Routine Collection of Patient-Reported Outcomes in HIV Clinics: Findings After >100,000 Assessments

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CNICS CFAR Network Of Integrated Clinical Systems

BACKGROUND

- Patient-reported measures and outcomes (PROs) provide important information to supplement routine clinical care and facilitate research.
- The CFAR Network of Integrated Clinical Systems (CNICS), a network of multi-provider, outpatient HIV clinics, has integrated PRO collection into routine care to improve clinical care and facilitate research.
- The routine collection of PROs was initiated at the University of Washington in 2009 and has since been expanded to 8 sites across the United States.

METHODS

- People living with HIV (PWH) presenting for care completed touch-screen-based assessments at routine clinic visits every 3-6 months using a web-based application.
- The length and number of instruments are optimized based on prior responses, skip patterns, time since the last PRO, and other factors.
- Assessments are available in English and Spanish, and more recently Amharic, Haitian Creole, and Brazilian Portuguese.
- The assessment includes validated instruments on antiretroviral medication adherence, mental health, substance use, quality of life, symptom burden, HIV stigma, social support, sexual risk behavior, intimate partner violence (IPV), and other clinically relevant domains.

RESULTS

- **20,455** unique PWH patients with an average of **5.7 PROs** completed
- **65% of patients** have 3 or more PROs completed
- CNICS PROs have been utilized in **80+ research papers** to date

Figure: PROS (n=116, 895) by Site and Region

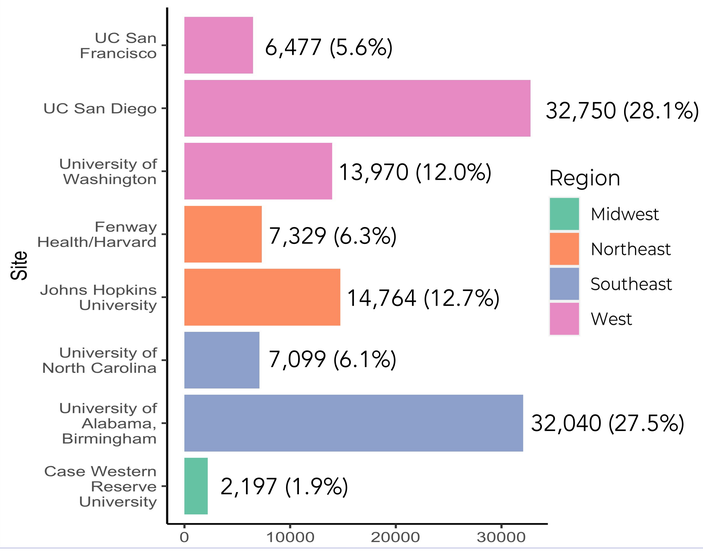

Table 1: Demographic Characteristics of PWH

	All Individuals (N=20455)
Age at Assessment	
Mean (SD)	43.9 (11.5)
Median [Range]	44 [18, 93]
Female Sex	3435 (16.8%)
Transgender	338 (1.7%)
Race	
White	8800 (43.0%)
Black	7508 (36.7%)
Hispanic	3046 (14.9%)
Other/Unknown	1101 (5.4%)

Table 2: Proportion of PWH Reporting Actionable Patient Reported Outcomes and Measures at first and last PRO and mean number of times reported

	Initial PRO % (95%CI)	Last PRO % (95%CI)	PROs per Person Mean (±SD)		Initial PRO % (95%CI)	Last PRO % (95%CI)	PROs per Person Mean (±SD)
Moderate-severe depression	25 (24, 26)	22 (21, 22)	5.3 (±4.4)	Current cocaine use	9 (8, 9)	8 (7, 8)	5.1 (±4.3)
Suicidal Ideation	4 (2, 4)	5 (5, 5)	5.0 (±4.3)	Current methamphetamine use	11(10, 11)	11 (10, 11)	5.1 (±4.3)
Anxiety/Panic Attack	28 (27, 29)	27 (25, 27)	5.3 (±4.5)	Current opioid use	4 (3, 4)	4 (3, 4)	5.1 (±4.3)
At-risk/Hazardous Alcohol use	19 (18, 19)	17 (16,17)	5.2 (±4.4)	Any current meth, cocaine, opioid use	18 (18, 19)	17 (17,18)	5.1 (±4.3)
Current Binge Alcohol use	35 (35, 36)	32 (31, 33)	5.3 (±4.5)	Intimate Partner Violence	11 (10,12)	10 (9, 10)	2.7 (±1.9)
Current Cigarette use	39 (38, 40)	36 (35, 37)	4.3 (±3.5)	Concern for STI	18 (18, 20)	18 (17, 19)	2.5 (±1.8)

CONCLUSIONS

- PRO collection can be efficiently and effectively implemented in the daily workflow of busy HIV primary care clinics.
- PROs provide insight into behavioral health challenges that may otherwise be unobserved.
- Key example: PROs identified a high prevalence of depression, anxiety, substance use, and intimate partner violence.

1 in 5 reported moderate-severe depression

1 in 3 reported binge drinking

More than **1 in 6** reported recreational cocaine, opioid, or methamphetamine use

1 in 10 reported concern for intimate partner violence

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