

The Positive Perspectives Study

Simone Marcotullio

22 Settembre 2017, Roma

A Murungi,¹ B Spire,² M Muchenje,³ A Namiba,⁴ K Parkinson,⁵ S Marcutullio,⁶ M Krehl,⁷ B Allan,⁸ Y Punekar,¹ A de Ruiter,¹ S Barthel,⁹ J Koteff,¹⁰ B Young,¹¹ A Ustianowski¹²

¹ViiV Healthcare, Brentford, UK;

²French National Institute for Medical Research (INSERM), Paris, France;

³Women's Health in Women's Hands Community Health Centre, Toronto, ON, Canada;

⁴Salamander Trust, London, UK;

⁵Beacon Project, St Louis, MO, USA;

⁶Nadir Onlus, Rome, Italy;

⁷European AIDS Treatment Group, Germany;

⁸Living Positive, Victoria, Australia;

⁹GlaxoSmithKline, London, UK;

¹⁰ViiV Healthcare, Research Triangle Park, NC, USA;

¹¹International Association of Providers of AIDS Care, Denver, CO, USA;

¹²Pennine Acute Hospitals NHS Trust, Manchester, UK

- A steering committee made up of patient organization members and HIV clinicians contributed to the development of the questionnaire and subsequent descriptive analysis.
- The survey was conducted between November 2016 and April 2017 in 9 countries.
- Individuals were invited to participate via outreach from charities, patient support groups, NGOs, online communities, and social media.
- All respondents were assessed for eligibility (diagnosed with HIV and aged ≥ 18 years) by telephone screening before being sent a URL link to the online questionnaire for self-completion and were compensated according to local guidelines.

Content order



The slide deck proceeds as follows...

1 **Experience of living with HIV**

Perceived health and impact of living with an HIV diagnosis on outlook and aspirations

2 **Emotional impact & support**

Rating of emotional impact and sources of support - at diagnosis versus today

3 **Disclosure and stigma**

Openness with HIV status, extent of disclosure to others & perceived level/type of stigma

4 **Relationship and comfort level with HCP**

Type & frequency of HCP seen, & level of comfort in raising issues of concern

5 **Experience with treatment**

Current ARV treatment, level of satisfaction, dosing, time on ARV, time since & reasons for last switch, side effect impact

6 **Appetite for reduction in pill/drug burden**

Fatigue in daily pill-taking, desire for longer-acting meds and concern over long-term impact of multi-drug regimens

Global scope and sample size

n=1085 people living with HIV



35-minute
online self-
completion
interviews



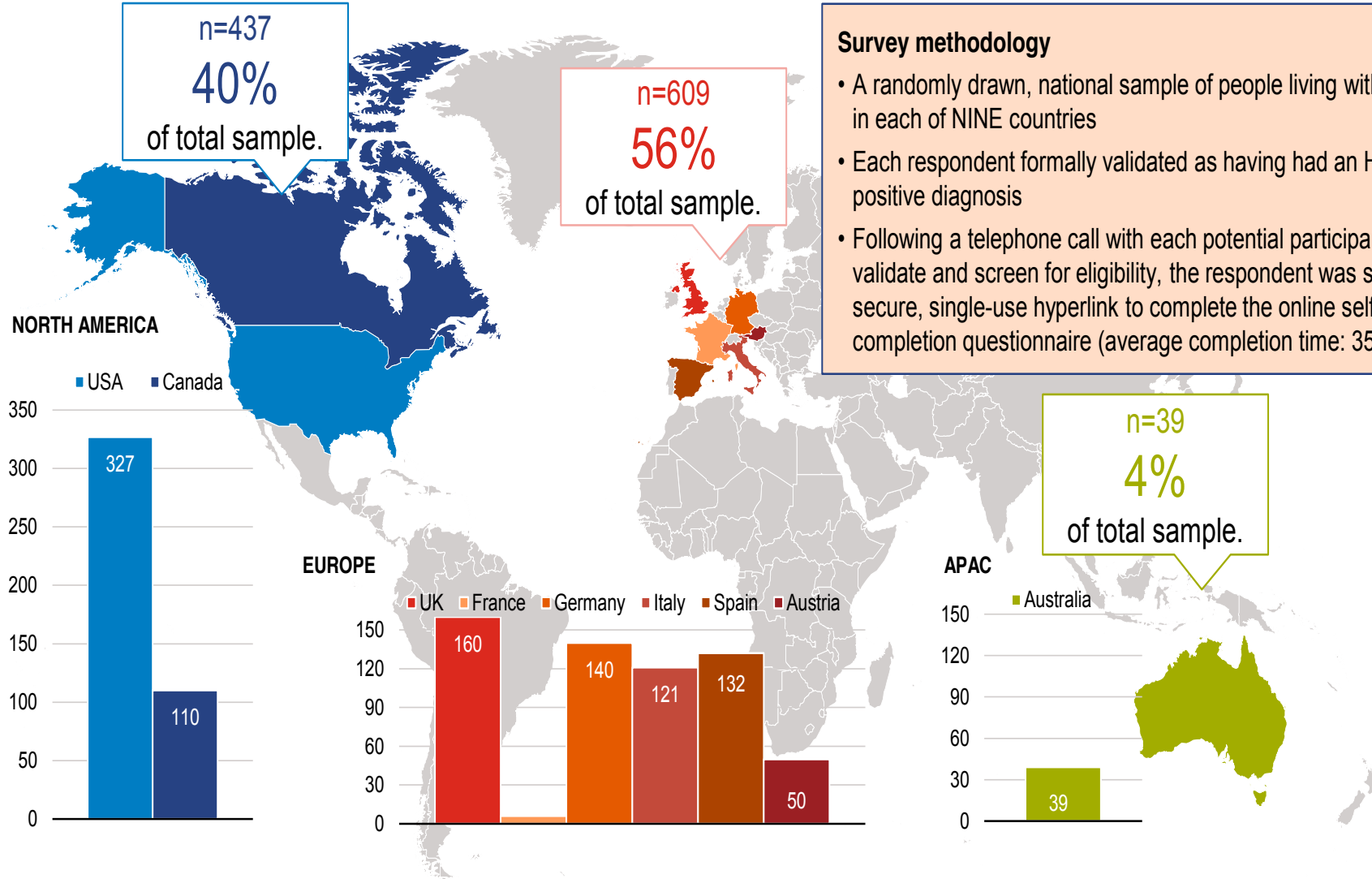
n=437
40%
of total sample.

n=609
56%
of total sample.

n=39
4%
of total sample.

Survey methodology

- A randomly drawn, national sample of people living with HIV in each of NINE countries
- Each respondent formally validated as having had an HIV-positive diagnosis
- Following a telephone call with each potential participant to validate and screen for eligibility, the respondent was sent a secure, single-use hyperlink to complete the online self-completion questionnaire (average completion time: 35 mins)



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

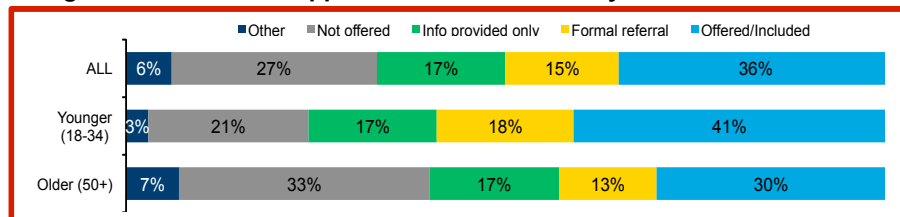
A Murungi,¹ B Spire,² M Muchenje,³ A Namiba,⁴ K Parkinson,⁵ S Marcotullio,⁶ M Krehl,⁷ B Allan,⁸ Y Punekar,¹ A de Ruiter,¹ S Barthel,⁹ J Koteff,¹⁰ B Young,¹¹ A Ustianowski¹²

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

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 were more likely to turn to a close family member (31%)

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

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

