



Experience of Living With HIV: Diagnosis and Disclosure – Findings From the Positive Perspectives Study

**Allan B,¹ Murungi A,² Spire B,³ Muchenje M,⁴ Garcia D,⁵
Parkinson K,⁶ Namiba A,⁷ Marcutullio S,⁸ Krehl M,⁹ Barthel F,¹⁰
deRuiter A,² Punekar Y,² Koteff J,¹¹ Young B,¹² Ustianowski A¹³**

¹Living Positive Victoria, Melbourne, VIC; ²ViiV Healthcare, Brentford, UK; ³French National Institute for Medical Research, Marseille, France; ⁴Women's Health in Women's Hands Community Health Centre, Toronto, ON, Canada; ⁵European AIDS Treatment Group, Spain; ⁶Beacon Project, St Louis, MO; ⁷Salamander Trust, London, UK; ⁸Nadir Onlus, Rome, Italy; ⁹European AIDS Treatment Group, Germany; ¹⁰GlaxoSmithKline, London, UK; ¹¹ViiV Healthcare, Brentford, UK; ¹²ViiV Healthcare, Research Triangle Park, NC, USA; ¹³International Association of Providers of AIDS Care, Washington, DC, USA; ¹³Pennine Acute Hospitals NHS Trust, Manchester, UK

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia



Introduction

- Treatment advances have dramatically improved the life expectancy of PLHIV
- We conducted an international survey of PLHIV to explore 3 key themes
 - Psychosocial aspects of living with HIV
 - HCP-patient dialogue
 - Satisfaction with current ARV treatment
- This presentation will focus on psychosocial aspects of living with HIV, namely
 - Impact and sources of emotional support at diagnosis
 - Impact of living with an HIV diagnosis on outlook and aspirations
 - Level of stigma perceived and/or experienced and the impact this has on disclosure

ARV, antiretroviral; HCP, healthcare practitioner; PLHIV, people living HIV.

Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia

Methods



Survey Scope and Sample Size (N=1085)

Country	n	Country	n
Australia	39	Italy	121
Canada	110	Spain	132
UK	160	Austria	50
France	6	USA	327
Germany	140		

- Participants were recruited via charities, patient support groups, NGOs, online communities, and social media promotion
- All respondents were telephone-screened before being sent a URL link to an online questionnaire for self-completion and compensated according to local guidelines
- Survey was conducted between November 2016 and April 2017
- Qualitative interviews (90 minutes) were performed with 24 PLHIV (USA, UK, Spain, and Austria) to refine the hypothesis
- Overall there were 1085 respondents to the survey

NGO, nongovernmental organization.

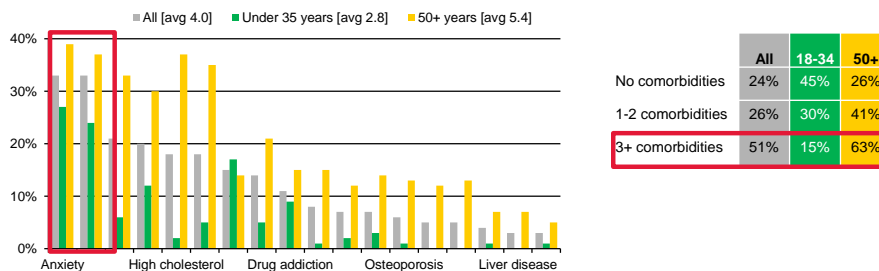
Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia

Prevalence of Comorbidities



- 71% of respondents reported a comorbidity, with mental health comorbidities being the most common
 - 51% had 3 or more comorbidities



BPD, bipolar disease; COPD, chronic obstructive pulmonary disease; GI, gastrointestinal; TB, tuberculosis.

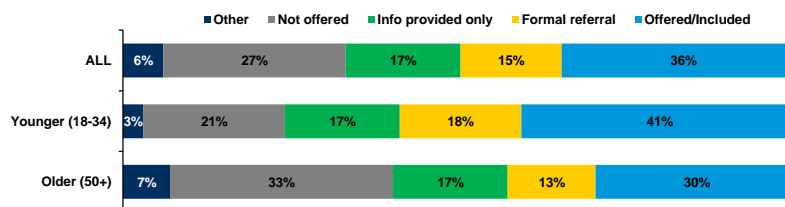
Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia

Emotional Support/Guidance Offered by Main HCP



- 76% of respondents in the 18- to 34-year age group and 60% in the >50-year age group felt they had been offered some form of emotional support/guidance from their main HCP at diagnosis
- A close friend (45%) was the most common form of support turned to at diagnosis; however, women were more likely to turn to a close family member (31%)



HCP, healthcare practitioner.

Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia

Life Impact of HIV Diagnosis



- 9 in 10 respondents 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
- 27% did not tend to plan too far in the future

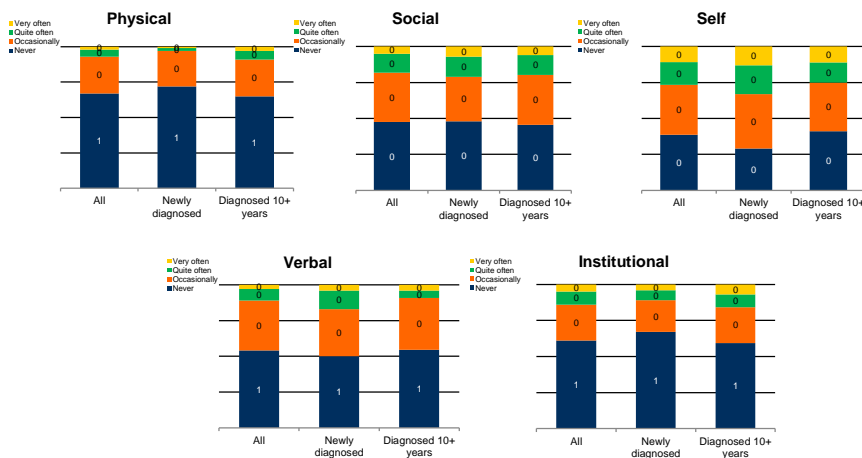
“It seems to make every aspect of life harder, due to the stigma. Fears of the future - loss of employment, housing and relationships.”

AU, Female, Heterosexual, 18-34 years old

Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia

Newly Diagnosed PLHIV Are More Likely to Suffer From Self-stigma



Note: Newly diagnosed = diagnosed in the last 2 years.
PLHIV, people living with HIV.

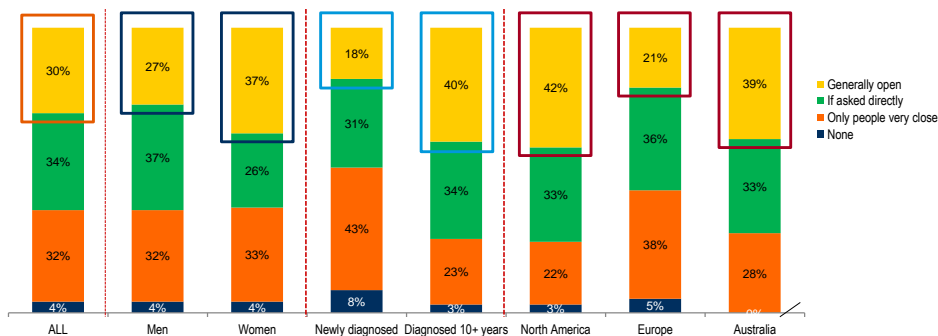
Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia

Disclosure of HIV Status



- 30% of respondents were generally open to disclosing their status, with differences seen between gender, time since diagnosis, and region



Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia

Health and Openness to Sharing HIV Status: Association With Perceived Level of Stigma



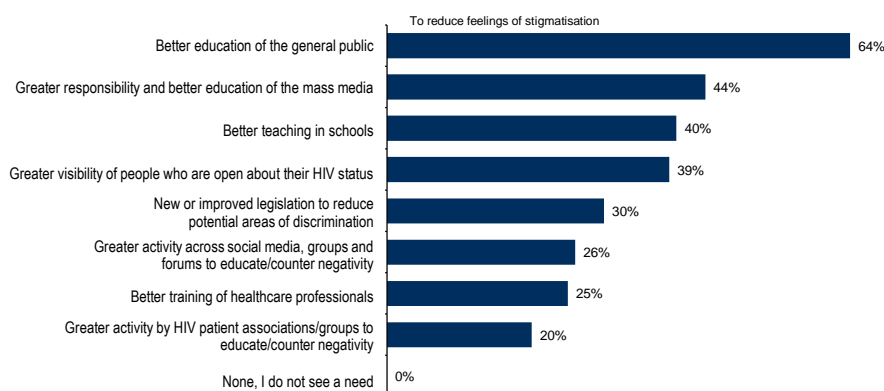
Stigma type	Open about status			Anxiety/Depression comorbidity		Mental health self-rating	
	All	Yes	No	Yes	No	Rated "very/quite good"	Rated "fair/quite poor/very poor"
Physical	7%	9%	6%	10%	4%	4%	11%
Verbal	11%	13%	10%	13%	9%	8%	16%
Social	19%	19%	18%	24%	14%	13%	28%
Institutional	14%	14%	14%	18%	12%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

- The highest rates of self stigma were reported in respondents who were not open about their status, suffered from anxiety/depression, or had lower mental health self-ratings

Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia

Better Education of the Public Seen as a Potential Avenue of Reducing Stigma



Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia



Conclusions

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

PLHIV, people living with HIV.

Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia



Disclosures of Interest

- This study was sponsored by ViiV Healthcare and conducted by GfK UK Ltd
- This is an encore presentation of data previously presented at the IAS Conference on HIV Science (IAS 2017), 23-27 July 2017, Paris, France, Abstract WEPED1423

Allan et al. ASHM 2017; Canberra, Australia. Slides 320.

Australasian HIV&AIDS Conference; November 6-9, 2017; Canberra, Australia
