

Leveraging Web-based Technologies to Improve the Health, Well-being, and Quality of Life of Women Living with HIV: Findings from The Well Project's 2016 User Survey

AUTHORS: Krista Martel, The Well Project; Jenna Conley, The Well Project; Judith D. Auerbach, PhD, University of California, San Francisco

BACKGROUND

The Well Project is the premier, global, non-profit online resource on women and HIV, focused on three key areas—information access, community support, and advocacy. Directly reaching more than one million users annually, The Well Project's online resources include more than 110 regularly updated fact sheets, treatment advocacy programming, English and Spanish blogs, extensive social media offerings, and reports from the Women's Research Initiative on HIV/AIDS. In 2016, we conducted an online user survey to ascertain how The Well Project's resources are used by women living with HIV (WLHIV) and with what impact on their health and well-being along and beyond the HIV care continuum.

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 CAB 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. We report here on findings from the subsample of 136 self-identified WLHIV (of the total 229 user sample).

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%
Transwoman	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%

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%

RESULTS

Overall, WLHIV respondents were diverse in age and racial/ethnic background, and were well-educated, but underemployed and of low-income (see tables below left). More than three-quarters (76.5%) of WLHIV reported having experienced some form of trauma or multiple traumas. Nearly half (49.6%) of WLHIV experienced stigma or discrimination in the healthcare setting and 62.7% experienced it in other settings (e.g., from family members and friends). Top reasons for using The Well Project resources were to address their needs as WLHIV (85.3%), provide support and information as peer educators/advocates (62.5%), and educate people (55.9%). The most commonly shared resource was the fact sheets (41.7%).

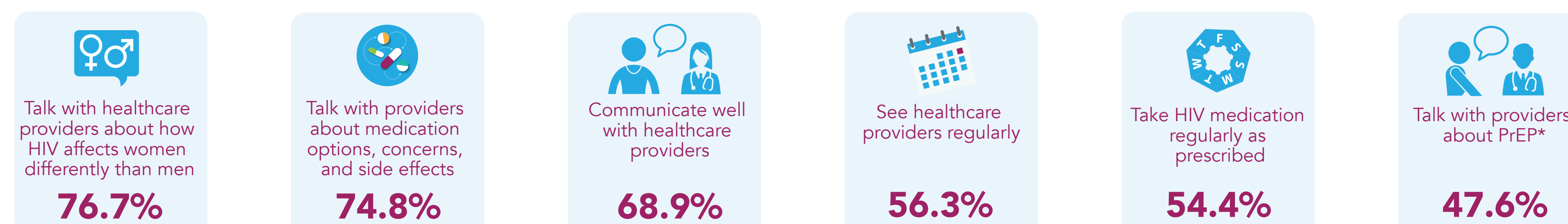
Regarding the impact of The Well Project's resources on users' engagement in care, WLHIV reported they were "somewhat" or "much more" likely to: talk with providers about medication options, concerns, and

side effects (74.8%); communicate well with healthcare providers (68.9%); see healthcare providers regularly (56.3%); and take HIV medication as prescribed (54.4%).

Regarding the impact of The Well Project's resources on users' self-care and outlook on living with HIV, WLHIV reported they were "somewhat" or "much more" likely to: feel hopeful about the future (75.7%); experience less HIV self-stigma (65.0%); feel connected to a community (81.6%); accept only respectful, caring behavior from partners, family, and/or friends (70.9%); advocate for themselves (82.5%); and advocate for the needs of others living with HIV (80.6%). Respondents also provided suggestions for improving The Well Project's offerings.

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 "somewhat" or "much" 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 "somewhat" or "much" 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 "somewhat" or "much" more likely to:



CONCLUSIONS

The Well Project's 2016 user survey data underscore the fact that WLHIV around the world continue to face individual, interpersonal, and social-structural challenges to optimizing their health and well-being, including stigma and isolation. These data also demonstrate that 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 home. The Well Project's holistic approach and use of technology facilitate an evolutionary process among WLHIV users. First WLHIV 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. This participation in a supportive, empowered community can improve their self-esteem and decrease self-stigma, and may be particularly helpful to those who are isolated or not connected to a local support network. From there is it a short step to advocating for themselves, and eventually seeking ways to advocate for others living with HIV. The Well Project's 2016 user survey data demonstrate that leveraging technology to provide HIV information, community support, and advocacy building is an effective way to improve the health, well-being, and empowerment of WLHIV across the U.S. and internationally.