

# Evaluation of the Psychometric Properties of the HIV Disability Questionnaire (HDQ) Among Adults Living with HIV in London, United Kingdom: A Cross-Sectional Self-Report Measurement Study

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## Background:

The HIV Disability Questionnaire (HDQ)<sup>1,2</sup> is a patient-reported outcome measure (PROM) derived from the Episodic Disability Framework<sup>3</sup>, a conceptual framework developed from the perspectives of people living with HIV (PLHIV) in Canada, to characterise health-related challenges. The HDQ describes the presence, severity and episodic nature of disability, measuring across six domains: physical, cognitive and, mental and emotional health symptoms and impairments, uncertainty, difficulty with day-to-day activities and challenges to social inclusion. The HDQ is novel in that it is the sole HIV-specific PROM of disability<sup>4</sup>, and has demonstrated validity and reliability when used with PLHIV in Canada<sup>5</sup>, Ireland<sup>6</sup>, and the United States<sup>7</sup>. However, the ability of the HDQ to measure disability in the United Kingdom (UK) is unknown. Our aim was to assess the psychometric properties, specifically internal consistency reliability, precision of measurement and construct validity of the HDQ for its ability to measure disability experienced by PLHIV in London, UK.

Table One: HDQ Summary Scores for Participants in the UK Sample (n=243)

HDQ Subscale (# items)	HDQ Presence (Median, IQR) (Range)	HDQ Severity Score (Median, IQR) (Range)	HDQ Episodic Presence Score (Median; IQR) (Range)*
Physical symptoms and Impairments (20 items)	25 (15, 45) Range: 0-90	9 (4, 18) Range: 0-58	5 (0, 20) Range: 0-80
Cognitive symptoms and impairments (3 items)	33 (0, 67) Range: 0-100	8 (0, 25) Range: 0-100	0 (0, 0) Range: 0-100
Mental-emotional health symptoms and impairments (11 items)	54 (27, 82) Range: 0-100	18 (7, 34) Range: 0-89	0 (0, 27) Range: 0-100
Uncertainty (14 items)	<b>64 (43, 86)</b> Range: 0-100	<b>27 (14, 41)</b> Range: 0-98	0 (0, 7) Range: 0-86
Difficulties with Day-to-Day Activities (9 items)	0 (0, 22) Range: 0-100	0 (0, 7) Range: 0-61	0 (0, 0) Range: 0-89
Challenges to Social Inclusion (12 items)	33 (17, 58) Range: 0-100	12 (4, 27) Range: 0-81	0 (0, 0) Range: 0-83
Total HDQ Score	38 (22, 57) Range: 0-93	14 (8, 23) Range: 0-70	2 (0, 16) Range: 0-81

Higher scores indicate greater presence, severity and episodic nature of disability.

**Bold** indicates the highest score across all domains;

\*For the episodic scores, due to the higher rate of missingness we conducted a post hoc comparison and found no difference in episodic scores post median imputation.

## Methods:

This is a cross-sectional self-report measurement study. We recruited adults living with HIV during routine outpatient HIV care in London, UK. We administered the HDQ paired with seven criterion measures and a demographic questionnaire. We calculated median and interquartile ranges (IQR) for HDQ disability presence, severity and episodic scores. For internal consistency reliability, we calculated Cronbach's alpha ( $\alpha$ ) and Kuder-Richardson-20 (KR-20) statistics for disability and episodic scores, respectively (>0.80 considered acceptable). For precision, we calculated the smallest detectable change (SDC) for each HDQ severity domain. For construct validity, we tested 36 a priori hypotheses assessing correlations between HDQ and criterion measure scores (>75% confirmed hypotheses demonstrated construct validity).

Table Two: Internal Consistency Reliability for HDQ Items (n=243)

HDQ Items	HDQ Severity Scale		HDQ Episodic Scale	
	Cronbach Alpha (Raw values)	95% confidence interval	Kuder-Richardson Statistic (Raw values)	95% confidence interval
HDQ Items (all)	0.96	0.96, 0.97	0.95	0.94, 0.96
Physical Symptoms and Impairments	0.87	0.85, 0.90	0.84	0.80, 0.88
Cognitive Symptoms and Impairments	0.85	0.80, 0.90	0.74	0.66, 0.83
Mental and Emotional Health Symptoms and Impairments	0.93	0.91, 0.94	0.90	0.87, 0.92
Uncertainty	0.90	0.88, 0.92	0.91	0.89, 0.94
Difficulty with Day-to-Day Activities	0.90	0.86, 0.93	0.82	0.73, 0.91
Challenges to Social Inclusion	0.87	0.84, 0.90	0.84	0.79, 0.89

95% Confidence Interval: asymptotically distribution free (ADF) for non-normal data.  
 Median imputation of episodic scores; >0.8 defined as acceptable for individual patients

## Results:

Of N=243 participants, all identified as male, median age 40 years, 94% taking antiretroviral therapy, and 22% were living with >2 concurrent health conditions. Median HDQ severity domain scores ranged from 0 (IQR: 0,7) (difficulties with day-to-day activities domain) to 27 (IQR: 14, 41) (uncertainty domain) (Table One). Cronbach's alpha for the HDQ severity scale ranged from 0.85 (95%CI: 0.80-0.90) in the cognitive domain to 0.93 (95%CI: 0.91-0.94) in the mental-emotional domain (Table Two). The KR-20 statistic for the episodic scale ranged from 0.74 (95%CI: 0.66-0.83) in the cognitive domain to 0.91 (95%CI: 0.89-0.94) in the uncertainty domain. The SDC ranged from 7.3-15.0 points for the difficulties with day-to-day activities and cognitive symptoms domains, respectively. The majority of the construct validity hypothesis (n=30/36, 83%) were confirmed.

## Conclusion:

The HDQ possesses internal consistency reliability and construct validity with varied precision when administered to males living with HIV in London, UK. Clinicians and researchers may use the HDQ to measure the nature and extent of disability experienced by PLHIV in the UK, and to inform HIV service provision to address the health-related challenges among PLHIV. Future research should consider cross-cultural, international comparisons of disability among PLHIV, and the ability of the HDQ to detect clinically important changes in disability for examining effectiveness of interventions.



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