

# Experience of Living with HIV: Diagnosis and Disclosure – Findings from the Positive Perspectives Study

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## Introduction

- While treatment advances have dramatically improved the life-expectancy of people living with HIV (PLHIV), a number of important needs remain
- We conducted an international survey of PLHIV to explore 3 key themes
  - Psychosocial aspects of living with HIV
  - HCP-Patient dialogue
  - Satisfaction with their current antiretroviral (ARV) treatment
- This poster focuses on the psychosocial aspects of living with HIV, namely
  - The impact and sources of emotional support at diagnosis
  - The impact of living with an HIV diagnosis on outlook and aspirations
  - The level of stigma perceived and/or experienced - and the impact this has on disclosure

## Methods

- Qualitative interviews (90 min) were performed with 24 PLHIV (USA, UK, Spain and Austria) to refine the hypothesis
- Steering committee (patient organization members and HIV clinicians) contributed to the development of the questionnaire and subsequent analysis
- Survey was conducted between November 2016 – April 2017 in 9 countries (Table 1)
- Participants were recruited via charities, patient support groups, NGO's, online communities and social media promotion (Facebook/Instagram/Twitter, etc.)
- All respondents were telephone-screened for eligibility
- Eligible respondents were sent a URL link to the online questionnaire for self-completion, and compensated according to local guidelines

## Results

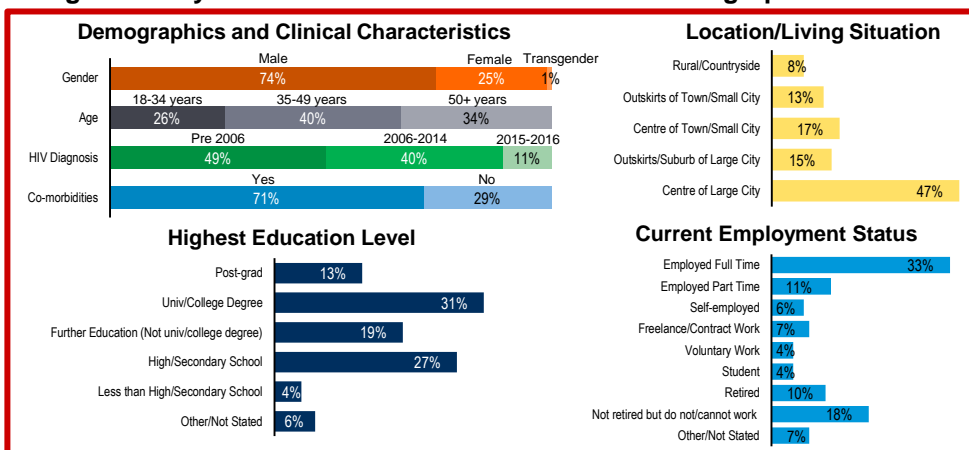
- Overall there were 1085 respondents to the survey. Country breakdown is shown below (Table 1)

Table 1. Survey Scope and Sample Size

Country	n=	Country	n=
USA	327	Italy	121
Canada	110	Spain	132
UK	160	Austria	50
France	6	Australia	39
Germany	140	<b>Total</b>	<b>1085</b>

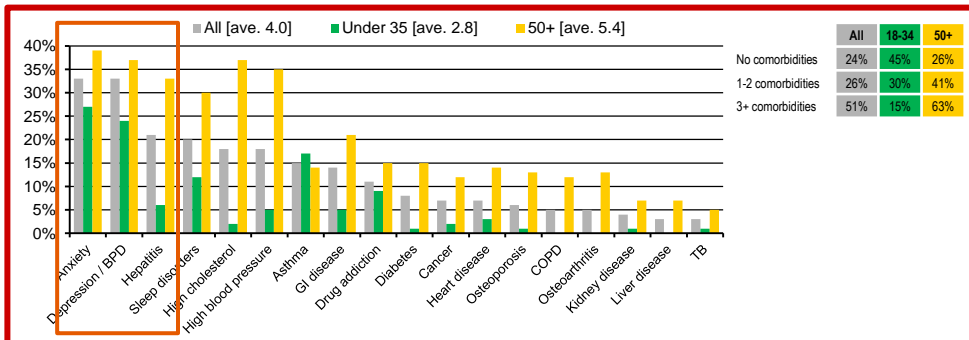
- Key demographics are highlighted in the charts below (Figure 1)

Figure 1. Key Cohort Characteristics and Social Demographics



- 71% reported a co-morbidity with 51% having 3 or more co-morbidities (Figure 2)

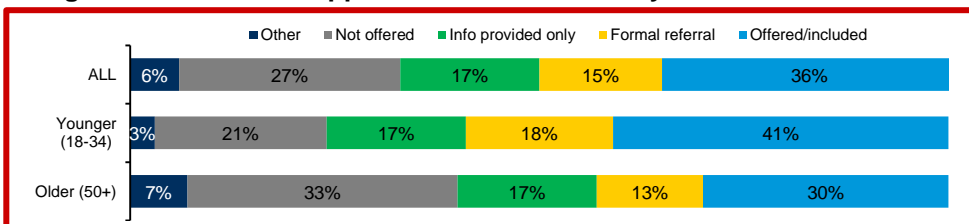
Figure 2. Prevalence of Co-morbidities



## Emotional Support at Diagnosis

- At diagnosis when asked the level of emotional support they received from their main HCP, 68% felt they had been offered some form of emotional support/guidance
- Differences between the 18-34 year (76%) and >50 year age groups (60%) were noted (Figure 3)

Figure 3. Emotional Support/Guidance Offered by Main HCP



- A close friend (45%) was the most common form of support turned to at diagnosis, however, women more likely to turn to a close family member (31%)

## Life impact of HIV diagnosis

- On exploring the impact diagnosis has on outlook on life
  - 9 in 10 believe their quality of life will improve with advances in treatment.
  - Over 40% feel they will have a reduced life expectancy due to their diagnosis
  - A significant minority (27%) did not tend to plan to far in the future

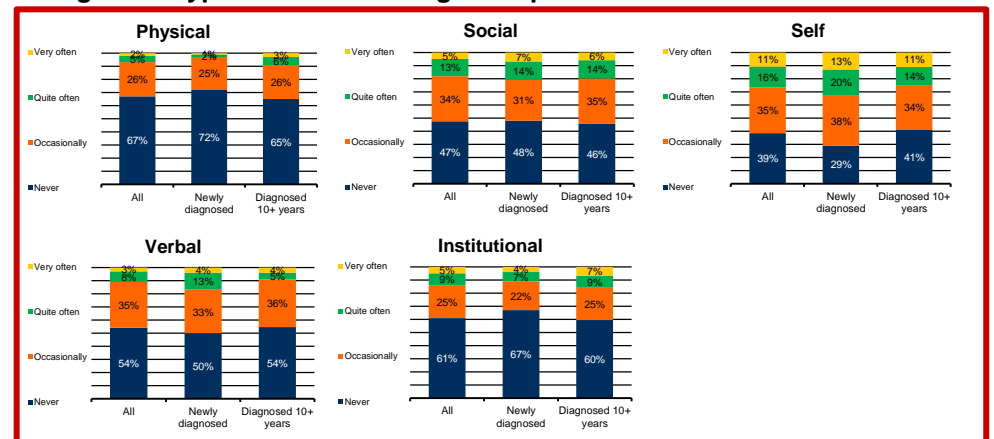
"I am amazed that I am now a pensioner and had never imagined I would live to reach such an age"

(UK, MSM, 67 yo, diagnosed in 1982)

## Stigma and Disclosure (overall population/Diagnosed 2015/16 and Diagnosed pre-2006)

- Most respondents (82%) continue to perceive/experience some form of stigma, with newly diagnosed PLHIV more likely to suffer from self-stigma (Figure 5)

Figure 5. Type and Level of Stigma Experienced in Last 12 Months



"Stigma and self-doubt can leave me lonely and without a partner. It can be overwhelming at times and there is not a lot of people you can turn to who understand"

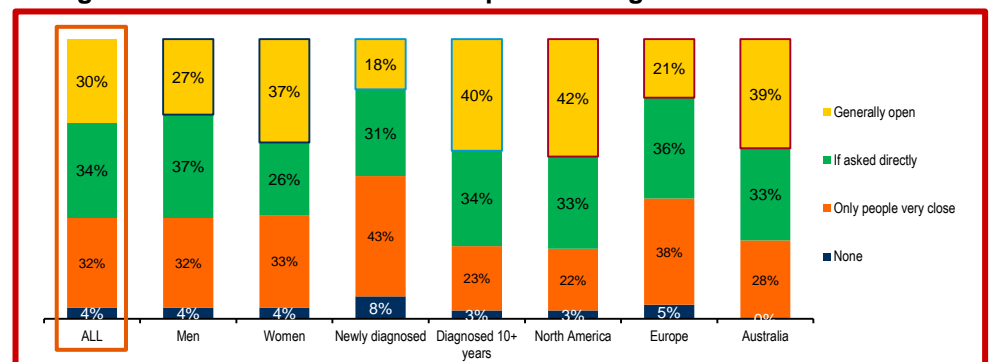
(UK, MSM, 28yo, diagnosed in 2010)

"I am a nurse and patients with HIV visit the hospital, and there are always judgements and criticism. Many don't know much about this disease and the current advances. It bothers me as they would judge me and take things out of context if they knew I had the disease..."

(Spain, female heterosexual, 41yo, diagnosed in 2009)

- 30% were generally open to disclosing their status with differences seen between gender, time since diagnosis and regions (Figure 6)

Figure 6. How You Feel About People Knowing Your HIV Status



- Higher rates of stigma were associated with lower rates of disclosure, lower self perceived health (mental) and more likely to be diagnosed with depression/anxiety (Table 2)

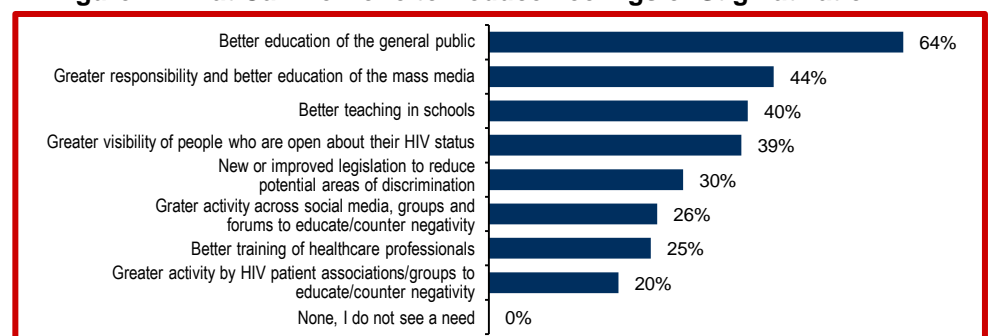
Table 2. Health and Openness to Sharing HIV Status: Association With Perceived Level of Stigma\*

Stigma type	Total	Open about status		Anxiety/depression co-morbidity		Mental health self-rating	
		Yes	No	Yes	No	Rated 'very/quite good'	Rated 'fair/quite poor/very poor'
Physical	7%	9%	6%	10%	4%	4%	11%
Verbal	11%	13%	10%	13%	9%	8%	16%
Social	19%	19%	18%	24%	14%	13%	28%
Institutional	14%	14%	14%	18%	12%	11%	20%
Self	27%	17%	31%	33%	22%	17%	43%
None	18%	28%	14%	13%	23%	24%	10%

\*Stigma experienced in last 12 months, % stating "quite often" or "very often."

- When asked what ways could stigma be reduced: Majority (64%) chose better education of the public as a potential avenue of reducing stigma (Figure 7)

Figure 7. What Can Be Done to Reduce Feelings of Stigmatization?



## Conclusions

- PLHIV experience varying levels of emotional support and guidance at diagnosis from their main healthcare provider
- Despite advances in treatment and improvement in life expectancy, there is still a proportion of PLHIV who expect a reduced life expectancy and don't plan for their future
- Stigma remains one of the biggest issues that affect the quality of life of PLHIV