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## Patient acceptability and usability of a self-administered electronic patient-reported outcome assessment in HIV care: relationship with health behaviors and outcomes

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### Abstract

We assessed acceptability/usability of tablet-based patient-reported outcome (PRO) assessments among patients in HIV care, and relationships with health outcomes using a modified version of the 6-item Acceptability E-Scale (AES) within a self-administered PRO assessment. Using multivariable linear regression, we measured associations between patient characteristics and continuous combined AES score. Among 786 patients (median age=48; 91% male; 49% white; 17% Spanish-speaking) overall mean score was 26/30 points (SD: 4.4). Mean scores per dimension (max 5, 1=lowest acceptability, 5=highest): ease of use 4.7, understandability 4.7, time burden 4.3, overall satisfaction 4.3, helpfulness describing symptoms/behaviors 4.2, and enjoyability 3.8. Higher overall score was associated with race/ethnicity (+1.3 points/African-American patients (95% CI:0.3-2.3); +1.6 points/Latino patients (95% CI:0.9-2.3) compared to white patients). Patients completing PROs in Spanish scored +2.4 points on average (95% CI:1.6-3.3). Higher acceptability was associated with better quality of life (0.3 points (95% CI:0.2-0.5)) and adherence (0.4 points (95% CI:0.2-0.6)). Lower acceptability was associated with: higher depression symptoms (-0.9 points (95% CI:-1.4 to -0.4)); recent illicit opioid use (-2.0 points (95% CI:-3.9 to -0.2)); multiple recent sex partners (-0.8 points (95% CI:-1.5 to -0.1)). While patients endorsing depression symptoms, recent opioid use, condomless sex, or multiple sex partners found PROs to be less acceptable, overall, patients found self-administered, tablet-based PRO assessments to be highly acceptable and easy to use.

### Keywords

patient reported outcomes; HIV care; electronic PRO administration; acceptability

## Introduction

Routine collection of patient-reported measures and outcomes (PROs), which are self-reported assessments of patient health (U.S. Department of Health and Human Services & Federal Drug Administration, 2006), has improved patient health outcomes (Dewalt & Revicki, 2008; Wittink, Yilmaz, Walsh, Chapman, & Duberstein, 2016), aided in management of chronic conditions (Chen, Ou, & Hollis, 2013; Dobscha, Gerrity, & Ward, 2001; Marshall, Haywood, & Fitzpatrick, 2006), and reduced under-detection of depression and suicidal ideation (H. M. Crane et al., 2017; Lowe et al., 2003; Staab et al., 2001), substance use (Conigliaro, Gordon, McGinnis, Rabeneck, & Justice, 2003; H. M. Crane et al., 2017; Messiah, Loundou, Maslin, Lacarelle, & Moatti, 2001), and inadequate adherence to medication regimens (Bangsberg et al., 2001; H. M. Crane et al., 2017; Gross, Bilker, Friedman, Coyne, & Strom, 2002; Paterson et al., 2000). On-site PRO collection prior to routine clinical care appointments via hand-held computer tablets with real-time results available to providers during clinic visits has improved provider ability to detect and address these issues (H. M. Crane et al., 2017; R. J. Fredericksen et al., 2016). Providers specializing in treatments of chronic conditions, such as cancer, rheumatoid arthritis, and HIV, have found PROs to be useful in practice (R. J. Fredericksen et al., 2016; Stover et al., 2015; Wolfe, Pincus, Thompson, & Doyle, 2003); they have improved patient-provider communication (Brown, Butow, Dunn, & Tattersall, 2001; Detmar, Muller, Schornagel, Wever, & Aaronson, 2002; Taenzer et al., 2000; Velikova et al., 2004; Wagner et al., 1997) and increased satisfaction with care (Chen J., 2013; Nelson et al., 2015; Taenzer et al., 2000; Wasson et al., 1999). Increasing regulatory demands aimed at improving patient outcomes, making the most meaningful use of visit time, managing costs, and amplifying patients' voice as a proactive partner in their care, highlight the use of PROs as a catalytic tool toward attaining these goals.

Successful integration and use of PRO collection in primary care is known to be dependent on multiple factors, such as buy-in from stakeholders, including providers, administrators, and patients (R. J. Fredericksen et al., 2012; R. J. Fredericksen et al., 2018). Patients must experience PROs as easy to self-administer and acceptable to use on a routine basis in order to ensure ongoing success as a patient-provider communication tool. A few studies, mostly from cancer care, predominantly with small sample sizes, and qualitative in nature, have found the use of computerized PRO assessments to be acceptable to and/or usable by patients (Jones et al., 2014; Sarabia et al., 2015; Sharma, Dunn, Wei, Montie, & Gilbert, 2016; Stover et al., 2015; Wasson et al., 1999; Wolpin et al., 2008; Wu, Johnson, Schepp, & Berry, 2011).

While PRO assessments have been found to be acceptable to patients across several chronic conditions in a variety of care settings (Girgis et al., 2017; Gressel et al., 2019; Madden, Hopwood, Neale, & Treloar, 2019; van Egdom et al., 2019; Wong et al., 2017), less is known about acceptability of tablet-based PROs in HIV clinical care. We conducted this study to determine the usability and patient acceptability of an approximately 10-12 minute clinical assessment of tablet-based PROs integrated into routine HIV care with results available to providers in real-time. Furthermore, we examined relationships between patient

acceptability and demographic and clinical characteristics including risk behaviors and depression.

## Methods

### Overview

English and Spanish speaking patients living with HIV (PLWH) completed an electronic self-administered, tablet-based clinical assessment that is part of their routine care, consisting of several PRO measures in their respective languages, at the beginning of their clinic visit. Within the PROs, we briefly included a measure of the platform and assessment's usability and acceptability, in terms of platform technological attributes and the assessment's content.

### Setting

We conducted this study among PLWH from two sites in the Centers for AIDS Research Network of Integrated Clinical Systems (CNICS) cohort: Owen Clinic at the University of California-San Diego (UCSD) and Madison Clinic at Harborview Medical Center/University of Washington-Seattle (UW).

### Data Sources

We utilized CNICS data from two sites (UCSD, UW) to characterize demographic, behavioral, and clinical factors of PLWH based on PRO acceptability. The CNICS cohort has been described in detail elsewhere. Briefly, it is a prospective observational cohort that integrates clinical data on >32,000 PLWH 18 years of age or older who have received routine clinical care at 8 sites in the United States. The CNICS data repository captures longitudinal data on the CNICS cohort (Kitahata et al., 2008). It integrates comprehensive clinical data from outpatient and inpatient encounters, including standardized HIV-related information collected at enrollment (initial clinic visit), demographic, clinical, medication, laboratory, and socio-demographic data obtained from each site's electronic health record and other institutional data sources, and PRO data.

### Study population

The study population consisted of English and Spanish-speaking PLWH aged 18 and over in care at one of two HIV care clinics within CNICS. Patients with known cognitive impairment or physical inability to self-administer PROs were excluded.

### Procedures

**PROs administration**—PLWH routinely complete the CNICS PRO assessment (Heidi M. Crane et al., 2007; R. J. Fredericksen et al., 2012) approximately every 4-6 months, on-site, at the beginning of their clinic visit. Patients self-administer the assessment using touch-screen computer pads immediately before seeing their provider. Providers review a summary document of patient responses prior to meeting with the patient and review the responses with them during the visit. The PRO assessment is heavily skip-patterned to minimize patient burden and takes 10-12 minutes to complete.

**Measures**—Measures include: antiretroviral medication adherence (a visual analog scale to assess percentage of medication taken, the Self-Rating Scale, a 7-day missed dose recall item, and an item querying patients' last missed dose) (Chesney et al., 2000; Lu et al., 2008; Walsh, Mandalia, & Gazzard, 2002), depression (PHQ-9) (Kroenke, Spitzer, & Williams, 2001; Spitzer, Kroenke, & Williams, 1999), anxiety (PHQ-5) (Spitzer et al., 1999), substance use (AUDIT/AUDIT-C and ASSIST) (Bradley et al., 2003; Bush, Kivlahan, McDonell, Fihn, & Bradley, 1998; Newcombe, Humeniuk, & Ali, 2005; 2002), tobacco use (Kiechl et al., 2002), sexual risk behavior (Risk Assessment Battery) (Metzger, Nalvalline, & Woody, 2001), HIV symptoms (Justice et al., 2001), perceived body morphology (Tien et al., 2006), and health-related quality of life (EQ-5D visual analog scale) (EuroQol Group, 1990).

We used the 6-item Acceptability E-Scale (AES) (see Table 1), a validated measure developed by Tariman et al (Tariman, Berry, Halpenny, Wolpin, & Schepp, 2011), adapted for readability for our patient population, to measure acceptability and usability of the PRO assessment. This measure was selected due to minimal patient burden, low reading level requirements, prior validation work, and assessment of multiple dimensions of acceptability. The AES includes dimensions of ease of use, understandability of questions, enjoyability of experience, whether the length of time to take the PROs is acceptable, helpfulness in describing symptoms and behaviors, and overall satisfaction, using a 5-point response scale for each item (1=not acceptable, 5=highly acceptable). The measure was shown at the end of the CNICS PROs. The measure was translated into Spanish by GlobalVision International, Inc., a certified translation agency.

All CNICS sites have Institutional Review Board approval to conduct CNICS protocols.

**Analysis**—We hypothesized that one or more of the following factors may influence the responses to the AES items; age, sex, race/ethnicity, language, sexual orientation, HIV transmission risk factor(s), use of antiretroviral therapy (ART), self-reported ART adherence in prior 30 days (scale of 0-100), viral load and CD4 cell counts closest to assessment time, depression symptoms, health-related quality of life (scale of 0-100), at-risk alcohol use (AUDIT-C score >4 for males, >3 for females), current illicit drug use (overall and by drug class), receipt of treatment for drug/alcohol use, poor engagement in care (missed visit ratio >0.25), number of sex partners, whether engaged in condomless anal or vaginal sex in the past 6 months, whether engaged in sex with a partner of unknown HIV status in the past 6 months, and number of times a patient had previously taken the PROs. We were particularly interested in learning whether more stigmatized, “private”, and/or difficult-to-discuss symptoms and behaviors such as depression, sexual risk behavior, and substance use were associated with acceptability levels. Given potential generational differences in comfort levels with technology, we were also interested in whether age influenced usability and acceptability of the assessment.

The primary outcome of interest was the overall score on the six AES items. For each question, the respondent could respond with a score of 0-5 resulting in a combined total of 30 possible points for the primary outcome. We were also interested in assessing the continuous score on each individual question based on patient characteristics as secondary

outcomes. Patients that did not answer all items were not included in the overall score. In addition, we looked at demographic characteristics of participants who completed every item vs. those who skipped one or more items.

Multivariable linear regression analysis was used to measure the association between patient characteristics and the primary outcome (continuous combined score on the six AES Items) and for each secondary outcome (continuous score on each of the AES Items as a separate outcome). Analyses were adjusted for age and site.

## Results

The AES was completed by 786 PLWH. The median age of participants was 48; 91% were male; 49% white, 31% Latino, and 13% African-American; and 17% were Spanish-speaking (Table 2). The overall mean score, out of 30 points, was 26 (+/- standard deviation (sd) 4.4, see Table 1). The mean score for each of the dimensions was: ease of use 4.7; understandability 4.7; time burden 4.3; overall satisfaction 4.3; helpfulness in describing symptoms and behaviors 4.2; enjoyability of assessment 3.9. About 5% of patients missed or skipped one or more questions. There were no significant differences between those who skipped items and those who did not by sex, race, language in which the AES was administered (English or Spanish), study site, or whether it was their first time taking the survey vs. having taken it before (Table 3; see Table S1 for item response-specific details). However, older age approached significance (mean age was 49 for those who skipped items vs. 46 for those who completed every item,  $p=.051$ ).

### Demographic and clinical characteristics and overall acceptability

Higher overall acceptability score was associated with African-American race (compared to white race, 1.3 points higher (95% CI: 0.3-2.3)), Latino ethnicity (compared to white race, 1.6 points higher (95% CI: 0.9-2.3)), Spanish-speaking (compared to English speaking, 2.4 points higher (95% CI: 1.6-3.3)), better health-related quality of life (per 10 point increment in EQ-5D score, 0.3 points higher (95% CI: 0.2-0.5)), and better adherence (per each 10 point increment, 0.4 points higher (95% CI: 0.2-0.6)) (Table 4). Lower acceptability score was associated with more depression symptoms (-0.9 points lower (95% CI: -1.4 to -0.4)), illicit opioid use in past 3 months (-2.0 points lower (95% CI: -3.9 to -0.2)), having 2 or more sex partners in the past 6 months (-0.8 points lower (95% CI: -1.5 to -0.1)), and any condomless sex in the past 6 months (-0.9 points lower (95% CI: -1.6 to -0.2)). Previously taking a PRO or being on ART were not associated with acceptability.

### Demographic and clinical characteristics and dimensions of acceptability

In addition to overall score, we examined demographic and clinical characteristics with each dimension of acceptability including ease of use, comprehension, enjoyability, helpfulness, time burden, and satisfaction (Table 4). Key findings are described below.

#### Ease of use

Patients reporting PROs as easier to use had higher health-related quality of life scores (0.05 points (95% CI: 0.02-0.07)), and higher adherence to antiretroviral medication (0.08

points (95%CI: 0.03-0.12)), while lower reported ease of use was associated with higher depression score (−0.09 points (95%CI: −0.13 to −0.05)), recent illicit opioid use (−0.3 point (95%CI: −0.6 to −0.1)), and having a viral load > 400 copies/mL (−0.2 points (95%CI: −0.4 to −0.04)).

### **Understandability of questions (comprehension)**

Patients reporting higher health related quality of life and higher adherence reported less difficulty understanding PRO questions (both  $p < .001$ ) (Table 4). Patients with higher depression scores reported more difficulty understanding the PROs (−0.02 points lower (95%CI: −0.13 to −0.08)).

### **Enjoyability of assessment**

Finding the PROs to be “enjoyable” was associated with African-American race (0.3 points higher (95%CI: 0.02-0.6)) and Latino ethnicity (0.5 points higher (95%CI: 0.3-0.7)), both compared to white race; Spanish-speakers, compared to English-speakers, also found the PROs more enjoyable (0.8 points higher (95%CI: 0.5-1.0)). Additionally, reporting better health-related quality of life was associated with a higher level of enjoyment (0.08 points higher (95%CI: 0.04-0.12)) (Table 4). Lower enjoyability was associated with a higher depression score (−0.1 points lower (95%CI: −0.2 to −0.03)), recent marijuana use (−0.2 points lower (95%CI: −0.4 to −0.03)), and reporting having had condomless sex in the past 6 months (−0.3 points lower (95%CI: −0.5 to −0.1)).

### **Helpfulness in describing symptoms and behaviors**

Higher satisfaction with helpfulness in describing symptoms and behaviors was associated with African-American race (0.3 (95%CI: 0.04-0.5)) and Latino ethnicity (0.4 (95%CI: 0.2-0.5)), both compared to white race; Spanish-speaking compared to English speaking (0.6 (95%CI: 0.4-0.8)); better health-related quality of life (0.07 (95%CI: 0.03-0.1)), and better adherence (0.06 (95%CI: 0.01-0.1)) (see Table 4). Lower satisfaction was associated with higher depression score (−0.08 (95%CI: −0.13- −0.02)).

### **Acceptability of time burden to complete**

Higher satisfaction with time burden was associated with African-American race (0.4 (95%CI: 0.1-0.6)) and Latino ethnicity (0.4 (95%CI: 0.2-0.5)), both compared to white race, Spanish-speaking (compared to English-speaking, (0.5 (95%CI: 0.3-0.7))), heterosexual orientation both as risk factor for HIV acquisition (compared to male sex with male (MSM), 0.2 (95%CI: 0.03-0.4)) and as self-identified sexual orientation (0.2 (95%CI: 0.01-0.4), compared to “lesbian, gay, or homosexual” identity), better health-related quality of life (0.05 (95%CI: 0.02-0.09)), and better adherence (0.1 (95%CI: 0.04-0.2)) (see Table 4). Lower satisfaction with time burden was associated with having a viral load > 400 (−0.3 (95%CI: −0.5- −0.1)), higher depression symptoms (−0.08 (95%CI: −0.1- −0.02)), recent illicit opioid use (−0.5 (95%CI: −0.9- −0.1)), and condomless sex (−0.2 (95%CI: −0.4- −0.1)).



## Overall satisfaction

Higher satisfaction was associated with African-American race (0.3 (95%CI: 0.1-0.5)) and Latino ethnicity (0.3 (95%CI: 0.2-0.5), both compared to white race); Spanish-speaking (compared to English speaking, (0.5 (95%CI:0.3-0.7)), better health-related quality of life (0.04 (95%CI: 0.01-0.07)) and higher adherence (0.08 (95%CI: 0.03-0.14)) (see Table 4). Lower satisfaction was associated with higher depression symptoms (-0.06 (95%CI: -0.1- -0.01)), recent illicit opioid use (-0.5 (95%CI: -0.9- -0.2)), and condomless sex in the past 6 months (-0.3 (95%CI: -0.4- -0.1)).

## Discussion

Patients found electronic, self-administered PRO assessments completed on-site at the beginning of their appointments to be highly acceptable and usable overall, with some variation between groups based on demographic and clinical characteristics. Although all categories of inquiry were rated highly, categories of “ease of use” and “understandability of questions” were rated highest. We found higher acceptability overall and across several item categories among those more adherent to their ART regimen, and among those reporting higher quality of life scores. Patient attributes may be driving this result: these patients may be more engaged in their care in general, feel healthier, and may be willing to do more for their health, such as participate in PRO assessments.

Acceptability was rated higher among African-Americans compared to those who identified as white race; those with Latino ethnicity compared to whites; and among Spanish speakers compared to English speakers. Social desirability bias, and not necessarily PRO acceptability, may explain these findings. More research is needed to better understand reasons for these differences. While patients reporting higher levels of depression, recent illicit opioid use, having two or more sex partners in the past six months, and/or engaging in condomless sex reported lower acceptability of PROs, acceptability was still relatively high. More research is needed to better understand why these particular symptoms and behaviors linked to lower acceptability, in particular, why this was true among illicit opioid users but not users of other substance types. In the case of depression, which had negative correlations across all items categories, reasons for lower acceptability may be intuited: depression is known to lower satisfaction with any activity (American Psychiatric Association, 2013). Patients reporting condomless sex, arguably a sensitive topic for many patients, reported less satisfaction and “enjoyability” with the PROs, and felt PROs to be more time-burdensome. Lower satisfaction and enjoyment among these patients may be due in part to anticipated and/or internalized stigma from sharing highly personal information. Another reason may be the extra time burden of the measure itself, which is heavily skip-patterned, but queries further when additional types of sexual behavior (oral, vaginal, anal sex) or partner types (HIV-negative, HIV-positive, status unknown) are endorsed.

Interestingly, the hypothesis that longer assessment time reduces acceptability of PROs was not true of users of most substance types, with the exception of illicit opioid users. The ASSIST drug use instrument was among the longer of the measures administered; as with the sexual risk items, endorsement of each additional drug prompts additional follow up questions regarding recent use and impact, increasing time burden. Similarly, for alcohol



use, the AUDIT-C automatically expands to the full AUDIT for those reporting substantial alcohol use. Yet, despite the additional time burden, compared to those reporting potentially at-risk sexual behavior, PROs were well-tolerated by at-risk alcohol users and users of most drug categories. It is possible that patients perceive reporting at-risk sexual behavior as more cumbersome or embarrassing than reporting drug or alcohol use. Another possibility is that attributes specific to these particular instruments drove satisfaction differences.

We argue that the benefit of identifying and addressing at-risk behaviors, such as suicidal ideation, intimate partner violence, substance abuse, or HIV/STI transmission risk behavior, outweighs the risk of patients experiencing moderate dissatisfaction with completing the PROs. However, we must strike a balance between these risks and benefits. Several factors are integral to this balance. Selection of PROs that are brief, skip-patterned, and clinically relevant are key to maintaining stakeholder engagement and avoiding disruption of clinic flow (R. J. Fredericksen et al., 2012; R. J. Fredericksen et al., 2018). In addition, we stress that the PRO assessments should be presented to patients as an optional tool that, like a vital sign procedure, may help their provider better understand their health and needs. Finally, we recommend qualitative exploration of reasons driving demographic and outcome-based differences in acceptability and usability of PRO assessments in order to identify measures and platform attributes that are most relevant and engaging to patients.

Our findings are instructive for clinics that may be considering implementation of electronic tablet-based PROs in that patient acceptability and usability of this procedure is unlikely to be a barrier to such efforts. Consistent with recent findings in HIV clinic settings (Fredericksen RJ, 2020), patients appear to value PROs as a tool for helping summarize symptoms and health behaviors, with an acceptable level of effort and time burden.

### **Limitations**

There are some important limitations to consider. First, patients who dislike answering questionnaires most likely self-selected out of the activity altogether, resulting in a sample of patients that by definition tolerate the activity. In addition, social desirability bias may have influenced responses. The authors also acknowledge that lower representation among women (consistent with the HIV epidemic in the US) and higher representation of patients who had taken the PROs before may limit the generalizability of our findings.

### **Strengths**

We recruited a demographically diverse, multi-site sample of patients with a broad range of health behaviors.

### **Conclusion**

PLWH attending routine HIV care appointments and endorsed depression, recent opioid use, recent condomless sex, or multiple sex partners found self-administered electronic tablet-based PRO assessments to be less acceptable. However, overall, PLWH found PRO assessments to be highly acceptable and easy to use.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## References:

- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.).
- Bangsberg DR, Hecht FM, Clague H, Charlebois ED, Ciccarone D, Chesney M, & Moss A (2001). Provider assessment of adherence to HIV antiretroviral therapy. *J Acquir Immune Defic Syndr*, 26(5), 435–442. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=11391162](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=11391162) [PubMed: 11391162]
- Bradley KA, Bush KR, Epler AJ, Dobie DJ, Davis TM, Sporleder JL, ... Kivlahan DR (2003). Two brief alcohol-screening tests From the Alcohol Use Disorders Identification Test (AUDIT): validation in a female Veterans Affairs patient population. *Arch Intern Med*, 163(7), 821–829. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=12695273](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=12695273) [PubMed: 12695273]
- Brown RF, Butow PN, Dunn SM, & Tattersall MH (2001). Promoting patient participation and shortening cancer consultations: a randomised trial. *Br J Cancer*, 85(9), 1273–1279. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=11720460](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=11720460) [PubMed: 11720460]
- Bush K, Kivlahan DR, McDonell MB, Fihn SD, & Bradley KA (1998). The AUDIT alcohol consumption questions (AUDIT-C): an effective brief screening test for problem drinking. Ambulatory Care Quality Improvement Project (ACQUIP). Alcohol Use Disorders Identification Test. *Arch Intern Med*, 158(16), 1789–1795. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=9738608](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=9738608) [PubMed: 9738608]
- Chen J, Ou L, & Hollis SJ (2013). A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Serv Res*, 13, 211. doi:10.1186/1472-6963-13-211 [PubMed: 23758898]
- Chen J, O. L, Hollis SJ (2013). A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Services Research*, 13(211).
- Chesney MA, Ickovics JR, Chambers DB, Gifford AL, Neidig J, Zwickl B, & Wu AW (2000). Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: the AACTG adherence instruments. Patient Care Committee & Adherence Working Group of the Outcomes Committee of the Adult AIDS Clinical Trials Group (AACTG). *AIDS Care*, 12(3), 255–266. doi:10.1080/09540120050042891 [PubMed: 10928201]
- Conigliaro J, Gordon AJ, McGinnis KA, Rabeneck L, & Justice AC (2003). How harmful is hazardous alcohol use and abuse in HIV infection: do health care providers know who is at risk? *J Acquir Immune Defic Syndr*, 33(4), 521–525. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=12869842](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=12869842) [PubMed: 12869842]
- Crane HM, Crane PK, Tufano JT, Ralston JD, Wilson IB, Brown TD, ... Fredericksen RJ (2017). HIV Provider Documentation and Actions Following Patient Reports of At-risk Behaviors and Conditions When Identified by a Web-Based Point-of-Care Assessment. *AIDS Behav*, 21(11), 3111–3121. doi:10.1007/s10461-017-1718-5 [PubMed: 28205041]
- Crane HM, Lober W, Webster E, Harrington RD, Crane PK, Davis TE, & Kitahata MM (2007). Routine collection of patient-reported outcomes in an HIV clinic setting: the first 100 patients. *Current HIV Research*, 5(1), 109–

118. Retrieved from <http://offcampus.lib.washington.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=17266562&site=ehost-live> [PubMed: 17266562]
- Detmar SB, Muller MJ, Schornagel JH, Wever LD, & Aaronson NK (2002). Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *Jama*, 288(23), 3027–3034. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=12479768](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=12479768) [PubMed: 12479768]
- Dewalt DA, & Revicki DA (2008). Importance of Patient-Reported Outcomes for Quality Improvement. National Quality Measures Clearinghouse.
- Dobscha SK, Gerrity MS, & Ward MF (2001). Effectiveness of an intervention to improve primary care provider recognition of depression. *Eff Clin Pract*, 4(4), 163–171. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=11525103](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=11525103) [PubMed: 11525103]
- EuroQol Group. (1990). EuroQol--a new facility for the measurement of health-related quality of life. *Health Policy*, 16(3), 199–208. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/10109801> [PubMed: 10109801]
- Fredericksen RJ, Crane P, Tufano J, Ralston J, Schmidt S, Brown T, ... Crane H (2012). Integrating a web-based patient assessment into primary care for HIV-infected adults. *Journal of AIDS and HIV Research*, 4(1). Retrieved from <http://www.academicjournals.org/JAHR>
- Fredericksen RJ, S. D, Fitzsimmons E, Jacobs B, Musten A, Korlipara D, Suri S, Hodge V, Ramgopal M, Gough K, Bacon J, McReynolds J, Lober W, Crane HM. (2020). Patient perceptions of the utility and impact of a same-day self-administered routine electronic patient-reported outcomes (PRO) assessment in HIV care in two North American clinics. Paper presented at the International Society for Quality of Life Research, online.
- Fredericksen RJ, Skalicky A, Kleinman L, Collins E, Lober W, Crane HM, & Short D (2018). Lessons learned: key implementer perspectives on successful interoduction and administration of electronic tablet-based patient reported outcome (PRO) measures in routine HIV care. Paper presented at the International Society of Quality of Life Research Dublin, Ireland.
- Fredericksen RJ, Tufano J, Ralston J, McReynolds J, Stewart M, Lober WB, ... Crane HM (2016). Provider perceptions of the value of same-day, electronic patient-reported measures for use in clinical HIV care. *AIDS Care*, 1–6. doi:10.1080/09540121.2016.1189501
- Girgis A, Durcinoska I, Levesque JV, Gerges M, Sandell T, Arnold A, ... Group, P. R.-C. P. (2017). eHealth System for collecting and utilizing Patient Reported Outcome Measures for Personalized Treatment and Care (PROMPT-Care) among cancer patients: mixed methods approach to evaluate feasibility and acceptability. *J Med Internet Res*, 19(10), e330. doi:10.2196/jmir.8360 [PubMed: 28970188]
- Gressel GM, Dioun SM, Richley M, Lounsbury DW, Rapkin BD, Isani S, ... Novetsky AP (2019). Utilizing the Patient Reported Outcomes Measurement Information System (PROMIS(R)) to increase referral to ancillary support services for severely symptomatic patients with gynecologic cancer. *Gynecol Oncol*, 152(3), 509–513. doi:10.1016/j.ygyno.2018.10.042 [PubMed: 30876496]
- Gross R, Bilker WB, Friedman HM, Coyne JC, & Strom BL (2002). Provider inaccuracy in assessing adherence and outcomes with newly initiated antiretroviral therapy. *Aids*, 16(13), 1835–1837. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=12218400](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=12218400) [PubMed: 12218400]
- Jones J, Stephenson R, Smith DK, Toledo L, La Pointe A, Taussig J, & Sullivan PS (2014). Acceptability and willingness among men who have sex with men (MSM) to use a tablet-based HIV risk assessment in a clinical setting. *Springerplus*, 3, 708. doi:10.1186/2193-1801-3-708 [PubMed: 25525569]
- Justice AC, Holmes W, Gifford AL, Rabeneck L, Zackin R, Sinclair G, ... Wu AW (2001). Development and validation of a self-completed HIV symptom index. *J Clin Epidemiol*, 54 Suppl 1, S77–90. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=11750213](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=11750213) [PubMed: 11750213]
- Kiechl S, Werner P, Egger G, Oberhollenzer F, Mayr M, Xu Q, ... Willeit J (2002). Active and passive smoking, chronic infections, and the risk of carotid atherosclerosis: prospective results from the Bruneck Study. *Stroke*, 33(9), 2170–2176. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/12215582> [PubMed: 12215582]

- Kitahata MM, Rodriguez BG, Haubrich R, Boswell S, Mathews WC, Lederman MM, ... Saag MS (2008). Cohort profile: the Centers for AIDS Research (CFAR) Network of Integrated Clinical Systems (CNICS). *Int J Epidemiol*, 37(5), 948–955. [PubMed: 18263650]
- Kroenke K, Spitzer RL, & Williams JB (2001). The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med*, 16(9), 606–613. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=11556941](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=11556941) [PubMed: 11556941]
- Lowe B, Grafe K, Zipfel S, Spitzer RL, Herrmann-Lingen C, Witte S, & Herzog W (2003). Detecting panic disorder in medical and psychosomatic outpatients: comparative validation of the Hospital Anxiety and Depression Scale, the Patient Health Questionnaire, a screening question, and physicians' diagnosis. *J Psychosom Res*, 55(6), 515–519. [PubMed: 14642981]
- Lu M, Safren SA, Skolnik PR, Rogers WH, Coady W, Hardy H, & Wilson IB (2008). Optimal recall period and response task for self-reported HIV medication adherence. *AIDS Behav*, 12(1), 86–94. doi:10.1007/s10461-007-9261-4 [PubMed: 17577653]
- Madden A, Hopwood M, Neale J, & Treloar C (2019). Acceptability of Patient-Reported Outcome and Experience Measures for Hepatitis C treatment among people who use drugs. *Patient*, 12(2), 259–265. doi:10.1007/s40271-018-0332-6 [PubMed: 30270403]
- Marshall S, Haywood K, & Fitzpatrick R (2006). Impact of patient-reported outcome measures on routine practice: a structured review. *J Eval Clin Pract*, 12(5), 559–568. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=16987118](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=16987118) [PubMed: 16987118]
- Messiah A, Loundou AD, Maslin V, Lacarelle B, & Moatti JP (2001). Physician recognition of active drug use in HIV-infected patients is lower than validity of patient's self-reported drug use. *J Pain Symptom Manage*, 21(2), 103–112. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=11302118](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=11302118) [PubMed: 11302118]
- Metzger DS, Nalvalline HA, & Woody GE (2001). Assessment of substance abuse: HIV risk assessment battery. In Carson-Dewitt (Ed.), *Encyclopedia of Drugs, Alcohol, and Addictive Behavior*. Farmington Hills, MI: Macmillian Reference USA.
- Nelson EC, Eftimovska E, Lind C, Hager A, Wasson JH, & Lindblad S (2015). Patient reported outcome measures in practice. *BMJ*, 350, g7818. doi:10.1136/bmj.g7818 [PubMed: 25670183]
- Newcombe DA, Humeniuk RE, & Ali R (2005). Validation of the World Health Organization Alcohol, Smoking and Substance Involvement Screening Test (ASSIST): report of results from the Australian site. *Drug Alcohol Rev*, 24(3), 217–226. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=16096125](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=16096125) [PubMed: 16096125]
- Paterson DL, Swindells S, Mohr J, Brester M, Vergis EN, Squier C, ... Singh N (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Ann Intern Med*, 133(1), 21–30. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=10877736](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=10877736) [PubMed: 10877736]
- Sarabia S, Perez-Cosio A, Brown C, Leung Y, Gill G, Liang M, ... Howell D (2015). Are palliative patients less accepting to self-report symptom measures for clinical management than curative patients?. *Journal of Clinical Oncology*, 33(29), 79.
- Sharma P, Dunn RL, Wei JT, Montie JE, & Gilbert SM (2016). Evaluation of point-of-care PRO assessment in clinic settings: integration, parallel-forms reliability, and patient acceptability of electronic QOL measures during clinic visits. *Qual Life Res*, 25(3), 575–583. doi:10.1007/s11136-015-1113-5 [PubMed: 26373852]
- Spitzer RL, Kroenke K, & Williams JB (1999). Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. *Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. Jama*, 282(18), 1737–1744. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=10568646](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=10568646) [PubMed: 10568646]
- Staab JP, Datto CJ, Weinrieb RM, Gariti P, Rynn M, & Evans DL (2001). Detection and diagnosis of psychiatric disorders in primary medical care settings. *Med Clin*

- North Am, 85(3), 579–596. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=11349474](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=11349474) [PubMed: 11349474]
- Stover A, Irwin DE, Chen RC, Chera BS, Mayer DK, Muss HB, ... Reeve BB (2015). Integrating Patient-Reported Outcome Measures into Routine Cancer Care: Cancer Patients' and Clinicians' Perceptions of Acceptability and Value. *EGEMS (Wash DC)*, 3(1), 1169. doi:10.13063/2327-9214.1169 [PubMed: 26557724]
- Taenzer P, Bultz BD, Carlson LE, Specia M, DeGagne T, Olson K, ... Rosberger Z (2000). Impact of computerized quality of life screening on physician behaviour and patient satisfaction in lung cancer outpatients. *Psychooncology*, 9(3), 203–213. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=10871716](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=10871716) [PubMed: 10871716]
- Tariman JD, Berry DL, Halpenny B, Wolpin S, & Schepp K (2011). Validation and testing of the Acceptability E-scale for web-based patient-reported outcomes in cancer care. *Appl Nurs Res*, 24(1), 53–58. doi:10.1016/j.apnr.2009.04.003 [PubMed: 20974066]
- Tien PC, Benson C, Zolopa AR, Sidney S, Osmond D, & Grunfeld C (2006). The study of fat redistribution and metabolic change in HIV infection (FRAM): methods, design, and sample characteristics. *Am J Epidemiol*, 163(9), 860–869. doi:10.1093/aje/kwj111 [PubMed: 16524955]
- U.S. Department of Health and Human Services, & Federal Drug Administration. (2006). Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. *Health Qual Life Outcomes*, 4, 79. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=17034633](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=17034633) [PubMed: 17034633]
- van Egdom LSE, Oemrawsingh A, Verweij LM, Lingsma HF, Koppert LB, Verhoef C, ... Hazelzet JA (2019). Implementing Patient-Reported Outcome Measures in clinical breast cancer care: a systematic review. *Value Health*, 22(10), 1197–1226. doi:10.1016/j.jval.2019.04.1927 [PubMed: 31563263]
- Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, & Selby PJ (2004). Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *J Clin Oncol*, 22(4), 714–724. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=14966096](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=14966096) [PubMed: 14966096]
- Wagner AK, Ehrenberg BL, Tran TA, Bungay KM, Cynn DJ, & Rogers WH (1997). Patient-based health status measurement in clinical practice: a study of its impact on epilepsy patients' care. *Qual Life Res*, 6(4), 329–341. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9248315> [PubMed: 9248315]
- Walsh JC, Mandalia S, & Gazzard BG (2002). Responses to a 1 month self-report on adherence to antiretroviral therapy are consistent with electronic data and virological treatment outcome. *Aids*, 16(2), 269–277. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=11807312](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=11807312) [PubMed: 11807312]
- Wasson JH, Stukel TA, Weiss JE, Hays RD, Jette AM, & Nelson EC (1999). A randomized trial of the use of patient self-assessment data to improve community practices. *Eff Clin Pract*, 2(1), 1–10. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=10346547](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=10346547) [PubMed: 10346547]
- WHO ASSIST Working Group. (2002). The Alcohol, Smoking and Substance Involvement Screening Test (ASSIST): development, reliability and feasibility. *Addiction*, 97(9), 1183–1194. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=12199834](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=12199834) [PubMed: 12199834]
- Wittink MN, Yilmaz S, Walsh P, Chapman B, & Duberstein P (2016). Customized Care: An intervention to Improve Communication and health outcomes in multimorbidity. *Contemp Clin Trials Commun*, 4, 214–221. doi:10.1016/j.conctc.2016.10.002 [PubMed: 28191546]
- Wolfe F, Pincus T, Thompson AK, & Doyle J (2003). The assessment of rheumatoid arthritis and the acceptability of self-report questionnaires in clinical practice. *Arthritis Rheum*, 49(1), 59–63. doi:10.1002/art.10904 [PubMed: 12579594]
- Wolpin S, Berry D, Austin-Seymour M, Bush N, Fann JR, Halpenny B, ... McCorkle R (2008). Acceptability of an Electronic Self-Report Assessment Program for patients with cancer. *Comput*

Inform Nurs, 26(6), 332–338. Retrieved from [http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list\\_uids=19047882](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=19047882) [PubMed: 19047882]

Wong D, Cao S, Ford H, Richardson C, Belenko D, Tang E, ... Mucsi I (2017). Exploring the use of tablet computer-based electronic data capture system to assess patient reported measures among patients with chronic kidney disease: a pilot study. *BMC Nephrol*, 18(1), 356. doi:10.1186/s12882-017-0771-7 [PubMed: 29212466]

Wu WW, Johnson R, Schepp KG, & Berry DL (2011). Electronic self-report symptom and quality of life for adolescent patients with cancer: a feasibility study. *Cancer Nurs*, 34(6), 479–486. doi:10.1097/NCC.0b013e31820a5bdd [PubMed: 21372703]

**Table 1:**

Acceptability of a tablet-based clinical assessment of patient reported outcomes in routine clinical care among 786 patients living with HIV

	<b>N</b>	<b>Mean score (SD)</b>	<b>Median Score</b>
How easy was this assessment for you to use?	777	4.72 (0.74)	5
How understandable were the questions?	776	4.72 (0.69)	5
How much did you enjoy using this assessment?	772	3.87 (1.27)	4
How helpful was this assessment in describing your symptoms and health behaviors?	764	4.27 (1.00)	5
Was the amount of time it took to complete this assessment acceptable?	767	4.34 (0.98)	5
How would you rate your overall satisfaction with this assessment?	763	4.31 (0.96)	5
Combined acceptability score	741	26 (4.40)	28

SD: standard deviation

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**Table 2:**

Demographic and clinical characteristics of patients living with HIV who completed the Acceptability E-Scale (N=786)<sup>a</sup>

Age (continuous [median, IQR])	48 (37-54)	
Age (categorical)		
<30	67	8.50%
30-39	159	20.20%
40-49	223	28.40%
50-59	245	31.20%
60	90	11.50%
Site		
UCSD	552	70.20%
UW	234	29.80%
Male sex	713	91.10%
Male gender identity	716	91.10%
Race/ethnicity		
White	384	48.90%
African-American	102	13.00%
Latino	241	30.70%
Other/unknown	59	7.50%
Survey language		
English	654	83.20%
Spanish	132	16.80%
Taking ART	694	88.30%
Sexual orientation		
Lesbian, gay or homosexual	456	66.40%
Straight or heterosexual	138	20.10%
Bisexual	57	8.30%
Something else	13	1.90%
Don't know	23	3.30%
Missing*	99	
HIV risk factor		
MSM	537	68.30%
IDU	82	10.40%
MSM+IDU	30	3.80%
Heterosexual	117	14.90%
Other/unknown	20	2.50%
Initial vs. follow-up PRO		
Initial	76	9.70%
Follow-up PRO	707	89.90%
CD4 cell count, cells/mm <sup>3</sup> closest to assessment		
500	508	64.60%

350-499	134	17.00%
200-349	88	11.20%
100-199	34	4.30%
<100	21	2.70%
VL 400 copies/ml closest to assessment	86	11.00%
Poor engagement in care (missed visit ratio >0.25)	26	3.30%
Depression score (median, IQR)	4 (1-19)	
Health related quality of life score (median, IQR)	78 (62-90)	
Adherence percentage in prior 30 days (median, IQR)	98 (94-100)	
At-risk alcohol use	157	20.00%
Current cocaine/crack use	34	4.30%
Current methamphetamine/crystal use	102	13.00%
Current illicit opioid use	25	3.20%
Current marijuana use	222	28.20%
Current illicit substance use (cocaine/crack, methamphetamine/crystal, or illicit opioid)	127	16.20%
Substance use treatment	39	5.00%
Number of sex partners		
0-1	253	32.20%
2	524	67.40%
Condomless sex	294	37.40%
Not sexually active	253	32.20%
HIV status of partners unknown	108	13.70%
Ever had anal sex	643	81.80%

<sup>a</sup>Numbers shown as n (%) or median(IQR) unless otherwise noted

Abbreviations: ART, antiretroviral therapy; IDU, injection drug use; IQR, interquartile range; MSM, men who have sex with men; PRO, patient reported outcomes assessment; UCSD, University of California San Diego; UW, University of Washington; VL, viral load.

\* Note this item was added to the assessment during the study period so was not asked of many PLWH

**Table 3.**

Demographic characteristics of participants that completed every item vs. those that skipped at least one item

Characteristic (n(%))	Participants that completed every item (n=741)	Participants that skipped at least one item (n=45)	p-value
Age (mean (SD))	46 (11)	49 (10)	0.051
Site			0.23
UW *	217 (29)	17 (38)	
UCSD **	524 (71)	28 (62)	
Race			0.06
White	364 (49)	20 (44)	
Black	96 (13)	6 (13)	
Hispanic	230 (31)	11 (24)	
Other	51 (7)	8 (18)	
Male Sex	677 (91)	39 (87)	0.28
Survey Language			0.86
English	617 (83)	37 (82)	
Spanish	124 (17)	8 (18)	
PRO Type			0.22
Initial	74 (10)	2 (4)	
Follow-up	664 (90)	43 (96)	

\* UW: University of Washington

\*\* UCSD: University of California, San Diego

**Table 4:**

Variations in PRO acceptability scores overall and by each dimension based on demographic and clinical characteristics of people living with HIV in routine care

	Continuous overall acceptability score		Ease of use		Understandability of questions		Enjoyability		Helpfulness in describing symptoms and behaviors		Acceptability of time burden		Overall satisfaction	
	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P Value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value
<b>Gender identity (ref male)</b>														
Female	0.7 (-4, 1.8)	0.23	0.03 (-0.2, 0.2)	0.77	0.1 (-0.04, 0.3)	0.13	0.2 (0.1, 0.5)	0.28	0.1 (-0.1, 0.4)	0.37	0.2 (-0.1, 0.4)	0.18	0.1 (-0.2, 0.3)	0.57
<b>Race/ethnicity (ref white)</b>														
African American	<b>1.3 (0.3, 2.3)</b>	<b>0.01</b>	-0.1 (-0.2, 0.1)	0.45	-0.1 (-0.2, 0.1)	0.44	<b>0.3 (0.02, 0.6)</b>	<b>0.04</b>	<b>0.3 (0.04, 0.5)</b>	<b>0.02</b>	<b>0.4 (0.1, 0.6)</b>	<b>0.00</b>	<b>0.3 (0.1, 0.5)</b>	<b>0.00</b>
Latino	<b>1.6 (0.9, 2.3)</b>	<b>0.00</b>	-0.04 (-0.2, 0.1)	0.52	0.01 (-0.1, 0.1)	0.83	<b>0.5 (0.3, 0.7)</b>	<b>0.00</b>	<b>0.4 (0.2, 0.5)</b>	<b>0.00</b>	<b>0.4 (0.2, 0.5)</b>	<b>0.00</b>	<b>0.3 (0.2, 0.5)</b>	<b>0.00</b>
Other/unknown	-0.8 (-2.1, 0.4)	0.25	<b>-0.3 (-0.5, -0.1)</b>	<b>0.01</b>	<b>-0.3 (-0.5, -0.1)</b>	<b>0.01</b>	0.1 (-0.3, 0.4)	0.64	0.03 (-0.3, 0.3)	0.85	-0.1 (-0.4, 0.1)	0.34	-0.1 (-0.3, 0.2)	0.71
<b>Survey language (ref English)</b>														
Spanish	<b>2.4 (1.6, 3.3)</b>	<b>0.00</b>	-0.01 (-0.1, 0.2)	0.96	0.1 (-0.02, 0.2)	0.11	<b>0.8 (0.5, 1.0)</b>	<b>0.00</b>	<b>0.6 (0.4, 0.8)</b>	<b>0.00</b>	<b>0.5 (0.3, 0.7)</b>	<b>0.00</b>	<b>0.5 (0.3, 0.7)</b>	<b>0.00</b>
<b>Taking ART</b>	-0.3 (-1.3, 0.8)	0.15	-0.2 (-0.3, 0.01)	0.06	-0.1 (-0.2, 0.1)	0.27	0.1 (-0.2, 0.3)	0.76	-0.01 (-0.2, 0.2)	0.90	-0.03 (-0.3, 0.2)	0.80	-0.17 (-0.2, 0.2)	0.88
<b>Sexual orientation (ref lesbian, gay or homosexual)</b>														
Straight or heterosexual	0.5 (-3.2, 1.4)	0.90	-0.1 (-0.3, 0.03)	0.13	-0.02 (-0.1, 0.1)	0.82	0.1 (-0.1, 0.4)	0.29	0.1 (-0.1, 0.3)	0.16	<b>0.2 (0.01, 0.4)</b>	<b>0.04</b>	0.1 (-0.1, 0.3)	0.33
Bisexual	-0.6 (-1.9, 0.6)	0.57	-0.2 (-0.4, 0.03)	0.10	0.01 (-0.2, 0.2)	0.91	-0.1 (-0.5, 0.2)	0.42	-0.1 (-0.4, 0.2)	0.59	-0.1 (-0.4, 0.2)	0.39	-0.2 (-0.4, 0.1)	0.24
Other	-0.5 (-3.1, 2.0)	0.16	-0.4 (-0.8, 0.01)	0.054	-0.1 (-0.5, 0.2)	0.49	0.0 (-0.7, 0.7)	0.998	0.3 (-0.3, 0.9)	0.35	-0.1 (-0.7, 0.5)	0.75	-0.3 (-0.8, 0.3)	0.37
Don't know	1.2 (-0.7, 3.1)	0.17	-0.2 (-0.5, 0.1)	0.24	-0.02 (-0.3, 0.3)	0.89	<b>0.6 (0.1, 1.1)</b>	<b>0.03</b>	0.3 (-0.1, 0.7)	0.16	0.1 (-0.4, 0.5)	0.81	0.1 (-0.3, 0.5)	0.79

	Continuous overall acceptability score		Ease of use		Understandability of questions		Enjoyability		Helpfulness in describing symptoms and behaviors		Acceptability of time burden		Overall satisfaction	
	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P Value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value
<b>HIV risk factor (ref MSM)</b>														
IDU	-0.1 (-1.2, 1.0)	0.90	-0.03 (-0.2, 0.2)	0.81	0.04 (-0.1, 0.2)	0.64	-0.2 (-0.3, 0.2)	0.35	0.1 (-0.2, 0.4)	0.43	0.00 (-0.3, 0.2)	0.99	-0.02 (-0.3, 0.2)	0.90
MSM+IDU	0.5 (-1.2, 2.1)	0.57	-0.2 (-0.5, 0.1)	0.12	0.03 (-0.2, 0.3)	0.82	-0.2 (-0.4, 0.2)	0.47	0.1 (-0.3, 0.5)	0.55	0.1 (-0.2, 0.5)	0.46	0.3 (-0.03, 0.7)	0.08
Hetero	0.7 (-0.3, 1.6)	0.16	-0.1 (-0.2, 0.1)	0.38	0.01 (-0.1, 0.1)	0.98	0.04 (-0.6, 0.3)	0.77	0.2 (-0.6, 0.4)	0.16	<b>0.2 (0.03, 0.4)</b>	<b>0.02</b>	0.1 (-0.1, 0.2)	0.27
Other/unknown	1.4 (-0.6, 3.4)	0.17	0.01 (-0.3, 0.4)	0.94	-0.1 (-0.4, 0.2)	0.68	0.1 (-0.9, 0.3)	0.74	0.2 (-0.2, 0.7)	0.35	0.4 (-0.1, 0.9)	0.08	0.2 (-0.2, 0.7)	0.34
<b>CD4 count (ref &gt;500)</b>														
350-499	-0.3 (-1.2, 0.5)	0.45	-0.1 (-0.2, 0.1)	0.37	<b>-0.1 (-0.3, -0.01)</b>	<b>0.04</b>	-0.03 (-0.3, 0.2)	0.80	-0.01 (-0.2, 0.2)	0.89	-0.04 (-0.2, 0.2)	0.71	0.1 (-0.1, 0.3)	0.32
200-349	-0.3 (-1.3, 0.7)	0.54	-0.1 (-0.3, 0.1)	0.25	0.02 (-0.1, 0.2)	0.81	-0.1 (-0.4, 0.2)	0.42	-0.1 (-0.3, 0.1)	0.44	-0.1 (-0.3, 0.12)	0.63	0.08 (-0.14, 0.3)	0.48
100-199	-0.9 (-2.5, 0.7)	0.25	-0.1 (-0.3, 0.2)	0.70	0.1 (-0.1, 0.3)	0.41	-0.2 (-0.6, 0.3)	0.44	-0.2 (-0.6, 0.2)	0.25	-0.3 (-0.6, 0.1)	0.12	-0.2 (-0.5, 0.2)	0.39
<100	-1.4 (-3.4, 0.6)	0.16	-0.3 (-0.6, 0.1)	0.10	-0.3 (-0.6, 0.03)	0.08	-0.3 (-0.9, 0.3)	0.30	0.01 (-0.4, 0.5)	0.97	-0.4 (-0.9, 0.03)	0.07	-0.1 (-0.5, 0.4)	0.73
<b>VL &gt;=400 copies/ml</b>														
Poorly engaged (missed visit ratio >0.25)	-1.0 (-2.0, 0.5)	0.06	<b>-0.2 (-0.4, -0.04)</b>	<b>0.02</b>	0.01 (-0.2, 0.2)	0.93	-0.1 (-0.4, 0.2)	0.60	-0.1 (-0.3, 0.1)	0.42	<b>-0.3 (-0.5, -0.1)</b>	<b>0.01</b>	-0.1 (-0.4, 0.1)	0.83
Poorly engaged (missed visit ratio >0.25)	0.0 (-0.8, 0.8)	0.99	-0.02 (-0.3, 0.3)	0.82	-0.2 (-0.5, 0.6)	0.71	0.1 (-0.5, 0.6)	0.84	-0.01 (-0.2, 0.2)	0.96	-0.04 (-0.2, 0.1)	0.66	-0.04 (-0.2, 0.1)	0.67
Depression score (per 5 points)	-0.9 (-1.4, -0.4)	<b>0.00</b>	-0.09 (-0.13, -0.05)	<b>0.00</b>	-0.02 (-0.13, 0.08)	<b>0.00</b>	-0.1 (-0.2, -0.03)	<b>0.01</b>	-0.08 (-0.13, -0.02)	<b>0.01</b>	-0.08 (-0.13, -0.02)	<b>0.01</b>	-0.06 (-0.11, -0.01)	<b>0.04</b>
Health related QOL (per 10 points)	0.3 (0.2, 0.5)	<b>0.00</b>	0.05 (0.02, 0.07)	<b>0.00</b>	0.00 (0.00, 0.01)	<b>0.00</b>	0.08 (0.04, 0.12)	<b>0.00</b>	0.07 (0.03, 0.10)	<b>0.00</b>	0.05 (0.02, 0.09)	<b>0.00</b>	0.04 (0.01, 0.07)	<b>0.02</b>
Adherence (per 10 points)	0.4 (0.2, 0.6)	<b>0.00</b>	0.08 (0.03, 0.12)	<b>0.00</b>	0.01 (0.00, 0.01)	<b>0.00</b>	0.06 (-0.02, 0.13)	0.12	0.06 (0.01, 0.11)	<b>0.04</b>	0.10 (0.04, 0.15)	<b>0.00</b>	0.08 (0.03, 0.14)	<b>0.00</b>
At-risk alcohol use	-0.3 (-1.1, 0.5)	0.42	-0.1 (-0.2, 0.1)	0.46	0.00 (-0.1, 0.1)	0.96	0.2 (-0.4, 0.02)	0.12	-0.1 (-0.2, 0.1)	0.18	-0.04 (-0.2, 0.1)	0.69	-0.1 (-0.2, 0.1)	0.57

	Continuous overall acceptability score		Ease of use		Understandability of questions		Enjoyability		Helpfulness in symptoms and behaviors		Acceptability of time burden		Overall satisfaction	
	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P Value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value	Coefficient (95%CI)	P value
Current cocaine/crack use	0.02 (-0.01, 0.05)	0.98	0.01 (-0.2, 0.3)	0.92	0.2 (-0.1, 0.4)	0.22	0.02 (-0.4, 0.5)	0.08	-0.1 (-0.5, 0.3)	0.57	-0.1 (-0.4, 0.3)	0.74	0.04 (-0.3, 0.4)	0.81
Current methamphetamine/crystal use	-0.5 (-1.5, 0.4)	0.27	-0.9 (-0.2, 0.1)	0.27	0.01 (-0.1, 0.2)	0.88	-0.1 (-0.4, 0.2)	0.41	-0.1 (-0.3, 0.1)	0.52	-0.2 (-0.4, 0.01)	0.07	-0.1 (-0.3, 0.1)	0.25
Current illicit opioid use	-2.1 (-3.9, -0.2)	<b>0.03</b>	-0.3 (-0.6, -0.1)	<b>0.02</b>	0.04 (-0.2, 0.3)	0.76	-0.4 (-0.9, 0.2)	0.17	-0.4 (-0.8, 0.03)	0.72	-0.5 (-0.9, -0.1)	<b>0.02</b>	-0.5 (-0.9, -0.2)	<b>0.01</b>
Current marijuana use	-0.6 (-1.3, 0.2)	0.13	0.01 (-0.1, 0.1)	0.95	-0.03 (-0.1, 0.1)	0.63	-0.2 (0.4, -0.03)	<b>0.02</b>	-0.1 (-0.3, 0.04)	0.14	-0.1 (-0.3, 0.04)	0.15	-0.1 (-0.3, 0.04)	0.13
Any use of cocaine/crack, methamphetamine/crystal or opiate	-0.5 (-1.3, 0.4)	0.29	0.1 (-0.2, 0.5)	0.54	-0.1 (-0.4, 0.2)	0.52	0.5 (-0.1, 1.1)	0.12	0.2 (-0.1, 0.5)	0.28	0.2 (-0.3, 0.7)	0.44	0.1 (-0.4, 0.5)	0.83
Substance use treatment	0.6 (-1.0, 2.1)	0.48	0.00 (-0.3, 0.3)	0.99	0.1 (-0.1, 0.3)	0.34	0.1 (-0.4, 0.5)	0.73	0.2 (-0.1, 0.5)	0.28	0.1 (-0.2, 0.4)	0.58	0.1 (-0.2, 0.4)	0.47
Number of sex partners (ref 0-1)														
2	-0.8 (-1.5, -0.1)	<b>0.02</b>	0.00 (-0.1, 0.1)	0.98	-0.1 (-0.2, 0.04)	0.19	-0.03 (-0.2, 0.2)	0.80	0.1 (-0.4, 0.3)	0.13	-0.1 (-0.2, 0.1)	0.31	-0.1 (-0.3, 0.1)	0.18
Condomless sex	-0.9 (-1.6, -0.2)	<b>0.02</b>	-0.9 (-1.6, -0.2)	<b>0.02</b>	-0.2 (-0.1, 0.1)	0.69	-0.3 (-0.5, -0.1)	<b>0.01</b>	-0.6 (-0.2, 0.1)	0.48	-0.2 (-0.4, -0.1)	<b>0.01</b>	-0.3 (-0.4, -0.1)	<b>0.00</b>
Not sexually active	-0.04 (-0.8, 0.7)	0.43	-0.1 (-0.2, 0.4)	0.20	-0.1 (-0.2, 0.02)	0.11	0.03 (-0.2, 0.2)	0.80	-0.1 (-0.3, 0.04)	0.13	0.1 (-0.1, 0.2)	0.31	0.1 (-0.1, 0.3)	0.18
HIV status of partners unknown	1.2 (-1.8, 4.2)	0.43	1.2 (-1.8, 4.2)	0.43	0.1 (-0.4, 0.6)	0.62	<b>0.8 (0.1, 1.6)</b>	<b>0.04</b>	0.3 (-0.3, 0.9)	0.32	-0.1 (-0.8, 0.6)	0.77	0.5 (-0.1, 1.1)	0.12
Ever had anal sex	-0.2 (-1.1, 0.7)	0.21	<b>0.2 (0.04, 0.3)</b>	<b>0.01</b>	0.1 (-0.04, 0.2)	0.16	-0.2 (-0.4, 0.1)	0.15	-0.1 (-0.3, 0.1)	0.58	-0.1 (-0.3, 0.1)	0.45	-0.1 (-0.3, 0.1)	0.43
Previously answered PRO	0.2 (-0.9, 1.2)	0.77	0.03 (-0.2, 0.2)	0.71	0.1 (-0.1, 0.2)	0.45	-0.2 (-0.5, 0.2)	0.34	-0.01 (-0.3, 0.2)	0.94	0.1 (-0.1, 0.4)	0.36	-0.03 (-0.3, 0.2)	0.80

Abbreviations: CI, confidence interval; ART, antiretroviral therapy; MSM, men who have sex with men; IDU, injection drug use; VL, viral load; PRO, patient reported outcomes questionnaire.