positive stimmen 2.0

Living with HIV, breaking down discrimination

Insights and results from a participatory research project on living with HIV in Germany

umfrage zu
hiv-bezogener
diskriminierung

positive-stimmen.de

IDZ
Institut für Demokratie
und Zivilgesellschaft

Deutsche
Aidshilfe

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‘positive stimmen 2.0’ is a collaborative project of Deutsche Aidshilfe (DAH) and the Institut für Demokratie und Zivilgesellschaft (IDZ). Further information on the project: www.positive-stimmen.de

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AMADEU ANTONIO STIFTUNG

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THEN
NOW

Dear readers,

There is good news and there is bad news: people living with HIV in Germany actually no longer experience the infection itself as a limitation. However, a large proportion feel affected by the prejudice associated with HIV.

Even today, people with HIV are fearful of disclosure and suffer from shame, blame and a lack of self-esteem – even more so if their skin isn't white, if they are women, if they live in rural areas, or if they have a low socio-economic status. They are shunned at work, experience rejection when dating, and in medical practices they are confronted with statements reminiscent of 1985, which seem to demonstrate not the least bit of willingness to find out about the developments of the last decades.

For the second time since 2011, people from the HIV positive community have asked others wo are living with HIV about life as an HIV positive person. As a project that has been developed and implemented in a participatory way, 'positive stimmen 2.0' conveys vivid impressions of aspects of positive living that reach beyond advancements in medical science. More than numbers and diagrams, it is individual statements that make us conscious of what stigmatisation and marginalisation can do to people – for example when we read statements of someone who is feeling "dirty, worthless and like garbage", prefers to avoid sex with a potential partner out of fear of disclosure, or reports that one particular sentence, after a long time spent in hiding, now rolls off the tongue more easily – "with less pain and suffering": I am HIV positive. Only few trust that society is now well informed about Treatment as Prevention and able to realise how much relief this message brings.

'positive stimmen 2.0' has given us an invaluable treasure trove of insights, and for this we thank everyone who has made this project possible, supported it and worked alongside it: the Bundesministerium für Gesundheit (Federal Ministry of Health) and the Institut für Demokratie und Zivilgesellschaft (Institute for Democracy and Civil Society), the Antidiskriminierungsstelle des Bundes (Federal Anti-Discrimination Agency), the project advisory committee made up of community and research representatives, GNP+ as the international organisation hosting the PLHIV Stigma Index, as well as the project team at Deutsche Aidshilfe (DAH). Mentioned above all should be the interviewers and interviewees who have given the project their voices: thank you all very much for your great commitment and your candour!

The first survey resulted in concrete measures against the stigmatisation and for the empowerment of people living with HIV, such as the Buddy Project and the Contact Point for HIV-related Discrimination. We would like to build on this work and appreciate the many important ideas that resulted from the June 2021 symposium. It has already become clear that we will need strong alliances to realise our ideas, e.g. regarding vocational education and professional development in the health care sector.

Notably, we have already achieved one of our goals: both interviewers and interviewees have reported how much strength they have drawn from their participation in 'positive stimmen 2.0' alone. This motivates and drives us to continue aiming high!

The Board of Deutsche Aidshilfe

Dear readers,

‘positive stimmen 2.0’ – the name itself refers to one of the central tenets characterising our work here at the Institut für Demokratie und Zivilgesellschaft (Institute for Democracy and Civil Society) and the Amadeu Antonio Stiftung (Amadeu Antonio Foundation) as its parent organisation: the perspective of those affected by dehumanisation and discrimination based on belonging to a certain group must be better heard in a democratic and diverse society. Only then can it bring about change in the dominant society and its structures, paving the way to a truly inclusive and open society.

In this context, different forms of dehumanisation must not be pitted against each other. Even 40 years after the global HIV/AIDS crisis, HIV-related stigmatisation and discrimination are not marginal issues, they continue to require increased public awareness, as well as countermeasures. The marginalisation of people living with HIV is closely linked to racist and homonegative discrimination. Where such practices and the related attitudes can prevail unopposed, right-wing extremists also find fertile ground, and can use prejudice and fear to agitate for their misanthropic world view.

It is worthwhile looking at this phenomenon also in light of its historical context: as we are experiencing during the current coronavirus pandemic, anti-Semitism, racism and homonegativity are ideologies that have since the emergence of HIV/AIDS been linked to the search for a group to blame and to scapegoat. Can we learn from the successes of dealing with discrimination and dehumanisation in the context of the HIV/AIDS crisis?

We are pleased to be able to carry out this important research project on HIV-related stigmatisation and discrimination in Germany together with Deutsche Aidshilfe. Five years after the foundation of the Institut für Demokratie und Zivilgesellschaft in Jena, the work on the ‘positive stimmen 2.0’ project takes its rightful place among a broad range of important studies in the fields of discrimination, ideologies of unequal human worth, and right-wing extremism. I thank the colleagues working on the project for their committed efforts under the scientific direction of Dr Janine Dieckmann, wishing you an inspiring read of the project results presented here, and I look forward to feedback, discussions and collaborating further in this field.

With best wishes,

Timo Reinfrank,
Executive Director of the Amadeu Antonio Foundation


TOGETHER

Dear interested friends,

I was very pleased to become patron of the ‘positive stimmen 2.0’ symposium. With this publication, we can now present you with the results of this important research project about the experience of stigmatisation and discrimination among people living with HIV in Germany.

The first part of the ‘positive stimmen’ project from ten years ago had broken new ground already: people living with HIV were asking other people living with HIV about their experiences with stigmatisation and discrimination. This approach has now been continued with around 500 interviewees, and as a joint project of Deutsche Aidshilfe (German AIDS service organisation) and the Institut für Demokratie und Zivilgesellschaft (Institute for Democracy and Civil Society). It is complemented by an online survey of around 1000 respondents.

At this point, I would again like to expressly laud the chosen approach of peer interviewing as exemplary: interviews on an equal footing not only engender trust and in-depth conversations – they also empower both participating parties: interviewees and interviewers alike.

We know that HIV infection can now be treated successfully, and that effective treatment reduces transmissibility practically to zero. But has this development also made experiences of discrimination less common?

This, as we know very well from our own counselling practice, is unfortunately not the case. It is especially frustrating that, even in the important field of health care services, knowledge deficits, prejudice and irrational fears still lead to the stigmatisation of people living with HIV, exemplified by the fact that dentists, for example, at times refuse to treat people. This is even worse for those affected, as they are subject to a power imbalance and are scarcely able to avoid situations where they are disadvantaged. Discrimination is also experienced in other areas of life – whether at work, at home, or when dealing with government authorities.

However, encouragement should be drawn from the fact that people living with HIV can fall back on a network whose strength is second to none. The community provides support, lively exchange, and emotional backing. This is the fruit borne by decades of work by peer support organisations!

The community and researchers have jointly developed recommendations for action as part of this project. My hope for all of us is that these recommendations will be heeded and implemented. Protection from stigmatisation and discrimination means participation in and quality of life, as well as maintaining physical and mental health. These are fundamental rights, which we must insist on – for everyone.

Bernhard Franke, kommissarischer Leiter der Antidiskriminierungsstelle des Bundes (Acting Head, Federal Anti-Discrimination Agency).

0.0 Contents

Introduction

1.0

1.0 Introduction

Dear readers,

In this brochure, we would like to offer you insights and results from the ‘positive stimmen 2.0’ project.

How are people with HIV living today? Are they being discriminated against? If yes – where, and in what form? Are they experiencing stigmatisation?

These are some of the questions we pursued in this research project. This brochure provides some background to the study, core results from the surveys, as well as recommendations – developed together with many partners – for interventions and actions. These are intended to contribute to people living with HIV experiencing less stigmatisation and marginalisation in the future. You can find the complete research results in our scientific report, which you can download at **www.positive-stimmen.de**.

We, the Deutsche Aidshilfe (DAH) and the Institut für Demokratie und Zivilgesellschaft (IDZ), have conducted the ‘positive stimmen 2.0’ research project together. The study consists of two modules:

- A peer survey based on the global ‘People Living with HIV (PLHIV) Stigma Index’, which is coordinated internationally by GNP+, the ICW and UNAIDS (Module A).
- An online survey complemented by focus groups (Module B)

The results of the first round of the ‘PLHIV Stigma Index’ conducted in Germany in 2012 have already become central to the development of anti-discrimination activities, and have strengthened those involved and the communities.

‘positive stimmen 2.0’ is a community based and participatory research project. Without the many participants who – despite the particular challenges posed by the coronavirus pandemic – were intensely committed to the project and engaged with it creatively, we would not be able to present these results to you.

A central goal of ‘positive stimmen 2.0’ and the PLHIV Stigma Index is for the results to have an impact, and for people living with HIV to become empowered. We know from the peer interviewers that the many conversations they had on an equal footing with their interviewees have already led to a feeling of self-

empowerment. The project is also intended to help break down structural discrimination and marginalisation. For this purpose, recommendations for action were developed on the basis of the results.

Participation and involvement in the context of the HIV positive community and HIV-related anti-discrimination activities do not end with the conclusion of the research project. With this in mind, we now also place the results of ‘positive stimmen 2.0’ in your hands.

In the 2012 project brochure, Dr Carolin Vierneisel, project coordinator of the first ‘positive stimmen’ survey in Germany, and member of the current project advisory committee for ‘positive stimmen 2.0’, articulated three goals. To accompany this current 2021 brochure, we would like to put these to you to as a source of hope and encouragement:

- **Become informed** about the results of ‘positive stimmen 2.0’.
- **Let yourself be inspired**.
- **And let yourself be spurred on:** spurred on to work with the results, to implement the recommendations for action, and to become (even more) active against discrimination.

It is our hope that this brochure may activate you – so that people living with HIV will not just be able to keep living well with their infection, but in future also experience less stigmatisation and discrimination.

The ‘positive stimmen 2.0’ team

Heike Gronski, Matthias Kuske, Eléonore Willems (DAH)

Dr Janine Dieckmann, Franziska Hartung, Marie-Theres Piening, Clemens Lindner, Marie Kaiser (IDZ)

What do we mean by stigmatisation and discrimination in the context of ‘positive stimmen 2.0’?

Stigmatisation

Analogous to the first ‘positive stimmen’ project, we use the term **‘stigmatisation’** instead of ‘stigma’ in this brochure because it is about the **description of a complex societal and individual process of attribution and judgement**, not about a negative or disadvantageous characteristic that a person possesses. By ‘stigmatisation’, we therefore mean the process of **ascribing negative attributes** to people or groups of people on the basis of one or more particular **characteristics**. These (ascribed) attributes are defined as ‘deviating’ from **societal norms and values**, which brings with it a range of devaluing interpretations (particularly blaming). When (societal) ideas about normality change, stigmatising attributions may also change in some circumstances. Numerous characteristics exist that are stigmatised by society. They may be present in people from birth, but some also vary or are added along the life course.

Examples of socially stigmatised characteristics:

- Skin colour
- Culture/origin
- Sex/gender identity
- Sexual orientation
- Religion
- Physical and cognitive disability/impairment
- Homelessness
- Substance use
- Chronic illness
- Promiscuity
- Sex work

People who deviate from a societal idea of normality based on these characteristics are primarily perceived through the lens of said characteristic(s) (‘foreigners’, ‘the disabled’). This causes a distinction between **‘us’** and **‘them’**, which is associated with stigmatising attributions ascribed to whoever ends up in the ‘them’ category. This leads to **distancing** from this group of people, which is devalued and marginalised as a result. From a societal perspective, this finally results in a **lower social status** and reduced **participation** of those people or subgroups who are stigmatised. Thus, there is a **connection between stigmatisation and societal power structures**.

Even when people are themselves socially stigmatised based on some characteristic, they are still able to stigmatise others, as they, too, have learned social norms and reproduce these in relation to other characteristics. For example, a gay, white cis man (himself subject to social stigmatisation) may in turn be stigmatising people living with HIV or people with migration experiences.

Discrimination

When concrete disadvantage arises from stigmatisation, we speak of discrimination. Discrimination can be defined as disadvantage imposed on persons or groups on the basis of the attribution of a socially stigmatised characteristic. While stigmatisation does not need to result in discrimination to have negative effects, discrimination always results from societal stigmatisation.

Discrimination can take place on several levels – the individual level (from person to person) and the institutional level (from institutions to persons). Moreover, discrimination can also appear on a (socio-) structural level, e.g. when we talk about disadvantage with respect to social participation and access to resources, or about social inequality. Discrimination takes place on the basis of all socially stigmatised characteristics.

As they are socially and culturally determined processes, it is possible to counter stigmatisation and discrimination, and to take action so that people who experience discrimination will experience less of it in the future.

Measures against stigmatisation can start with the person who carries the characteristic, e.g. through **empowerment** or **developing resilience**, and also on the structural and societal level. Protecting minorities from discrimination is an important principle of our democracy. All the more important is **legal protection from discrimination**, which was enacted in Germany in 2006 in form of the **General Act on Equal Treatment (Allgemeines Gleichbehandlungsgesetz, AGG)** – at least with respect to some areas (e.g. the employment and housing markets, goods and services) and on the basis of some personal characteristics.

> **“Discrimination is the illegitimate unequal treatment of people (or groups) on the basis of the attribution of a specific characteristic [...]. The characteristics concerned are legally stipulated in [AGG] § 1 of the Federal Republic of Germany.”**
>
> *Source: Dieckmann 2017 www.idz-jena.de/wsddet/was-ist-diskriminierung-ueber-illegitime-ungleichbehandlung-demokratie-und-sand-im-getriebe*

In practice, and in the lived experience of those affected, discrimination manifests itself in various forms:

- **Insult, bullying, harassment**
- **Exclusion** – e.g. when, as a matter of principle, gay men are not permitted to donate blood
- **Restrictions** – e.g. when gays, lesbians, bisexuals or trans* people are not permitted to marry/adopt children
- **Criminalisation** – e.g. when young black men are systematically subjected to police checks more frequently than others
- **Preferential treatment** – e.g. when German citizens are preferred as tenants and, associated with this, **disadvantage** – e.g. when looking for a place to rent or a job is made more difficult because of a non-German-sounding name
- **Segregation** – e.g. when people with a disability are employed in sheltered workshops without the opportunity to participate in the mainstream employment market
- **Access** – e.g. when public buildings are not wheelchair accessible.[1]

Like stigmatisation, discrimination is also a very complex phenomenon: many people experience discrimination not just on the basis of a stigmatised characteristic. Discrimination can be experienced on the basis of several characteristics, e.g. in one instance on the basis of skin colour, and, in another situation, on the basis of sexual orientation. Different dimensions of discrimination also blend and become interwoven, e.g. when women* with a disability experience discrimination differently to men* with a disability. This is also called **intersectionality or multidimensional discrimination**.

Perceived stigma and internalised stigmatisation

Even in the absence of concrete experiences of discrimination, HIV-related stigmatisation has an impact on those affected. This is because they are themselves part of society, have absorbed its value system, take in negative attributions, and are aware of the fact that they may themselves potentially be affected by stigmatising and discriminating reactions. This aspect is called **perceived or anticipated stigma**. The perception of stigmatisation can lead to a fear of rejection and marginalisation. Often, those affected conceal or hide the potentially stigmatised characteristic if possible, and avoid certain situations where discrimination could take place.

Negative societal attributions are also often adopted by those affected as part of their self-image, and thus internalised. We then speak of **internalised stigmatisation**. It has previously also been referred to as self-stigmatisation. This term, however, is misleading, as the person is not stigmatising themselves, but internalises the prevailing stigma. Individuals perceive themselves as deficient and thus devalue themselves. This can result in feelings of shame and guilt, social withdrawal, stress, fear, and depression. As a response, however, internalising stigmatisation is not inevitable. Stigmatising attributions can also be processed and overcome in different ways by those affected, e.g. through empowerment, activism, and involvement.

HIV-related stigmatisation and discrimination

People living with HIV are often affected by stigmatisation and discrimination.

Their perceived and internalised stigmatisation, and their experiences of discrimination can have substantial effects with regard to quality of life and health – a relationship confirmed by the results of 'positive stimmen 2.0'.

At the same time, stigmatisation presents the biggest obstacle to HIV prevention. On the one hand, marginalisation (incl. the fear of it) and stigma-based theories of disease (e.g. assumptions regarding so-called 'risk groups' and routes of transmission) affect preparedness to be tested for HIV and, on the other hand, HIV testing is not actively offered to people who are not ascribed any risk – especially women over 40 years of age. Stigmatisation and discrimination are thus contributing to the fact that, in Germany, even today 1/3 of HIV infections are not detected until a late stage, which means that people are facing significant health disadvantages for not being able to benefit from timely HIV treatment.

Intersectional aspects also play a large role with regard to HIV. From the beginning, HIV was portrayed as an infection that affects 'others'. HIV is thus – regardless of the statistical facts – primarily being attributed to groups that had been stigmatised even before the beginning of the HIV pandemic, such as 'promiscuous' gay men, sex workers, people who use drugs, and black people.

In addition, many experience HIV stigmatisation not only on the basis of their HIV infection, but also on the basis of other stigmatised characteristics, e.g. as a gay man, as a trans* person, as a black person or person of colour, as a woman, as a person who uses drugs, or as a sex worker. These forms of stigma not only lead to 'more' stigmatisation and discrimination by accumulation, they also interweave, and so lead to individualised experiences of stigmatisation and disadvantage. In this way, the life of an HIV positive, young gay cis man who is middle class and has a university degree may not differ so much from that of an HIV negative man, while an HIV positive black woman without residency permit and health insurance is likely to find it difficult to obtain life-saving medication and take care of her health.

[1] *Source: adapted from Amnesty International www.amnesty.ch/de/themen/diskriminierung/zahlen-fakten-und-hintergruende/was-ist-diskriminierung.*

The project

2.0

2.1

Project history and background

2.1.1. The ‘People Living with HIV (PLHIV) Stigma Index’

Whether on the basis of HIV, sexual orientation, racist attributions, drug use or other characteristics: stigmatisation and discrimination can negatively affect the physical and mental health, as well as the quality of life of people living with HIV. The goals of the global PLHIV Stigma Index are to bring to light the discrimination experiences of people living with HIV through a community-based research project, and to develop concrete interventions and recommendations for action in response.

The PLHIV Stigma Index was developed by the global network of people living with HIV (GNP+), together with the International Community of Women living with HIV (ICW), the International Planned Parenthood Federation (IPPF, PLHIV Stigma Index 1.0 only), and UNAIDS. Since 2008, it has been implemented using a standardised questionnaire in more than 100 countries across the globe. In Germany, the PLHIV Stigma Index 2010–2012 was carried out by Deutsche Aidshilfe under the title ‘positive stimmen’.

Following the GIPA (Greater Involvement of People Living with HIV) principles, people living with HIV are responsible for the project’s processes on all levels. Implementing the Stigma Index in a country is intended to contribute to the development of national networks of people living with HIV, reflect the diversity of the community of people living with HIV, and, last but not least, strengthen the advocacy of people living with HIV.

Based on the results of the first PLHIV Stigma Index, the revised version ‘PLHIV Stigma Index 2.0’ was launched at the World AIDS Conference in Amsterdam in 2018. This questionnaire includes new areas of investigation regarding stigmatisation and discrimination of different population subgroups among people living with HIV, an extended section on the health care system, and reflects changes to the HIV epidemic and the global response.

The PLHIV Stigma Index 2.0 was implemented as part of ‘positive stimmen 2.0’ in form of Module A (peer interviews).

2.1.2 Research design

Module A: Participatory research

- **450 peer interviews**
- **Standardised questionnaire (PLHIV Stigma Index)**
- **Quantitative**
- **Data collection between May 2020 and January 2021**

→ Description in Chapter 2.2

Module B: Mixed methods approach

B1: Online survey

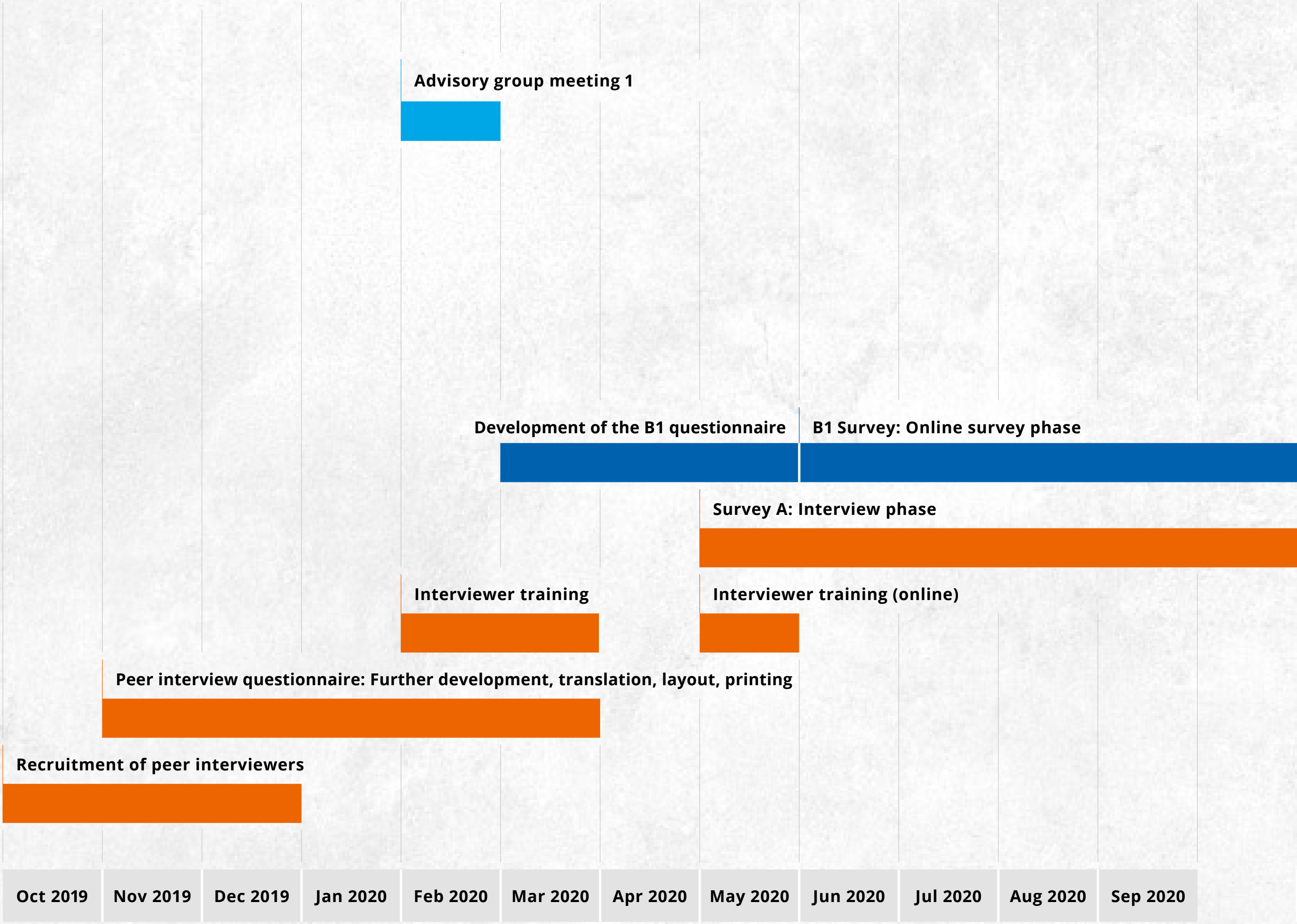
- 935 participants
- Questionnaire design by IDZ and DAH
- Quantitative
- Data collection between June and October 2020

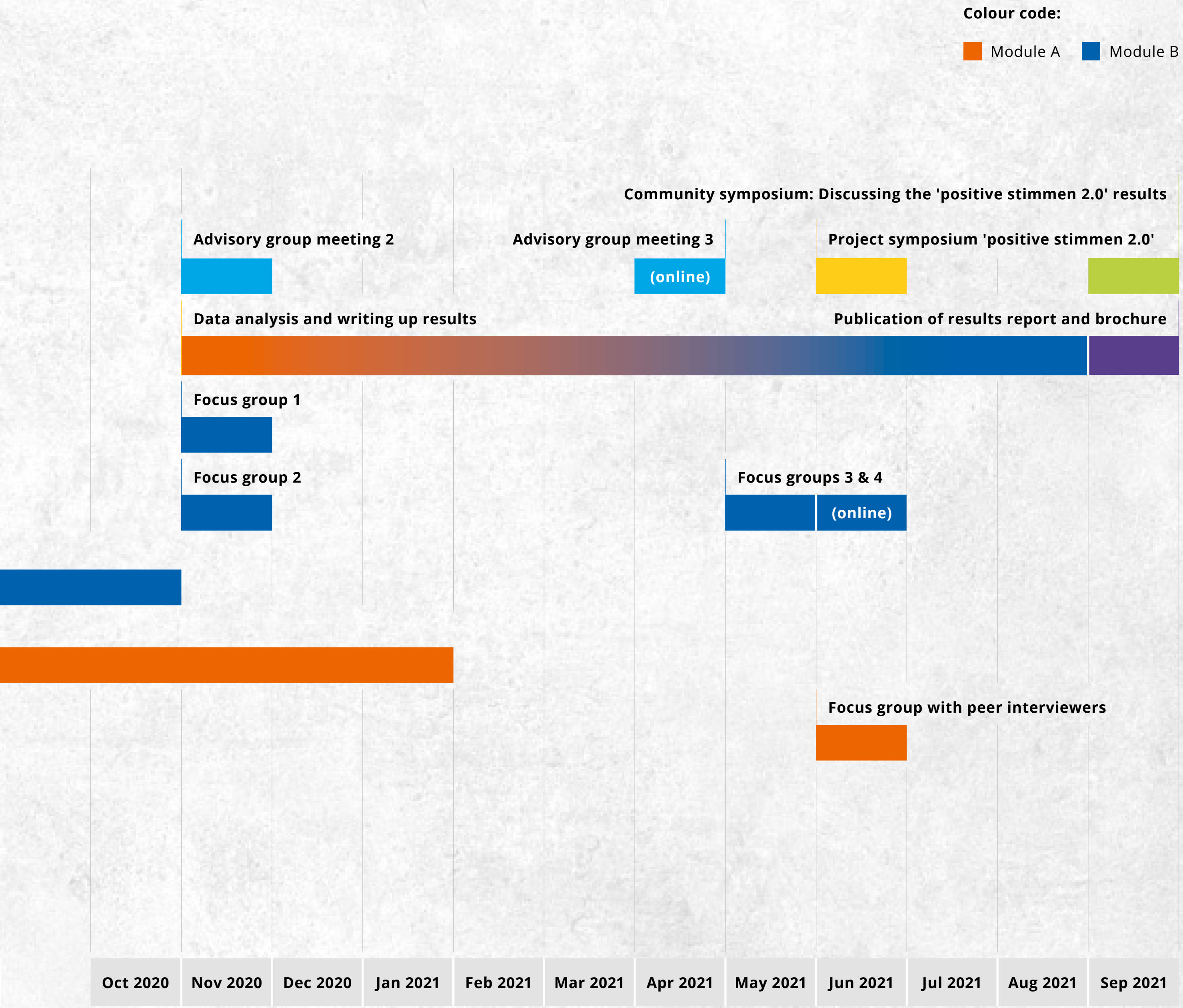
B2: Focus groups

- 4 Focus groups and subgroups focusing on different topics
- Qualitative
- Data collection between November 2020 and June 2021

→ Description in Chapter 2.3

2.1.3 Project timeline




Colour code:
Module A
Module B
Community symposium: Discussing the 'positive stimmen 2.0' results
Advisory group meeting 2
Advisory group meeting 3
(online)
Project symposium 'positive stimmen 2.0'
Data analysis and writing up results
Publication of results report and brochure
Focus group 1
Focus group 2
Focus groups 3 & 4
(online)
Focus group with peer interviewers
Oct 2020
Nov 2020
Dec 2020
Jan 2021
Feb 2021
Mar 2021
Apr 2021
May 2021
Jun 2021
Jul 2021
Aug 2021
Sep 2021


00:33:09

The virtual 'positive stimmen 2.0' symposium took place on 5th and 6th June 2021. For many participants, the panel discussion with peer interviewers was the highlight of the event. The symposium served to present and discuss the initial results of the project, and the participatory development of recommendations for action by working groups on specific topics.

2.1.4 Project participants

‘positive stimmen 2.0’ is a participatory project. It thrives on the involvement of people living with HIV in particular.

Peer interviewers

33 people living with HIV have used interviews with others living with HIV to collect data on HIV-related discrimination. According to the participatory research approach, no scientific experience was required to participate as an interviewer. The central criterion was that the person was living with HIV. In addition, the project tried to select interviewers in order to achieve an appropriate level of regional representation, as well as representation from different communities. This was intended to ensure that the group of interviewees was as diverse as possible, so that the data would reflect the experiences of a range of groups and communities of people living with HIV.

In this brochure, 12 of the 33 peer interviewers describe their experience of participating in the project (see Chapter 2.2).

The project advisory committee

A 10-member advisory committee worked alongside the project and provided advice. It was composed of 6 community representatives, 3 members from the scientific community, and one representative of the Federal Ministry of Health. It met three times. Moreover, the committee was included on important topics by group email.

The tasks of the committee were as follows:

- Supporting the project from the scientific and community perspectives
- Advising the project team
- Process support and suggestions
- Support for analysis and interpretation of the data collected, as well as checking and providing feedback on project results.

The members of the ‘positive stimmen 2.0’ project advisory committee were Michael Dyrna, Anke Geißler, Aminata Giese, Prof. Dr Kai Jonas, Edgar Kitter, Kerstin Mörsch, Sabin Schumacher, Christian Szillat, Prof. Dr Hella von Unger und Dr Carolin Vierneisel.

Screenshot from the last advisory group meeting

Collaboration between Deutsche Aidshilfe and the Institut für Demokratie und Zivilgesellschaft

‘positive stimmen 2.0’ is a collaborative project of Deutsche Aidshilfe(DAH) and the Institut für Demokratie und Zivilgesellschaft (IDZ). It was carried out by teams from both organisations.

Deutsche Aidshilfe

The Deutsche Aidshilfe (German AIDS Service Organisation, DAH) is the peak body for around 130 associations and agencies in Germany. Its various campaigns target groups in society who are particularly at risk of HIV/AIDS and other sexually transmitted infections. It advocates publicly for people living with HIV/AIDS, as well as in the areas of policy, science and medical research. The first ‘positive stimmen’ survey on HIV-related stigmatisation conducted in 2012 is a milestone for anti-discrimination activities at Deutsche Aidshilfe. ‘positive stimmen 2.0’ follows in its footsteps. As part of the project, the DAH’s core responsibility focussed on the peer interviews, and on the involvement of people living with HIV and their communities.

The Institut für Demokratie und Zivilgesellschaft

The Institut für Demokratie und Zivilgesellschaft (Institute for Democracy and Civil Society, IDZ) – Thuringian bureau for documentation and research against enmity between groups – is a non-university research institution under the auspices of the Amadeu Antonio Foundation. In relation to ‘positive stimmen 2.0’, the IDZ was responsible for scientific coordination and oversight. The IDZ team focussed on designing and implementing Module B – a combination of a quantitative online survey complementing the questions posed in the peer interviews, and qualitative focus group interviews.

The ‘positive stimmen 2.0’ project was funded by the Bundesministerium für Gesundheit (Federal Ministry of Health).

Gefördert durch:

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für Gesundheit

aufgrund eines Beschlusses
des Deutschen Bundestages

2.2 positive stimmen 2.0: a participatory research project (Module A)

2.2.1 What is participatory research?

Participatory research investigates topics in partnership with people who know about them from their own lived experience. Stakeholders from within the researched settings are involved in a particular way: whereas they are merely being questioned in most cases of classical research, in participatory research they are included as co-researchers (or peer researchers). They participate in all stages of the research project – from planning to data analysis. For community members, participation not only means *taking* part, but actually *being* part of the project. This means that co-researchers have decision making authority as part of the research process.

The 'Levels of participation' model according to Wright/von Unger/Block (2010) distinguishes nine different forms of participation of community partners. It can be used to identify the point at which a research process can be considered participatory. In this model, instrumentalisation (1) and instruction (2) are non-participatory, or merely give the impression of participation, and should be avoided. Information (3), consultation (4) and inclusion (5) are considered important precursors to participation. According to this model, however, participation only begins when peer researchers are able to share in decision making with respect to the project design (6), share decision making regarding project components (7), or themselves make important decisions about the project (8). Level 9 describes the processes of community-owned initiatives and goes beyond participatory research.

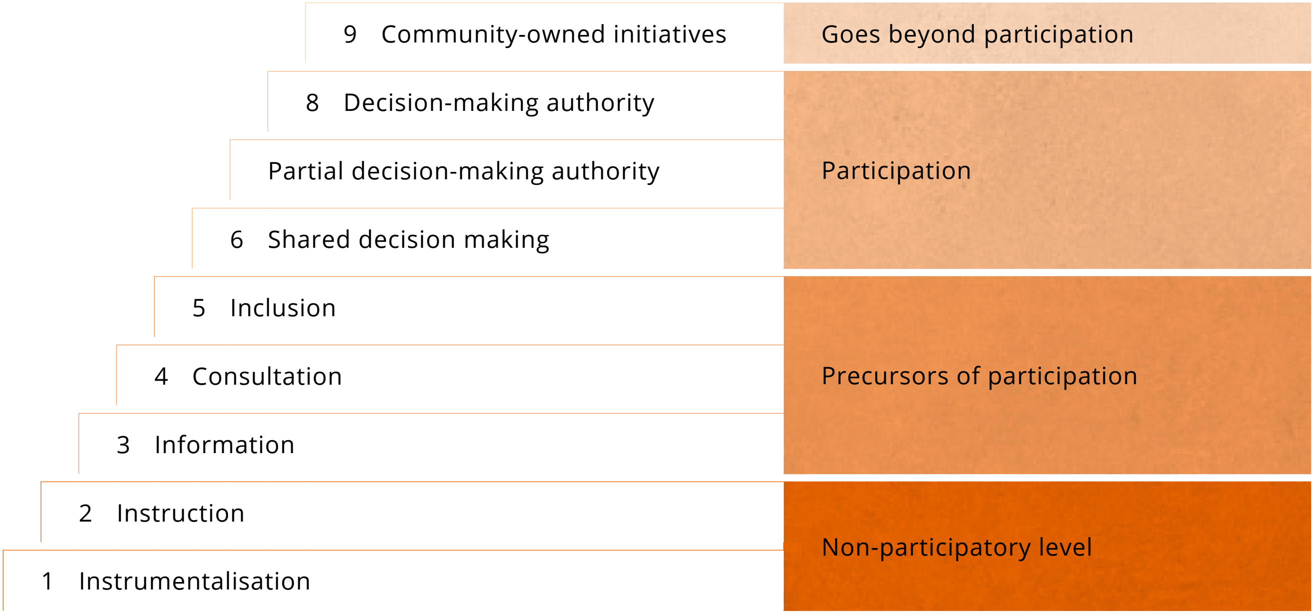
Both partners are intended to benefit from the synergies between scientists and practitioners: the social reality being investigated is then better *understood*, and is also being *influenced*. In her book 'Partizipative Forschung – Einführung in die Forschungspraxis' (participatory research – an introduction to research practice), Hella von Unger articulates this as follows:

> **"The creation of knowledge is an essential part of participatory research, but not its end point or main goal. Essentially, it is about opening up approaches and alternative courses of action through reflection and the generation of new knowledge."**

The evidence, data, and statements gained throughout the research process are intended to help communities to advocate for their political interests.

Another core component of participatory research is that the process creates added value for the participating peer researchers. Through acquiring new competencies (e.g. as a result of training and working with data), through new insights and through empowerment processes, peers can, in the best case scenario, emerge strengthened from having participated.

Stufen der Partizipation



9 Community-owned initiatives	Goes beyond participation
8 Decision-making authority	Participation
Partial decision-making authority	
6 Shared decision making	
5 Inclusion	Precursors of participation
4 Consultation	
3 Information	
2 Instruction	Non-participatory level
1 Instrumentalisation	

Staged model of participation (according to Wright et al. 2010c)

2.2.2 Participatory research in practice: peer researchers explain Module A (peer interviews)

According to the GIPA principle ‘Nothing about us without us!’, people living with HIV were involved in all stages of the project. As a global network of people living with HIV, **GNP+** has initiated the Stigma Index and co-designed its questionnaire. The network coordinates the project on the international level. The **project advisory committee** that worked continuously alongside the project team and provided advice consisted mainly of community representatives. The **project symposium** was intended to afford as many people living with HIV as possible the opportunity to contribute to, and, in particular, to co-develop the recommendations for action presented in Chapter 4. Community representatives were involved during the entire project period through community symposiums and the involvement of networks, as well as through presentations at conferences.

The bulk of community participation consisted of the 33 people living with HIV who worked on the project as peer researchers. The many different voices of these interviewers explain their own experience of the project in the next chapter. Their numerous contributions come from three different sources: responses to a questionnaire about the interviewers’ experiences during the project, which they provided shortly after the interviewing period; excerpts from the panel discussion at the concluding project symposium, and excerpts from a focus group with six interviewers conducted on 6 June 2021.

PREPARATION FOR THE TASK OF INTERVIEWING AND SUPERVISION

Training

> **“That our colleagues from the IDZ were also present at the training created a foundation of trust. It wasn’t just like ‘the scientists are just crunching numbers, and we are only numbers’, but it created trust in that everything will be handled well.”** *Steffen*

“We were still able to meet face to face then, and were briefed accordingly. From psychological tricks for us, like ‘how can we handle situations that are difficult for us?’, to all the legal stuff (privacy and data protection, confidentiality, transparency etc.). We looked at the questionnaire together at a time when we were still able to have some input. Meaning we were still able to intervene and make corrections where questions had not been defined clearly enough, or where misunderstandings might arise, and we could design things in a way that made us feel comfortable, and able to pass this feeling on to the interviewees.” *Isabel*

→ Recruiting interview partners

“As I haven’t been around the community for that long and don’t know so many people who are HIV positive, I had to join groups in order to do the recruiting: Pro Plus Hessen, Aids-Hilfe Gießen etc. But because of corona, the Aids-Hilfe Gießen was closed until further notice, which made it even more difficult to find people. But through the meeting at Waldschlösschen and the requests coming from the DAH, in the end there were quite a few after all.” *Nicole*

Hallo liebe Nürnbergerinnen und
Nürnberger, macht bitte mit:

Ich bin Karin, 64 Jahre, geschieden,
Mutter und seit 24 Jahren wissentlich HIV-positiv.
Du wohnst im Großraum Nürnberg und hast Zeit und Lust mitzumachen?
Dann melde dich gerne bei mir: community.nuernberg@gmail.com

Wir können das Interview vor Ort, im geschützten Raum der Aidshilfe
Nürnberg, oder an einem anderen Ort deiner Wahl machen.
Wenn die Entfernung zu groß ist, habe ich gute Erfahrungen mit einer
gesicherten Videokonferenz gemacht. Deine Daten sind geschützt, und
werden nicht weitergegeben.
Du kannst wählen, in welcher Form du die
Befragung machen möchtest.

Liebe Grüße von Karin

Several interviewers created profiles of themselves for the purposes of recruiting interview partners, as Karin has done in this example.

Supervision in the form of virtual debriefing meetings

erschrocken, wie viel Stigma und Diskriminierung es noch gibt

Sehr dankbare Menschen kennengelernt

Danke für die Betreuung der DAH!

wertvoll

aufregend!!!

wertschätzend

Es war anstrengend, aber hochinteressant und auch teilweise sehr emotional. Ich habe mir bekannte Menschen neu und/oder von einer anderen Seite kennengelernt.

war für mich eine sehr gute Erfahrung ✓

es war aufgrund von Corona auch anstrengend, weil vieles nicht so ging, wie es schön gewesen wäre…

viele unterschiedliche Umgangsarten

Das Thema Selbststigma, scheint ein wichtiges Thema für die Zukunft zu sein.

neue TN* für die Positivengruppe in MS

Sehr interessant

Es war eine sehr intensive Zeit!

Tolle Leute kennengelernt

Es war spannend und es waren intensive Gespräche

überrascht, wie schwierig es doch war

schwierig, überraschend,interessant, emotional

viel Unwissenheit

erschrocken über viele Ängste

viel Vertrauen und Sympathie gegenseitig

Ich war oft sehr beeindruckt und Vertrauen

Ich war keine Interviewerin, aber finde es unglaublich was ihr gerockt habt!!

Sehr dankbar daran teilgenommen zu haben

Neue Sichtweisen

[illegible] begeistert, wie gut meine [illegible] Partner mitgemacht haben. Es war teils sehr intensiv.

Virtual whiteboard on which participants in the debriefing meeting on 21 January 2021, at the end of the interview phase, could document their impressions on the topic 'What was it like to be an interviewer?'.

PEER INTERVIEWS

Interview setting

"As the interviews were about to start, the first lockdown happened. I thought 'What do I do now?' … Then I looked for spots in public parks where I could do interviews outdoors. After I had checked out one such spot with a friend, I conducted almost all the interviews there." *Brigitte*

"My shortest interview lasted an hour, but my longest was four hours. The shortest ones were those I conducted online via Zoom. They went more quickly, because face to face you can meet on a more intimate level. That was a bit of a downer for me, because the training was about doing interviews side-by-side, i.e. you sit next to each other looking at the same questionnaire, and it was a pity this wasn't possible." *Andreas*

"It made you very creative as far as choosing interviewing locations was concerned. This was actually something quite enriching. Otherwise, it would maybe all have happened on Aids-Hilfe premises. Sitting amongst nature can be a bit empowering, and make you more relaxed." *Dennis*

The questionnaire for the peer interviews with 78 questions was available in German, English and Russian.

Experiences with the peer approach during the interviews

"I tried to develop the interview as a relaxed conversation. I made sure we sat together for a while after the interview. The interviewee could then ask me some personal questions. I wasn't just the person collecting data then, but I also gave something of myself, my experiences, and how I handled various situations." *Brigitte*

"I met one of my interview partners at the Aids-Hilfe. Before I asked her whether she wanted to participate, I told her confidently 'I am HIV positive' … she just stared back at me and was very surprised that I would say it so casually. It is empowering to see other people for whom HIV is not a problem. There was no way she could say no after that … (laughter)" *Nicole*

"I now have three new people in our local PLHIV group. That's a beautiful outcome as well." *Andreas*

"Many people, whom I had already known for a long time, did open up to me in a whole new way. This was quite empowering for both sides." *Dennis*

"It was a very thankful task, especially during these difficult corona times, where many people didn't have any contact anyway, that someone gave two hours of their time just to talk about this issue." *Denis*

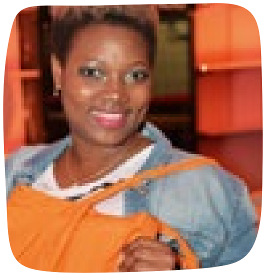
"Another HIV positive person is most likely able to empathise with what was happening at the moment you experienced HIV-related discrimination, or when you hit a sticky spot somewhere in your life. When these stories were told, I knew how it felt, and people sensed this." *Christian*

"My most intense experience was the candour of one woman, whom I was privileged to get to know, with her fears and feelings. I was overwhelmed and astonished by how differently I had experienced her before. She hides her HIV in everyday life, but during the interview she was totally frank with me. I realised that she is a totally different person when she can speak openly. It triggered astonishment in me and a deep sadness." *Karin*

EMPOWERMENT AND ADDED VALUE FOR PEER INTERVIEWERS

➡ Changes to own self-image as a person living with HIV

"The range of stories I heard gave me more courage to talk about HIV. There were several people who are very scared of talking about it and haven't even told their parents. This, in turn, made me think that I don't want to live that way." *Nicole*

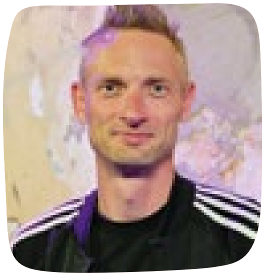


"I believe I have to divide my life afresh, into 'before the interviews' and 'after the interviews'."

"Because of the interviews, I have come out completely during those six months. (...) As recruitment was difficult because of corona, I made a flyer with my photo and my private details on it. I sent it to everyone and uploaded it to my WhatsApp status. And, with that, I triggered a coming out avalanche for myself. It was an amazing experience. And for my husband as well, who grew alongside me on this issue."

"It gave me such a boost! The results of the study, according to which those who are out only a little bit experience the greatest level of stress, and those who are almost completely out are living much more carefree lives, that's what I experienced first-hand! Yes, I can definitely confirm this result." *Andreas*

"For me it wasn't so much a change, but confirmation. That the path I chose with my infection had been the right one. My interview partners encouraged me to keep going this way." *Denis*



Empowerment through recognition

"The empowering bit for me was the recognition of my work. The intense gratitude that many of my interview partners showed me, motivated me every time to approach the next interview joyfully." *Christian*

"I enjoyed it immensely to encourage other interview partners. I had a few who were simply grateful to be listened to at last, and to have been given a voice. This, in turn, was very good for me." *Isabel*

Broadening horizons

"I became aware how quickly an 'image' of others becomes lodged in my head. Through the interviews, I noticed that these are often a mirage. I have resolved to ignore these images in future, and not to be led by them any longer." *Karin*

"For me, it was enriching to meet the most diverse range of people." *Ian*

"The project was very taxing, but it has given me a lot. I found it most beautiful and interesting that I got to know people whom I already knew afresh again, sometimes in a very different way, and much more intensely. I felt respect and admiration." *Dieter*

The highlight of the first day of the 'positive stimmen 2.0' symposium was a panel discussion with five of the interviewers. This graphic recording image summarises the key points of the discussion.

2.2.3 Challenges

Limits of participation

The fact that participatory research is ‘a very ambitious endeavour’[2] was felt first-hand by the project team during the process of conducting the ‘positive stimmen 2.0’ project.

Although participants in the interviewers’ focus group reported that they were able to ‘influence decisions every step of the way’, participation according to the Levels of Participation model (see page 29) wasn’t present in all individual project steps. Some decisions about the project were made within the team, without involving the advisory committee or the interviewers. This is true especially for those measures for which we were tied to the budget, and for which flexibility in decision making was therefore very limited.

Overall, not all interviewers participated equally. There may be several reasons: first, interviewers and advisory committee members were volunteers with different amounts of (time) resources. In addition, some were more prepared – beyond conducting the interviews – to participate in exchanging ideas than others. We tried to accommodate this range of participation, e.g. by informing all interviewers by group email about opportunities for support and involvement, but also by accepting and appreciating those who ‘only’ could or wanted to conduct interviews. Interviewers also felt part of the group in unequal measure, and, overall, a joint meeting of all interviewers was sorely missed in this regard.

> **“Imagine there was no coronavirus and we could have had meetings in between. Yes, this was something that was missing a bit. That to this day I don’t really know who exactly were my comrades-in-arms.”**
>
> *Andreas, peer interviewer*

---

[2] *Hella von Unger in her talk at the ‘positive stimmen 2.0’ symposium*

Challenges related to the interviews

Recruiting interview partners

The coronavirus epidemic brought with it great uncertainties, for interviewers as well as for their interview partners. This made the recruitment of interview partners a great deal more difficult. Especially people with no relationship to the community could scarcely be reached, as access to points at which they could have come into contact with the project (e.g. medical practices, counselling services etc.) was often limited because of Covid-19. Community events (e.g. the biennial PLHIV conference 'Positive Begegnungen') were also missing as important locations for recruitment and conducting interviews.

> **"It was a particular challenge to conduct interviews despite corona while at the same time reducing the risk of infection to myself and the interviewee."** *Interviewer*

Apart from the pandemic, the feedback often also included reports that many people weren't prepared to engage with the topic of 'HIV-related discrimination', or that it did not play any role in their lives.

'Difficult' interviews

> **"I had two very difficult interviews with people who had lived with HIV for a long time. These people have remained traumatised to this day! Unfortunately, they rejected any suggestion of change. I found this exhausting and very sad. But I was able to separate myself from it, and afterwards I went for a long run to release any of the energy that may have got stuck to me … "** *Brigitte, peer interviewer*

In order to equip interviewers as well as possible for this kind of situation, the training included a discussion on how to deal with emotionally challenging situations, and on what interviewers can do to keep stress to a minimum. The ability of interviewers to refer appropriately was strengthened: interviewers didn't have to solve all personal problems mentioned during the conversation. Instead, they could refer people to counselling and other support services.

To absorb any stress experienced during the interview phase, we had regular contact through email, by telephone or through virtual group meetings, where the exchange of experiences from the interviews was encouraged. However, it can't be ruled out that we didn't become aware of some difficult interviews if interviewers didn't want to discuss their experiences with the project team.

Discomfort with the questionnaire

The internationally standardised questionnaire that was used to guide the interviews was in part also problematic. Some questions were of limited or no relevance at all in the German context. These questions confused some interviewees. In addition, the wording of some questions required further explanation. For this reason, each of the questions was discussed with the interviewers during the training.

> **"Often, the questions weren't understood correctly. The interviewees and I found the wording very cumbersome and tiring."**
>
> *Karin, peer interviewer*

An interviewer is interviewed

Peer interviewer Collins himself gave an interview during the data collection phase, providing first-hand insights into the project. Here is an excerpt:

As the title suggests, 'positive stimmen 2.0' follows on from a previous project. In 2011, people living with HIV in Germany were interviewed about their experiences with marginalisation and stigmatisation for the first time. Did you also participate in this community research project at that time?

This is my first time. The idea behind the project – to collect scientifically sound data on discrimination using a large survey – is very important to me. Only when we know how and where people living with HIV are still discriminated against, can we take targeted action.

I experience time and time again in my community that people living with HIV don't talk to anybody about their infection, don't exchange experiences with others, and are therefore completely alone with their condition. This is why I hope that, through 'positive stimmen', we can find ways to help people like this to better deal with their infection.

Have you been active in the HIV community for a while?

Since 2007, I have been working with AfroLebenPlus, the Germany-wide association of HIV positive migrants, and I am also active in prevention.

How are the interviews conducted?

We have a fixed set of questions, which I go through at the beginning in order to make sure everything is being understood. If people are then prepared to go through with the interview, I ask them to sign the required consent form.

How long does such an interview take?

That depends very much. Some people answer the questions very swiftly, others need a little more time and want to use the opportunity to talk about their experiences. This can bring up emotions, and then we may have a short break. On average, an interview lasts for about an hour.

Have you sometimes been surprised by the events and experiences that interviewees have told you about, or have your expectations been mostly confirmed?

Two of the life stories have moved me deeply. I interviewed a gay man who had to leave his home country because he knew that if people found out about his homosexuality, they would kill him. During another conversation, a young man told me about life with his family. When he uses the toilet, he has to disinfect everything because his relatives are scared of catching the infection from him. He even has to use his own dishes. It is hard to imagine what life would feel like under these circumstances.

Have you also interviewed people who have hardly experienced any discrimination, who are living well with HIV, without negative experiences?

Yes, this also happens, and it's very pleasing to find out that it does. For example, one man told me about his family's reaction to his HIV diagnosis. They didn't have a problem with it at all and said: "It's not your fault, we aren't scared, and we are always there for you."

What are the insights and impacts you are hoping will result from the study?

Many people are still afraid of discrimination, and don't dare to visit places where they will meet other people living with HIV and where they can exchange experiences. I hope that the project will help find ways to lead these people out of this kind of loneliness. The first important step is to accept the infection yourself.

Collins, peer interviewer

2.3 Module B – online survey and focus group interviews

In addition to conducting the peer interviews as part of the PLHIV Stigma Index in Germany (Module A), the project collected data from two additional sources in a second Module (Module B).

Module B combines data from an online survey and the focus groups. Linking different research methods and types of data – quantitative and qualitative – is also called a *mixed method approach*.

In this part of the study, the project focused on research questions illuminating, among other aspects, the effects of and responses to HIV-related stigmatisation and discrimination, as well as the importance of the HIV positive community to people living with HIV. In addition, several areas that are only broadly – or not at all – covered by the standardised questionnaire used in the peer interviews, were investigated in more detail here (e.g. questions regarding the health care system that are applicable to the German context).

Specific research questions included:

- What are the effects of HIV-related stigmatisation and the experience of discrimination in different parts of life? Which coping mechanisms are becoming apparent?
- What is the influence of the non-transmissibility of HIV under treatment on the lives of people living with HIV?
- How does the interwovenness of HIV-related stigmatisation with other stigmatised characteristics affect people living with HIV?

The online questionnaire was divided into the following topic areas:

- Personal demographic data
- Living with HIV
- HIV-related stigmatisation
- Experiences of discrimination on the basis of HIV status
- Responses to experiences of discrimination
- General wellbeing and quality of life
- Relationships and sexuality
- Experiences of discrimination on the basis of characteristics (or attributions) other than HIV
- Relationship to other people living with HIV, and to the HIV positive community

The online survey gave people living with HIV an option for low-threshold and anonymous participation. This also enabled people to participate who may not have wanted to disclose their infection, or who may not have wanted or been able to participate in the peer interviews for other reasons. Between June and October 2020, a total of 935 people participated.

The online survey was complemented by four focus groups, which were intended to help explain, illustrate and provide depth to the statistical analyses. Two focus group interviews were specific to subgroups – one was attended by HIV positive mothers only, the other exclusively by young people living with HIV. This allowed the gathering of specific insights into the stigmatisation experiences of these two target groups. The other two focus groups were mixed.

Depending on the focus group, participant numbers ranged from 3 to 10. In the spirit of the participatory research approach, the focus groups were facilitated by a person representing the community (DAH). The focus groups followed a flexible set of guiding questions, which were also informed by the results of the online survey. In general, participants were invited to speak as freely as possible, to explain and to reflect on what affected them personally in relation to the topic of 'HIV-related discrimination and stigmatisation'. The closeness, familiarity and openness of the focus groups made it possible to raise aspects and situations that hadn't been covered in the surveys, but which were important to the participants personally.

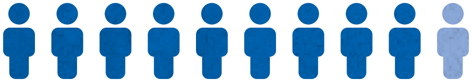
The focus group conversations were recorded, transcribed and anonymised. Afterwards, the participants' statements were analysed thematically and linked with the quantitative data. Chapter 3 of this brochure presents many quotes from the focus groups.

Results

3.0

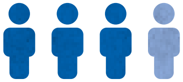
3.0 Core results at a glance

Core results at a glance – quotes from respondents living with HIV



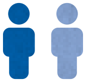
9 out of 10

“I am living well with my HIV infection.”



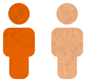
3 out of 4

“In many parts of my life, nobody knows that I am HIV positive.”



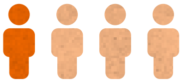
1 out of 2

“Prejudices towards people living with HIV are affecting my life.”



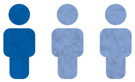
1 out of 2

“In general, it has become easier for me over time to disclose my HIV status.”



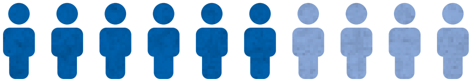
1 out of 4

“I feel guilty for being HIV positive.” and/or “I feel ashamed of being HIV positive.”



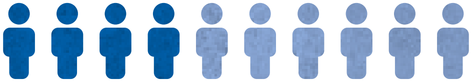
1 out of 3

“I am scared of infecting someone during sex.”



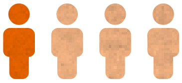
6 out of 10

“In the last 12 months, I have had at least one negative experience in the health care system on the basis of HIV status.”



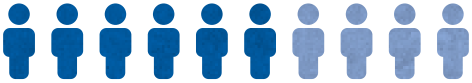
4 out of 10

“HIV has strengthened my sexual awareness.”



1 out of 4

“I normally don’t disclose my HIV status in the health care system.”



6 out of 10

“I am experiencing additional discrimination on the basis of characteristics other than HIV.”

The most important facts in brief

We, the project team, are pleased to present to you the results of ‘positive stimmen 2.0’. We are pleased because of the interest in and successful implementation of the project during a time in which the coronavirus pandemic put many obstacles in the way for all of us.

Less pleasing are the results of the surveys: in 2020, stigmatisation and discrimination still remain a burden on health and on life satisfaction among people living with HIV.

The data show that people living with HIV are even today still experiencing discrimination and marginalisation on a daily basis. HIV-related stigmatisation affects numerous areas in the lives of people living with HIV. Especially in the health care system, but also in their private lives, in their sex lives and in the media, people living with HIV experience discriminating behaviour and face prejudices related to HIV. These experiences have significant effects: they not only lead to an inferior health status, lower levels of wellbeing, and less sexual satisfaction, but also affect how people deal with their own HIV infection (e.g. speaking less openly about HIV), and their self-image or internalised stigmatisation.

Many people living with HIV are stigmatised and discriminated against not only on the basis of HIV, but also as a black person or person of colour, as a person who uses drugs, as a woman, a trans* person, a gay man, or on the basis of another stigmatised characteristic. Multidimensional stigmatisation and discrimination have a large impact on the lives of many people living with HIV. It appears that the more socially stigmatised characteristics a person has, or has attributed to them, in addition to their HIV positive status, the higher will be their level of internalised stigmatisation.

The quantitative data collected in the survey clearly show how much stigmatisation and discrimination people living with HIV still experience even in 2020 – despite all the medical progress achieved with respect to treatment options. In general, the survey asked about experiences within the last 12 months. This means that, in most cases, the reported experiences of discrimination don’t date back very far.

Within this brochure, you will time and again come across selected quotes from the many very authentic reports from participants. The empirical data from both parts of the study form the basis of recommendations for action intended to contribute to people living with HIV experiencing less marginalisation in the future. You will find these in Chapter 4.

In the following, you will find an overview of the core results from both of the project’s two research modules. The complete and comprehensive analyses are contained in the research report, which you can download at **www.positive-stimmen.de**, or obtain using **order number 029005** in the Deutsche Aidshilfe online shop at **www.aidshilfe.de/shop**.

This brochure is also available in its German version, which can be accessed via the two websites listed above.

Two modules, two samples, two colours

Data collection for 'positive stimmen 2.0' was carried out in two separate modules *(see 'Research design' on pages 20–21)*. In representing the results (diagrams, tables and quotes), we are using the following colour code to show which study module they originate from.

Module A:
Peer interviews

Module B:
Online survey and focus groups

The composition of the two survey samples is as follows (selected characterstics; see research report for detailed description of the samples):

	Module A (N = 450)	**Module B1 (N = 935)**
Average age	45 years	46 years
HIV diagnosis received ...		
• less than 2 years ago	4%	11%
• more than 20 years ago	23%	18%
Gender identity (self-identified)		
• Female	28%	13%
• Male	71%	86%
• Trans*, inter, other	1%	1%
Gay/MSM	58%	84%
BPoC[1]	18%	6%
Living in a place with ...		
• less than 100,000 inhabitants	25%	33%
• more than 100,000 inhabitants	44%	34%

[1] *Black person, non-white person, or person of colour (self-identified)*

3.1 Living with HIV and speaking openly about one's HIV infection

The majority of respondents living with HIV is able to live well with their HIV infection.

However, HIV-related prejudice is still experienced as a strong limitation, and has significant negative effects on the quality of life of people living with HIV (incl. wellbeing, self-image, sexuality, health status).

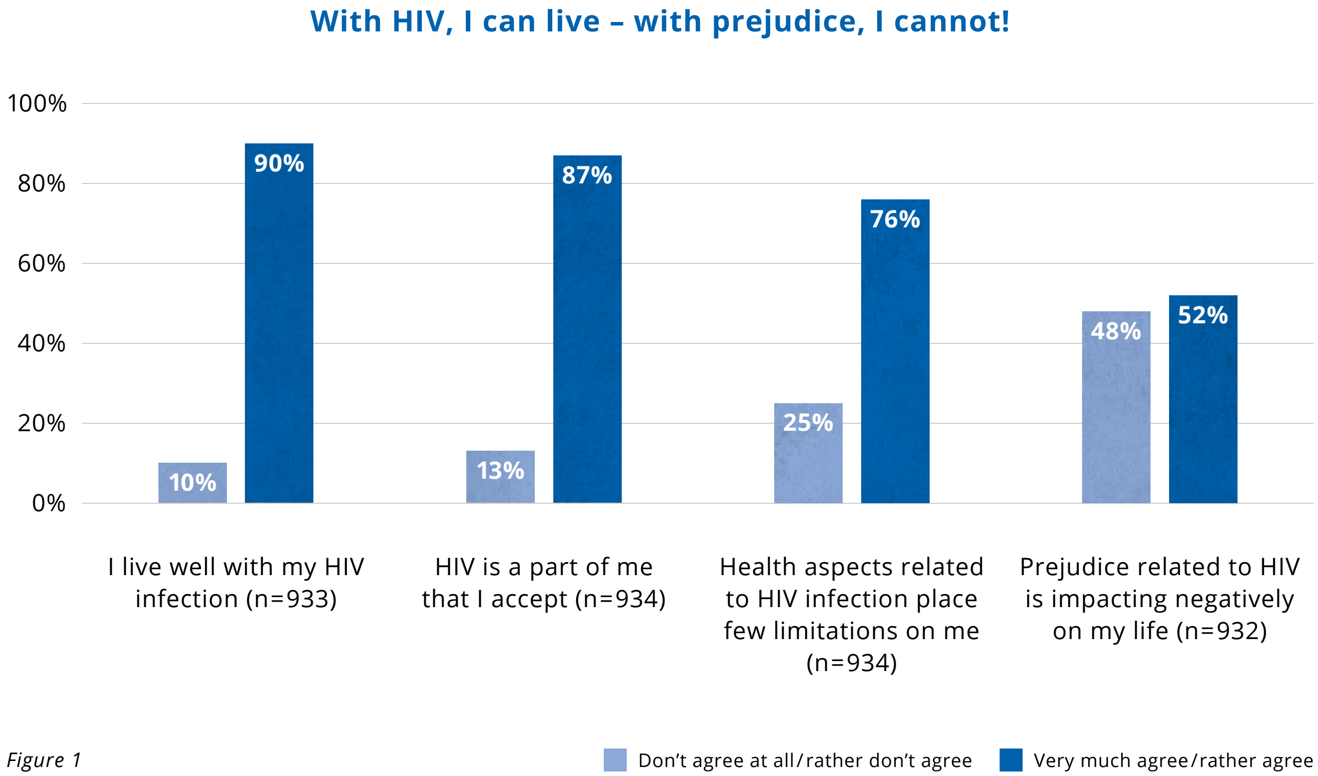


Figure 1

While most respondents to the online survey state that they are living well with HIV infection (90%), and HIV-related health aspects are not limiting them much (76%), half of the respondents (52%) report that HIV-related prejudice is affecting their life *(see Fig. 1)*. Today, stigmatisation and discrimination have a greater impact on the quality of life of many people living with HIV than the infection itself.

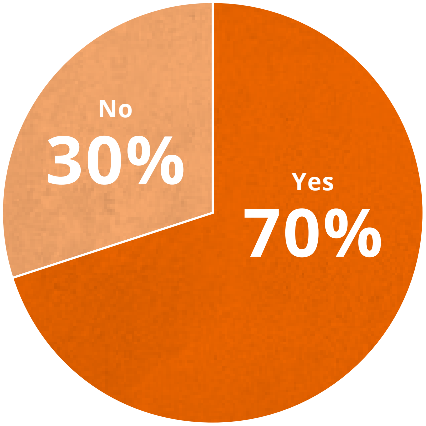
> **“Despite people being well informed, and the fact that living with HIV can be so normal, there’s an […] underlying sense of abnormality. And it sucks, damn it!”**

> **“I am a person, and yet I am being reduced to HIV. But HIV is only one of the many facets of ‘me’.”**

Dealing openly with HIV is a great challenge for many people living with HIV:

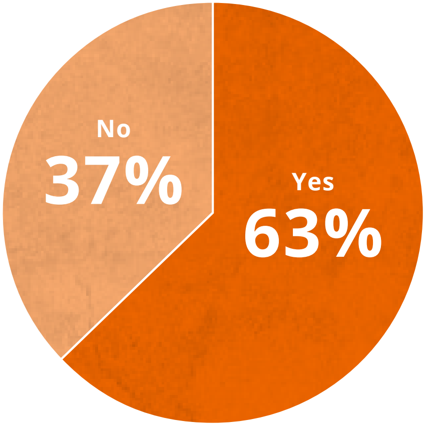
> **“I consider very carefully whom I will tell about my HIV infection.”**

Most respondents living with HIV consider very carefully if and when they will deal with their HIV infection openly. Accordingly, 70% of respondents to the peer interviews report that they are finding it difficult to talk about their HIV infection *(Fig. 2)*, and 63% hide it from others *(Fig. 3)*. Of the respondents to the online survey, 87% also consider very carefully whom they will tell about their HIV infection. In this context, three quarters of the respondents agree with the statement that in many parts of their lives, nobody knows about their HIV infection. The fact that many people living with HIV perceive the disclosure of their status as a risk seems to play a role here. Almost 80% of online respondents agreed with this statement *(see Fig. 4)*.



“It is difficult for me to tell others about my HIV infection”
n=447

Figure 2



“I hide my HIV status from others”
n=449

Figure 3

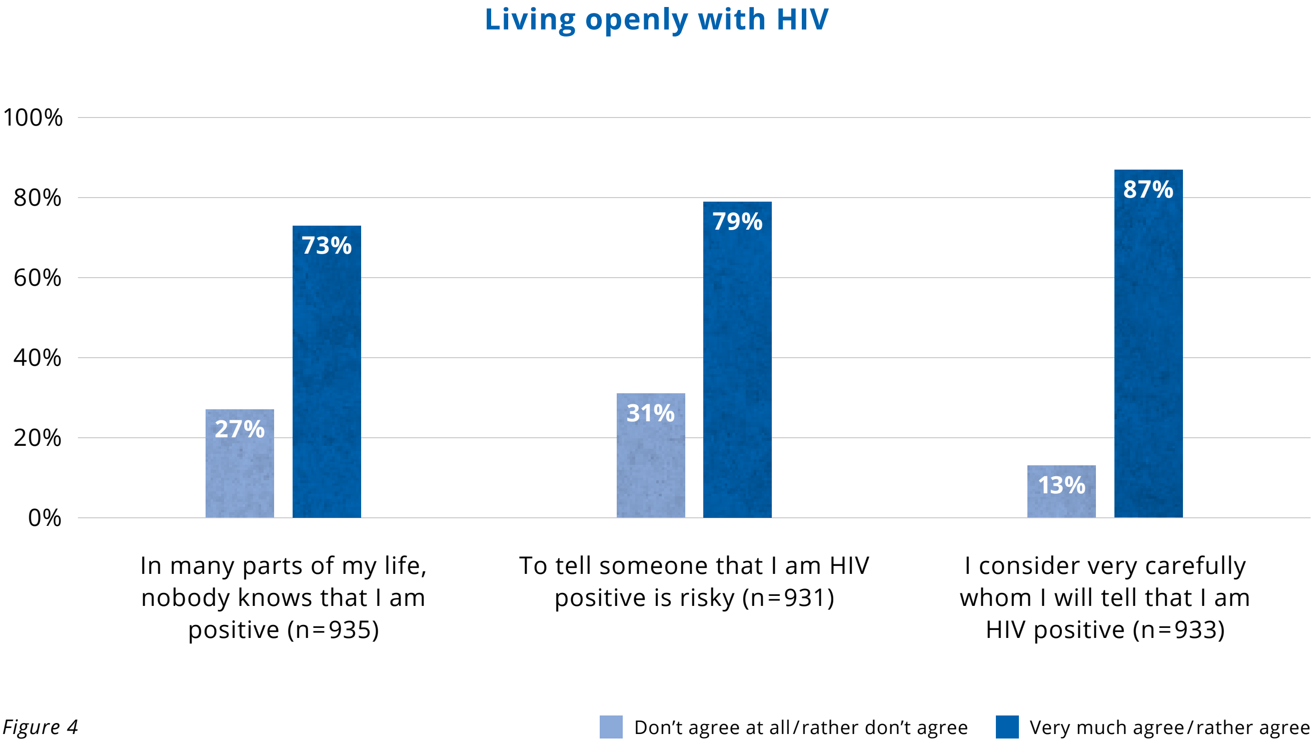


Figure 4

> **“I am not open about it in any part of my life. Even when I was at school, I picked up that AIDS had negative connotations, so I think that I have a fear of being judged there.”**

The (in)ability to speak openly about HIV *(Fig. 4)* is reflected in actual disclosure of HIV status *(Fig. 5)*. Almost half of the respondents to the online survey (43%) rarely or never speak openly about their HIV infection, and 13% of these never do. Only about a quarter generally deals with their HIV infection openly (28%), while only 7% report that they always deal with it openly. This can also be found in quotes from the online survey:

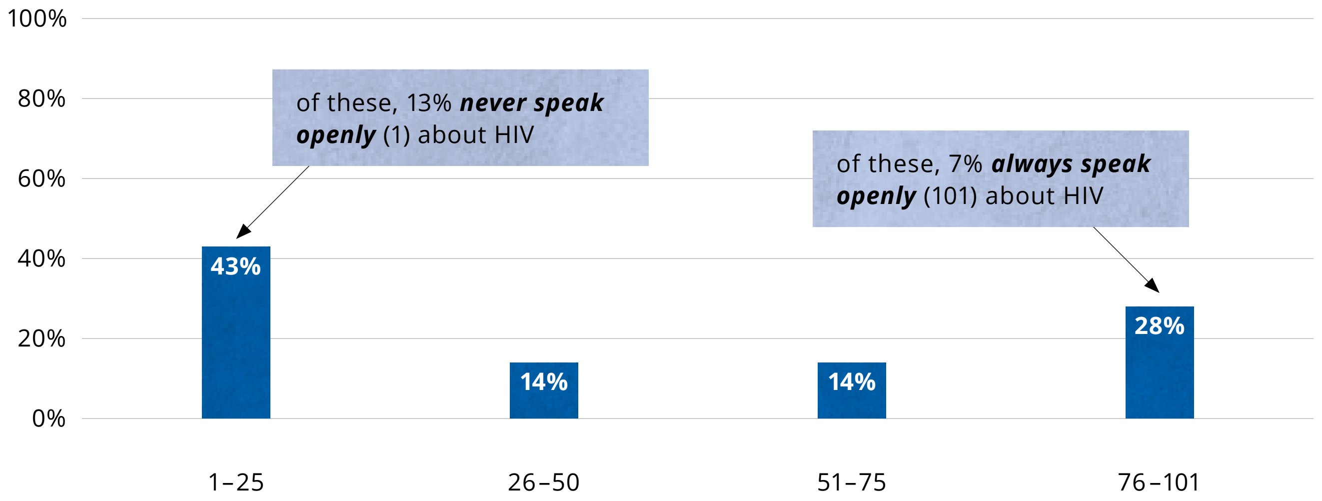
> **“I can’t speak openly about my infection with anyone because I am afraid of marginalisation and rejection.”**

> **“It’s still not possible to come out without facing negative consequences.”**

> **“Weighing up carefully who is told about HIV status, no mention of it if in any doubt at all.”**

Speaking openly about my HIV infection

(n = 862; Scale: 1 = *never openly*; 101 = *always openly*)



of these, 13% ***never speak openly*** (1) about HIV

of these, 7% ***always speak openly*** (101) about HIV

Figure 5: ‘In general, how openly do you speak with others about your HIV infection?’ (scale from 1 = never openly to 101 = always openly)

Over time, it becomes easier to deal more openly with HIV

> “After the initial shock, I continue to live my live as before.”

> “I don't worry about HIV these days, that's just bacckground noise. The arthritis in my hip is what I have a problem with.”

It seems that it becomes easier with time to speak about one’s own HIV infection. The longer respondents have been living with their HIV diagnosis, the easier they find it to deal with the infection openly.

Accordingly, 46% of respondents to the peer interviews report that it has become easier with time to tell others about their HIV infection *(no Fig.)*.

> “At that time, I learned that, if I keep locking this up inside me and deny it, I am somehow destroying myself. At some point I told myself that I want to be able to be open about it. I don’t want to hide!”

Similarly, it appeared that people who had been aware of their diagnosis for more than 20 years were being significantly more open about their HIV infection than those who had received their diagnosis less than 20 years ago *(Fig. 6)*.

> “Well, it took me several weeks the first few times I came out to someone, trying time and time again to talk to the person, for weeks on end, and I had to give up repeatedly, and now I realise […] that it rolls off the tongue more easily, and with less pain and less suffering.”

Speaking openly about HIV by time since diagnosis
(1 = *never openly* to 101 = *always openly*)

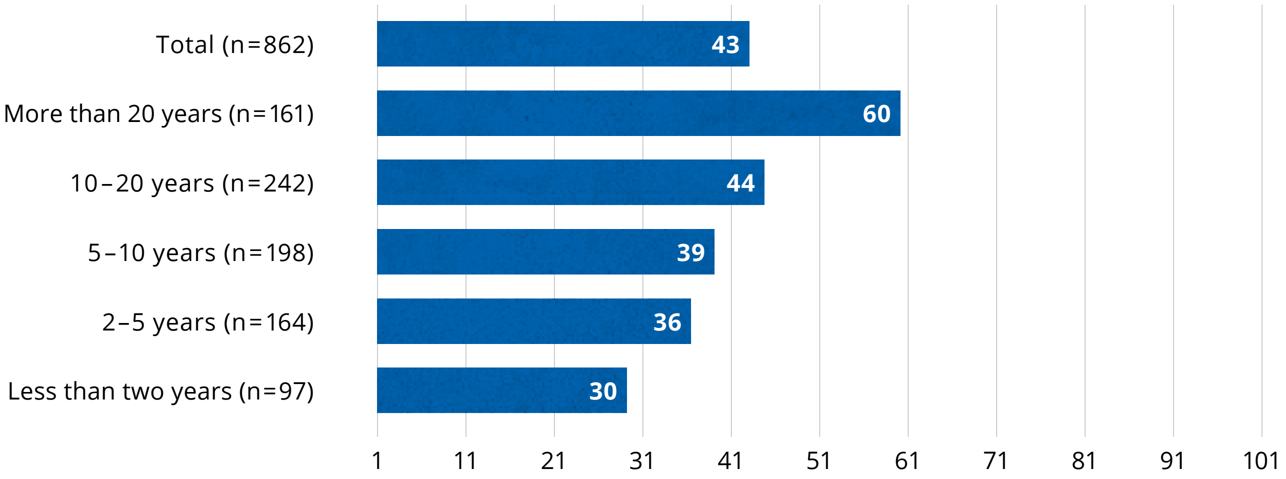


Figure 6: 'In general, how openly to you talk with others about your HIV infection?' (scale: 1 = never openly to 101 = always openly)

People living with HIV in rural areas are significantly less open in dealing with their HIV infection than people living in large cities.

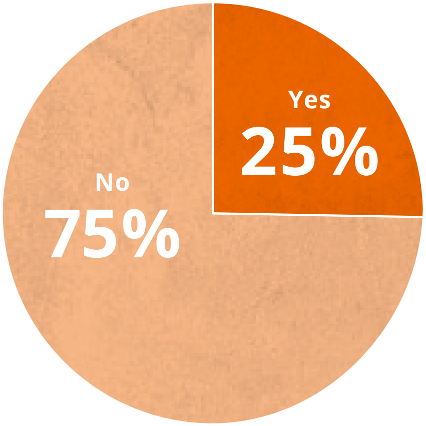
The respondents to the online survey who live in places with less than 20,000 inhabitants speak significantly less openly about their HIV infection than people living in places with more than 20,000 inhabitants. In addition, people living in metropolitan areas of more than one million people deal with their HIV infection significantly more openly than those living in cities under one million inhabitants *(no Fig.)*.

“So, I realise that I, since living in the countryside again, that I am hiding it more. […] it’s just that you always have to be careful what you talk about, and that’s always difficult. It does stress me out, and that is also one of the reasons why we are thinking about moving to the city again, because it’s more comfortable there. In my experience, the status isn’t the issue there, and isn’t a problem.”

3.2 Internalised stigmatisation

Social stigma in relation to HIV infection can be internalised. This can become apparent e.g. as low self-esteem and feelings of guilt. It is clearly evident in a quarter of all respondents from both modules.

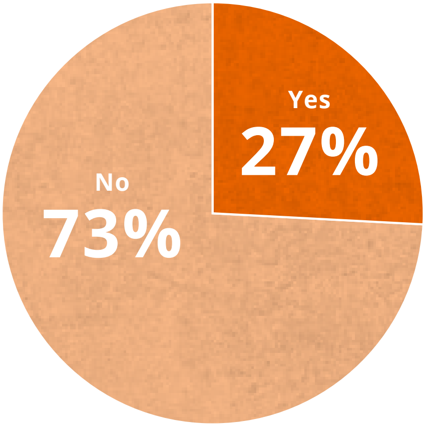
> “These spectres you are feeding by not talking about it, they get bigger, it becomes a sort of getting stuck in internalised stigmatisation, based on probably actual experiences as well as fear of encountering more. But you leave the status quo alone, and so we stay inside this slimy, dark, grey substance, and it casts shadows on the beautiful rainbow life we could be living, whether we are gay, lesbian, hetero or whatever.”



“I feel ashamed that
I am HIV positive”
n=451

Figure 7

> **“[...] that’s why the question of blame arises again, meaning that my friends know, of course, how I’ve been whoring around, which I like doing, I am having fun with it, but now, like, with the result of getting HIV, despite everything, as a kind of punishment, or it’s that thing ‘it’s your own fault’ again, which is the discrimination, I really do feel it like that and I don’t know how to deal with it for myself, and that was and still is horrible.”**



“I feel guilty for being HIV positive”
n=451

Figure 8

A negative self-image pointing to internalised stigmatisation is evident quite consistently in about a quarter of respondents from both surveys. Accordingly, 25% of the respondents to the peer interviews reported that they are feeling ashamed *(Fig. 7)*, and 27% that they are feeling guilty (Fig. 8) for being HIV positive. This is confirmed by the online survey, where also a quarter of respondents agree with the statements regarding having a feeling of not being as good as others, and thinking badly about themselves *(Fig. 9)*.

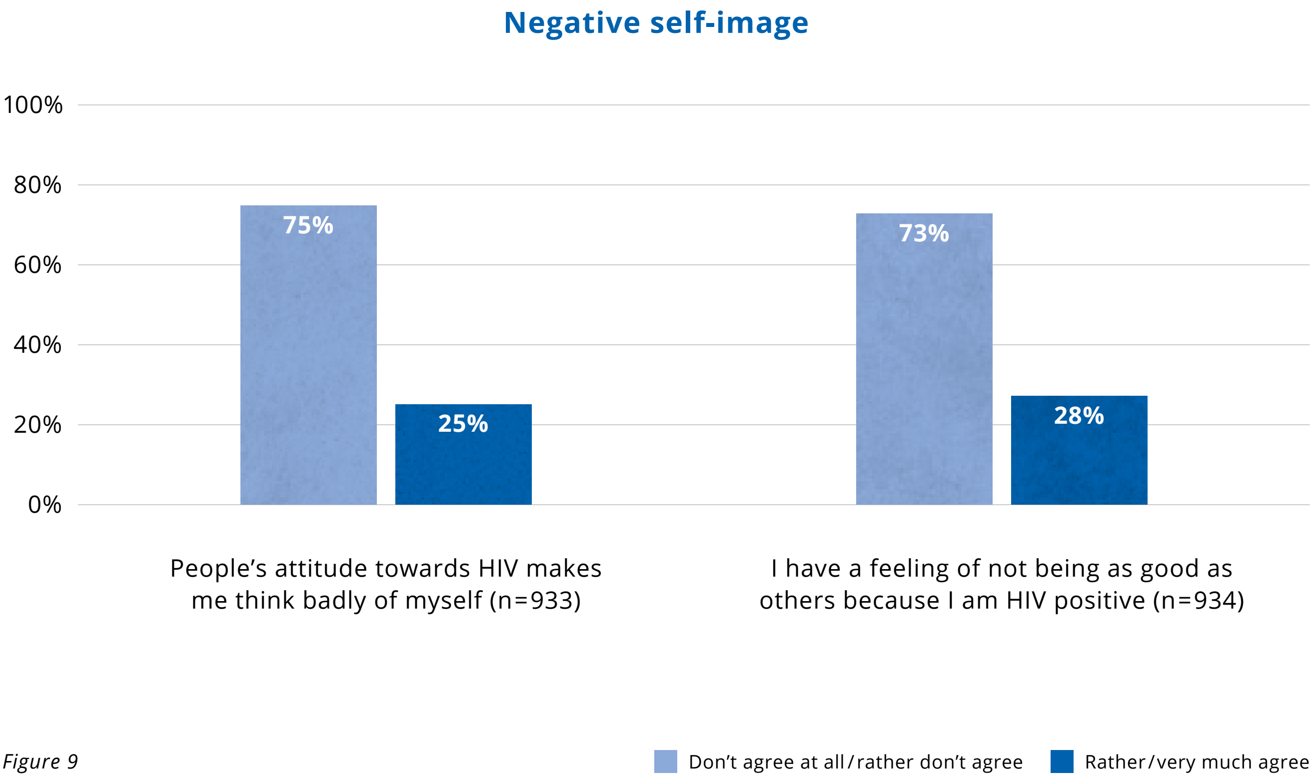


Figure 9

Taking a closer look at these feelings of guilt, only 47% of respondents to the online survey state that they don't experience feelings of guilt *(no Fig.)*.

In addition, 57% have the feeling that others are blaming them for their infection. About one quarter of respondents in turn perceive their infection as punishment for their own actions, and 38% are blaming themselves because of their infection *(Fig. 10)*. When comparing different subgroups with respect to feelings of guilt and self-esteem, it becomes apparent that the tendency towards internalised stigmatisation manifests differently among the different subgroups:

Especially black people and people of colour who were diagnosed with HIV less than 2 years ago, women, people with a low socio-economic status, and people living in places with less than 20,000 inhabitants show higher levels of internalised stigmatisation *(no Fig.)*.

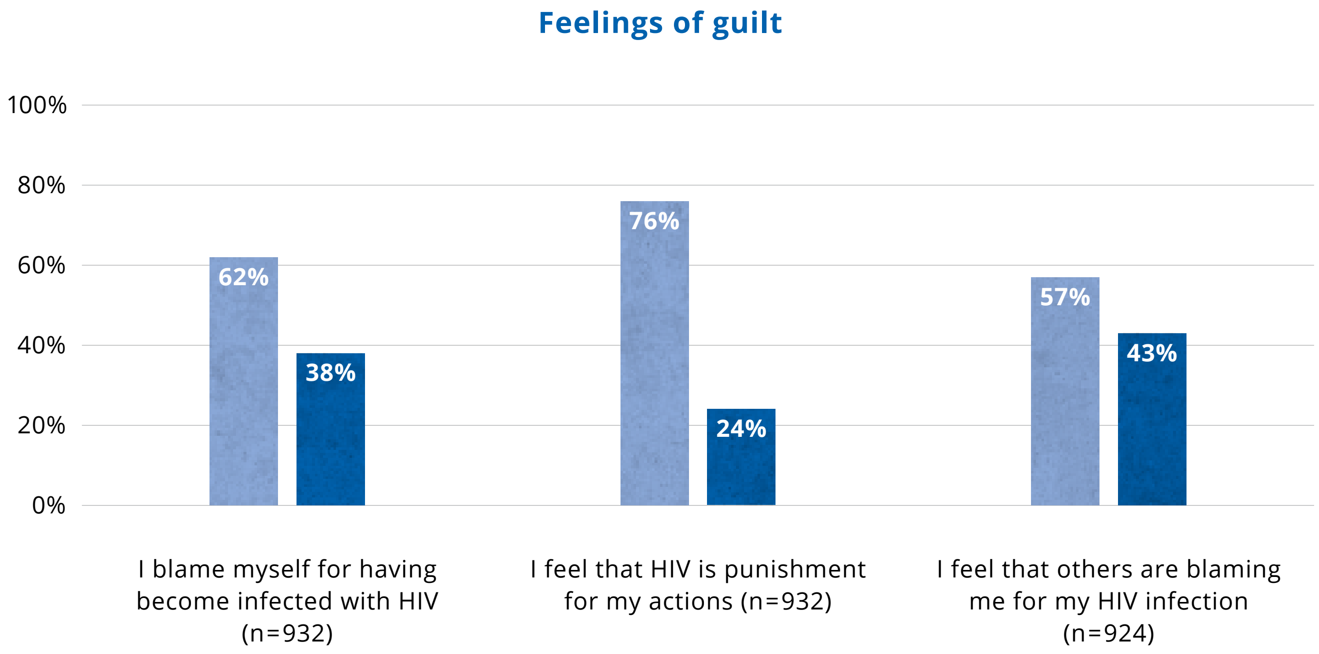


Figure 10

However, gay men and MSM (men who have sex with men), those over the age of sixty, and people who hadn’t had any of the kinds of discrimination experiences we asked about, showed rather lower levels of internalised stigmatisation.

3.3 HIV-related experiences of discrimination – focus on the health care system

HIV-related discrimination still happens, and, in 2020, was reported mainly from the health care system, the media, and peoples’ relationships and sex lives. Mentioned particularly frequently by respondents living with HIV, and experienced as especially stressful, are experiences of HIV-related discrimination in the health care system.

Discrimination in the health care system

> **“The worst discrimination and stigmatisation still occur in the health care system and in the context of care services, especially in hospitals and dental practices.”**

> **“I thought I would be in good hands at the health service. Unfortunately, the opposite is often true. Statements and behaviours like in 1985, how is that possible? I wish people were a lot more up to date with the latest scientific knowledge in this area.”**

We asked about experiences in both modules. Of the respondents to the peer interviews, 8% report that they had been refused a health care benefit on the basis of HIV status during the previous 12 months, and, in relation to dental care, the proportion was as high as 16%. About a quarter of respondents report for the same period that they had been asked inappropriate questions in relation to HIV status (e.g. how the person had become infected), that they experienced avoidance of physical contact, or that a visible marker had been placed on their medical record *(Fig. 11)*.

Frequency of discrimination experiences in the health care system in the previous 12 months

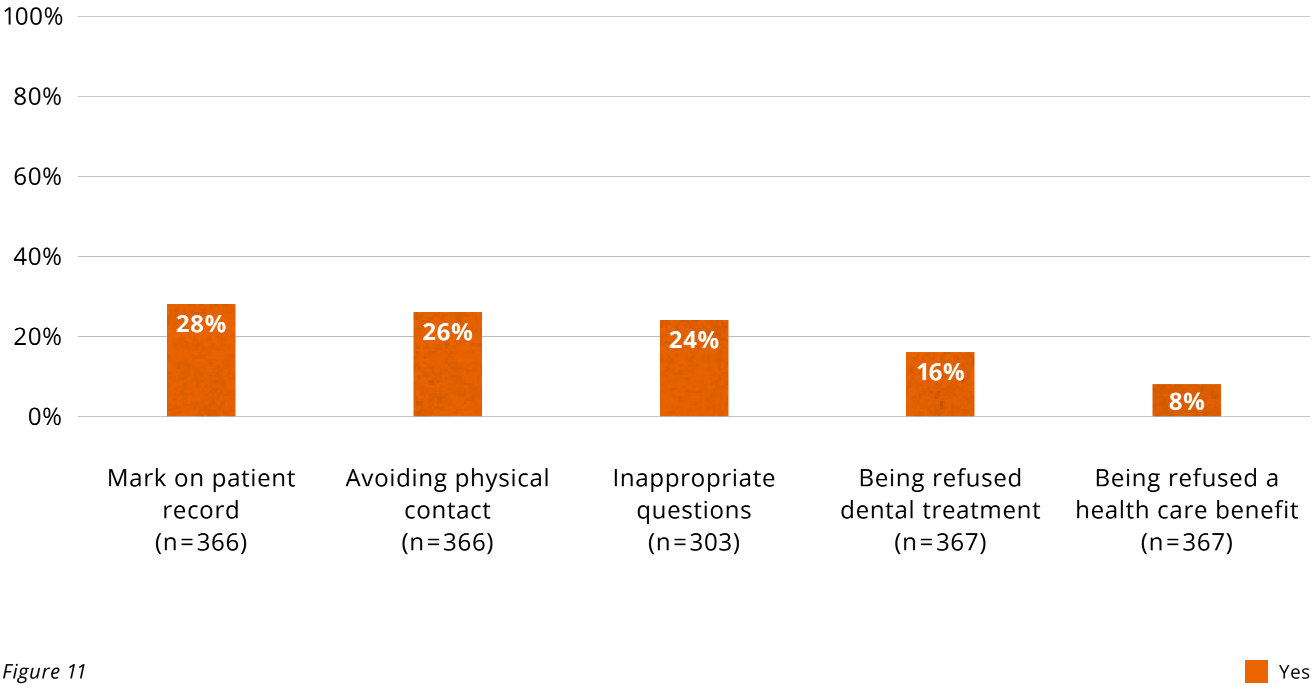
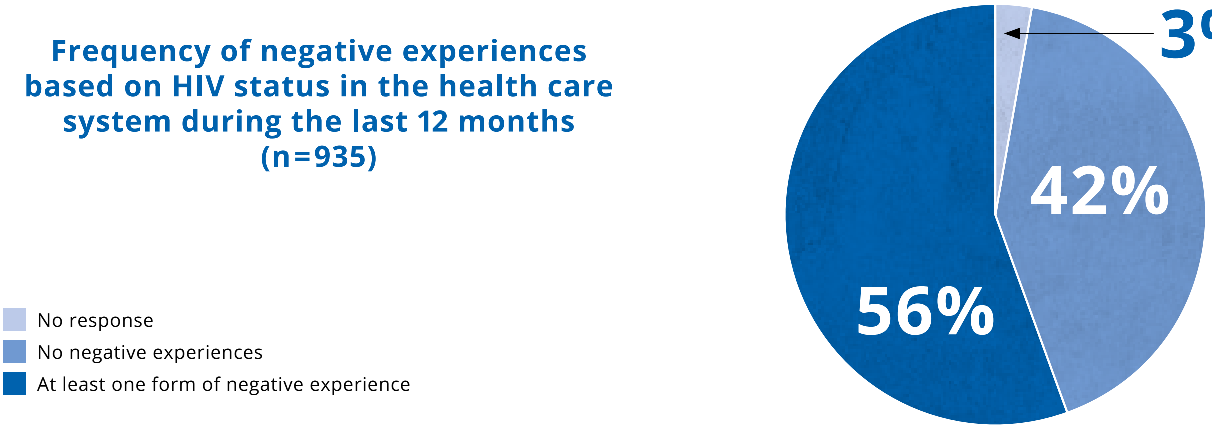


Figure 11

Of the respondents to the online survey, 56% report experiences of discrimination in the health care system during the previous 12 months *(Fig. 12). Figure 13 illustrates the kinds of discrimination reported by respondents.*

Of the online survey respondents, 21% also report that they were given a specific appointment time, generally at the end of the day *(Fig. 13)*.

We would like to emphasise here that, as part of 'positive stimmen 2.0', questions generally related to experiences during the last 12 months, and that these experiences do not date back further.



Frequency of negative experiences based on HIV status in the health care system during the last 12 months (n=935)

Figure 12

Types of negative experiences in the last 12 months (n=521)

10%

I was refused a health care benefit because of my HIV status

17%

I was asked inappropriate questions regarding my HIV infection (route of transmission etc.)

1%

Because of my HIV status, I was refused services in the area of sexual and reproductive health.

33%

My medical record was marked because of my HIV status

21%

I was given a special appointment time because of my HIV status (e.g. at the end of consultation hours)

2%

I was coerced or forced to undergo a medical procedure or health care procedure because of my HIV status (e.g. contraception, no breastfeeding etc.)

9%

My HIV status was disclosed to others against my will (e.g. to other doctors, life partners etc.)

8%

Something else happened to me

Figure 13

None of the experiences asked about and specified in the research are defensible on medical grounds, and are therefore perceived as stigmatisation and discrimination. It appears that discriminatory experiences on the basis of HIV status – even though at low levels – also occur in places where people living with HIV receive treatment, i.e. in specialist medical practices and HIV outpatient clinics.

During the analysis of all data, it became clear that discrimination experienced in the health care system is perceived as particularly stressful. In open-ended survey questions, as well as in the focus groups, the health care context is very often mentioned proactively, and many negative experiences are reported.

> **“As an HIV positive woman with an HIV positive child, one does quite often get asked uncomfortable questions at the doctor's. You often get compassion for the child, and as the mother you get the blame.”**

In order to avoid negative experiences such as those described by the respondents, some people living with HIV decide against telling health care personnel that they are HIV positive. Among the respondents from Module A, 25% indicate that they normally don’t disclose their HIV status when accessing health care benefits *(Fig. 14)*. This is occurring despite the fact that it can have significant disadvantages not to talk about HIV infection in this context, e.g. in relation to interactions between medications.

> **“I think very carefully about whom I will tell about my infection. I now also keep quiet about it with many doctors, as I have had very bad experiences over and over again.”**

In this setting, the preparedness to disclose HIV status is generally higher than in other areas of life. Apart from medical necessity, this is due to a high level of expectation on the part of medical personnel regarding the disclosure of the infection, related questions in medical history forms, and the patients’ hope for a trusting and open doctor-patient relationship.

When you access health care services outside of the HIV outpatient clinic/ specialised medical practice, do you normally disclose your HIV status? (n=453)

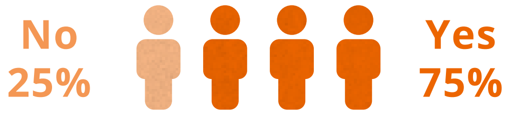


Figure 14

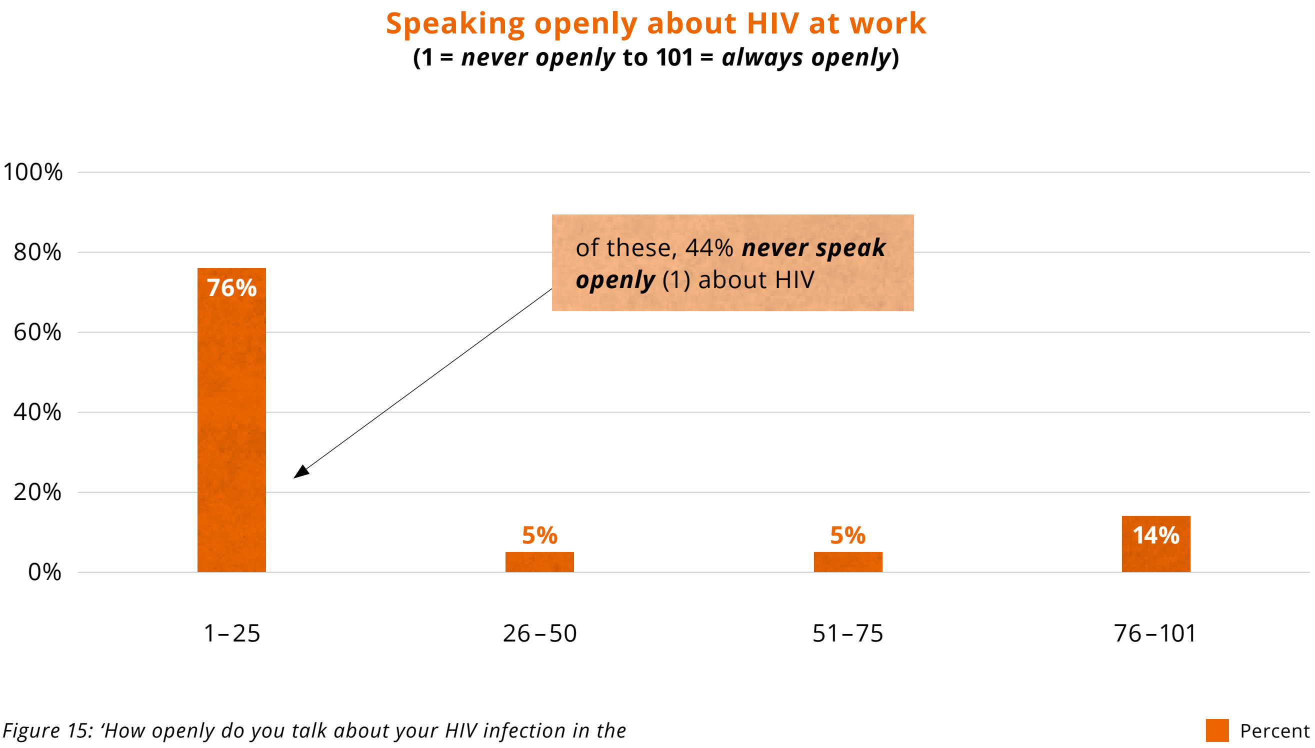


Figure 15: 'How openly do you talk about your HIV infection in the workplace?' (scale: 1 = never openly to 101 = always openly)

Participants in the online survey were asked how often they talk about their HIV infection in the workplace (Fig. 15). It becomes clear that HIV infection is talked about rather less openly in this setting. On a scale of 1 = *I never talk about it openly* to 101 = *I always talk about it openly*, participants indicated an openness value of 21. In total, 76% indicate values between 1 and 25, which corresponds to a low level of openness. Of these, a little less than half (44%) indicate that they *never openly* (1) talk about their HIV infection.

Discrimination is still occurring in people's work life *(see Table 1)*. A first glance, the numbers don't appear as high as in the health care setting. Considering, however, that almost half the respondents (44%) never talk about HIV in the workplace, these numbers take on a different meaning – if you don't talk about your HIV infection at work, you can't be discriminated against because of it.

And of those who disclose their status in the work setting, many experience discrimination. In fact, 31 people report that they have experienced discrimination in the last 12 months in the form of marginalisation, shunning or bullying in the workplace. 22 people were refused a job because of HIV. In the case of 39 persons, their HIV status was disclosed to others without their consent.

Discrimination incidents at the workplace in the last 12 months (n=935)

	Percent (n)
My HIV status was disclosed to third parties (e.g. superiors, colleagues) without my consent.	**4.2 (39)**
Because of my HIV status, I was marginalised, shunned or bullied in the workplace.	**3.3 (31)**
I have lost a source of income or job because of my HIV status.	**2.6 (24)**
I was refused a job because of my HIV status.	**2.4 (22)**
My job description or the nature of my work has changed because of my HIV status.	**2.2 (21)**
I was denied a promotion because of my HIV status.	**1.2 (11)**
Something else happened to me.	**3.4 (32)**

Table 1

Answers to the open questions and the focus group interviews underline how important this topic is to the respondents:

> **“Boss gossiped about my diagnosis. Had to leave the company.”**

> **“Recruitment process was stopped. Voiceover: ‘Because you can’t get rid of someone like that if it doesn’t work out.’ It was about the equal opportunity legislation.”**

> **“I had finally found a job in a bakery. When they went through their health questions, I had to say that I am HIV positive, and my employment was terminated immediately.”**

> **“In my experience, teachers living with HIV worry a lot more about stigmatisation and discrimination at work. While the legal situation is unequivocal, the worry and the fear have remained the same.”**

3.4 Sex life and relationships

HIV infection and the related stigmatisation and discrimination have an impact on sex life and relationships – despite Treatment as Prevention.

More than half (55%) of people living with HIV who participated in the online survey report at least one instance of sexual rejection on the basis of their HIV infection in the last 12 months. 28% report sexualised comments experienced in sex life and relationships, but also elsewhere *(Fig. 17)*.

Sexuality-related discrimination on the basis of HIV (last 12 months)

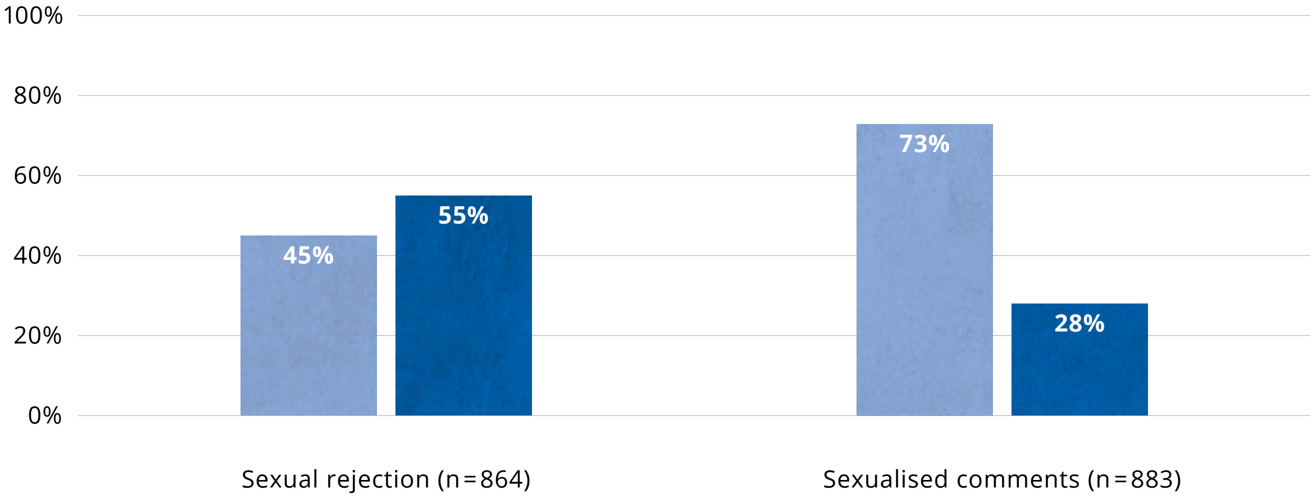


Figure 17

> “I have also already had bad experiences, I mean rejections, too. One sex partner had found my meds. Then he quickly wrote me a note, that he had found them and that he fled because of it, I mean he actually apologised a little bit like that. At that moment I found that really hard. I also think he did overreact a bit, he could also have just talked to me about it.”

> “Gulp, in your case it doesn’t matter anyway!”

Speaking openly about HIV in their sex lives and relationships remains one of the greatest challenges for many people living with HIV. For many, it is especially difficult to find the right time to talk about the infection.

Somewhat fewer than half of online respondents (48%) find it difficult to bring up their own HIV status with (potential) long-term partners. For (potential) sex partners, this is reported by 55%. Many people living with HIV feel particularly unsure about finding the right time to inform the other person of their HIV status. This is being reported by 62% of respondents *(see Fig. 18)*. The following quote from one of the focus groups illustrates the dilemma faced by people living with HIV in this situation:

> **“This happened on a date at a restaurant. We got to know each other, and at some point I talked about my HIV status. And then he just got up and took off. And I’m sitting there feeling dirty and worthless – like garbage. […] With the next person, I didn’t talk about until our fifth date, and he was angry and said ‘why didn’t you say at the beginning?’ Now I’m just confused!”**

Challenges of being open in sex life and relationships

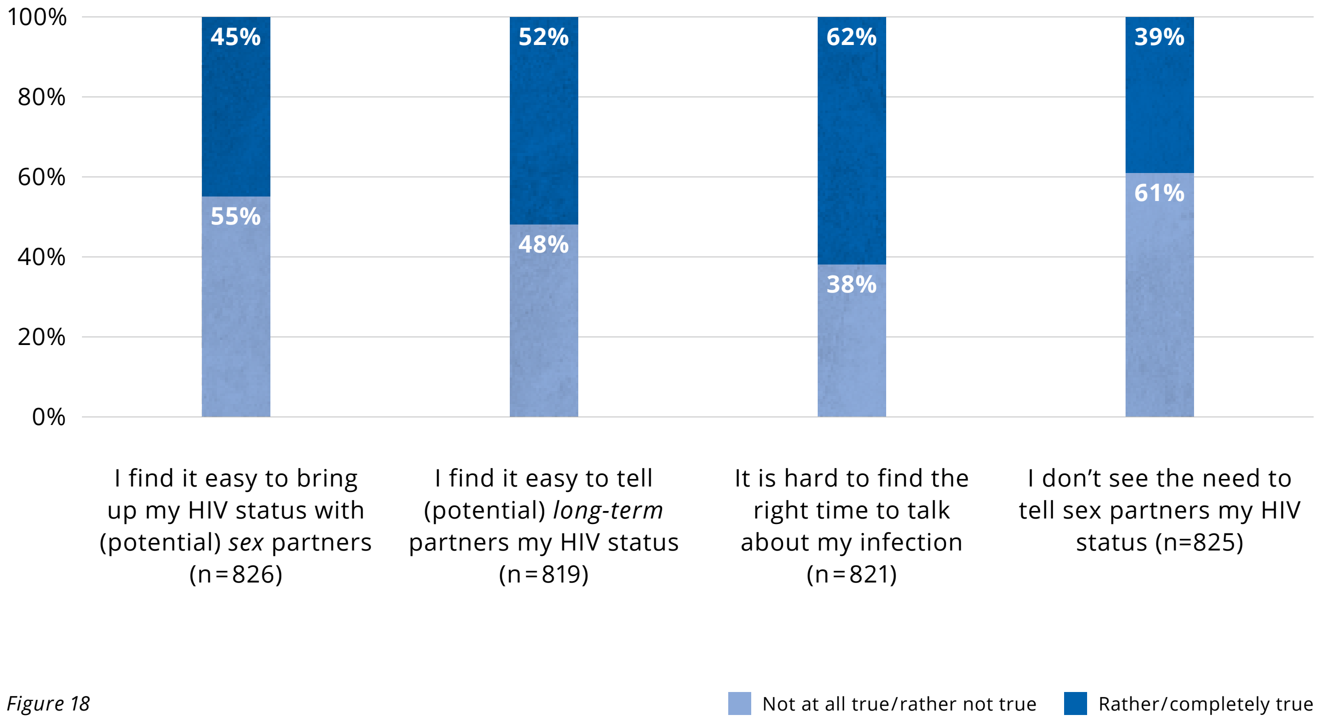


Figure 18

Within relationships, people generally communicate their HIV status openly (96%). In their sex lives, 29% decide according to the situation whether they will tell sex partners about their HIV status, 40% report that they see no need to inform sex partners about their HIV status *(no Fig.)*, and 46% generally communicate it openly in their sex lives. For a sizeable proportion of people living with HIV, one strategy to avoid potential HIV-related discrimination seems to be to say that they are a PreP user – in order not to come out as HIV positive. Of the respondents, 11% indicate that they use this strategy in their sex lives. 13% use the 'PreP' statement on online dating platforms. However, 36% communicate openly that they are HIV positive on online dating platforms.

In this context, 'speaking openly about HIV' means any communication of one's own HIV status (regardless of viral load) *(see Fig. 19)*.

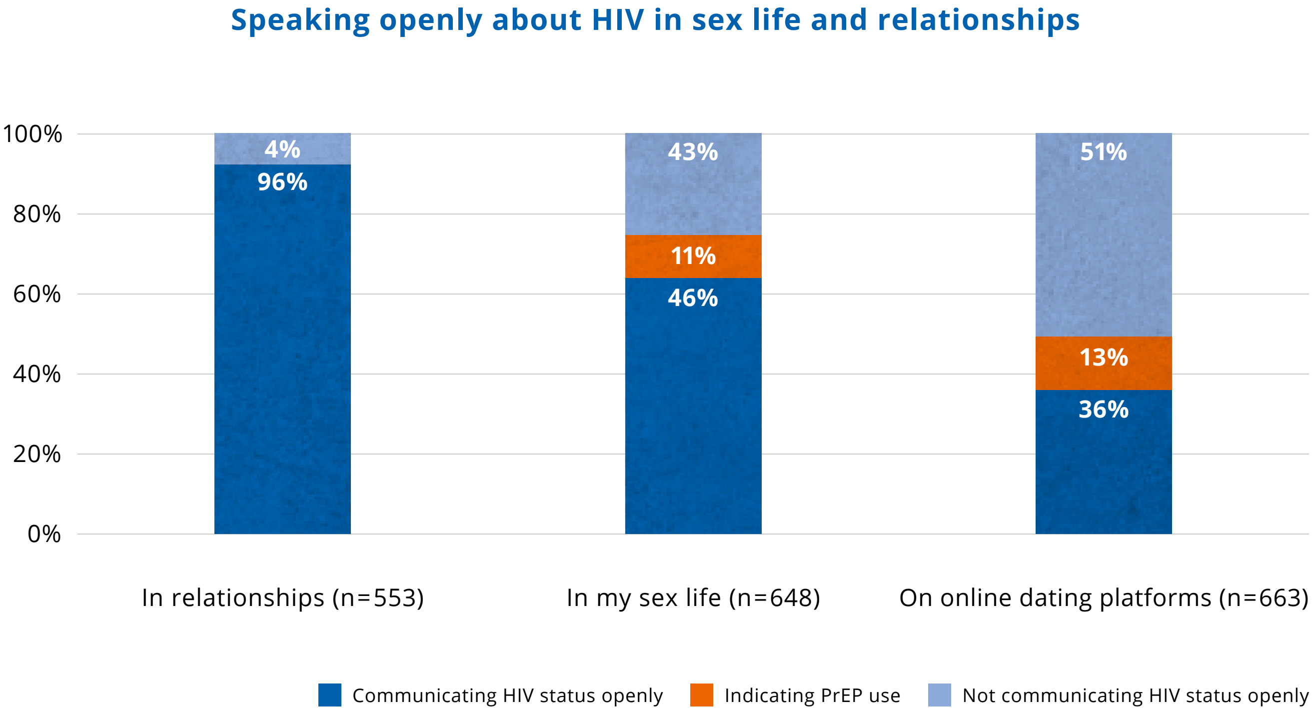


Figure 19: 'What does/do your long-term partner(s) know about your HIV status?'; 'What do you generally tell (potential) sex partners about your HIV status?' – communicating HIV status openly: proportions in % of respondents who indicate they are HIV positive

> **“On PlanetRomeo, many positive guys indicate ‘PreP’. For me, this means they are rather afraid of dealing with their infection, because when it says ‘PreP’ there, it must mean I am one of the good gays.”**

HIV infection has a marked influence on respondents’ sex lives and relationships. These can be positive effects, such as improved self-esteem, but also negative ones, such as avoiding sex.

Of online respondents, 58% agree/rather agree that their sexuality is *not* affected by HIV. The remaining 42% perceive a negative impact of HIV on their sex lives *(no Fig.)*.

Impact of HIV on sex life and relationships

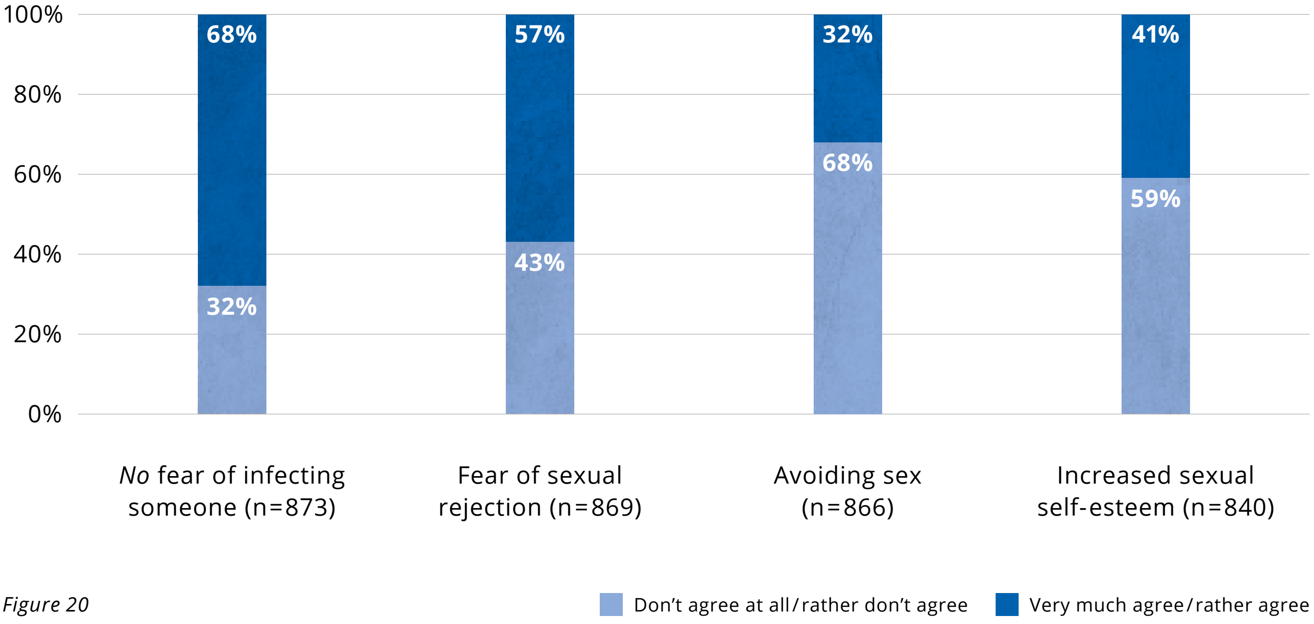


Figure 20

Around one third of respondents report fear of infecting others during sex – even though 95% of respondents have an undetectable viral load. Even today, HIV infection leads to a fear of sexual rejection for many (57% of the sample say 'yes'), and, especially for women, to the avoidance of sex. Of the respondents, 32% strongly agree or agree with the statement 'I sometimes avoid sex because of my HIV infection' – among women, this proportion is 53% *(no Fig)*.

> **"I haven't had sex since I became positive. In the beginning it was my own fear of infecting someone, now it's the rejection by potential partners."**

Again, it seems that, for a substantial proportion of the respondents, HIV also has a positive impact on their sex lives: 41% of respondents report that the HIV infection has increased their sexual self-esteem.

Trust in Treatment as Prevention is high, but the fear of being able to infect someone remains.

Treatment as Prevention has become an important topic for people living with HIV over recent years, and has contributed much to the relief of mental stress. The knowledge of no longer being able to infect others during sex has helped many people living with HIV be more carefree, and to no longer see themselves as 'viral scatterguns'. For a majority of respondents (88%), it reduces the fear of infecting others, for most (85%) it increases self-esteem, and it leads to around three quarters reporting that they enjoy sex more due to knowing about Treatment as Prevention *(see Fig. 21)*. Of the online respondents, 40% also indicate that they experience less discrimination as a result of Treatment as Prevention.

> **"Since the U=U message has been around in the last two to three years, it has triggered another thinking process for me again. Since then, I can enjoy sex more freely. I can also enjoy it the way I want to."**

Of the online survey respondents, 95% report an undetectable viral load. This approximately reflects the average rates for Germany.[1] 96% report relying on the protective effect of treatment *(Fig. 22)*. However, 32% of the same sample indicate that they continue to be afraid of infecting other people some of the time. This discrepancy points to the fact that, while respondents living with HIV have knowledge about Treatment as Prevention, this knowledge seems to remain 'in the head' for almost a third, and doesn't

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[1] *RKI: Epidemiological Bulletin 48/2020 from 26 November 2020*

always seem to have arrived ‘in the gut’. Objective knowledge of non-infectiousness still seems to be counteracted by a subjective fear of still being able to infect others.

Complementary and detailed analyses, incl. analyses regarding subgroups, can be found in the comprehensive research report.

Impact of ‘Treatment as Prevention’

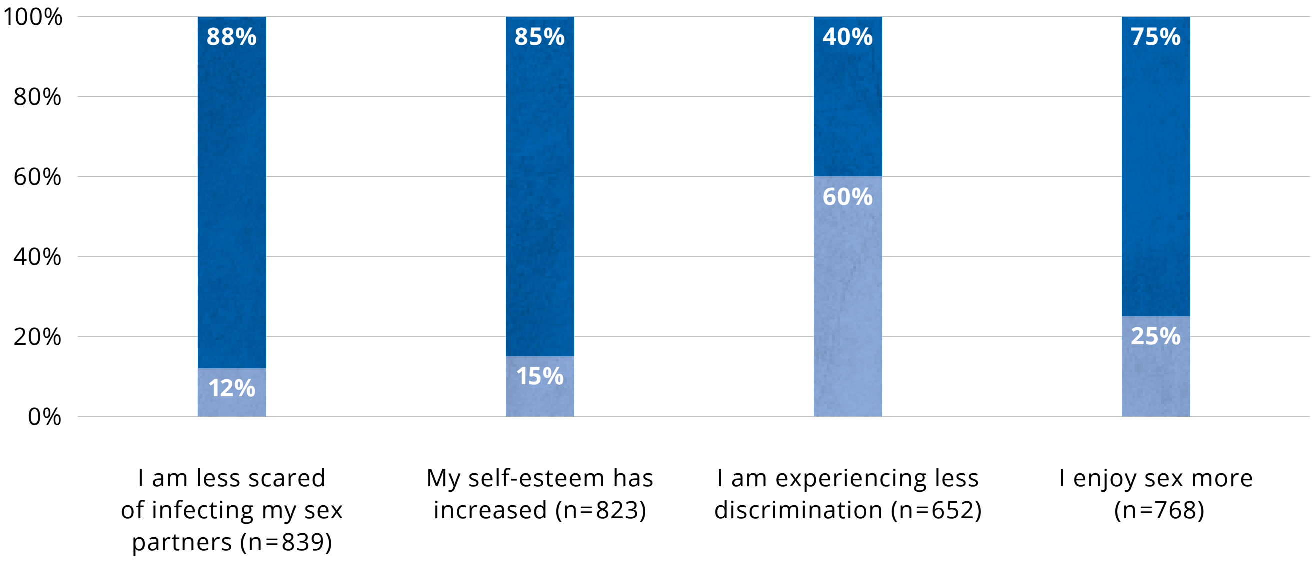
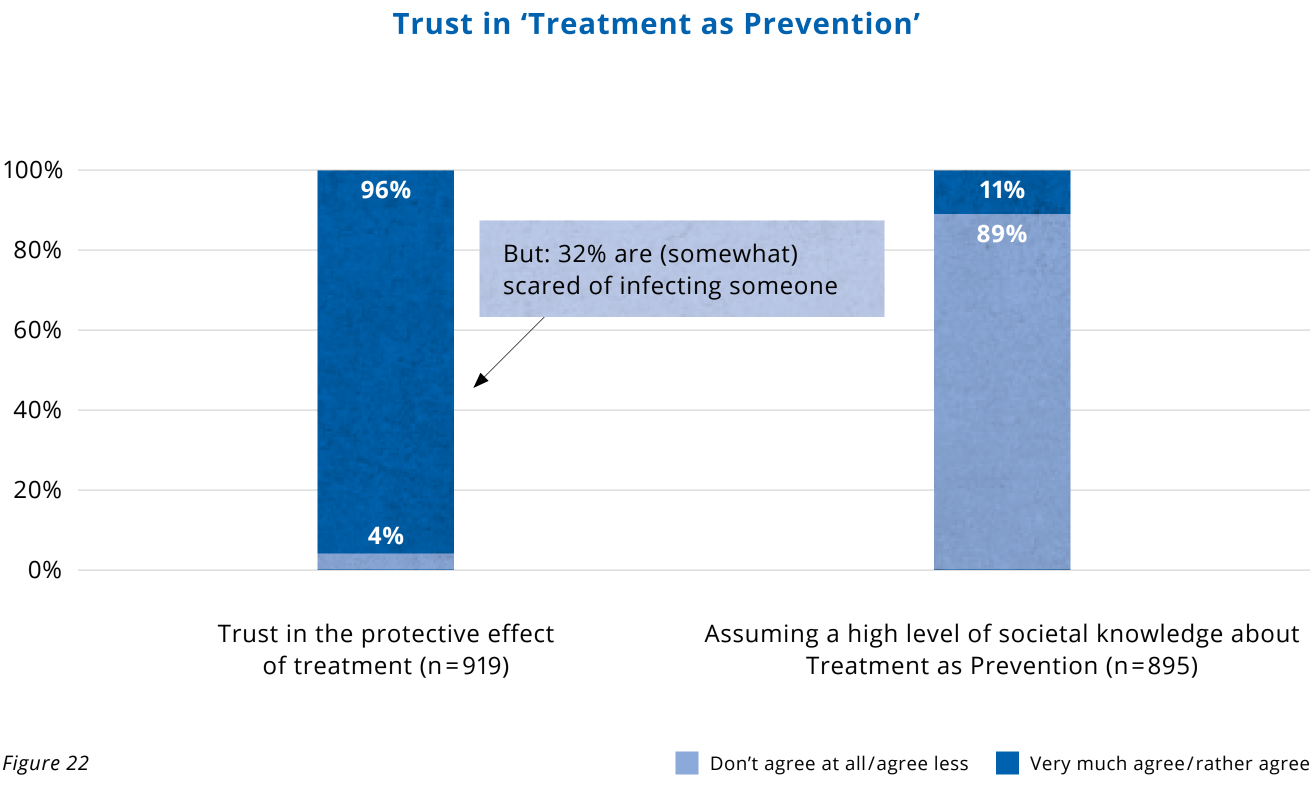


Figure 21



But: 32% are (somewhat) scared of infecting someone

Figure 22

HIV und guilt: Interview with Franziska Hartung

Franziska was part of the 'positive stimmen 2.0' team in her role as a researcher at the IDZ. Her focus were the topics of sexuality and stigmatisation. In the following, she reports on her findings from other research contexts regarding the issue of HIV and guilt.

In your book, you explore HIV and feelings of guilt. Why is this an important topic, and how did you end up focusing on it?

At the beginning of the 'AIDS epidemic' in the 1980s, HIV infection not only equalled a death sentence, it was also stigmatised with 'blame' and 'punishment' for deviating sexual behaviour. One could assume that this would no longer be an issue today. However, during my work as an HIV testing counsellor at the Leipzig public health authority, I often experienced that people who fear they may have become infected with HIV have enormous feelings of guilt and fears of being socially ostracised. Despite modern HIV treatments, the new prevention options (Treatment as Prevention and PrEP), as well as decades of education and anti-discrimination work by the community, HIV is obviously still linked to old – as well as new – stigmatising notions. And people do sense this when they have (potentially) become infected.

Where in your HIV test counselling work did you come across feelings of guilt?

Apart from anticipated blame, (self-) accusations of irresponsibility also often came into play, e.g. when the rules of Safer Sex had been broken, or if other people had potentially been 'exposed to risk'. I also observed that risks were assessed completely differently when a situation that was assumed to have posed a risk of infection is experienced as making the person culpable, e.g. when 'cheating' on a partner or having sex at a brothel. Sometimes I also had the feeling that, as a counsellor, I was hearing confession. I became interested in this correlation with regard to HIV and guilt. And, as there is hardly any scientific research on it, I wanted to contribute something.

What do you see as consequences of the old AIDS discourse, and what is different today?

Feelings of guilt originate, on the one hand, in the stubborn persistence of stigmatisation and attribution of blame with regard to 'risk groups' that is connected to the old AIDS discourse. On the other hand, guilt seems to have become subjectivised today. For example, there is more talk about 'responsibility of the self and of others', and of 'risk management', rather than of 'guilt' and 'punishment'. Today, we want to live our sexuality responsibly, safely, and healthily, but also with pleasure. This means that prevention messages have had an effect, and have been internalised. And this is a good thing, but new norms have also been imposed. And this balancing act between pleasure and the avoidance of infection is sometimes not that easy, and can lead to feelings of guilt at times when we are ‘not acting preventively enough’.

Are you saying that HIV prevention also plays a role in feelings of guilt?

HIV prevention must, for the purpose of avoiding infections, offer us options for protecting ourselves and for acting ‘correctly’ and ‘preventively’. It therefore always sets rules of behaviour. One example is the (moral) meaning of the condom. It took a long time to establish sex with a condom as ‘normal’ and ‘responsible’. Perhaps we have also found it hard to accept ‘Safer Sex 3.0’ for this reason. Especially during early debates about whether to promote ‘Treatment as Prevention’, and about PrEP being covered by health insurance, the accusation of irresponsibility (including that directed towards the welfare state) could be heard often when the possibility of sex without a condom was discussed – not only in the general population, but also inside the HIV positive community.

What is the role of our understanding of ‘health’ in this?

Current strands of the discourse about health and ‘personal responsibility’ that also touch on HIV prevention are playing a role as well. Today, health is associated with attributes such as ‘happiness’, ‘freedom’ and ‘performance’ as it finds expression in the neoliberal premise of ‘self-optimisation’. If these health requirements are not met, it can lead to feelings of guilt. This could be because we may ‘not have managed’ to protect ourselves, because we ‘gambled’ our health for ‘a few minutes of fun’, or because we are burdening the welfare system in the form of health insurance cover for our medications. (Sexual) health should also be considered not only in terms of the absence of physical illness. Sexual satisfaction and mental health are also important. It is a good thing that HIV prevention keeps this within its purview.

Would you say that there is also a general connection between sexuality and guilt? How, for example, do phenomena such as slut shaming and other forms of denigrating certain sexual behaviours relate to the phenomenon of HIV and guilt?

The relationship between sexuality and guilt is deeply rooted in our cultural history. The link between sexuality and guilt has its origin in the biblical creation story, in so-called ‘original sin’. In Christian doctrine, the term ‘sin’ is strongly correlated with the lustful and instinctual side of sexuality. On the one hand, the church attaches great importance and guilt to human sexuality, and at the same time it offers us the opportunity to free ourselves from this burden of guilt: confession. But confession rituals not only play a role in the religious context. They can also be found in other parts of society. One example are the various forms of compulsory counselling in the area of sexuality. Be it compulsory counselling as part of the new Prostitution Protection Act (Prostituierten-schutzgesetz), the assessment procedure within the framework of the ‘Transsexuals Act’ (Transsexuellengesetz), or compulsory counselling in case of 'pregnancy conflict' (Schwangerschaftskonflikt). With the inclusion of termination of pregnancy in the Criminal Code (Strafgesetzbuch), it is not only tainted with guilt in the moral sense, but also in the legal sense. In addition, our society continues to denigrate certain sexual behaviours. Exemplary here is the denigration of female and homosexual promiscuity ('slut shaming'). This is how double standards continue today. Finally, we come full circle regarding HIV, as HIV is still – and this is also shown in my qualitative analysis – being linked with female and homosexual promiscuity, and denigrated as such.

In your research, have you come across anything that especially surprised or impressed you?

I was very much affected by the fact that two young men in my study reported that, in the context of coming out as homosexual to their families and friends, the first response was to remind them to be careful with regard to HIV. Of course, one may argue that men* who have sex with men* (M*SM*) are statistically at a higher risk of HIV, but this also accepts the old stigma of HIV as a 'gay disease'. I again became conscious of the individual, but also the collective burden this results in for gay people. It suggests that they have a special responsibility for protecting themselves (and the general population). I would like to see this responsibility distributed among everyone, regardless of sexual orientation. Especially since infection rates among gay men* and M*SM* keep falling, while heterosexuals don't feel it's their issue, and HIV infections in this group are often only detected at a late stage. The topics of guilt and responsibility must also be considered in the current prevention and counselling context, without reducing them to the old AIDS discourse we inherited.

What are the kinds of developments or changes you would like to see in this regard?

The topics of guilt and responsibility must also be considered in the current prevention and counselling context, without reducing them to the inherited old AIDS discourse. Especially when looking at a holistic understanding of sexual health, I feel it is necessary to consider the normative messages of HIV prevention, and to aim prevention interventions not only at avoiding infections, but increasingly towards sexual satisfaction. De-stigmatisation should remain a priority in this endeavour. This does not only apply to HIV, but also to sexual behaviours that are denigrated by society, such as female and homosexual promiscuity, as well as to social minorities being associated with HIV, such as M*SM*, trans* and inter* persons, sex workers, and black people and people of colour.

Do you believe we can also reduce such feelings of guilt in ourselves? What would be starting points/ strategies?

I think feelings of guilt are human, and that we can't and shouldn't rid ourselves of them in general. They are in some ways our internal ethical compass. However, it depends on the origin of these feelings of guilt. Are they informing us about something we actually did wrong in our own eyes, and that we are ourselves disappointed with? Or are they based on the anticipated apportioning of blame and the moral beliefs of others, which we don't share? Or are they irrational feelings of guilt whose origin is no longer detectable to us at all, because they have inscribed themselves onto our minds in the course of our socialisation? These are not always easy to discern, but it can be helpful to explore the cause of feelings of guilt. In general, we should be more welcoming of our own and others' mistakes, and talk more about questions of responsibility, especially in relation to Safer Sex. For me, communication – especially about sexuality – is key. It also helps to break down taboos that exist inside our heads and in the society.

Publication: Franziska Hartung. 2020.
HIV und Schuldgefühle. Zur Psychodynamik in der HIV-Testberatung. Book series: Angewandte Sexualwissenschaft. Psychosozial-Verlag

3.5 Multidimensional discrimination and stigmatisation

If we want to reduce the stigmatisation and discrimination of people living with HIV, we must also include in our purview stigmatisation and discrimination experiences on the basis of other (attributed) characteristics, as well as their complex interactions. Multidimensional discrimination – in the society in general, but also inside the HIV positive community – plays a significant role in the lived experience of people living with HIV.

> “Poverty discrimination and age discrimination are everyday occurrences that many are exposed to. Discrimination on the basis of sexual identity or general health issues and HIV come on top of this. All of this adds up to quite a potent brew :-/”

Of the respondents to the online survey, 65% indicate that they are discriminated against on the basis of at least one additional characteristic other than HIV. 32% have one additional such characteristic, 18% have two, and 15% have three *(see Table 2)*.

Multiple/multidimensional discrimination subgroups

	In %	n
HIV+0	**31**	**289**
HIV+1	**32**	**297**
HIV+2	**18**	**166**
HIV+3 or more	**15**	**144**

Table 2: Multiple/multidimensional discrimination: percentage of all respondents who experience discrimination on the basis of HIV or/and are affected by discrimination on the basis of other aspects in addition to HIV.

The interwovenness of different stigmatised characteristics makes these experiences of stigmatisation and discrimination more complex. For example, the following can be stated based on the analyses of stigmatised characteristics among respondents to the online survey: the more stigmatised characteristics a person living with HIV possesses, or has attributed to them, the higher is their level of internalised HIV stigmatisation.

While life satisfaction for people living with HIV surveyed online is relatively high on average (average value M = 7.13 on a scale of 1 = *not satisfied at all* to 10 = *completely satisfied*), in the presence of further reasons for discrimination in addition to HIV, reported general life satisfaction drops significantly as other aspects of discrimination increase.

A similar pattern emerges for health status. Overall, a relatively good health status was reported on average (M = 78.65; scale from 1 very bad to 101 very good; n = 881). However, a less positive health status is reported as the number of reported discrimination aspects increases.

A detailed analysis can be found in the comprehensive research report.

Which additional characteristics form the basis of people living with HIV (online survey respondents) experiencing discrimination? Of these respondents, 44% ticked 'sexual orientation/sexual desire' in answer to this question. Among those who indicated being gay or M*SM* in the questionnaire (n = 783), more than half (52%) are discriminated against because of it. For 30% of those over 60 years old, age is a characteristic on whose basis they are experiencing discrimination. Of the women, 18% report experiencing gender-based discrimination. Finally, 6% of the sample report racist discrimination. When looking at the responses from black people and people of colour (n=53), 62% report 'racism' as a basis for discrimination *(see Table 3)*.

> **"It is always difficult to discern why I am being discriminated against. During the course of the interview, it became clear to me that I experience most discrimination because of the colour of my skin. That's what people notice straight away, HIV they don't."**

Comparing the relevance each person attributes to the diverse aspects of discrimination in relation to discrimination on the basis of HIV, marked differences emerge. Especially discrimination on the basis of racism is considered particularly relevant compared to HIV, and discrimination on the basis of sex/gender identity and sexual orientation is also perceived as markedly more relevant. The respective data are contained in the research report.

> **"Well, I am black, so where do you want me to start?"**

Question: 'On the basis of which aspects other than HIV are you experiencing discrimination?' (multiple answers possible) n=935

	Proportion of total sample	Proportion of respective subgroup
Sexual orientation/sexual desire	**44%**	**Of those who are gay and M*SM* (n=783), 52% report this**
Age	**21%**	**Of those older than 60 (n=79), 30% report this**
Because I (allegedly) have many sex partners	**12%**	
Sex/gender identity	**6%**	**Of the women (n=121), 18% report this**
Racism	**6%**	**Of black people and people of colour (n=53), 62% report this**
Unemployment	**5%**	
Others	**10%**	

Table 3

"I really just feel uneasy because of the stigmatisation of my migration background. Every time I go to pick up my medication, 'oh that's just that one from another country', meaning 'a foreigner', 'and those people are just a burden on German health insurance'."

HIV-related stigmatisation is associated with a range of discriminating attributions, e.g. in relation to the denigration and discrimination of non-normative sexualities (homosexuality and promiscuity) and lifestyles (e.g. drug use), as well as cultural affiliations.

Almost 60% of respondents to the online survey report attributions on the basis of HIV status *(Fig. 24)*. This happens especially frequently in relation to sexual orientation and the number of sexual partners. For example, 40% of respondents report that they had, on the basis of their HIV status, attributed to them the (alleged) fact that they have many sexual partners. This shows that promiscuous sexuality still has a stigma (of guilt) attached to it.

> **“For me it’s not at all about the discrimination of HIV, it’s my sex life that’s being discriminated. Because, excuse my French: I am a slut!”**

Discriminatory attributions (in %) n = 935

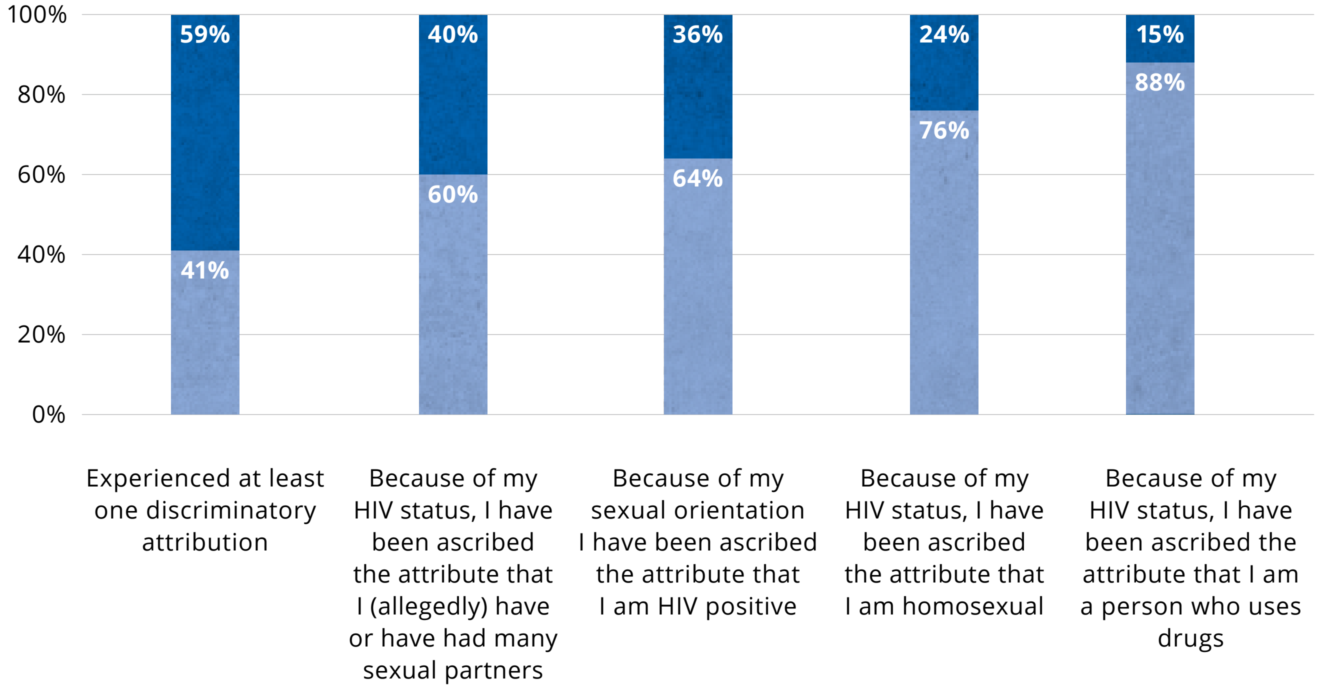


Figure 24

3.6 Dealing with discrimination and community

The HIV positive community and contact with other people living with HIV is empowering, and helps people cope with the infection, and the stigmatisation and discrimination they experience.

Of online respondents, 97% know other people living with HIV personally, and the vast majority feels connected to other people living with HIV. Even though these results are not representative for the entirety of people living with HIV in Germany, a sense of unity or community seems to have become established. Of the respondents, 22% indicate that they have been involved as a volunteer, and 40% of respondents to the peer interviews are members of a peer support group.

Most of the participants in the online survey indicate the following motivations for volunteering (n = 205):

- To help other people living with HIV (10%)
- To educate other people about HIV (10%)
- To work towards social and political change (10%)
- Connection to other people living with HIV (10%)

> **“It’s important to me to deal with HIV openly, to give HIV a face, to break down discrimination and to make HIV a normal part of society. Even among well informed doctors, there still are a lot of feelings of insecurity.”**

A strong sense of belonging to the HIV positive community therefore goes hand in hand with a strong motivation to become involved in the area of HIV, a lower level of internalised stigma, and a more open approach to dealing with HIV (online survey, see research report for details).

> **“I definitely did need many other positive opinions to support me, which said ‘you are not solely responsible for this’ and ‘you don’t have to tell anyone’, yes, that helped me a lot to get my sexuality back.”**

At the same time, the community of people living with HIV is very diverse, and consists of many subgroups or subcommunities. This means that the HIV positive community can also be experienced as a place of discrimination and marginalisation.

The 178 respondents who experienced discrimination inside the HIV positive community were asked for the reasons for their experiences of discrimination *(Table 4)*: the most frequently mentioned reason was discrimination on the basis of age, followed by an attribution of having many sexual partners as the reason for discrimination, and discrimination on the basis of sexual orientation or sexual desire *(see Table 4)*. At 17.4%, the aspect of disability was also mentioned frequently, which corresponds to the findings regarding representation within the HIV positive community.

Discrimination within the community

Reason	Proportion (in %)	n
Age	**32**	**57**
Allegedly many sexual partners	**24**	**42**
Sexual orientation/sexual desire	**21**	**37**
Disability/chronic illness other than HIV/AIDS	**17**	**31**
On the basis of another characteristic	**16**	**26**
I don’t know	**13**	**24**
Sex/gender identity	**12**	**22**
Income	**10**	**18**
Drug use	**10**	**17**
Unemployment	**7**	**13**
Racism	**6**	**11**
Education level	**5**	**9**
Sex work	**5**	**9**
Religion	**4**	**7**

Table 4: ‘What do you think are the reasons why you were discriminated against within the community?’ (multiple answers possible)

“I think that the worst discrimination happens on the net. I’m talking about HIV here, not about being gay. And by ‘net’ I mean online gay networks first of all. Inhibitions on the net are lower than face-to-face. I get annoyed with the question: ‘Are you healthy?’, like we positive people are responsible for bringing pestilence to the gay community so that it has to protect itself. --> assigning blame (in the abstract and concretely). Dividing the gay community into the ‘clean, good gays, who are living as heteronormatively as possible’ and the ‘filthy, perverse gays’. Discrimination because of HIV isn’t as obvious anymore, it’s shifted more towards the net.”

“At a positive people’s gathering [I was asked] by an older positive man why and how I could have got infected despite all that prevention education. I perceived this as discriminatory. I wasn’t expecting it in a place like that.”

“As a former drug user I’m often ignored and not noticed.”

“Discrimination by positive men: ‘What does a woman like you want here?’ ‘AIDS organisations are gay!’”

“Heterosexual people living with HIV thought they were the ‘better positives’, because they became infected ‘innocently’ and aren’t whoring around like the gays.”

Recommendations for action

4.0

4.0 Recommendations for action

Background

The ‘positive stimmen 2.0’ project serves not only to take stock of the current situation, it is above all intended to promote the breaking down of stigmatisation and discrimination of people living with HIV. For this reason, those involved in the project – interviewers and interviewees, as well as focus group and symposium participants – were also asked about which measures should be taken to break down HIV-related stigmatisation and discrimination.

This participatory process produced numerous proposals and demands directed at a range of stakeholders: e.g. AIDS service organisations, policy makers, the health care system, communities of people living with HIV, the media, the Federal Anti-discrimination Agency, patient representatives, medical associations and the Federal Center for Health Education. In this chapter, we present the – from the point of view of the project team – most important results of this process: 7 demands and 17 concrete recommendations to various stakeholders for actions aimed at the implementation of these demands.

These demands and the recommendations for action follow on from the measures identified as a result of the first ‘positive stimmen’ project from 2021, and are intended to contribute to finally ending the unacceptable discrimination of people living with HIV.


ACT
NOW
if NOT
NOW
THEN
WHEN ?

4.1 ‘positive stimmen’ demand…

1. End substandard treatment and people living with HIV being denied medical treatment!

Still today, people living with HIV are denied health care benefits, or they are offered them in a restricted manner or only at certain times, e.g. at the end of consulting hours. In all medical facilities, people living with HIV can and must be treated like any other patient. ‘Special infection control measures’ are unnecessary and do not conform with generally accepted professional standards.

2. Maintain data protection and privacy in all sectors of the health care system!

The right to self-determination regarding personal information also extends to data relating to HIV infection. For example, the medical records of people living with HIV must not be marked as such, and others must not be informed about someone’s HIV infection without the person’s consent, nor learn about it when, for example, conversations between staff members can be overheard by others.

3. Process complaints quickly and competently!

Medical associations and complaints offices must process complaints more quickly, and with professional competence in the area of HIV. To this end, medical associations and complaints offices must continuously train their personnel (or have them trained elsewhere) on current facts about HIV (e.g. HIV transmission, non-transmissibility and living with HIV).

4. Abolish the ‘ANST’ police databases Germany-wide!

The acronym ANST (meaning ‘infection risk’) is used in police databases in Germany to register persons infected with HIV, hepatitis B and/or hepatitis C. We demand the Germany-wide abolition of this stigmatising practice because it does not contribute to the protection of officers, is counterproductive in terms of HIV prevention, and because it violates the right to self-determination regarding personal information (see also the National AIDS Advisory Committee recommendation from 2016).

5. End the criminalisation of (exposure to) HIV transmission!

People living with HIV must not be pushed into taking sole responsibility for protection during sex. The criminal prosecution of (exposure to) HIV transmission during consensual sexual encounters is stigmatising and harms HIV prevention. In the Oslo Declaration of 2012, civil society organisations from across Europe point out the harmful effects of criminalisation. According to an assessment by the National AIDS Advisory Committee from 2013, 'attributions of perpetrator and victim' are 'inappropriate' in this context. Should court proceedings nevertheless arise, sexual non-transmissibility while on treatment must be taken into account.

6. Depict people living with HIV, as well as life with HIV factually in the media, and without stigmatisation or discrimination!

Media professionals have an obligation to become informed about life with HIV today and about the lived experience of the diverse key groups for HIV prevention in order to report adequately. In their media contributions, they must pay attention to language and image selection that is aware of potential discrimination, and follow the handouts and guidelines developed for this purpose.

7. Promote participation and diversity in the settings that AIDS service organisations work in, and address discrimination with intersectionality in mind.

AIDS service organisations and their projects must expand participatory structures, and involve the key groups for whom they are creating services, including decision-making authority in development and decision-making processes. AIDS service organisations must become more diverse and actively promote diversity. This also includes dealing comprehensively and self-reflectively with (structural) racism and other forms of oppression and discrimination – including the way these interweave (intersectionality/multiple discrimination), as well as passing on resources and forging alliances.

> **“My society-wide demand, but also directed at politicians, is to actually finally get away from this damned heteronormativity, from this illusion of a happy, monogamous nuclear family. […] I think our society could really benefit from that.”**
>
> *Focus group participant*

4.2 ‘positive stimmen’ recommend…

Health care system

1. Doctors, nurses and other health care personnel should be better trained regarding HIV, both as part of their vocational education and through regular professional development.

- An important practical approach is the training (both vocational and further education) of teaching personnel in nursing schools and on-the-job trainers in care services (‘train the trainer’ model). AIDS service organisations should be involved in the creation of content for vocational and further education. This also applies to the curricular content of new tertiary courses of study (e.g. ‘Master of Health Care Education’).
- Since 2020, HIV and LGBTIQ* are topics within the Germany-wide framework curricula for nursing studies. These have the effect of recommendations for state-based curricula and the curricula of nursing colleges. AIDS service organisations should offer German state governments as well as nursing colleges to collaborate on creating training modules about HIV together with them and representatives of the communities.
- The content of medical and nursing training and further education regarding HIV should not only focus on infection control, but especially on living with HIV today, HIV stigmatisation, as well as on stigmatising and discriminatory behaviours. Doctors, nurses and counsellors (e.g. in pregnancy and family counselling centres) should also be trained on the topic of HIV and sexuality (incl. Treatment as Prevention, stigma-related causes of sexual dysfunction, chemsex, HIV disclosure in sexual and relationship contexts, HIV and pregnancy etc.).
- People living with HIV from a range of communities should be involved in further education and professional development for health care personnel, and should be paid an allowance for this work. Materials for further education and professional development should be designed, created and evaluated in collaboration with people living with HIV.
- Doctors should be trained how to sensitively communicate a HIV diagnosis.

> **“The doctor who diagnosed us did it on the phone, while I was driving. […] That sort of thing can really backfire.”**
>
> *Focus group participant*

- Doctors and hospital administrators should sensitise their practice and hospital personnel to stigmatisation and discrimination issues, and make their facilities into safe spaces for people living with HIV, LGBTIQ* persons and people with diverse cultural and linguistic backgrounds (see www.praxis-vielfalt.de).

2. Especially right after diagnosis, many people living with HIV need competent contact persons. For this reason, AIDS service organisations should establish or expand services for newly diagnosed people that are easy to access, and ensure their geographic coverage, as well as link their psychosocial services better with HIV medical care.

- Counsellors at AIDS service organisations can, for example, offer (more) consultation times at hospital outpatient departments, specialised medical practices and/or online.
- Doctors should refer patients to AIDS and peer support services (e.g. to the Buddy Project at Deutsche Aidshilfe).

> **“The most delicate phase was actually the first period, the first few days after diagnosis, and the time immediately afterwards. […] I didn’t get a good reception at the time, and I think that people at this point in their life with HIV could be better looked after.”**
>
> *Focus group participant*

Media

3. To ensure that media professionals depict people living with HIV and life with HIV in a sensitive, well-informed way, free from stigma and discrimination (e.g. on World AIDS Day), Deutsche Aidshilfe should develop and disseminate a press code.

4. In order for people living with HIV to communicate with journalists and other media professionals confidently and on an equal footing, AIDS service organisations should offer them support and media training.

Anti-discrimination activities

5. The DAH’s Contact Point for HIV-related Discrimination should be extended and made better known, so that more people living with HIV can defend themselves against discrimination, and can be assisted when discrimination occurs.

6. Anti-discrimination agencies should become better networked and exchange their knowledge. All anti-discrimination agencies should receive further education and professional development regarding HIV. In this area, we would like to see the Federal Anti-discrimination Agency take on a coordinating role.

7. Federal and state patient advocates should be further sensitised regarding HIV and discrimination.

8. In the event of discrimination in the health care system, AIDS service organisations and anti-discrimination agencies should encourage people living with HIV to file a lawsuit on the basis of the General Act on Equal Treatment (Allgemeines Gleichbehandlungsgesetz, AGG) and support them in taking this step. A model lawsuit could ensure that the Act is actually applicable in such cases, which had remained in doubt until the Federal Anti-discrimination Agency issued a statement in 2020 (see text box), and for which there doesn't yet exist a court ruling.

Protection through the AGG in the event of discrimination in the health care system.

The General Act on Equal Treatment (Allgemeines Gleichbehandlungsgesetz, AGG) only offers protection in cases of discrimination on the basis of HIV where a so-called 'bulk business' transaction ('Massengeschäft'), or a contract comparable to a bulk business transaction, is concerned. Bulk business means everyday transactions typically carried out without regard of person or where the regard of person is of subordinate significance, and the legal contract arises 'in a large number of cases under comparable conditions' (Section 19.1.1.). Whether contracts for medical treatment constitute bulk business, and whether the Act (AGG) therefore also applies to discrimination in the health care system, had remained in doubt for a long time. In 2020, the Federal Anti-discrimination Agency issued a statement on this matter (Statements No 01 – 09/2020), according to which contracts for medical treatment are considered a contract comparable to bulk business and therefore fall under the protection of the Act (AGG). This statement must now be applied to real life situations.

Education

9. The general population should be educated more and continuously about the non-transmissibility of HIV under effective treatment. Deutsche Aidshilfe should therefore ask the Federal Center for Health Education (Bundeszentrale für Gesundheitliche Aufklärung, BZgA) to integrate the topic 'Treatment as Prevention' into their LIEBESLEBEN campaign by featuring it on posters.

10. People living with HIV should become even more visible and audible. For example, they can contribute as role models, 'show their faces' in interviews, and appear in features, podcasts, photographic series and campaigns to inform about living with HIV today, and so contribute to the de-stigmatisation of people living with HIV. AIDS service organisations should encourage people living with HIV and support them with resources so that they can take their own perspectives of living with HIV into the public domain, and they should keep asking media professionals to confront the topic of life with HIV today, and offer them opportunities to do so.

Empowerment

11. Deutsche Aidshilfe, local AIDS service organisations, and funding bodies should expand measures for the empowerment of people living with HIV. 'Positive stimmen' suggests

- To integrate debating workshops into empowerment training programmes so that people living with HIV are enabled to defend themselves against discrimination and marginalisation

- To focus more strongly on and practice how to deal with societal stigmatisation, and how to overcome internalised stigmatisation (incl. as part of community-based interventions)
- To design specific empowerment training for key subgroups, such as women and BPoC living with HIV.

12. Deutsche Aidshilfe, local AIDS service organisations, and funding bodies should provide stronger and continuous support to the organisation of self-advocacy and peer support. The following are examples of interventions that could make a contribution:

- Providing information (e.g. in the form of podcasts, video tutorials, talks or seminars) on topics such as ‘founding a peer support group’ and ‘maintaining group motivation’
- Establishing and expanding peer support groups in rural areas
- Founding Germany-wide online peer support groups (also for key subgroups) with regular online meetings, to promote networking within the communities and regions
- Securing long-term resources for peer support (financing, premises etc.).

Sexuality

13. Deutsche Aidshilfe and local AIDS service organisations should focus on a holistic understanding of sexual health in their work. This means, among others:

- Training for personnel in the area of ‘sexuality and HIV’, i.e. on aspects such as (sexual) self-esteem after HIV diagnosis, chemsex, reflecting on responsibility, sex-positive communication, gender-sensitive communication, and HIV disclosure in sex life and relationships
- Qualified sexuality counselling in AIDS service organisations: training counsellors on the topic of sexuality and establishing targeted services for people living with HIV and key subgroups.

14. Deutsche Aidshilfe and local AIDS service organisations should expand sexuality education for adolescents and adults, and develop sexuality education methodologies that transmit information about all methods of protection against HIV transmission (condoms, Treatment as Prevention, PrEP) and also address aspects such as desire, responsibility, living with HIV today, and the stigmatisation of people living with HIV and AIDS.

Diversity

15. In order to make AIDS services more diverse and inclusive, ‘positive stimmen’ recommends, among others

- Diversity training for AIDS service organisation personnel
- Training activities on discrimination-aware communication
- Recruiting/contracting people from the HIV positive communities as staff members, trainers, presenters, journalists etc. Positions must be advertised in a way that actually reaches different communities of people living with HIV (language,

imagery, dissemination). This means that AIDS service organisations must organise their internal structures so that people from diverse key subgroups have a realistic chance of becoming employed (e.g. by recognising international vocational qualifications and allowing multilingual operations within AIDS service organisations).

Communities of people living with HIV

16. The different communities of people living with HIV should reflect on their resources and privileges (e.g. finances, decision making power) and share them in solidarity. Communities with more power are privileged in relation to communities facing multiple levels of disadvantage, and should devolve their resources and power.

17. People living with HIV should reject all societal attributions of ‘guilt’ and the separation into ‘good’ and ‘bad’ people living with HIV – including inside their own communities. How and when a person living with HIV becomes infected is irrelevant to others.

Acknowledgements and further information

5.0

5.0 Acknowledgements and further information

Thank you very much!

We, the ‘positive stimmen 2.0’ team, would like to thank all who supported us and the project very much. Without the active contributions and input of many people, this participatory research project could not have been implemented successfully.

33 peer researchers interviewed other people living with HIV on an equal footing. The fact that you, thanks to your extraordinary commitment, conducted almost 500 interviews despite the challenges posed by the coronavirus pandemic can’t be appreciated enough. A special thank you to you all for your commitment.

Our gratitude also belongs to all those who agreed to be interviewed, and who participated in the online survey and in the focus groups. Your responses and your feedback form the foundation for the scientific analysis and the resulting recommendations for action. They make an important contribution to reducing the discrimination experienced by people living with HIV in the future. Your honesty and your trust in us and in the project, and especially the experiences and events you reported, have moved us deeply. Thank you so much!

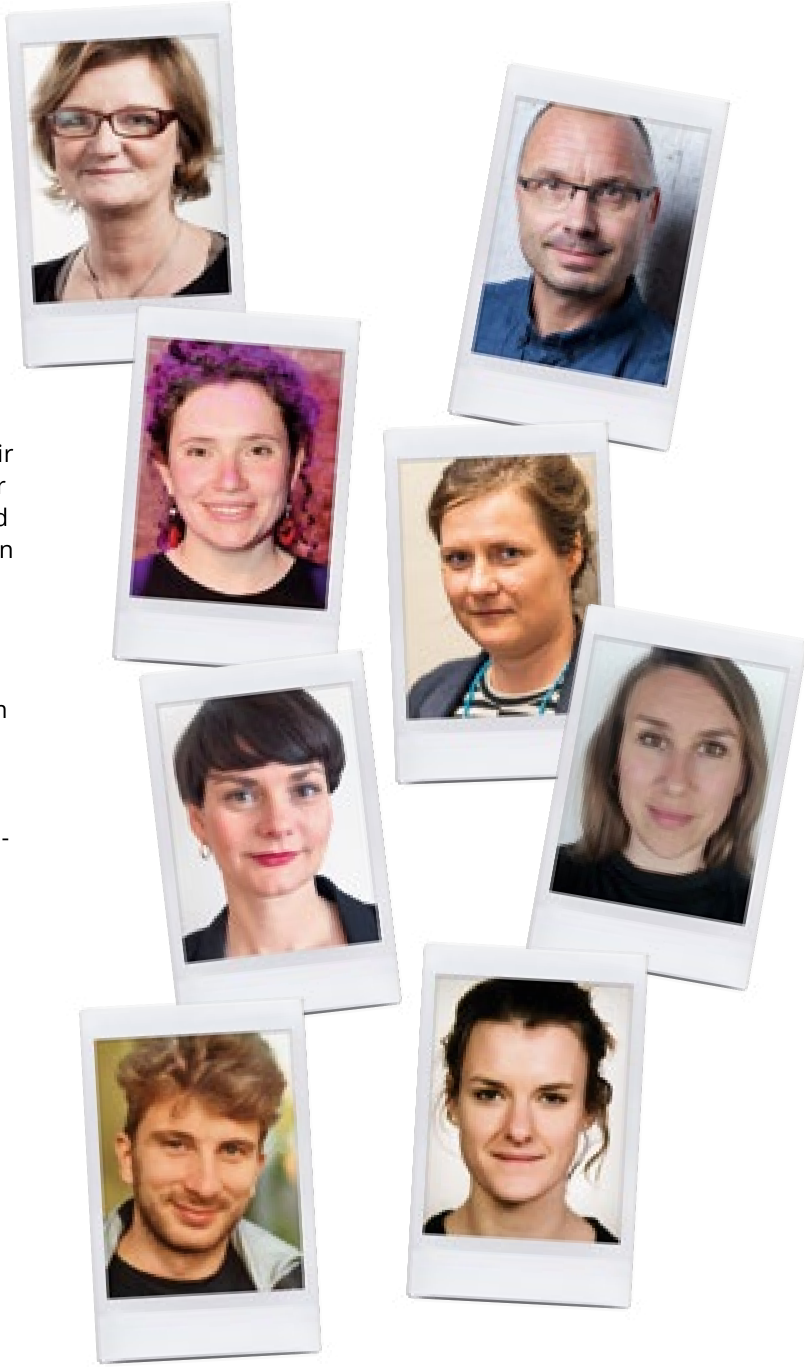
A big thank you also to the advisory committee of community and scientific representatives, who advised and supported the project intensively. We thank you for your expertise, your feedback, and your commitment to ‘positive stimmen 2.0’: Michael Dyrna, Aminata Giese, Edgar Kitter, Kerstin Mörsch, Sabin Schumacher, Christian Szillat, Prof. Dr Kai Jonas, Prof. Dr Hella von Unger, Dr Carolin Vierneisel, Anke Geißler.

We would like to thank very much the participants of the symposium ‘positive stimmen 2.0’ on the 4th and 5th of June 2021 for their interest, the lively discussions, and their important contribution to the development of the recommendations for action. The feedback of so many activists from the communities of people living with HIV, the committees, networks and peer support organisations, among others through the community symposiums, is very important to us and to the project, and of great importance to its success. We hope that the results will provide you with new ideas for your work. We depend on your contributions when it comes to pushing for the adoption of the recommendations. Without financial support from the Federal Ministry of Health, this project would not have been possible. Many thanks for the opportunity to extend the project period by three months in order to compensate for some of the delays caused by the coronavirus pandemic.

Our gratitude also belongs to GNP+ as international coordinating body for the PLHIV Stigma Index for their advice and support in the implementation of the peer interviews. We are pleased to contribute our data and the implementation of the PLHIV Stigma Index 2.0 in Germany to the global fight against stigmatisation.

Last but not least, our thanks go to the Acting Head of the Federal Anti-discrimination Agency, Mr Bernhard Franke. He has agreed to be patron for the symposium and the welcome messages in the project's publications. We would be pleased if this collaboration were to lead to closer cooperation in the future, and a stronger visibility of the topic of HIV-related discrimination on the anti-discrimination agenda.

Your 'positive stimmen 2.0' team



Support services, further information and links

Project partners

Deutsche Aidshilfe (German AIDS Service Organisation, DAH): **www.aidshilfe.de**

Institut für Demokratie und Zivilgesellschaft (Institute for Democracy and Civil Society, IDZ):
www.idz-jena.de

The Institut für Demokratie und Zivilgesellschaft (Institute for Democracy and Civil Society, IDZ) – Thuringian bureau for documentation and research against enmity between groups – is a non-university research institution under the auspices of the Amadeu Antonio Foundation:
www.amadeu-antonio-stiftung.de

Support in case of discrimination

Kontaktstelle HIV-bezogene Diskriminierung (Contact Point for HIV-related Discrimination) at DAH, and overview of local counselling services
Email: **gegendiskriminierung@dah.aidshilfe.de**
Telephone: **030/690087-67**
hiv-diskriminierung.de/kontaktstelle

Antidiskriminierungsstelle des Bundes (Federal Anti-discrimination Agency) and overview of other counselling services:
www.antidiskriminierungsstelle.de

Further information and services

'Positive stimmen' website:
www.positive-stimmen.de

➡ ***Via this link, you can also download the comprehensive research report, as well as this brochure in German and in English.***

To order this brochure and other materials, go to:
www.aidshilfe.de/shop

DAH websites on HIV-related discrimination:
www.hiv-diskriminierung.de

Antidiskriminierungsstelle des Bundes (Federal Anti-discrimination Agency):
www.antidiskriminierungsstelle.de

DAH buddy peer support project: people living with HIV assist and support newly diagnosed people living with HIV in dealing with HIV infection:
www.buddy.hiv

Online and telephone counselling service of the German AIDS service organisations:
www.aidshilfe.de/beratung

Local contact points:
Local AIDS service organisations and counselling services:
www.aidshilfe.de/adressen

People Living with HIV Stigma Index 2.0

The PLHIV Stigma Index 2.0 is a joint initiative of:

Global Network of People Living with HIV (GNP+):
www.gnpplus.net

International Community of Women Living with HIV/AIDS (ICW): **www.icw.org**

Joint United Nations Programme on HIV/AIDS (UNAIDS): **www.unaids.org**