing HIV?* (DO NOT READ; circle **one** only) BARD

People do not choose to get tested _____ 1
People unaware of HIV/AIDS signs and symptoms _____ 2
Clinicians do not order HIV tests _____ 3
Lack of HIV testing capabilities _____ 4
Other (specify) _____ 5
Other (specify) _____ 6
Other (specify) _____ 7
Don't Know _____ 88

38. *Regarding access to health services, what is the most important obstacle that PLWAs have in this area?* (DO NOT READ; circle **one** only) SBAR

Lack of financial means _____ 1
Lack of knowledge of having the disease _____ 2
Difficulty getting to the health facility _____ 3
Fear of being stigmatized _____ 4
Belief that they will not receive any health care that will help them ___ 5
Fear of discrimination by clinical and/or non-clinical health personnel _ 6
Prefer traditional or homeopathic medicine _____ 7
Other (specify)_____ 8
Other (specify)_____ 9
Don't Know _____ 88

39. *What is the most important obstacle to treating infections or conditions related to AIDS* (such as opportunistic infections, tuberculosis, Kaposi's Sarcoma, and AIDS dementia)? (DO NOT READ; circle **one** only) BART

Availability of diagnostic testing _____ 1
Availability of medications for opportunistic infections _____ 2
Attitudes of clinical staff _____ 3
Patient's inability to pay _____ 4
Other (specify) _____ 5
Other (specify) _____ 6
Other (specify) _____ 7
Don't Know _____ 88

Please indicate how often in the PAST TWELVE MONTHS YOU have prescribed the following therapies for the treatment of HIV or HIV-related conditions. (Choose 1-5 or 88 for Q40-44)

Resource	Always	Most of time	Sometimes	Rarely	Never	Cannot prescribe	Don't Know
40. Antiretrovirals RARV	1	2	3	4	5	6	88
41. Antibiotics RANT	1	2	3	4	5	6	88
42. Immunizations RIMM	1	2	3	4	5	6	88
43. Nutritional supplements RNUT	1	2	3	4	5	6	88
44. Traditional/homeopathic RTRA	1	2	3	4	5	6	88

Professional Education/Training:

45. ***Please indicate the types of training you have received on HIV/AIDS.*** **(READ ALL CHOICES; circle** all **that apply)** HIVT **No training _____0 [GO TO Q53]**

Courses as a medical/nursing student ___1
Continuing medical/nursing education __2
Conferences on HIV/AIDS _____3
Review of current literature/journals ___4
Books _____5
Internet updates _____6
Other (specify) _____7
Don't Know _____88

Please indicate whether you consider your training on the following HIV/AIDS issues to be either "adequate" or "inadequate." **(circle one for each, Q46-Q52)**

		Adequate	Inadequate	DK
TSIG	**46.** ***Recognizing signs and symptoms of HIV/AIDS and related conditions***	**1**	**2**	**88**
TTRT	**47.** ***Treatment of HIV infections and related conditions***	**1**	**2**	**88**
TICP	**48.** ***Strategies for individual and community prevention***	**1**	**2**	**88**
TELO	**49.** ***Ethical and/or legal obligations of health care providers***	**1**	**2**	**88**
THCD	**50.** ***Health consequences of discrimination***	**1**	**2**	**88**
THPN	**51.** ***HIV/AIDS and health policy in Nigeria***	**1**	**2**	**88**
THPN	52. Counseling HIV/AIDS patients	1	2	88

53. *Would you like to receive additional training on HIV/AIDS issues*? (circle **one**) ATR

No _____ 0
Yes _____1
Don't Know _____88

Do you believe that you have an ethical responsibility to participate in the following activities? (circle one for each, Q54-Q58)

		YES	NO	DK
RCTA	54. *Clinical treatment for HIV/AIDS and related conditions*	1	2	88
RICP	55. *Individual and community prevention measures*	1	2	88
RPEA	56. *Public education on HIV/AIDS issues*	1	2	88
RPRC	57. *Policy reforms to improve clinical treatment of HIV/AIDS and related conditions*	1	2	88
REAP	58. *Education and advocacy to prevent social discrimination toward PLWAs*	1	2	88

Please answer YES or NO for the following questions. In the past year, have you observed or participated in any of these acts against ***HIV/AIDS patients***. (circle **one** for each, Q59-Q68)

		YES	NO	DK
ORC1	59. *Have you observed others refusing to care for an HIV/AIDS patient?*	1	2	88
ORC2	60. *Have you refused to care for an HIV/AIDS patient?*	1	2	88
OTA1	61. *Have you observed others refuse an HIV/AIDS patient admission to a hospital*	1	2	88

OTA2 62. *Have you refused an HIV/AIDS patient admission to a hospital?* 1 2 88
OBC1 63. *Have you observed others give confidential information to a family member?* 1 2 88
OBC2 64. *Have you given confidential information to a family member?* 1 2 88
OCM1 65. *Have you observed others give confidential information to a non-family member* 1 2 88
OCM2 66. *Have you given confidential information to a non-family member?* 1 2 88
OVM1 67. *Have you observed others verbally mistreat an HIV/AIDS patient?* 1 2 88
OVM2 68. *Have you verbally mistreated an HIV/AIDS patient?* 1 2 88

69. *If health care providers discriminate against HIV/AIDS patients, what do you think should be done to prevent these forms of discrimination*? (DO NOT READ CHOICES; circle **all** that apply) PHPD

Education of health personnel 1
Punishment of health personnel if they discriminate 2
Policies at health facilities against discrimination 3
Stronger laws against discrimination 4
Nothing 5
Other (specify) 6
Other (specify) 7
Don't know 88

70. *What are YOUR THREE most important concerns or fears about treating HIV/AIDS patients*? (DO NOT READ; circle **three** only) TRTC

No particular concerns 1
Fear of becoming infected 2
Contamination of materials /facility/ instruments 3
Waste of resources because they will die 4
Personal /professional stigma by association 5
Stigma to clinic/facility 6
Don't know how to treat 7
Don't know how to protect self/others 8
Don't have materials needed to treat 9
Don't have materials to protect self others 10
Other (specify) 11
Don't know 88

I am going to read some statements one at a time. For each, please say "I AGREE" or "I DISAGREE".

Regarding the care and treatment of HIV/AIDS patients:

[Circle One]

Statement	**Agree**	**Disagree**	**DK**	**NR**
71. *A person's HIV status can e determined by his/her appearance* LOOK	**1**	**0**	**88**	**99**
72. *Treating someone with HIV/AIDS is a waste of resources* NWT	**1**	**0**	**88**	**99**
73. *A person with HIV/AIDS cannot be treated effectively in this facility* CTE	**1**	**0**	**88**	**99**
74. *Medications to treat opportunistic infections may prolong an HIV positive patient's life* OIM	**1**	**0**	**88**	**99**

75. *It is OK to test someone for HIV without their knowledge* NCT	**1**	**0**	**88**	**99**
76. *Many of those who contract HIV/AIDS behave immorally and deserve to have the disease* DES	**1**	**0**	**88**	**99**
77. *If someone has HIV/AIDS his employer/coworkers should be told even is she/he does not give permission.* EMPL	**1**	**0**	**88**	**99**
78. *A health professional with HIV/AIDS should not be working in any area of the health profession* that requires patient contact. HPNW	**1**	**0**	**88**	**99**
79. *It is OK to dismiss a health professional found to have HIV/AIDS or to ask him/her to resign from his/her job.* DHP	**1**	**0**	**88**	**99**
80. *People with HIV/AIDS should not be employed in the health field* NEHF	**1**	**0**	**88**	**99**
81. All prospective workers should submit to mandatory HIV/AIDS testing SUBM	**1**	**0**	**88**	**99**
Statement	**Agree**	**Disagree**	**DK**	**NR**
82. *All prospective health care workers should submit to mandatory HIV/AIDS testing* HWMT	**1**	**0**	**88**	**99**
83. *People with HIV/AIDS should be on a separate ward in a hospital or clinic* HCI	**1**	**0**	**88**	**99**
84. *Staff and health care professionals should be told when a patient has HIV/AIDS so they can protect themselves* STAF	**1**	**0**	**88**	**99**
85 *The charts/beds of HIV/AIDS patients should be marked so that clinic/hospital workers know the patient's status* CHRT	**1**	**0**	**88**	**99**
86 *The treatment of opportunistic infections in HIV/AIDS patients wastes precious resources* TWR	**1**	**0**	**88**	**99**
87 *The quality of life of HIV/AIDS patients can be improved with counseling* QUAL	**1**	**0**	**88**	**99**
88 *I can refuse to treat an HIV/AIDS patient to protect myself and family* **PROT**	**1**	**0**	**88**	**99**
89 *There are circumstances that are appropriate to test a patient for HIV/AIDS without asking the patient for permission/without telling the patient* CIRT	**1**	**0**	**88**	**99**
90 *There are circumstances where it is appropriate to reveal a persons HIV status to others without the patients knowledge/permission* CIRR	**1**	**0**	**88**	**99**
91 *There are circumstances where it is appropriate **NOT** to reveal a person's HIV status to him or her.* NRS	**1**	**0**	**88**	**99**
92 *Relatives and sexual partners of HIV/AIDS patients should be notified for the patients HIV/AIDS status even without his/her consent* NOTF	**1**	**0**	**88**	**99**

Regarding women's roles in society:

.....

[Circle One]

Statement	**Agree**	**Disagree**	**Don't Know**	**NR**
93 *I believe that there should be mandatory premarital HIV/AIDS testing of women* PTW	**1**	**0**	**88**	**99**
94 *I believe that there should be mandatory premarital HIV/AIDS testing of men* PTM	**1**	**0**	**88**	**99**
95 *I believe that a good wife obeys her husband even if she disagrees* OBEY	**1**	**0**	**88**	**99**
96 *I believe it's a wife's obligation to have sex with her husband even if she doesn't want to* OSEX	**1**	**0**	**88**	**99**
97 *I believe that any woman has a right to refuse sex* RSEX	**1**	**0**	**88**	**99**
98 *I believe any woman has a right to refuse sex if a man refuses to use a condom* COND	**1**	**0**	**88**	**99**
99 *I believe a man has the right to beat his wife if she disobeys him* BEAT	**1**	**0**	**88**	**99**
100 *I believe that women and girls need more education about their rights to refuse sex* ESEX	**1**	**0**	**88**	**99**
101 *I believe more should be done to protect women and girls from having sex when they don't want to* **PROT**	**1**	**0**	**88**	**99**
102 *I believe that women should have inheritance rights* WIR	**1**	**0**	**88**	**99**
statement	**Agree**	**Disagree**	**DK**	**NR**
103 *I believe that women with HIV/AIDS should have inheritance rights* HWIR	**1**	**0**	**88**	**99**
104 *I believe that Women with HIV/AIDS should not lose custody of their children* CUST	**1**	**0**	**88**	**99**
105 *I believe that women with HIV/AIDS should not be asked to leave their home* WNL	**1**	**0**	**88**	**99**
106 *I believe that there should be legal protections for the rights of women* LPRW	**1**	**0**	**88**	**99**
107 *I believe that there should be legal protections for the rights of people with HIV/AIDS* LPRH	**1**	**0**	**88**	**99**
108 *I believe that women (not men) are responsible for the transmission of most heterosexual HIV cases* WRT	**1**	**0**	**88**	**99**

Health Care Facility Survey
October, 2002

I am working with the Policy Project, the Center for the Right to Health and Physicians for Human Rights. I would like to speak to you about health care for people living with HIV/AIDS in Nigeria. We are gathering information from doctors and nurses in Nigeria to help inform policy for HIV/AIDS patients. There will be no direct benefit to you or this health care facility, however, we hope to improve policies overall. We have randomly selected health facilities and providers in an effort to identify possible concerns and problems. This is a confidential survey and we will not reveal the identity of any participants. This interview will take approximately 30 minutes. I will ask you a series of questions. If you do not understand a question, please ask me to explain it to you. If a question makes you uncomfortable, you may choose to skip the question. Do I have your permission to begin? Do you have any questions before we begin?

0. Consent given (circle one): CNST
No _____0
Yes _____*1*

1. Location Code _____ (1, 2, 3…) LCD
2. Interviewer ID _____ (1, 2, 3…) ICD
3. Respondent code_____ (1-2000) RCD
4. Date_____ (day) _____ (month), 2002 DATE
5a. Health Facility Code _____ (1, 2, 3…)HFC
5b. Participation Outcome: [Circle ONE] OUTC

Eligible/Survey Complete	= 1
Not Eligible	= 2
Not Available (2 visits)	= 3
Refusal	= 4a=Lack Time; 4b=Fear Reprisal; 4c=Opposed to Study; 4d=Other (specify)_____
Unable to Complete	= 5a=Interrupted; 5b=Emotional; 5c=Safety; 5d=Other(specify) _____

6. Gender Female _____1 SEX
Male _____2

7. Age _____ years AGE

8. *What is your Profession, specialty, title, the number of years that you have practiced in your profession and the number of years that you have practiced at this facility?*

Profession	Specialty	Title/ position in	# Years Experience	# years at this facility
			_____	_____
Doctor _____1	Midwife_____1	Administrator ___1		
Nurse _____2	Community Nurse_2	General Director _2	YEXP	YFAC
Midwife _____3	General Nurse ___3	Medical Director _3		
	Surgical Nurse ___4	Owner _____4		
PRO	OB GYN _____5	Manager _____5		
	Surgeon _____6	Staff _____6		
	Internal medicine 7	Resident _____7		
	Pediatrics _____8	ADMP		
	General practitioner 9			
	Other (specify)___10			
	SPEC			

9 *What level is this facility* FLEV
Primary _____1
Secondary_____2

Tertiary _____ 3
Other (specify) _____ 4

10. *What type is this facility?* FTYP
Maternity _____ 1
Primary Health Center _____ 2
General Hospital _____ 3
Teaching Hospital _____ 4
Federal Medical Center _____ 5
Specialized Health Center (specify) _____ 6
Other (specify) _____ 7

11. *Is this facility public or private?* PUPR
Private _____ 1
Public _____ 2

12. Facility Location (per Nigeria MOH definition) FLOC
Urban _____ 1
Rural _____ 2
Peri-urban _____ 3

13. *What is the estimated population (# persons) served by facility?* _____ EPSF

14. *What is the total number of staff at facility?* _____ TNFS

How many?

15. Doctors _____ TND
16. Nurses _____ TNNF
17. Midwives _____ TNMF
18. TBAs _____ TNTF
19. Lab technicians _____ TNLF
20. Other (specify) _____ TNOF

15. *What percent of the month does the facility have?*
21. Electricity _____ %PTE DK
22. Refrigeration _____ %PTR
23. Sterilization Capabilities _____ %PTSC
24. Sterile gloves _____ %PTG
25. Telephone service _____ %PTTS
26. Record keeping ability _____ %PTRK
27. Running water _____ %PTCS
28. Disposal of blood contaminated products _____ %PTCD
29. Sterile syringes _____ %PTCS
30. Private counseling space _____ %PTPS
31. Laboratory with HIV testing capability _____ %PTL

16. *What is used for sterilizing Medical Equipment*? (DO NOT READ; circle **one**)
CME
Water only _____ 1
Water & Soap _____ 2
Chemical Sterilization method _____ 3
Heated Sterilization method _____ 4
Other (specify) _____ 5

17. *How Often are "universal precautions" practiced in this facility. By "universal precautions" I mean the use of protective barriers such as gloves, gowns, aprons, masks, or protective eyewear, which can reduce the risk of exposure to potentially infective materials at all times regardless of a patient's HIV or other status*. (READ ALL CHOICES; circle **one**) FUP

Always	1	[GO TO Q19]
Most of the time	2	[GO TO Q18]
Sometimes	3	[GO TO Q18]
Rarely	4	[GO TO Q18]
Never	5	[GO TO Q18]
Don't know	88	[GO TO Q18]

18. *Why are universal precautions not always practiced?* (DO NOT READ; circle **all** that apply)

UNP

Lack of materials	1
No need to practice universal precautions all the time	2
Patients do not want the practice	3
Other (specify)	4
Don't know	88

19. *Does the facility have Textbooks (Less than 3 years old) including information on HIV/AIDS and/ or journals on HIV/AIDS for use by staff* FHHT

No	0
Yes	1
Don't Know	88

What percentage of the month does the health facility have the following medications

	% of time available	Don't Know
20. Antibiotics	_____% PTSA	DK
21. Anti-retrovirals	_____% PTAR	DK
22. Anti-Tuberculosis drugs	_____% PTTD	DK
23. Anti-Malarials	_____% PTAM	DK
24. Doxycycline	_____% PTDX	DK
25. Folic Acid	_____% PTFA	DK
26. Iron tablets	_____% PTIT	DK
27. Vitamin A	_____% PTVA	DK
28. Tetanus	_____% PTTN	DK
29. Intravenous Fluids	_____% PIVF	DK
30. Oral rehydration salts	_____% PORS	DK
31. Condoms	_____% PTCN	DK

32. *In the past year, estimate the number of patients seen in this facility on average, EACH MONTH.*

_____TPTN

33. *In the past year, estimate the number of known HIV/AIDS patients seen in this facility, on average, EACH MONTH.* _____APTN

34. *What diagnostic tests are available for HIV at your facility?*
(READ ALL CHOICES; circle **all** that apply)

HIVT

None	0
Western blot analysis	1
ELISA	2
Antigen testing (levels)	3
Rapid antigen	4
Samples sent out to other lab	5
Don't Know	88

35. *In this facility, how often are patients who are scheduled for routine surgery routinely tested for HIV?*
(READ ALL CHOICES; circle **one**) FHIV

No surgery and/other procedures at this facility	0
Always	1
Most of the time	2

Sometimes ____ 3
Rarely ____ 4
Never ____ 5
Don't Know ____ 88

36. *How often are women attending antenatal care clinics at this facility tested for HIV?* (READ ALL CHOICES; circle **one**) FAT

No antenatal care clinics at this facility ____ 0
Always ____ 1
Most of the time ____ 2
Sometimes ____ 3
Rarely ____ 4
Never ____ 5

37 *Estimate the number of HIV tests that are ordered on average,* ***each month*** ____ MHIV

38. *Estimate the number of HIV tests that were ordered in the past TWELVE months* ____ YHIV

39. *What is included in the written HIV policy at this facility?* (READ ALL CHOICES; circle **all** that apply) POLS

No written policy ____ 0 [GO to Q42]
Informed consent (Researcher read DEFINITION BELOW) 1
Pre testing counseling ____ 2
Post test counseling ____ 3
Post test referral ____ 4
Other (specify) ____ 5
Other (specify) ____ 6

40. *In practice, how often do health personnel in this facility adhere to the HIV/AIDS testing policy?* (READ ALL CHOICES; circle **one**) APOL

Always ____ 1 [GO to Q42]
Most of the time ____ 2 [GO to Q41]
Sometimes ____ 3 [GO to Q41]
Rarely ____ 4 [GO to Q41]
Never ____ 5 [GO to Q41]
Don't Know ____ 88 [GO to Q41]

41. *What happens to health personnel when they do not adhere to the HIV/AIDS testing policy*? (DO NOT READ; circle **all** that apply) CNTP

Fired ____ 1
Warned ____ 2
Provided with training ____ 3
Transferred ____ 4
Suspended ____ 5
Reported to professional association ____ 6
Reported to Federal Ministry of Health ____ 7
Lose pay ____ 8
Nothing ____ 9
Other (Specify) ____ 10
Other (Specify) ____ 11
Don't know ____ 88

42. *What happens if a patient refuses to take an HIV/AIDS test*? (DO NOT READ; circle **all** that apply) PREF

Nothing ____ 0
Patient is refused treatment ____ 1
Patient is referred to another physician/dept in this facility 2
Patient is referred to another facility ____ 3

The patient is tested for HIV anyway _____4
Patient is treated but with increased precautions _____5
Other (Specify) _____6
Not Aware of patient refusals _____7
Don't Know _____88

RESEARCHER, PLEASE READ STATEMENT:

I will now ask you questions about informed consent, for the purpose of this study, "informed consent" means that a patient who is competent to make decisions is informed and consulted about his/her care. The clinician must let the patient know about any procedure or other medical decisions and about any reasonable alternatives to it. The clinician must also tell the patient about the risks, benefits, uncertainties, and possible consequences related to each alternative. The health care provider must ensure that the patient understands the information and that the patient gives consent to it voluntarily. The discussion should be carried out in layperson's terms and the patient's understanding should be assessed along the way.

Informed Consent

43. *In your experience, in what percentage of cases is informed consent of the patient obtained in medical practice in Nigeria*? NIC

_____%
Don't Know ____DK

44. *To the best of your knowledge, what percentage of all HIV tests in this facility are performed with the informed consent of the patient?* FIC

_____%.
HIV tests are not performed at this facility _____NP
Don't know _____DK

45. *Is there a consequence for health personnel who do not obtain informed consent from their patients?* (DO NOT READ; circle **all** that apply) CNIC

No consequence _____0
Fired _____1
Warned _____2
Provided with training _____3
Transferred _____4
Suspended _____5
Reported to professional association _____6
Reported to FMOH_____7
Lose pay _____8
Don't know _____88

46. *To protect yourself and others, what other measures does the facility take when a patient is known or thought to be HIV positive?* (DO NOT READ; circle **all** that apply)

PREC

Extra gloves/protective gear _____1
Invasive procedures are not performed_____2
HIV status clearly marked on chart or file_____3
Separated from other patients _____4
None; they are treated like any other patient _____5
We do not admit/treat people who are HIV positive __6
Other (specify) _____7

47. *In the communities you serve, what primary factor do YOU think is contributing to the spread of HIV/AIDS?* (DO NOT READ; circle **all** that apply) CFAC

Heterosexual sex _____1
Homosexual sex _____2
Prostitution _____3
Injection drug use _____4
Mother to child transmission _____5

Transfusions with blood products _____6
Sinful/inappropriate/immoral behavior ____7
Other (specify) _____8
Don't Know _____88

48.*In the communities you serve, what is the most important obstacle to preventing HIV infection?* (DO NOT READ; circle **one** only) BARP

Lack of public education _____1
Unprotected sexual intercourse _____2
Lack of medical treatment _____3
Lack of HIV testing capabilities _____4
Inability of women to protect themselves from HIV infected spouse ___5
Other (specify) _____6
Don't Know _____88

49. *In the communities you serve, what is the most important obstacle to accurately diagnosing HIV?* (DO NOT READ; circle **one** only) BARD

People do not choose to get tested _____1
People unaware of HIV/AIDS signs and symptoms _____2
Clinicians do not order HIV tests _____3
Lack of HIV testing capabilities _____4
Other (specify) _____5
Other (specify) _____6
Other (specify) _____7
Don't Know _____88

50. *What is the most important obstacle to treating infections or conditions related to AIDS* (such as opportunistic infections, tuberculosis, Kaposi's Sarcoma, and AIDS dementia)? (DO NOT READ; circle **one** only) BART

Availability of diagnostic testing _____1
Availability of medications for opportunistic infections _____2
Attitudes of clinical staff _____3
Patient's inability to pay _____4
Other (specify) _____5
Other (specify) _____6
Other (specify) _____7
Don't Know _____88

51. *Regarding access to health services, what is the most important obstacle that PLWAs have in this area?* (DO NOT READ; circle **one** only) SBAR

Lack of financial means _____1
Lack of knowledge of having the disease _____2
Difficulty getting to the health facility _____3
Fear of being stigmatized _____4
Belief that they will not receive any health care that will help them ____5
Fear of discrimination by clinical and/or non-clinical health personnel _6
Prefer traditional or homeopathic medicine _____7
Other (specify)_____8
Other (specify)_____9
Don't Know _____88

52. *Does this facility have <u>written</u> guidelines for treatment of HIV &/or related conditions*? FGT

No _____ 0 [GO TO Q53]
Yes _____ 1 [GO TO Q54]
Don't Know _____ 2 [GO TO Q56]

53. *Why does this facility not have written guidelines for treatment of HIV/AIDS &/or related conditions?* (DO NOT READ; circle one) NFGT

This facility does not treat people with HIV/AIDS or related conditions _____ 1
This facility does not have disease specific guidelines _____ 2
There is no treatment available for people with HIV/AIDS or related conditions _ 3
It is not possible to treat people with HIV/AIDS or related conditions _____ 4
Not required to _____ 5
Not important _____ 6
Don't know _____ 88 **[GO TO Q56]**

54. *What is the source for the written guidelines for treatment of HIV/AIDS &/or related conditions at this facility?* (DO NOT READ; circle one) SFGT

Federal Ministry of Health _____ 1
World Health Organization _____ 2
UNAIDS _____ 3
This health facility _____ 4
Other (Specify) _____ 5
Other (Specify) _____ 6
Don't Know _____ 88

55. *What happens to health personnel when they do not adhere to the guidelines for treatment of HIV/AIDS &/or related conditions?* (DO NOT READ; circle all that apply)

CFGT

Fired _____ 1
Warned _____ 2
Provided with training _____ 3
Transferred _____ 4
Suspended _____ 5
Reported to professional association _____ 6
Reported to Federal Ministry of Health _____ 7
Lose pay _____ 8
Nothing _____ 9
Don't know _____ 88

56. *What treatment modalities are available for people with HIV/AIDS in this facility.* (READ ALL CHOICES; Circle all that apply) TMF

Treatment with Anti-retrovirals _____ 1
Treatment of opportunistic infections _____ 2
Nutritional counseling _____ 3
MACS (Multivitamins, Aspirin, Chloroquine and Selenium) _____ 4
SAM (Selenium, Aspirin and Multivitamins) _____ 5
Referral _____ 6
Homeopathic _____ 7
Traditional _____ 8
Spiritual _____ 9
Home based care _____ 10
Social services _____ 11
Others (specify) _____ 12
Don't know _____ 88

57. *In your area, is there a coordinated effort for care and treatment of HIV/AIDS patients with other larger referral centers or local resources?* CECT

No _____ 0
Yes _____ 1

Don't know _____ 88

*Please answer YES or NO for the following questions. In the past year, have you observed or had reported to you any of these acts against **HIV/AIDS patients**.* (circle **one** for each, Q73-Q82)

		YES	NO	DK
ORC1	58. *Have you observed others refusing to care for an HIV/AIDS patient?*	1	2	88
ORC2	59. *Have you had reported to you refusal to care for an HIV/AIDS patient?*	1	2	88
OTA1	60. *Have you observed others refuse an HIV/AIDS patient admission to a hospital*	1	2	88
OTA2	61. *Have you had reported to you refusal to admit an HIV/AIDS patient to a hospital?*	1	2	88
OBC1	62. *Have you observed others give confidential information to a family member?*	1	2	88
OBC2	63. *Have you had reported to you the giving of confidential information to a family member?*	1	2	88
OCM1	64. *Have you observed others give confidential information to a non-family member*	1	2	88
OCM2	65. *Have you had reported to you the giving of confidential information to a non-family member?*	1	2	88
OVM1	66. *Have you observed others verbally mistreat an HIV/AIDS patient?*	1	2	88
OVM2	67. *Have you had reported to you the verbal mistreatment of an HIV/AIDS patient?*	1	2	88

68. *What do you think should be done to prevent these forms of discrimination by health personnel against HIV/AIDS patients*? (READ ALL CHOICES; circle all that apply) PHPD

Education of health personnel _____ 1
Punishment of health personnel if they discriminate _____ 2
Policies at health facilities against discrimination _____ 3
Stronger laws against discrimination _____ 4
Nothing _____ 5
Other (specify) _____ 6
Other (specify) _____ 7
Don't know _____ 88

69. *What happens in this facility to health personnel when they engage in these forms of discrimination*? (DO NOT READ; circle all that apply)

CHPD

Fired _____ 1
Warned _____ 2
Provided with training _____ 3
Transferred _____ 4
Suspended _____ 5
Reported to professional association _____ 6
Reported to Federal Ministry of Health _____ 7
Lose pay _____ 8
Nothing _____ 9
Other (specify) _____ 10
Don't know _____ 88

70. *As a policy maker / administrator for this facility, what are your concerns or fears about treatment of HIV/AIDS patients in the facility?* (DO NOT READ; circle all that apply?)

TRTC

No particular concerns _____ 1
Fear of staff becoming infected _____ 2
Contamination of materials /facility/ instruments _____ 3
Waste of resources because patients will die _____ 4
Personal /professional stigma of staff by association _____ 5
Stigma to clinic/facility _____ 6
Don't know how to treat _____ 7
Don't know how to protect self/others _____ 8
Don't have materials needed to treat _____ 9
Don't have materials to protect self others _____ 10
Other (specify) _____ 11
Don't know _____ 88

I am going to read some statements one at a time. For each, please say if you agree or disagree

Regarding the care and treatment of HIV/AIDS patients:

[Circle One]

Statement	**Agree**	**Disagree**	**DK**	**NR**
71 *You can tell by looking at someone whether he/she has HIV/AIDS* LOOK	**1**	**0**	**88**	**99**
72 *Treating someone with HIV/AIDS is a waste of resources* NWT	**1**	**0**	**88**	**99**
73 *A person with HIV/AIDS can not be treated effectively* in this facility CTE	**1**	**0**	**88**	**99**
74 *Medications to treat opportunistic infections will prolong an HIV positive patient's life* OIM	**1**	**0**	**88**	**99**
75. *It is OK to test someone for HIV without their knowledge* NCT	**1**	**0**	**88**	**99**
76 *Many of those who contract HIV/AIDS behave immorally and deserve to have the disease* DES	**1**	**0**	**88**	**99**
77 *If someone has HIV/AIDS his employer/coworkers should be told even is she/he does not give permission.* EMPL	**1**	**0**	**88**	**99**
78 *Any health professional with HIV/AIDS should not be working in the health profession* HPNW	**1**	**0**	**88**	**99**
79 *It is OK to dismiss a health professional found to have HIV/AIDS or to ask him/her to resign from his/her job* DHP	**1**	**0**	**88**	**99**
80 *People with HIV/AIDS should not be employed in the health field* NEHF	**1**	**0**	**88**	**99**
81. *All prospective workers should submit to mandatory HIV/AIDS testing* SUBM	**1**	**0**	**88**	**99**
82 *All prospective health care workers should submit to mandatory HIV/AIDS testing* HWMT	**1**	**0**	**88**	**99**
83. *If someone has HIV/AIDS his neighbors/community should be told even is she/he does not give permission* NBRS	**1**	**0**	**88**	**99**
84 *People with HIV/AIDS should be in isolation in a health care setting* HCI	**1**	**0**	**88**	**99**
85 *Staff and health care professionals should be told when a patient has HIV/AIDS so they can protect themselves* STAF	**1**	**0**	**88**	**99**
86 *The charts/beds of HIV/AIDS patients should be marked so that clinic/hospital workers know the patient's status* CHRT	**1**	**0**	**88**	**99**
87 *The treatment of opportunistic infections in HIV/AIDS patients wastes precious resources* TWR	**1**	**0**	**88**	**99**
88 *The quality of life of HIV/AIDS patients can be improved with counseling* QUAL	**1**	**0**	**88**	**99**
89. *Staff in this facility can refuse to treat an HIV/AIDS patient to protect themselves and family* **PROT**	**1**	**0**	**88**	**99**
90 *There are circumstances that are appropriate to test a patient for HIV/AIDS without asking the patient for permission/without telling the patient* CIRT	**1**	**0**	**88**	**99**
91 *There are circumstances where it is appropriate to reveal a persons HIV status to*	**1**	**0**	**88**	**99**

others without the patients knowledge/permission CIRR				
92 *There are circumstances where it is appropriate to **NOT** reveal a person's HIV status to him or her.* *NRS*	**1**	**0**	**88**	**99**
93 *Relatives and sexual partners of HIV/AIDS patients should be notified for the patients HIV/AIDS status even without his/her consent* NOTF	**1**	**0**	**88**	**99**

Regarding women's roles in society:

[Circle One]

Statement	**Agree**	**Disagree**	**DK**	NR
94 *I believe that there should be mandatory premarital HIV/AIDS testing of women* PTW	**1**	**0**	**88**	**99**
95 *I believe that there should be mandatory premarital HIV/AIDS testing of men* PTM	**1**	**0**	**88**	**99**
96 *I believe that a good wife obeys her husband even if she disagrees* OBEY	**1**	**0**	**88**	**99**
97 *I believe it's a wife's obligation to have sex with her husband even if she doesn't want to* OSEX	**1**	**0**	**88**	**99**
98 *I believe that a woman has a right to refuse sex* RSEX	**1**	**0**	**88**	**99**
99 *I believe a woman has a right to refuse sex if a man refuses to use a condom* COND	**1**	**0**	**88**	**99**
100 *I believe a man has the right to beat his wife if she disobeys him* BEAT	**1**	**0**	**88**	**99**
101 *I believe that women and girls need more education about their rights to refuse sex* ESEX	**1**	**0**	**88**	**99**
102 *I believe more should be done to protect women and girls from having sex when they don't want to* **PROT**	**1**	**0**	**88**	**99**
103 *I believe that women should have inheritance rights* WIR	**1**	**0**	**88**	**99**
104 *I believe that women with HIV/AIDS should have inheritance rights* HWIR	**1**	**0**	**88**	**99**
105 *I believe that Women with HIV/AIDS should not lose custody of their children* CUST	**1**	**0**	**88**	**99**
106 *I believe that women with HIV/AIDS should be asked to leave the home* WN	**1**	**0**	**88**	**99**
107 *I believe that there should be legal protections for the rights of women* LPRW	**1**	**0**	**88**	**99**
108 *I believe that there should be legal protections for the rights of people with HIV/AIDS* LPRH	**1**	**0**	**88**	**99**
109 *I believe that women (not men) are responsible for the transmission of most heterosexual HIV cases* WRT	**1**	**0**	**88**	**99**

PLWA FORM

Hello, my name is_____ I am working with the Policy Project, the Center for the Right to Health and Physicians for Human Rights. You were contacted about this study through your support group and I understand that you agreed to speak to us about your experiences as a person living with HIV/AIDS. We are gathering information from people living with HIV/AIDS in Nigeria which, we hope will help us better understand their experiences and help to change and improve health care policy for people living with HIV/AIDS. We are only here to ask questions. We are not here to provide medical or other assistance. Your current social support and/or medical services will not change as a result of participating in this survey. We will not report any information in a way that will reveal your identity. It is important that we have some privacy for our conversation because some of the questions may be sensitive. If you do not understand a question, please ask me to explain it to you. You are free to stop at any time during the interview. If a question makes you uncomfortable, we will skip the question and go to the next question. This interview will take approximately 40-50 minutes. Do I have your permission to begin? Do you have any questions before we begin?

0. Consent given (circle one): CNST

No _____0
Yes_____1

1. Location Code _____ (1, 2, 3…) LCD
2. Interviewer ID _____ (1, 2, 3…) ICD
3. Respondent code _____ (1-2000) RCD
4. Date _____ (day) _____ (month), 2002 DATE
5. Participation Outcome: [Circle ONE] OUTC

Eligible/Survey Complete	= 1
Not Eligible	= 2
Not Available (2 visits)	= 3
Refusal	= 4a=Lack Time; 4b=Fear Reprisal; 4c=Opposed to Study; 4d=Other
Unable to Complete	= 5a=Interrupted; 5b=Emotional; 5c=Safety; 5d=Other

6. Gender SEX

Female _____1
Male _____2

7. *What is your age*? _____years AGE

8. *Which of the following best describes your marital status?* MAR

Single_____1
Married_____2
Divorced due to HIV/AIDS status_____3
Divorced unrelated to HIV/AIDS status_____4
Widowed_____5
Widowed due to HIV/AIDS _____6
Separated due to HIV/AIDS status_____7
Separated unrelated to HIV/AIDS status_____8

9. *Have you lost inheritance rights (passed down in the family such as land, property or money/valuables) because you have HIV/AIDS ?* INH

No _____0
Yes _____1
Don't know _____88

10. *How many years of school have you completed?* _____ years EDU

11. *What is the highest level of education you have completed?* (Circle **ONE**) HDU

Primary _____1

Secondary _____2
Tertiary _____3

12. *What is your current employment status* ? (DO NOT READ; circle **one**)

CWRK

Unemployed _____1 [GO To Q13]
Self employed_____2 [GO To Q14]
Student _____3 [GO To Q14]
Housewife_____4 [GO To Q14]
Retired _____5 [GO To Q14]
Casual worker _____6 [GO To Q14]

13. *Why are you unemployed?* (DO NOT READ; Circle one)

JOBS

Dismissed; unrelated to HIV status _____1
Dismissed due to HIV status _____2
Asked to resign; unrelated to HIV status ___3
Asked to resign; unrelated to HIV status ___4
Due to poor health _____5
No job available _____6
Other (specify) _____7
Don't know _____8

14. *How much do you earn from your job and ANY other sources of income in Naira PER MONTH?*

_____ *Naira* INC

HIV/AIDS TESTING

15. *In what year were you informed about your HIV positive status?*

DDIG

_____year

16. *Where did you first get tested/diagnosed for HIV*?
(READ ALL CHOICES; circle **one**)

LDIG

Teaching hospital _____1
General hospital _____2
Health center _____3
Private hospital _____4
NGO _____
_____5
Private laboratory _____6
Other (specify)_____7

17. *Why did you get tested?* (DO NOT READ; circle **all** that apply)RDIG

Was sick all the time _____1
Worried about a sexual contact ___2
Spouse/Partner tested positive ___3
Asked by family _____4
Forced by family _____5
Tested unknowingly _____6
Pre-employment criterion_____7
To donate blood _____8
Antenatal _____9
Required for military service ____10
Hospital admission _____11

Insurance _____12
Other (specify) _____13
Don't know _____88

INFORMED CONSENT

18. *Did you know you were being tested for HIV when they took your blood?*

RTST

No _____0
Yes _____1
Don't Know _____88

19. *Whose idea was it for you to get tested for HIV*?
(DO NOT READ; circle **one**) ITST

No one, I did not know I was being tested __1
Mine_____2
My doctor or health worker _____3
Spouse or partner _____4
Family _____5
Friend _____6
Employer _____7
Other (specify) _____8

20. *Were you asked to sign a consent form for the HIV test*? CTST

No _____0 [GO TO Q23]
Yes _____1
Don't Know _____88

21. *Was the consent form explained to you by a health care provider or a social worker?*

CEXP

No _____0
Yes _____1
Don't Know _____88

22. *Did you sign a consent form <u>for</u> the HIV/AIDS test?* STST

No _____0
Yes _____1
Don't Know _____88

PRE TEST COUNSELING

23. *Who explained to you what the HIV test was all about before you took the test?*
(DO NOT READ; circle **all** that apply) WCNS

No one_____0 [GO TO Q24]
Doctor _____1 [GO TO Q25]
Nurse _____2 [GO TO Q25]
Laboratory technician _____3 [GO TO Q25]
Trained counselor _____4 [GO TO Q25]
NGO worker _____5 [GO TO Q25]
Others (specify) _____6 [GO TO Q25]
Don't Know _____88 [GO TO Q25]

24. *Please list the reasons why you believe counseling was **NOT** offered.*
(DO NOT READ; Circle **one**) NCNS

Services not available _____1
Services available, but clinicians do not offer _____2
Was not told I was being tested _____3
Services available, but patients would not accept ____4
Other (specify) _____5

Don't know _____ 88

25. *Did you understand the explanation*? UCNS

No _____ 0
Yes _____ 1
Don't Know _____ 88

26. *Were you encouraged to ask questions*? ENCQ

No _____ 0
Yes _____ 1
Don't Know _____ 88

27. *Did you ask any questions*? ASKQ

No _____ 0
Yes _____ 1
Don't Know _____ 88

POST-TEST COUNSELING

AFTER your test result were you counseled about the following?

	Yes	**No**	
28. *The meaning of being HIV positive*	1	0 [GO To Q34]	MHIV
29. *Where to go for help/information/advice*	1	0 [GO To Q34]	WADV
30. *Safe sex*	1	0 [GO To Q34]	HPRT
31. *How to cope at home*	1	0 [GO To Q34]	COPE
32. *None of the above/not counseled*	1	0 [GO To Q33]	NONE

33. *Please list the reasons why you believe counseling was **NOT** offered AFTER your positive HIV test.* (DO NOT READ; circle **all that apply**) RNCA

Services not available _____ 1
Services available, but clinicians do not offer _____ 2
Was not told I was being tested _____ 3
Services available, but patients would not accept ____ 4
Other (specify) _____ 5
Don't know _____ 88

34. *Were you encouraged to return for further counseling and/or care?*

KTN

No _____0
Yes _____1
Don't Know _____88

35. *Did you receive referral to social services/NGOS/ support groups*?

REF

No _____0
Yes _____1
Don't Know _____88

36. How did you first find out about your HIV/AIDS test result?
(DO NOT READ; circle **all that apply**)

HFOR

Doctor _____1
Nurse _____2
Laboratory technician _____3
Trained counselor _____4
NGO worker _____5
Social worker _____6
Through rumors _____
_____
_____7
Through employer _____
_____8
Fired _____
_____
_____9
Shunned _____
_____
_____10
Kicked out of home _____
_____11
Other (specify) _____12
Don't Know _____88

FAMILY, SOCIAL AND PERSONAL INTERACTIONS

37. Are your current sexual partners *aware of your HIV status*? PAHS

No _____0 [GO TO Q39]
Yes _____1 [GO TO Q38]
No current sexual partners __2 [GO TO Q39]
Don't know _____88 [GO TO Q39]

38. Did any of the following individuals notify your sexual partner (s) of your HIV status without your permission? (READ CHOICES; circle **all** that apply) WTPS

None _____0
Doctor _____1
Nurse _____2
Laboratory technician ____3
Trained counselor _____4
NGO worker _____5
Social worker _____6

Through rumors _____7
Through employer _____8
Fired _____
_____9
Relative _____10
Friend _____11
Other (specify) _____12

39. *Has anyone revealed your HIV status to **anyone** without your permission*?
(READ; circle **all** that apply) ARNP

No _____0
Doctor _____1
Nurse _____2
Laboratory technician ___3
Trained counselor _____4
NGO worker _____5
Social worker _____6
Friend _____
_____7
Employer _____8
Other (specify) _____9
Don't Know _____88

40. *Has others knowing your HIV status caused you any of the following problems*?
(READ; Circle **all** that apply) KPRB

No problems_____0
Fired from job _____1
Not hired for job _____2
Shunned by family _____3
Shunned by community ___4
Lost home _____5
Could not get insurance __6
Lost custody of children __7
Other (specify) _____8
Don't know _____88

ACCESS TO HEALTH CARE

Treatment in Health care System

In the past year, have you experienced or observed any of the following forms of discrimination on account of your HIV/AIDS status by doctors, nurses or support staff in any health facilities? (provide responses for Q41-Q46)

Form of Discrimination	**Experienced: Yes/No**	***Where?***	***Type of Facility***	***Who* (List ALL that apply)**
41. *Have you been refused medical care* ORC				
42. Have you observed anyone being refused medical care ORC2				
43. *Have you ever been refused admission to a hospital* OTA				
44. Have you observed an HIV patient being refused admission to a hospital? OTA2				
43. *Has anyone given confidential information to a family member* OBC				
44. *Has anyone given confidential information to a non-family member* OVM				

45. *Have you observed confidential information of a PLWA given to a family member* OBC				
46 . *Have you observed confidential information given of a PLWA given to a non-family member* OBC2				
47. Has anyone verbally mistreated you? VBT				
48. Have you observed a PLWA patient being verbally mistreated? Vbt2				
	0= No 1=Yes 88=Don't Know EXPD	1=Maternity 2=Primary Health Center 3=General hospital 4= Teaching Hospital 5= Federal Medical Center 6= Specialized Center (specify) 88= Don't Know FACD	1=Public 2=Private 88= Don't know TFCD	0= None 1=Doctor 2=Nurse 3=Support staff 4= Other (specify) WHOD

49. *What are your sources of information about HIV/AIDS?*
(DO NOT READ; circle **all** that apply) SINF

Newspaper _____1
Magazine _____2
Radio _____3
Television _____4
Health care worker_____5
Clergy _____6
NGO (specify) _____7
Book _____8
Friend _____9
Teacher _____10
Other (specify)_____11
Don't Know _____88

50. *What is the most important obstacle that people with HIV/AIDS face in trying to access health services in your area?* (DO NOT READ; circle **three** only) ABAR

Lack of financial means _____1
Lack of knowledge of having the disease _____2
Difficulty getting to the health facility _____3
Fear of being stigmatized _____4
Belief that they will not receive any health care that will help them ____5
Fear of discrimination by clinical and/or non-clinical health personnel__6
Other (specify) _____7
Don't Know _____88

HIV/AIDS Treatment Practices:

51. *Are you currently taking medications called anti-retrovirals for HIV or HIV-related conditions?*
HMED

No _____0 [GO To Q50]
Yes _____1 [GO To Q51]
Don't Know _____88 [GO To Q50]

52. Have you EVER taken Anti-retrovirals for HIV or HIV-related conditions?

ARV

No _____0
Yes _____1
Don't Know _____88

53. Have you taken antibiotics for HIV or HIV-related conditions?

ANT

No _____0
Yes _____1
Don't Know _____88

54. Have you received counseling and/or support services for HIV or HIV-related conditions?

SUP

No _____0
Yes _____1
Don't Know _____88

55. Have you received Nutritional supplements for HIV or HIV-related conditions?

NUT

No _____0
Yes _____1
Don't Know _____88

56. Have you received traditional or herbal treatments for HIV or HIV-related conditions?

TRA

No _____0
Yes _____1
Don't Know _____88

Can you afford a monthly supply of the following medications or treatments?

	Yes	**No**
57. *Anti-retrovirals* _____	1	0
58. *Antibiotics* _____	1	0
59. *Nutritional supplements* _____	1	0
60. *Traditional/herbal supplements*_____	1	0

Financial Information

61. *How much do the drugs that you are currently using for HIV/AIDS cost per month*?

_____Naira MMED

62. *Who pays for your medications*? (DO NOT READ; Circle **all** that apply?)

WPAY

Government _____1

Employer _____2
Self _____3
Voluntary or NGOs _____4
Family _____5
Others (specify) _____6
Don't Know _____88

63. *What special precautions, if any, have you observed by hospital or clinic staff when you are seen in a health facility?* (READ ALL CHOICES; Circle **all** that apply) PREC

Extra gloves/protective gear _____1
Invasive procedures are not performed _____2
HIV status clearly marked on chart or file __3
Separated from other patients _____4
Charged more than other patients_____5
None; I am treated like any other patient ___6
Not seen in hospital or clinic _____7
Other (specify) _____8
Don't Know _____88

64. *What is the main factor you think is contributing to the spread of HIV/AIDS in your community*? (DO NOT READ; circle **one**) SFAC

Heterosexual sex _____1
Homosexual sex _____2
Prostitution _____3
Injection drug use _____4
Mother to child transmission _____5
Transfusions with blood products _____6
Sinful/inappropriate/immoral behavior _____7
Violence_____8
Desire for large family_____9
Other (specify) _____10
Don't know_____88

65. *What is the main obstacle to preventing HIV infection in your community*? (DO NOT READ; circle **one** only) BPRV

Lack of public education _____1
Unprotected sexual intercourse _____2
Lack of medical treatment _____3
Lack of HIV testing capabilities_____4
Inability for women to protect themselves from HIV infected spouse __5
Low social status _____6
No legal protection for people's rights _____7
Stigma _____8
Mother to Child Transmission _____9
Other (specify) _____10
Don't know _____88

66. *What is the main obstacle to diagnosing (testing for) HIV in your community*? (DO NOT READ; circle **one** only) SIGB

People do not choose to get tested _____1
People unaware of HIV/AIDS signs and symptoms_____2
Clinicians do not order HIV tests _____3
Lack of HIV testing capabilities _____4
Other (specify)_____5
Don't know_____88

67. *What is the main obstacle in treating infections/conditions related to AIDS (such as opportunistic infections, tuberculosis, Kaposi's Sarcoma, and AIDS dementia) in our community?* (DO NOT READ; circle **one** only)

OITB

Availability of diagnostic testing_____1
Availability of medications _____2
Attitudes of clinical staff _____3
Patient's inability to pay _____4
Other (specify) _____5
Don't know_____88

68. *Based on your experience with doctors and nurses as a PLWA, what concerns or fears do you believe doctors and nurses have in treating HIV/AIDS patients*? (READ; circle all that apply)

PHCC

No particular concerns _____1
Fear of becoming infected _____2
Contamination of materials /facility/ instruments ____3
Waste of resources because they will die _____4
Personal /professional stigma by association _____5
Stigma to clinic/facility _____6
Don't know how to treat _____7
Don't know how to protect self/others _____8
Don't have materials needed to treat _____9
Don't have materials to protect self others _____10
Other (specify) _____11
Don't know _____88

I am going to read some statements one at a time. For each, please say "I AGREE" or "I DISAGREE".

Q#	Statement	**Agree**	**Disagree**	**DK**	**NR**
69	*People should be tested compulsorily for HIV/AIDS* CTST	**1**	**0**	**88**	**99**
70	*People do not need to be counseled before taking an HIV test* NCON	**1**	**0**	**88**	**99**
71	*People do not need to be counseled after taking an HIV test* YCON	**1**	**0**	**88**	**99**
72	*A doctor or nurse does not need the permission of a person with HIV to reveal to others that he/she has HIV* NNIC	**1**	**0**	**88**	**99**
73	*A doctor or nurse does not need a patient's permission before a patient can be tested for HIV.* YNIC	**1**	**0**	**88**	**99**
74	*A doctor or nurse has the right to refuse to care for a person with HIV/AIDS* RRC	**1**	**0**	**88**	**99**
75	*People wanting to marry should be required to obtain a certificate that they do NOT have HIV* CERT	**1**	**0**	**88**	**99**
76	*The health worker has a right to abort a pregnancy of an HIV/AIDS woman without her consent* ABRT	**1**	**0**	**88**	**99**
77	*All prospective workers should submit to mandatory HIV/AIDS testing* JOBT	**1**	**0**	**88**	**99**
78	*It is OK to dismiss an employee found to have HIV/AIDS or to ask him to resign from his/her job.* FIRE	**1**	**0**	**88**	**99**
79	*People with HIV should not be allowed to bear children* CHLD	**1**	**0**	**88**	**99**
80	*There is a government policy protecting the rights of people living with HIV/AIDS* GPOL	**1**	**0**	**88**	**99**
81	*Health professionals have a responsibility to participate in clinical treatment for HIV/AIDS and related conditions* ETHC	**1**	**0**	**88**	**99**
82	*Health professionals have a responsibility to participate in Individual and community prevention measures* ETHP	**1**	**0**	**88**	**99**

83	*Health professionals have a responsibility to participate in public education on HIV/AIDS issues* ETHE	**1**	**0**	**88**	**99**
84	*Health professionals have a responsibility to participate in policy reforms to improve clinical treatment of HIV/AIDS and related conditions* ETHR	**1**	**0**	**88**	**99**
85	*Health professionals have a responsibility to participate in education and advocacy to prevent social discrimination toward people living with AIDS.* ETHD	**1**	**0**	**88**	**99**

***Regarding the care and treatment of HIV/AIDS patients*:** **(Circle One}**

Q#	Statement	Agree	Disagree	DK	NR
86	*A person's HIV status can be determined by his/her appearance* LOOK	**1**	**0**	**88**	**99**
87	*Treating someone with HIV/AIDS is a waste of resources* NWT	**1**	**0**	**88**	**99**
88	*A person with HIV/AIDS can not be treated effectively* CTE			**88**	**99**
89	*It is OK to test someone for HIV without their knowledge* NCT	**1**	**0**	**88**	**99**
90	*Many of those who contracted HIV/AIDS had immoral behavior and deserved have the disease* DES	**1**	**0**	**88**	**99**
91	*If someone has HIV/AIDS his employer/coworkers should be told even is she/he does not give permission.* NBRS	**1**	**0**	**88**	**99**
92	*A health professional with HIV/AIDS should not be working in any area of the health profession* that requires patient contact. HPNW	**1**	**0**	**88**	**99**
93	*It is OK to dismiss a health professional found to have HIV/AIDS or to ask him to resign from his/her job.* DHP	**1**	**0**	**88**	**99**
94	*People with HIV/AIDS should not be employed in the health field* NEHF	**1**	**0**	**88**	**99**
95	*All prospective health care workers should have mandatory testing for HIV.* HWMT	**1**	**0**	**88**	**99**
96	*If someone has HIV/AIDS his neighbors and community should be told even is she/he does not give permission* NBRS	**1**	**0**	**88**	**99**
97	*People with HIV/AIDS should be on a separate ward in a hospital or clinic* HCI	**1**	**0**	**88**	**99**
98	*People with HIV/AIDS should be kept away from other people in their community* COMI	**1**	**0**	**88**	**99**
99	*It is OK for health facilities to refuse to care for a patient with HIV/AIDS* RCAR	**1**	**0**	**88**	**99**
100	*Staff and health care professionals should be told when a patient has HIV/AIDS so they can protect themselves* STAF	**1**	**0**	**88**	**99**
101	*The charts/beds of HIV/AIDS patients should be marked so that clinic/hospital workers know the patient's status* CHRT	**1**	**0**	**88**	**99**

Regarding women's roles in society: ***(Circle One)***

Q #	Statement	Agree	Disagree	DK	NR
102	*I believe that women should have to be tested for HIV/AIDS before getting married* PTW	**1**	**0**	**88**	**99**
103	*I believe that a good wife obeys her husband even if she disagrees* OBEY	**1**	**0**	**88**	**99**
104	*I believe it's a wife's obligation to have sex with her husband even if she doesn't want to* OSEX	**1**	**0**	**88**	**99**
105	*I believe that any woman has a right to refuse sex* RSEX	**1**	**0**	**88**	**99**
106	*I believe a woman has a right to refuse sex if a man refuses to use a condom* COND	**1**	**0**	**88**	**99**
107	*I believe a man has the right to beat his wife if she disobeys him* BEAT	**1**	**0**	**88**	**99**
108	*I believe that women and girls need more education about their rights to refuse sex* ESEX	**1**	**0**	**88**	**99**
	I believe more should be done to protect women and girls from having sex when they don't want to PROT	**1**	**0**	**88**	**99**
110	*I believe that women should have inheritance rights* WIR	**1**	**0**	**88**	**99**
111	*I believe that women with HIV/AIDS should have inheritance rights* HWIR	**1**	**0**	**88**	**99**
112	*I believe that Women with HIV/AIDS should not lose custody of their children* CUST	**1**	**0**	**88**	**99**
113	*I believe that women with HIV/AIDS should not be asked to leave her home* WNL	**1**	**0**	**88**	**99**
114	*I believe that there should be legal protections for the rights of women* LPRW	**1**	**0**	**88**	**99**
115	*I believe that there should be legal protections for the rights of people with HIV/AIDS* LPRH	**1**	**0**	**88**	**99**
116	*I believe that women (not men) are responsible for spreading most heterosexual HIV cases* WRT	**1**	**0**	**88**	**99**

Regarding care of HIV/AIDS patients

Q #	Statement	Agree	Disagree	DK	NR
117	*There are no medicine that can help people with HIV/AIDS* NMED	**1**	**0**	**88**	**99**
118	*The quality of life of HIV/AIDS patients can be improved with counseling* QUAL	**1**	**0**	**88**	**99**
119	*There are times when it is right to test a patient for HIV/AIDS without asking the patient for permission or notifying him/her* TCRC	**1**	**0**	**88**	**99**
120	*There are times when it is right to tell a persons HIV status to others without the patient's knowledge or permission* RCRC	**1**	**0**	**88**	**99**
121	*There are circumstances where it is appropriate **NOT** to reveal a person's HIV status to him or her.* NRS	**1**	**0**	**88**	**99**
122	*Relatives of HIV/AIDS patients should be told the patients HIV/AIDS status even without his/her consent* NOTF	**1**	**0**	**88**	**99**

123	*Sexual partners of HIV/AIDS patients should be told his/her HIV/AIDS status even without his/her consent* SOTF	**1**	**0**	**88**	**99**

NARRATIVE SECTION

143. *.Please tell me briefly about any experience/circumstance you had in which you were treated disrespectfully by medical personnel on account of your HIV status.*

_____
_____
_____
_____
_____
_____
_____
_____
_____

144 *Please tell me briefly about any experience/circumstance you had in which you were refused medical care or treatment on account of your HIV status.*

_____
_____
_____
_____
_____
_____
_____
_____
_____

145. *Please tell me briefly about any other experiences/circumstances you had in which you believe you were discriminated against because of your HIV status.*

_____
_____
_____
_____
_____
_____
_____
_____
_____

146. *Is there anything else you want to tell me?*

_____
_____
_____
_____
_____
_____
_____
_____
_____

APPENDIX B: Interviewer Training

Interviewers for the access of PLWA to health care in Nigeria study were recruited by the Center for the Right to Health (CRH) based on criteria decided upon by PHR and CRH. These included education, knowledge of languages, and experience with research and knowledge of HIV/AIDS. Training lasted for four full days, from October 15 through 18, 2002.

Day 1

Training began with the introduction of participants and trainers, as well as introductions to PHR, CRH and the Policy Project. Trainees were provided with an overview of the project and its goals. CRH then distributed a brief confidential survey to assess participants' knowledge of HIV/AIDS. The results of this were used to inform the training on HIV/AIDS conducted by CRH and for other aspects of training. Trainers and trainees also agreed upon rules of conduct for the training. PHR trainers then discussed ethical issues with trainees including detailed discussions of expectations for researcher conduct, professional integrity and dignity, confidentiality, information sharing, impartiality, and accuracy in transmission of information from the research participant. These themes were raised again as appropriate later in the training. The plan for the rest of the training was then covered.

Day 2

Trainee questions and or comments were addressed. Copies of survey instruments were distributed and trainees were asked to read through the questionnaires in order to familiarize themselves with the instrument's contents. PHR trainers then introduced participants to the survey and reviewed the instrument question by question. Discussion included the meaning and purpose of the questions as well as how to follow written instructions and mark responses correctly. Trainees followed on their copies of the questionnaire and were given the opportunity to ask questions and provide comments/feedback.

Participants then observed a mock-interview between the two primary CRH trainers and were asked to mark the correct answers on their copies of the survey instrument. Trainees again had the opportunity to give feedback, ask questions, and suggest changes. Trainees submitted the marked surveys to the trainers. These were reviewed that night to identify recording errors that needed to be corrected and areas that required reinforcement during training the following day. Trainers' initial assessments of the researchers' capabilities were based on this first exercise.

Day 3

Researchers were grouped into teams of three comprising at least one of the stronger trainees on each team. The 6 strongest trainees who were judged to be most capable of accurately completing questionnaires and who had prior experience of research and/or of working on issues relating to HIV/AIDS were selected to be trained on an additional instrument to be administered to PLWAs.

Trainers opened the day by dividing trainees into groups. Trainers then returned the marked assessment papers and discussed issues identified after a review of the previous day's assessment exercise. After all questions were addressed, trainees conducted mock interviews in their groups taking turns to administer, respond to and observe the survey. After each mock interview, each member in each team of three provided feedback to the rest of his/her team. Trainers from PHR and CRH observed the teams, took notes and provided feedback on demeanor and accuracy. Trainers also answered any questions that arose.

During a break from the mock interviews, CRH provided an overview of the states where the survey would be conducted highlighting the cultural differences and expected conduct. Trainers explained the plan for the following day including a final assessment exercise and selection of researchers for the study.

On the final day, trainees continued to conduct mock interviews. The six people (two teams) selected to conduct the PLWA interviews were introduced to the PLWA instrument and began training. Assessment began mid

morning. Each researcher was provided with the same two-page questionnaire that they had to administer to one of the trainers. The responses given by the trainer were the same for all trainees and were meant to assess whether each trainee was capable of asking questions as written, to correctly mark responses and catch inconsistencies. The demeanor of the trainee and his/her reaction to responses was also assessed. Two other trainers (one from PHR and one from CRH) evaluated each trainee's performance based on pre-determined criteria that were shared with trainees before assessment began. After all trainees were assessed, the twenty-five trainees with the highest scores were selected as researchers.