

Looking Beyond Viral Suppression: Findings from The Well Project's 2016 User Survey on Factors Influencing the Health, Well-being, and Quality of Life of Women Living with HIV

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BACKGROUND

The HIV care continuum has become the predominant framework for assessing progress in HIV treatment and prevention, with viral suppression as the ultimate outcome of interest. This is codified in the UNAIDS "90/90/90" campaign, which has been adopted by numerous countries. But for women living with HIV, viral suppression may not be the only outcome of interest, as psycho-social factors—including those related to gender, HIV identity, and mental health—significantly affect their overall health, well-being, and quality of life.

The Well Project is the premier, global, non-profit online resource on women and HIV, focused on three key areas:

- Information access
- Community support
- Advocacy and capacity building

Directly reaching more than one million users annually, The Well Project's online resources include:

- A library of more than 110 regularly updated fact sheets
- Treatment advocacy programming
- English and Spanish blogs (*A Girl Like Me/Una Chica Como Yo*)
- Extensive social media offerings
- Reports from the Women's Research Initiative on HIV/AIDS

In 2016, we conducted an online user survey to ascertain factors influencing the experiences of women living with HIV (WLHIV) along and beyond the HIV care continuum and to assess the impact of The Well Project's resources.

METHODS

The Well Project's 2016 user survey was developed by the organization's executive director and a research consultant and was reviewed by The Well Project staff and consultants, select board members, and community advisory board members. Respondents were recruited through The Well Project's website, newsletters, virtual flyers, and social media outreach. The survey was administered through Survey Monkey and included closed- and open-ended questions. The total sample with complete survey data was 229 women and men. We report here on findings from the subsample of 136 self-identified WLHIV.

LIFE CIRCUMSTANCES of Women Living with HIV (n=136)

Level of Education	
High School or Less	28.7%
Higher Education	71.3%
Paid Employment Status	
Employed Full Time	28.7%
Employed Part Time	18.4%
Unemployed/Seeking Work	9.6%
Unemployed/Not Seeking Work	4.4%
Homemaker	2.2%
Retired	10.3%
Disabled/Unable to Work	26.5%
Household Income (U.S. Dollars Equivalents)	
\$0 - \$39,999 per year	78.7%
\$40,000 or more per year	13.9%
Can't Calculate in USD	7.4%

KEY FEATURES of Women Living with HIV (n=136)

Age	
19 to 29	7.4%
30 to 39	11.0%
40 to 49	27.2%
50 to 59	32.4%
60 or older	22.0%
Gender Identity	
Woman	97.8%
Trans Woman	2.2%
Sexual Orientation	
Heterosexual	86.0%
Gay, Lesbian, or Queer	5.9%
Bisexual	6.6%
Pansexual	0.7%
Asexual	0.7%
Race/Ethnicity	
Aboriginal, Native, or Indigenous	1.5%
African, African Descent, or Black	50.0%
Asian, East Asian, or PI	1.5%
Caucasian, Non-Hispanic White	32.3%
Hispanic or Latino	10.3%
Multiracial	4.4%
Global Location	
Africa	11.7%
Asia & South Asia	1.5%
Europe	1.5%
North America	85.3%

RESULTS

WLHIV respondents came from North America (85.3%), Africa (11.7%), Asia (1.5%), and Europe (1.5%) and their average time since HIV diagnosis was 16.3 years.

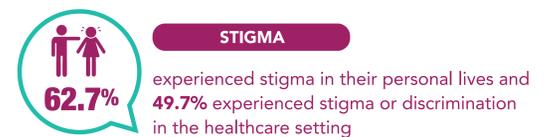
Of the 136 self-identified WLHIV respondents:

97.8% reported seeing an HIV healthcare provider

97.7% said they were currently on antiretroviral therapy

77.3% self-reported having an undetectable viral load

Notwithstanding these high levels of engagement in care and viral suppression, WLHIV identified other important factors affecting their overall health, well-being, and quality of life that require further attention:



The Well Project has had a significant impact on users' engagement in care, as well as on factors beyond the care continuum.

ENGAGEMENT IN CARE

When asked about how The Well Project's resources had influenced specific aspects of their engagement in care with providers, WLHIV responded they were more likely to:



SELF-CARE

When asked how The Well Project's resources had affected aspects of self-care related to their emotional well-being, WLHIV responded they were more likely to:



OUTLOOK ON LIVING WITH HIV

When asked to assess The Well Project's influence on their outlook on living with HIV, WLHIV responded they were more likely to:



CONCLUSIONS

While viral suppression is a meaningful outcome for WLHIV, it is not the only measure of their health and well-being. The Well Project's 2016 user survey data underscore the following:

- Psycho-social factors (including trauma, stigma, and discrimination) and behavioral health issues are important additional influences that must be addressed in order for WLHIV to achieve optimal quality of life
- WLHIV depend on The Well Project to provide credible, up-to-date information and empowerment tools that optimize their health and connect them to a supportive community—all from the comfort and privacy of their own home

The Well Project's holistic approach and use of technology facilitate an evolutionary process among WLHIV users:

- They are imbued with a sense of hope as they realize they are not alone; they then become more engaged with other women in our community; participation in this community improves their self-esteem and decreases their self-stigma, particularly among those who are isolated from a support network; and they become more empowered to advocate for themselves and others living with HIV.

The Well Project's 2016 user survey data demonstrate the importance of a holistic approach that goes beyond the HIV care continuum in improving the health, well-being, and empowerment of WLHIV across the U.S. and internationally.