

Tell me your story  
and I'll be your voice

summary



POSITIVE  
VOICES

Research  
into quality  
of life

## Colophon

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## SUMMARY

# Tell me your story and I'll be your voice

Research into quality of life



# RESEARCH DESIGN

In 2014 and 2015 the Dutch Association of People Living with HIV (Hiv Vereniging Nederland, HVN) carried out the research Positive Voices. Volunteers living with HIV were trained in interview skills to implement a standard questionnaire to their peers – other people living with HIV. The 40 trained volunteers carried out 468 interviews. Each interview took an average of two and a half hours. The volunteer interviewers were encouraged to reach out to own their social and personal contacts to recruit interviewees. Participants were also recruited through HVN's own channels, network organisations and HIV-treatment centres. Face-to-face interviews between two people living with HIV produce more information than research carried out through online surveys. In addition, this method is beneficial both to the interviewers and the interviewees in improving the way they deal with HIV. The method also strengthens their (support) networks.

The following questions were key to the research: What is the quality of life of people living with HIV in the Netherlands in 2014? What are their needs? To what extent are they acquainted with the Dutch Association of People Living with HIV (HVN) and how do they perceive the services of the organisation? What are the differences in the quality of life of people living with HIV in all their diversity and different backgrounds? The interview included 178 multiple-choice questions and 41 open questions. The results will guide HVN's policies in the coming years. The research was carried out amongst people with HIV over 18 years old and living in the Netherlands. The interviews took place in 2014 and the analysis in 2015.



## THE BACKGROUND OF THE PARTICIPANTS

The study made great efforts to ensure that research participation was broadly representative of the population of people with HIV who are aware of their HIV status in the Netherlands. The participant data was compared with the national HIV monitoring database of the Stichting HIV Monitoring, which registers anonymous demographic and epidemiological data of almost all people living with HIV and in care in the Netherlands. Below is a comparison between those participating in the study and those on the national register:

- The cultural background of participants reflects the geographic origin of people living with HIV in the Netherlands. For instance, 25% of participants in Positive Voices are from Africa or other non-Western regions, compared to 28% for the entire group of people living with HIV in the Netherlands.
- The age of participants in Positive Voices is also a representative sample: three percent more young people (under 36 years of age) participated, and four percent less people of 55+ years.
- More women (29%) participated in Positive Voices, when compared to the 20% of women among all people living with HIV in the Netherlands.
- More heterosexuals (40%) participated in Positive Voices, as compared to the 30% of heterosexuals among all people living with HIV in the Netherlands.<sup>1</sup>

<sup>1</sup> The Positive Voices research enquires about sexual identity, whereas the registration of people living with HIV involves the transmission route.



In addition, attention was paid to regional coverage and to the inclusion of heterosexual men, current or former sex workers, incarcerated people and drug users, as well as migrants from particular groups in the Netherlands that are known to include many people living with HIV.

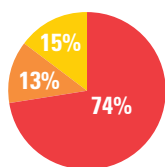
Participation in the research was always anonymous and the resulting data cannot be traced back to specific individuals. Due to the guaranteed confidentiality and the sensitivity of the information, all data were anonymized and no personal details on participants were saved after the research was completed. For reasons of privacy, no names of people living with HIV who participated in any manner whatsoever in the research are mentioned in the report.

### **Analysis by three characteristics relating to background**

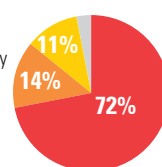
Various large cross-sections were made. The goal was to create separate groups large enough for comparisons to be made. Subgroups may sometimes appear to have been lumped together. For example, the larger group “MSM”. This includes homosexual and bisexual men, and other men who have sex with men – none of whom identify themselves as a heterosexual. All men who identified as heterosexual are included in the group of heterosexual men, even if they also identified as MSM, bisexual, migrant, drugs’ user, etc. This cross-section differentiates between women, heterosexual men and MSM. A breakdown has been made according to domestic area to identify important differences between participants who live in cities of more than 200,000 inhabitants, participants in other urban areas and in a rural environment. For the distinction according to cultural background, the group “other non-Western

regions” includes very diverse origins: from Asian, East European and Arabic to Caribbean and Latin American. “African” includes all sub-Saharan countries. Analyses were also made by demographic characteristics such as to age, number of years living with HIV, income level, level of education, etc.

**People with HIV in the Netherlands**



**Participants in Positive Voices**

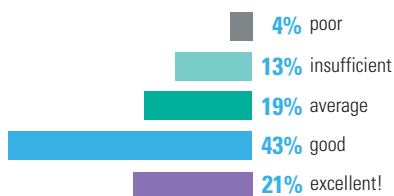


### **Some differences based on the three background characteristics**

- Women and heterosexual men are more likely to have children, are somewhat more religious, are more likely to be less educated and are more often dependant on benefits than men who have sex with men.
- 60% of heterosexual men live alone; for women and men who have sex with men, the figure is around 40%. There are also fewer singles amongst the group of Dutch or other Western origin, than amongst people of non-Western origin.
- People from Africa or other non-Western regions are younger on average than people of Dutch or other Western origin. The percentage of people of 55+ years is largest amongst men who have sex with men.
- Most men who have sex with men live in the large cities and have higher education levels and an above average income. 20% of men who have sex with men live at subsistence level; amongst women and heterosexual men, the figure is considerable, with 50%.
- The percentage of young people living with HIV is highest in provincial towns, and discrimination and exclusion based on HIV occur more frequently here than in large cities or in rural areas.
- People from Africa represent by far the largest percentage of both recent diagnoses and people who do not know how long they have lived with HIV. Veterans (people who have been living with HIV since before the year 2000) are most frequently found amongst HIV-positives of Dutch or other Western origin.

# PHYSICAL HEALTH

## How do you rate your physical health at the moment?



64% of participants in Positive Voices currently consider their physical health as good or excellent, 17% as poor or insufficient, and 19% are in between. Women and heterosexual men experience more health problems than men who have sex with men. 77% of the latter enjoy good or excellent health. 25% of people from other non-Western regions indicate suffering from insufficient or poor health.

About half of the participants are (very) optimistic about future physical health. About one fifth have a bleaker view of the future. People are often concerned about other conditions (comorbidity), but also about the many years of medicine use. When it comes to future expectations some participants compare to people who do not have HIV.

## Some differences in physical health based on the three background characteristics

- Women are less positive about their physical health.
- The majority of men who have sex with men consider their health as being very good and are more involved with sports than other groups.
- (Recreational) drug use occurs amongst half of the group of men who have sex with men and 10% of women. Heterosexual men and men who have sex with men are more likely to smoke, drink and take stimulants than women. People of African origin are less likely to smoke and/or use drugs.





### PERSONAL STRATEGIES

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Nearly all strategies that people apply to maintain their health as long as possible since they are aware of their HIV status involve life style adjustments:

- 1 Healthy food.
- 2 Exercise.
- 3 Sufficient rest; stress avoidance.
- 4 Reduce or give up alcohol, other drugs and/or smoking.
- 5 Take HIV medication according to prescription.

### EXTERNAL NEEDS

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- 1 HIV medication.
- 2 Access to good quality healthcare.
- 3 Money.
- 4 Social contacts.



#### PERSONAL STRATEGIES

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- Social contacts.
- Entertainment.
- (Volunteer) work.
- A positive outlook and enjoyment of life.
- Receive help, especially at the psychological level, and/or provide help.
- Religion and other forms of spirituality.

#### EXTERNAL NEEDS

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- Finding and keeping (suitable) work.
- Having sufficient money.
- Having rewarding social contacts.
- The acceptance of HIV by society and fighting stigma.



**I want to be able to discuss HIV-related matters with people who show understanding**

## MENTAL HEALTH

76% take pleasure in the things they do and 82% believe they have personal qualities to be proud of. Relatively speaking feelings of self-worth and self-image are lowest amongst heterosexual men. One third of the participants suffers from low energy levels and lack of lust for life; one third also reports sleeping problems. Men who have sex with men score higher than women and heterosexual men when it comes to energy and lust for life.

Women are more likely to have gone through experiences which have a negative impact on their current state of mind. This is most prominent amongst people from other non-Western regions (44%), followed by people from Africa (36%) and people from the Netherlands or other Western countries (29%).

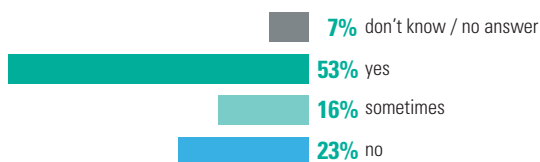
Concentration problems and depression are found more frequently amongst heterosexual men and amongst women. People from non-Western backgrounds are twice as likely to encounter these issues as people from the Netherlands or other Western countries. People in provincial towns are more likely to feel guilty or ashamed about the HIV infection than people in cities or in the countryside. Women and heterosexual men suffer more from this than men who have sex with men.

### **Some differences in mental health based on the three background characteristics**

- Women are more likely to suffer from psychological problems.
- Heterosexual men are slightly more ashamed of their HIV status.
- People from Africa or other non-Western regions are more likely to suffer from psychological problems and also more likely to seek comfort in prayer, faith or spirituality.
- Men who have sex with men feel good mentally and are proud of themselves, in contrast to heterosexual men, who have a lower self-image.
- Shame about HIV is practically non-existent amongst men who have sex with men, whereas this is often the case amongst the other groups.

# SEXUAL HEALTH

## Are you satisfied with your sex life in general?



53% are generally satisfied with their sex life, 23% are dissatisfied and 16% are between these two. Among men who have sex with men, 10% are not sexually active, while the figure for women is 34%, and 37% for heterosexual men. In provincial towns people are less satisfied with their sex life, less sexually active, and also less frequently tested for STDs than in large cities. Heterosexual men in particular indicate that HIV has an influence on finding a new sex partner (61%), while this figure lies under 40% for the two other groups. In contrast to men, a large majority of women do not have preference for a partner also living with HIV. The experience of being rejected due to HIV was regularly raised. Fear plays an important role amongst those who perceive HIV as having an influence on their enjoyment of sex: fear of transmitting HIV to sexual partners, as well as fear of HIV in the sexual partner, was seen as impacting upon fulfilling sexual relationships. Some participants reported that HIV led to them no longer having, or seeking, sexual contacts. Others reported no longer having sex due to absence of libido (sex drive, or erectile dysfunction, often reporting this was due to the side effects of medication).



One man was crazy about me,  
but when I told him, he ran off.

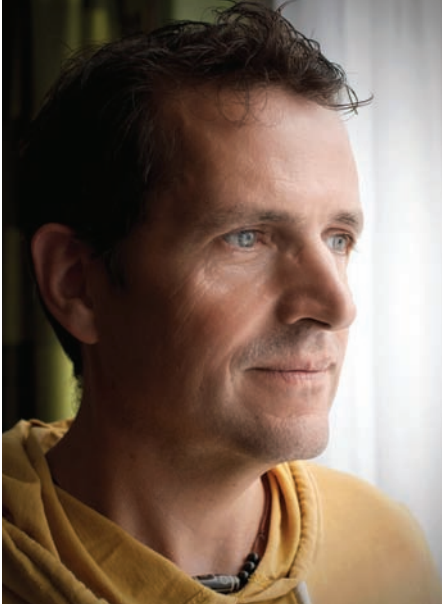
### EXTERNAL NEEDS

- The opportunity of meeting other people with HIV.
- Acceptance and understanding of one's partner with regards to HIV.
- A society better capable of dealing with HIV. More knowledge on HIV is reported as a requirement in this regard.
- More familiarity with the Swiss position, as this can lead to fewer stigmatizing reactions.



### Some differences in sexual health based on the three background characteristics

- Heterosexual men who are not involved in a relationship are somewhat more likely to actively look for a partner than women and men who have sex with men; in the process they more often experience HIV as an impediment. Heterosexual men, and women, are less sexually active than men who have sex with men, but are not less satisfied regarding feelings of excitement during sex.
- People of African origin are somewhat more active in looking for a partner; when asked they are less likely to disclose their HIV status than the other two groups.
- People of African origin are less sexually active and less satisfied about their sexual desire than the other two groups.
- Heterosexual men without a relationship are more eager to find a partner than women, or than men who have sex with men.
- Men who have sex with men are more sexually active and more satisfied with their



sexual desires than heterosexual men, or women.

## SOCIAL AND ECONOMIC CIRCUMSTANCES

About half of the interviewees are generally satisfied with their social and economic circumstances. These are often the participants from the Netherlands or other Western countries with a job, an adequate income, higher education and no children. 87% feel safe in their daily circumstances. Heterosexual men, and women, feel more frequently unsafe than men who have sex with men. People from Africa in particular feel insecurity. 54% does feel supported by parents or other family members, but women and heterosexual men are more likely than men who have sex with men to lack a good relationship with their family. People who originate from Africa are especially lacking in support from family, friends and/or a partner. Financial problems are more likely amongst heterosexual men, women, and people who originate from Africa or other non-Western regions.

### **Some differences in social and economic circumstances based on the three background characteristics**

- Women are financially somewhat less well off.
- Women and heterosexual men experience less support from their social environment.
- Men who have sex with men enjoy a good financial situation. They also experience support from their social environment, feel safe and are satisfied with their social circumstances.
- People from Africa or other non-Western regions feel less safe.
- People from Africa experience less support from their social environment than the two other groups.



HIV should be normalized, and no longer a stigma.

### PERSONAL STRATEGIES

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- 1 Finding and keeping (adapted or suitable) work.
- 2 Follow a training to improve access to labour.
- 3 Save and be frugal with money.
- 4 Do volunteer work for the social contacts and to increase the chances of finding a paid job.
- 5 Actively look for new social contacts and maintain existing contacts.

### EXTERNAL NEEDS

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- People with work: more job security.
- People without (paid) work: a paid job. This is more frequently an issue for participants from Africa or other non-Western regions; these participants are less likely to have paid work and more likely to live at subsistence level. Participants indicate that they feel discriminated against.
- Better financial support of people with HIV.
- Fight stigma and discrimination, in particular through better information on HIV. Participants believe that awareness of HIV in Dutch society is very important for their own circumstances, as this makes it possible for them to be open about their HIV.

# STIGMA, DISCLOSURE AND INFORMATION

## Disclosure of HIV

Participants are most likely to disclose their HIV status (more than 90%) to other people living with HIV, health-care workers, their partner and their social worker. The percentage of people who do not tell their partner is highest amongst people from Africa or other non-Western regions (7%). Amongst the group originating from Africa, 20% have told their parents, while this figure is about 50% amongst the other groups. Participants are least likely to have shared their HIV status with their customers (in case they have their own business), the Kindergarten or school of their children, community leaders, and teachers at their children's school. Almost half of employed men who have sex with men have told their boss. The other groups are more reserved regarding this issue.

### CONSIDERATIONS FOR NOT DISCLOSING:

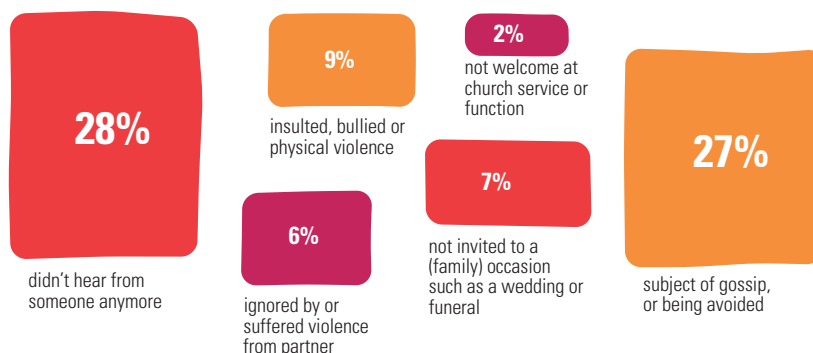
- To avoid stigmatizing reactions.
- People don't want to see their identity reduced to HIV.
- Protection of the immediate group or family (partner, children, family).
- Not to burden people with one's problems.
- It is not always relevant.

### CONSIDERATIONS FOR DISCLOSING:

- To fight stigma.
- Relief at no longer having to live with a secret.
- Relevant information for the other, for instance in a situation in which HIV could be transmitted, as in a sexual relationship, or in health-care.
- To get more understanding or support.
- HIV is part of one's identity.



### Percentage of participants with negative experiences after their HIV status was disclosed



Amongst heterosexual men with HIV, 17% don't know anyone else with HIV. That figure lies at 12% for women and at 4% for men who have sex with men. People who originate from Africa or other non-Western regions are more frequently confronted with their HIV status being shared without their consent – including within the health sector. People from Africa are most frequently (8%) pressured to disclose their HIV status, compared with 1% for the other groups.

### Negative experiences

The most frequently encountered negative experiences (more than one quarter) involve people who stop communicating, or gossip, or avoidance. A number of participants have had a negative experience with an institution, such as an insurance company, which turned them down or treated them differently. In addition, problems getting a visa are mentioned repeatedly. In daily life the most frequent negative reactions come from the school or Kindergarten, or else from the media or civil servants. Participants experience discriminatory reactions within the healthcare sector. This is more likely to occur amongst women and in provincial towns. Women are the ones who most frequently are confronted with discriminatory reactions from partners or parents. For people from Africa, it is most frequently friends or neighbours who react in a discriminatory manner. And yet, in the vast majority of situations, people primarily react with understanding and in a supportive manner when someone discloses their HIV status to them. Most people experience understanding and support.



### **The influence of HIV on one's feelings**

Seven out of ten people have the feeling that they have become stronger by disclosing their HIV status, and three out of ten do not. Heterosexual men in particular have the feeling they did not become stronger by disclosing. One out of five heterosexual men has told no one. The negative feelings pertaining to HIV that are most frequently reported:

- Afraid of consequences for one's partner, children and/or parents (26%).
- Afraid that people will no longer want to have anything to do with them (23%).
- Afraid of gossip (23%).

Many participants indicate that they have become more careful as a result of living with HIV. In addition, many participants have started living more consciously. Others experience a negative effect on themselves due to HIV; they have a decreased sense of self-esteem. This occurs more frequently amongst participants who have more recently become aware of their HIV status. HIV has little or no influence on the behaviour or decisions of yet another group of participants. Some people indicate that HIV did have an effect on them in the past.



**I have become more careful when  
it comes to trusting people.  
Not everyone wishes you well.**

### **The influence of HIV on decisions and behaviour**

Most frequently noted behavioural change relating to HIV:

- Not having (more) children (13%).
- Not marrying or becoming involved in a relationship (12%).
- Not applying for work or promotion (11%).
- Avoiding contact with family or friends (11%).
- Going to a more distant hospital or pharmacy (10%).

### **Fighting stigma**

39% consider that organisations do enough to fight stigma, while 61% find these efforts insufficient. Some of the participants are satisfied about the information and actions in the media to fight stigma relating to HIV. Other participants are extremely dissatisfied about this, because they still experience stigma, because the public awareness about HIV is insufficient, or because campaigns to fight stigma stress that HIV is found in particular amongst certain groups.

### **Information**

More than three quarters of participants indicate being informed about scientific developments relating to HIV, as well as of the Swiss position (In monogamous sero-discordant heterosexual couples without other STI's the HIV+ partner with an undetectable viral load does not transmit the virus to the partner when having unprotected sex). More than half are aware of developments regarding hepatitis C, and one third of the Partner Study (The Swiss study expanded with homosexual couples, showing that even when there are STI's, there is no transmission of HIV when the viral load is undetectable). During the interviews people were asked about the sources of information of which they are aware, and the sources they find reliable and up-to-date. The most frequently cited reliable and up-to-date source of information (mentioned by 42%) are HIV practitioners and HIV nurses. The best known sources of information provided by HVN are Hivnieuws and hivnet.org: 59% are acquainted with these and other sources of information of HVN. 38% of participants consider these up-to-date and reliable.

### **The importance of scientific breakthroughs**

Around one third of participants have a very positive impression of the developments. For some people, this optimism plays an important role in their acceptance of HIV. However, good news can also lead to negative feelings. When the outside world learns that people living with HIV can simply grow old without problems, then the medical problems experienced by people living with HIV are sometimes disregarded or not recognized. One group has little faith in developments and the opportunities they will provide them.

### **Some differences in stigma, disclosure and information based on the three background characteristics**

- Heterosexual men are somewhat less communicative about their HIV.
- Women experience stigma somewhat more frequently.
- People from Africa or other non-Western regions are less likely to have disclosed their HIV status to people in their environment and more likely to experience self-stigma.
- Men who have sex with men are more open about their HIV and experience more support from those who know. Stigma and self-stigma have practically no influence on their decisions or behaviour. However, this does not mean that they do not experience stigma as bothersome.



## Dutch Association of People Living with HIV (HVN)

### **Acquaintance with HVN**

45% (211) of participants are insufficiently acquainted with the services of HVN to be able to form an opinion. This lack of knowledge does not vary significantly according to the background of participants.

### **Appreciation of the activities of HVN**

Amongst participants who are acquainted with the services 61% have a positive appreciation of the activities of the HVN. Activities that are often mentioned and that are rated very positively include the activities for women, those of Jong Positief (Young Positive) and Poz&Proud, the workshop series Positief Leven (Living Positively) and the interviews of Positive Voices. 5% of participants who are aware of HVN confuse their activities with those of other organisations. 7% assess the activities negatively, 10% say that there is room for improvement, and 7% report feeling no need for activities. The most important suggestions for improvement:

- Pay more attention to people other than native Dutch men who have sex with men (9%).
- Organise more activities outside of Amsterdam and outside of Randstad (9%).

### **Appreciation of the advocacy**

52% of participants are not aware of HVN's advocacy work. Of the 48% of participants who are aware of it, 67% rank it as positive and very important, 13% as negative and 15% believe there is room for improvement. There is much criticism on the lack of attention for migrants and heterosexuals.

### **Appreciation of the information**

The information provision (hivnet.org, Hivnieuws and brochures) is one of the best known and most appreciated aspects of HVN. Yet 28% of participants are still unaware of this information provision. Amongst participants who are indeed acquainted with it, 67% are positive, 10% negative and 15% think there is room for improvement. Hivnieuws and hivnet.org are the best known sources of information. Although many are positive about Hivnieuws, it is also regularly called “boring”, with a difficult and uninviting writing style, and a lack of information for certain target groups. Various participants confuse information from HVN and that from other organisations.

### **Appreciation of the Servicepunt**

47% of participants are not acquainted with the Servicepunt. 59% of those who are (53% of participants), value it positively as being: professional, accessible, with sufficient up-to-date information, friendly, deals well with one’s privacy, provides very good help, provides a good explanation. 4% are negative, 7% think there is room for improvement and 18% has never had personal contact with it. Negative points that are mentioned include: the limited opening hours, not meeting a peer or like-minded person, no possibility for face-to-face contact; it is sometimes experienced as chaotic or as a type of service counter; people did not find the peer or specialist they were looking for.

### **The most important priorities of HVN for the coming five years, according to participants**

- Advocacy: lobby for the rights of all HIV positives; access to work, and to medical and psychological care; cultural shift towards more diversity in organisation and policy, both in terms of regional spread and target groups; take the issues relating to migrants seriously.
- Information provision: transmit up-to-date information on HIV and the risk of infection to the health-care sector, the labour market and the public at large; anti-stigma public campaign; HIV must take on a contemporary face. Pay more attention to young people, heterosexuals and migrants. Communicate HVN’s efforts and activities in order to increase involvement.
- Mutual contact and support: position HVN closer to patients in treatment centres; overall approach, involve not only people with HIV but also their environment. More attention to empowerment and health promotion; more diversified activities for like-minded people as a precursor to more mutual involvement within the organisation.

The board of HVN gave great importance to the results of the Positive Voices research in its policy plan for 2015-2020, titled “Equal, Connective and Energetic”.



