

# EXAMINING THE MANY FACES OF HIV STIGMA AND THE SPACES IN WHICH THEY OCCUR

Findings from waves 1 and 2 of the Positive Perspectives Survey  
of people with HIV in Spain

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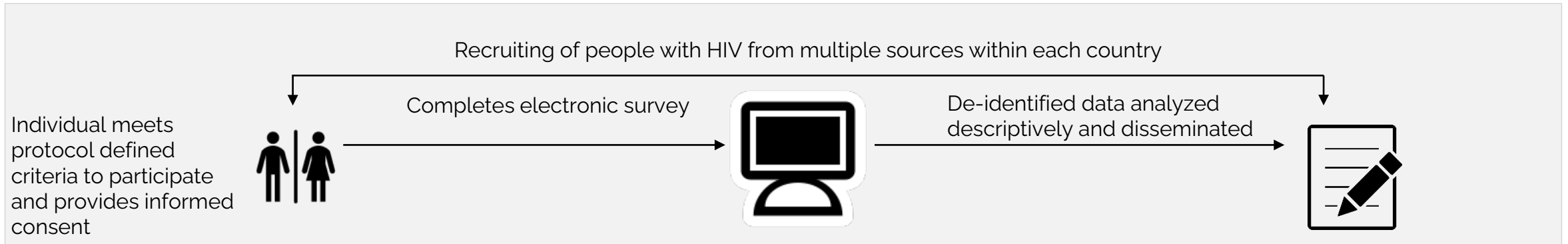
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# Study aim and approach

**Aim:** Examine different forms of stigma experienced by people with HIV in Spain within various settings, including from healthcare professionals (HCPs) within healthcare facilities.

## Data source

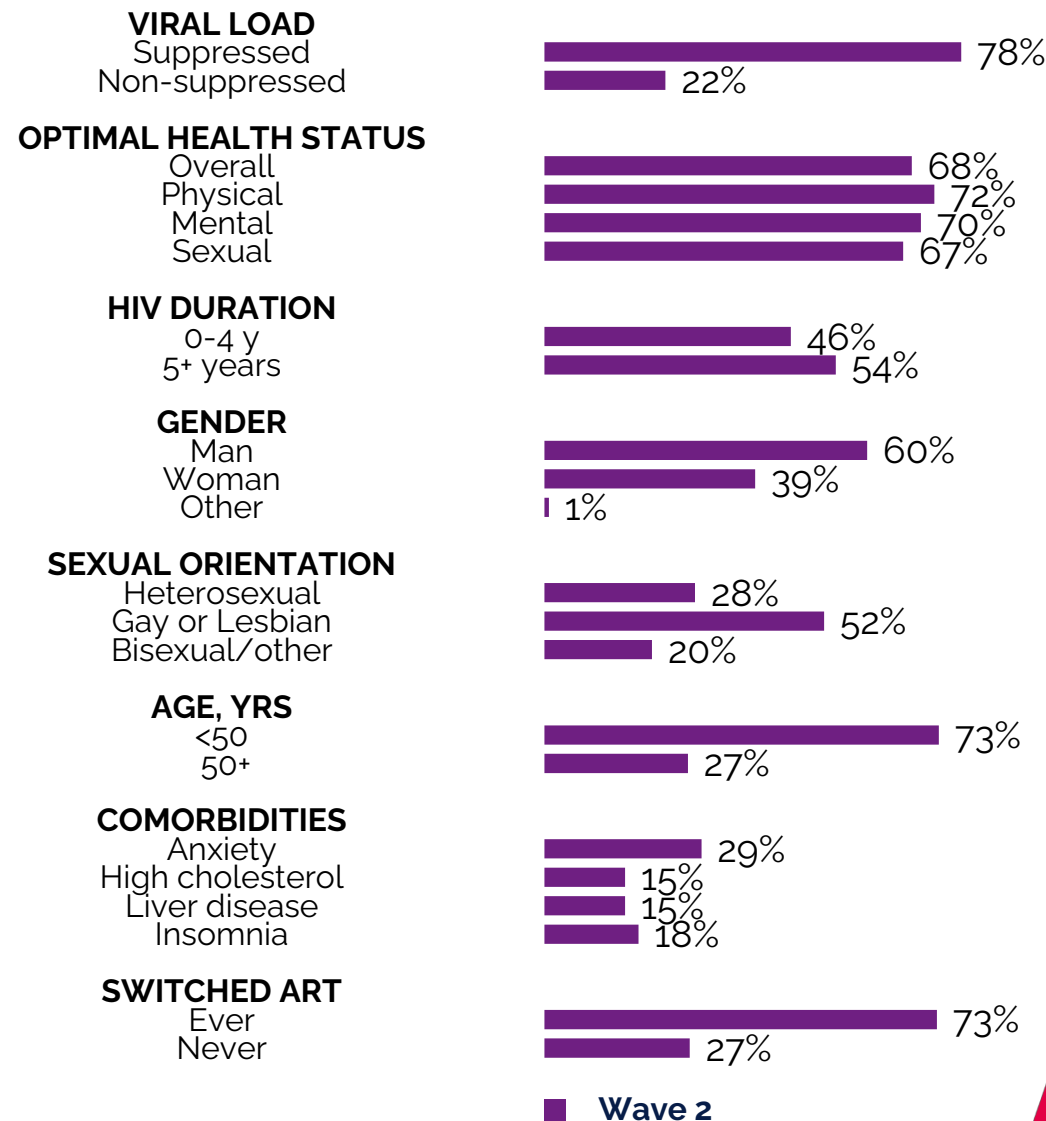
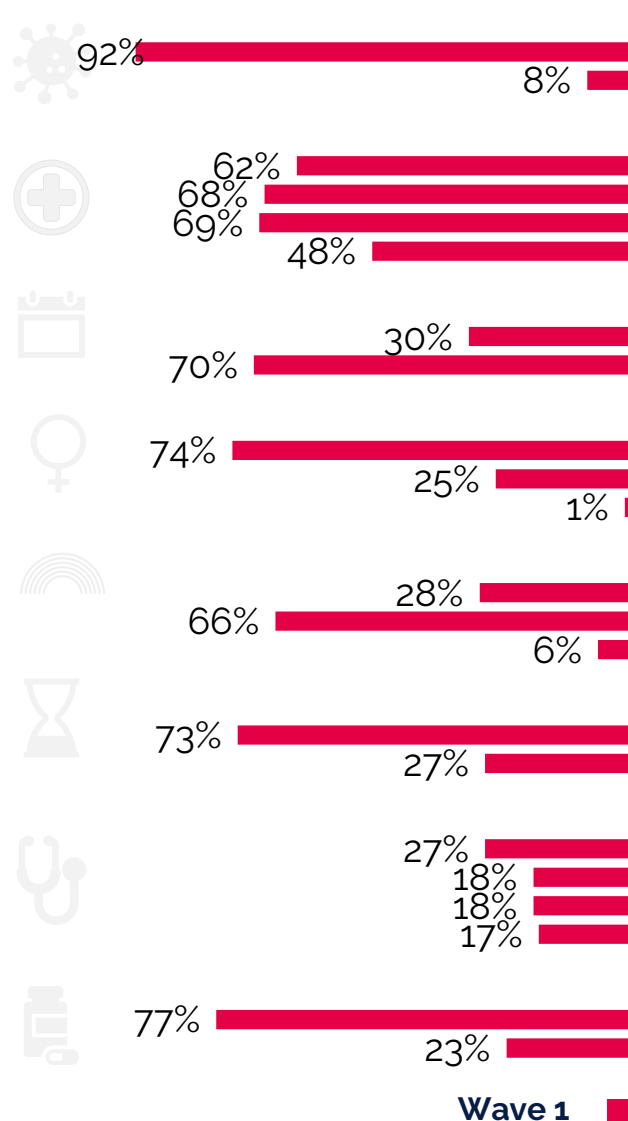


- ✂ Data were from repeated cross-sectional studies: Waves 1 and 2 of the Positive Perspectives survey of people with HIV (PHIV) from Spain
  - Wave 1 (PP1, 2017, n=132 from a total N=1,110) assessed aspects of experienced stigma
  - Wave 2 (PP2, 2019, n=120 from a total N=2,387) captured anticipated stigma
- ✂ Analyzing both waves therefore provided a comprehensive picture of HIV stigma
- ✂ Data were summarized using percentages

# Characteristics of the study population

**!** Mean age was 42 years in both Waves. The distributions of self-rated health, age, and ever switching of ART among those on treatment were also similar between both Waves

**Base:** Switching of ART was assessed only among those on ART (n = 128 of 132) in Wave 1, but among all participants in Wave 2 (n = 120). All other indicators were assessed among all participants in both Waves. Direct comparisons cannot be made between the two waves because of non-probability sampling



# Stigma and HIV care



Some participants reported stigma in healthcare facilities, including pity, fear or mistreatment directed towards them.



Stigma was associated with treatment avoidance behavior. Yet, 1 in 3 had not been told of U = U to incentivize adherence.

**Q:** The following question asks about your life satisfaction in the past 4 weeks ...<sup>†</sup>

Can you describe one or two examples in the last 12 months where you have personally felt stigmatised as a result of your HIV<sup>†</sup>

**Base:** All participants in Wave 1 (n = 132)

## Wave 1 participants

Not pleased with how healthy I've have been<sup>†</sup>



HCPs have felt afraid of/ unwilling to treat me<sup>‡</sup>



HCP felt pity/resignation for my HIV status<sup>‡</sup>



Denied/ mistreated at health services<sup>‡</sup>



## Wave 2 participants

Not comfortable discussing with HCP 'Concerns about privacy and not disclosing my HIV status'<sup>\*</sup>



My provider has not told me about U=U<sup>\*</sup>



Missed ART ≥1 time in the past month because of 'privacy/confidentiality' concerns<sup>\*\*</sup>



Missed ART ≥1 time in the past month because of wanting 'to forget about having HIV'<sup>\*\*</sup>



**Q:** How much do you agree or disagree with each of the following statements?<sup>\*</sup>

In the past month, how often have you missed taking your HIV medication because you...?<sup>\*\*</sup>

**Base:** All participants in Wave 2 (n = 120)

# Life impact of HIV status



The disrupting impacts of HIV were far-reaching, from the intimate (sexual life) to the ordinary (daily life)



1 in 2 felt HIV will reduce their lifespan. This negative perception affected how some lived their lives, as a quarter no longer planned for their old age

**Q:** To what extent do you agree or disagree with each of the following statements? †

Which of the following best describes how you feel about people knowing your HIV status? †

**Base:** All participants in Wave 1 (n = 132)

## Wave 1 participants

I feel that advances in HIV treatment will improve my quality of life †



Although my HIV can be controlled, I worry about its impact on my sex life †



I feel that HIV limits my life †



My status is only known to people very close to me and I would not tell others even when asked †



## Wave 2 participants

HIV will reduce my lifespan \*



My work/career aspirations have changed because of my HIV \*



Experiencing an overall negative impact from living with HIV \*\*



Because of my HIV, I do not plan for my old age \*



**Q:** How much do you agree or disagree with each of the following statements? \*

How would you describe the overall impact that living with HIV has on your life? \*\*

**Base:** All participants in Wave 2 (n = 120)

# Past-5-year changes living with HIV



Compared to 5 years prior, between 10-20% of PHIV in Wave 1 felt more motivated and were living fuller, healthier lives at the time of the survey

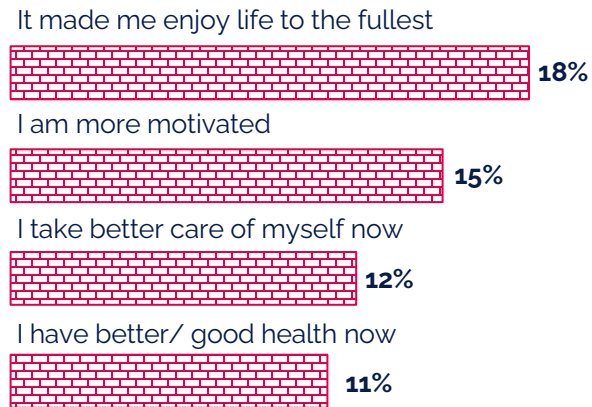


Yet, 16% felt little progress had been made in reducing HIV stigma, the impacts of which were consequential

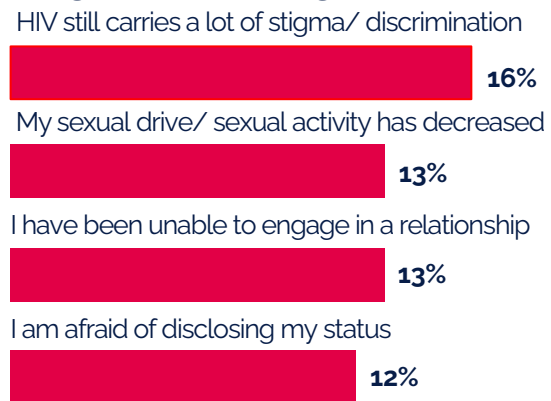
**Q:** Can you think of any examples of how your experience of living with HIV has changed over the last 5 years?

**Base:** Those diagnosed as HIV+ ≥5 years ago in Wave 1 (n=92)

## Positive changes



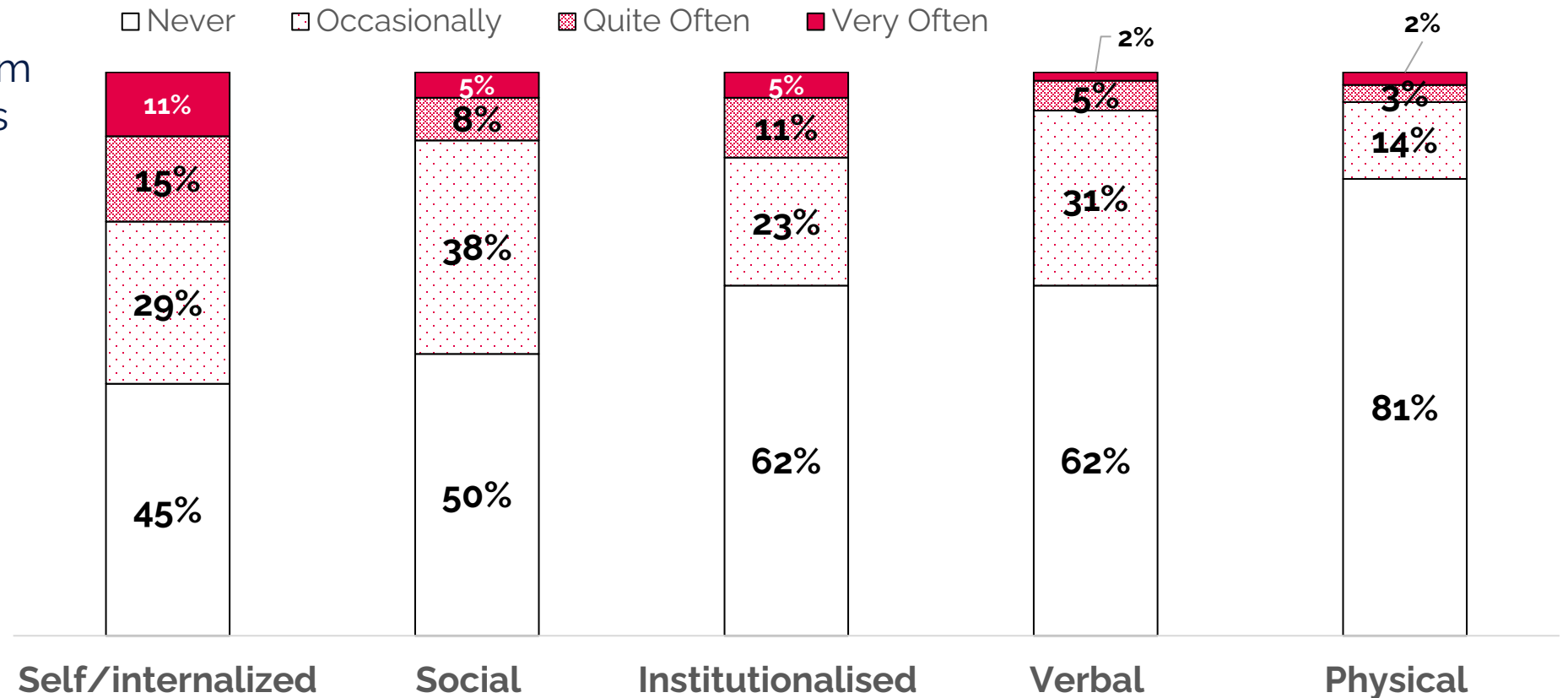
## Negative changes



# Frequency of past-year exposure to different forms of stigma



The most common form of stigma reported was self-stigma; 55% of all Wave 1 participants reported experiencing self-stigma 'Occasionally', 'Quite often', or 'Very often'.



**Q:** People living with HIV may report a feeling of stigmatization in different ways. In the last 12 months, how often, if at all, have you experienced stigma in each of these ways? 4-pt scale

**Base:** All participants in Wave 1 (n = 132)

# HOW COMFORTABLE are you with sharing your HIV status?

Whilst a quarter are comfortable sharing their HIV status, this is outweighed by almost three-fifths who are not



Those diagnosed within the last two years and younger PLHIV appear to be more comfortable sharing their HIV status than others

**58%**  
Uncomfortable



**24%**  
Comfortable!

**18%**  
Uncertain

All 'very comfortable' or 'comfortable' sharing status	Base n=	Comfortable
Male	72	<b>24%</b>
Female	46	<b>26%</b>
Younger (18-34)	34	<b>35%</b>
Older (50+)	32	<b>22%</b>
Diagnosed <2 years	17	<b>41%</b>
Diagnosed 10+ years	50	<b>26%</b>
Homosexual	63	<b>21%</b>
Heterosexual	33	<b>21%</b>
On STR	60	<b>18%</b>
Not on STR	60	<b>30%</b>
Satisfied with currentART	89	<b>27%</b>
Not satisfied with currentART	31	<b>16%</b>

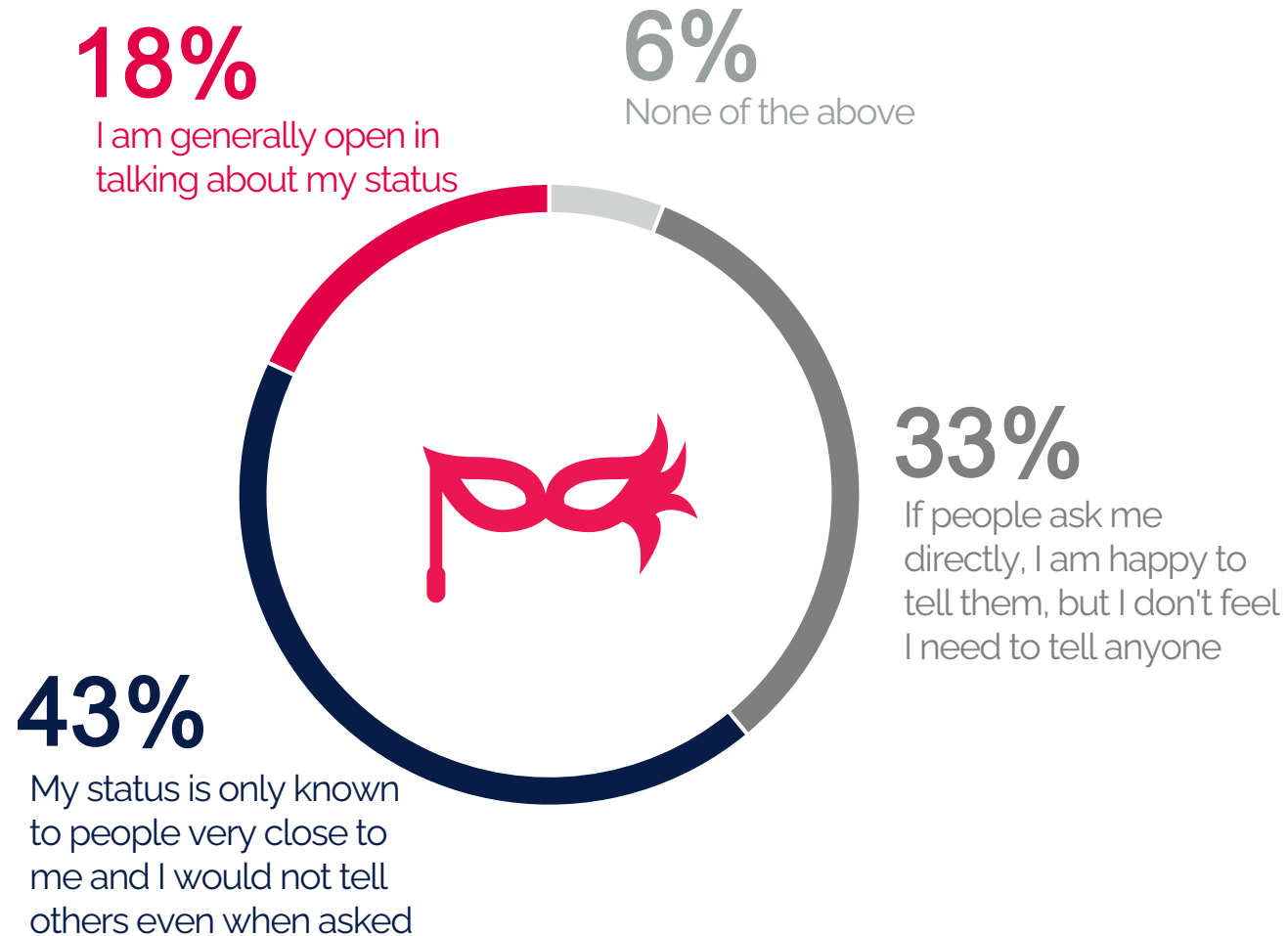
Q: In general, how comfortable are you with sharing your HIV status?, 5-pt scale

Base: All participants in Wave 2 (n = 120)



# Which of the following best describes how you feel about people knowing your HIV status?

**!**  
43% were willing to share their HIV status only to people very close to them whereas 18% were open to openly sharing their sero-status.



**Q:** Which of the following best describes how you feel about people knowing your HIV status?

**Base:** All participants in Wave 1 (n = 132)

# Other people that know about HIV status



Nine in 10 of those sharing their diagnosis have told their partner, whilst over 8 in 10 have told their family doctor and/or close friends

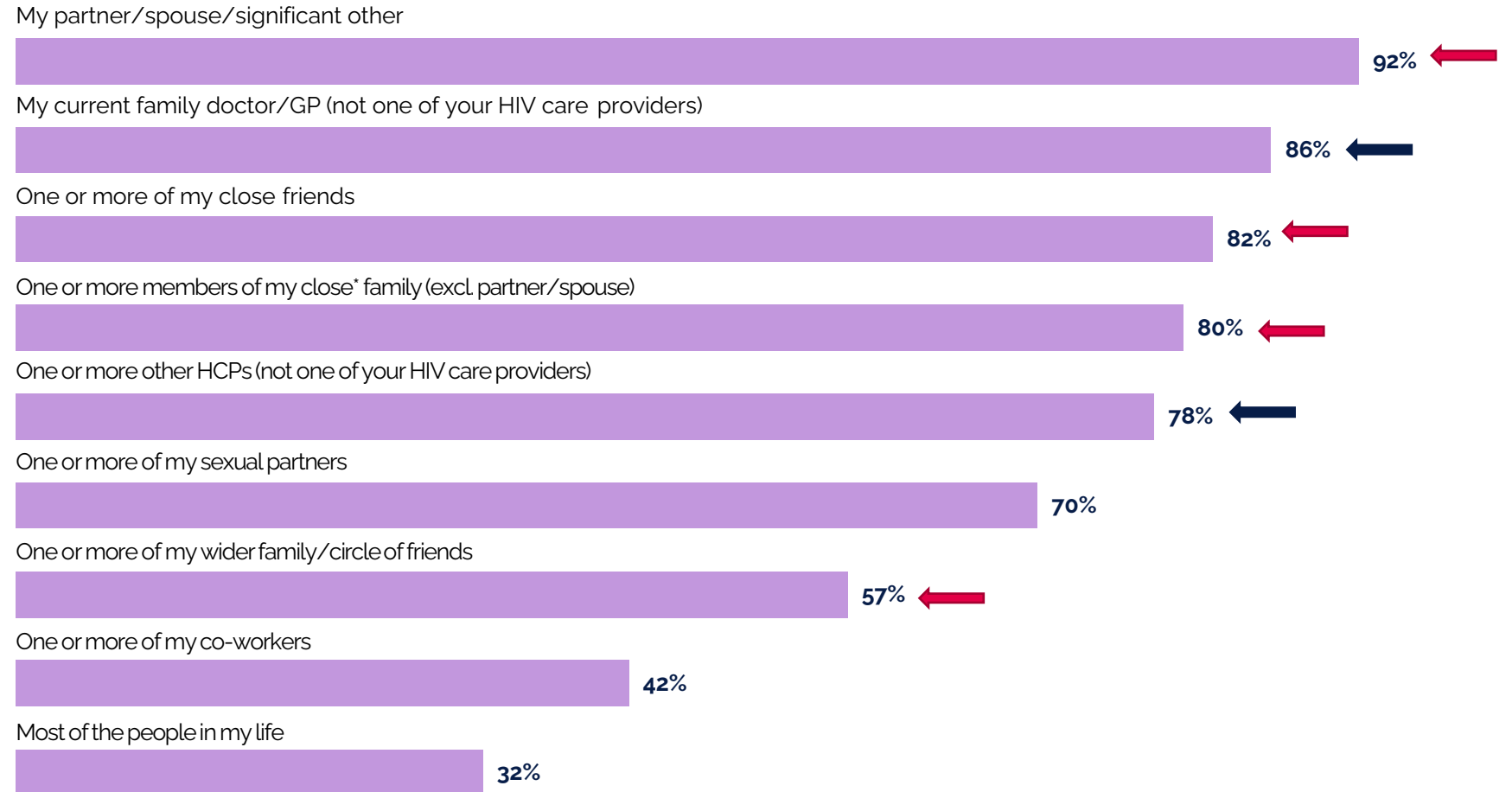


Indeed, almost a third of those sharing their diagnosis have done so with most of the people in their life

**Q** Other than your HIV care providers, who knows about your HIV status?, Pre-coded

**Base:** All with others aware they have HIV, n=109

## % having told people in each group



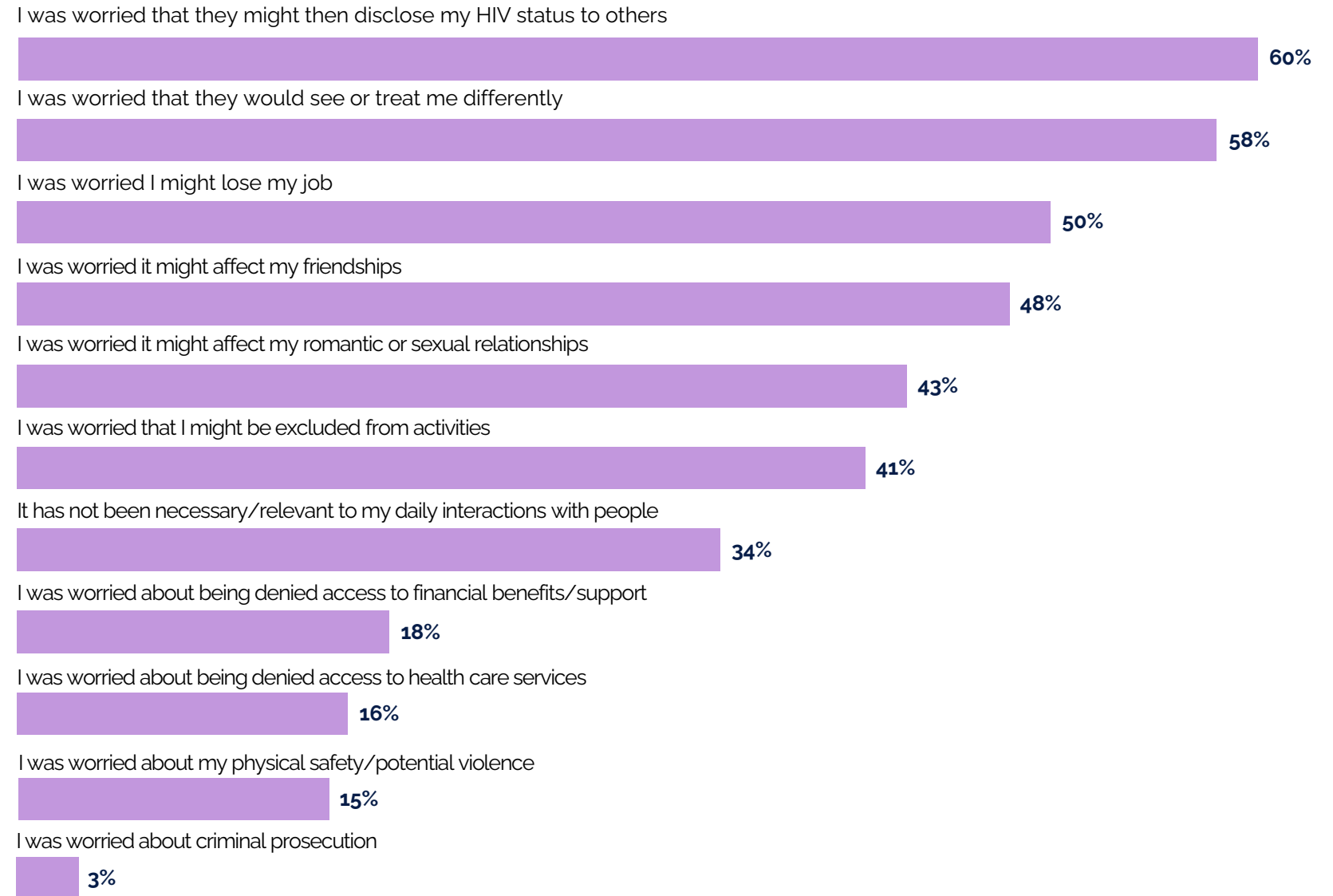
Please note that results exclude those stating a group is 'not applicable' to their situation. \*Close family was defined as parents, siblings and children only

# Reasons for NOT sharing HIV status



The top three reasons for not sharing HIV status with others were fear of gossip, being treated differently, or job loss

## % reporting they have ever refused to share their HIV status for the specified reason



**Q:** For what reasons, if any, have you not shared your HIV status with someone in the past? Please select all that apply

**Base:** All participants in Wave 2 (n = 120)

# hidden/disguised medication to avoid revealing HIV status In last 6 months

Just over half of PHIV have hidden or disguised their HIV medication in the last 6 months in order to avoid revealing their HIV status

**48%**  
No



**52%**  
Yes



Younger PHIV and those with a recent diagnosis are much more likely to have done this

**Q:** In the past 6 months, have you ever hidden or disguised your HIV medication to avoid revealing your status?, Yes/No

**Base:** All participants in Wave 2 (n = 120)

All who have hidden/ disguised HIV medication in last 6 months	Base n=	Yes
Male	72	<b>53%</b>
Female	46	<b>52%</b>
Younger (18-34)	34	<b>76%</b>
Older (50+)	32	<b>25%</b>
Diagnosed <2 years	17*	<b>71%</b>
Diagnosed 10+ years	50	<b>30%</b>
Homosexual	63	<b>52%</b>
Heterosexual	33	<b>27%</b>
On STR	60	<b>50%</b>
Not on STR	60	<b>55%</b>
Satisfied with currentART	89	<b>57%</b>
Not satisfied with currentART	31	<b>39%</b>

\* CAUTION : small sample size <20 interviews

# Level of stress/anxiety caused if someone found MY HIV pills

Over two-fifths would feel stressed if someone they didn't want to see their HIV medication found their pills, although a similar proportion would not be concerned

**42%**  
No real stress



**44%**  
Some real stress

**13%**  
Uncertain



Younger PLHIV, those with a recent diagnosis and women are more likely to feel stressed by this possibility

All likely to feel 'some real stress'	Base n=	Some real stress
Male	72	<b>39%</b>
Female	46	<b>52%</b>
Younger (18-34)	34	<b>65%</b>
Older (50+)	32	<b>28%</b>
Diagnosed <2 years	17*	<b>53%</b>
Diagnosed 10+ years	50	<b>24%</b>
Homosexual	63	<b>38%</b>
Heterosexual	33	<b>33%</b>
On STR	60	<b>48%</b>
Not on STR	60	<b>40%</b>
Satisfied with currentART	89	<b>45%</b>
Not satisfied with currentART	31	<b>42%</b>

Q: If someone you did not want to see your HIV pills were to find them, how much stress or anxiety would than cause you, if any?. 5-pt scale

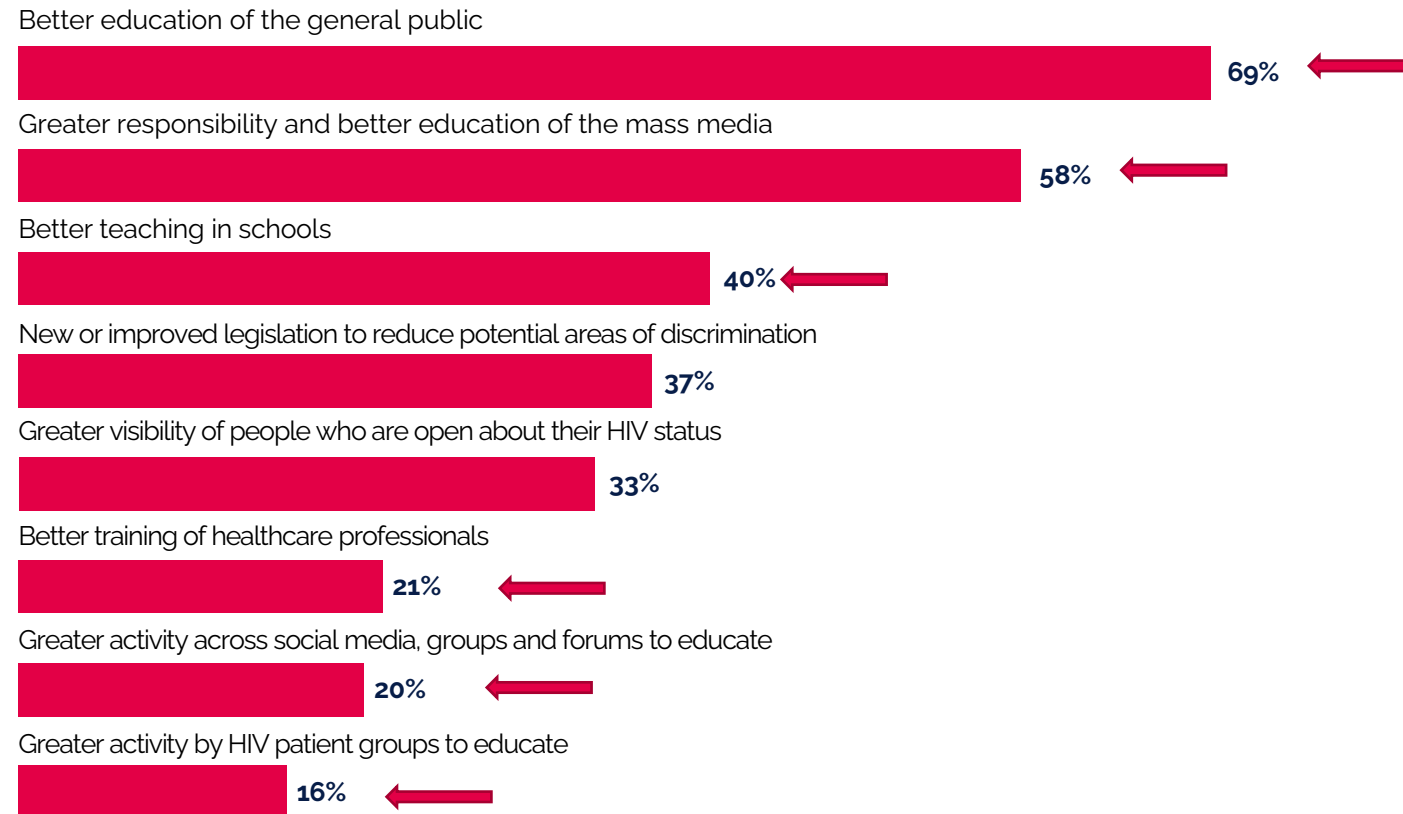
Rated on a 5-pt scale, where 5 = it could cause me a LOT of stress/anxiety and 1 = it would not cause me ANY stress/anxiety. Rated 5/4 = 'some real stress' and 1/2 = 'no real stress'

Base: All participants in Wave 2 (n = 120)

# Perceived solutions to stigma

**!**  
Educational interventions targeted at different segments of the population were identified as potential solutions for HIV stigma.

Notably 1 in 4 felt there was a need for better training of HCPs



**Q:** Which of the following do you think would help reduce feelings of stigmatization amongst people living with HIV?

**Base:** All participants in Wave 1 (n = 132)

# Key takeaways



Stigma was common among surveyed PHIV and was associated with treatment avoidance behavior and reports of reduced quality of life in various aspects



To reduce internalized stigma among people with HIV, HCPs can reevaluate treatment plans to address privacy concerns



In the broader society as well, patient organizations and HCPs can promote educational interventions such as “U=U” to help reduce enacted stigma.

# Muchas gracias

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