

Supporting for HIV-Positive People



PLACE Tokyo (Non-profit Organization)
<http://www.ptokyo.org/>

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Activities of PLACE Tokyo 2015

Preventive awareness

Running a part of Tokyo HIV/AIDS Hotline by TMG
Hotline calls for gay/straight people Total 2,873 calls/year
Running websites / Making brochures

Direct Support

Peer meetings for HIV-positive , families, and partners: 1,166 times, Sending Buddy program (21 people used)
Face-to-face / telephone counseling services
Total 2,807 cases / year

Research / Training

Sending teachers/speakers
Planning & operating training
JICA/Local governments/Companies
Health and Labour Sciences Research, Independent research

217 Volunteers (As of the end of March 2015)
[Female-male ratio: 50/50 Few un-identified]

9 Staff members

[2 Full-time, 6 Part-time members (Including 1 Accountant), 1 Pro-bono staff]

HIV/AIDS telephone consultation- we hear the uneasiness that you can not talk about elsewhere.

A support service for pre/post-testing

- Consultation before testing (sex activities, test schedule)
- Support after testing (understanding the result and future action)
- Mental support for pre/post-testing
(Supporting individuals to face negative image of internal disease)
- Tokyo HIV/AIDS telephone consultation
- PLACE TOKYO HIV/AIDS telephone consultation
- For gay by gay HIV/AIDS telephone consultation



Contracted to create a booklet “Tanpopo” published by Tokyo Metropolitan Government

<http://www.fukushihoken.metro.tokyo.jp/iryō/kohō/kansen.files/tanpopo.pdf>

The guidebook for people who were recently found to be HIV positive that PLACE Tokyo helped to create. Distributed at Public health centers, Testing office, and other medical institutions. A PDF version is also available online and publicly accessible. It is not for a workplace but can be used to spread understandings on HIV/AIDS.

- 1) If the HIV test result is positive.
- 2) What is AIDS?
- 3) Going to a Hospital
- 4) To lead a decent and fulfilling life.
- 5) For healthy and safe sex life
- 6) Telling others for yourself. To whom and How much?
- 7) Privacy
- 8) Useful Information on welfare and services
- 9) The list of consultation Services

Written and edited by Non-profit organizations, HIV-positive people, and local government officers in charge.
Containing the voices of many HIV-positive people.

★Tokyo edition, Kansai edition, Aichi edition, Kanagawa edition, Akita edition (coming soon)



Contracted project by the Ministry of Health, Labour and Welfare

PLACE Tokyo Positive Line

Started in June, 2009

telephone consultaion for HIV positive people, their partners/families



Monday - Saturday 1pm - 8pm

0120-02-8341

*Accessible by cellphones and PHS in addition to the land lines

Consultation in foreign languages
(Available using the phone numbers via 3 organizations)

- CRIATIVOS
- Portuguese, Spanish, English, Japanese
- SHARE
- Thai, English, Japanese
- CHARM (Own business since 2012)
- Thai, Filipino, Spanish, Portuguese
English, Japanese



Consulting Topics for HIV-positive people and their partners/families/friends (Not mutually exclusive) in FA2015

Regarding mental health	939
Advise on daily life.....	823
Communication such as contacts.....	631
Regarding interaction with others.....	464
Advice regarding the support system.....	301
Disease, change of the clinical condition and medicines	289
Regarding the medical system and visiting hospital	204
Regarding testing and disclosure	45
Vague anxiety just after diagnosis.....	143
Accessing support system/resources other than medical institutions ...	20
From people who partners/families and others.....	257
From outside expertise for consulting or partnerships	75

Buddy (Volunteer) Placement

Clients' (users') status As of January, 2011

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Needs	Conversations	Conversation	Going out	Conversation	Conversation	Hospital visit	Conversation/Shopping	Conversation/Shopping	Conversation	Conversation	Going out	Conversation	Going out	Conversation
Placement	House	House	House	House	Hospital room	House	House	House	House	House	House	Hospital room	House	House
Other people in household	Single	Single	Single	Brother (Mother)	Single	Single	Single	Single	Mother	Single	Parents	Single (Partner)	Brother	Single
Remark	Tumor / Hikikomori	Hikikomori	Tumor / Hemiplegia	General paralysis	Hemiplegia	Hemiplegia	Defect in vision	Defect in vision	Hemiplegia / Mental illness	Hemiplegia	Hemiplegia	Mental (illness)	Hemiplegia / Mental illness	Mental illness

★The service is sending volunteers who received training to clients. The priority is that they use the public service. Volunteers are additional options.

NEST Program

Interaction Program for HIV-positive people & partners/families(2015)

Total: 1,166 cases

⇒ To participate, it is necessary to accept the ground rule and complete a user registration.

⇒ Created the program to respond to the highly-requested needs addressed by interviews and counseling

Programs for HIV-positive people

- Peer Group Meeting (PGM) for newly diagnosed HIV-positive people
 - Within 6 months after being diagnosed
- Woman's Salon – HIV-positive women
- Networking meetings for heterosexuals
- meeting for over the 40s /10s ~ 30s HIV-positive men
- Introduction to Stress Management/Assertive Communication
- Basic class “Social Welfare System”
- Seminars for HIV-positive people by specialists
Lawyers, pharmacists, doctors, life, insurance, employment
- **Meeting to report job hunting experiences**
(General/physically challenged people)
- **Talk Salon: People who work in the nursing care such as nurses**

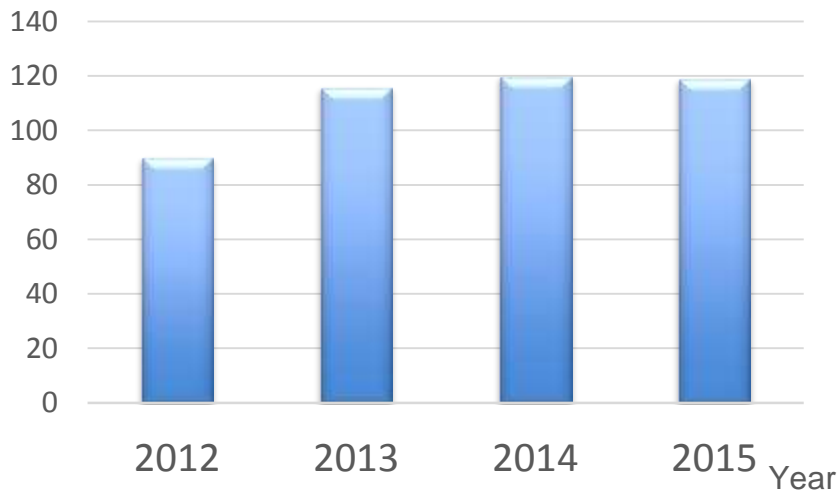
Programs for the partners/families

- HIV-negative partner meetings
- Momen no Kai
 - Society of mothers supporting HIV/AIDS
- Networking event for couples
 - (+/-)(+/-) couple

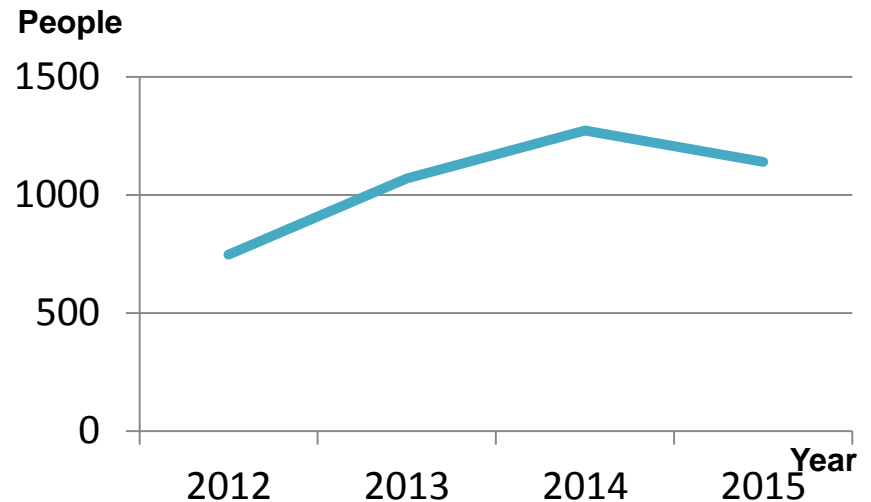
Note: Users are mainly gay, so there is no special group

NEST Program

* The number of the NEST Programs being held

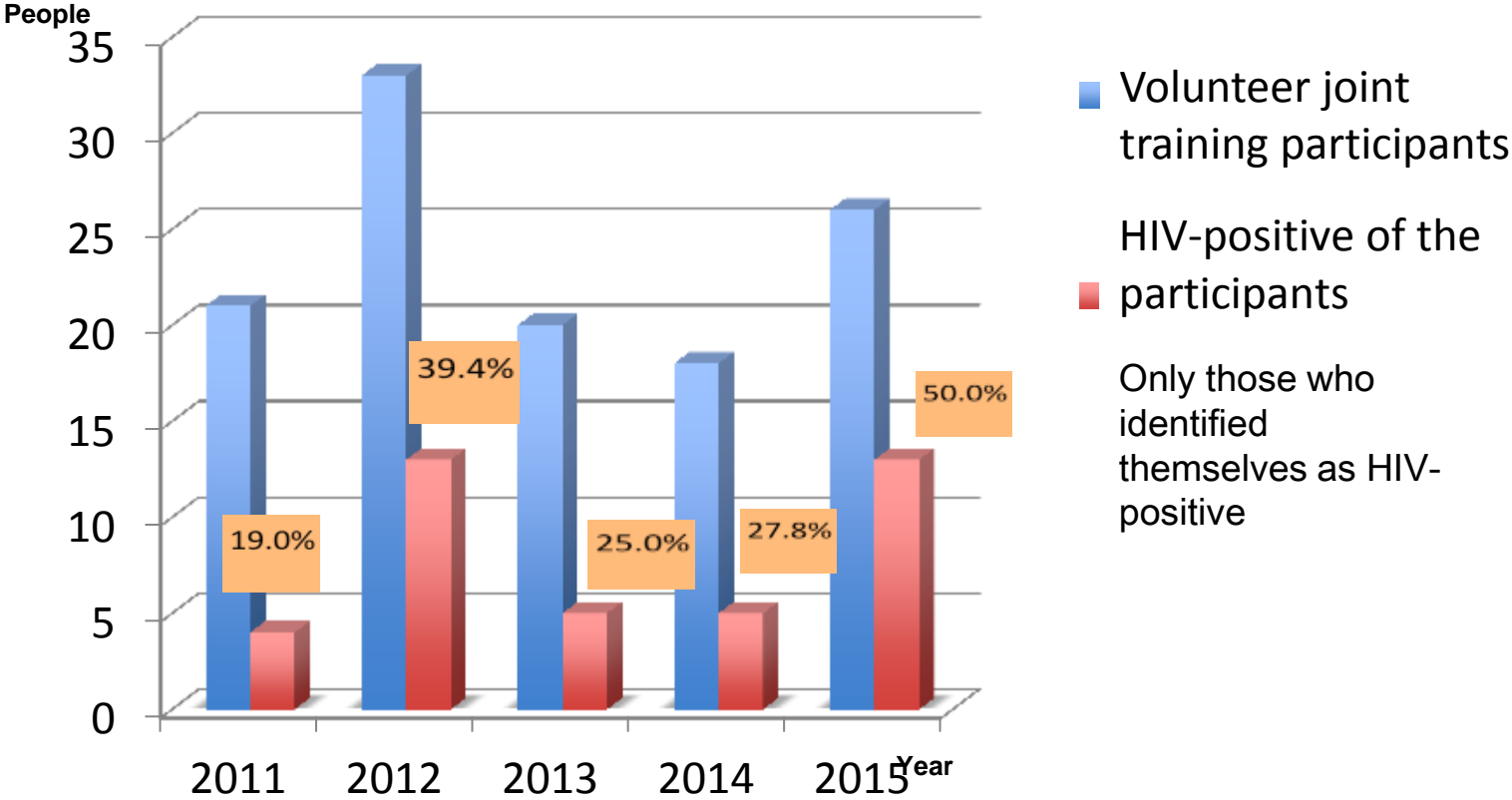


* The number of people who attended the Nest Program



- Targeting to have more than 1000 participants each year
- Increasing number of program

Background of volunteer training participants



Former service users became volunteers.



Some staff members and supporters

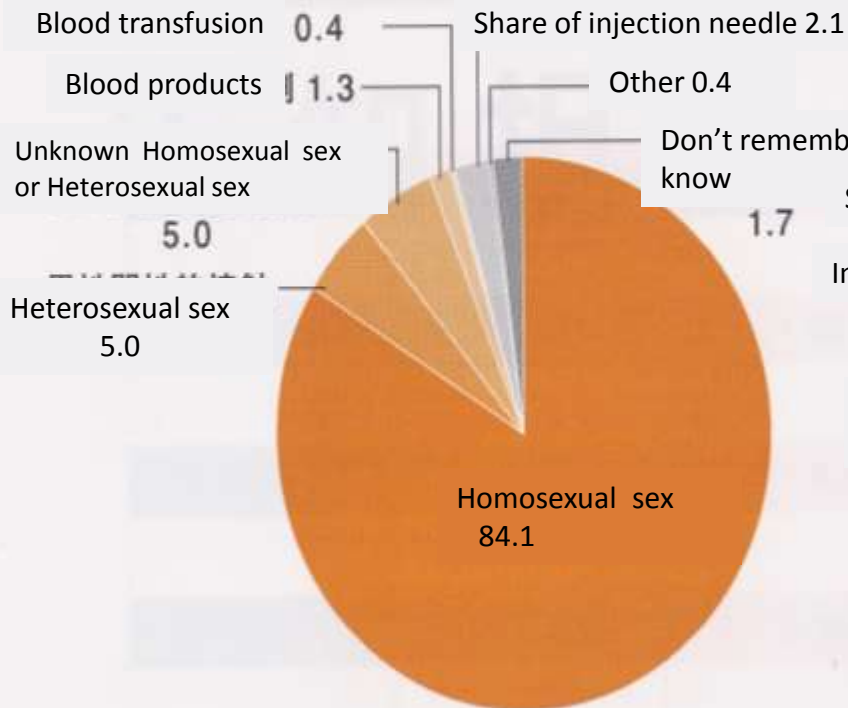
PLACE

Positive Living And Community Empowerment TOKYO

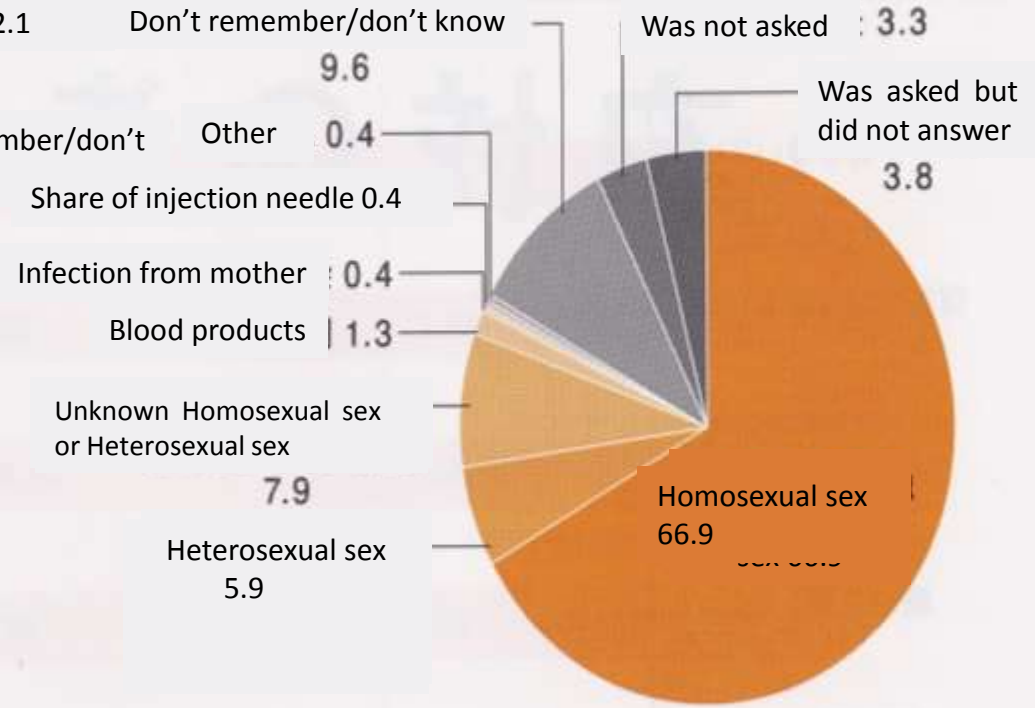
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“Test / Disclosure, 239 HIV-positive People have experienced” 2011 PLACE Tokyo , JaNP +

What do you think is the cause HIV-infected?
(%)



How did you answer when you were asked about your HIV-infected route? (%)



From the “Research on Life and Participation in Society of HIV-positive People”

- The total of 9 hospitals including the main block hospitals in 8 regions in Japan and the National Center for Global Health and Medicine, participated the survey. The number of surveyed patients accounts for the 40 percent of HIV-positive people who visit each hospital, and for 2 hospitals, we decreased the rate of extraction considering their operation.
- Distributed 1,786 survey forms in total, and received **1,100 answers** (61.6%). The forms are distributed from the medical personnel, anonymously filled by patients and then collected by mail. The survey period was from July to December 2013.

There was another survey targeted to the main core hospitals conducted at the same time. Here, we only present the data from the hospitals in the main block.

Member of the research project: Chihiro Wakabayashi (Saitama Prefectural University)

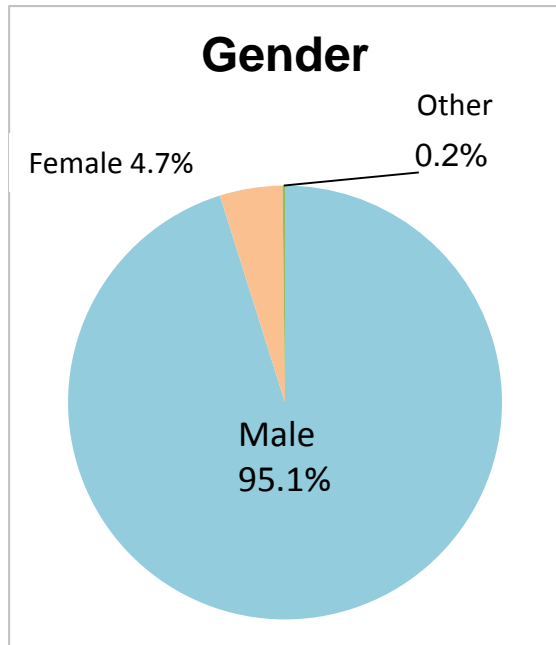
Health and Labor Science Research Grant 2012 - 2014 (Research Project for Prevention of AIDS)

“Research of Mental Health Support for HIV-positive Patients in the Community”

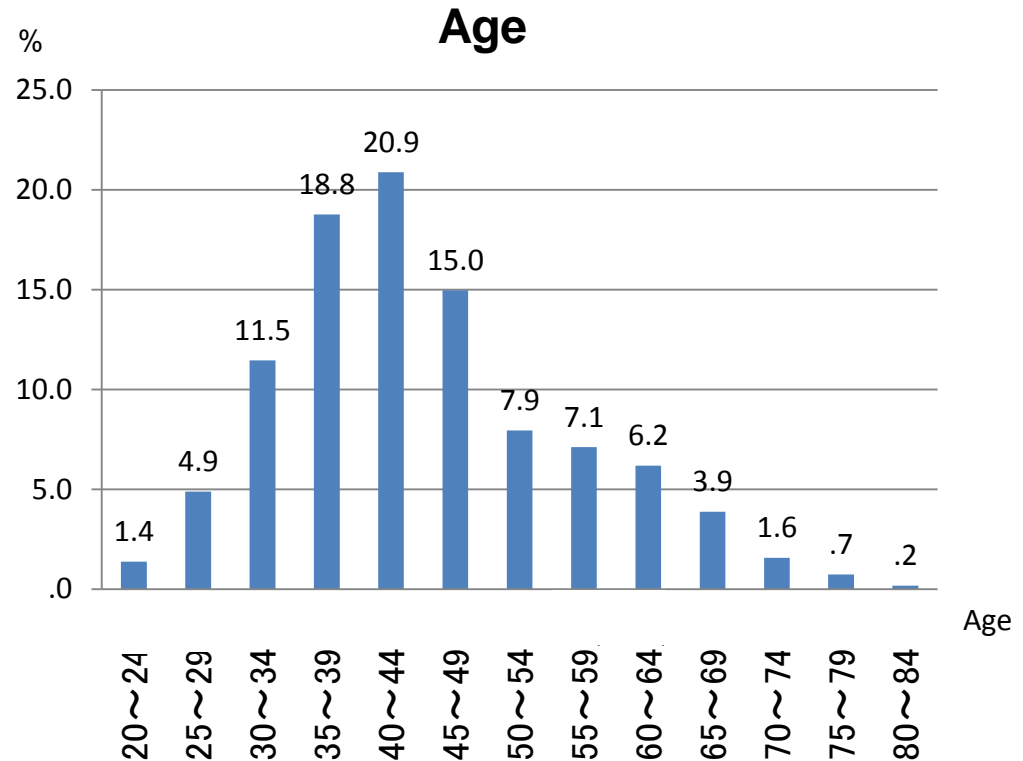
Lead Researcher: Masayoshi Tarui (Director of PLACE Tokyo (Non-profit Organization) / Professor Emeritus, Keio University)

<http://www.chiiki-shien.jp/>

Basic Data



Nationality: Japanese 98.3%



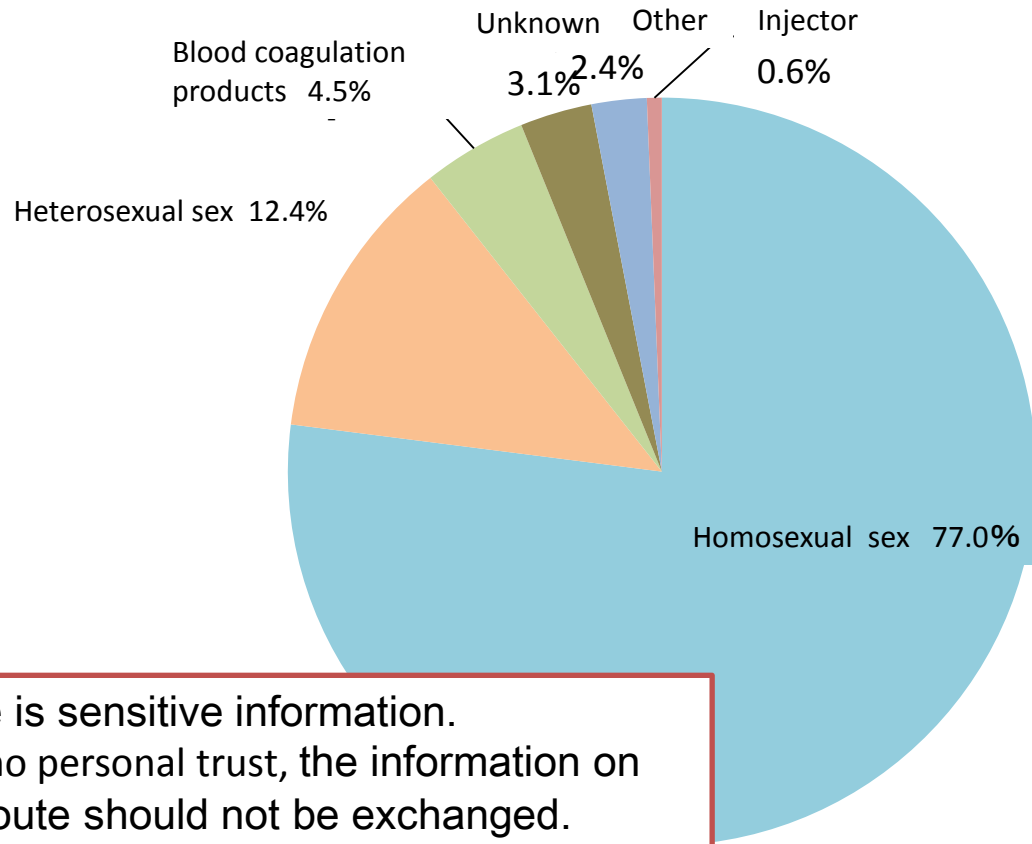
Average is 44.6 ± 11.3 -year-old,

Age range is from 20 to 84

Over 60 year-old is 12.6%,

Over 65 year-old is 6.4%

Infection Route



N=1092

Recount: Recount based on the new classification of the Ministry of Health, Labour and Welfare surveillance.

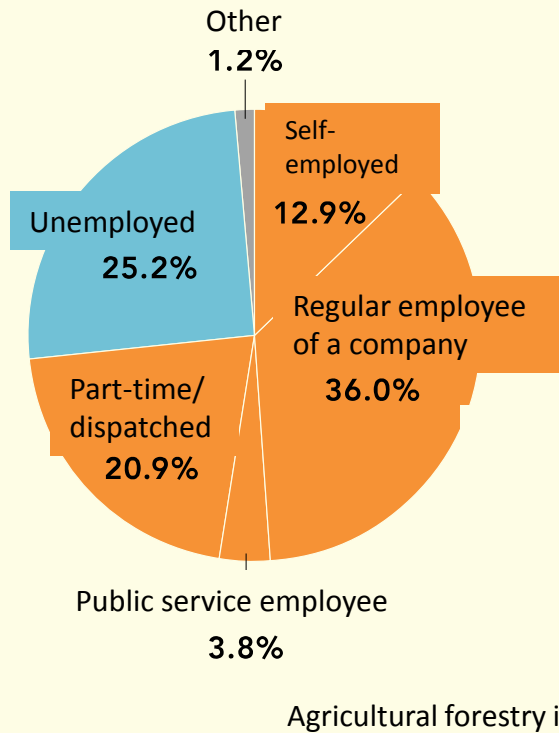
Infection route is sensitive information. While there is no personal trust, the information on the infection route should not be exchanged.

Changes in 10 years

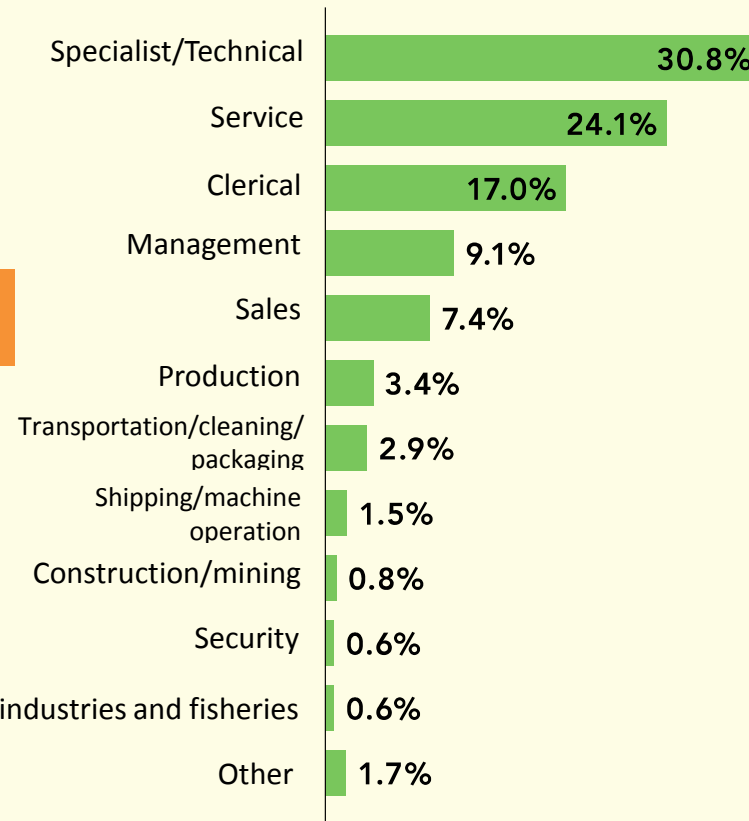
	Conducted in 2003 and 2004	Conducted in 2013 and 2014	Trend
Number of valid response (Collection %)	566 (72.3%)	1100 (61.6%)	
% of people taking anti-HIV medicine	74.5%	94.5%	Increase
% of people taking medicine by frequency (Once or twice per day)	once : 3.1% twice : 81.0%	once : 58.1% twice : 35.7%	Increase in once Decrease in twice
% of people with the physical disability certificate	Immunity & duplicates : 74.7%	Immunity : 92.1% (including duplicates)	Increase
% of people who “want to work without restriction” (Intention to work)	37.2%	58.4%	Increase
Percentage of workers employed as disabled	2.9%	4.0%	Slight increase
<u>% of people over 60 year-old</u>	2.8%	12.6%	<u>Increase</u>
% of people who go to hospital once in 2-3 months	37.2%	73.5%	Increase
<u>Unemployment rate</u>	Unemployed : 24.2% Taking leave : 0.7%	Unemployed : 23% Taking leave : 1.9%	<u>No change</u>
<u>Coming out in the workplace</u>	Colleague : 14.5% Boss : 16.2% Employer, manager : 13.2% HR : 6.8% Industrial physician : 4.2%	Colleague, subordinate : 7.4% Boss : 10.7% Employer, manager : 8.3% HR : 5.8% Industrial physician : 3.5%	<u>Slight decrease</u>

However, 25.2% are unemployed

Employment of HIV-positive people (Figure 4)

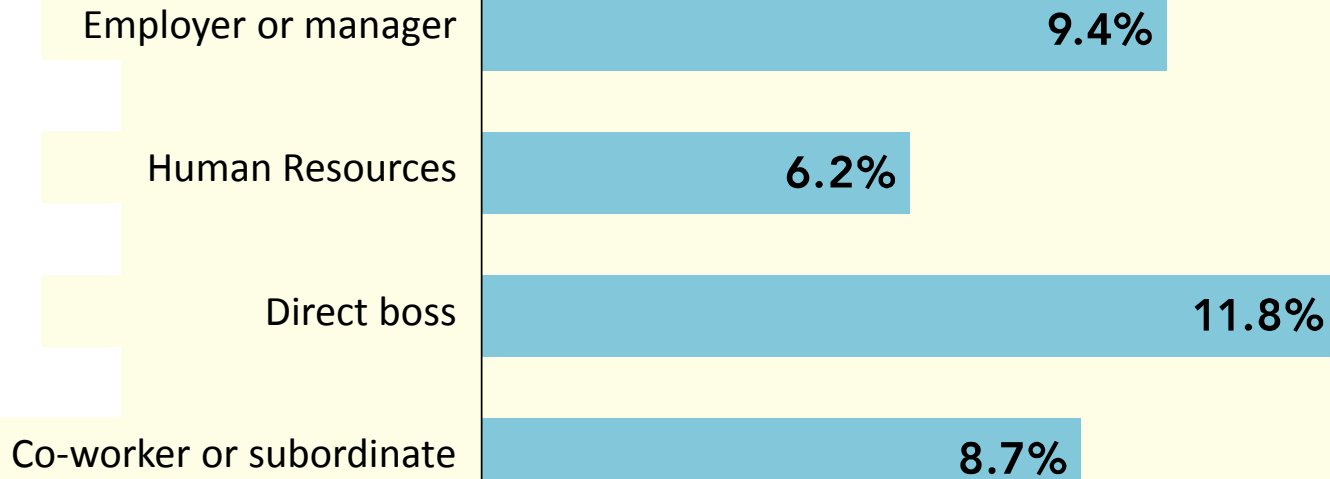


Occupation of workers (Figure 5)

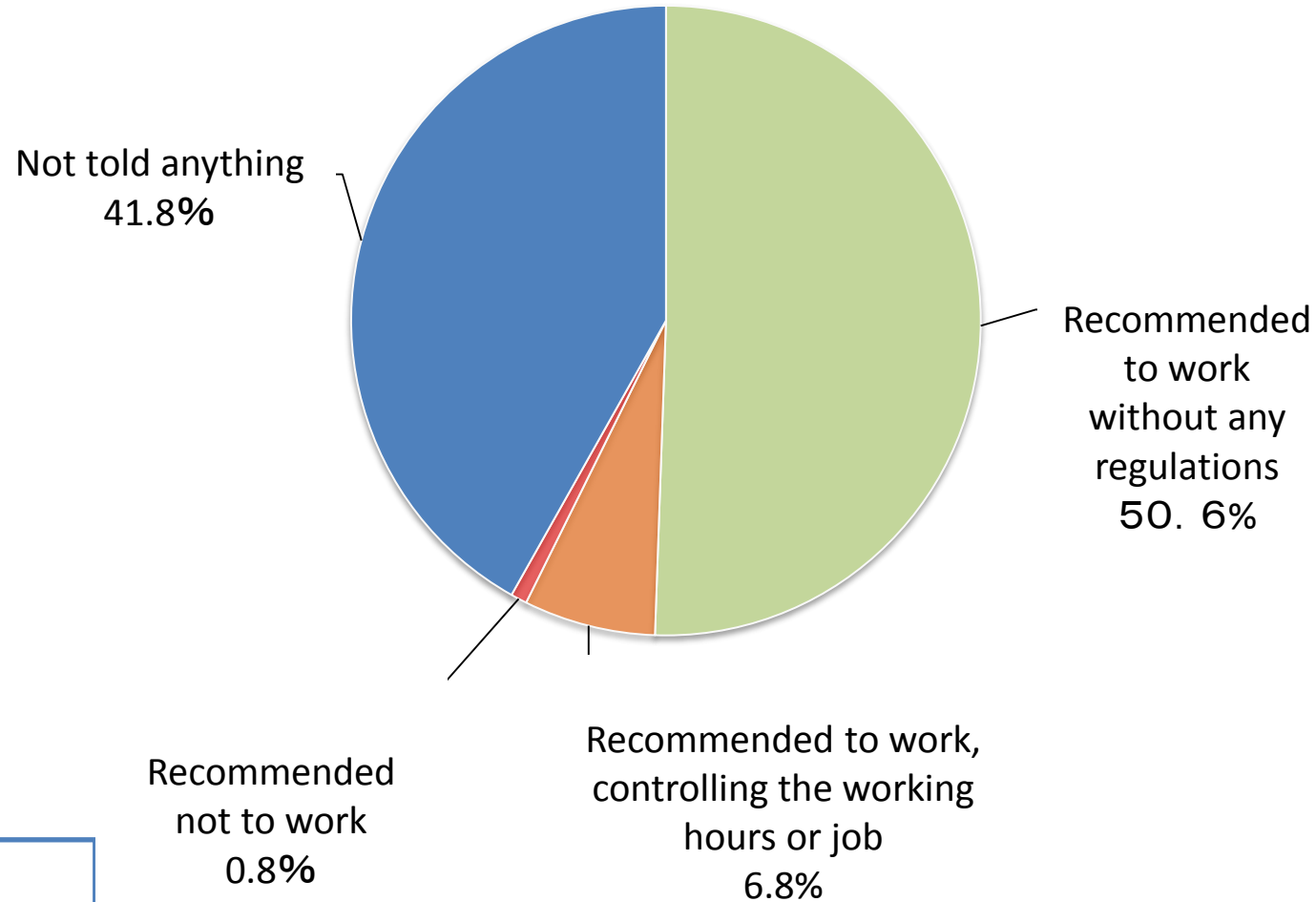


It is hard to consult in the workplace

People who you have told about your
HIV-positive in the work place.(Figure 6)

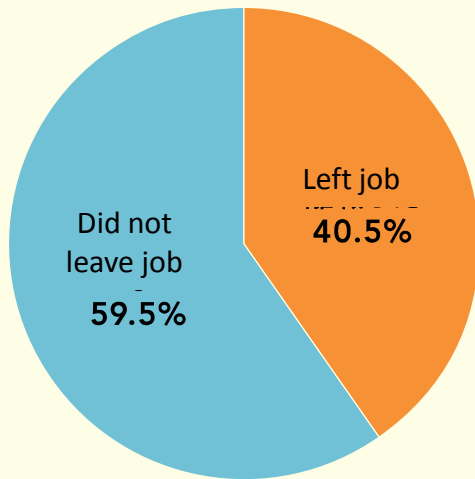


Advice about working from the physician in charge

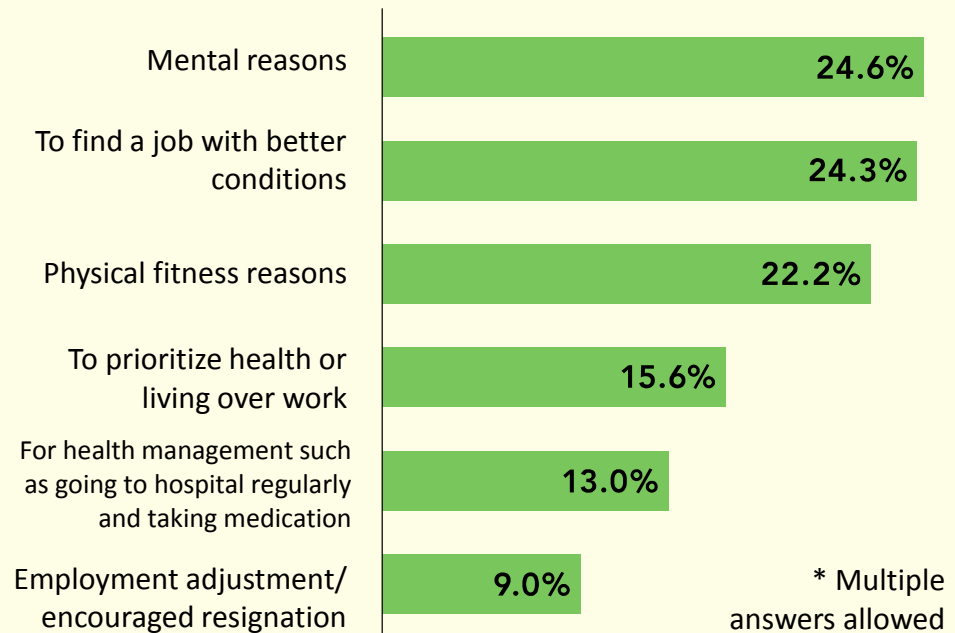


Leaving jobs, changing jobs, and mental problems are big problems

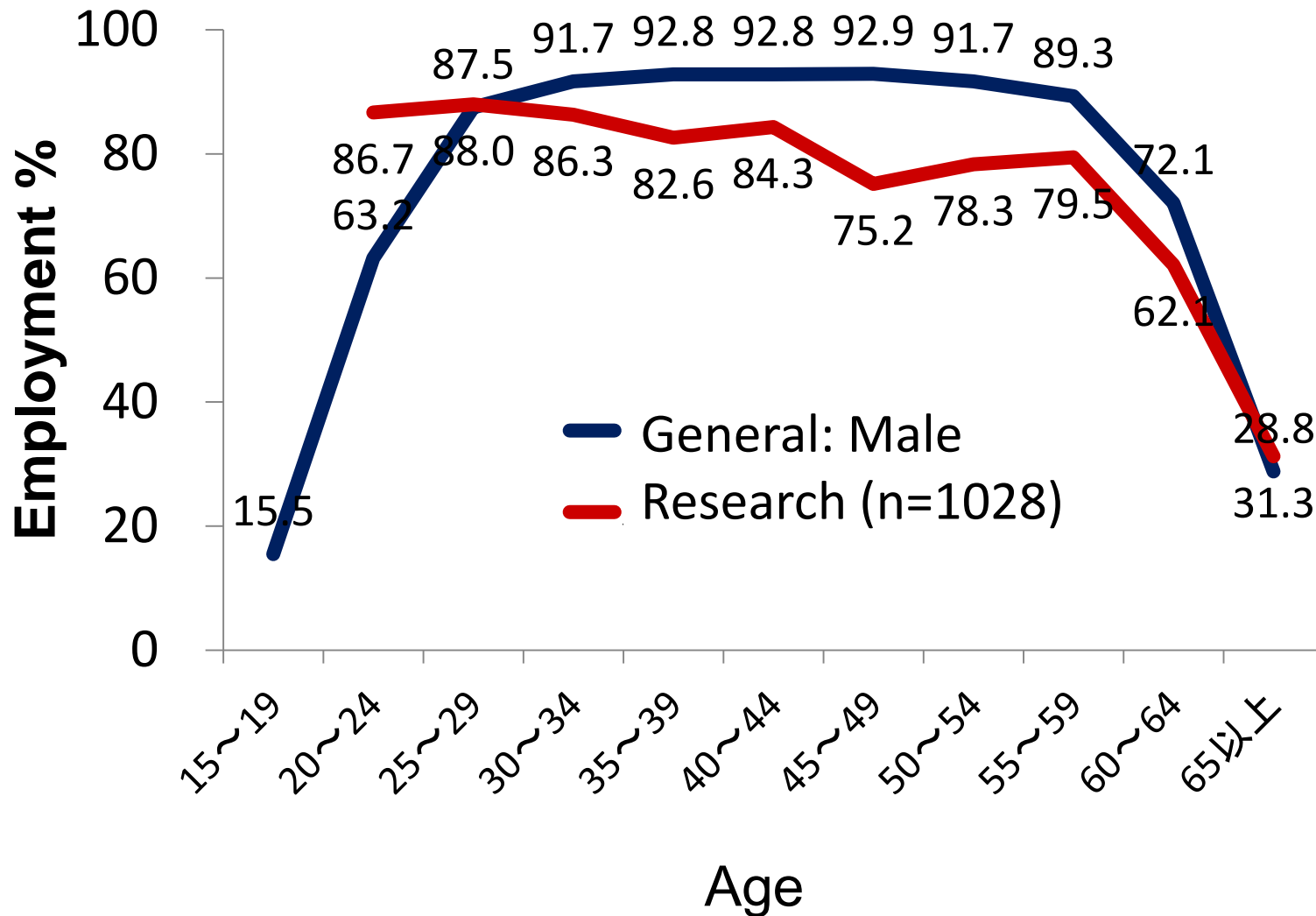
Leaving or staying job after founding that you are HIV-positive (Figure 7)



Reasons for leaving job (Figure 8)

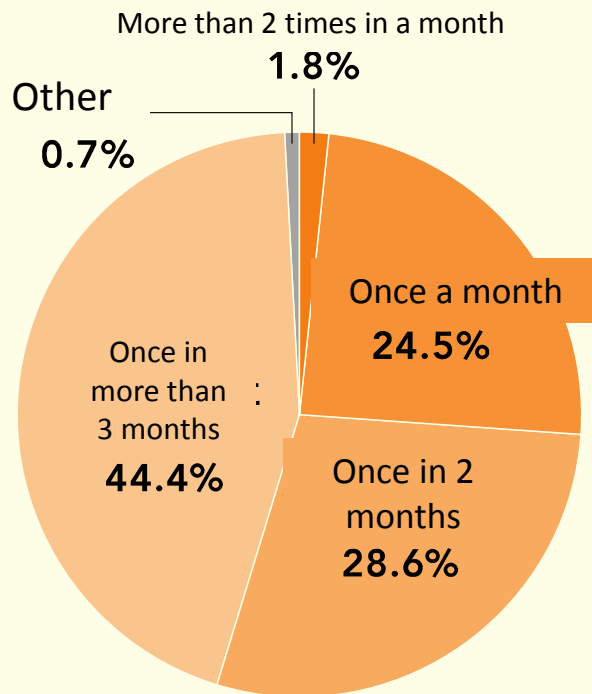


Male employment rate by age: Comparison with the general statistics

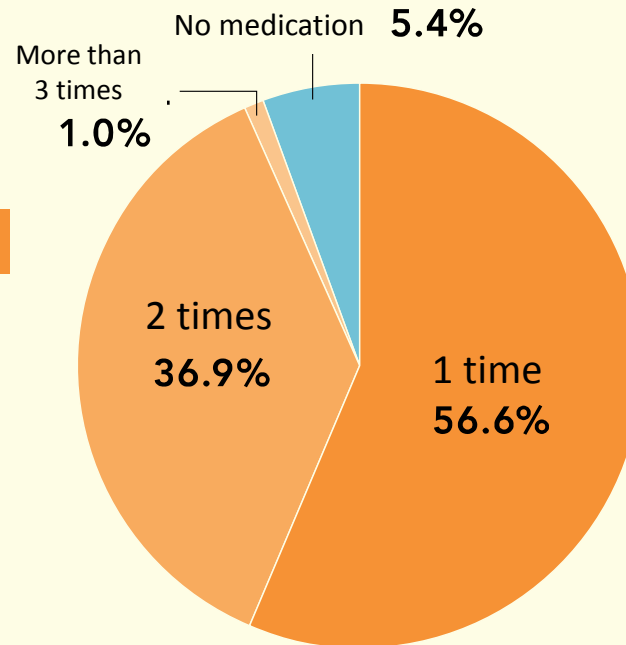


It is required to take stable medicine and visit hospital.

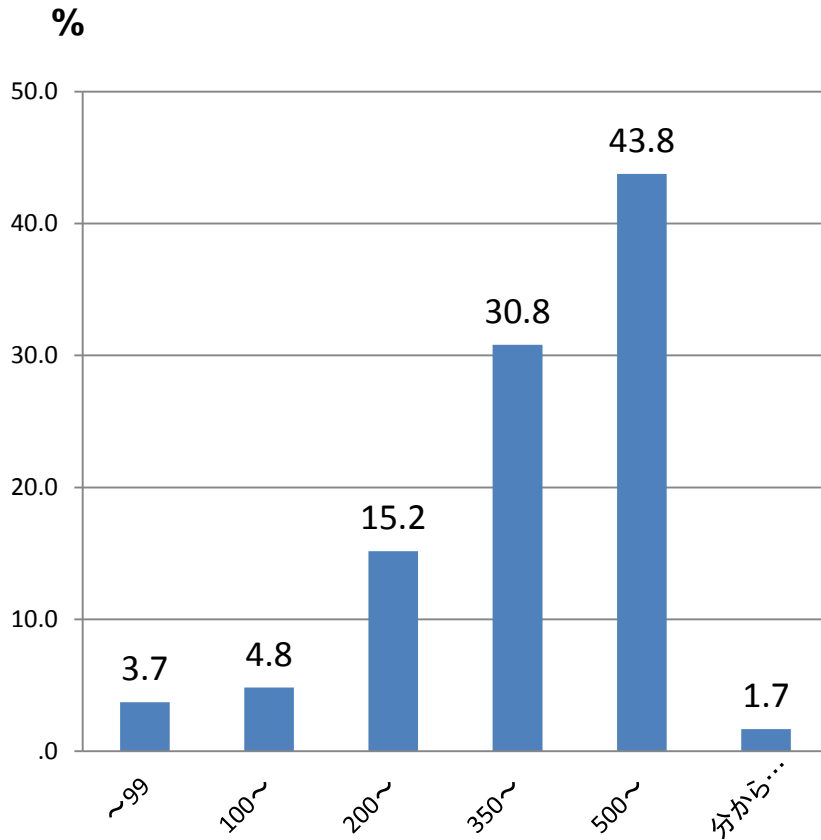
Frequency of visiting hospital
(Figure 1)



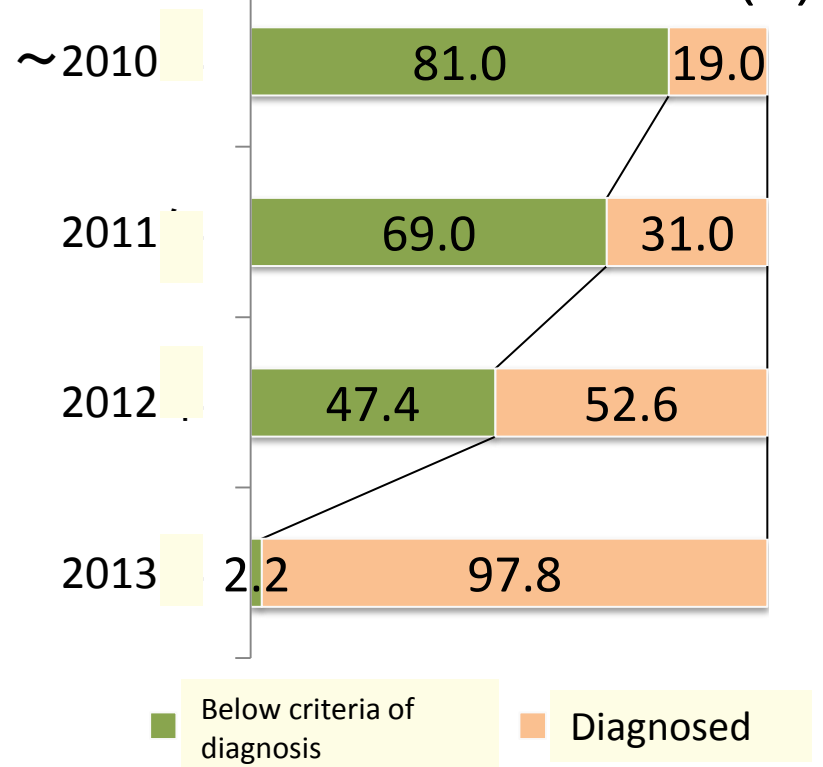
Intake of anti-HIV medications per day
(Figure 2)



Number of CD4 cell (/μℓ)

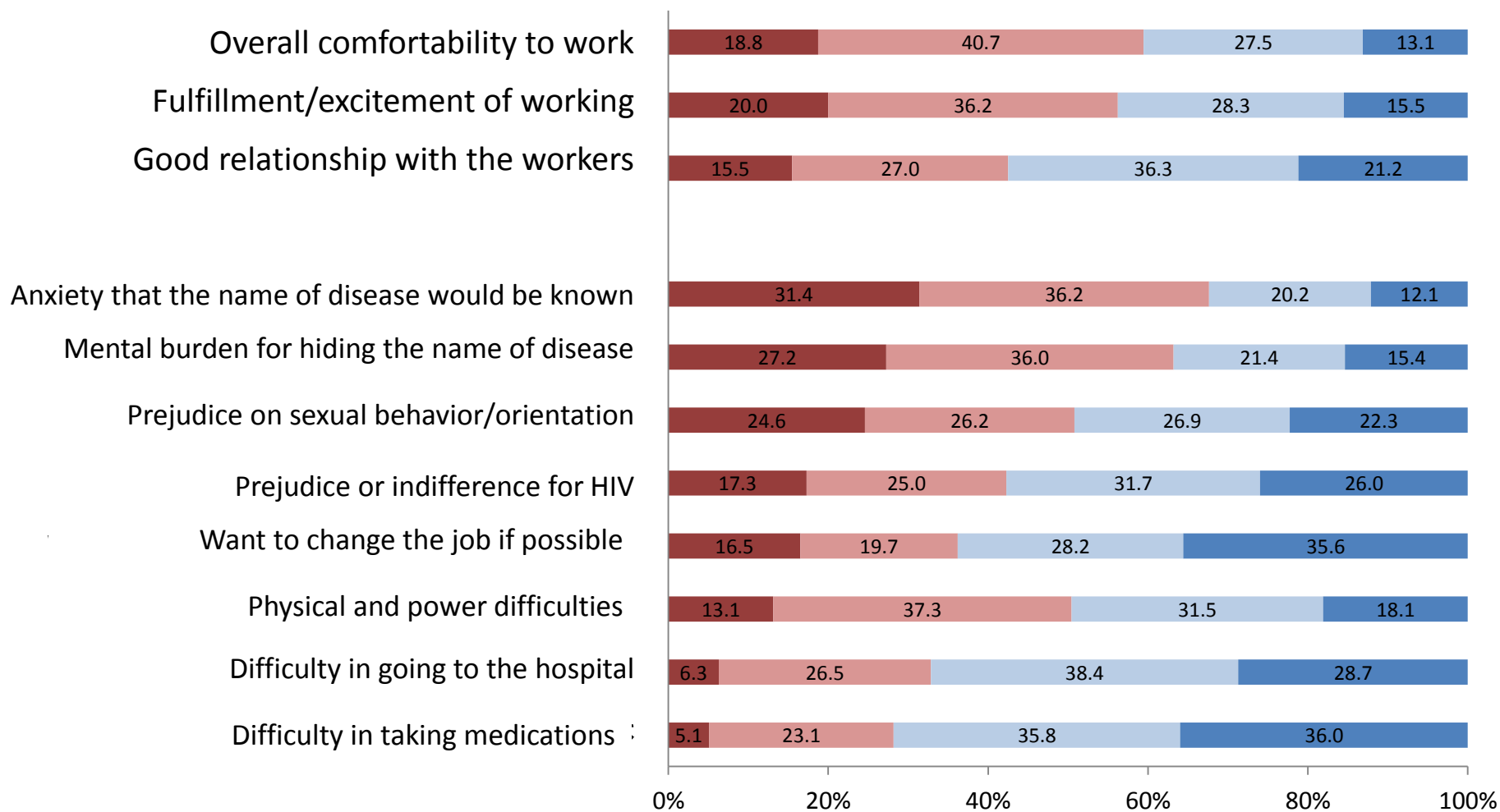


Diagnosed year, amount of virus (%)



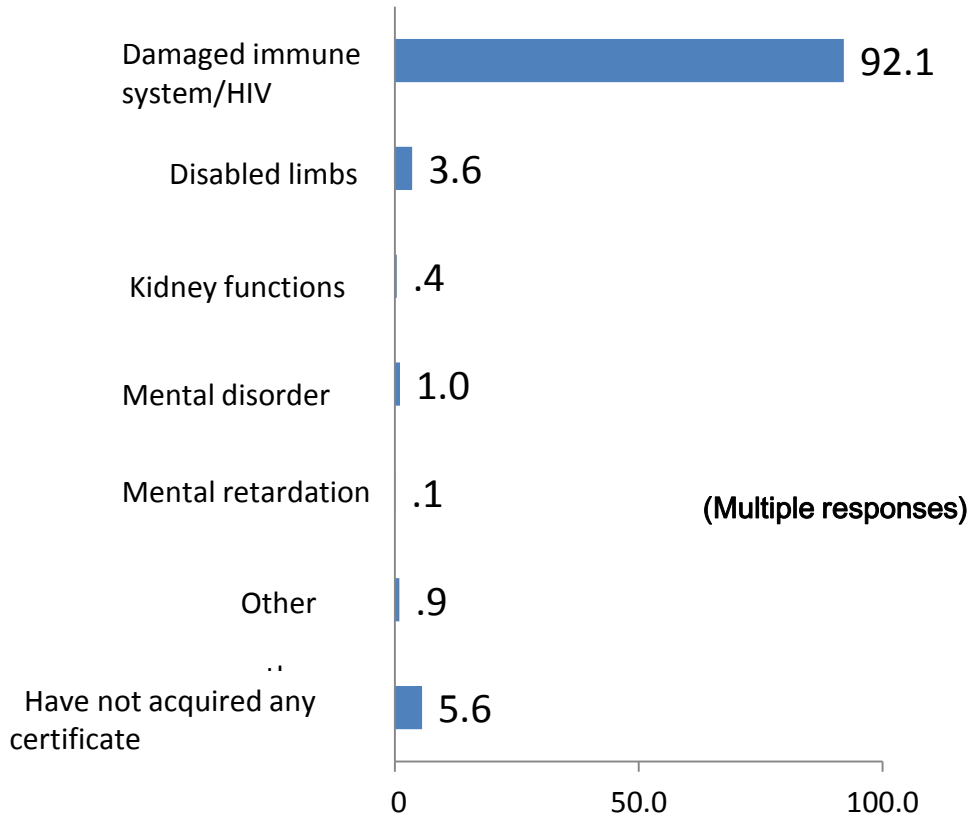
Reputation in the workplace

■ Strongly agree
 ■ Slightly agree
 ■ Disagree
 ■ Strongly disagree

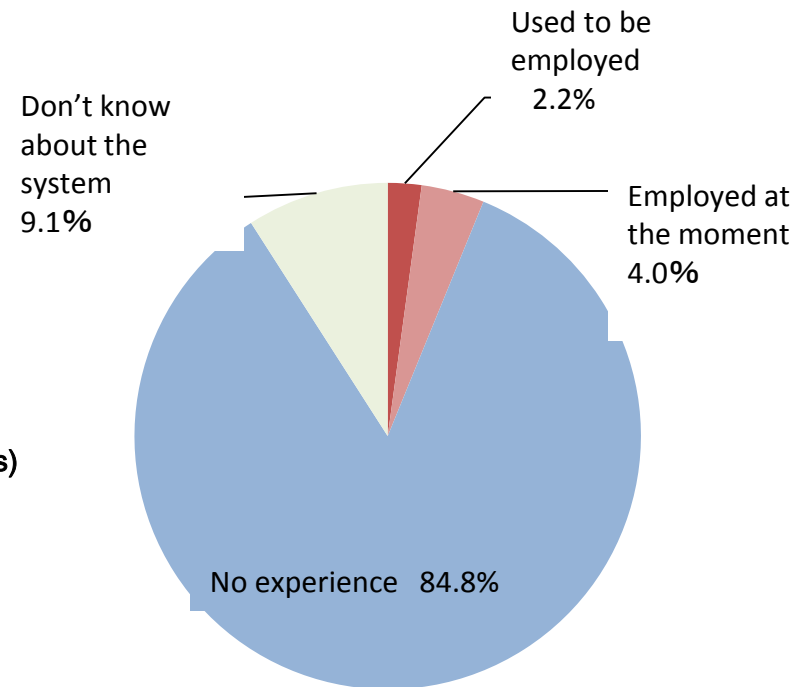


Certificate of disability

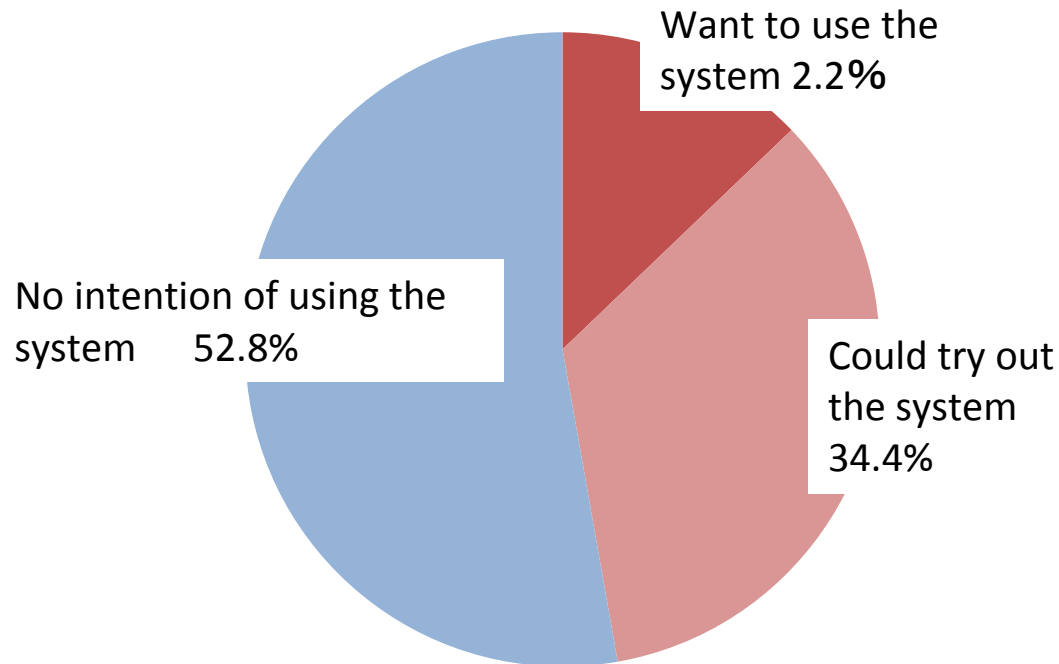
Certificate of disability ID



Working experiences under the Employment System for Persons with Disabilities



Working intention under the Employment System for Persons with Disabilities



47.2% of people who have the intention to use the Employment System for Persons with Disabilities in the future

The nationwide surveys focusing on the life and health of the HIV-positive people are conducted once every 5 years

Health and Labor Science Research Grant Research on “Health and Life survey of HIV-positive People”

The 1st Survey

2003

- 5 hospitals, 566 collected/783 distributed Collection rate: 72.3%
- Hokkaido, Tokyo, Osaka, Kyushu, core, block, ACC

The 2nd Survey

2008

- 33 hospitals 1,203 collected /1,813distributed Collection rate: 66.4%
- Nationwide core, block, ACC

The 3rd Survey

2013

- 31 hospitals 1,469 collected/2,473 distributed
- (Block, ACC survey, 9 hospitals 1,100 collected/1,786distributed Collection rate: 66.4%)
- (Core survey, 22 hospitals 369 collected/687distributed Collection rate: 53.7%)

Change of treatment for HIV over the past 10 years(2003-2013)

Percentage of people who
take anti-HIV medication

74.5% ▶ 94.6%

The guideline for non-onset HIV-positive people regarding the start of medication was changed and the benefits of early treatment has been found. Thereby, the percentage of people taking medications have increased.

- Change of treatment for HIV
over the past 10 years(2003-2013)-

Percentage of people who visit the
hospital once in 2-3 months

37.2% ▶ 73.0%

People visit the hospital in short spans right after being diagnosed as HIV-positive, however, there is a trend that the span of visiting the hospital prolongs as their physical states become more stable.

- Change of treatment for HIV over the past 10 years(2003-2013)-

Percentage of people who take anti-HIV medications once a day

2.3% ▶ 56.6%

HIV-positive people needs medication every day. As the treatment techniques enhanced, more people were able to get good enough effect with just one medication a day, which decreased the burden of medication.

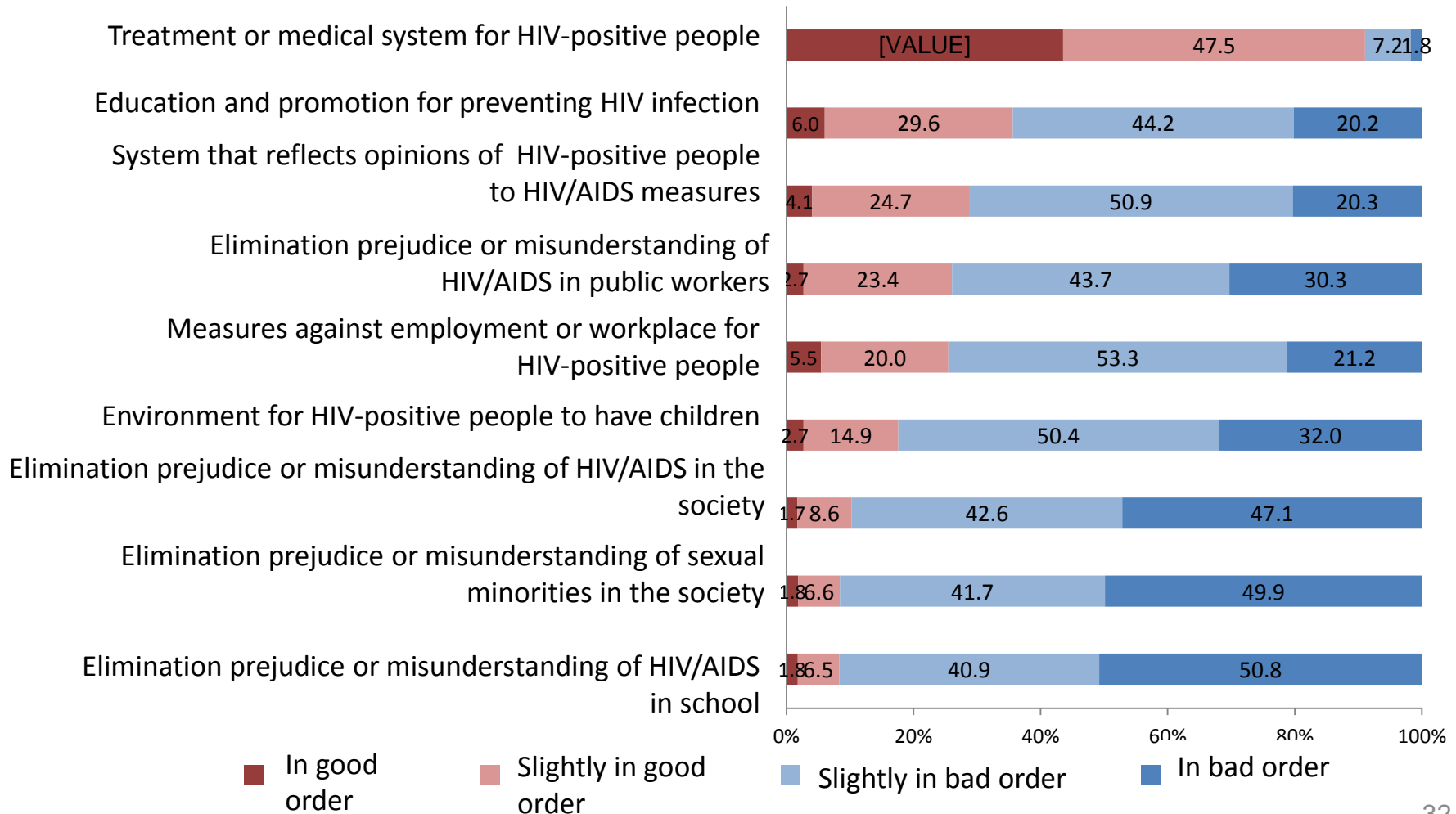
- Change of treatment for HIV
over the past 10 years(2003-2013)-

Percentage of people who want
to work without any restrictions

37.2% ▶ 58.7%

The number of people who want to work by restricting work and caring about their health has decreased in the last 10 years, and more people are wanting to work without any restrictions.

Evaluation of Japanese AIDS-related political measures

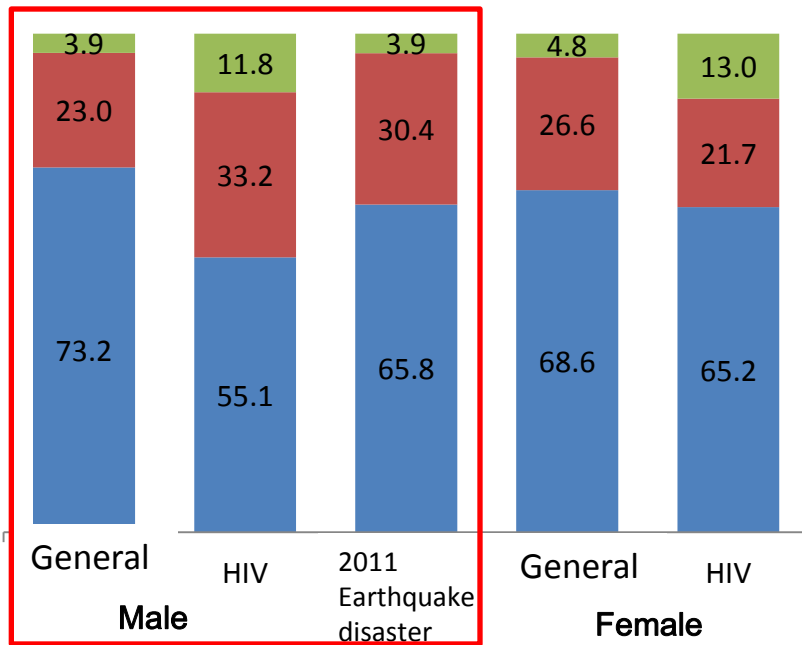


Mental health of HIV-positive people

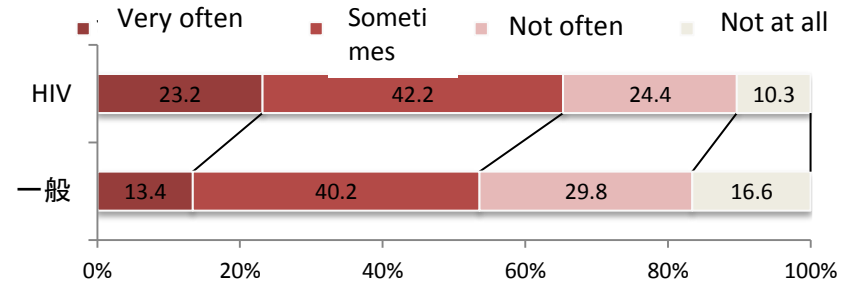
* Data published at the Japanese Society of Public Health 73rd general meeting

Mental sanity K6: HIV and ordinary people

■ 0~4 pts ■ 5~12 pts ■ 13 pts or more

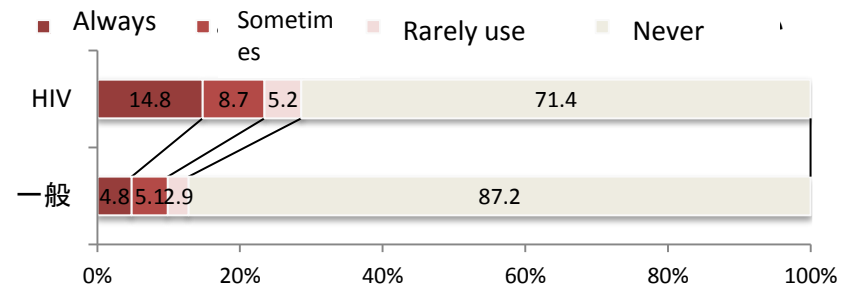


Sleeping problem (e.g. insomnia)



* General: Ministry of Health, Labor, and Welfare "2011 fiscal year Natio

The use of sleeping pills and stabilizer



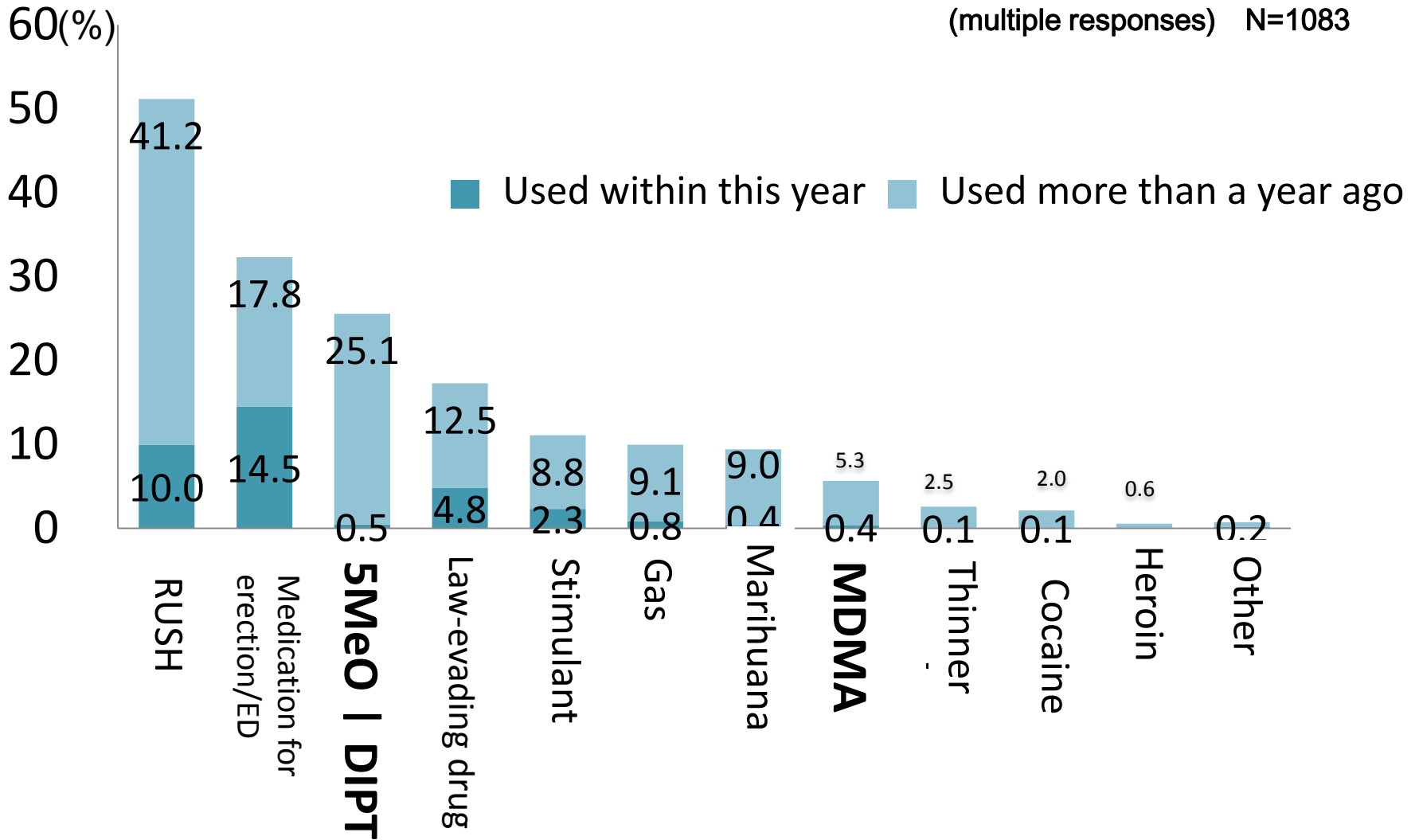
* General: Ministry of Health, Labor, and Welfare "2008 fiscal year Natio

* General: Ministry of Health, Labor, and Welfare "Con

Reference: Research by Research Project for Prospective Investigation of health problems Among Survivors of the Great East Japan Earthquake and Tsunami Disaster, 2011 male

K6 is a screening measure of depression and anxiety disorders. 5 selections with 0 to 20 points. More than 5 points / 13 points mean high risk. The condition is much worse compared to the ordinary people. The rate of people who regularly go to psychopathology is 11.2%. The rate of people who have sleeping problems is high, and the rate of using sleeping pills is also high.

Usage status by drug type



Problems found from the survey and activities

- Human network of HIV-positive people tend to be small
- Continuation of employment for HIV-positive people
- Improvement of mental health and prevention of using drugs
- Offering supports for support providers such as HR, nursing/medical care providers

What PLACE Tokyo Support at Workplace

- As requested by Hello Work (Vocation support center for persons with disabilities), we offered a training program for HR staff and workplace. Entertaining program for 30 minutes using quizzes while two staff members give a lecture, one of them comes out as HIV-positive. The objective is to show that you cannot tell who HIV-positive people are by their appearance and that there are many people who do not come out. In addition, we want to challenge the stereotype.
- We encourage people to understand HIV-positive people as one of their colleagues and as related each health.



Episode 1

- When PLACE Tokyo visited a company in Tokyo for training, this is what the personnel manager said to the employees.
- “We employ people without discrimination against HIV positive people. The fact that you are employees will not change depending on whether you are HIV positive or not.”
- Later, there was an email from the HR staff that after Mr. Ikushima visited, some of the people had taken HIV tests.
- A working environment without discrimination is good for the employees, and at the same time, it will make easier for them to take HIV tests.

Episode 2

- One young man in 20s, who came to us for the counseling was about to start job hunting. He said that being HIV positive wasn't a shameful thing. So he was going to tell the company that he regularly had to go to the hospital.
- Ikushima got worried and said to him not to try too hard himself because the level of understanding of HIV differs in companies.
- The next time his visit was after he had had about 10 interviews with companies. And he said, "Being HIV positive is something that I shouldn't be mentioning." A society where the HIV-positive patient has to be silent is a society where even reality cannot be seen.

It is hard to see the figure of HIV positives in the society

UPDATE YOUR REALITY

There is a huge gap between the image that the society has towards HIV-positive people and their actual feelings.

There is the reality that the society's lack of understanding is heavily bearing upon HIV-positive.

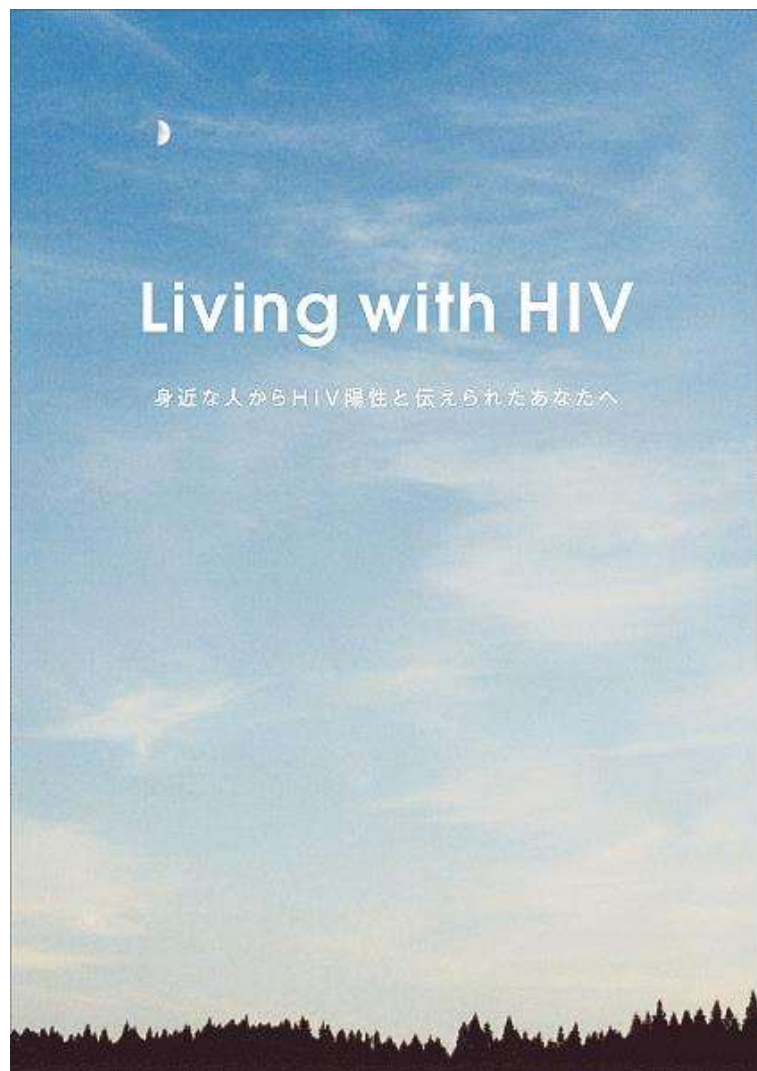
In such a situation coming-out is still very difficult.

On the other hand, it is also important for people who will take the HIV tests.

If it was positive, they can not draw the image well, even if they think about the previous thing.

Living with HIV

For you who have been told to HIV-positive from someone close to you



In this booklet, there are 24 stories experienced by partners, families, friends, and colleagues who were told that people close to them are HIV-positive, the notes of the HIV-positive people themselves and the short columns about basic knowledge and some data.

<http://lwh.ptokyo.org/>

Training for those who conduct HIV testing

Supporting the administration's training session for HIV testing staffs. Conducted in Tokyo and other destinations all around the country. In addition to lectures, role-playing is done assuming that 3~4 gay men are taking the HIV test. They notice a lot of things and that is leading to ease of use of services.

This training was conducted in Sendai/Tohoku, Tokyo, Chiba, Kanagawa, Okayama, Okinawa, and in the past, 4 prefectures in Shikoku and also Nagano.



A survey was conducted on SNS focusing on MSM 2016.9.22~10.22 *under analysis*



Respondents: 10544

men	:10375
TG men (who are men although their birth certificates are female at birth)	: 38
TG women (Who are women although their birth certificates are male at birth)	: 60
women	: 11
others	: 60

Sexuality

Gay	: 8102
Bisexual	: 1809
Heterosexual	: 39
Do not want to be determined	: 227
Do not know	: 192
Others	: 34

Partnership with the National Center for Global Health and Medicine and community center akta

Sending counseling staff to distribute HIV test kits 2016



To MSM who are over 20 years old, we distributed **1,301** test kits. There were **187** people who wanted counselling (**14.4%**)

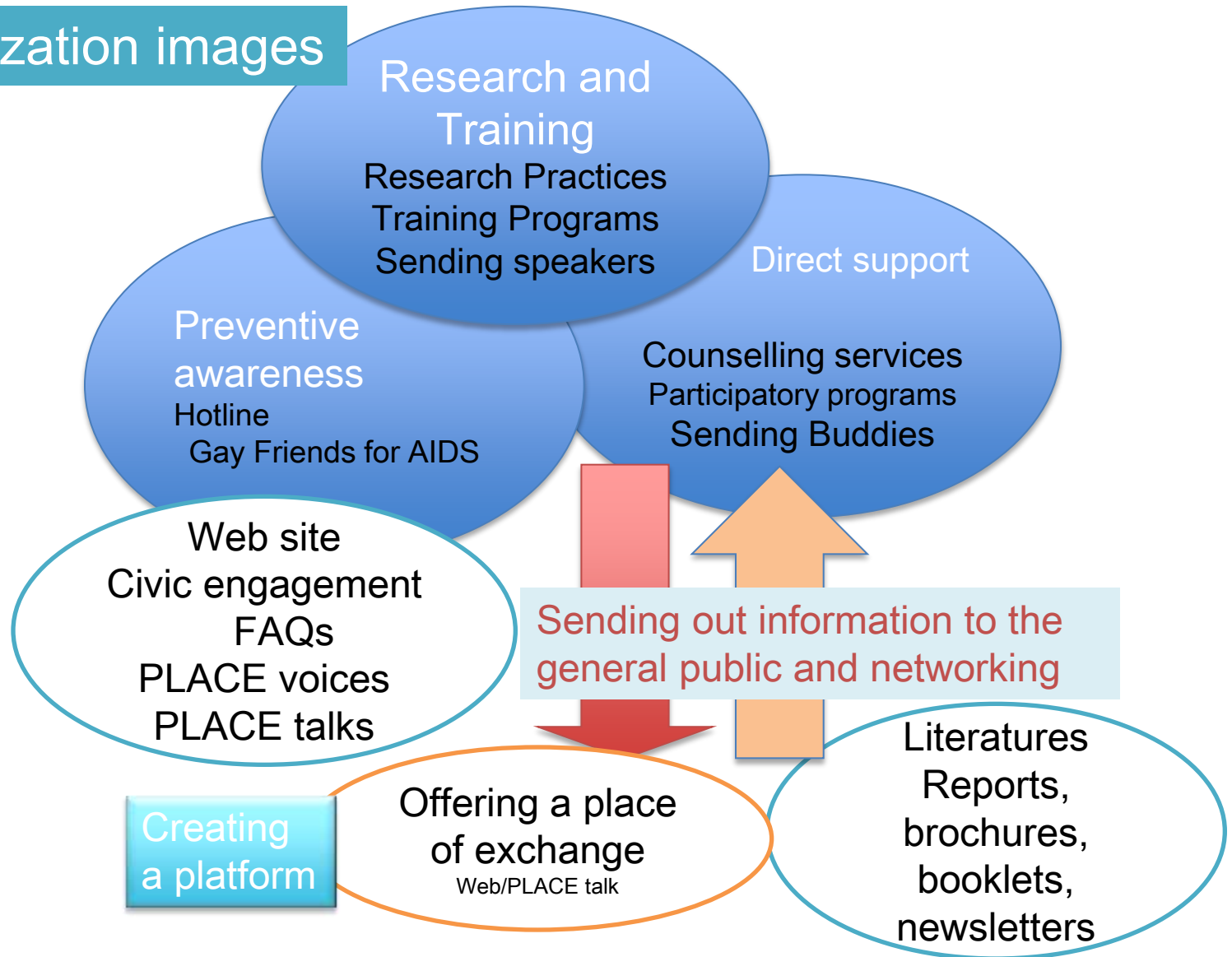
Gay Mens Chorus 2016

12.10(Sat)16~ National Center for Global Health and Medicine



**TOKYO
AIDS
WEEKS**

New organization images



Participants can become supporters, and share experiences with their communities to the donors.

➔ 第31回 日本エイズ学会学術集会・総会

The 31st Annual Meeting of the Japanese Society for AIDS Research

未来へつなぐ
ケアと予防

Living Together

日時：2017年11月24日（金）～11月26日（日）

会場：中野サンプラザ 他 〒164-8512 東京都中野区中野4-1-1 TEL：03-3388-1151
