

The Well Project User Survey Report

2014



FINAL REPORT: The Well Project's 2014 User Survey

TABLE OF CONTENTS

Dedication.....	2
Thanks.....	2
Background.....	2
Methods	3
Findings.....	4
<i>Multiple Roles and Overlapping Identities</i>	6
<i>Use of The Well Project's Resources</i>	8
<i>Experiences Living with HIV/AIDS.....</i>	9
<i>The Impact of The Well Project.....</i>	10
<i>Perceptions of Barriers and Research Needs.....</i>	10
<i>Assessments of The Well Project's Resources.....</i>	11
<i>Participant Recommendations for The Well Project... </i>	11
Discussion.....	13
Recommendations and Next Steps	15
Conclusion.....	17

DEDICATION

The Well Project team and Board of Directors would like to dedicate the work described in this report to women and girls living with HIV around the globe who every day overcome enormous obstacles and face interpersonal and structural challenges, including gender-based violence, socio-economic inequalities, lack of access to education, institutional racism, overwhelming stigma, and more. We would like to recognize that despite these realities, these are the same women who organize our communities, advocate for access to healthcare and treatment, raise our families, and change policy and laws. We also want to dedicate our efforts to the millions of women who have died not only due to health complications from HIV, but also as a result of stigma and discrimination.

THANKS

We at The Well Project 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 would like to thank the 2014 Community Advisory Board members, Kate Borloglou, Jyoti Dhawale, Monica Johnson, Maria Mejia, Phiwe Mchunu, Abosede Olotu and Sonia Rastogi, for their invaluable contributions. We would also like to thank the advisors and reviewers who played critical roles in the development of the survey and analysis plans, including Dawn Averitt, Abby Charles, Vickie Lynn and Laurel Sprague. Finally, we would like to thank the supporters without whom our work would not have been possible; Abbvie, Bristol-Myers Squibb, Gilead Sciences, Janssen Therapeutics, Merck and ViiV Healthcare. 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. The Well Project leverages technology to improve health outcomes and increase quality of life for women and girls living with HIV by expanding access to HIV information and improving health literacy; providing community building and support;

“Since its founding, The Well Project has established itself as the premier online resource on women and HIV, both nationally and globally.”

engaging in advocacy and capacity development; and advancing the research agenda on women and HIV. We accomplish all of this work by disseminating accurate, useful and timely information about HIV/AIDS research, policy, prevention and care; creating and fostering forums that provide connection and mutual support among women living with HIV and those who care for and support them; and developing community capacity for advocacy around HIV/AIDS research, policy, prevention and care that is responsive and appropriate to the specific needs of women living with HIV/AIDS and their supporters.

In order to maximize The Well Project's effectiveness and continuously strengthen the impact of our programs, it is important that we understand how our resources and services are experienced, integrated and applied by those who utilize them. Past user surveys, for example, have shown us that for most individuals who access The Well Project's online resources, the primary goal is to secure accurate, relevant information about HIV disease and treatment. In the past, we have also been able to demonstrate the effectiveness of The Well Project's online resources in breaking down barriers to HIV testing and supporting women as they access care along each point of the HIV care continuum.

Each year, we develop and implement new survey questions in order to assess our reach and impact, and identify areas for improvement and enhancement. This report provides a descriptive analysis of findings from the 2014 online user survey, with a focus on the impact of The Well Project's online resources on users' health behaviors and quality of life. Questions in this survey focused on participants' experiences using The Well Project's online HIV information resources, social networking links and blog features. Survey participants were asked to evaluate the quality and utility of various dimensions of each of these features, to describe the impact of those online resources on their health behaviors and quality of life, and to provide recommendations to further develop those and other resources. It is our goal to use this survey to even better position ourselves to help women and girls improve their quality of life, move along the HIV continuum of care appropriately, and maximize their health outcomes.

METHODS

In order to develop the current survey, The Well Project's executive director, managing editor and communications consultant created a preliminary draft of the survey design and data gathering questions in the fall of 2014. Over a period of a few months, this draft was reviewed and commented on by The Well Project's founder and emeritus board member, a current board member, and six Community Advisory Board (CAB) members. Significant design input was also solicited from an incoming CAB member who is a Ph.D. student studying behavioral health. At all stages of development, feedback from both The Well Project team and previous survey participants was incorporated into the survey design in order to maximize clarity for survey users and accuracy and completeness of the data to be collected. The final versions of the questions were used to create an online survey using the Survey Monkey platform.

Beginning on November 2014, survey participants were recruited through online appeals to The Well Project users and networking efforts with community partners. Visitors to The Well Project's webpage were invited to complete the survey using a link embedded directly in the site and email invitations to complete the survey were included in monthly subscriber newsletters. Community partners were asked to disseminate the survey web link directly to their users, and the link was posted to multiple list serves to which women living with HIV might subscribe, including the ATHENA Network list serv and the Positive Women's Network. In addition, The Well Project's CAB members were encouraged to disseminate the survey link through social media, including posts on Twitter and Facebook, many of which were later re-tweeted by entities reaching large numbers of people living with HIV, such as The Body and POZ magazine. As incentive, users who completed the survey were entered into a raffle to receive one of 20 \$20 Amazon gift cards.

"It is our goal to use this survey to even better position ourselves to help women and girls improve their quality of life, move along the HIV continuum of care, and maximize their health outcomes."

Data collection began with the opening of the Survey Monkey web link, email invitations and website-based data collection in November of 2014 and continued through March of 2015. When users clicked on the link provided, the survey opened in Survey Monkey, and instructions and questions were presented in a page-by-page format, wherein users clicked "Next" at the bottom of each page to proceed to the next one. The opening page of the survey addressed its purpose, as well as consent, privacy and confidentiality issues for the user to consider. Users were then presented with 50 items that included closed-ended questions in yes/no and multiple

choice formats, Likert and other types of rating scales, and open-ended questions, focused on individuals' demography, experiences using The Well Project's online resources, and beliefs about the impact of using those resources on their health behaviors and quality of life. On the last page of the survey, users were asked to share final comments in an open-ended format and click "Submit" to send their survey responses to The Well Project.

As surveys were submitted and logged via Survey Monkey, members of The Well Project team monitored those submissions using Survey Monkey's administrative view and eliminated submissions that included no content, as well as duplicate submissions from individuals who completed the survey more than once. At the conclusion of data collection, the 20 promised \$20 Amazon gift cards were distributed via email to randomly selected survey participants. The Well Project team conducted a preliminary review of the data and ultimately decided to hire a research consultant to complete the final data analysis. A Ph.D. level social worker with both research and practice experience focused on women living with HIV/AIDS was hired for this purpose in June 2015.

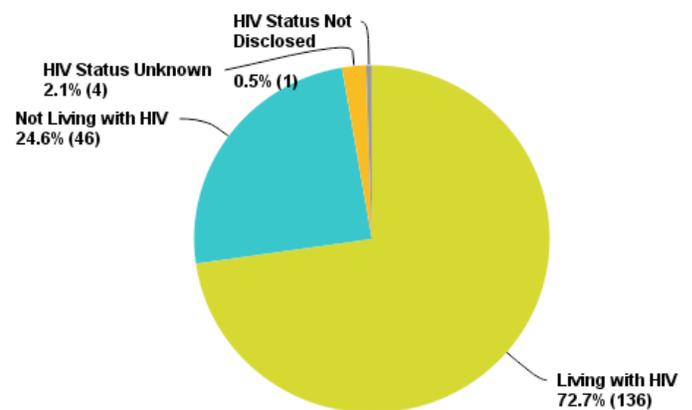
The consultant began data cleaning, processing and analysis in July 2015. The first stage of these processes involved eliminating cases that included no information beyond personal contact information and reviewing individual submissions to clarify conflicting responses related to HIV status and other important identifiers. In this way, the survey sample size was reduced from 213 to 187 unique cases for analysis purposes. In consultation with The Well Project team, the consultant next developed a plan for data analysis and summary reporting. It was determined that analysis would focus on (1) descriptive analysis of the survey participants, highlighting the interrelated identities of people living with HIV and service providers, (2) key information related to health status, engagement in care and experiences with HIV stigma among people living with HIV, (3) perceptions about barriers to viral suppression, ending the spread of

HIV and research needs focused on women and HIV, and (4) experiences using and sharing The Well Project's resources, the impact of resource use on health behaviors, relationships and quality of life, and recommendations for further development of The Well Project's resources and efforts.

FINDINGS

In order to develop a clear description of the participants and compare specific findings on the basis of participant characteristics, survey participants were asked to provide a variety of demographic information. These questions examined various aspects of individual identity, including HIV status, age, gender identity, sexual orientation, race/ethnicity, and country of residence. As presented in Figure 1, of the 187 survey participants whose responses are analyzed here, 72.7% (n=136) self-identified as individuals living with HIV, 24.5% (n=46) did not and 2.6% (n=5) indicated that they either did not know or did not wish to disclose their HIV status.

FIGURE 1.
Survey Participants' Self-Identified HIV Status



Comparing Survey Participants

Based on participants' responses to demographic questions, Table 1 presents information on aspects of identity for all 187 survey participants, as well as side-by-side comparisons of identity features based on participants' self-identified HIV-status.

TABLE 1. Identity Features of Survey Participants

Identity Feature	All		HIV+		HIV-	
	N = 187	%	n = 136	%	n = 46	%
Age						
20-34	44	23.5%	27	19.8%	15	32.6%
35-44	45	24.1%	30	22.1%	13	28.2%
45-54	58	31.0%	51	37.5%	7	15.2%
55 or older	40	21.4%	28	20.6%	11	24.0%
Gender						
Woman	139	74.4%	104	76.5%	35	76.0%
Man	44	23.5%	30	22.1%	11	24.0%
Transwoman	1	0.5%	1	0.7%	0	-
Transman	1	0.5%	0	-	0	-
Other	2	1.1%	1	0.7%	0	-
Sexual Orientation						
Heterosexual	131	70.1%	93	68.4%	36	78.3%
Gay, Lesbian or Queer	34	18.2%	27	19.9%	5	10.9%
Bisexual	19	10.1%	15	11.0%	4	8.7%
Other	3	1.6%	1	0.7%	1	2.2%
Race/Ethnicity						
Asian, East Asian or PI	13	6.9%	8	5.9%	4	8.7%
South Asian or Indian	6	3.2%	2	1.5%	4	8.7%
Black, African, African Descent	53	28.3%	41	30.1%	12	26.1%
Hispanic or Latino	9	4.8%	7	5.2%	1	2.2%
Middle Eastern or Arab	3	1.6%	1	0.7%	1	2.2%
Non-Hispanic White	87	46.5%	66	48.5%	20	43.4%
Multiracial/Other	16	8.5%	11	8.1%	4	8.7%
Global Geography						
Africa	26	13.9%	16	11.8%	10	21.7%
Asia, South Asia and East Asia	19	10.2%	11	8.1%	8	17.4%
Central America	3	1.6%	3	2.2%	0	-
Europe	7	3.7%	4	2.9%	2	4.4%
Middle East	1	0.5%	0	-	0	-
North America	130	69.5%	102	75.0%	25	54.3%
Oceania	1	0.5%	0	-	1	2.2%

Table 1 reveals that both participants who self-identified as living with HIV and those who did not are predominantly female (76.5% and 76.0%, respectively) and are most likely to identify either as Non-Hispanic white (48.2% and 43.4%, respectively) or as black, African American, or of African descent (30.1% and 26.1%, respectively).

Table 1 also reveals that participants who self-identified as living with HIV and those who did not vary somewhat in terms of age, sexual orientation, and global geography. Participants living with HIV were most likely to be between the ages of 45 and 54, whereas those who are not were most likely to be between the ages of 20 and 34. Although the majority of both sets of participants (68.4% and 78.2%, respectively) identified as heterosexual, those living with HIV were somewhat more likely to identify as gay, lesbian, queer or bisexual than those who were not. Finally, although the majority of both sets of participants (75.0% and 54.3%, respectively) hailed from North America, those not living with HIV were more likely to be located outside of North America, specifically in Africa, Asia, South Asia or East Asia.

The survey's demographic questions also asked participants to provide information about their life circumstances, including housing status, residential setting, level of education, employment status and annual income. Table 2 presents this information for all 187 survey participants, as well as side-by-side comparisons of life circumstances based on participants' self-identified HIV-status. Table 2 reveals

“All participants were asked to identify their primary, secondary and tertiary roles in relation to their use of The Well Project’s resources.”

that both participants who self-identified as living with HIV and those who did not are most likely to live in urban settings (54.4% and 58.6%, respectively). However, the life circumstances of these participants differ in many other important ways: those living with HIV were more much likely than those who are not to have no permanent housing, to live in supported housing, assisted living or subsidized housing, and to depend on family and friends for housing (33.9% and 6.5%, respectively), while participants not living with HIV were far more likely to rent or own their housing (93.5% and 66.1%, respectively).

Table 2 also reveals important differences in education, employment and income between these two groups of participants. Those living with HIV were most likely to have attended some college or earned a two-year degree (30.1%), whereas those not living with HIV were most likely to possess a graduate degree (45.6%). Participants living with HIV were far less likely to be employed full time for wages than those who were not (24.3% and 67.4%, respectively).

Those living with HIV and were also much more likely to be unable to work due to medical disability (24.3% and 0.0%, respectively). Predictably, participants living with HIV were also much more likely than those not living with HIV to report annual incomes of less than \$20,000 per year (34.5% and 0.0%, respectively).

Multiple Roles and Overlapping Identities

In order to fully understand survey participants' motivations and needs when engaging with The Well Project's online resources, all participants were asked to identify their primary, secondary and tertiary roles in relation to their use of The Well Project's resources. Of note, among the 136 survey participants who identified themselves as people living with HIV, only 79.4% (n=108) identified being a person living with HIV as their primary role in their interactions with The Well Project's resources. The balance identified their primary role as that of peer educator or advocate (5.8%, n=8), HIV/AIDS educator (3.6%, n=5), volunteer, coach or provider of other forms of support (2.9%, n=4), employee of AIDS service organizations or related CBO (2.2%, n=3), health care provider (1.1%, n=1) or friend or family member of a person living with HIV (1.1%, n=1).

In addition, most participants who identified themselves as individuals living with HIV also identified important secondary and tertiary roles beyond their own needs as people living with HIV in their use of The Well Project's resources. For example, 37.5% (n=51) of individuals living with HIV also identified themselves as peer educators

Table 2. Life Circumstances of Survey Participants

	All		HIV+		HIV-	
Life Circumstance	N = 187	%	n = 136	%	n = 46	%
Housing Status						
No Permanent Housing	7	3.7%	5	3.7%	0	-
Supported/Assisted Living	11	5.9%	9	6.6%	1	2.2%
Subsidized Housing	17	9.0%	17	12.6%	0	-
Depend on Family/Friends	17	9.0%	15	11.0%	2	4.3%
Rent Housing	80	42.8%	55	40.4%	23	50.0%
Own Housing	55	29.4%	35	25.7%	20	43.5%
Residential Setting						
Rural	39	20.9%	30	22.1%	8	17.4%
Suburban	43	23.0%	32	23.5%	11	24.0%
Urban	105	56.1%	74	54.4%	27	58.6%
Level of Education						
Less than High School	11	5.9%	8	5.9%	1	2.2%
High School or Equivalent	37	19.8%	32	23.5%	4	8.7%
Some College/2 Year Degree	47	25.1%	41	30.1%	4	8.7%
College/4 Year Degree	46	24.6%	30	22.0%	16	34.8%
Graduate Degree	46	24.6%	25	18.4%	21	45.6%
Employment/Work Status						
Employed Full Time	64	34.2%	33	24.3%	31	67.4%
Employed Part Time	28	15.0%	22	16.1%	4	8.7%
Self Employed	16	8.6%	12	8.8%	4	8.7%
Unemployed/Seeking Work	13	7.0%	10	7.4%	1	2.2%
Disabled/Unable to Work	33	17.6%	33	24.3%	0	-
Retired	15	8.0%	13	9.6%	2	4.3%
Volunteer (only)	11	5.9%	7	5.1%	3	6.5%
Student (only)	4	2.1%	3	2.2%	1	2.2%
Homemaker	3	1.6%	3	2.2%	0	-
Annual Income (U.S. Residents Only)						
\$0 - \$19,999 per year	50	26.7%	47	34.5%	0	-
\$20,000 - \$49,999 per year	48	25.7%	37	27.2%	11	23.9%
\$50,000 - \$99,999 per year	26	13.9%	16	11.8%	10	21.7%
\$100,00 or more per year	7	3.7%	3	2.2%	4	8.7%
N/A/Live outside of U.S.	56	30.0%	33	24.3%	21	45.7%

and advocates and 36% (n=49) also identified themselves as HIV educators. In addition, 21.3% (n=29) also identified themselves as employees of AIDS service organizations or related CBOs, 13.9% (n=19) as friends or family members of other people living with HIV, and 10.2% (n=14) as health care providers.

Virtually all of the survey participants who did not identify as people living with HIV indicated that they engage with The Well Project's resources primarily in the context of addressing the needs of people living with HIV.

Among those 46 individuals, 39.1% (n=18) described themselves as current or past employees of AIDS service organizations or related CBOs, 21.7% (n=10) as friends or family members of people living with HIV, 13% (n=6) as health care providers, 13% (n=6) as HIV/AIDS educators, 4.3% (n=2) as advocates, 4.3% (n=2) as public health officers/administrators and 2.1% (n=1) as a funder. When asked to identify the specific roles they played in health care provision, eight identified themselves as social workers, five as nurses, three as case managers and community workers, and two as physicians.

Understanding these complex identities and overlapping roles is important when interpreting the rest of the survey's findings. This overview speaks to the critical contextual fact that most survey participants seek and use HIV information, connect to others in the community, and educate and advocate for others in the course of fulfilling multiple personal and professional roles. As such, it is critical to emphasize that most participants report using The Well Project's resources to address personal needs related to their own health, the health of friends and family members, or both, in addition to using those resources to address professional needs related to the provision of health care and supportive services to others living with HIV.

Use of The Well Project's Resources

All survey participants were asked to describe the frequency and duration of their use of The Well Project's online resources. When asked how long they had been using these resources, 23.5% (n=27) of responding survey participants reported that they had been doing so for six months or less, 24.3% (n=28) for between six and 12 months, 39.1% (n=45) for between one and five years, and 13.0% (n=15) for five years or more. When asked about the frequency of their use of these resources, 16.3% of responding participants (n=29) reported that they use them a few times per year, 18.0% (n=32) reported using them once per month, 16.9% (n=30) reported using them once per

week, 19.1% (34) reported using them several times per week and 7.3% (13) reported using them every day.

Participants were also asked to identify the single most important reason for their use of The Well Project's online resources, as well as the most common purpose or application of that use. The most commonly identified reason for using The Well Project's online resources, reported by 40.5% (n=51) of responding survey participants, was to increase knowledge of HIV disease and its treatments. The

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second most commonly identified reason for use, cited by 19.8% (n=25) of participants, was to connect with other women living with HIV and the third, cited by 16.7% (n=21) of participants, was to learn how to advocate and obtain skills to help themselves and others. In line with these finding, 54% (n=68) of responding participants indicated that they most often use The Well Project's online resources for the purpose of addressing their own needs. The second most commonly reported purpose, at 15.9% (n=20), was to build educational programs or resources for other organizations, the third, at 8.7% (n=11), was to help patients or clients, and the fourth, at 7.1% (n=9), was to help friends or loved ones.

Survey participants were also asked about their patterns of sharing The Well Project's online resources, including the number of other people with whom they have shared them and which materials they most often share. Of note, only 5.5% (n=7) of responding participants indicated that they had never shared any of The Well Project's online resources. 38.9% (n=49) reported that they had shared these resources with between one and 10 individuals, 29.4% (n=37) with between 25 and 100 individuals

and 24.6% (n=31) with 500 individuals or more. Several participants commented that they share these resources through social media such as Facebook and Twitter, as well as public presentations. A few participants also commented that although they have not yet shared any of The Well Project's resources with others, they intend do so in the future. Responding participants reported that they were most likely to share information and articles from The Well Project website (28.6%, n=36), followed by blogs, stories and information from *A Girl Like Me* (23.8%, n=30), and news and reports from the Women's Research Initiative (15.9%, n=20).

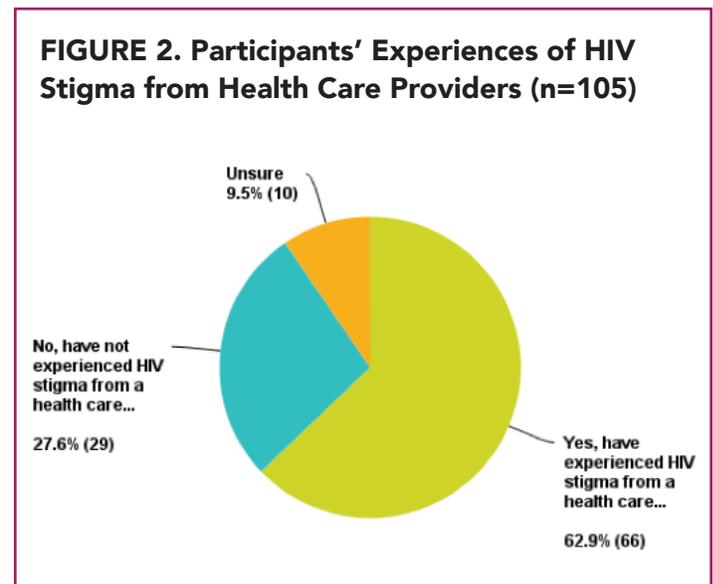
Experiences Living with HIV/AIDS

In order to assess their needs and experiences accurately, participants who self-identified as people living with HIV were asked to provide information about their experiences living with HIV disease and with HIV treatment. Through these questions, we learned that responding participants had been aware of their HIV status for an average of 15 years and eight months and had been taking HIV medications for an average of 11 years and six months. 80% of responding participants (n=100) reported that their viral loads were undetectable. Among responding participants who reported that they were not taking HIV medications (n=17), the most commonly reported reasons were that it was not needed (29.4%, n=5), followed by lack of transportation or difficulty getting treatment (23.5%, n=4), lack of access to health care (17.6%, n=3), and HIV stigma (17.6%, n=3). When asked about timing for treatment onset, 51.3% (n=58) of responding participants indicated that a person should begin HIV medications as early as possible after an HIV diagnosis.

When asked whom they considered their primary care provider in managing HIV, 59.6% (n=62) of responding participants identified their HIV specialist, followed by 18.3% (n=19) who named themselves. When asked about clinical trial participation, 56.9% (n=58) of responding participants indicated that they had taken part in at least one clinical trial. Many commented

that these had been positive experiences, but others expressed frustration with their lack of access to trials, and with their inability to get information about or qualify for them. Alternately, one participant commented: "I've never qualified for a study that I was aware of. Also, I'm a bit fearful with my other obligations as a mother of a young child. Being on medicine, which keeps me healthy and virally suppressed, seems wonderful. I'm almost scared to mess that up."

Regrettably, HIV stigma appeared to remain a significant presence in the lives of survey participants living with HIV. As presented in Figure 2, 62.9% (n=66) of these responding participants reported experiencing HIV stigma or discrimination from health care providers.



The providers most commonly associated with these experiences were nurse practitioners and registered nurses (39.3%, n=24), hospital staff (34.4%, n=21), emergency room providers (32.8%, n=20), primary care providers (31.1%, n=19) and dentists (26.2%, n=16). These participants also reported experiencing HIV stigma and discrimination outside of health care settings, most frequently from friends (42.9%, n=42), family (40.8%, n=40), dates, (39.8%, n=39), places of work/employers (30.6%, n=30), and in online forums/

chat rooms (19.4%, n=19). In addition, 27.2% (n=28) of these participants reported that their partners, spouses, children or other family members had experienced HIV stigma or discrimination because of their HIV status.

The Impact of The Well Project

In order to assess the impact of use of The Well Project's resources on the health and wellbeing of HIV-positive users, participants who self-identified as people living with HIV were asked to assess changes in their own behavior before and after use of those resources. When asked to assess the impact of using The Well Project's resources on their self-care behaviors, 53.5% (n=46) of responding participants living with HIV indicated that since beginning to use these resources, they were "more likely" or "much more likely" to engage in better overall self-care, including moving more, eating better, and getting enough sleep. In addition, 29.1% (n=25) indicated that they were "more likely" or "much more likely" to take HIV medications daily as prescribed and 28.0% (n=24) indicated that they were "more likely" or "much more likely" to see health care providers regularly or stay connected to care.

Assessing the impact of using The Well Project's resources on their communication and engagement with health care providers, 46.5% (n=40) of responding participants living with HIV indicated that since beginning to use these resources, they were "more likely" or "much more likely" to talk with health care providers about how HIV impacts women differently than men. In addition, 43.0% (n=37) indicated that they were "more likely" or "much more likely" to communicate better with their health care providers and 33.7% (n=29) indicated that they were "more likely" or "much more likely" to talk with their health care providers about their HIV medication options.

Perhaps most significantly, responding participants living with HIV indicated that utilizing The Well Project's resources had improved their quality of life in significant ways. Specifically, 58.1% (n=50) of these participants reported that since beginning to use these

resources, they were "more likely" or "much more likely" to feel more hopeful or positive about the future. In addition 55.8% (n=48) reported that they were "more likely" or "much more likely" to feel more confident or experience greater self-esteem, and 38.4% (n=33) reported that they were "more likely" or "much more likely" to feel less alone or less isolated.

Perceptions of Barriers and Research Needs

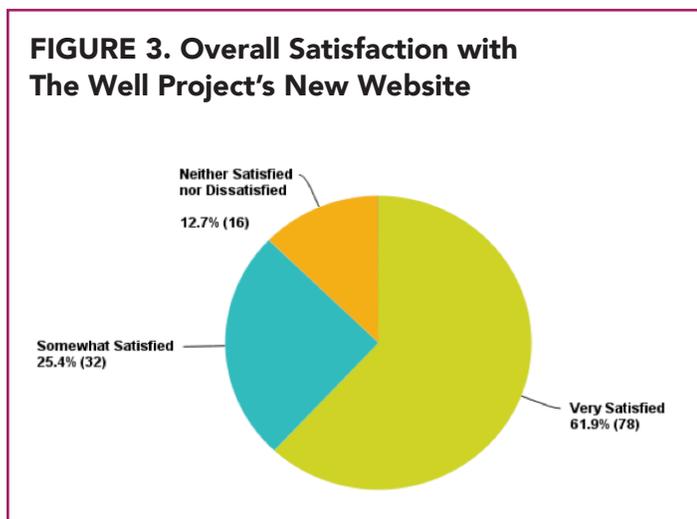
All survey participants were asked to identify the major barriers to combatting HIV and addressing the needs of women living with HIV. When asked to identify the biggest barriers to people in their communities achieving viral suppression, 59.4% (n=82) of responding survey participants identified HIV-related stigma, 47.1% (n=65) identified lack of

58.1% of participants reported that since beginning to use The Well Project's resources, they were more likely to feel more hopeful and positive about the future.

funds/cost of treatment, and 27.5% (n=38) identified drug and alcohol use. When asked to identify the single biggest barrier to ending the HIV epidemic in their home countries, 54.5% (n=66) of responding participants once again identified HIV-related stigma. Many participants also offered comments about the critical need to address social inequities based on race, gender, sexual orientation and socio-economic status, and the impact of for-profit health care models on medication costs. Finally, when participants were asked to identify areas related to women and HIV that they believe require more research and attention, they identified a variety of interrelated issues including sex, dating and relationships, stigma and discrimination, sex and gender-based issues in HIV treatment and medication use, pregnancy, aging and menopause, substance abuse, interpersonal violence, and mental health issues.

Assessments of The Well Project's Resources

When asked to assess their overall satisfaction with The Well Project's new website, participants provided very favorable feedback overall. As seen in Figure 3, fully 61.9% (n=78) of responding participants reported that they were "very satisfied" with the new website, 25.4% (n=32) indicated that they were "somewhat satisfied," and no participants indicated that they were "somewhat dissatisfied" or "very dissatisfied" with it.



Participants were also asked to rate the value of six different elements of The Well Project's online offerings, including articles and fact sheets on HIV, the *A Girl Like Me* blog, the "Get Connected" social features (including groups, forums and chat functions), The Well Project Update e-newsletter, news and reports from the Women's Research Initiative on HIV/AIDS, and news and information posted to The Well Project's Facebook and Twitter accounts. For each of these features, between 82.0% and 99.2% of responding participants rated the materials in question as "extremely valuable," "somewhat valuable" or "valuable." The resources most commonly identified as "extremely valuable" were articles and fact sheets on HIV (68.9%, n=84), news and reports on the WRI (59.8%, n=73) and the *A Girl Like Me* blog (52.9%, n=64). When asked to

identify which newly introduced feature of The Well Project's redesigned website they enjoyed most, 45.2% (n=57) of responding participants selected the HIV information features, 21.4% (n=27) identified the integration of *A Girl Like Me* into the website, and 13.5% (n=17) identified the new design and layout of the website.

Participant Recommendations for The Well Project

All survey participants were asked a series of questions about their recommendations to build on and improve The Well Project's online resources. When asked to suggest topics for new articles and/or fact sheets, participants offered a variety of ideas. The most frequently identified topics focused on HIV research, statistics and medication, with special interest in information about PrEP and its side effects and progress toward an HIV cure. A number of participants suggested topics related to dating and disclosure, especially in the context of sero-discordant relationships. Others requested honest information about safer sex needs for those with undetectable viral loads for both patients and providers, and relationship-oriented information for partners not living with HIV.

Other participants suggested topics related to long-term survivors, HIV and aging, and menopause. Different participants suggested topics related to HIV outside of the United States, people of varied ethnicities, gender identities and sexual orientations, and children of people living with HIV. Finally, many participants suggested topics related to HIV stigma, disclosure, family issues, and how women living with HIV can share their experiences and support one another. One participant suggested creating a "HOPE section" focused on providing follow-up information about individuals who have previously been featured in The Well Project's media.

Survey participants were also asked what might encourage them to use The Well Project's website more frequently. The most common response to this

question, by far, was that participants would visit the website more frequently if they simply had more time to do so and/or had more consistent access to the internet away from the workplace. However, a number of participants also suggested that they might do so if prompted by email alerts about new posts, updates or blogs. Others noted that since they use social media more than they visit websites, more posts to and links through Facebook, Twitter, Instagram and other social media platforms would bring them into more frequent contact with The Well Project's resources. Several participants indicated that they would visit the site more often if they saw more frequent updates to blogs, HIV treatment information and updates, and news/current events items. Others suggested that they would be encouraged by seeing greater diversity among *A Girl Like Me* bloggers in relation to ethnicity, age, sexual orientation and gender identity.

Other participants suggested that they would visit The Well Project website more frequently if it offered more webinars, newsletters and opportunities for real time chat between women living with HIV as well as their partners. In line with our expectations of users' desire for interactive features, survey participants were also asked specifically which among a list of website features they thought would be most useful to their communities in facilitating social interaction between women living with HIV. In response to this question, 30.3% (n=33) of responding participants identified message boards, 29.4% (n=32) identified "Ask the Expert" forums, and 21.1% (n=23) indicated webinars and/or conference calls with *A Girl Like Me* bloggers.

Survey participants were also asked whether or not they had any interest in opportunities for increasing their treatment advocacy skills and/or skills that might help them publicly support or recommend HIV-treatment related policies. 80.2% (n=101) of responding participants indicated that they would be interested in such opportunities. Participants were then asked about the treatment advocacy training

formats in which they would be most interested. 68.0% (n=66) of responding participants indicated that they would be interested in online courses, 54.6% (n=53) indicated that they would be interested in on site/in-person trainings, 48.5% (n=47) indicated that they would be interested in live webinars and 41.2% (n=40) indicated that they would be interested in video trainings.

"Survey participants expressed gratitude for The Well Project's presence, work, content, commitment to and genuine support of women living with HIV."

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Finally, as a part of The Well Project's active solicitation of input from online resource users, survey participants were given the opportunity to provide any other suggestions for improvement of The Well Project's resources. In line with other findings presented here, one of the most frequent suggestions made was to increase opportunities for real time interaction with *A Girl Like Me* bloggers, CAB members and other users for purposes of social support, connection and information and resource sharing. Another common suggestion was that The Well Project should pursue a larger presence on and greater integration with social media platforms like Facebook, Twitter and Instagram. Other specific suggestions included creating new sections of the website for FAQ question and answer interactions with experts, employment connections, dating profiles, and recipe and nutrition information exchanges. More global suggestions included adding more Spanish language content, more videos and photos, and creating available archives of past webinars and presentations.

When given the opportunity to provide any additional comments, participants offered a variety of thoughts and observations, the most common of which was gratitude for The Well Project's presence, work, content, commitment to and genuine support of

women living with HIV. As one participant wrote, “I love this website, it helped me a lot in terms of understanding HIV as a woman and how to live a positive lifestyle.” Another thanked The Well Project specifically for “bringing information to our door step” and yet another simply wrote, “Thank you for a website for women!!!” Other participants took this opportunity to comment on unexpected developments in their HIV journeys. In these narratives participants reflected on being faced with health issues related to aging that had once seemed irrelevant because of an HIV diagnosis, and being well enough to return to work after many years of receiving disability benefits but not being able to afford to do so because of the cost of HIV medications.

“Feedback provided through this survey represents the experiences of an extremely diverse group of individuals.”

Along with these expressions of thanks and reflections on personal journeys, some participants offered general suggestions related to The Well Project’s website. These included, once again, increasing The Well Project’s social media presence and building opportunities for empowering and connecting women living with HIV, especially through efforts to connect advocates and leaders in this arena. Other participants suggested offering more resources focused on girls and women in developing nations, including updates on the rights of people living with HIV, policy agendas focused on women and HIV and opportunities for sustainable economic development. A number of participants remarked on the potential for The Well Project to bring knowledge, information and emotional support to people across the globe. Reflecting on her own experiences and those of other women, one participant noted “I feel I’ve been very fortunate in my struggle with HIV; I’ve had a lot of support from family and friends and continuous

access to care. It saddens me greatly that many others with this condition do not have similar support.”

DISCUSSION

In reviewing the survey data, several issues emerge that need to be considered when interpreting the findings presented here. The first is that the feedback provided through this survey represents the experiences of an extremely diverse group of individuals who vary widely in age, gender expression, sexual orientation, race/ethnicity and geography, as well as in relation to their life experiences with education, employment, income and housing. The accessible nature of The Well Project’s online resources means that survey participants include physicians practicing in East Asia and Pacific islands, boarding school students in Africa, and parents living in isolated areas of the southeastern United States. These survey participants include individuals who identify themselves as not having stable places to live, as well as individuals who earn more than \$150,000.00 U.S. per year. This variety of experiences lends richness and diversity to the information provided but also means that there are sometimes limited areas of consensus in relation to issues of concern.

It’s also critical to remember that participants’ responses are colored by their varied reasons for accessing The Well Project’s resources. Many users identified their main directives as seeking information, connection with others and empowerment in the context of addressing their own HIV-related needs. Many more are focused both on addressing their own health and wellness needs and meeting the needs of other people living with HIV whom they serve through volunteering, paid employment and family caregiving. Finally, still another subset of survey participants responded to the questions presented from the perspective of professionals who provide medical care and other services to people living with HIV, those who conduct research, enact policy and provide funding for HIV programs, and friends and family members who provide care and

support to individuals living with HIV. Once again, these varying orientations in relation to resource use provide a rich and diverse range of perspectives on The Well Project's offerings, but may not always lend themselves to consensus around a variety of issues.

Another important issue is that among survey participants who identified themselves as individuals living with HIV there is significant variance in the amount of time that has elapsed since their HIV diagnosis, their level of engagement in HIV care and their level of knowledge about HIV care protocols. There is even wider variance in the self-

“There is a widespread belief among women living with HIV that using The Well Project’s resources has positively influenced their self-care behaviors, communication and engagement with healthcare providers and quality of life in significant ways.”

reported duration and frequency of their use of The Well Project's resources. Thus, some participants' responses to questions about The Well Project's resources and the impacts of using those resources represent the experiences of veterans of many personal and professional battles against HIV. Others represent the perspectives of individuals who may be in the very early stages of their efforts to gather information about HIV, seek appropriate care, connect to others living with HIV and identify and advocate for their HIV-related needs.

One central and critical finding presented here is that among survey participants who represent The Well Project's target users, women living with HIV, there is widespread belief that using The Well Project's resources has positively influenced their self-care behaviors, communication and engagement with health care providers and quality of life in significant ways. A majority of these participants reported that since beginning to use The Well Project's resources, they were “more likely” or “much more likely” to

engage in a variety of positive health behaviors. Specifically 60.8% (n=42) reported being more likely to engage in better overall self-care (defined as moving more, eating better and getting enough sleep), 55% (n=38) reported being more likely to talk with their health care providers about gender-specific aspects of HIV and HIV treatment, and 53.9% (n=34) reported being more likely to communicate better with their health care providers in general.

In line with these findings, a majority of survey participants who identified themselves as women living with HIV also reported that since beginning to use The Well Project's resources, they were “more likely” or “much more likely” to experience enhanced quality of life in various ways. Specifically, 67.7% (n=46) reported being more likely to feel confident and experience greater self-esteem and 72.3% (n=47) reported being more likely to feel hopeful or positive about the future. In addition, almost half of these participants, 44.3% (n=31) reported that they were less likely to feel alone or isolated.

Another critical issue that emerges from these findings is that participants living with HIV continue to experience unacceptably high levels of HIV stigma. A majority of these participants report experiencing stigma in the course of accessing health care, and their comments indicate that these experiences occur in the context of accessing primary care, HIV care, emergency care, dental care and orthodontic care, as well as health care coverage and benefits. In addition, many participants' comments provide descriptions of experiences with HIV stigma that have occurred in the course of interactions with friends, family members and romantic partners, as well as in the workplace, at school, at church and through online social forums. A number of other participants made a point of adding comments expressing that they have not experienced HIV stigma, only because they are not “out” about their HIV status, explaining that they have either not revealed their HIV status to anyone or have revealed it only to a few key individuals as necessary for care and support purposes.

The issue of HIV stigma also emerged as predominant when participants were asked about barriers to achieving viral suppression and ending the HIV/AIDS epidemic in their home countries. The majority of all participants and of participants living with HIV identified HIV stigma as the single most important barrier to both of these goals. In line with these concerns, many participants' responses to open-ended questions highlight the belief that more needs to be done to reduce the fear and prejudice that fuel HIV stigma. At the same time, many participants commended The Well Project specifically for its efforts to combat stigma and the processes and issues that underlie it. Of note, one participant commented, "I personally think we as women can help 'turn the tide' on HIV/AIDS related stigma. We can lead the change from talking about HIV in terms of segregated populations.... Instead talk about, as the name says, HUMAN immunodeficiency virus. That's only way we will truly get rid of stigma."

"Many participants commended The Well Project specifically for its efforts to combat stigma and the processes and issues that underlie it."

Another critical finding is the heavy emphasis survey participants place on the practice and value of information sharing in the context of connecting with others. The need to connect and share information is raised repeatedly by survey participants throughout this survey: It is identified as a primary reason for using The Well Project's resources, as a determinant of the relative value participants assign to specific features of The Well Project's offerings, as well as of which features participants use most frequently. Among survey participants who self-identify as women living with HIV, "connecting with other HIV-positive women and feeling less isolated" is identified as the single most important reason to use The Well Project's resources.

The need to forge connections among survey participants appears to be driven in large part by the desire to exchange information, resources and support. Indeed, when women living with HIV were asked about their patterns of sharing The Well Project's online resources, 41.0% (n=32) reported that they had shared these resources with between one and 10 individuals, 23.1% (n=18) reported sharing with between 25 and 100 individuals and 29.5% (n=23) reported sharing with 500 individuals or more. This distribution of sharing patterns appears to reveal high levels of social media use among women living with HIV, specifically. Indeed, a number of these participants commented that because they share The Well Project's resources through social media such as Facebook, Twitter and Instagram, they have little way of knowing exactly how many people they have actually shared them with.

This focus on connection and information sharing also underlies many of the ideas and suggestions offered by survey participants for further development of The Well Project's online presence. The Well Project's very existence as an online medium is intended to support our goal of helping women living with HIV connect with one another, and this underpins our larger goal of facilitating the exchange of information, resources and support among these women. Feedback from survey participants, however, emphasized that The Well Project should build on the strengths of its current online resources by further integrating them with multiple forms of social media. These comments suggest that greater integration with Facebook, Twitter and Instagram would help maximize opportunities for information sharing and increase both the depth and breadth of efforts to identify new and emerging needs among The Well Project's users.

RECOMMENDATIONS AND NEXT STEPS

The mission of The Well Project is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls. Based in part on the assessments and recommendations

identified through this survey, we have developed a strategic plan that builds on our strengths as an online presence and will both reinforce and increase the reach of our information dissemination efforts. Over the next two years, this plan will enable us to focus our energy and resources on activities that address identified gaps in our services and add value to our overall response to the HIV/AIDS crisis.

The first key objective of our strategic plan is to become the global leader in online resource provision around women and HIV by providing accurate, current and culturally relevant information to women at risk for and living with HIV, as well as those who care for them. In order to enhance the reach and content of The Well Project's online offerings, we will continue to update our existing content and develop new content based on newly identified gaps and needs. We plan to invest in various forms of outreach and partnerships to increase linkages, referrals to and use of The Well Project's resources among AIDS Service Organizations, CBOs, women's organizations, and health care provider associations. We also intend to translate key elements of our web content into Spanish, as well as assess needs and opportunities for translation of these materials into additional languages.

In multiple areas of this survey, numerous participants emphasized the importance of using social media to build community, support and information sharing capacities among women living with HIV. Accordingly, another objective of our strategic plan is to continue to build and enhance a strong and engaged global network of women living with HIV using these media. We are working to develop and enhance The Well Project's social media presence in a variety of ways, including increasing the number and diversity of *A Girl Like Me* bloggers, expanding the reach of our blogs through additional blog platforms, and adding new dedicated resources to our social media platforms.

Participants in this survey were also asked to

provide feedback on the idea of developing and implementing a treatment advocacy and leadership training program at The Well Project. Participant responses revealed high levels of interest in this endeavor and as such, the final objective of our strategic plan is to build leadership and advocacy capacity among women and girls affected by HIV. The development and implementation of *A Place at the Table: WATCH!* (Women's Advocacy Training Coalition on HIV) launched in 2015 with the goal of enhancing health literacy, capacity building and treatment advocacy skills among women and girls living with HIV.

"Participant responses revealed high levels of interest in treatment advocacy and leadership training."

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To achieve this goal, The Well Project developed a curriculum comprised of fact sheets and slide sets for an eight-week online treatment advocacy training series and provided scholarships for women to attend key scientific conferences. We are also working to create mentoring partnerships with relevant organizations and individuals, and have begun to identify and train "Ambassadors" from different countries to engage with relevant organizations in their respective locales in order to incubate future leaders among women living HIV.

Finally, The Well Project developed a set of interrelated strategies intended to address our programmatic research needs over the next several years. The first is to design a new user survey in collaboration with proven partners and our CAB, with an eye to improving the reliability and validity of the data collected on user experiences and program impacts. Through the improvement of our item design, participant recruitment and data collection methods, we will be able to evaluate and report on the reach and impact of our program in relation to user demographics and behavioral changes associated with the HIV continuum of care.

These efforts will also help us achieve greater racial/ethnic balance among future survey participants, increase the user friendliness of our survey for non U.S.-based participants, and collect additional data on women-specific issues, in support of future initiatives conducted through strategic partnerships. In addition, we are also in the process of developing an analytics system that will help us better understand the emerging needs of our users by tracking their searches and web use preferences.

CONCLUSION

Through all of these planned activities, The Well Project will continue to provide women and girls living with and at risk for HIV with the tools necessary to optimize their emotional, mental and physical health and wellness. By providing expanded online resources for HIV information, support and social interactivity, we will help improve these women's health literacy, increase their engagement in health care, and enhance health-related behaviors like patient-provider communication and medication adherence. By doing so, we hope to ultimately both improve the quality of life of and increase the number of women living with HIV who are virologically suppressed. We will continue to prioritize reaching African-American women, Latinas, young women, transgender women and women in high-impact regions with our services.

By providing leadership training and capacity building around HIV treatment advocacy, we will fill an existing gap and establish a strong network of women living with HIV who are empowered and trained to voice the needs and experiences of their communities. We believe this represents an important opportunity to create a "place at the table" and effect change to existing guidelines, research and policies. This initiative will also ensure that the voices of women living with HIV are included among industry, academic and government researchers in discussions of the factors that inhibit women's engagement along various points of the HIV care continuum.

By implementing new methods to assess The Well Project's reach, impact and areas for potential growth, we expect to increase both the impact of our programming on users' health and quality of life and the collection of women-specific data critical to the development of research and program initiatives.

Through the use of technology and new social media platforms, The Well Project has revolutionized the availability and accessibility of important, relevant information and has created a support community designed specifically for women and girls living with HIV. The evolution of technology and the new and emerging ways in which people access information and connect to one another have dramatically increased the reach of our resources, and the new "sharing economy" of information has exponentially expanded our impact. Over the coming years, we

"The Well Project has revolutionized the availability and accessibility of important, relevant information and has created a support community designed specifically for women and girls living with HIV."

will continue to help women and girls living with HIV progress along the HIV continuum of care in order in order to improve both their health and quality-of-life outcomes. Using the feedback provided by our users, we will continue to fine tune our efforts to provide information, support and advocacy that help women make positive changes in their lives and empower them to share information and help others.