
HIV AND CONFIDENTIALITY IN CHINA

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“...the public health goal is to safeguard the health of communities through the collection, analysis, dissemination, and use of health data, which must be carefully balanced with the individual’s rights to privacy and confidentiality”. ^[1]

---- UNAIDS

1. Introduction

The right to privacy is an important civil right of all citizens. This includes privacy of personal information and the right to make personal decisions, including the right to keep personal information confidential. Under privacy provisions, health institutions and medical personnel should not disclose any personal information about people to a third party without consent. ^[2]

Disclosure of HIV status without consent can have serious consequences for people living with HIV, especially in a social environment where stigma and discrimination are pervasive. Negative repercussions may even extend into the work and home environments in the form of limited career development opportunities, denial of employment and damaged familial and social networks. ^[3]

In order to protect the rights of people with HIV to privacy, China recently developed a range of policies. These include the *Law on the Prevention and Treatment of Infectious Diseases* (revised in 2004), the *Tort Liability Law* (2010) and the *HIV/AIDS Prevention and Control Regulation* (2006). In the international community, several standards and guidelines have been developed to address the rights of people living with HIV. In 2010, the International Labour Conference adopted the *Recommendation Concerning HIV and AIDS and the World of Work (R200)* to protect the rights of people with HIV. The UNAIDS *Guidelines on Protecting the Confidentiality and Security of HIV Information* in 2007 and the *WHO/UNAIDS Guidance on Provider-initiated HIV Testing and Counseling in*

Health Facilities in 2007 also provide guidance on managing information related to HIV status. However, despite these international standards and national policies, privacy violations of people with HIV are still occurring on a regular basis in China.

To better understand the situation of HIV related rights to privacy in China, the China Center for Disease Control and Prevention (China CDC) and the ILO HIV Program jointly conducted research in late 2010. Stakeholders interviewed included 103 people with HIV¹ and 19 staff from provincial CDCs in Henan, Beijing and Yunnan². The research analyzed the relevant systems of HIV related testing, epidemiological investigation, on-line reporting and follow up visits provided by China's CDCs and hospitals, and identified those stages in the process where the personal information of people with HIV risked disclosure.

2. Relevant policies and international guidelines on HIV and confidentiality

2.1 China's existing policies on HIV and confidentiality

In China there is typically a low level of awareness about what privacy is and the right to privacy. Chinese culture has a long history of valuing the public over the private, which, in this context, stresses the 'right to know' over the 'right to privacy'. Underlying this is the fact that the right to privacy is not recognized as an independent right under the 1986 Chinese Civil Law. [4] Currently, although China has not developed any specific laws to protect an individual's rights to privacy, these rights are reflected in other laws and opinions of members of the judiciary.

The Supreme People's Court issued Opinions on the Implementation of General Principles of the Civil Law, Article 140 of which states that "*revelation of another's privacy which results in a bad impact should be treated as an invasion of an*

¹ These interviews were conducted by Marie Stopes International and the ILO.

² These interviews were conducted by the China CDC.

individual's reputation". This is the first judicial interpretation of privacy rights in China. In 1993, the Supreme People's Court issued Several Issues about the Trial of Cases Concerning the Right of Reputation. Article 7 states that *"leakage of another's privacy without informed consent, which results in a damaged reputation for the person, should be treated as an invasion of an individual's reputation"*.

In recent years, there have been a number of laws and regulations formulated for the specific purpose of protecting the privacy of people with HIV, some of which are highlighted below.

Article 8 of the Interpretation of the Supreme People's Court on Several Issues about the Trial of Cases Concerning the Right of Reputation in 1998, states that *"behavior of the staff of healthcare facilities that causes exposure of patient medical conditions such as gonorrhea, syphilis, leprosy and HIV/AIDS and causes damage to the reputation of the patient should be determined as damaging the right to reputation of the patient."*^[5]

The Notice of the Ministry of Health on the Management of People with HIV/AIDS (1999), stipulates that *"positive cases confirmed by a laboratory should be reported according to the requirements of the infectious diseases report system and such reports comprise personal information that should be kept confidential."*

^[6]

Article 12 of the Law on the Prevention and Treatment of Infectious Diseases, which was revised in 2004 specifies that *"disease prevention and control agencies and health facilities should keep information and materials containing personal information confidential and those who breach confidentiality... will face a penalty..."*^[7]

The National Management Method for HIV/AIDS Testing issued in 2006 requires that the *“HIV confirmatory testing report should be delivered confidentially and the result should be given to the subject...the laboratory staff should not break the confidentiality of the information of people living with HIV, such as name, address or testing result”*^[8].

The Regulation on the Prevention and Treatment of HIV/AIDS issued in 2006, stipulates that people living with HIV enjoy lawful rights and interests related to the protection of their privacy and *“health facilities that disclose the information of people living with HIV and their family members”* should be punished in accordance with the Law on Infectious Diseases Prevention and Treatment.

There are challenges with the implementation of these policies. To date there have not been any reports of any health facility having ever been prosecuted for breaching the confidentiality of people living with HIV, despite many reported instances of this happening. This lack of enforcement is largely due to the limited feasibility of applying these laws and regulations in practice.

2.2 International Guidelines on Confidentiality and HIV

The UNAIDS *Guidelines on Protecting the Confidentiality and Security of HIV Information* (the Guidelines) in 2007 provides guidance on how HIV related information should be stored and protected. These recommendations include that all countries should have confidentiality laws in place and that all countries and organizations at all levels of the healthcare system should have a written policy that defines security procedures concerning the way data are collected, stored, transferred and released. Further, these policies should be formulated in consultation with all stakeholders, including people living with HIV and must be implemented at all relevant levels. They must be understood by staff who have signed an agreement stating that they will implement them and have received

training. The Guidelines further provide that breaches of confidentiality should be properly investigated and appropriate sanctions imposed.

The *WHO/UNAIDS Guidance on Provider-initiated HIV Testing and Counseling in Health Facilities* (2007) provides basic operational guidance on provider-initiated testing and counselling in health facilities and recommends an “opt out” approach to provider-initiated HIV testing in particular healthcare settings. It also notes that “*when recommending HIV testing and counseling, service providers should always aim to do what is in the best interests of the individual patient. This requires giving individuals sufficient information to make an informed and voluntary decision to be tested, maintaining patient confidentiality, performing post-test counseling and making referrals to appropriate services*”. “*Endorsement of provider-initiated HIV testing and counseling by WHO and UNAIDS is not an endorsement of coercive or mandatory HIV testing. WHO and UNAIDS do not support mandatory or compulsory testing of individuals on public health grounds*”.^[9]

The *ILO Code of Practice on Protection of Workers’ Personal Data* developed in 1997 provides a comprehensive framework for member states to protect privacy and is directly relevant to people living with HIV. For example, section 6.2. states “*If it is necessary to collect personal data from third parties, the worker should be informed in advance, and give explicit consent*” and section 10.1. states that “*Personal data should not be communicated to third parties without the worker’s explicit consent...*”. Similarly, section 6.7 recommends “*Medical personal data should not be collected except in conformity with national legislation, medical confidentiality and the general principles of occupational health and safety, and only as needed (a) to determine whether the worker is fit for a particular employment; (b) to fulfill the requirements of occupational health and safety; and (c) to determine entitlement to, and to grant, social benefits*”.

As noted above, in 2010, the ILO adopted *Recommendation Concerning HIV and*

AIDS and the World of Work (No. 200). This Recommendation is the first international legal instrument to address the protection of the rights of people with HIV in the world of work. Recommendation No. 200 states that “*the result of HIV testing should be confidential and not endanger access to jobs, tenure, job security or opportunities for advancement*”. Article 37 (c) states that national policies and programs on HIV and AIDS should “*provide for measures in national laws and regulations to address breaches of privacy and confidentiality and other protection afforded under this Recommendation*”.

The ILO Code of Practice on HIV/AIDS and the world of work contains several detailed sections that address confidentiality in the context of people living with HIV. These include section 4.7 which prohibits job applicants or workers from being obliged to disclose their HIV status and sections 5.2(g), 5.3 (j) and 7.4 which are concerned with the storage and access to the HIV related information of an individual in an employment context. Section 8 is concerned with testing and provides guidance as to the limited situations in which testing in the workplace may be appropriate and states that “*Even outside the workplace, confidential testing for HIV should be the consequence of voluntary informed consent and performed by suitably qualified personnel only, in conditions of the strictest confidentiality*”.^[10]

3. Key findings

3.1 Process of VCT

The process of Voluntary Counseling and Testing (VCT) includes pre-test counseling, HIV testing, the provision of results and post-test counseling. In China, VCT services are delivered under the *Management of Free HIV/AIDS Voluntary Counseling and Testing (trial)* issued in 2004. CDC staff interviewed in the course of the research advised that clients are not required to provide personal identification details at the preliminary testing stage however they do need to provide a telephone number so that they can be informed when test results

become available.

“...There is no need to provide any personal information for the testing. A telephone number is enough...” (Staff member, County STI/HIV Division, CDC)

“We don’t ask for ID cards in the preliminary testing stage. Of course, he can leave it with us if he wants to... But a telephone number is required.” (CDC staff, County level)

In some health services, clients were encouraged to leave their personal details on a voluntary basis.

“We try to persuade people to bring their ID cards and provide their real names when doing preliminary testing...” (Staff member, County HIV/AIDS office)

In the event that the preliminary test result is positive, the client is required to undergo a further stage of confirmatory testing and must provide his/her ID card for this purpose. This is a requirement of the epidemiological information system that is used by the China CDC that links information to real names.

“One has to bring his ID card or household registration to confirmatory testing...” (Staff member, county HIV/AIDS office)

“...We contact him and ask to him have a confirmatory test with his ID card.” (Staff member, District CDC)

Clients are informed of their test results in person. VCT staff are prohibited from informing clients of their results over the phone or indirectly through a third person. If the testing result is positive, VCT staff are requested to provide the test result in writing to the client in a private and quiet location.

“...We tell him by phone that his test result is available and invite him to come in and get it in person... We never give the result over the telephone.... the client himself must come to receive the result. If he cannot make it, he can entrust another person but this person has to provide his ID card and bring with him the original ID card of the client and his authorization letter”. (Staff member, AIDS Department, District level CDC)

“...all of us will refuse to provide test results over the telephone...sometimes, the client will say that he is out of town, we will tell him to come in person when he is back... sometimes the client will say that he is not available and his family members can help, in that case we will tell him to provide his ID card and a signed authorization letter to his family member. We can't identify who is on the telephone line... There were incidences of someone trying to obtain the results of other people. It happened several times” (VCT Doctor, District level CDC)

3.2 Process of HIV testing in hospitals

In China, HIV testing in hospital settings is typically performed before a patient undergoes surgery or other invasive procedures. In a number of cases, people with HIV had been seeking treatment at a hospital for their medical issues for a long period of time prior to being tested at the hospital and consequently diagnosed as HIV positive. For others, they discovered their HIV status after undertaking HIV testing services at a hospital or were diagnosed after completing an employer organized health check.

Procedures of HIV testing in hospitals are different from those undertaken in VCT centers. The current practice in hospitals is based on the WHO/UNAIDS *Guidance on Provider-initiated HIV Testing and Counseling*. However, most often, patients are not informed of the HIV testing before they undergo a test. This partly explains the complaints about compulsory testing in hospitals expressed by some patients.

According to the *China CDC Guidelines on HIV/AIDS Case On-line Reporting*, “in health facilities where continuing relationships with patients typically do not exist, doctors should get clients personal data such as personal general information and risk factors, especially telephone number, address and risk behaviors, before HIV testing is arranged”.^[11] Therefore doctors in hospitals are requested to obtain the personal information of patients before HIV testing takes place.

3.3 Process of on-line reporting and epidemiological investigation

China uses a HIV epidemic on-line reporting system for monitoring HIV cases. The national infectious disease on-line reporting system was launched in January 2004 and it has been the most important tool for the country in terms of collecting information and data, and monitoring the spread of infectious disease. In 2005, the HIV epidemic on-line reporting system was established, and the system was upgraded to its current version in 2008.^[12] The procedures for HIV epidemic on-line reporting are described below.^[13]

“When a person tests positive to HIV in the preliminary testing stage, VCT staff are asked to complete the so-called HIV Related Information Form. To fill in the form, the staff will ask the individual concerned to provide the following information: name, ID card number, employer, telephone number, current address, hukou address, marriage status, education level, occupation, as well as details of any HIV related risk behaviors they may engage in, such as sharing needles, extramarital sex, MSM, blood selling etc”.^[14]

“When a person is identified as HIV positive in the confirmatory testing stage, staff in the health facility will ask him/her to provide information to fill the so-called Infectious Disease Reporting Card. Information will include name, ID card number, employer, telephone number, hukou, current address, occupation etc and provide other information to fill the form of HIV related Information Card, including race,

marriage status, education level, risk factors (for example sharing needles, extramarital sex, MSM etc), history of STI, transmission mode, testing place and others”.^[15]

“For hospitals with the capacity to report on-line, the relevant health worker will enter all the relevant information into the on-line reporting system within 24 hours of the case being identified. These include information from the completed Infectious Disease Reporting Card and HIV related Information Card”.^[16] *For those hospitals without capacity to report on-line, “the hospital is required to report all the required information from the HIV Related Information Form and the Infectious Disease Reporting Card to the local China CDC within 24 hours of the case being identified. County level China CDC should then report the case on-line within 2 hours of receiving the information from the hospital”.*^[17]

According to the China CDC, epidemiological investigations should be conducted within 10 days after the HIV case is reported on line. During the investigation stage, China CDC staff will contact the newly identified people with HIV to double check with them that the information they have provided on the *HIV Related Information Form* and the *Infectious Disease Reporting Card* was correct. The China CDC staff will then ask the person to provide more information to complete the so-called *HIV Case Follow-up Form*. This information will include their name, ID Card details, telephone number, current address, as well as details of their symptoms in the past 6 months, condom use in the past 3 months, needle sharing in the past 3 months, pregnancy status in the past 3 months, and if they were pregnant, whether they delivered the baby in the past 3 months as well as any support obtained in the past 6 months (including publicizing materials, condoms, drugs for opportunistic infections, other care and support service), the results of TB screening undertaken in the past 6 months, ARV treatment, CD4 count etc.^[18]

As illustrated above, a significant amount of personal information is obtained from

an individual who tests positive for HIV and there is an established system of reporting in place, which provides for the prompt transfer of an individual's personal information from the testing site to the China CDC for the purpose of monitoring new cases and providing people with HIV with follow-up services. The design of this system means that staff involved in the on-line reporting of information and the delivery of follow-up services, which are discussed below, have wide access to the personal information of an individual who tests positive for HIV.

3.4 Process of follow-up services

After a person tests positive and his/her information is reported to the China CDC and the epidemiological investigation is completed, a regime of follow-up services under the guidance of the China CDC *Free ARV Treatment Manual* is provided. According to this manual, "*the China CDC provides long term clinic care and support for people with HIV, which includes diagnosis, prevention and treatment of opportunistic infection, ARV treatment, and palliative care. Home visits and regular follow-ups should be utilized to achieve this end.*"^[19] The manual also says "*people who test positive for HIV should be covered by the local care and support system and receive regular follow-up services. The aim of follow-up services is to assess health status of the people with HIV. For those without symptom and with high CD4 count, the CDC provides two CD4 count tests each year to assess their disease progress.*"^[20] In practice, this means that people who test positive for HIV in China are actively pursued by the China CDC to receive follow-up services.

The staff members who provide follow-up services have authority to access the on-line reporting system, obtain the personal information of people with HIV and contact them by phone or visit their house for the purpose of conducting follow-up visits. During the course of this research, China CDC staff advised that they would visit the house of people with HIV in person in circumstances where they

encountered difficulties contacting them by telephone. It was apparent from the accounts of China CDC staff interviewed that a significant amount of time and resources were involved in locating people with HIV and providing them with follow-up services.

“Most of the cases we failed to follow up are healthy. These cause us headaches. When we lose contact with them, we would normally contact their family members and ask them to help. Generally speaking, after trying several times later, the PLHIV will be found” (Staff member, District level CDC)

“The main reason we fail to track HIV positive people is the social environment. PLHIV have great pressure on them and they don’t want others to know their status” (Staff, District level CDC)

“If people with HIV say it is not convenient for them to meet us, we will ask them to identify a place and we will send staff to go to them to get a blood sample for CD4 testing.” (Follow up service officer, CDC)

“From the first case in 1985 to a total of 200 cases now and the figure becoming bigger year by year, we are really shorthanded for follow up. We only have 4 staff who barely manage to make all the phone calls...If there were measures to attract PLHIV to contact us, that would be really good”(chief of HIV/AIDS Section of a district CDC)

It is not clear from the ARV Free Treatment Manual as to whether it is possible for clients to refuse to accept follow-up services, however the experiences related by both China CDC workers and people living with HIV suggest that participation in such follow-up services provided by the China CDC is considered mandatory.

3.5 Issues of confidentiality during testing, on-line reporting and follow up visits

The management and control approach taken by the China CDC to the HIV epidemic has resulted in a system whereby the confidentiality of information relating to people with HIV is at risk at various points in the system. This may be a result of disclosure by either health workers themselves or due to failures in the systems used to manage the information of people with HIV.

“The workplace organized a medical check-up...I didn’t know HIV was in it...the hospital informed my supervisor when the result came out” (42 years old, male, clerk, Liaoning Province)

“I felt uncomfortable.... The County hospital did a HIV test for me... when the result came out, they informed my boss in the workplace...” (37 years old, male, civil servant)

“I am transparent in my hometown now...when we were in the hospital I felt only my wife and I knew... I don’t know what happened...anyway I feel that all of the people in my hometown know my status now”. (30 years old, male, Henan Province)

In hospitals, interviews with health care workers indicated that doctors, nurses and laboratory staff all have access to information relating to people with HIV. This is of particular concern in small towns where health care workers and patients may be personally known to one another.

“...Doctors or nurses may release the information of infected people in their conversation. This happened in low prevalence areas...” (Staff member, Provincial level CDC)

“The test report will be sent to the ward, doctors and nurses will see it...” (Staff member, District level CDC)

As noted earlier, after testing has been undertaken in hospital settings, the focal point in the hospital is required to report the information relating to the individual who has tested positive to HIV to the China CDC within a short timeframe. The reporting and epidemiological investigation stages of the system create further risks of information disclosure, as identified by health care staff interviewed below.

“The hospital will send us the information collected from the epidemiological investigation and when the fax comes, unconcerned staff may see it” (Staff, District CDC)

“If an epidemiological investigation is conducted in hospital, staff in the departments of health promotion and disease control in the hospital will know” (Staff, District CDC)”

Many people with HIV interviewed during the course of the research described how China CDC staff did not maintain the confidentiality of their personal information in the course of conducting epidemiological investigation or delivering follow-up services.

“The CDC visited my family and informed my neighbors of my HIV status...from then on, my neighbors didn’t come to visit us. They avoid my relatives as much as possible...” (28 years old, male, Hebei Province)

“I was tested in Beijing and then was reported on line. The CDC in my Hukou area went to my family...All of a sudden, the village government, neighbours and my

parents knew my HIV status.” (35 years old, male, Hebei Province)

“I thought I was the only person who knew the result when I was in hospital. I don’t know what happened when the result report went to CDC...My mom called me and asked “Everyone talks about your HIV issue, is it true?” I was shocked. How did people know before I went back?” (26 years old, male, Hubei Province)

“I was confirmed as HIV positive in Shanghai. Half a month later, my brother called me and said that the local CDC had looked for me everywhere and said I was infected by HIV. They even persuaded my brother and sister-in-law to do HIV testing.” (32 years old, male clerk, Hebei Province)

“I have a friend working in a hospital, so with his help, I took a HIV test without registration and found I was positive. The hospital tried hard to find me because they needed to report me to the CDC ... I was so scared of this. My friend in the hospital told me that if they could not find me anymore, he would be fired. This time was so hard for me...Finally, I found a way. I asked another friend to spread the news that I had committed suicide in my hometown... They (the hospital staff) heard of my death and gave up looking for me.”(34 years old, male, clerk)

In addition, during the course of this research, CDC staff advised that when they visited the house of people with HIV, they were aware that sometimes their vehicle, clearly marked with the CDC logo, was parked near the house of the person with HIV. Subsequently this sometimes aroused the curiosity of neighbors and family members and led to the exposure of that person’s HIV status.

As illustrated above, the risk of harm to people living with HIV from health care workers failing to maintain confidentiality is significant and can lead to discrimination and other negative consequences. In addition, the failure to

maintain confidentiality may have other broader impacts, such as increasing the fear of people to utilize VCT services and access HIV treatment when they need to.

“MSM (men who have sex with men) don’t want to come (for VCT). They worry about their privacy” (Staff member, City level CDC)

The China CDC has sought to address the issue of confidentiality by requiring all of its staff members to sign confidentiality agreements. Confidentiality agreements on their own are not considered to be sufficient to ensure that the personal information of people undergoing testing is properly protected.

In addition to the on-line reporting and epidemiological investigation stages, follow-up services are of particular concern in terms of confidentiality, due to the few restrictions placed on health care workers in relation to accessing the large volume of personal information relating to people living with HIV. The system is designed to enable health workers to track and contact clients to ensure follow-up services are delivered in accordance with the China CDC’s management and control approach to the HIV epidemic.

To better understand issues related to confidentiality, the ILO research team conducted in-depth interviews with two county level China CDC staff that were responsible for undertaking follow-up visits with people living with HIV. Both staff interviewed considered that delivering follow-up services was mainly technical work in which protecting individual and public health was of higher priority than protecting the personal information of people with HIV. They also indicated that they thought it was important to provide follow-up services to people with HIV, even when their health was in good condition.

“Follow-up services are irrelevant to any law or right. It is a medical issue. The aim of follow-up services is to monitor PLHIV’s health conditions and ARV treatment compliance.” (Follow up service officer, CDC)

“It is similar for healthy HIV positive people. The disease will develop anyway. Without follow-up services, how does he know his CD4 count? How does he know his liver or kidney functions well?” (Follow up service officer, CDC)

“Privacy protection is important. We know that. We have the infectious disease law and the HIV/AIDS regulation. I cannot see the need to develop a policy or special rule for follow-up services with the aim to protect the rights to privacy” (Follow up service officer, CDC)

Both of the China CDC staff interviewed reported that they were not aware of any cases where the private information of a HIV positive people had been disclosed during the course of their work.

The level of knowledge and awareness of the need to maintain confidentiality among healthcare workers seemed to vary depending on which aspects of HIV services they were involved in, with staff involved in testing generally demonstrating greater knowledge and awareness of the need to maintain confidentiality than those involved in providing follow-up services, who appeared to be less knowledgeable and more resistant to recognizing the rights of people living with HIV to have their personal information kept confidential.

“We have a good sense of how to protect rights to confidentiality. We send staff to pick up the HIV Case Follow-up form from hospitals, just in case private information is released through the post office” (Staff, District CDC)

“Anyone who leaks the private information of people with HIV must be severely punished... Some healthcare workers entertain each other with relevant information and think it is not a big deal... If private information is disclosed, what we can do? Who will be responsible for the bad impact on people with HIV?” (Head of the HIV/AIDS department, District CDC)

During the interviews with people with HIV, while many interviewees complained that China CDC staff had failed to maintain the confidentiality of their personal information, others recounted very positive interactions with China CDC staff. In many cases China CDC staff providing follow-up services had established positive and supportive relationships with their patients.

“Dr. Bao from the CDC encouraged me and watched over my health. I felt hopeless and tried to take my own life three times. Dr. Bao stayed with me every day back then.” (50 years old, male, Shanghai)

“My husband has HIV. He used to be a drug user. The day of our wedding ceremony, our family members were there and CDC staff including the director, doctors from the Treatment Station and others” (35 years old, female, Xinjiang Province)

“(After I was infected with AIDS), the company asked me to go home. At that time, I felt that only the CDC could help me out. The City CDC staff went to my workplace and talked with my employer...They have done a lot of things like this.”(39 years old, female, department manager, Zhejiang)

“The government (CDC) cared about us and helped us a lot, such as arranging for my kids to go to school... They will help whenever they are asked to...”(age unknown, male, migrant worker, Henan)

In addition to the risk of disclosure by health care workers themselves, some aspects of information handling in the HIV diagnosis and treatment process that created risks of disclosure were identified by China CDC staff during the course of interviews and included the following:

- counseling services are sometimes provided in an unsuitable environment, where the result may be overheard or seen by others;
- the result reports are not properly kept and may be seen by others; and
- records are sometimes cast away as waste paper rather than being shredded, thereby risking the privacy of the individual concerned.

While China CDC staff interviewed for this research reported that training workshops on confidentiality are delivered to health care workers on an annual basis, these training workshops appear to focus on physical security procedures such as keeping files secure, closing down computer monitors and providing notification of testing results in a quiet place. They do not include education about the rights of people living with HIV to privacy and the relevant laws, regulations and penalties if an individual's privacy is breached.

“To protect PLHIV’s privacy in hospital, we organize training workshops for health care workers each year and ask them to keep relevant files as well...When we develop the agreement on confidentiality we try our best to include shredding PLHIV printing documents, closing computer monitors when leaving the desk and other details in it. We also highlight these details during training workshops.” (Staff member, District level CDC)

“We organize a training workshop on confidentiality for staff from the Department of Administration and the Department of Nursing once a year. We have

emphasized again and again that they are to blame if a patient's information gets out.” (Head of the HIV/AIDS Department, District CDC)

“...we sign the Agreement on Confidentiality with CDC each year. The information in the on-line reporting cases is requested to be kept confidential too...our computers are not allowed to be used by others in the office. We are also requested to change computer passwords monthly...”(VCT staff, District CDC)

“We are asked to throw printed documents into shredders once the information is put into the reporting system and shutdown the computer when we leave the desk.” (VCT staff, District level CDC)

The current system of managing the personal information of people undergoing HIV testing in China, where many health care workers have access to an individual's personal information with few protections in place, means that in the event that an individual's personal information is released, it is unlikely that the person responsible will be able to identified for the purposes of corrective action. This suggests that the system needs to be improved, not only to prevent breaches of confidentiality from occurring in the first place, but when breaches do occur, there should be a procedure to take corrective action.

3.6 Other countries' experiences in providing HIV services

The experiences of the United States Center for Disease Control (United States CDC) is useful in illustrating how to encourage people to utilize HIV related services without health care providers actively following up each individual with HIV.

The United States CDC does not directly provide health services but develops guidelines and recommendations for HIV testing and treatment based on research and evidence. People seeking to undergo HIV testing attend the same hospitals

and clinics as the general public and as a result, their attendance is not automatically associated with having HIV in the same way that people living with HIV in China attending CDC offices may be. In the United States, where there are strict privacy protocols in place, people with HIV are more willing to attend hospitals and clinics for check-ups and treatment as the risk of their personal information being disclosed is very small.

Like other countries, service providers in the United States have no designated staff to provide services for people who have tested positive to HIV. Despite this, the United States provides high quality HIV related services and while the total number of people living with HIV in the United States has increased with better testing and treatment options, the number of new HIV infections has remained relative stable.^[21] It is estimated by that only one in five people with HIV in the United States do not know their HIV status,^[22] as compared to China, where it is estimated that 56% of all people who are HIV positive are unaware of their status.

In the United States, as in China, not all clients who receive pretest HIV counseling and testing return to receive their test results. According to one study, the return rate ranged from 41% to 86% and varied by age, sex, race and self-reported risk behavior. To improve the return rate, the United States CDC *Technical Guidance on HIV Counseling* suggests that VCT programs should be active in addressing the problem of failure to return for HIV post-testing counseling. They suggested that program managers should determine if specific operational barriers exist that prevent clients from returning for HIV post-test counseling. Program managers were urged to check if the time that the clients waited for testing result was too long, whether the distance between clients' locations and clinics was too far, or whether the language/accents of service providers was not appropriate etc. When less than 50% of high-risk clients are receiving counseling and testing, or when low return rates (e.g. less than 80% for seropositives and less than 60% for high-risk seronegatives) are identified, documented "action steps" must be initiated to determine the reasons for such low

rates and to resolve barriers to clients in accessing services, learning their test results and obtaining counseling and referral services.^[23]

In this way, the United States CDC guides service providers to improve service quality to attract key affected populations including people living with HIV, to utilize services, rather than attempting to contact each HIV positive individual and monitoring them through follow-up services.

3.7 Comparison of China's approach to providing HIV services with international practice

The cases of information disclosure discussed above indicate that the current system of HIV diagnosis and treatment of HIV in CDC offices and hospitals in China lacks sufficient protocols to protect confidentiality. Protecting the personal information of people participating in HIV testing does not appear to be a priority for the CDC, which sees its primary role as providing testing and treatment services to people with HIV for the purpose of epidemic control. This is consistent with the *China CDC Guidelines on HIV Case On-line Reporting* which do not make any reference to issues of confidentiality.

The disease control centered approach taken by China CDC, which involves contacting people who test positive for HIV for the purposes of epidemiological investigation and follow-up visits does not reflect the UNAIDS and WHO recommended approaches that emphasize the need to create an environment in the health system where people are comfortable accessing services on their own initiative.^[24]

Informed consent and confidentiality are core tenets of HIV testing, and on this basis, testing should only be conducted when the client is fully informed about the testing process and makes a decision to undergo testing, especially when testing is undergone in hospitals. In the context of follow-up services provided by the

China CDC, it is unclear whether in consenting to undergo HIV testing, people also give informed consent to receive follow-up services.

Applying the principle of informed consent and giving clients the right to decline testing and associated services would greatly assist to resolve concerns surrounding compulsory testing.

The acknowledgement by some China CDC staff during the research that follow-up services may not be necessary for all people with HIV, and that some of those people may not wish to receive such services suggests that there is a potential for a shift taking place from a purely epidemic control approach to HIV to one that balances the need to collect data with the rights and needs of the individual. This “People Centered Approach” adopted by the United States as well as Australia^[25], Canada^[26] and Europe^[27], in providing HIV services should be taken into consideration as a model for China in delivering HIV testing and treatment.

As noted earlier, China has several laws and policies that recognize the rights of people living with HIV to confidentiality. However, in practice, such provisions have little or no effect in practice, as this report illustrates. Further, the lack of knowledge and awareness about the importance of maintaining confidentiality in HIV testing and other related services demonstrated by the health care workers interviewed in the course of the research suggests inadequacies in the current training programs that are delivered to staff in China CDC offices and hospitals.

4. Recommendations

4.1 Revise relevant policies and guidelines and incorporate rights perspectives into them

The HIV/AIDS Prevention and Control Regulation is an essential legal instrument

for China CDC in their provision of HIV related services. However, since the regulation only provides general principles, it is not very well implemented at the provincial level. Many CDC staff during the research interviews advised that a comprehensive review of the regulation was needed, especially on aspects of rights protection, including rights to privacy.

On this basis, it is recommended that the China State Council HIV and AIDS Committee carry out a joint assessment on the implementation of the HIV/AIDS Prevention and Control Regulation together with the UN Joint Program and people living with HIV. The assessment should identify implementation barriers, and develop detailed guidelines to strengthen rights protections especially rights to confidentiality in the course of HIV related service provision. In addition, an accountability system should be in place for those who violate rights of people with HIV in the guidelines.

Secondly, as discussed above, the documents entitled *China CDC Guidelines on HIV/AIDS Case On-line Reporting*, and *China ARV Free Treatment Manual* are essential to the work of China CDC. They provide guidance to China CDC staff in performing their daily work, such as the collection of personal information from people who test HIV positive, case reporting, epidemiological investigation and follow-up services. Both documents are lacking in their coverage of rights protection, especially in relation to the right of people with HIV to confidentiality.

It is recommended that the China CDC review and revise these two documents to incorporate the right to confidentiality into the new versions, and ensure that they are consistent with the international standards and the WHO/UNAIDS relevant guidelines.

4.2 Develop Guidelines on Protecting the Confidentiality of HIV Information in China's health system

The research shows that the right of people with HIV to confidentiality could be better protected within the current health system, especially in the course of the epidemiological investigation and follow-up services.

To address these issues, guidelines to protect the rights of people with HIV including the right to confidentiality are needed. The China CDC should take the lead to develop such guidelines in full consultation with people living with HIV. The guidelines should clarify the HIV related service procedures and explain how the rights of people with HIV to confidentiality will be protected during testing, epidemiological investigation and follow up services.

These guidelines should be incorporated into existing training programs and delivered to all health care staff in both China CDC offices and hospitals, as well as to people with HIV and other key affected populations.

4.3 Build the capacity of staff in CDCs and hospitals to protect rights of people with HIV to privacy

CDC staff interviewed for this research reported that the current measures in place to address the maintenance of confidentiality consist primarily of training workshops for staff on privacy protection. However, these training workshops focus on details of working procedures such as keeping files secure, closing down computer monitors and providing notification of testing results in a quiet place etc., rather than educating health care workers about the rights of people with HIV to privacy and the relevant laws, regulations and penalties if an individual's privacy is breached. This suggests a need for the content of workshops currently being delivered to be strengthened.

Therefore, it is recommended that China CDC revise the current training programs on privacy protection and strengthen training modules on the rights to confidentiality of people with HIV and other key affected populations. These training programs should be appropriately tailored to the work of staff in the different departments of VCT, epidemiological investigation and follow-up services.

4.4 Strengthen the capacity of legal aid centers

As awareness levels of rights to privacy increase among people with HIV and the general population, there is likely to be a commensurate increase in the number of people seeking legal advice in respect of their rights. Currently, very few legal aid centers in China have the capacity or expertise to provide legal services for people with HIV. In most cases, even where people with HIV are aware of their rights, they are not able to access the legal advice and support they require to ensure that their rights are protected. For this reason, capacity building of public interest lawyers and legal aid centers is urgently needed in China.

5. Conclusion

In China, where many citizens, including government officials, medical staff, CDC employees, and even people with HIV themselves lack awareness of their rights to privacy, people with HIV and other key affected populations face significant challenges in ensuring that their personal information is adequately protected.

The Chinese Government should take further steps to increase the level of protection afforded to the privacy rights of people with HIV and others, not only to comply with their commitments to the international community to protect human rights, but also to achieve the objectives of the Twelfth Five-year Action Plan.

People with HIV and other vulnerable groups expect that the China CDC should have sufficient protections in place to ensure the security of their personal information. To be in a position to do this, the China State Council HIV and AIDS Committee together with the China CDC needs to revise relevant policies and guidelines and incorporate rights perspectives into them; develop guidelines on protecting the confidentiality of HIV information in China's health system; build the capacity of staff in CDC offices and hospitals to protect rights of people with HIV to privacy; and strengthen the capacity of legal aid centers to provide advice to people with HIV on privacy issues.

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