The results of the statistical analysis from “positive stimmen”

(“positive voices – the PLHIV Stigma Index in Germany”)

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Deutsche AIDS-Hilfe

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Deutsche AIDS-Hilfe e.V.
Wilhelmstr. 138, 10963 Berlin, Germany
Phone: 0049 30 69 00 87-0
E-Mail: dah@aidshilfe.de
Online: aidshilfe.de
positive-stimmen.de

Translation: Chelsea Wright
Original Text: Carolin Vierneisel
Editorial: Holger Sweers
Graphics: Carmen Janiesch
Layout: Ulrich Sporleder

Donations:
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The People Living with HIV Stigma Index was developed by these four organisations:

- The Global Network of People Living with HIV/AIDS (GNP+);
- The International Community of Women Living with HIV/AIDS (ICW);
- The International Planned Parenthood Federation (IPPF); and
- The Joint United Nations Programme on HIV/AIDS (UNAIDS).

Deutsche AIDS-Hilfe coordinated the German rollout of the PLHIV Stigma Index.

At the heart of the roll-out in Germany stood 40 overwhelmingly motivated interviewers who have accomplished to spread the word of the project in PLHIV communities and who succeeded in conducting more than 1100 interviews.

A big thank you also to all 1148 people who took the time for the interviews and decided to be part of this fantastic worldwide initiative.

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Introduction

Within around 6 months in 2011/2012 and 2,000 hours of interviews[1] , 40 interviewers asked 1,148 people living with HIV from the entire federal territory how they experience stigmatization and discrimination.

With these interviews around 1.6% of all people living with HIV in Germany were reached[2]. The interviews were conducted with the help of a standardized questionnaire developed at the international level. A few questions were open-ended; the majority had predetermined answer choices. In order to end up with comparable data, only experiences from the past 12 months (unless otherwise specified) were requested.

In this brochure we present selected results from the statistical analysis broken down into the following areas of focus:

1. The interviewees (social demographic)
2. Social environment
3. Healthcare
4. Work and employment
5. Sexuality
6. Openness about HIV-status
7. Internalization of stigmatization
8. Rights, laws, guidelines
9. Effecting changes.

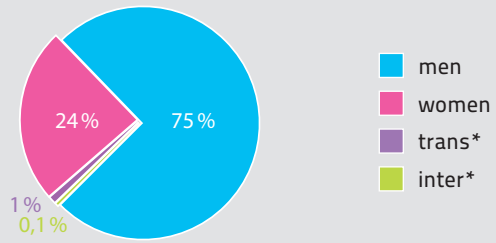
The account will be completed with a discussion of the findings.

At the end of 2013 a detailed composition appeared as an online publication. In another step assessments can be made as to whether and how the subgoal of mobilization of people living with HIV could be accomplished.

1. The interviewees (social demographic)

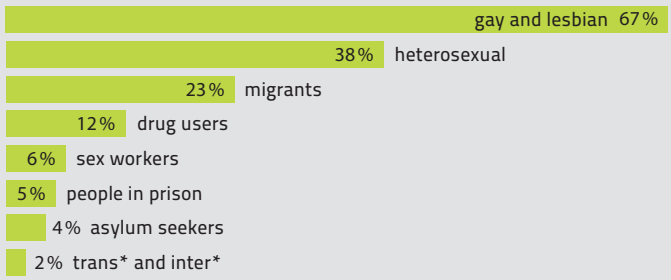
75% of the interviewees are men, 24% are women, and approximately 1% are trans* and intersex people.

Distribution according to gender



The interviewees assign themselves to the following groups, in which it can be about both a current as well as former affiliation.

Self-chosen current/former group affiliation(s); multiple entries possible



The group of gay and lesbian interviewees (67%) is composed predominantly of gay men (n= 694). Only 31 women plus 8 trans* and inter* people also assign themselves to this category.

1 Source: Survey of the interviewers as part of the monitoring of the project.

2 According to Robert Koch Institute (National epidemiological Institute) there were 73.000 people living with HIV in Germany at the end of 2011.

Trans* people are those who have a different gender identity, or live out/display themselves differently than the gender they were assigned at birth. They are those who present themselves in a matter that doesn't correspond to the traditional gender roles based on assigned gender at birth. This can be done out of inner compulsion, preference or freedom, and with the help of language, clothing, accessories, cosmetics or bodily modifications. They are, including and not restricted to, transsexual and transgendered people, transvestites, cross-dressers, asexuals, multi-gender and genderqueer people.

Inter* people are those who cannot be distinctly assigned to the male or female gender due to genetic (due to the sex chromosomes) and/or anatomical (due to the sex organs) and hormonal (due to the quantities of sex hormones) factors.

38% of the interviewees check the category "heterosexual". For the analysis however only those who did not also check "gay or lesbian" were assigned to this group, as it is expected that the indication of "heterosexual" by those who also checked "gay or lesbian" refers to them identifying as heterosexual in the past. The adjusted statistic is 33% of interviewees identifying as "heterosexual". The shape of this group gets even clearer once the overlaps in group affiliations are considered: the group is predominantly female (61%), 28% state having a migratory background, and 25% state a history of drug-usage.
To establish the "migratory background" category (overall 23% of the interviewees), information related to residence permit status, origin from a land with a wide distribution of HIV and citizenship was also considered in addition to self-chosen group affiliation. Interviewees identifying as having a migratory background rank more often among the sex workers group (11%) than those without a migratory background. Among male interviewees with a migratory background, the percentage of those who identify themselves as "gay" (69%) is lower than among male interviewees without a migratory background.

Within the group of former or current drug users (12% of all interviewees), the percentage of women is disproportionately high at 53%. Sex workers are also strongly represented in this group with 24%. Of current or formers drug-using men, 33% have a migratory background, which is relatively high. Of current or former drug-using women only 15% have a migratory background. 28% of men and 19% of women with a history of drug use also assign themselves to the gay or lesbian groups.

In terms of age, 30–49 year olds form the biggest proportion of the interviewees with 58%, followed by those over 50 (27%), and those under 29 (15%). Among the women the proportion of those in the middle-aged category is especially high (62%).

44% of the women state being infected for 15 years or longer; this percentage is clearly higher than among the men. Among the men, 29% have not been infected for more than 4 years. Overall, the greatest proportion of interviewees (41%) has lived with HIV for 5–14 years.

The level of education of the whole group of interviewees is relatively high, in which the men declare a high level of education more often than the women do (men: 52%, women: 44%). Nevertheless many of the interviewees are unemployed or employed only part-time (women: 81%, men: 59%). 27% of the men and 34% of the women live on a household income of less than 1,000 Euro per month, and merely 35% of the men and 26% of the women live on a household income of over 2,000 Euro per month.

2. Social Environment[3]

13% of the interviewees report having been excluded from a social gathering such as a club activity or festivity at least once in the past 12 months; 6% attribute this directly to their HIV-infection. There is a similar occurrence during family activities: 13% of the interviewees report an exclusion with 7% experiencing it due to their HIV-infection.

On the question of whether others had gossiped behind their back, over half of the interviewees (55%) answered yes and 31% attribute this directly to their HIV-status.

29% of the interviewees state having been verbally offended in the 12 months prior to the interview and 14% say this happened in connection to their HIV-infection. 11% of the interviewees were physically threatened, with 5% stating their HIV-infection as the cause. 8% of the interviewees were actually physically attacked, with 3% believing it to be in direction connection with their HIV-infection.

Have you had this experience in the past 12 months? And if so, was this due to your HIV-infection?

Social exclusion experience	Yes	Total due to HIV-infection
Exclusion from a gathering	13%	6%
Exclusion from family	13%	7%
Gossiping	55%	31%
Verbal insult	29%	14%
Physical threat	11%	5%
Violent assault	8%	3%
None of these experiences		39%

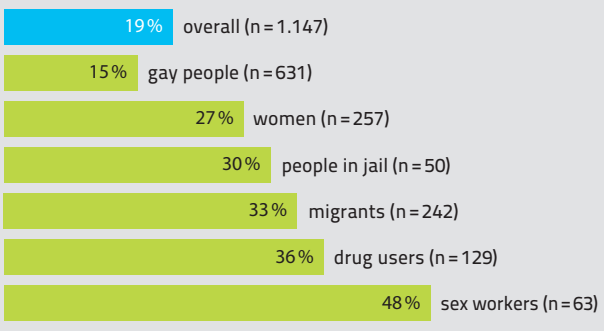
If the negative experience is not attributed directly to the HIV-status, 41% attribute it to their sexual orientation, 11% to their migratory background, 10% to their history of drug usage and 3% to their sex work, with the remaining 34% stating other reasons.

Female interviewees are considerably more affected by verbal insult and physical threat than male interviewees, however for violent assaults no difference between the genders is found. Here the data suggest that men are often physically attacked in connection to their sexual orientation.

3. Experiences in healthcare

19% of the interviewees state a healthcare service such as a dental treatment being denied to them in the year before the interview, with the experiences differing greatly according to group affiliation (women, people with a history of drug use, sex workers, etc.). See below.

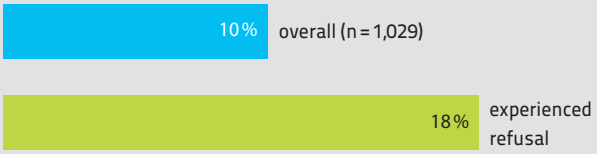
Were you denied medical services (including dental treatment) due to your HIV-status in the past 12 months? (Yes answers)



3 On the method: In the section "discrimination and stigmatization in the social environment" people were asked on general negative experiences. If such an experience was stated the next step was to ask them if they attributed the experience to their HIV-status.

10% of the interviewees answer affirmatively that they forwent a rather necessary doctors visit at least once in the past 12 months. The percentage of those in this group who were also refused a treatment in the same timeframe is 18%.

"I have avoided going to a local doctors office though it would have been necessary in the past 12 months."(Yes answers)



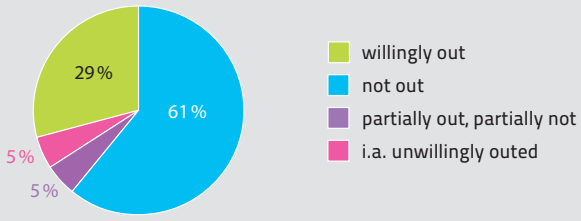
Only 37% of the interviewees are sure that medical documents about their HIV-infection are handled completely confidentially, 49% are not sure and 13% find it obvious that confidential handling is not ensured.

From the question about HIV-testing the following picture appears: 20% state that they were tested for HIV without their knowledge, and under pressure or even coercion (16% of those who have been positive for up to 4 years, 25% of those who have been positive for over 15 years, 27% of the women, 30% of the migrants, 33% of the drug users, 39% of the interviewees without a school leaving certificate). Within the category "unknowingly/under pressure/under coercion" [tested for HIV] the share of "unknowingly tested" is highest.

4. Work and employment

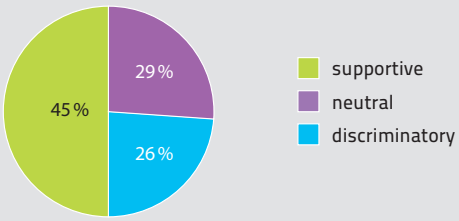
54% of the interviewees are full- or part-time employed. 29% of them declare being open about their HIV-status towards their employer, 61% are not open about their status and 5% are partly open about their status. The other 5% report being outed to some extent against their own will ("i.a. unwillingly outed").

Are you out towards your employer, and if so, how?



45% of those who are out with their HIV-infection in the workplace report a supportive reaction from their employer, 29% a neutral reaction and 26% a discriminatory reaction.

How was the reaction of your employer to your outing? (n=287)



From those who lost their jobs in the year before the interview and base this on their HIV-infection, more cite HIV-related discrimination as the basis for their dismissal rather than HIV-related poor health status.

Connection between HIV-infection and dismissal

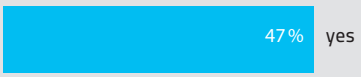
Discrimination from employer	46%
Combination of discrimination and poor heath status	38%
Poor heath status	13%
Other connection with HIV	4%

Question: If HIV-status was the reason, how does your HIV-infection stand in connection to it? (n=24)

5. Sexuality

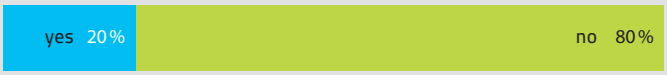
Almost half of the interviewees experienced sexual rejection due to their HIV-status during the year before the interview, with no differences between the genders. Especially high percentages are seen in the 16–29 year olds (57%), migrants (57%) and drug users and sex workers (each at 56%).

Were you sexually rejected due to your HIV-status in the past 12 months? (n = 666)



20% of all interviewees state that they abstained from sex due to their HIV-infection at least once in the past year. The percentage is higher in men under 26 years old (28%), women over 50 years old (29%) and men with a history of drug use (32%).

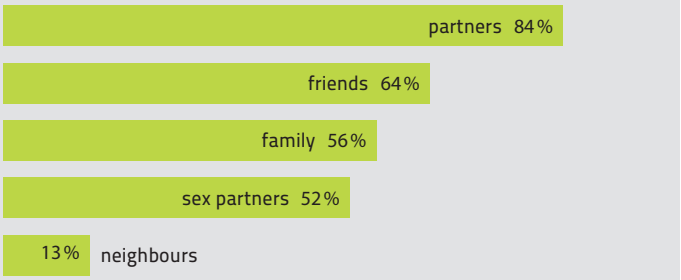
Have you decided not to have sex due to your HIV-infection once in the past 12 months? (n=1,068)



6. Openness with HIV-status

84% of the interviewees state being completely and voluntarily open about their HIV-status with their partner. The percentage among female interviewees is 80%, among men under 26 years old is 73%, among migrants is 72%, among people with a history of drug use is 71% and among sex workers is 53%.

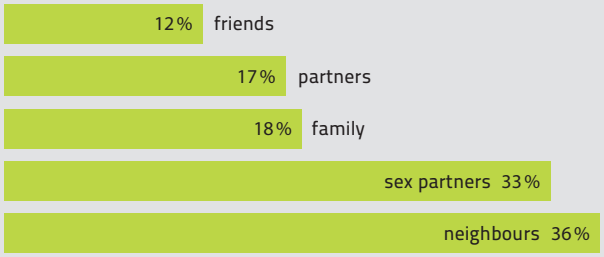
With whom are you completely open and voluntarily out as positive?



64% of the interviewees are completely and voluntarily open with friends, 56% with family, 52% with sex partners and 13% with neighbours.

17% of the interviewees have experienced a discriminatory reaction from partners, 12% from friends, 18% from family, 33% from sex partners and 36% from neighbours.

Did the following groups have a discriminatory reaction to the disclosure of your HIV-status? (Yes answers)

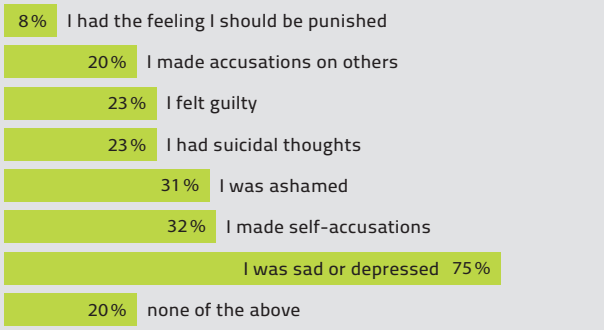


19% state that they always experienced the disclosure of their status to be strengthening, 31% state that it was often strengthening, 36% state it was sometimes strengthening, and 14% state that it was never strengthening.

7. Internalization of stigmatization

42% of all interviewees had low self-esteem due to their HIV-infection at least once in the year before the interview. 75% state being sad and depressed due to their infection, 32% made self-accusations, 23% had feelings of guilt, and 8% agreed with the statement “I had the feeling I should be punished”. Merely 20% state that they experienced no negative feelings in connection with their HIV-infection in the past 12 months.

Did you have one of these feelings in the past 12 months? (Yes answers)



8. Rights, laws, guidelines

16% of the interviewees report that they were denied insurance in the year before the interview. 13% wanted to travel to a land where entry is denied to people living with HIV (the question asked about travel intent, not a real experienced entrance denial).

Restriction due to HIV	Yes
Insurance denied	16%
Entry into a country not possible	13%
Disclosure because of residence	5%
Isolation, segregation, quarantine	3%
Arrest/prosecution	2%
Other	5%
None	68%

Question: Have you experienced one of the following situations due to your HIV-status in the past 12 months?

For a residence permit or citizenship application 5% of the interviewees had to disclose their HIV-status (here it is almost exclusively concerned with people with a migratory background).

3% of the interviewees state that they were isolated, segregated or quarantined, and 2% report being arrested and prosecuted in connection with their HIV-infection (mainly drug users).

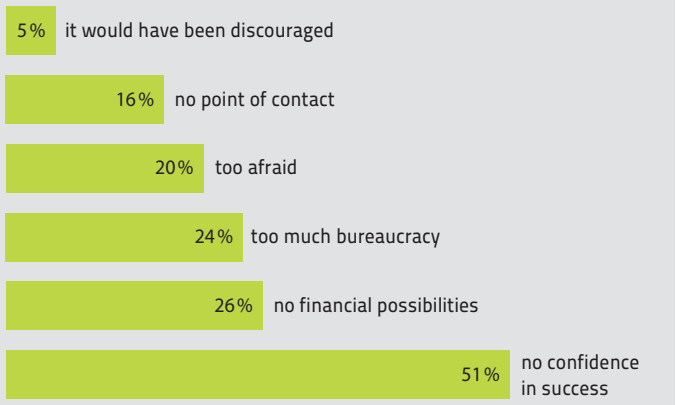
9. Effecting changes

51% of the 1,148 people interviewed stated that they were engaged in the field of HIV during the year before the interview; the majority as members of a self-help initiative or a network of people living with HIV (45%). 26% were engaged in a program during the specified period and 9% were involved in a petition or the development of guidelines. Of those interviewees not active in the field of HIV, 35% showed interest in future engagement.

Percentage of those engaged in HIV self-organization (n=1,148)	
Member of a self-help group/network	45%
Program involvement (12 Mo.)	26%
Petition involvement (12 Monate)	9%
Overall engaged	51%
Interested but not yet engaged	35%

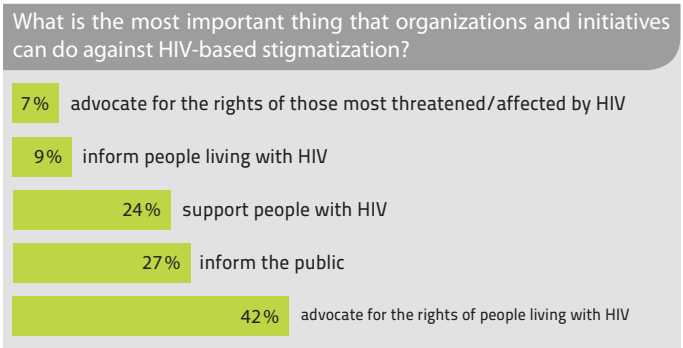
If interviewees who gave an own account that their rights in the year before the interview were violated initiated no legal steps, 51% named lack of confidence in success as their reason, 26% lack of financial possibilities, and 24% “too much bureaucracy”.

Why didn’t you initiate any legal steps to come into your own?



While 36% of all interviewees enlightened or confronted someone who treated them poorly or discriminated against them in the past 12 months, the percentage is 58% among those engaged in field of HIV.

What is the most important thing that organizations and initiatives need to do in reference to discrimination and stigmatization? 42% say to campaign for the rights of people living with HIV, 27% say the duty of informing the public, and 24% say the support of people living with HIV.



Discussion of the findings

The distribution of the interviewees according to self-chosen group membership displays the epidemiological situation in Germany comparatively well, even though it is not possible to have representativeness in the research with and from people living with HIV due to the unclear basic population (it is unknown how many people living with HIV don't know they are infected).

Nonetheless the data and findings based on group representation compiled here can be generalized. However the following must be considered:

- In comparison to the epidemiological data of the Robert Koch Institute this study reached many younger people.
- The level of education of the group of interviewees is clearly higher than that of the general population.
- Simultaneously both the employment situation and household income of the interviewees are more precarious than in the general population.

The negative experiences within the social environment of the interviewees make the concept of "HIV-related stigmatization" clear: 50% of those who were excluded from a social get-together in the year before the interview state their HIV-infection as the cause.

Among those who gave another reason 41% named sexual orientation. HIV-related stigmatization includes both: Stigmatization due to HIV and due to phenomena in combination with it such as sexual orientation, migratory background, drug use and sex work. In order to be able to develop strategies to reduce HIV-related stigmatization, the topic must be focused on in its entirety.

Generally one acts on the assumption that people living with HIV in Germany are provided good healthcare, with the exception of people in jail or undocumented people. The findings of this study however clearly show that discriminatory conduct of medical personnel can restrict access to the healthcare system: almost every fifth interviewee was denied a health service at least once during the year before the interview — an alarming fact given the direct negative effects on health and given the consequences: 10% of all interviewees, and 18% of those who were denied a service, refrained from a necessary doctors visit during the 12 months before the study.

Almost one third of the full- or part-time employed interviewees state being open about their status towards their employer. 45% of interviewees state a positive and supportive reaction from their employers upon the disclosure of their HIV-status; an encouragingly higher percentage than the totally unacceptable 26% of employers who reacted with discrimination. Here there is still much to be done to bring positive examples of accepting and supportive contact to the attention of the public.

Equally inacceptable is the fact that these days people living with HIV still lose their jobs due to HIV-related discrimination (even so, the fact that people more often lose their job due to discrimination than to a poor health status is remarkable: it underlines the well-known reality that people living with HIV who receive successful HIV treatment are equally capable and not sick more often than their colleagues).

On the topic of sexuality of people living with HIV, one quickly runs into fears, uncertainties, and open questions. This is also reflected in the findings: it is alarming that almost half of the sexually active interviewees state that they experienced sexual rejection due to their HIV-infection in the 12 months before the interview, in light of the fact that it had nothing to do with their personality or attractiveness, but instead with an avoidable infectious disease. Such rejections due to HIV-infection can be very hurtful and can have strong consequences on psychological balance, especially for those who have the experience more often. This can be seen in the fact that 20% of the interviewees abstained from sex at least once due to their HIV-infection during the year before the interview. The reasons for rejection lie mostly in the fears and uncertainties of potential sex partners who often drastically overestimate their risk of becoming infected. This also shows that the knowledge that HIV is not transmittable when treated effectively needs to become more widely known.

In light of the negative experiences many people living with HIV have after the disclosure of their HIV-status, it isn't surprising that many come out only in specific social contexts and not in others. Looked at in this way, the indication of openness with HIV-infection is reflected in the respective reaction of the environment, and vice versa. The data also show that handling HIV-infection status openly can also have positive impacts on people living with HIV— that's encouraging!

People internalize norms and pictures of the society they live in; this also applies to people living with HIV. For the most part society's pictures of HIV/Aids are connected to uncertainty, fear and threat, and personal experiences with stigmatization and discrimination leave their mark — the data clearly prove this. Furthermore, many people living with HIV still have feelings of guilt and a sense of shame due to their infection, a diminished sense of self worth, or are affected by depressive experiences.

There are no special rights for people living with HIV, but they should be entitled to the same rights as all others. It is therefore inacceptable that, as the data show, people living with HIV are still refused insurance, are affected by travel and residency restrictions, are isolated, or are accused of (potential) HIV-transmission. As a minority they should enjoy much more specific protection of their rights. This could be realizable, for example, through the admission of chronic illnesses in the General Equal Treatment Act ("Allgemeines Gleichbehandlungsgesetz").

The result of self-organization of people living with HIV gives hope: getting involved pays off! The support of people living with HIV as they lobby for their own interests on a small- and large-scale also needs to be a priority for all stakeholders in the field of HIV. The renowned stigmatization researchers Parker and Aggleton put it like this in 2003[4]:

"Only more rarely have interventions been designed with the goal of unleashing the power of resistance on the part of stigmatized populations and communities – in spite of the fact that empirical studies of empowerment and social mobilization in response to HIV and AIDS have clearly demonstrated that the most effective and powerful responses to the epidemic (or 'natural experiments' if one prefers the language of much public health research) have taken place precisely when affected communities have mobilized themselves to fight back against stigmatization and oppression in relation to their lives."

4 Parker, R. & Aggleton, P. (2003). HIV- and AIDS-related stigma and discrimination: a conceptual frame - work and implications for action. Social Science and Medicine (57), 13–24