# Detailed Insight from Electronic Health-related Quality of Life Data in HIV for Payer Decision Making — A Way to Better Allocate Resources and Support Patients

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## Introduction

- There has been an increased interest in the applications of realworld data (RWD) in drug development.
- Many organizations now have or are in the process of building RWD analytical capabilities. Patient registries, healthcare databases and pharmacy/ insurance databases have been used as sources of data.
- The life expectancy of people living with HIV (PLHIV) in the United States (US) has improved dramatically in the last 25 years and more than ever are virally suppressed (VS). However, HIV is a complex chronic condition associated with myriad concurrent conditions.
- A novel approach to collecting RWD was utilized to understand the unmet needs and health-related quality of life (HRQoL) of PLHIV.

## Objectives

- This study aimed to:
  - Evaluate HRQoL and treatment satisfaction in PLHIV who have achieved viral suppression.
  - Explore the potential of novel data collected through electronic administration of a survey via mobile app to inform payer decision-making.

## Methods

### Study Design

- The "Real-world Insights of patients living with HIV (PLHIV) Shared through Electronic devices" (RISE) study was a cross-sectional survey to obtain a current understanding of the impact HIV has on patients' lives in the US.

### Patient Population

- Patients were eligible to participate if they were at least 21 years old, read and understood English or Spanish, diagnosed with HIV, and had a smartphone with access to internet.
- PLHIV were recruited through several social media platforms and completed the survey on a mobile app downloaded directly to their device.

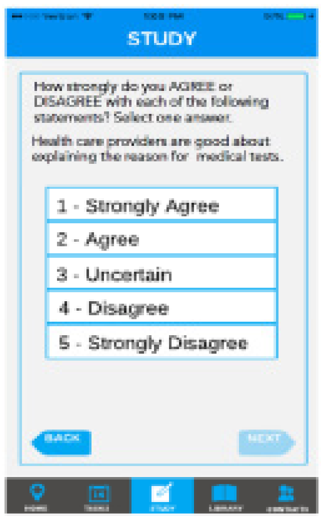
### Measures

- The survey included a sociodemographic and clinical section, and seven validated patient-reported outcome (PRO) measures. Results from the Functional Assessment of HIV Infection (FAHI), Patient Satisfaction Questionnaire (PSQ-18), Patient Health Questionnaire (PHQ-2), and medication adherence visual analog scale (VAS) were presented to three US payers from Medicaid and commercial plans. Figure 1 shows an example screenshot from the RISE mobile app.

### Statistical Analyses

- Study measures were summarized using descriptive statistics. Frequencies and percentages were reported for categorical variables; means, medians, and standard errors for continuous variables. In addition, differences in respective scores were evaluated using analysis of variance (ANOVA).

**Figure 1. Example Screenshot of RISE Mobile App**



How strongly do you AGREE or DISAGREE with each of the following statements? Select one answer.

Health care providers are good about explaining the reason for medical tests.

1 - Strongly Agree
2 - Agree
3 - Uncertain
4 - Disagree
5 - Strongly Disagree

## Results

### Demographics

- Of the 11,687 PLHIV who passed screening, only 2,648 consented to participate in RISE. Completion rates for the measures ranged from 46.3%–44.7%.
- Overall, 1,226 completed the RISE study, with 1,134 patients being virally suppressed. A majority of the sample (n=695; 56.7%) completed the survey on an Android device. Virally suppressed participant demographics are presented in Table 1.
- The majority reported taking a single treatment regimen (63.2%) and were very satisfied with their treatment (76.3%). Most patients reported visiting their HIV provider every three (48.9%) or six (41.8%) months.
- Patients averaged 3.8 comorbidities, with most reporting experiencing anxiety (84.1%), other sexual transmitted infections (50.4%), and depression (47.0%).

### HRQoL by Insurance Groups

- Table 2 shows the results of the FAHI score by insurance group. All mean FAHI scores were larger on average for private health insurance; however, the key drivers of this increased HRQoL were the physical and functional/ global well-being scores.
- Medicaid patients showed a higher tendency for depression compared with other insurance groups with a score of 2.3 on the PHQ-2 (p<0.005).
- Patients with private health insurance reported higher general satisfaction (p=0.01), technical quality (p=0.04), and accessibility and convenience score (p=0.003) compared with other insurance groups; Medicaid patients reported higher satisfaction with financial aspects (p<0.005).
- Patients on private health insurance also reported higher adherence rates (mean=95.5) relative to patients on Medicaid, who reported the lowest adherence (mean=88.5) (p<0.005).

## Results (cont'd)

**Table 1. Virally Suppressed Patient Demographic Characteristics**

| Sociodemographic Characteristics | Virally-suppressed (n=1,134) |
|---|---|
| Gender | |
| Male | 933 (82.3%) |
| Female | 184 (16.2%) |
| Transgender – Male to Female | 10 (0.9%) |
| Transgender – Female to Male | 3 (0.3%) |
| Other | 4 (0.4%) |
| Sexual Orientation | |
| Heterosexual/Straight | 188 (16.6%) |
| Homosexual/Gay/Lesbian | 883 (77.9%) |
| Bisexual | 53 (4.7%) |
| Asexual | 3 (0.3%) |
| Other | 6 (0.5%) |
| Prefer Not to Say | 1 (0.1%) |
| Age | |
| Less than 50 Years Old | 641 (56.5%) |
| ≥50 Years Old | 489 (43.1%) |
| Missing | 4 (0.4%) |

| Sociodemographic Characteristics | Virally-suppressed (n=1,134) |
|---|---|
| Type of Health Insurance | |
| Private Health Insurance | 486 (42.9%) |
| Ryan White | 134 (11.8%) |
| Medicare | 256 (22.6%) |
| Medicaid | 191 (16.8%) |
| Military Healthcare (Tricare/VA) | 19 (1.7%) |
| Other Government Program | 33 (2.9%) |
| No Coverage of Any Type | 8 (0.7%) |
| Don't Know | 7 (0.6%) |
| US Region | |
| Northeast | 193 (17.0%) |
| Midwest | 176 (15.5%) |
| South | 497 (43.8%) |
| West | 268 (23.6%) |
| Ethnicity/Race | |
| Black, Non-Hispanic | 286 (25.2%) |
| White, Non-Hispanic | 617 (54.4%) |
| Hispanic or Latino | 181 (16.0%) |
| Other | 50 (4.4%) |

Abbreviations: US, United States; VA, Veteran's Affairs

**Table 2. FAHI Scores by Insurance Group**

| FAHI Score | Insurance (N=1,051) Private Health Insurance (n=480) | Ryan White (n=129) | Medicare (n=254) | Medicaid (n=188) | p-value[1] | Effect Size[2] |
|---|---|---|---|---|---|---|
| Total Score | | | | | | |
| Mean (SE) | 122.0 (1.41) | 110.5 (2.73) | 105.4 (1.94) | 104.1 (2.26) | <0.0001 | ES12=0.37<br>ES32=0.16<br>ES42=0.19 |
| Median (Q1, Q3) | 126.0 (101, 145) | 111.0 (87, 140) | 106.1 (85, 128) | 101.5 (81, 131) | | |
| Physical Well-being Score | | | | | | |
| Mean (SE) | 31.84 (0.37) | 28.80 (0.71) | 25.88 (0.51) | 26.24 (0.59) | <0.0001 | ES12=0.41<br>ES32=0.34<br>ES42=0.29 |
| Median (Q1, Q3) | 34.0 (28, 37) | 30.0 (23, 36) | 26.5 (20, 33) | 27.0 (20, 34) | | |
| Emotional Well-being Score | | | | | | |
| Mean (SE) | 26.83 (0.42) | 24.85 (0.80) | 26.18 (0.57) | 24.51 (0.67) | 0.0113 | ES12=0.22<br>ES32=0.14<br>ES42=0.04 |
| Median (Q1, Q3) | 28.5 (22, 33) | 26.0 (17, 34) | 27.0 (19, 34) | 25.5 (18, 32) | | |
| Functional and Global Well-being Score | | | | | | |
| Mean (SE) | 36.20 (0.47) | 32.05 (0.90) | 28.40 (0.64) | 29.56 (0.75) | <0.0001 | ES12=0.42<br>ES32=0.35<br>ES42=0.22 |
| Median (Q1, Q3) | 38.0 (30, 44) | 32.0 (25, 41) | 27.0 (21, 36) | 28.0 (22, 37) | | |
| Social Well-being Score | | | | | | |
| Mean (SE) | 18.99 (0.36) | 17.51 (0.69) | 17.75 (0.49) | 17.06 (0.58) | 0.0148 | ES12=0.19<br>ES32=0.03<br>ES42=0.05 |
| Median (Q1, Q3) | 19.0 (13, 25) | 18.0 (10, 24) | 18.0 (12, 24) | 17.0 (10, 24) | | |
| Cognitive Functioning Score | | | | | | |
| Mean (SE) | 8.11 (0.13) | 7.29 (0.26) | 7.19 (0.18) | 6.76 (0.21) | <0.0001 | ES12=0.28<br>ES32=0.03<br>ES42=0.17 |
| Median (Q1, Q3) | 8.0 (6, 10) | 7.0 (5, 10) | 7.0 (5, 9) | 7.0 (5, 9) | | |

Abbreviations: FAHI, Functional Assessment of HIV Infection; SE, standard error

### US Payer Interviews

- Payers acknowledged there was still unmet needs in HIV due to the increased longevity of PLHIV. These included living with comorbidities, adherence and compliance, and extended quality of life.
- Payers agreed that RWD studies provide an opportunity to capture the patient's voice but would be more likely if they were developed with the goal of providing actionable items (i.e., roadmaps to improving patient care).
  - A way to enhance RWD studies is to include payer stakeholders at the study design and initial development stage.
- Overall, the payers found the RISE results interesting but suggested the following:
  - Dive deeper into the healthcare system and generate actionable ways to improve care
  - Provide longitudinal follow-up with RISE patients to assess long-term changes in treatment care
  - Include case-control comparisons with US general population
- Physicians and case managers may benefit the most from studies such as RISE to help target ways to improve HRQoL within specific groups of interest.

## Limitations

- A number of limitations were identified—these pertained largely to the recruitment and data collection methods employed in the study. Participants were recruited via social media and were required to complete the survey via a mobile app, which may have contributed to the sociodemographic bias observed in the sample. There was evidence of reduced ethnic diversity in the study population with under-representation of Black and Hispanic individuals when compared with the US HIV population data (Center for Disease Control and Prevention 2016).
- In addition, there was a substantial survey non-completion rate (22.7%), such that potential participants completed eligibility questions, but did not complete informed consent. Only 46.3% of participants who consented downloaded the app and completed at least the sociodemographic and medical information section. This reduction in consent and mobile app download could also have contributed to the sociodemographic bias found in the sample, with certain participants being more likely to consent and download the app than others. Previous studies have indicated a significant difference in key characteristics of responders and non-responders in surveys (Hill et al. 1997).
- Study participants were required to self-report sociodemographic and biomedical characteristics, including their diagnostic and viral suppression status. While this is common practice for this type of cross-sectional survey study, some consideration should be given to the potential for unreliable or inaccurate reporting.

## References

Centers for Disease Control and Prevention (CDC). HIV Surveillance Report, 2016; vol. 28. http://www.cdc.gov/hiv/library/reports/hiv-surveillance.htmlc. Published November 2017. Accessed 19 November 2018.

Hill A, Roberts J, Ewings P, Gunnell D. Non-response bias in a lifestyle survey. Journal of Public Health. 1997;19(2):203-207.

## Conclusions

- Payers believe that RWD offers enormous potential for decision-making, especially in resource allocation or policy and formulary design.
- HIV patients still have unmet needs related to HRQoL that require consideration from a variety of stakeholders, including education and access to treatment to improve adherence.
- Electronic mobile patient surveys can be beneficial to inform decision-making in a wide range of diseases, including diabetes, asthma, and oncology.

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