

# The Positive Perspectives Survey Report

**A view into the lives  
of people living with HIV**



The background of the page is a photograph of a clear blue sky with a white airplane flying in the upper left. In the foreground, there is a grey brick wall and a wooden ladder leaning against it. Two large, semi-transparent circles are overlaid on the sky: a yellow one on the left and a larger purple one in the center.

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There are a number of terms or abbreviations (acronyms) that may be unfamiliar. They are listed in the table below.

<b>Antiretroviral Therapy (ART)</b>	Medications used to treat or prevent HIV; can reduce the amount of virus in blood to undetectable levels, preventing HIV-related illness or transmission.
<b>Bisexual</b>	Sexually attracted to both men and women
<b>Comorbidity</b>	A condition that exists at the same time as another condition
<b>Heterosexual</b>	Sexually attracted to people of the opposite sex
<b>Homosexual</b>	Sexually attracted to one's own sex
<b>MSM</b>	Men who have sex with men
<b>PLHIV</b>	People living with HIV
<b>QoL</b>	Quality of life
<b>Switch</b>	To change from one treatment to another
<b>WSW</b>	Women who have sex with women

#### Survey respondent numbers:

Throughout this report you will see that alongside every percentage/statistic from the Positive Perspectives survey, there is a number in brackets. This is the actual number of respondents represented by that percentage. For example, if a figure is shown as 68% – which reflects 755 out of 1,111 PLHIV – then it would be shown as: 68% (755).

Please refer to page 9 for the base values of country respondents and demographic breakdowns.

## Glossary



# Foreword

There have been incredible advances in biomedical interventions for the treatment and prevention of HIV, and current treatments are highly effective in preventing disease progression, death from AIDS, and transmission to others. However, in order to provide a truly holistic package of care for PLHIV, it is vital that these clinical advances are complemented with a strong understanding of the perspectives of PLHIV, including an understanding of the pressures that stigma and disclosure decisions put on PLHIV at diagnosis, and throughout their lives.

The importance of involving experiences and knowledge of PLHIV in decision-making around their medical care has been appreciated ever since it was enshrined in the 1983 Denver Principles. With this background, the Positive Perspectives survey sought to capture the experiences and opinions of a large and diverse international group of PLHIV, on the topics of the psychosocial aspects of living with the virus, dialogues between patient and healthcare provider and satisfaction with current antiretroviral therapies.

Regarding their relationship with HCPs, nearly all (94%) of those surveyed said that they felt quite or very comfortable in raising concerns with their HCPs. For me, this captures the essence of why we conducted this research. The willingness among PLHIV to discuss these issues with caregivers tells us loud and clear that we need to be ready to support this community, not only with medical treatment, but with counsel on every aspect of living with HIV, and activities which help them where they feel the greatest need.



**By Dr Benjamin Young**

Senior Vice President and Chief Medical Officer of the International Association of Providers in AIDS Care (IAPAC)





# About this report

This report focuses on the results from the Positive Perspectives survey that was created by ViiV Healthcare to understand the emerging needs of PLHIV.

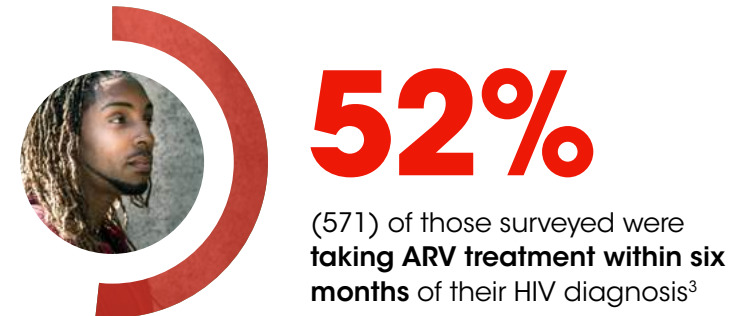
This report covers:

- The emotional support/guidance PLHIV received at diagnosis and where they turn to for support now
- How open PLHIV are about disclosing their status
- Experiences with stigma
- PLHIV and their treatment
- Enhancing communications between PLHIV and their doctor

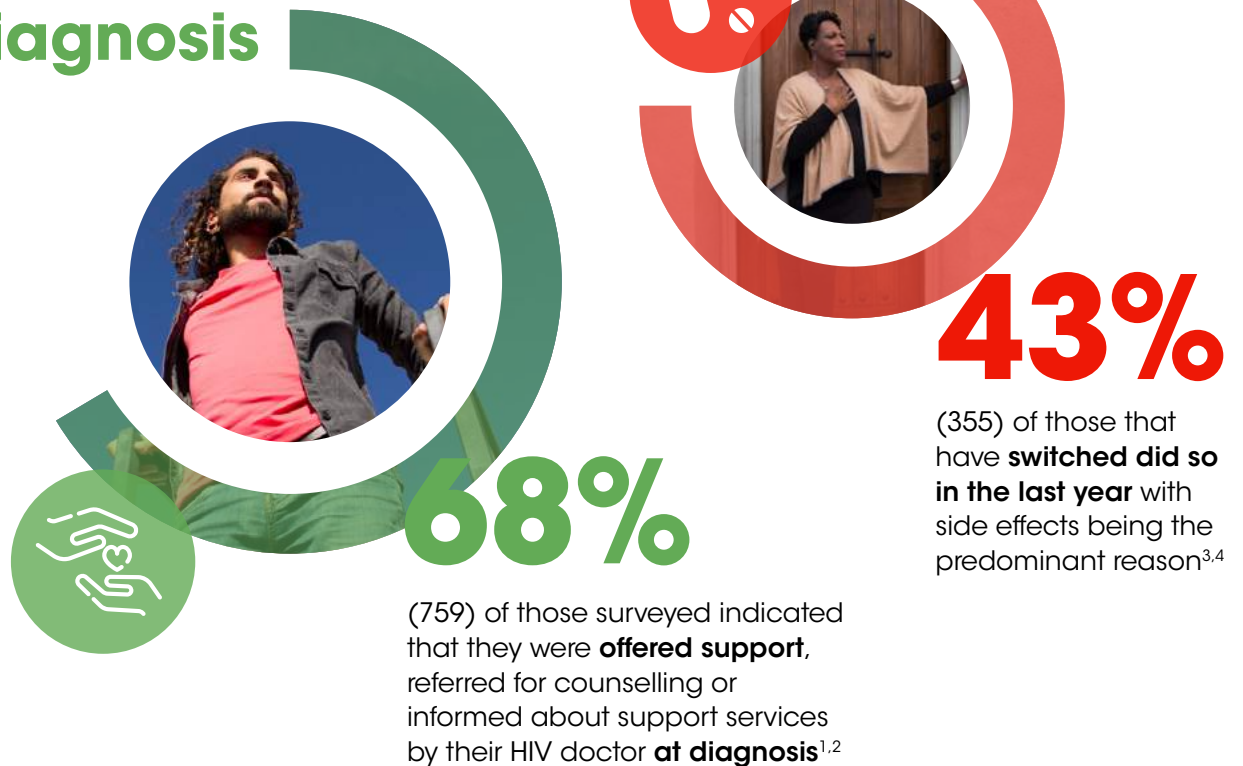
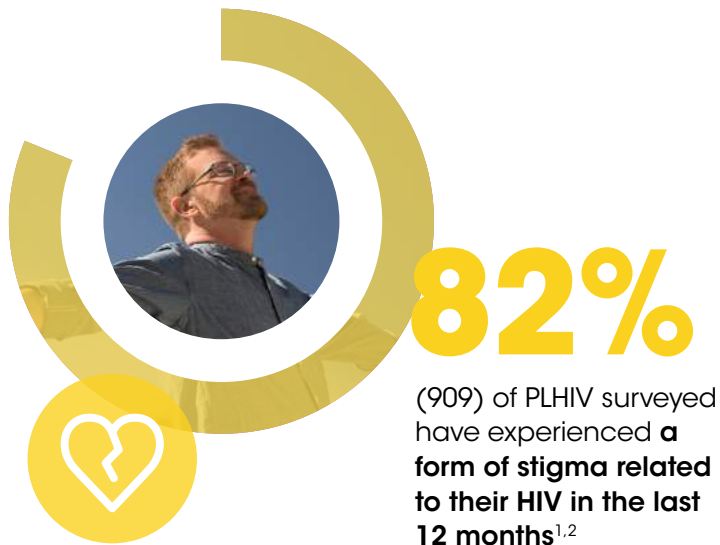


# Key insights

## Getting on treatment



## Diagnosis





# Key insights

## Conversation between PLHIV and their doctor



(789) of PLHIV are **very comfortable with raising issues of concern** with their main HIV doctor<sup>4</sup>



**89%**

(987) of PLHIV believe that advances in HIV treatment **will improve their quality of life**<sup>1,2</sup>

## Treatment satisfaction



**72%**

(783) worry about the **long-term effects of their HIV treatment**<sup>4</sup>



**56%**

(604) of those surveyed that are **currently on treatment** are **very satisfied with it**<sup>3</sup>

# Expert panel

The Positive Perspectives survey was conducted by ViiV Healthcare in collaboration with an international, multi-disciplinary expert panel that included: HIV physicians, PLHIV and patient group representatives. The expert panel contributed to the development of the survey themes and quantitative research questions, and participated in the communication of these results.



**Brent Allan**  
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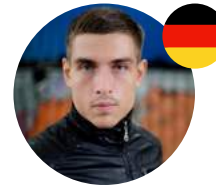
**Diego Garcia Morcillo**  
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Member of the European AIDS Treatment Group (EATG), European Community Advisory Board (ECAB) and Chair of the BOD of ADHARA



**Professor Rob Horne**  
UK

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# Survey methodology\*

The Positive Perspectives survey was undertaken in two phases:

1. A preliminary phase of qualitative research was carried out in June/July 2016 with 24 PLHIV, across four countries, to help understand the key areas of focus.
2. An in-depth quantitative survey was carried out in nine countries.

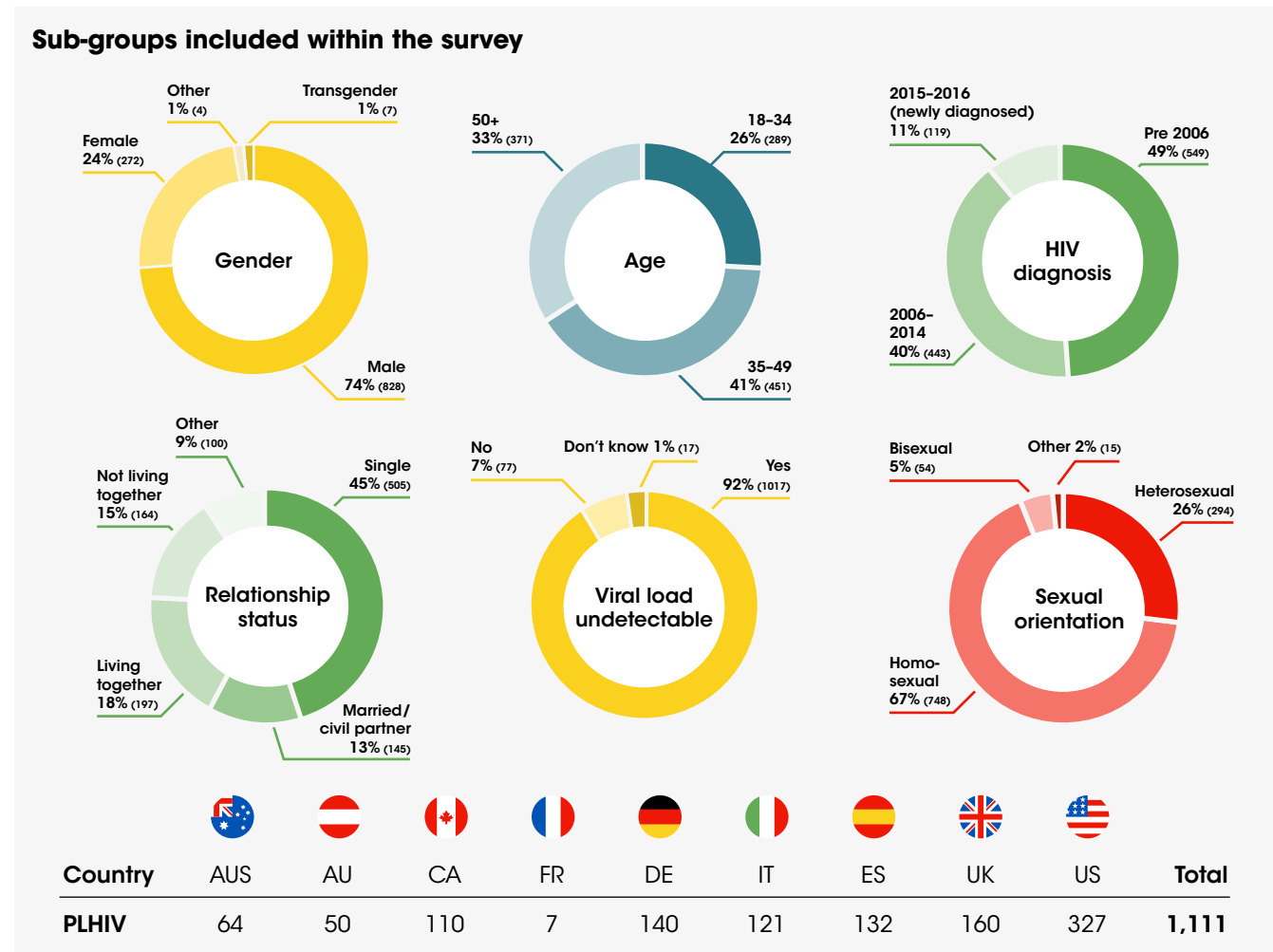
Participants were recruited in multiple ways, including: working with an expert panel (who supported recruitment via their own connections and networks), collaborating with charities, patient support organisations, non-government organisations and HIV online communities and promoting the research via social media:



PLHIV were eligible to enter the survey if they were over the age of 18 and diagnosed with HIV.

The screening process for participants involved completing a pre-questionnaire followed by a telephone interview.

The respondents below are broken down by country and sub-group.



\*Further information on the methodology of the Positive Perspectives survey is available upon request.

## Chapter 1: Diagnosis

Diagnosis is the first step of an important journey for PLHIV and is a step which many find challenging.<sup>5</sup> Out of the 1,111 PLHIV surveyed, 83% (923) stated that their diagnosis had a negative impact on their emotional well-being.<sup>3</sup>

“I no longer have the motivation for things I used to do. I feel as though I have ‘lost myself’ and don’t know where to find it...”

**Female  
Aged 35–49  
Canada**



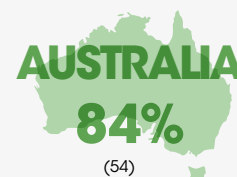
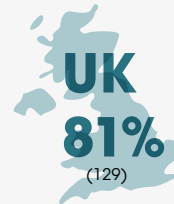
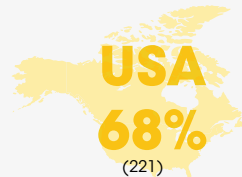
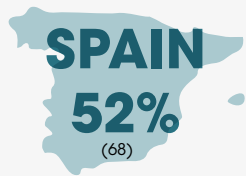
# Chapter 1: Diagnosis

**At the time of diagnosis, how do countries differ when looking at access to emotional support or guidance for PLHIV from their main doctor?<sup>1,2</sup>**



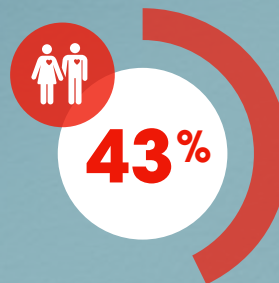
**68%**  
(759)

of those surveyed indicated that they were offered support, referred for counselling or informed about support services by their main doctor **at diagnosis**



The results also show that those diagnosed over 10 years ago may have been offered less support at diagnosis (61%, 337)<sup>2</sup> than those diagnosed within the last two years (72%, 86).<sup>2</sup> Even with this positive change, the results suggested that further improvements still need to be made, with nearly a quarter (23%, 27)<sup>2</sup> of PLHIV who were diagnosed in 2015 to 2016 not being offered support, referred for counselling or informed about support services by their main doctor at diagnosis.

The Positive Perspectives survey results also highlighted that following diagnosis nearly half (45%, 502) of PLHIV turned to a close friend for emotional support,<sup>1,2</sup> underlining the importance of personal relationships for those who are recently diagnosed.



of PLHIV (477) surveyed stated that being diagnosed with HIV has helped them to form more satisfying relationships<sup>2</sup>



# Chapter 1: Diagnosis

The Positive Perspectives survey showed that 90% (998) of PLHIV actively sought support at diagnosis,<sup>2</sup> highlighting the importance of PLHIV being able to access the appropriate services and support networks at this time.

There were differences seen by country in those deciding not to seek support at diagnosis ranging from 2% (2) in Canada to 17% (20) in Italy.<sup>2</sup>

“ Reading other people’s experiences helps me to believe that I am going to be OK ”

**Male**  
**Aged 18–34**  
**UK**

“ My friends and family stand behind me even after the diagnosis and support me ”

**Female**  
**Aged 18–34**  
**Germany**



# Chapter 1: Diagnosis

When looking at where PLHIV seek emotional support immediately following diagnosis we can see that:



**45%** (502)

of PLHIV from the above countries stated that **they would turn to a close friend for emotional support**<sup>2</sup>



**54%** (27)

of PLHIV in Austria chose their main HIV doctor as their number one choice for emotional support<sup>2</sup>

HIV patient support organisations are the number one choice for emotional support:<sup>2</sup>

**36%** (98)

For women



**37%** (109)

For heterosexuals



Compared with women, **more men seek emotional support from a close friend at diagnosis**<sup>2</sup>

**MSM are more likely** than heterosexuals to turn to someone they know living with HIV for emotional support<sup>2</sup>



**51%** (422)



vs

**28%** (76)



# Chapter 1: Diagnosis

The respondents in the Positive Perspectives survey showed that how they gain emotional support today seems to have changed.

Of the 342 PLHIV surveyed that had a partner, **98%** (335) said that their partner knew about their HIV status:<sup>2</sup>

- **36%** (124) have HIV-positive partners<sup>2</sup>
- **63%** (215) have HIV-negative partners<sup>2</sup>
- **1%** (3) preferred not to say the HIV status of their partner<sup>2</sup>

"I am happy.  
Life is smiling  
on me"

Female  
Aged 50+  
Spain

## What type of support do PLHIV turn to their partners for?



**74%**  
(248)

Emotional support



**52%**  
(174)

Reminds them to take  
their medication



**36%**  
(121)

Helps them to organise  
their HIV medication



**46%**  
(153)

Reminds them about  
their HIV appointments



**44%**  
(146)

Helps them to decide what  
they need to discuss with their  
main HIV healthcare provider



**21%**  
(72)

Goes with them to routine doctor/  
nurse appointments related to  
their partner's HIV but does not sit  
in the consultation itself



**33%**  
(112)

Goes with them to routine doctor/  
nurse appointments related to  
their partner's HIV and sits in the  
consultation itself

## Source of emotional support today



From the four countries above, PLHIV are  
most likely to turn to their main HIV provider  
(35%, 255) for emotional support today<sup>2</sup>



Whilst PLHIV in Italy (31%, 38), Australia  
(39%, 25) and Austria (38%, 19) are  
most likely to still turn to a **close friend**  
as they did at diagnosis<sup>2</sup>



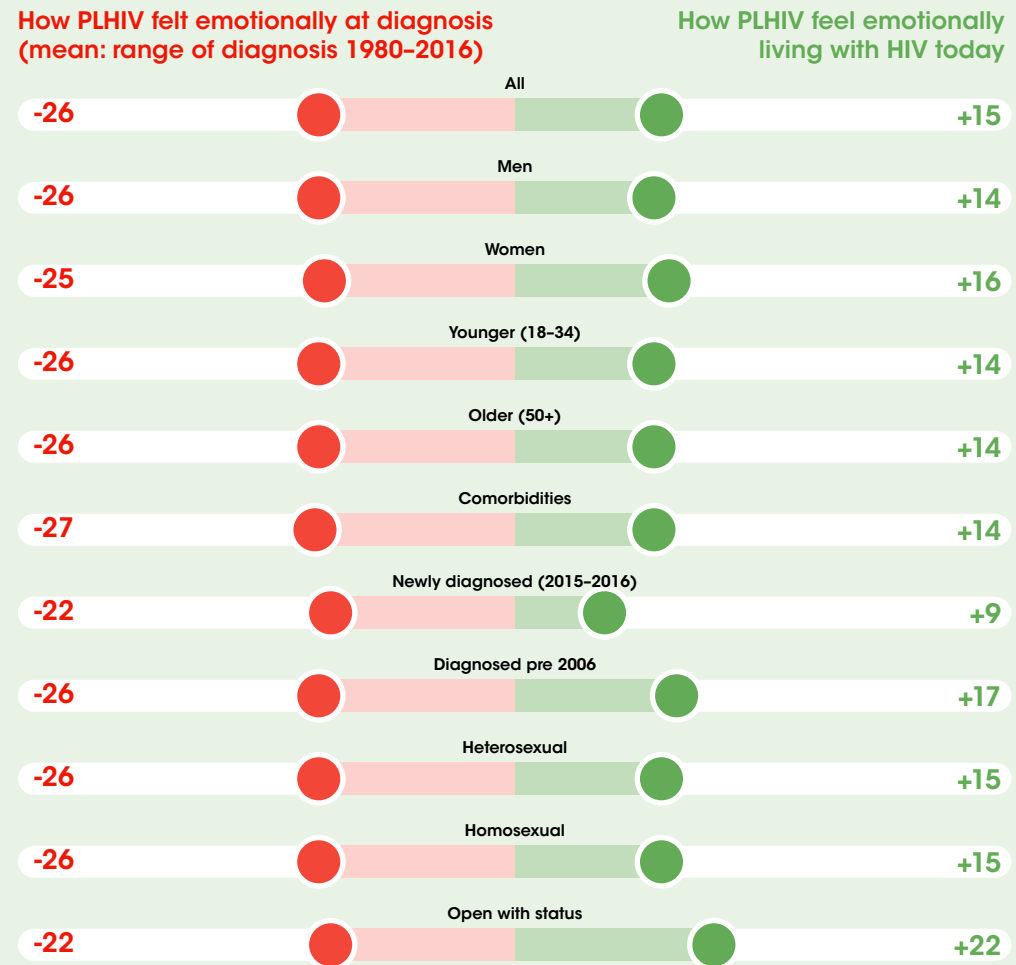
PLHIV in Germany stated  
that they are most likely  
to turn to their **partner** for  
emotional support  
(32%, 45)<sup>2</sup>



# Chapter 1: Diagnosis

HIV diagnosis has an emotional impact on people's lives. In the Positive Perspectives survey, PLHIV were asked to rate their emotional status on a scale from -50 to +50 at diagnosis and today:<sup>2</sup>

Mean rating of participants within the survey:



## Chapter 2: Stigma and disclosure

Even though there have been advances in HIV treatment since the 1980s, the stigma associated with HIV still remains.

Participants in the survey were asked how their lives had changed both positively and negatively over the last five years of living with HIV. The top two negative responses reported by those surveyed were:<sup>2</sup>

1. "HIV still carries a lot of stigma"
2. "I am unable to engage in a proper/stable relationship"

"There is still stigma with being HIV positive. I still have to hide my diagnosis "

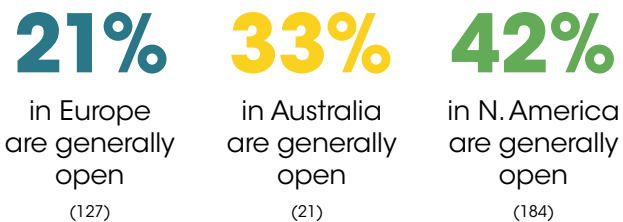
Male  
Aged 50+  
UK





## Chapter 2: Stigma and disclosure

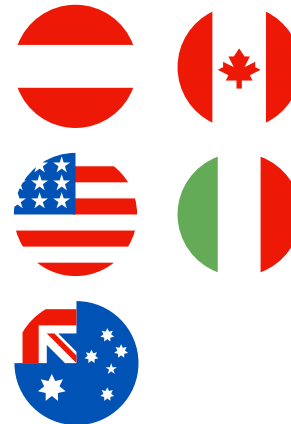
The Positive Perspectives survey showed there were regional differences in how open PLHIV were in disclosing their status.<sup>1</sup>



**93%** of PLHIV have told their doctor (GP) about their HIV status:<sup>(1,034)<sup>2</sup></sup>

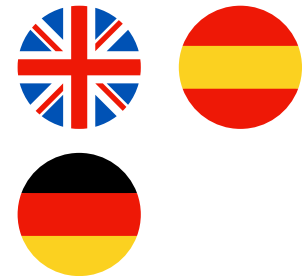
### #1 Reason:

Wanted their doctor to be involved in their HIV care as they believe that they need to know about all aspects of their health<sup>2</sup>



### #1 Reason:

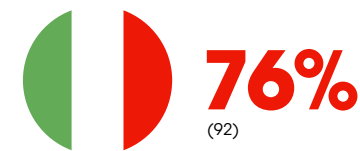
Their doctor should be aware of the HIV medication they are taking in case it caused problems with other medication they are on<sup>2</sup>



PLHIV are not open about disclosing their HIV status to current work colleagues:



of those surveyed have not disclosed their status to their colleagues<sup>2</sup>



of PLHIV in Italy have not disclosed their status to their colleagues<sup>2</sup>

" Stigma surrounding the disease is similar to that of the 1990s "

Male  
Aged 35–49  
USA

## Chapter 2: Stigma and disclosure

82% (909) of PLHIV surveyed have experienced a form of stigma related to their HIV in the last 12 months,<sup>1,2</sup> although this varies based on country, with 71% (86) of PLHIV in Italy having experienced recent stigma, and 90% (99) in Canada.<sup>2</sup>

### Self-stigma



- Feelings of self-blame
- Guilt
- Lack of worth
- Need for secrecy

### Institutionalised stigma



- Barred from jobs
- Being denied certain educational opportunities or health services

### Physical stigma



- Being shunned or abandoned
- Harassment
- Asked to use separate facilities from others

### Social stigma



- Feelings of isolation from my local community or social circle

### Verbal stigma



- Gossip
- Taunting
- Scolding
- Labelling

“ I feel dirty and stigmatised. I have a lot of fear and loneliness ”

Female  
Aged 35–49  
Spain



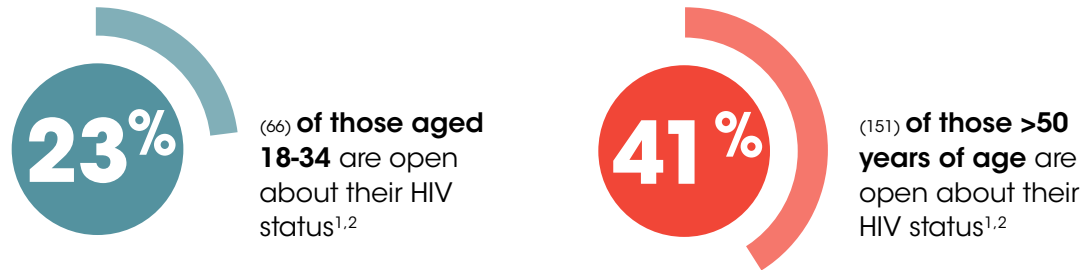
## Chapter 2: Stigma and disclosure

The Positive Perspectives survey results showed that self-stigma continues to have a big impact on the lives of PLHIV, with over a quarter (27%, <sup>297</sup>) stating feelings of self-blame, guilt and a need for secrecy.<sup>1,2</sup> Self-stigmatisation is reported more commonly in the UK (35%, <sup>56</sup>) and Canada (33%, <sup>36</sup>), but less so in Italy (19%, <sup>23</sup>) and Austria (20%, <sup>10</sup>).<sup>2</sup>

In relation to social stigma, nearly one in five (19%, <sup>207</sup>) stated that they have feelings of isolation from their local community.<sup>1,2</sup> Similarly, nearly a third (32%, <sup>355</sup>) of PLHIV noted that their HIV status is only known to people very close to them and, even when asked, would not tell others.<sup>1,2</sup>

## Chapter 2: Stigma and disclosure

The Positive Perspectives survey shows that:



When comparing how stigma can vary from country to country, it can be seen that:

- **Across all the countries surveyed**, social stigma is the second-most dominant form of stigma raised by PLHIV<sup>2</sup>
- Participants from **North America** indicate that social stigma is almost, if not as big, of an issue as self-stigma<sup>2</sup>
- Participants from **Germany, Italy and Australia** feel as though they are very rarely impacted by social stigma<sup>2</sup>
- Participants from **Spain** are more than twice as likely to be impacted by self-stigma than social stigma<sup>2</sup>





## Chapter 2: Stigma and disclosure

How to reduce feelings of stigmatisation:



**67%** <sup>(661)</sup>

of PLHIV from the countries above believe that better education for the general public was the number one way to address the issue<sup>2</sup>



**62%** <sup>(75)</sup>

believe that better teaching in schools was the number one way to address the issue<sup>2</sup>

A quarter <sup>(283)</sup> of those surveyed felt that better doctor education will reduce feelings of stigmatisation,<sup>1,2</sup> which was a strong priority for those in Germany:<sup>2</sup>

These 283 PLHIV believe that additional education is required for:<sup>2</sup>



**48%** <sup>(67)</sup>



**65%** <sup>(184)</sup>

GPs & primary care doctors



**64%** <sup>(181)</sup>

Hospital nurses



**60%** <sup>(171)</sup>

Dentists

Greater responsibility and better education of the mass media were also frequently selected as a way to combat stigma (44%, <sup>494</sup>),<sup>1,2</sup> particularly in Europe (50%, <sup>307</sup>), less so in North America (35%, <sup>153</sup>).<sup>2</sup>

"Be careful he is sick, he has AIDS, he is toxic"

Male  
Aged 35–49  
Italy



## Chapter 3: Getting on treatment

The time to initiation of treatment for PLHIV has reduced over the last 10 years, with 88% <sup>(102)</sup> <sup>2,3</sup> of those newly diagnosed, being on treatment within six months of diagnosis compared with 40% <sup>(218)</sup> of those diagnosed >10 years ago. This equates to 52% <sup>(571)</sup> across all PLHIV surveyed who have taken ARV treatment within six months of their HIV diagnosis.<sup>3</sup> A key reason for this improvement is due to evolving treatment guidelines recommending earlier initiation of treatment.<sup>6</sup>

Today's treatments are effective in managing HIV and the latest survey findings suggest that PLHIV are optimistic about ongoing progress in treatment development, with 89% <sup>(987)</sup> feeling that advances in HIV treatment will improve their quality of life.<sup>1,2</sup>

"These days I have greater faith in the research "

**Female  
Aged 50+  
Italy**

"Learning that I could keep from passing the virus on if I stay at non-detectable levels was a game changer in how I felt when seeking medical care. I have returned to work part time after being out of work for nearly a decade because of the advancements in treatment "

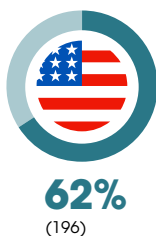
**Male  
Aged 35-49  
USA**





# Chapter 3: Treatment satisfaction

Of the 98% (1,085) who are currently on treatment,<sup>4</sup> 56% (604) are very satisfied with their treatment. This is quite consistent across gender, age and time since diagnosis.<sup>2,3</sup> However, there are differences when looking at the results from various countries:<sup>2</sup>

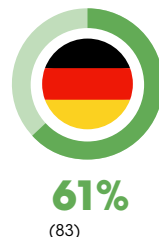
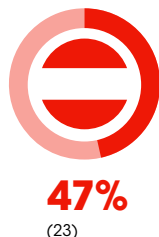
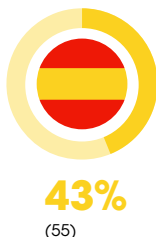


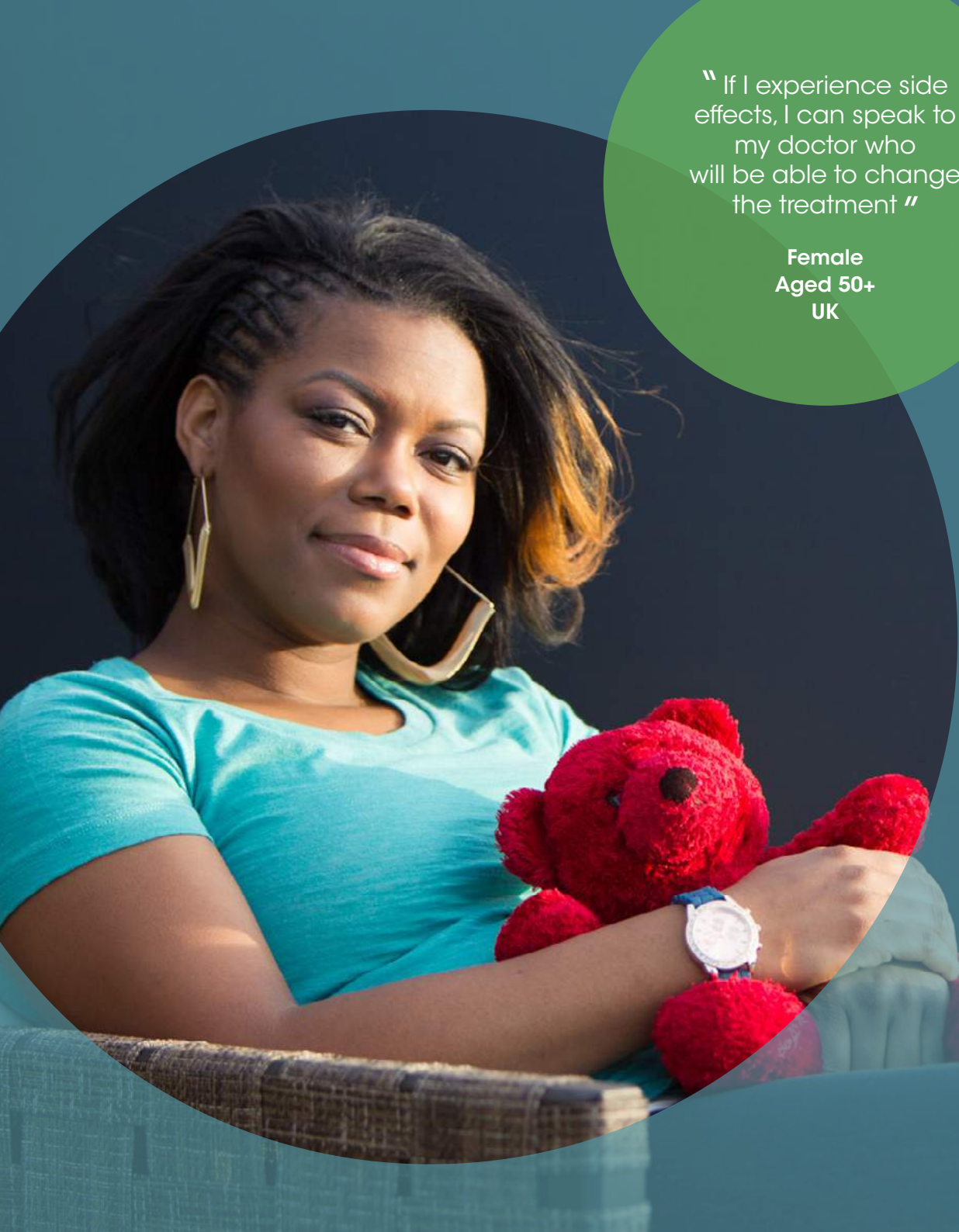
of PLHIV in the US **are currently very satisfied** with their HIV treatment, which is the highest when compared with other countries.



of PLHIV in Canada **are very satisfied**

In Europe, **lower treatment satisfaction levels** are seen in Spain and Austria, whilst **higher levels** are seen in the UK and Germany.<sup>2</sup>





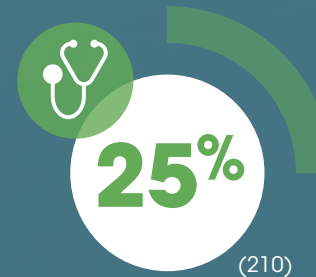
“ If I experience side effects, I can speak to my doctor who will be able to change the treatment ”

Female  
Aged 50+  
UK

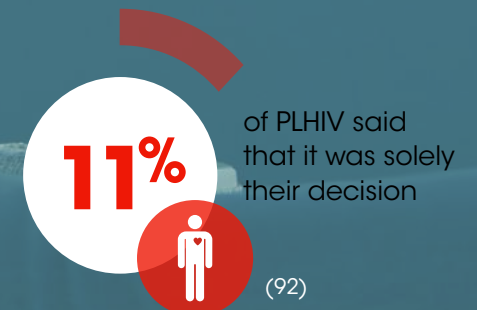
## Chapter 3: Treatment satisfaction

Around 3 in 10 PLHIV agree that their HIV treatment gives them unpleasant side effects, which were seen as the predominant reason for 43% <sup>(355)</sup> of those surveyed to switch their treatment.<sup>3,4</sup> Other reasons for switching include helping to improve QoL (37%, <sup>310</sup>) and to reduce the number of pills they need to take (32%, <sup>264</sup>).<sup>2</sup>

When looking at how PLHIV made the decision to switch treatment, 55% <sup>(460)</sup> reported that the decision was jointly made between them and their main HIV doctor:<sup>3</sup>



said that it was solely or primarily their doctor's decision



of PLHIV said that it was solely their decision



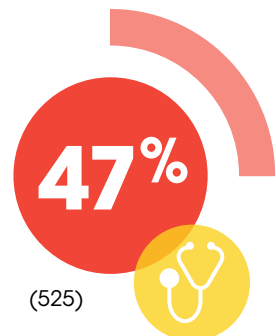
## Chapter 4: Conversations between PLHIV and their doctor

While the majority (71% <sup>(789)</sup>) of PLHIV reported being very comfortable with raising issues of concern with their main doctor, this was lower in newly diagnosed individuals, with only 61% <sup>(73)</sup> feeling very comfortable.<sup>2</sup>

Interestingly, when this is broken down to a regional and country level there are some significant differences, with 81% <sup>(353)</sup> very comfortable in North America<sup>3</sup> versus 62% <sup>(381)</sup> in Europe.<sup>2</sup> Within Europe, the lowest levels are seen in Italy with only 56% <sup>(68)</sup> very comfortable and in Spain with 50% <sup>(66)</sup>.<sup>2</sup>

“I hate when it comes to taking medication and when I have to go to doctors’ appointments ”

Male  
Aged 35–49  
Canada



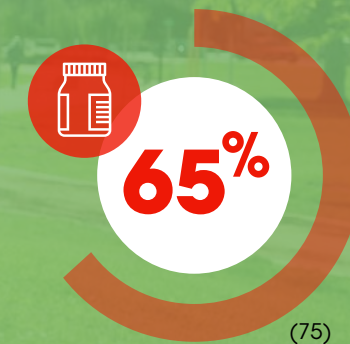
of those surveyed visited their HIV doctor at least four times in the past 12 months.





## Chapter 5: Long-term effects of treatment

Although, 72% <sup>(783)</sup> of PLHIV worry about the long-term effects of HIV treatments, more than a quarter (26%, <sup>206</sup>) have not discussed this concern with their doctor.<sup>3</sup>



of PLHIV that are newly diagnosed worry about the long-term effects of treatment<sup>2</sup>

" I have been on medication for HIV since 1996 and do sometimes worry what the long-term effect this is having on my body. Although I feel well and healthy at the moment I was diagnosed with osteoporosis about 8 years ago, and so sometimes I think what else could I develop as I get older? "

Male  
Aged 50+  
UK



## Chapter 5: Long-term effects of treatment

Long-term effects from treatment appear to be a large worry for those living with HIV. When asked on how to mitigate the impact of long-term ARV treatment, those surveyed answered:<sup>3</sup>



**13%**

(103)

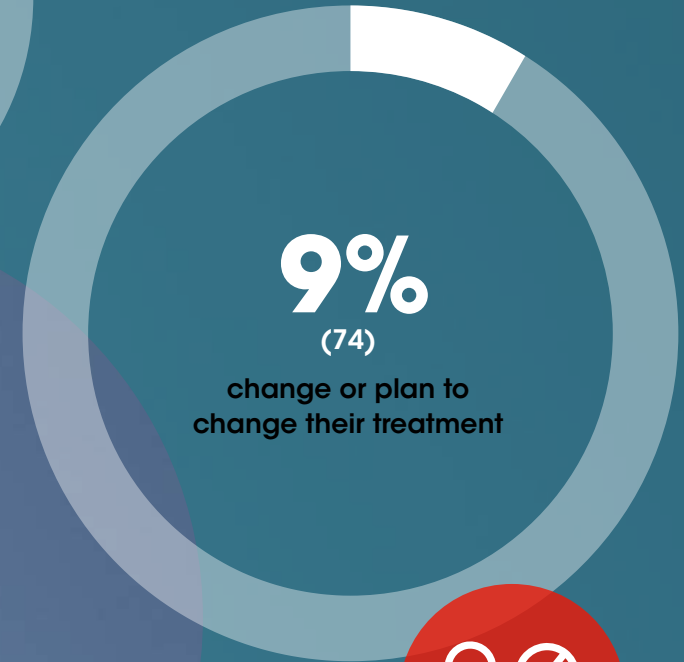
speak to their doctor for  
support and information



**19%**

(147)

read up and educate  
themselves about HIV



# References

- 1 Murungi A, et al. Experience of living with HIV: Diagnosis & Disclosure – findings from the Positive Perspectives study. Presented at the IAS Conference on HIV Science (IAS 2017), 23-26 July 2017, Paris, France. Abstract: WEPED1423
- 2 Positive Perspectives Survey, 2017 DOF
- 3 Young B, et al. Patient Experience & Views on Antiretroviral Treatment – Findings from the Positive Perspectives Survey. Presented at the Infectious Disease Week (ID Week conference), 4–8 October 2017, San Diego, USA. Abstract number #1393.
- 4 Marcotullio S, et al. EU Patient Experience & Views on Antiretroviral Treatment – Findings from the Positive Perspectives Survey. Presented at the 16th European AIDS Conference (EACS), 25–27 October 2017, Milan, Italy. Abstract number #PE25/9.
- 5 Moskowitz JT, et al. Illness Appraisals and Depression in the First Year after HIV Diagnosis. *PLoS ONE*. 2013;8(10):e78904.
- 6 Trickey A, et al. Survival of HIV-positive patients starting antiretroviral therapy between 1996 and 2013: a collaborative analysis of cohort studies. *Lancet HIV*. 2017 [http://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018\(17\)30066-8/fulltext?elsca1=tlpr](http://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(17)30066-8/fulltext?elsca1=tlpr)

Stay tuned for the attitudes  
and perspectives of the  
partners/significant others  
of those that live with HIV  
– **Coming in 2018!**



## About ViiV Healthcare

ViiV Healthcare is a global specialist HIV company established in November 2009 by GlaxoSmithKline (LSE: GSK) and Pfizer (NYSE: PFE) dedicated to delivering advances in treatment and care for PLHIV and for people who are at risk of becoming infected with HIV. Shionogi joined in October 2012. The company's aim is to take a deeper and broader interest in HIV/AIDS than any company has done before and take a new approach to deliver effective and innovative medicines for HIV treatment and prevention, as well as support communities affected by HIV. For more information on the company, its management, portfolio, pipeline and commitment, please visit [www.viivhealthcare.com](http://www.viivhealthcare.com).

## About Positive Perspectives survey

The Positive Perspectives survey was sponsored by ViiV Healthcare and conducted by GfK UK Limited, an independent market research agency. The survey was conducted in nine countries (Austria, Australia, Canada, France, Germany, Italy, Spain, UK and USA) with a total of 1,111 PLHIV. The recruitment of PLHIV for this survey included working with charities, patient support groups and NGOs, HIV online communities and also promoting the research via social media (Facebook / Instagram / Twitter) in each country. The survey questionnaire was designed by ViiV Healthcare in collaboration with GfK UK Limited and through consultation with an independent Steering Committee of HIV professionals and advocates. The Positive Perspectives survey data are owned by ViiV Healthcare and will be presented at upcoming conferences, subject to abstract acceptance. ©2017 ViiV Healthcare group of companies or its licensor.

Hear more about the Positive Perspectives survey on Twitter and LinkedIn:

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