

The China Stigma Index Report



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1. Introduction

This report is based on a survey of the experience of more than 2000 respondents living with HIV in China. The survey will increase the understanding of how stigma and discrimination is experienced by people living with HIV (PLHIV) and it is hoped that the results will inform future discussions, programmes and policies in China.

The China Stigma Index survey was funded by UNAIDS China, with additional resources made available by the Bill and Melinda Gates Foundation. It is based on a methodology developed by the People Living with HIV Stigma Index project, managed by the International Planned Parenthood Federation (IPPF) in partnership with UNAIDS, the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW). The partnership is supporting the roll-out of similar projects all over the world, including training and advocacy efforts in China based on the main findings of this report.

In China, the project is driven by PLHIV, their networks and other key stakeholders including the Institute of Social Development Research of the Chinese Central Party School, the Marie Stopes International project "Positive Talks" and UNAIDS. The benefits of the project go further than collecting much-needed data. The project aims to be a catalyst for change through involving and empowering PLHIV, their networks and communities throughout all stages of the project from design, to implementation, analysis and dissemination of the results.

The information gained will provide data on the current situation and areas requiring future action. These include anti-stigma and anti-discrimination campaigns, improving workplace and education sector policies, informing the formulation of laws relevant to the AIDS response and promoting the realization of human rights. Consequently, the report is an advocacy tool, which will support the collective goal of the Government, the UN, NGOs and community based organisations alike to reduce stigma and discrimination linked to HIV in order to reach the goal of Universal Access to prevention, treatment, care and support, and the Millennium Development Goals (MDGs).

The survey was implemented by members of the Positive Talks project, who are all PLHIV, with the technical support of the Institute of Social Development Research of the Chinese Central Party School and UNAIDS. The data collection emphasized informed consent and confidentiality. The sampling technique was designed to maximize the number of respondents and give a realistic picture of the PLHIV community in China. Current knowledge of the demographic profiles of PLHIV in China based on data from the China Centre for Disease Control (CDC) was used to select respondents in a way that no group would be significantly over- or under-represented as compared to the total population of PLHIV in China. Hence, non-proportional quota sampling was used based on gender, province, residence (urban or rural hukou) and mode of HIV transmission. In total, more than 2000 PLHIV in 25 provinces were interviewed by interviewers who themselves are PLHIV. This approach was chosen to create trust between the interviewee and the interviewer and to increase the likelihood of open and accurate responses.

Despite these measures, the results may not be fully representative of the experiences and opinions of all people living with HIV in China. A large proportion of those living with HIV have not been diagnosed and are not yet aware of their status, and therefore would naturally not be part of the survey. Others may not agree to reveal their HIV status or refuse to be part of the sample. However, these possible biases cannot be overcome through any survey methodology and the results presented in this report may be seen as the most reliable indicators of the current situation in China.

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2. Demographic Information

Information on the age distribution, marital status, levels of education and ethnicity of respondents is given in Table 1.

A total of 2096 people living with HIV participated in the survey. Around two thirds (67.8 percent) of these were male, and around one third (31.9 percent) female. Three respondents identified themselves as transgender people and two respondents chose not to identify their genders. Their responses to other questions have been included in the total column.

Table 1. Demographic Characteristics of Survey Respondents

	Women		Men		Total	
	Number	Percent	Number	Percent	Number	Percent
Age						
0-14	10	1.5	7	0.5	17	0.8
15-19	1	0.2	12	0.9	13	10.6
20-24	26	3.9	79	5.6	106	5.1
25-29	91	13.7	209	14.7	301	14.4
30-39	278	41.7	613	43.2	892	42.7
40-49	191	28.7	382	26.9	573	27.4
50+	69	10.4	117	8.3	187	8.9
Total	666		1419		2089	
Marital Status						
Married/Living together	399	60.6	597	42.3	998	48.1
Married/Cohabiting but partner temporarily living elsewhere	22	3.3	35	2.5	58	2.8
In a relationship but not living together	18	2.7	46	3.3	64	3.1
Single	80	12.1	551	39	633	30.5
Divorced	61	9.3	138	9.8	199	9.6
Widowed	79	12	43	3	122	5.9
Total	659		1410		2074	
Residence						
Urban Hukou	337	51.1	877	62.1	1217	58.6
Rural Hukou	322	48.9	535	37.9	858	41.3
Total	659		1412		2078	
Highest Level of Education						
Primary or Below	174	26.1	230	16.2	404	19.4
Junior Middle	282	42.3	557	39.3	842	40.3
Senior Middle	150	22.5	308	21.7	458	21.9
Diploma	46	6.9	178	12.6	225	10.8
Undergraduate degree	14	2.1	123	8.7	137	6.6
Post-graduate degree	1	0.2	21	1.5	22	1.1
Total	667		1417		2088	
Ethnicity						
Han	579	87.3	1289	90.9	1871	89.7
Other	84	12.7	129	9.1	214	10.3
Total	663		1418		2085	
Total	669	31.9	1422	67.8	2096	

Note: Not all respondents answered each question, therefore the totals are of those that responded and are slightly less than the sample size.

More than half of respondents (58.6 percent) had urban hukou (household registration), and 41.4 percent had rural hukou. It should be noted that hukou status is not always an accurate guide to the actual place of residence of its holder, as many people with rural hukou may migrate to urban areas to work and live. Respondents came from 25 different Chinese provinces, autonomous regions and municipalities. Provinces accounting for more than 5 percent of respondents included Yunnan (14.8 percent), Henan (12.9 percent), Guangdong (8.6 percent), Hunan (7.7 percent), Sichuan (7.0 percent) and Xinjiang (6.8 percent).

In terms of self-identified sexual orientation, the majority of survey respondents were heterosexual. The male sample exhibited a greater degree of variability in terms of sexual orientation, with 18.3 percent of male respondents identifying themselves as homosexual and 9 percent as bisexual.

More than two thirds of respondents (68.3 percent) reported that their likely point of infection was within the past 4 years. More than one fifth (22.9 percent) reported having acquired HIV within the year prior to the survey. Just under 7 percent of respondents said they had been infected more than 10 years ago.

Information on reported transmission modes and employment status of respondents is given in Tables 2 and 3.

Table 2. Reported Modes of HIV Transmission

Mode of Transmission	Women		Men		Total
	Number	Percent	Number	Percent	Percent
Homosexual Transmission	≤1%	≤1%	337	23.8	16.6
Heterosexual Transmission	280	42.0	335	23.6	29.4
Bi-sexual Sexual Activity	8	1.2	82	5.8	4.3
Homosexual Commercial Sex	≤1%	≤1%	32	2.3	1.8
Heterosexual Commercial Sex	30	4.5	66	4.7	4.6
Injecting Drug Use	132	19.8	526	37.1	31.5
Blood Selling	152	22.8	205	14.5	17.2
Blood Transfusion Recipient	117	17.5	138	9.7	12.2
Other	63	9.5	63	4.4	6.0

Note: Some respondents selected multiple categories, this may be because they were unsure of the exact mode of transmission or because they selected both homosexual or heterosexual transmission together homosexual commercial sex or heterosexual commercial sex respectively.

Over a third of respondents reported that their mode of transmission was through injecting drug use. Of all respondents, 18.3 percent selected homosexual transmission and/or homosexual commercial sex as their transmission pathway, while 31.7 percent selected heterosexual transmission and/or heterosexual commercial sex. Among female respondents, heterosexual sex was the main reported mode of transmission, while for men it was injecting drug use.

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Table 3. Respondent Employment Categories

	Number	Percentage
Employment		
Low Skilled Labourer	120	5.8
Farmer	511	24.6
Teacher or Scientist	33	1.6
Commercial or Service Industry Worker	194	9.4
Civil Servant	23	1.1
Medical Worker	12	0.6
Self Employed	135	6.5
Employee of Private or Joint Venture Company	72	3.5
Driver	36	1.7
Retired	40	1.9
Student	37	1.8
Seeking Work	375	18.1
Unemployed	375	18.1
Other	112	5.4

3. Stigma

3.1 Exposure

The greatest fear of people living with HIV was that their HIV status would be exposed without their consent. More than half (57 percent) of respondents worried about their status being revealed by other PLHIV. Almost half (48.6 percent) said that they feared that others, including family members, social workers or NGO employees, might reveal their status. A major concern for respondents was that they might become the victims of gossip if their status was known with 87.3 percent of female respondents and 79.4 percent of respondents overall expressing this concern. More than half of respondents worried about being insulted or threatened, and almost one quarter worried about being physically attacked.

Table 4. Fears and Reactions to Exposure of HIV Status

	Total Percentage	Sample Size
Sources of Pressure and Anxiety		
Having status revealed by other PLHIV	57.0	2065
Having status revealed by family member/social worker	48.6	2058
Do you worry about the following things since you have been infected?		
Being gossiped about	79.4	2067
Being insulted/threatened	52.0	2054
Being harassed/physically threatened	30.8	2037
Being physically attacked	24.2	2032
Withdrawing from educational/training opportunities	26.8	2010
Being sexually rejected	43.8	2036
What would happen/has happened if others knew /know your status?		
I feel hurt	51.8	2052
I regret telling others	52.4	2052
Others avoid having physical contact with me	48.2	2042
People stop calling me	34.0	2034
Others make judgments about my lifestyle	43.0	2030
Others will worry about being alienated because of their connection with me	48.6	2038
They won't allow me near their children	49.4	2031
They distance themselves from me	53.7	2047
I lose friends	50.5	2041
They think of me as immoral	38.0	2027

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Less than two thirds of respondents said that their close family members knew about their HIV status: 63 percent said their parents knew, 61.6 percent said their partners knew (55.9 percent for males and 72.8 percent for females), and 61.2 said their siblings knew about their status (57.3 percent for males and 69.2 percent for females). 49.5 percent of those that reported having children said their children were aware of their HIV status (46.4 percent for males and 53.7 percent for females). Very few respondents said their normal friends or co-workers were aware of their status (11.7 percent and 6.4 percent respectively). These figures are an indication of the gravity of stigma surrounding HIV, with such high proportions of PLHIV feeling unable to tell even those closest to them about their HIV infection.

3.2 Breach of Confidentiality

Of those respondents whose partners were aware of their HIV status, 88.1 percent had told their partners themselves. Of respondents whose other family members knew about their status, 85.8 percent had told them themselves. Of those whose friends and neighbours knew of their status, 47.1 percent had told them themselves.

Worryingly, almost half of respondents (49.8 percent) whose friends or neighbours were aware of their status said that these people had been told about their HIV status by someone else without their consent. A total of 664 people, or 32 percent of all respondents, said that their status had been revealed to others without their permission. What is more, as is discussed in the next section, 15.3 percent of respondents said that a healthcare professional had told other people about their HIV status, without their permission.

These figures demonstrate that confidentiality is a major issue for PLHIV. Moreover in some cases, even healthcare professionals are not respecting the privacy and confidentiality of PLHIV.

3.3 Internalised Stigma

Self-stigma is a common problem for people living with HIV and this was clearly reflected in the survey results. Almost two out of three (62.1 percent) respondents reported that they had felt ashamed and 43.2 percent said they had felt guilty about their HIV status. Almost three quarters blamed themselves (74.5 percent) or had low self esteem (75.4 percent). Over half of women and over 40 percent of men had considered suicide since being infected.

Self stigma had also led respondents to take or avoid taking various types of action. For example, more than half (60.8 percent) of those aged between 15 and 50 said that they had decided not to have children as a result of being HIV positive, 34.7 percent of those of working age had decided to stop working and over 55 percent had chosen not to attend social gatherings (55.4 percent) or had isolated themselves from family and friends (58.1 percent).

3.4 Understanding

Respondents reported that those who were most understanding about their status were PLHIV community partners – friends or colleagues from within the PLHIV community (90.3 percent “understanding” or “very understanding”). Respondents’ spouses/partners and children in their families also showed high levels of understanding, with 69.5 percent and 79.4 percent showing an “understanding” or “very understanding” attitude and reaction respectively. The most negative attitudes and reactions were shown by leaders/bosses (54.8 “discriminatory” or “very discriminatory”), colleagues (50.0 percent “discriminatory” or “very discriminatory”), and customers (also 50.0 percent “discriminatory” or “very discriminatory”). It should be noted that for these last three categories, the number of respondents who said these people were aware of their status was quite low, (124, 216 and 50 people respectively), demonstrating that few respondents were willing to reveal their status to people in these categories. High levels of discrimination among medical staff, government officials and teachers (26 percent, 35.3 percent and 36.2 percent respectively) are of particular concern given that these people occupy important positions of responsibility.

Table 5. Attitudes and Reactions to Exposure of HIV Status

	Very discrim. (%)	Discrim. (%)	No Change (%)	Supportive (%)	Very supportive (%)	Sample Size
Category of Person						
Spouse/Partner	5.3	8.7	16.53	42.53	26.94	1258
Other adult family members	3.7	10.5	17.5	49.4	12.9	1410
Children in the family	2.2	4.7	18.7	51.9	27.5	534
Friends/Neighbours	7.7	35.5	18.5	30.9	7.4	637
Colleagues	14.3	35.7	17.6	26.9	5.6	216
Teachers	15.9	20.3	30.4	21.7	1.2	69
Leaders/Bosses	16.9	37.9	12.9	26.6	5.6	124
Clients	16.0	34.0	20.0	20.0	10.0	50
Drug use partners	1.4	8.6	24.7	56.2	9.2	292
Heads of Community Residence Committees	10.3	20.1	41.3	24.7	3.6	562
Government officials	8.7	26.6	32.3	27.4	4.9	263
Media	5.6	20.4	23.1	40.7	10.2	108
PLHIV community partners	0.8	0.7	8.1	45.7	44.6	1073
Medical staff (not involved with testing)	10.2	15.8	20.0	37.3	15.6	461

4. Testing

4.1 Breach of Confidentiality by Testing Facility

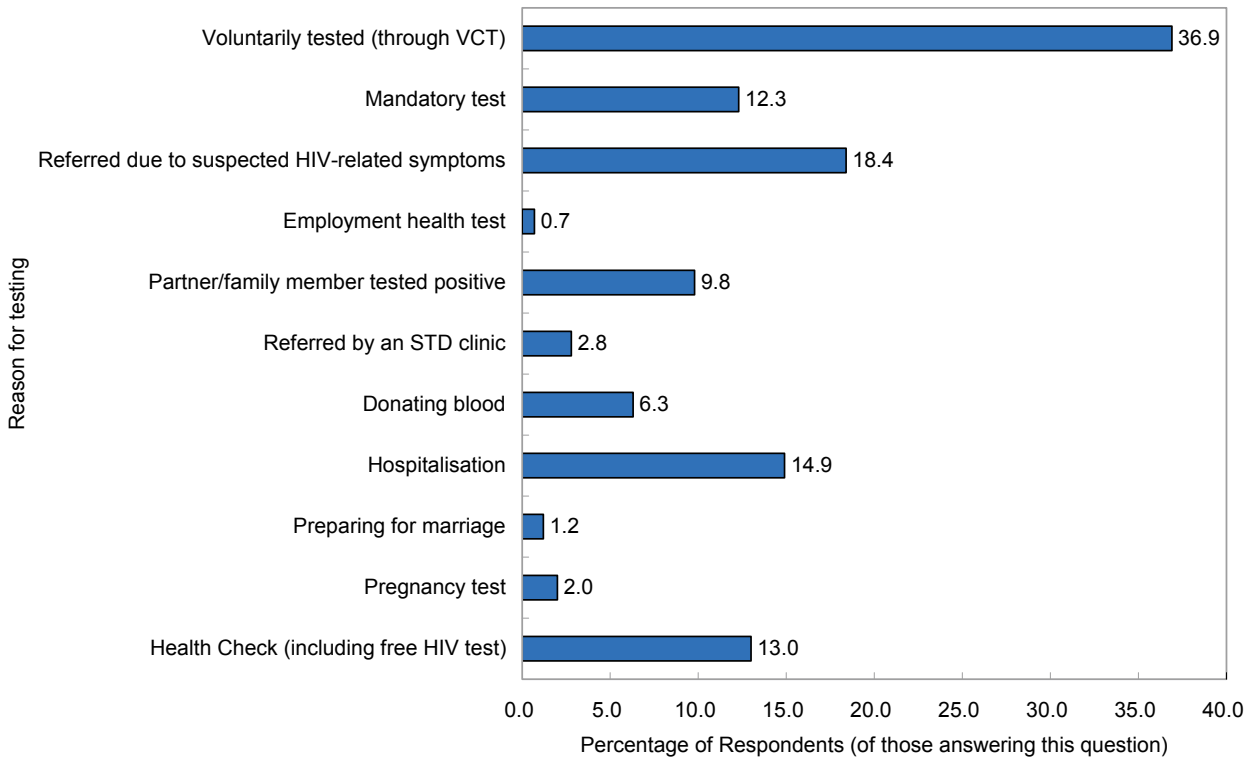
All people living with HIV have the right to privacy and confidentiality regarding their status. The need for strict rules of confidentiality in relation to HIV status derives from the intense atmosphere of fear, misunderstanding and prejudice that characterises many people's attitude to HIV. The consequences of a person's HIV status becoming known can often be disastrous for PLHIV and their families. As is also made evident by this survey, many people living with HIV have lost their jobs and their homes and have been rejected and isolated by family, friends, colleagues and society in general. There is an urgent need to ensure that both policies and practical guidelines are designed to protect the privacy of PLHIV.

In the survey respondents were asked about the confidentiality of their HIV-related medical records. While 40.7 percent were confident that their records were being kept confidential, 10.7 percent of PLHIV felt sure that their records were not kept confidential and 15.3 percent of respondents reported that a healthcare professional had told other people about their status without their permission. While these numbers may seem comparatively low, the implications for the individuals involved are very significant. Such breaches in confidentiality are against certain Chinese policies and international best practice and require urgent action. A lack of confidentiality alienates people and decreases people's confidence and willingness to present themselves to governmental and non-governmental institutions. Furthermore, knowing that medical records are not confidential may deter some from going to medical facilities when they are in need of treatment or care.

4.2 Types of Testing

The questionnaire survey finds that 36.9 percent of respondents were tested through voluntary counselling and testing (VCT). Other reasons for being tested are shown in Chart 1 (total is greater than 100 percent as multiple answers were allowed).

Chart 1. Reason for being Tested for HIV



Note: Multiple responses were permitted

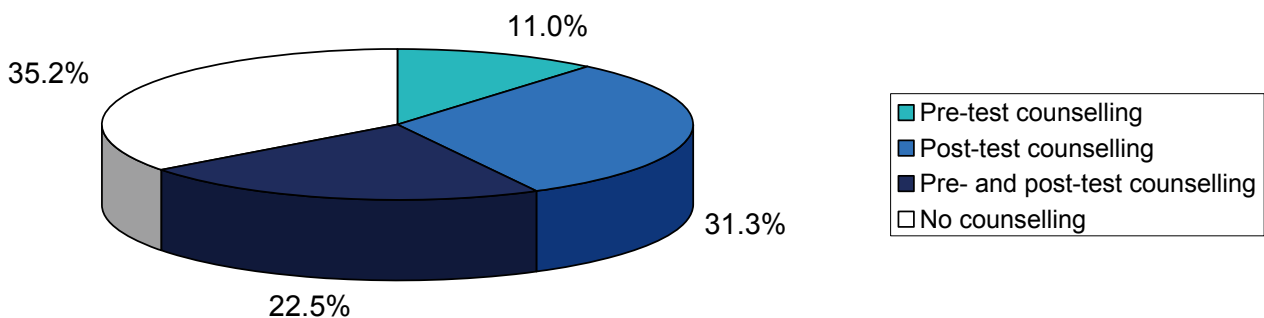
Many respondents were tested for HIV as part of some form of mandatory check including tests carried out at the time of hospitalization. Over one fifth (20.4 percent) of respondents reported that they were forced to take an HIV test during a medical examination.

Apart from voluntary testing, the most common reason for being tested was because the respondent had displayed symptoms of HIV infection. This may suggest that a relatively high proportion of respondents were tested positive relatively late after being infected, as HIV is generally asymptomatic during the earlier stages of the infection. Testing and counselling early during HIV infection is critical and means that people can ensure that PLHIV receive treatment at the appropriate time and that they take precautions with their partners to prevent transmission of HIV. Given the importance of knowing one’s HIV status, the proportion of those who were tested voluntarily is relatively low. Experience shows that ensuring testing is confidential and accompanied by high quality counselling is an effective means to increase the number of people who go for voluntary counselling and testing.

5. Counselling

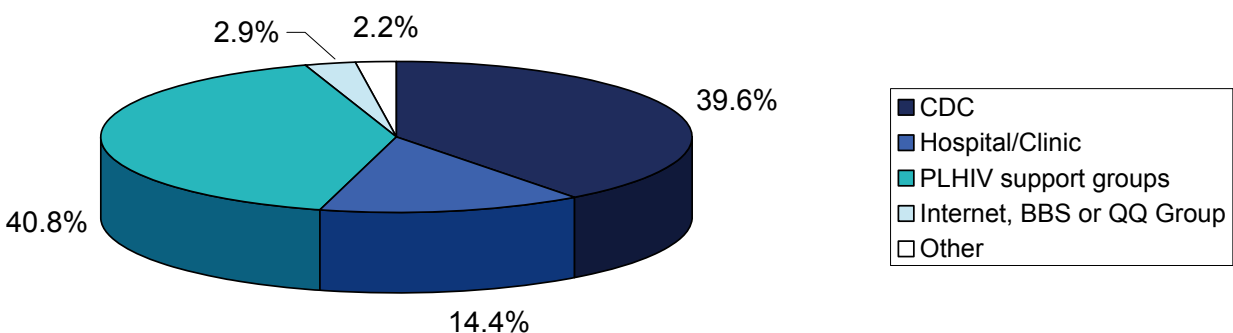
HIV counselling is important in efforts to curb the further spread of HIV. Research has shown that undergoing a test with proper counselling increases the likelihood of behaviour change and reduces the risk of HIV transmission, both for those who are HIV positive and those who are HIV negative. Post-test counselling is particularly important for those who are living with HIV and who have to deal with the multiple levels of stress and fear associated with testing positive. People living with HIV should have easy access to voluntary and free counselling to ensure that they are informed of the consequences of HIV infection for themselves, in particular in relation to treatment and the risks for their partners. Rates of counselling among respondents were alarmingly low. More than one third (35.3 percent) of respondents received no counselling of any sort, 11.0 percent received pre-test counselling only, 31.3 percent received only post-test counselling. Only 22.5 percent of respondents received both pre- and post-test counselling (see chart 2). This situation must be addressed urgently.

Chart 2. Forms of Counselling Received by PLHIV Respondents



People getting tested, including people living with HIV, should have easy access to counselling. Of the 1004 respondents who said they had sought counselling, nearly three quarters did so through the CDC. Around one third of respondents sought counselling from hospitals or clinics. PLHIV groups also played an important role in providing counselling to survey respondents. Respondents were also asked to state which of the organisations or institutions providing counselling they had found the most helpful.

Chart 3. Respondents' Opinions on Most Helpful Sources of Counselling



Of those respondents who had sought counselling, 39.6 percent said that the CDC was the most useful source of counselling. With 40.8 percent, PLHIV groups served as the most useful source of counselling for survey respondents. However, due to the sampling methodology, the respondents included in the survey may be more likely to have contact with PLHIV groups than the overall population of PLHIV in China.

6. Discrimination

6.1 Medical and Reproductive Health

Of the total sample, 41.7 percent of respondents report having faced some type of HIV-related discrimination. The survey showed that 12.1 percent of respondents had been refused medical care at least once since they were tested positive. Although the majority of respondents received medical and health services, there are still medical staff who are discriminating against PLHIV. Stigma and discrimination originating from medical staff constitutes a significant obstacle to HIV prevention and treatment efforts as it may discourage people from being tested or obtaining treatment.

Of the respondents, 24 (1.3 percent) reported having been denied antiretroviral treatment (ART) on at least one occasion since being diagnosed with HIV. However, 50 percent of these respondents (12) said they were now on anti-retroviral treatment, 20.8 percent (5) had not yet met the criteria, and would from a medical point of view not need anti-retroviral treatments. The remaining 7 respondents were not on anti-retroviral treatment. 32 respondents (1.7 percent) said they had been refused family planning services and 28 respondents (1.5 percent) had been refused reproductive health services since being diagnosed HIV positive. Of those who responded to this specific question, 16.6 percent had been recommended by a health professional not to have children (165 respondents out of 996, 76 females, 89 males) and 21 (2.2 percent) of 962 who responded had been pressurised into undergoing sterilization by a healthcare professional.

Of female respondents who were married or who had had sexual partners since being infected, 11.9 percent (44 of 369 responding to this question) had been pressurised into terminating a pregnancy by medical staff/family planning department staff.

6.2 School, Work and Housing

As a very strong expression of stigma and discrimination, a significant proportion of PLHIV reported having lost their job, having been forced to leave school or move out of their home or even having found that their family members experienced discrimination in various forms, as a result of their HIV status. Since being diagnosed with HIV 277 respondents (14.8 percent of a total of 1877 respondents) said they had been refused employment or a work opportunity because of their HIV status (16.3 percent for men and 13 percent for women). Another 305 (16.8 percent) reported that their job or nature of work changed and 70 respondents (3.8 percent) said they had been denied a promotion because of their HIV status. These figures show that employment-related discrimination exists in China. More needs to be done, especially in terms of implementation of existing policies and laws to prevent stigma and discrimination against PLHIV in the workplace.

Of the 740 respondents that had ever been made unemployed or had lost income because of their HIV status, 22.4 percent said this was because of discrimination by employers/co-workers, 43.1 percent said it was a result of a deterioration in their health, 16.2 percent said it was both because of discrimination and because of poor health, and 23.9 percent said that it was because they had chosen to leave the job. Over a third of those that reported being unemployed or losing their income because of HIV related discrimination were self-employed or farmers.

Of the 449 respondents who had been forced to change their jobs or denied promotions because of their HIV status, 24.1 percent said this was because of discrimination by employers/co-workers, 19.3 percent said it was due to deterioration in their health, 11.4 percent said it was both because of discrimination and because of poor health, and 33.4 percent said it was their own choice to leave the job. Despite existing policies protecting employees against discrimination in the workplace, this survey shows that such discrimination is widespread.

Respondents reported having experienced discrimination not only in the workplace but also in terms of education, although to a much lesser degree than workplace discrimination. The survey sample did not include enough

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students to analyze discrimination of PLHIV in schools directly. However, 9.1 percent of those with children said that their children, although not necessarily HIV positive themselves, had been forced to leave school because of the HIV status of their parents.

Of the 113 respondents aged under 25, who would be most likely to be in education, 6.2 percent said they had been forced to leave school on at least one occasion as a result of their HIV status. As noted above, 36.2 percent of respondents said that teachers had shown a “discriminatory” or “very discriminatory” attitude on learning of their HIV status.

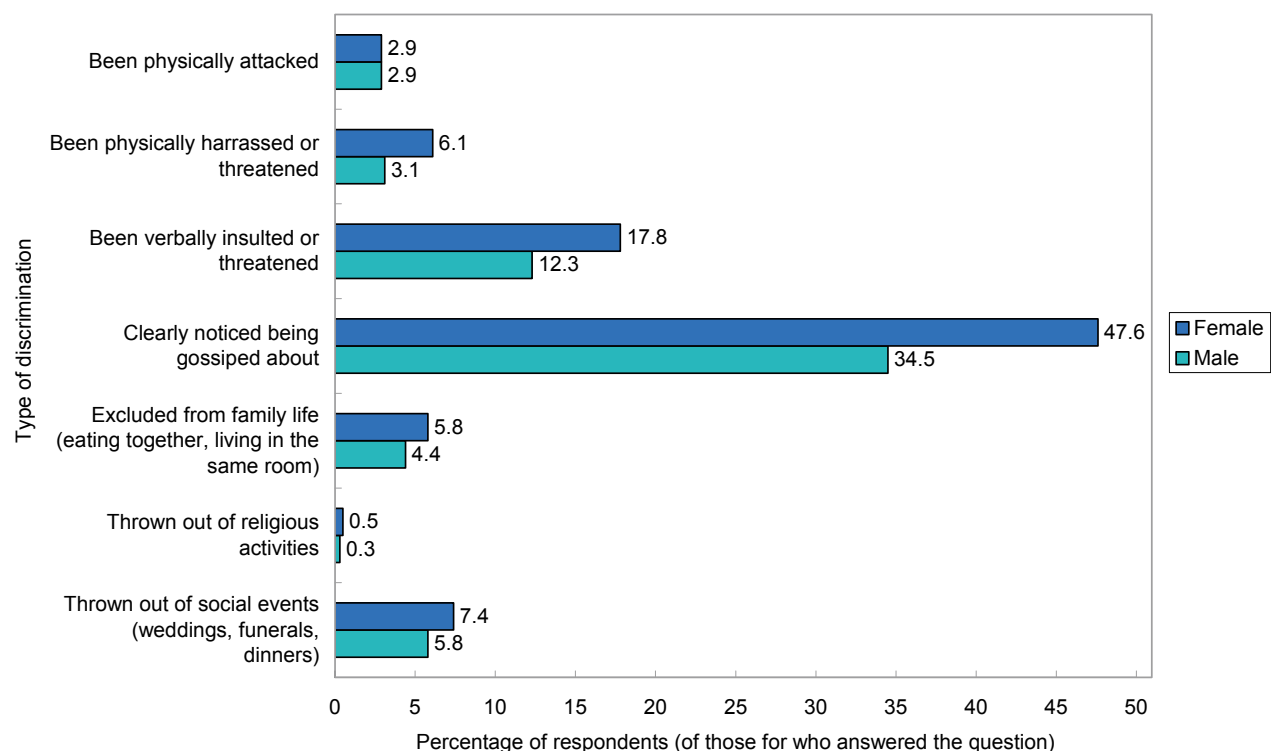
Of the 1892 respondents who responded to the question on accommodation, 7.1 percent (134 respondents) had, on at least one occasion since being diagnosed with HIV, been forced to move residence or had been unable to find accommodation because of their HIV status.

These figures show that discrimination in vital areas such as employment, education and housing is significant. Work related discrimination is the most prominent type of discrimination experienced by PLHIV. However, these situations are difficult to compare as, for example, it might be more common for people at the workplace to be aware of a respondent’s HIV status than it would be for a landlord.

6.3 Passive and Physical Harassment of PLHIV and their Family Members

Discrimination and stigma are also experienced outside of employment or educational settings. Chart 4 shows some of the types of discrimination that PLHIV respondents had experienced since being diagnosed with HIV.

Chart 4: Types of Discrimination Experienced by PLHIV Respondents Since Being Diagnosed with HIV

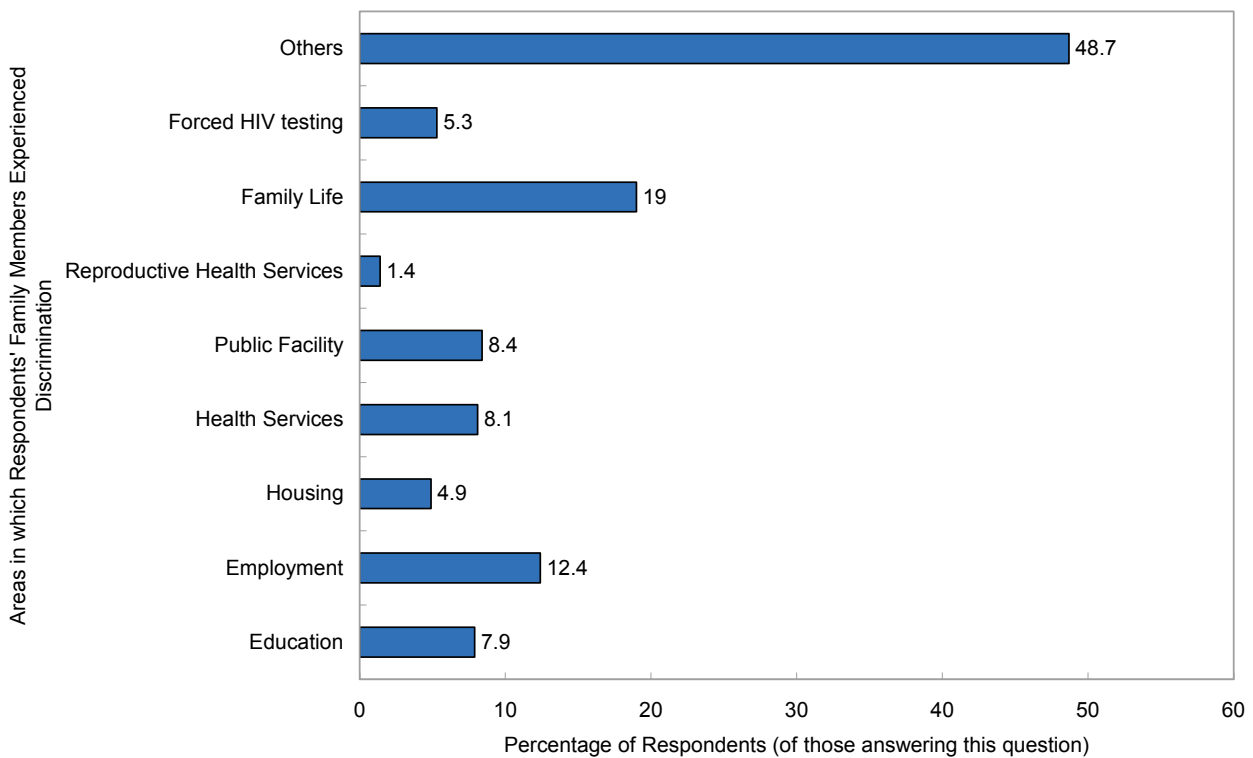


While not many respondents had experienced actual physical attacks, many had noticed others gossiping about them, a clear form of social discrimination. Almost one in five had been verbally insulted or threatened, clearly demonstrating the lack of acceptance of people living with HIV by mainstream society.

Women suffered from discrimination more often than men. For example, 725 respondents (38.8 percent) had been aware of being gossiped about at least on one occasion because of their HIV status. The proportions were 34.5 percent for men and 47.6 percent for women.

Of all survey respondents, more than 76 percent said that their family members had experienced discrimination as a result of their HIV status. Chart 5 shows the types of discrimination that family members of PLHIV may face.

Chart 5. Areas in which Respondents' Family Members Experienced Discrimination



The fact that not only people living with HIV, but also their family members, experience discrimination relating to HIV shows the high level of discrimination surrounding HIV. Approximately 1 in 8 respondents said their family members had experienced employment-related discrimination as a result of their HIV status. Approximately 1 in 5 respondents said their family members had experienced discrimination in their family lives.

6.4 Violation of Rights

Rights violations may occur in many ways, especially among marginalized populations, who are often less protected and less empowered in society. Discrimination and rights violations experienced by respondents because of their HIV positive status were noticeable and distinctive. Of the 1707 people who answered the question, more than 20 percent had experienced violations of their individual rights since being diagnosed with HIV, as a result of their HIV status. Respondents were subjected to a range of rights violations since being diagnosed with HIV, as shown in Table 6. In general, the proportion of women who had experienced rights violations was higher than the proportion for men.

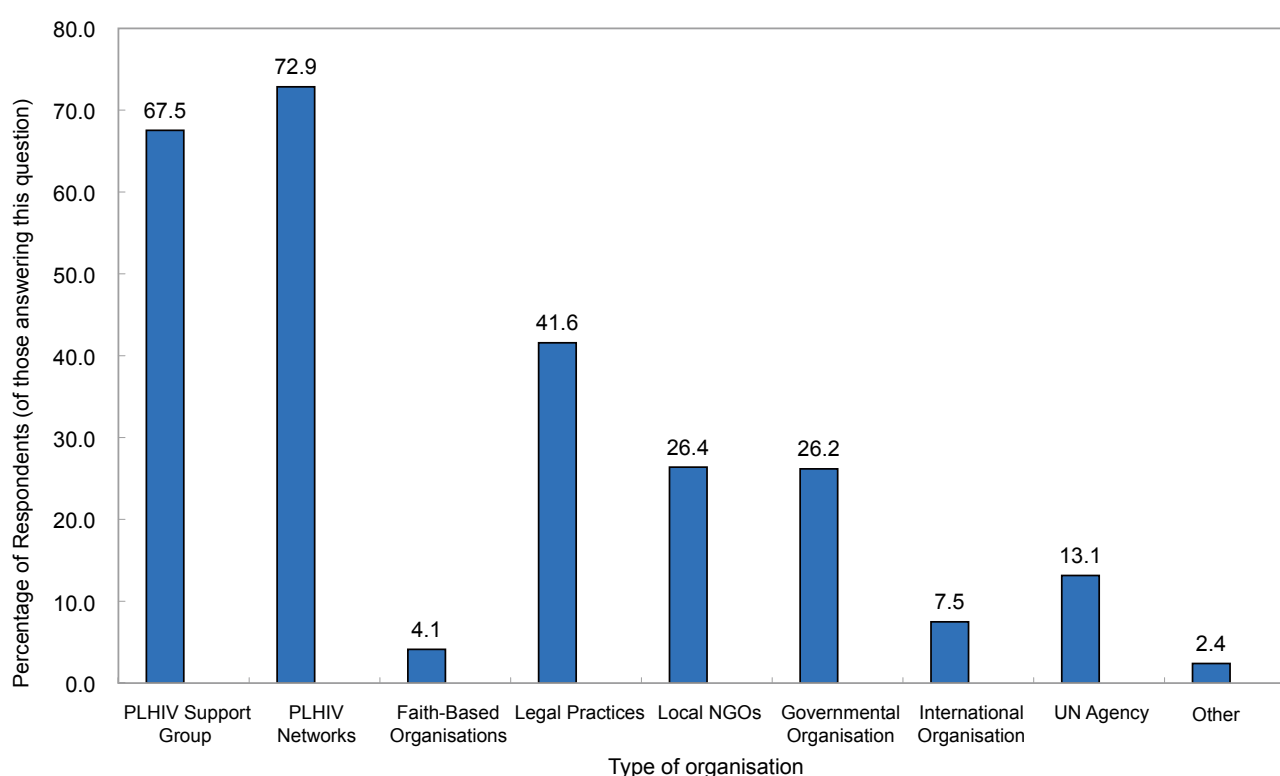
Table 6. Types of Rights Violations Experienced by Respondents

Situation	Male	Female	Total	Sample Size
Forced to submit medical / health report	11.3	11.7	11.5	2022
Forced to take HIV test during a medical examination	20.0	21.2	20.4	2030
Detained, quarantined or ostracised	5.9	7.1	6.3	2028
Denied health / life insurance	10.9	15	12.2	2028
Been refused an insurance payout	7.9	11.5	9.1	2022
Governmental department compulsory disinfection of home	1.7	2.0	1.8	2021
Denied entrance into another country	3.4	2.4	3.1	1998

Some 37 respondents even reported having their homes disinfected by government officials because of their HIV status. While this number may appear low, it is worrying that such serious violations of the human rights of PLHIV are occurring. More than one in five respondents said they were forced to take an HIV test during a medical examination. In many cases it may make good sense to ask a person seeking health services to take an HIV test. However, this should only happen with proper consent and quality counselling.

It is important for PLHIV to know who they can turn to for support in addressing discrimination and taking action against those that violate their rights. Chart 6 shows different organisations and institutions that are able to help PLHIV when they face discrimination and the extent to which respondents were aware of these organisations. PLHIV support groups and networks were the most well recognised groups. Government and other agencies should continue to support PLHIV groups as they constitute a very important source of support for PLHIV.

Chart 6. Types of Organisation Known by Respondents to be Sources of Help when they Experience Discrimination



Of the respondents who had experienced rights violations, 110 respondents (31.2 percent) had tried to seek redress. Of those that chose not to take any action against a violation of their rights, the primary reason given was a lack of faith in the possibility of success.

This lack of faith in the possibility of success seems to be based on a solid reality: of those that had sought redress for a violation of their rights, only 19.8 percent had been successful in their action, while for 68.3 percent the matter had still not been resolved. 37.8 percent of people who had had their rights violated had sought help from government employees to obtain redress. Of those people, 15.8 percent had had the matter resolved.

6.5 Health and Treatment

Antiretroviral treatment results in improvements in the general health and quality of life of PLHIV. Increased coverage of ART has led to a large reduction in HIV-associated morbidity and mortality globally. In this survey 62.9 percent of respondents said they were currently on antiretroviral treatment (females, 68.6 percent, males, 60.2 percent). Of those that are not currently receiving ART 78.6 percent say this is because they do not need them yet (have not yet met criteria to require treatment, which in China is a CD4 count of 350). Also encouraging was that of the 770 respondents who were currently not on antiretroviral treatment, 77.5 percent (597 people) were confident that when they needed antiretroviral in the future it would be easily and readily available to them and 97.7 percent said that it would be available to them free of charge. Of concern is the 2.9 percent of respondents not currently taking antiretroviral treatment citing cost as the reason.

Among the respondents 56 percent were currently taking some form of medication to prevent or treat opportunistic infections. Of those who took medication for opportunistic infections, 18.4 percent said they were receiving this completely free of charge, 34.2 percent had to pay for part of the costs and 47.5 percent said they were meeting the whole cost themselves. Of those that are not taking medication for opportunistic infections, 47.7 percent were confident that they would have access to such medication if the need arose.

Of the 171 female respondents who were HIV positive at the time of their pregnancy, only 40 people (23.4 percent) received antiretroviral treatment to prevent mother to child transmission. Others who were not taking antiretroviral treatment while pregnant (131) cited the following reasons for not having received this type of treatment: did not know that this type of treatment existed (20 respondents, 15.3 percent), refused treatment (4 respondents), physically unable to stand this type of treatment (3 respondents), no money to pay for treatment (3 respondents), did not know about HIV infection at time of pregnancy (92 people, 53.8 percent), could not find institution which could provide treatment (9 people, 6.9 percent).

Coverage of antiretroviral treatment is high among the people participating in the survey and almost 80 percent of those not receiving treatment were confident that they could access treatment when needed. This is encouraging. This should however not be extended to the whole population of people living with HIV as a large proportion are not in contact with the CDC, the health care system or other potential support organisations. Also, there seem to be significant problems with antiretroviral treatment to prevent mother to child transmission (MTCT) and coverage is low. This requires urgent action from the health sector, from support organisations, and from people living with HIV themselves.

7. Conclusion

The China Stigma Index survey is the first of its kind in China and among the first in the world. While technical support was provided by professionals, the data collection was carried out by people living with HIV. The methodology used means that it is not possible to extrapolate all results and conclusions to the whole population of people living with HIV in China. It does, however, give some very strong indications on existing problems that urgently need to be addressed.

First of all, stigma and discrimination experienced by people living with HIV is severe and most PLHIV try to protect themselves by not disclosing their status to people outside their immediate social circle. Unfortunately a large proportion of PLHIV experience problems with others revealing their status.

One third of all respondents said that their status had been revealed to others without their permission. Almost half of respondents whose friends or neighbours were aware of their status said that these people had been told about their HIV status by someone else without their consent. Nearly one sixth said that a healthcare professional had told other people about their HIV status, without their permission. This is obviously a violation of the rights of people living with HIV. Breaches in confidentiality are against policy in China and international best practice. Once a person's status is revealed, the attitudes of key people around them often change. Of concern is that a substantial proportion of medical staff (26.0 percent), government officials (35.3 percent) and teachers (36.2 percent) showed a "discriminatory" or "very discriminatory" attitude after learning of a person's HIV positive status. The situation requires urgent action. A lack of confidentiality decreases people's trust in the systems that are supposed to provide support and services. People do not get tested, do not get the information needed for prevention, care and support and some of those who need treatment do not get it in time.

Rates of counselling among respondents were alarmingly low. More than one third received no counselling of any sort, one tenth received pre-test counselling only, a third received only post-test counselling. Only slightly more than one fifth of respondents received both pre- and post-test counselling. People living with HIV and their families should have easy access to voluntary and free counselling to ensure that they are informed of the consequences of HIV infection including in relation to treatment and the risks for their partners. The results showed that both the CDC and PLHIV support groups played an important role with regard to provision of counseling. Over 80 percent of respondents who had sought counselling did so from one of these two organisations. PLHIV support groups often constitute a first point of contact, and a key source of information for those who have just been diagnosed with HIV and for those who are considering being tested. They are often able to work with and provide services to vulnerable and marginalized populations, which government may find hard to reach, and thus can play a critical role in stopping the spread of HIV among key populations.

More than forty percent reported having faced HIV-related discrimination. More than two thirds of all survey respondents said that their family members had experienced discrimination as a result of their HIV status. Since being diagnosed with HIV nearly one in six said they had been refused employment or a work opportunity because of their HIV status. Of those respondents with children, almost one tenth (9.1 percent) said that their children, who were not necessarily HIV positive themselves, had been forced to leave school because of the HIV status of their parents. Institutionalised discrimination of this kind is of great concern. This is also illustrated by the fact that 36.2 percent of respondents who had revealed their HIV status to teachers said that teachers had shown a "discriminatory" or "very discriminatory" attitude on learning of their HIV status.

More than 12 percent had been refused medical care at least once since they were tested positive. Often PLHIV are unable to obtain treatment at mainstream hospitals, and only have the option of going to the few existing hospitals with designated HIV departments. Even in these specialised centres, however, it is often difficult to obtain various specialist treatments and types of surgery.

In terms of reproductive rights, the survey also showed that more than 10 percent of female respondents (who answered the corresponding question) had been pressurised into terminating a pregnancy by health staff. Also, there seem to be significant problems with antiretroviral treatment to prevent mother to child transmission (PMTCT) and coverage is low. Less than a quarter of respondents who were HIV positive at the time of their pregnancy were able to obtain this type of treatment, which can significantly reduce the chances of them passing the virus on to their baby. Awareness and coverage of PMTCT needs strong attention in the health sector, among support organisations and people living with HIV themselves. These findings reflect a lack of understanding and training among medical personnel.

Almost 80 percent of those not in treatment were confident that they could access treatment when needed. This is encouraging. However it should not be understood as representative of the whole population of people living with HIV as a large proportion is not in contact with the CDC, the health care system or other potential support organisations.

The findings show that much more needs to be done, especially in terms of implementation of existing policies and laws to prevent stigma and discrimination against PLHIV and their family members in the workplace, the educational and health care system. It also underscores the importance of ensuring that health care professionals receive appropriate training to reduce stigma and discrimination and increase ability to provide appropriate services to people living with HIV.

Many of the respondents knew who they could turn to for support in addressing discrimination and taking action against those that violate their rights. PLHIV support groups and networks were the most well recognised groups. Unfortunately, the success rate when addressing problems encountered is very low.

It is important to note that the capacity of PLHIV support groups is limited. Further support and capacity building is critical in the full scale-up of the response to AIDS in China.

Very important progress has been made in the national response to AIDS in China in the last decade. This survey indicates that much work remains to be done in particular in addressing stigma and discrimination. Without addressing the high levels of stigma and discrimination it will not be possible to succeed in the fight against AIDS.