thewellproject

Your Voice Counts:

The Well Project 2016 User Survey Report

An Analysis of The Well Project's Reach and Impact on Women Living with HIV

> "I have a better appreciation for my lived experience as a person living with HIV. I know that **my health matters to a community** that is vast and accepting. **I feel I can't give up...** I don't want to because **this is a resource that connected me** to like-minded advocates."

#onewomanatatime

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Dedication

The Well Project team and Board of Directors would like to dedicate this report to women and girls living with HIV around the globe, who every day strive to overcome serious interpersonal and structural challenges, including gender-based violence, socio-economic inequalities, lack of access to education, institutional racism, stigma, discrimination, and more. It is these very women who, despite such obstacles, exhibit resilience, organize our communities, advocate for access to healthcare and HIV treatment, raise our families, and change policy and laws. We also want to dedicate this work to the millions of people who have died not only due to health complications from HIV, but also as a result of HIV stigma and discrimination.

> "Everyone needs love and care irrespective of their HIV status... One must learn to **be bold and fight for a chance to be heard** and by opening up, you help many people who may be going through the same issue but are afraid to speak up. HIV is just a disease...it can't take away our dignity, self-esteem, and confidence as women. **Let's fight and work hard to make better futures** for ourselves and loved ones."
>
> –SURVEY PARTICIPANT LIVING WITH HIV

Thanks

We would like to extend our thanks to all of the individuals whose hard work and dedication made the development, implementation, and analysis of this survey possible. Specifically, we thank the 2016 Community Advisory Board (CAB) members: Michelle Anderson, Kate Borloglou, Jyoti Dhawale, Arianna Lint, Tiommi Jenae Luckett, Vickie Lynn, Maria Mejia, Abosede Olotu, and Ieshia Scott for their invaluable contributions. We also thank the advisors and reviewers who played critical roles in the development of the survey and analysis plans, including Judith D. Auerbach, PhD, Abby Charles, Vignetta Charles, PhD, Jenna Conley, E. Maxwell Davis, PhD, Melissa Tischler, and Sweet Potato Design. Finally, we thank the funders without whom this work would not have been possible: Bristol-Myers Squibb, Broadway Cares, Gilead Sciences, Inc., Janssen Therapeutics, Merck, and ViiV Healthcare, as well as the many individual donors who contributed to The Well Project. We are deeply grateful for all of your input, guidance, and support.

Background

The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls. Since its founding by leading HIV activist Dawn Averitt, The Well Project has established itself as the premier online resource on women and HIV both nationally and globally, directly reaching more than one million users annually. Focusing on three critical areas related to women and HIV—information access, community support, and advocacy—The Well Project is leveraging technology to dramatically improve health outcomes and quality of life for women and girls living with HIV. We accomplish this work by disseminating accurate, useful, and timely information about HIV; creating and fostering connection and mutual support among women living with HIV; and developing community capacity for advocacy around HIV research, policy, prevention, and care.

In order to maximize The Well Project's effectiveness and continuously strengthen the impact of our programs, we need to understand how our resources and services are experienced, integrated, and applied by those utilizing them. We gather this information primarily from periodic user surveys. These surveys have shown us that individuals accessing The Well Project's online resources are looking to secure accurate and relevant information about HIV disease and treatment. We also have learned that accessing these resources has broken down barriers to HIV testing and supported our users as they engage in HIV care and treatment.

For each survey, we develop and implement new questions in order to assess our current reach and impact and to identify areas for improvement and enhancement. This report provides a descriptive analysis of findings from the 2016 online user survey. While our respondents included users of diverse gender and sexual identities and HIV sero-statuses, our primary constituents are women living with HIV (WLHIV), so we focused most of our findings on this group. Our analysis focuses on the impact of The Well Project's online resources on engagement with healthcare, HIV-related self-care, emotional well-being, personal relationships, and quality of life among WLHIV. It is framed within the context of the HIV care continuum, which charts the progression of individuals and populations from HIV testing through engagement in care, antiretroviral treatment uptake and adherence, and, ultimately viral suppression. ***Our data highlight some of the opportunities and challenges for women along the HIV care continuum, as well as the need to expand notions of optimal outcomes beyond viral suppression to include measures of broader health and quality of life.***

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. This group's feedback on overall survey design, question content, and formatting was incorporated into the final version of the survey, which was created using the Survey Monkey platform to include both closed-ended and open-ended questions. Recruitment of survey participants began in January 2016 and continued through June 2016. Information about the survey was posted to The Well Project's website, included in newsletters, and circulated in virtual flyers. The Well Project's CAB members were encouraged to disseminate the survey link through social media. Community partners were asked to disseminate recruitment materials to their networks, and these materials were posted to relevant list servs. All recruitment materials included invitations to complete the survey and embedded links through which to reach it.

Data collection began in March 2016 and continued until June 2016, when the survey closed. As incentive, users who completed the survey were entered into a raffle to receive one of 20 $20 Amazon gift cards. Once data were cleaned to include only cases with complete responses, the final sample size for analysis was 229 individuals. Key domains for analysis included: demographic characteristics of users; experiences of WLHIV related to HIV diagnosis and care, HIV stigma, and mental, emotional, and behavioral health issues; reasons for and goals of using The Well Project's online resources; assessments of the impact of using the resources on users' own HIV knowledge, HIV-related self-care, engagement with healthcare, and emotional well-being; assessments of the overall value of The Well Project's online resources; and recommendations for improvement.

Characteristics of the Survey Sample

As Table 1.1 shows, of the 229 participants in the final sample, 64.2% self-identified as living with HIV, 34.1% reported that they were not living with HIV, and 1.7% reported that they either did not know or did not wish to disclose their HIV status. The average age of all survey participants was 46.2 years. The vast majority (87.8%) were women, with 9.2% men, 1.8% transwomen, 0.9% transmen, and 0.4% other. With respect to sexual orientation, 75% were heterosexual, 14% gay, lesbian, or queer, 8.7% bisexual, and 2.2% asexual.

As reflected in Table 1.2, the largest proportion of respondents (46.7%) identified as African, of African Descent, or black, followed by Caucasian/non-Hispanic white (34.5%), Hispanic or Latino (8.7%), and multiracial (4.8%). Other race/ethnicities were less well represented. More than 80% reported living in North America, with Africa having the second largest proportion (11.4%). Nearly two-thirds (63.3%) reported living in urban settings, 20.5% in suburban settings, and 16.2% in rural settings. The vast majority (84.3%) of respondents reported speaking only English.

TABLE 1.1

Key Identity Features of Survey Participants (n=229)

Living with HIV	64.2%
Not living with HIV	34.1%
Did not wish to disclose	1.7%
Age (Average 46.2 years)	
19 to 29	14.4%
30 to 39	15.3%
40 to 49	26.7%
50 to 59	25.3%
60 or older	18.3%
Gender Identity	
Woman	87.8%
Man	9.2%
Transwoman	1.8%
Transman	0.9%
Other	0.4%
Sexual Orientation	
Heterosexual	75.1%
Gay, Lesbian, or Queer	14.0%
Bisexual	8.7%
Asexual	2.2%
Race/Ethnicity	
Aboriginal, Native, or Indigenous	0.9%
African, African Descent, or Black	46.7%
Asian, East Asian, or PI	1.3%
South Asian or Indian	1.8%
Southeast Asian	0.4%
Caucasian, Non-Hispanic White	34.5%
Hispanic or Latino	8.7%
Middle Eastern or Arab	0.9%
Multiracial	4.8%

TABLE 1.2

Geography and Language Characteristics of Survey Participants (n=229)

Global Location	
Africa	11.4%
Asia & South Asia	0.9%
Central America & Caribbean	1.8%
Europe	1.8%
North America	84.3%
Residential Setting	
Urban	63.3%
Suburban	20.5%
Rural	16.2%
Languages Spoken at Home	
English only	84.3%
Sub-Saharan African languages	6.6%
English & Spanish, Spanish only	5.2%
English & French, French only	1.8%
Asian Languages	1.8%

Table 1.3 shows that the sample was highly educated, with 59.0% having attended or completed at least some level of post-secondary education, and 17.9% having a graduate degree. Less than half (43%) of the participants were employed full-time, 18.3% were employed part-time, 18.3% were disabled/unable to work, 11.8% were unemployed, 7% were retired, and 1.3% were homemakers. Two-thirds (66.0%) of respondents engaged in either part-time (58.1%) or full-time (7.9%) volunteer work.

Nearly two-thirds (65.5%) of participants had household incomes of less than $40,000 (U.S.) per year, with a significant proportion (36.7%) having incomes less than $20,000 per year. The most common form of housing was rental (40.1%), with 30.6% of respondents owning a home and 6.1% having no stable housing. A majority (63.8%) of respondents lived in households with only one (29.3%) or two (34.5%) people. Just over one-third (35.4%) of respondents were caring for young children and/or adults.

TABLE 1.3

Life Circumstances of Survey Participants (n=229)

Level of Education	
Less than High School	0.4%
Some High School	2.6%
High School or Equivalent	20.1%
Some College/2 Year Degree	33.2%
College/4 Year Degree	25.8%
Graduate Degree	17.9%
Current Volunteer Status	
Not a Volunteer	34.0%
Part-Time Volunteer (Occasional)	29.7%
Part-Time Volunteer (Regular)	28.4%
Full-Time Volunteer	7.9%
Paid Employment Status	
Employed Full Time	43.2%
Employed Part Time	18.3%
Unemployed/Seeking Work	8.7%
Unemployed/Not Seeking Work	3.1%
Homemaker	1.3%
Retired	7.0%
Disabled/Unable to Work	18.3%

TABLE 1.4

Household Characteristics of Survey Participants (n=229)

Household Income	
(U.S. Dollar or Equivalent)	
$0 - $19,999 per year	36.7%
$20,000 - $39,999 per year	28.8%
$40,000 - $59,999 per year	13.1%
$60,000 - $79,999 per year	5.2%
$80,000 - $99,999 per year	4.4%
$100,000 or more per year	4.8%
Can't Calculate in USD	7.0%
Housing Status	
No Permanent Housing	6.1%
Supported/Assisted Living	0.4%
Subsidized Housing	14.0%
Depend on Family/Friends	8.8%
Rent Housing	40.1%
Own Housing	30.6%
Household Size	
One Person	29.3%
Two People	34.5%
Three People	13.1%
Four People	10.0%
Five People	7.4%
Six or More People	5.7%
Household Caregiving	
Care for Minor Child/ren	23.6%
Care for Adult/s	7.9%
Care for Child/ren & Adult/s	3.9%
No Caregiving	64.6%

Characteristics of the Women Living with HIV Sample

Given that WLHIV are the primary constituency of The Well Project, the bulk of the survey analysis focuses on this group of respondents, with particular attention to highlighting some of their experiences living with HIV, and assessing how The Well Project's online resources have impacted them.

As seen in Table 2.1, women living with HIV (WLHIV) comprised 59.4% of the overall sample of survey respondents. Of these, 97.8% (n=133) identified as women and 2.2% (n=3) identified as transwomen. The vast majority (86.0%) identified as heterosexual, 6.6% as bisexual, and 5.9% as gay, lesbian, or queer.

TABLE 2.1

Key Identity 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%
South Asian or Indian	–
Southeast Asian	–
Caucasian, Non-Hispanic White	32.3%
Hispanic or Latino	10.3%
Middle Eastern or Arab	–
Multiracial	4.4%

Half of the WLHIV respondents identified as African, of African descent, or black, 32.4% as Caucasian/non-Hispanic white, 10.3% as Hispanic/Latino, 4.4% as multiracial, 1.5% as Aboriginal, Native American, or Indigenous, and 1.5% as Asian, East Asian, or Pacific Islander.

More than 85% of respondents reported living in North America and another 11.8% in Africa. Only two respondents reported living in Europe and Asia, and no respondents were located in Central America/Caribbean or the Mideast/North Africa.

TABLE 2.2

Geography and Language Characteristics of Women Living with HIV (n=136)

Global Location	
Africa	11.7%
Asia & South Asia	1.5%
Central America & Caribbean	–
Europe	1.5%
North America	85.3%
Residential Setting	
Urban	63.2%
Suburban	22.8%
Rural	14.0%

As in the overall sample, WLHIV were a highly educated group (Table 2.3), with 61.8% having attended or completed at least some level of post-secondary education, and 9.6% having a graduate degree. Only 28.7% were employed full-time, 18.4% were employed part-time, 14.0% were unemployed, 10.3% were retired, 2.2% were homemakers, and 26.5% were disabled/unable to work. More than three-fourths (78.7%) of WLHIV had household incomes of less than $40,000 (U.S.) per year, with nearly half (47.1%) having incomes less than $20,000 per year. With respect to housing, 39% reported renting their home, with 22.8% owning theirs, 20.6% living in subsidized housing, and 5.1% experiencing unstable housing. About two-thirds (65.5%) lived in households with only one (32.4%) or two (33.1%) people; and nearly one-third (32.4%) were caring for young children and/or adults.

TABLE 2.3

Life Circumstances of Women Living with HIV (n=136)

Level of Education	
Less than High School	0.7%
Some High School	3.7%
High School or Equivalent	24.3%
Some College/2 Year Degree	41.9%
College/4 Year Degree	19.8%
Graduate Degree	9.6%
Current Student Status	
Not a Student	89.7%
Part-Time Student	8.8%
Full-Time Student	1.5%
Current Volunteer Status	
Not a Volunteer	24.3%
Part-Time Volunteer (Occasional)	33.8%
Part-Time Volunteer (Regular)	33.1%
Full-Time Volunteer	8.8%
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%

TABLE 2.4

Household Characteristics of Women Living with HIV (n=136)

Household Income	
(U.S. Dollars Equivalents)	
$0 - $19,999 per year	47.1%
$20,000 - $39,999 per year	31.6%
$40,000 - $59,999 per year	8.8%
$60,000 - $79,999 per year	2.9%
$80,000 - $99,999 per year	0.7%
$100,000 or more per year	1.5%
Can't Calculate in USD	7.4%
Household Size	
One Person	32.4%
Two People	33.1%
Three People	14.0%
Four People	8.1%
Five People	6.6%
Six or More People	5.8%
Household Caregiving	
Care for Minor Child/ren	17.6%
Care for Adult/s	9.6%
Care for Child/ren & Adult/s	5.1%
No Caregiving	67.6%

Key Experiences of Women Living with HIV Along the Care Continuum

HIV DIAGNOSIS: The 136 WLHIV participants reported being aware of their HIV status for an average of 16.3 years.

LINKAGE TO AND ENGAGEMENT IN CARE: Fully 97.8% of these participants reported that they were currently seeing a healthcare provider to manage their HIV. Among participants currently engaged in HIV care, 74.8% identified an HIV or infectious disease physician as their main care provider. Another 4.6% identified a nurse practitioner as their primary HIV care provider, 4.6% identified a primary-care physician or family practitioner, and 1.5% identified a community health or clinic worker. In addition, 14.5% of these participants identified themselves as their main HIV care providers, many of them citing the importance of their own advocacy, personal knowledge building, and active decision making in managing their HIV. The few participants who reported that they were not currently engaged with any healthcare provider attributed this to feeling that providers were not helpful to them, their own refusal to take medications, and, in one case, being an elite controller (technically having HIV infection, but exhibiting no symptoms) monitored by the National Institutes of Health.

Engagement in Care

97.8% of WLHIV participants reported seeing a healthcare provider to manage their HIV

TAKING ANTIRETROVIRAL MEDICATIONS: Almost all (97.7%) of the WLHIV indicated that they had taken HIV medications at some point since their diagnosis, and the same percentage reported that they were currently doing so. Among participants who reported any history of taking HIV medications, the average length of time since beginning to take HIV medication was 14.5 years. The earliest year anyone reported beginning to take HIV medication was 1985 and the most recent was 2016. Six participants reported not currently taking HIV medications for the following reasons: being told by a healthcare provider that they did not need medication, having decided on their own that they did not need it, being unable to tolerate medication side effects, using only natural medicine, and fearing that use of medication would reveal their HIV status to others.

Taking ART

97.7% of WLHIV participants reported currently taking HIV medications

ACHIEVING VIRAL SUPPRESSION: More than three-quarters (77.3%) of WLHIV reported that their viral loads were undetectable at last testing. An additional 15.2% of these individuals knew their most recent viral loads and provided numeric counts and 6.8% indicated that they were unaware of their current viral load. When participants who were unaware of their viral load were asked about the reasons for this, respondents (n=9) said that they simply could not remember their most recent results, had not looked at recent lab results, had not had testing repeated recently, were in the process of having new testing, or were waiting for the results of recent testing.

77.3%

Virally Suppressed

of WLHIV participants reported having undetectable viral loads

Factors Influencing Women Living with HIV's Experiences Along the Care Continuum

Regrettably, HIV stigma remains a significant presence in the lives of many WLHIV, manifesting in multiple dimensions within their personal lives and within healthcare settings.

STIGMA IN THE LIVES OF WLHIV

62.7% of WLHIV reported having personally experienced HIV stigma or discrimination in their pesonal lives

50.6% from family members

46.8% from friends

39.2% in their neighborhoods

31.6% at places of employment

24.1% in online forums/chats/groups

39.2% with romantic partners

27.8% at places of worship

14% at HIV service organizations

In their comments about these experiences, WLHIV described having neighbors, friends, and family members cut off contact or limit physical interactions with them, being rejected and/or belittled by romantic partners, confronting widespread community gossip about their HIV status, being asked to move, being prohibited from contact with others' children, being publicly rejected by religious communities, not being offered employment opportunities, and being dismissed from or choosing to leave a job—all due to HIV stigma. One participant commented that her former physically abusive partner was able to control her by assuring her that "no one would want me because of my HIV status and that he was the only person who did."

STIGMA IN HEALTHCARE SETTINGS

49.6% of WLHIV reported having personally experienced HIV stigma or discrimination in healthcare settings

41.3% healthcare staff

38.1% dentists

22.2% registered nurses

19.0% social workers

36.5% emergency department physicians

23.8% OB/GYNs

23.8% primary-care physicians

17.5% nurse practitioners

15.9% physician assistants

WLHIV described occasions when providers made numerous assumptions and disparaging comments about their behavior, personal histories, and risk factors; violated their patient confidentiality; refused to provide routine services; and, in some cases, substantially compromised the care that patients received. One participant described registering a formal complaint against a physician who told her that all American women living with HIV were sexually promiscuous.

> *"When I arrived [at the hospital]* ***the nurse yelled at me*** *for not disclosing my status; and after 1.5 hours a decision was made to discharge me, as they were so upset that they did not examine me further to realize that I was having a stroke."*

Nearly one quarter (24%) of WLHIV reported that their partners, spouses, children, or other family members had experienced associative HIV stigma or discrimination because of their HIV status. Participants describe their children being subjected to bullying, ridicule, and physical violence at school; their siblings, parents, and other family members being subjected to social distancing, hate mail, and harassing Facebook messages; their parents and children being gossiped about and excluded from religious communities; and their children losing playmates. One participant commented that when she was diagnosed, her family "told me not to tell anyone because they did not want to put shame on the family."

TRAUMA: 79.4% of WLHIV chose to respond to a series of optional questions about mental, emotional, and behavioral health issues. More than three-quarters (76.5%) of these participants reported that they had experienced some form of trauma—and, in many cases, multiple traumas that they believe led to mental, emotional, or behavioral health issues. The most frequently described traumas revolved around HIV diagnosis, HIV-related stigma and discrimination, and the loss of loved ones. Other prevalent traumas included intimate partner violence, rape, childhood sexual abuse, and childhood physical and emotional abuse. Some participants described traumas related to exposure to community violence, accidents, health crises, and interpersonal betrayals.

Mental Health

76.5% of participants* reported that they had experienced some form of trauma or multiple traumas

*Of the 104 (79.4%) WLHIV participants who chose to respond to a series of questions about mental, emotional, and behavioral health issues.

OTHER MENTAL, EMOTIONAL, AND BEHAVIORAL HEALTH ISSUES: Of the 76.5% of WLHIV reporting experiences of trauma in the prior section, 39.8% also reported that they had experienced mental, emotional, and behavioral health issues that made it more difficult for them to address their HIV-related care needs at some point in time. Many described scenarios in which depression, mental fogginess, substance abuse, and denial caused problems with their medication adherence and engagement with care providers. Others described ways in which these issues caused them to refrain from disclosing their HIV status to others or seek support when needed, resulting in increased isolation.

> *"Dealing with undiagnosed and untreated depression, anxiety, and substance use ultimately led me to increased drug use and unhealthy coping behaviors, which limited my ability to deal with reality or handle any major life decisions.* ***Addressing my HIV care needs became impossible."***

Among WLHIV who described experiencing mental, emotional, or behavioral health issues, 68.9% reported seeking professional care. More than three-quarters (76.8%) of these individuals said that they were able to access and engage the various types of care they needed, including: individual therapy, psychotropic medications, crisis counseling, participation in support groups, inpatient psychiatric hospitalizations, couples' therapy, inpatient and outpatient addiction treatment and relapse prevention programs, and religious counseling. Several participants attributed their success in securing care to the availability of free, low-cost, coordinated, or integrated "one-stop shopping" care at local AIDS service organizations and health clinics.

> *"Our system of care can be a* ***roller coaster of availability*** *and access. I often refer to it as a 'system of care that doesn't care.' One day you have care, the next day you don't. Maintaining access to care is challenging due to changing policies and political barriers."*

While most participants were able to access care and a few said they were satisfied with the care they received for mental, behavioral, or emotional health, many more participants expressed dissatisfaction with their care. Even more disheartening, many participants who described experiencing mental, emotional, or behavioral health issues reported being unable to secure any care to address those concerns.

Barriers Identified by WLHIV to Engaging in and Accessing Mental Healthcare

THE ROLE OF PARTICIPATION IN CLINICAL TRIALS: One more positive factor influencing some respondents' progress along the HIV care continuum is participation in HIV clinical trials. Among WLHIV, 48.8% indicated that they had taken part in at least one clinical trial. Of those, 80.3% reported that participation had been a positive experience, 16.4% that it had been a mixed experience, and 3.3% that it had been a negative one. The latter referred to difficulties associated with complicated medication regimens and challenging side effects. However, many more participants commented that during clinical trials, they received excellent care and learned a great deal about HIV and their own health. Many also noted that beyond the personal health benefits of participation, they valued these experiences as a way to contribute to the greater good and potentially help others.

48.8%

Clinical Trials

of WLHIV participants took part in at least one clinical trial and **80.3%** reported having a positive experience

Indeed, the vast majority of clinical trial participants reported that the biggest factor in their decision to participate was their desire to contribute to the greater good by helping to advance the development of HIV treatments, an HIV cure, and HIV prevention efforts, especially for women: "I wanted the people who are diagnosed after me to have even better options for medical regimens than myself." Many also commented that they were motivated by the excellent care they received during trials, the personal health benefits associated with their participation, and the opportunity to learn about HIV and their own health. Several also noted that the location of trial sites and the compensation offered were significant factors in their decision-making, as was concern about protecting their offspring from contracting HIV. One said, "I was pregnant and I would have done anything to ensure my child did not have to live with HIV." Some participants reported being picky about which trials to participate in (i.e., no blinded studies) and others noted feeling motivated to participate because "women don't sign up for them."

> ***"I love clinical trials*** *because they help scientists and researchers better understand not only the effects of HIV and people living with HIV but also get them closer to a cure, in my opinion."*

To this point, ***among respondents who had never participated in a clinical trial, most said they had not done so primarily because they had never been offered the opportunity.*** Many attributed this to not being aware of or asked to participate in trials, and many others attributed it to a lack of trial sites in their cities or regions. Several indicated that apprehension about risking adverse reactions to new medications or disrupting their stable health were barriers for them. Some indicated that they had refused opportunities to participate in trials because of parenting responsibilities, childcare, or transportation issues.

Use of The Well Project’s Resources

As we have seen, survey respondents who are WLHIV are diverse in age and racial/ethnic background, well educated but underemployed and of low income, highly engaged in HIV care and treatment, subject to stigma and discrimination both inside and outside of healthcare settings, survivors of trauma and behavioral health challenges, and beneficiaries of participation in clinical trials. It is important to know how these women have used The Well Project's resources and what impact those resources have had on their navigation of the HIV care continuum and overall health and well-being.

The primary online resources offered by The Well Project are:

- HIV Information and Fact Sheets
- *A Place at the Table: WATCH!* Treatment Advocacy Webinar Series
- Monthly E-Newsletters
- *A Girl Like Me/Una Chica Como Yo* Blogs
- Facebook and Twitter Postings
- News and Reports from the *Women’s Research Initiative on HIV/AIDS (WRI)*
- *Get Connected* Social Features (Groups, Forums, and Chats)

GOALS OF USING THE RESOURCES: WLHIV identified their primary goals in using The Well Project’s resources as (in order of magnitude):

TOP 3 GOALS OF WLHIV FOR USING THE WELL PROJECT’S RESOURCES

1. Increasing their knowledge of HIV and its treatments
2. Improving their health outcomes
3. Becoming more empowered to advocate for themselves

Additional goals included: feeling connected to a community of support, preventing the transmission of HIV and other STIs, and improving their relationships with healthcare providers.

WAYS OF USING THE RESOURCES: The reason most frequently cited for using The Well Project's resources, reported by 85.3% of WLHIV, was "to address my own needs as a person living with HIV." The second most frequently cited, reported by 62.5% of participants, was "to provide support and information as an HIV peer educator or advocate," and the third, reported by 55.9% of participants, was "to educate people as an HIV educator." In addition, 30.1% of WLHIV reported using The Well Project's resources "to address the needs of a friend, loved one, or partner living with HIV as an informal caregiver," 19.9% "to play another role in HIV services," and 16.2% "to address the needs of my patients or clients as a professional healthcare provider."

TOP 3 WAYS WLHIV ARE USING THE WELL PROJECT'S RESOURCES

1. Address their own needs as a person living with HIV
2. Provide support and information as a peer educator or advocate
3. Educate people as an HIV educator

DURATION AND FREQUENCY OF USE:

13.2% of WLHIV reported using The Well Project's resources for more than five years, 36.8% reported use for one to five years, 11.8% reported use for six to 12 months, 9.6% reported use for three to six months, and 28.7% reported use for three months or less.

6.6% of WLHIV reported daily use of The Well Project's resources, 22.8% reported use a few times per week, 16.2% reported use once per week, 24.3% reported use a few times per month, 5.1% reported use once per month, 17.6% reported use a few times per year, and 7.4% (mostly new users) reported use less than a few times per year.

SHARING THE WELL PROJECT'S RESOURCES: Given that social networking and resource sharing are important components of The Well Project's service model, survey participants were asked to estimate with how many people per year they share information they gleaned from The Well Project. They were also asked which resources they share most often. Of WLHIV participants responding to this question, 40.2% reported that they regularly share The Well Project's resources with one to 10 individuals each year, 15.7% said that they regularly share with 11 to 100 individuals each year, and 30.4% said that they regularly share with more than 100 individuals each year. Many of these participants provided estimates in the thousands,

Number of People with Whom WLHIV Participants Share The Well Project's Resources Annually

noting that they can only guess as to the large numbers because they share these resources through social media such as Facebook and Twitter, as well as in support groups, public presentations, and printed educational materials. About 13% of respondents indicated that do not regularly share any of The Well Project's online resources, but several of these noted that this is because they are new users.The most commonly shared resource (41.7%) was HIV information and fact sheets from The Well Project website. This was followed by information posted by The Well Project to Facebook and/or Twitter (14.3%); information from *A Place at the Table: WATCH!* Treatment Advocacy Webinar Series (13.1%); blogs, stories, and information from *A Girl Like Me* and/or *Una Chica Como Yo* (11.9%); and news and information from The Well Project's monthly e-newsletter and news and reports from the WRI (9.5% both).

> ***"I have 50 support groups of women** [for] which I translate and share in local language [information from The Well Project], and [use] as printed materials provided during the training."*

The Well Project Resource WLHIV Participants Were Most Likely to Share

41.7%
HIV information and fact sheets

14.3%
information posted on Facebook and Twitter pages

13.1%
information from treatment advocacy webinar series

11.9%
blogs from *A Girl Like Me/Una Chica Como Yo*

9.5%
news from e-newsletter

9.5%
reports from the WRI

Impact of The Well Project's Resources on Progress Along the HIV Care Continuum

As stated earlier, the results of our survey have been framed within the context of the HIV care continuum, which charts the progression of individuals and populations from HIV testing through engagement in care, antiretroviral treatment uptake and adherence, and viral suppression. While the HIV care continuum is a useful method to track the population level trajectory of people living with HIV toward one biological outcome (undetectable viral load), its "steps" are not inclusive of everything that affects how people fare with HIV disease. For example, most people living with HIV (including, but not limited to women) perceive that there is more to their health and quality of life than just having an undetectable viral load. Recognizing this, our survey included questions about basic HIV knowledge (a precursor to engaging in care), self-care, and outlook on living with HIV.

KNOWLEDGE: Many commented that through The Well Project, they had learned critical information about HIV treatment and how to proactively manage life with HIV. One noted, "your website is my go-to website if I need to find any answers to questions I might have and for keeping up with any updates about the disease." Other participants commented that information from The Well Project helped them learn how to actively engage with healthcare providers, address mental and emotional health issues, and combat stigma. Many noted that The Well Project's specific focus on women and HIV makes it uniquely valuable. As one participant said, "I always consult several sites to get more information about HIV/AIDS; I specifically go to The Well Project for information on issues affecting women." Others commented on the value of The Well Project's resources on HIV prevention, HIV policy issues, and general HIV knowledge.

Knowledge

70%

of WLHIV participants reported that their use of The Well Project's resources had helped them feel more knowledgeable about HIV

Several participants emphasized that the structure and format of The Well Project's resources actively support their knowledge development. One participant observed, "[The Well Project] is always useful to check accuracy of information, what the view is in the United States on issues, and what other women living with HIV think." Many participants also commented on The Well Project's unique value as a knowledge source for their work as public speakers, facilitators, trainers, community educators, and advocates, as well as for mentoring and supporting women newly diagnosed with HIV.

> *"[The Well Project's website is] enlightening, it keeps an open mind and I feel comfortable when I'm on it. I don't have to worry about saying the wrong thing.*
> ***I feel like it's MY website."***

ENGAGEMENT IN HIV CARE AND TREATMENT: Participants identified numerous ways in which this knowledge base from The Well Project facilitated their engagement in HIV care. A number reported that use of The Well Project resources had emboldened them to actively engage with healthcare providers, take charge of the lines of communication in those relationships, ask more detailed questions, and play a more active role in decision-making about care. Some participants noted that using The Well Project helped them better understand how HIV medications work and better appreciate the importance of medication adherence. One participant noted that "[The Well Project] kept me active in my relationship with my doctor and has helped me to understand the importance of staying on my medication, even when I didn't want to."

> ***"[The Well Project] has influenced me to be fully engaged in my HIV care*** *and to educate me about HIV and how to support others."*

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:***

Talk with healthcare providers about how HIV affects women differently than men **76.7%**	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%**	Take HIV medication regularly as prescribed **54.4%**	Talk with providers about PrEP* **47.6%**

*PrEP stands for Pre-Exposure Prophylaxis, a prevention method that involves taking one pill a day to prevent the transmission of HIV.

SELF-CARE: Self-care refers to a range of strategies individuals use to mitigate the kinds of mental and physical health challenges experienced by people living with HIV, such as stress, depression, and fatigue. Our survey asked respondents to assess how using The Well Project's resources had influenced specific aspects of self-care related to their emotional well-being. Many participants noted that these resources had motivated them to "come out" about their HIV status and to better understand their own mental and emotional self-care needs. One noted the value of highlighting "topics specific to the needs of women living with HIV, especially trauma-informed care...and mental health" and another commented that this "has helped me to live life to my full potential." Another participant commented: "I want a full quality of life and I want to decrease the spread of HIV and other STIs."

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:***

Accept only respectful, caring behavior from partners, family and/or friends	**70.9%**
Make an effort to get enough/good rest and eat healthy foods	**68.0%**
Exercise or move regularly	**63.1%**
Seek out care for depression or other mental/emotional health issues	**56.3%**
Practice safer sex	**53.4%**
Seek out support for past or current violence or trauma	**51.5%**

OUTLOOK ON LIVING WITH HIV: The Well Project believes that an important measurement of one's quality of life is related to one's outlook on living with HIV. Based on The Well Project's experience with the interconnectedness between decreased stigma and isolation and increased hopefulness, connectivity, and advocacy, the survey asked respondents to assess The Well Project's influence on their perspectives about living with HIV.

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:***

Advocate for themselves
82.5%

Feel connected to a community
81.6%

Advocate for the needs of others living with HIV
80.6%

Feel hopeful about the future
75.7%

Experience less HIV self-stigma
65.0%

Not feel alone
63.1%

61.2%
Experience less HIV stigma from others

> *"Being part of a group/community of other women who are living my life...has encouraged me to want to do better. I was not part of a group of women the first 17 years of living with HIV, I was doing it all alone, and now that I have poz sisters I will never do it alone again.* ***I have never felt more supported and loved.*** *I appreciate this website and everyone who supports it."*

VIRAL LOAD: Because participants self-reported viral load status, we cannot validate that outcome nor make any claims about the direct influence of The Well Project's resources on it. But it is probable that the kinds of enhancements in self-care, engagement with HIV care systems, uptake of and adherence to treatment, and outlook on living with HIV reported by WLHIV positively affected their viral loads.

> *"The connection with empowered, positive women* ***keeps me totally involved*** *in activism and the management of my health."*

Assessment of The Well Project Resources

The goals of The Well Project's primary constituency—WLHIV—in using the organization's resources for their own, personal needs have already been described. Another key constituency of The Well Project is people who provide care and support, formally and informally, to others living with HIV. In the overall survey sample, 54 respondents (38 of whom were also WLHIV) identified as informal caregivers (chiefly friends, partners, and family members) and 46 (16 of whom were also WLHIV) identified as professional healthcare providers (chiefly social workers; community health workers; education and outreach workers; and nurses). For both groups, the top two goals of using The Well Project's online resources were: 1) to increase their friends'/loved ones,' patients', or clients' knowledge of HIV and its treatments and 2) to improve the health outcomes of friends/loved ones, patients, or clients.

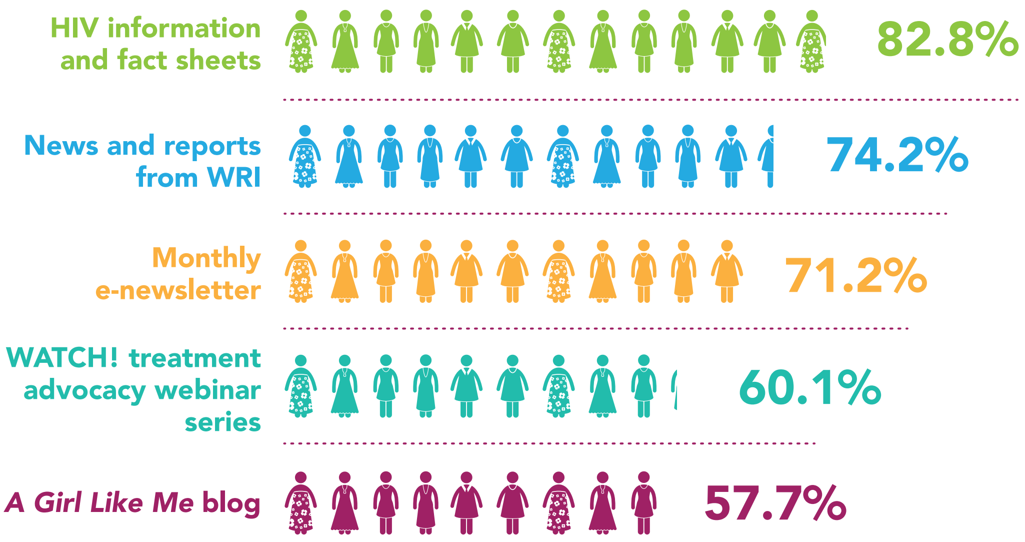
> *"The Well Project's resources have helped me learn more about HIV and empowered me to want to become an advocate and educator.* ***It also has helped me to step out of the shadows of feeling ashamed."***

In light of these goals from two key constituencies (WLHIV and those who care for them), findings from the full sample of respondents to the 2016 survey are combined and presented here to assess the overall value of and recommendations for improving The Well Project's resources from the point of view of the broad user community.

SATISFACTION: Participants' overall satisfaction with The Well Project's website was high. Of the 158 participants who identified as active users, 77.8% reported that they were "very satisfied" with the website, 13.9% were "somewhat satisfied," 6.3% were "neither satisfied nor dissatisfied," and 1.9% were "somewhat" or "very dissatisfied."

VALUE: Participants were asked to assess the value of each of the eight specific components of The Well Project's online offerings listed above. All of the resources were rated as either "extremely" or "very" valuable by a majority of participants who identified as active users and who accessed each specific resource. The HIV information and fact sheets ranked highest in value among the resources (82.8% extremely/very valuable), followed by news and reports from the WRI (74.2%), monthly e-newsletter (71.2%), *A Place at the Table: WATCH!* treatment advocacy webinar series (60.1%), *A Girl Like Me* blog and The Well Project's social media posts (both at 57.7%), and "Get Connected" social features (55.2%). The overall value rating for *Una Chica Como Yo* was skewed by the fact that most respondents (52%) did not access it, given that it is a Spanish-language resource and most participants only speak English. But, of the respondents who did access it (n=49), 61.2% said it was "extremely" or "very" valuable.

Survey Participants Ranked These Well Project Resources as "Extremely" or "Very" Valuable



Recommendations for Improving The Well Project's Resources and their Reach

When participants were asked what might encourage them to use The Well Project's website and other resources more frequently, the most common answer was that they would do so if they had more time and/or more consistent internet access. Some respondents said that they would engage with The Well Project's resources more frequently if prompted to do so by email alerts or newsletter items about new content or features. Others suggested that allowing users to sign up for the delivery of specific information, or providing printable cards or flyers that service providers could make available to potential users might be additional ways to increase general awareness of the resources.

Participants were also asked to provide general recommendations for improving The Well Project's resources. This produced a great deal of praise and gratitude for the organization's presence, work, content, and commitment to and support of women living with HIV. Many commented, "thank you for being there for me!" and encouraged The Well Project to "keep up the good work!" Others identified their favorite elements of The Well Project and praised specific resources like HIV fact sheets and the presentation of personal stories of "women rising above and living well." Some described The Well Project as a critical source of education and information and commented on how much they had learned from it, expressing thanks for "all your information, compassion, time, hard work, and research." Others highlighted how important The Well Project's supportive features had been for them. One commented, "I want to thank you for being there when I was first diagnosed as there was nothing for women in Utah...I was alone and scared."

> *"Being in a rural county and just trying to make a difference is hard, but knowing I have someone to talk to or somewhere to go keeps me going.* ***It gives me hope."***

In addition to these supportive comments, participants provided suggestions to improve The Well Project's offerings. Most common among these were recommendations related to adding or enhancing specific content in areas of mental and physical health, as well as findings from just-completed research. Other suggestions included:

- Enhancing information relevant to users in parts of the world other than the United States, especially sub-Saharan Africa and the United Kingdom
- Providing information in languages other than English and Spanish
- Developing programming that empowers consumer advocacy, such as resources for educating others and trainings for trainers
- Developing more "how-to" information packaged as toolkits

Participants also suggested ways to improve The Well Project's delivery of its content by making changes to its formatting, user interface, and page organization, such as:

- Including more images, videos and voice recordings on the website and creating related YouTube videos
- Offering more interactive features, such as interviews, quizzes, videos, video chats, and online support groups on the website, as well as tools that facilitate opportunities for users to meet offline

Many participants praised The Well Project's webinars as informative and useful, but also suggested ways to build on their success, including:

- Making all webinars accessible from mobile devices and offering them at varied hours in order to accommodate users' work schedules
- Creating webinars for "advanced" users
- Creating more easily downloaded printable versions of all website materials in multiple languages for distribution by clinics and nonprofit agencies

A number of participants remarked on the potential for The Well Project to bring even more knowledge, information, and support to women across the globe. Several expressed hope that The Well Project would expand its reach and develop relationships with brick and mortar NGOs and other nonprofits to fund and/or develop global HIV prevention and advocacy efforts. Others offered specific suggestions for collaborations with women-led, community-based organizations and faith-based NGOs. These included helping already trained peer counselors in sub-Saharan Africa spread knowledge more widely, and helping women living with HIV "play a meaningful role in the formulation of national SDG [anti-poverty] targets, implementation, and monitoring of national development goals."

As The Well Project seeks to ensure we are best addressing the needs of our users, we asked participants to share their perspectives on gaps and barriers. Participants identified areas related to women and HIV in need of more research and attention as follows:

Mental health issues	75.4%
PrEP	67.2%
Violence and trauma	65.0%
Reproductive health	59.0%
Co-morbidities	51.4%
Transgender women	45.4%
Hepatitis C	40.4%

Finally, when asked to identify the most significant barriers to ending the HIV/AIDS epidemic in their community, participants ranked the following as "very significant" barriers:

HIV stigma	73.8%
Economic inequalities	56.8%
Race and ethnicity-based inequalities	47.0%
Gender-based inequalities	44.3%

The recommendations and important insights for enhancing The Well Project's programs and resources will be invaluable to the organization's planning.

Conclusion

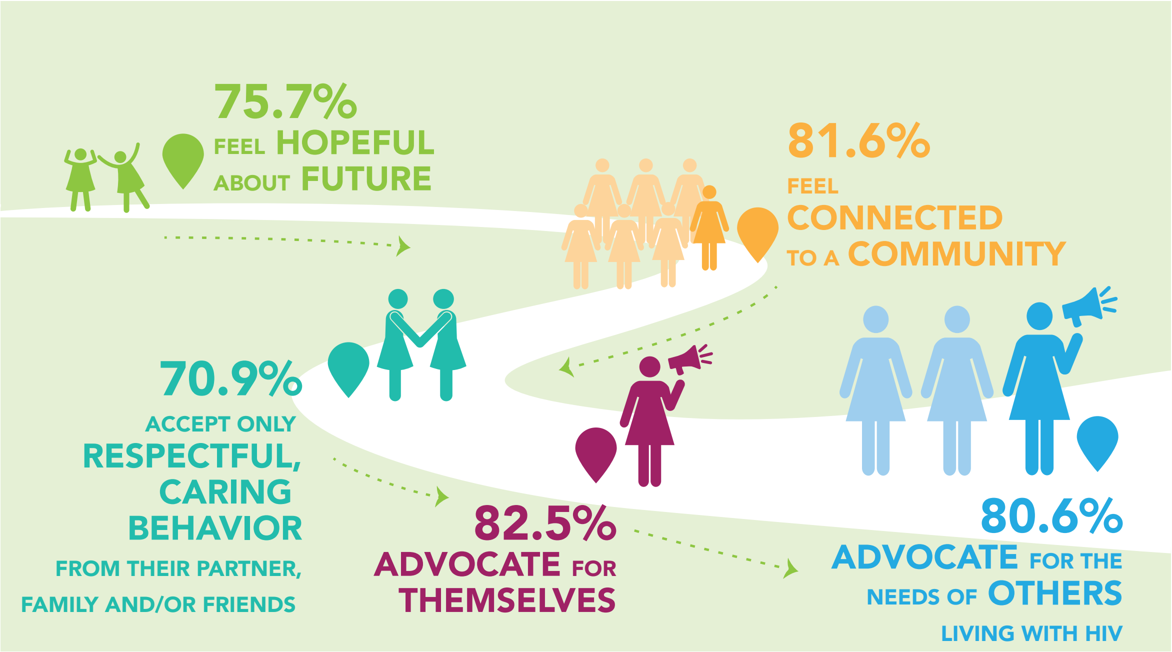
The Well Project's 2016 user survey data underscore the fact that women living with HIV around the world continue to face individual, interpersonal, and social-structural challenges to optimizing their health and well-being; and that they depend on The Well Project to provide the credible, up-to-date information and empowerment tools they need to advocate for themselves and to connect with and mobilize others. Happily, the vast majority of WLHIV who use The Well Project resources are engaged in HIV care, taking effective antiretroviral treatment, and communicating well with their primary-care providers. Unhappily, most have also experienced stigma and discrimination inside and outside of the healthcare system, violence and trauma in their personal lives and communities, and behavioral health issues that complicate their care. Survey responses make clear that the kinds of informational, educational, advocacy, and community-building tools offered by The Well Project support the resilience of these women and provide them with hope.

The 2016 user survey also demonstrates that for women (and men) living with HIV, there is more to their health, well-being, and quality of life than just achieving an undetectable viral load. Attention to behavioral health, social support systems, and environmental conditions is equally important for them and for the people who care for and love them. This holistic approach of addressing the whole person and needs of WLHIV is recognized and appreciated as a feature of The Well Project's programs and resources by the survey respondents.

This approach, which The Well Project undertakes by leveraging technology, often leads women living with HIV to experience an evolutionary process. First, upon discovering our online resources, they are imbued with a sense of hope as they realize they are not alone, and that others—like them—are not only living with HIV disease, but also thriving. Next, women become more engaged with other women in our community, reading and commenting on blogs, becoming bloggers themselves, and participating in educational and advocacy webinars. This participation in a supportive, empowered community can improve their self-esteem and decrease self-stigma, enabling them to accept only respectful and caring behavior from loved ones. From there is it a short step to advocating for themselves on a multitude of levels, and eventually seeking ways to advocate for others living with HIV—sometimes locally, regionally, nationally, and even internationally. While this process can take place over months or even years, such an evolution speaks to the significant impact The Well Project is having on women living with HIV around the world.

> ***"Online peer support is a goddess-send for me****, especially from/with other women living with HIV, regardless of what country they live in."*

Impact of The Well Project's Resources on Women Living with HIV



This survey feedback is only the latest in a long line of evidence of women becoming empowered by The Well Project's information, community, and advocacy resources. More often than not, our constituents then use what they've learned to empower others with the knowledge, hope, and confidence they have gained. The idea of building self-esteem, hope, and connectivity and then using it to empower others is key to The Well Project's mission.

The 2016 user survey provides ample feedback on what The Well Project should continue doing and how the organization can further improve, in order to best meet the needs of its constituencies. Moving forward, The Well Project will focus on deepening our impact by strengthening our resources and expanding their reach based on this feedback and with the assistance of our CAB, board of directors, partners, and users.

The Well Project's goals are lofty: we aim to become the premier global resource on women affected by HIV by providing accurate, current, culturally-relevant information to women living with and at risk for HIV. The organization is also committed to building a strong and engaged global network of women living with HIV. Finally, The Well Project is working to build leadership and advocacy capacity among women and girls affected by HIV. This survey demonstrates that the need for these resources continues to be profound. As an organization, The Well Project remains deeply committed to reaching women where they are with the information and support they need.

Together, we can change the course of the HIV epidemic...one woman at a time.