Assessing the sensibility and utility of a short-form version of the HIV Disability Questionnaire in clinical practice settings in Canada, Ireland and the USA: a mixed methods study

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ABSTRACT

Objectives The Short-Form HIV Disability Questionnaire (SF-HDQ) was developed to measure the presence, severity, and episodic nature of health challenges across six domains. Our aim was to assess the sensibility, utility, and implementation of the SF-HDQ in clinical practice.

Design Mixed methods study design involving semistructured interviews and questionnaire administration.

Participants We recruited adults living with HIV and HIV clinicians in Canada, Ireland, and the USA.

Methods We electronically administered the SF-HDQ followed by a Sensitivity Questionnaire (face and content validity, ease of usage, format) and conducted semistructured interviews to explore the utility and implementation of the SF-HDQ in clinical practice. The threshold for sensibility was a median score of ≥5/7 (adults living with HIV) and ≥4/7 (HIV clinicians) for ≥80% of items. Qualitative interview data were analysed using directed content analysis.

Results Median sensibility scores were ≥5 (adults living with HIV; n=29) and ≥4 (HIV clinicians; n=16) for 18/19 (95%) items. Interview data indicated that the SF-HDQ represents the health-related challenges of living with HIV and other concurrent health conditions; captures the daily episodic nature of HIV; and is easy to use. Clinical utility included measuring health challenges and change over time, guiding referral to specialists and services, setting goals, facilitating communication and fostering a multidisciplinary approach to care. Considerations for implementation included flexible, person-centred approaches to administration, and communicating scores based on personal preferences.

Conclusions The SF-HDQ possesses sensibility and utility for use in clinical settings with adults living with HIV and HIV clinicians in three countries.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Our mixed methods study involving qualitative and quantitative approaches ensured a comprehensive assessment of sensibility, utility and implementation of the Short-Form HIV Disability Questionnaire (SF-HDQ) in clinical practice.

⇒ Our multisite approach spanning different clinical contexts with both adults living with HIV and healthcare practitioners enabled us to assess the utility of the electronic mode of SF-HDQ administration, and examine considerations for implementation across three different healthcare contexts.

⇒ This study draws on a strong conceptual foundation of episodic disability (Episodic Disability Framework) and measurement of disability (SF-HDQ).

⇒ Given our SF-HDQ assessment was focused on electronic administration, this limited participation to adults living with HIV who had access to, and comfort with, the use of technology to complete the questionnaires and participate in the interview in a web-based format.

INTRODUCTION

In developed countries such as Canada, Ireland, and the USA, HIV is now experienced as a chronic illness. In 2018, an estimated 51% of Americans living with HIV were aged 50 and older and similar trends are forecast in other countries such as Canada and the UK with widespread access to treatment. Individuals with HIV can reach life expectancies similar to the general population. Thus, more individuals are living longer with the health consequences of HIV. People living with HIV can experience chronic conditions at higher rates compared with the general
ageing population \cite{16} such as cardiovascular disease \cite{7}, bone and joint disorders \cite{8,9}, diabetes \cite{10}, frailty \cite{11}, neurocognitive disorders \cite{12,13} and some forms of cancer \cite{14}. This multimorbidity can increase the severity and complexity of health consequences of those ageing with HIV \cite{15-18} collectively referred to as disability.\cite{17,19}

Disability is defined by people living with HIV as any physical, cognitive, mental-emotional symptoms, difficulties with day-to-day activities, challenges to social inclusion and uncertainty about future health.\cite{17} Disability including fatigue, pain, challenges engaging in employment and age-related issues of frailty, coupled with poor access to services, stigma and poverty, can pose barriers to remaining engaged in care, for people living with HIV.\cite{20}

Standardised patient-reported outcome measures (PROMs), developed to capture the nature and extent of disability and its fluctuation over time, are critical to identify the health priorities for those ageing with HIV, to guide the provision of timely and appropriate care and to determine the effectiveness of interventions.\cite{21-23} We developed a 69-item PROM, the HIV Disability Questionnaire (HDQ), to measure the presence, severity and episodic nature of disability experienced by people living with HIV.\cite{24} Derived from the *Episodic Disability Framework*, the HDQ measures disability across 69 items grouped into six domains: (1) physical, (2) mental-emotional, and (3) cognitive symptoms and impairments; (4) difficulties with day-to-day activities; (5) challenges to social inclusion; and (6) uncertainty about future health.\cite{25} The HDQ addresses gaps in previously existing health status measures to capture uncertainty (eg, worrying about the future) and challenges to social inclusion (eg, work, parental roles, relationships).\cite{26} In addition, the HDQ possesses sensibility, reliability and validity for use among people living with HIV in Canada, UK, USA and Ireland.\cite{27-29}

To date, the HDQ has been used primarily as a paper-based tool in research-focused settings, with little uptake in clinical practice due to concerns about the time it takes to complete. We recently revised the HDQ using Rasch analysis to a short-form version of the questionnaire (SF-HDQ) to enhance the feasibility for use in clinical practice.\cite{30} To date, the development and structural validity of the SF-HDQ primarily have been established in Canada.\cite{30} However, the sensibility, specifically the comprehensiveness, clarity, ease of usage and format for use of the SF-HDQ in clinical settings, is unknown.\cite{31-35}

Our aims were to (1) assess the sensibility (face and content validity, ease of usage, format) of the SF-HDQ, (2) explore the perspectives on the utility of the electronic SF-HDQ in clinical practice, and (3) identify implementation considerations for administration and communicating scores of the SF-HDQ in clinical practice in Canada, Ireland and the USA from the perspectives of adults living with HIV and HIV healthcare practitioners (HCP).

### METHODS

#### Study design

We conducted a mixed methods study with a convergent design using quantitative (questionnaire) and qualitative (interview) methods of data collection.

#### Study setting

This study was conducted at three clinical settings in three countries: Canada (Casey House, Toronto), Ireland (Department of Genitourinary Medicine and Infectious Diseases, St James’s Hospital, Dublin) and the USA (UCHealth Infectious Disease/Travel Clinic, University of Colorado). The UCHealth Infectious Disease/Travel Clinic is located in Aurora, Colorado, and provides care to people living with HIV in the Denver metropolitan area, and henceforth is referred to as the ‘Denver site’. The Dublin and Denver sites are HIV outpatient clinics and the Toronto site is a specialty HIV hospital including an inpatient and day health programme for people living with HIV. We received ethics approval at the three sites: University of Toronto (Protocol #38152), University of Colorado (Protocol #19–1895) and St. James’s Hospital (Protocol #2019–12) (online supplemental file 1).

#### Patient and public involvement

This research builds on a long-standing academic–clinical–community partnership among people ageing with HIV, researchers and clinicians who identified measurement of disability as a key research priority in HIV, ageing and rehabilitation as part of the Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC).\cite{34} Community members living with HIV were involved in the development of the original HDQ and the refinement of the SF-HDQ.

#### Participants

**Adults living with HIV**

We recruited adults (18 years of age or older) living with HIV from each site using a recruitment poster asking interested individuals to contact the local study investigator (by email or telephone). We used purposive sampling to obtain diversity in the sample based on age (≥50 years, <50 years) and clinical site.

**HIV Healthcare Practitioners (HCPs)**

We recruited HCPs working in HIV care at each site who self-identified as having a role in addressing disability due to HIV, ageing and multimorbidity. We emailed a targeted sample of HIV HCPs including (but not limited to) physicians, rehabilitation professionals (occupational therapy, physiotherapy), social workers and nurses requesting their participation in the study.

We obtained written or verbal consent from all participants prior to the scheduled administration of the questionnaires and interview.

#### Data collection

Adults living with HIV completed the electronic version of the SF-HDQ,\cite{30} a global rating scale of disability, a
Sensibility Questionnaire and a demographic questionnaire using the web-based software Qualtrics, (either via tablet at the clinical site or remotely via an email link), followed by a one-to-one semistructured interview (either in person or via Zoom). HCPs were asked to review the electronic version of the SF-HDQ and complete the Sensibility Questionnaire (via Qualtrics) prior to participating in the semistructured interview. Team members in Canada (RA), Ireland (NO’S) and the USA (MBoy) (all female) conducted the interviews and questionnaire administration. None had a prior relationship with participants.

Questionnaires
SF-HDQ: The SF-HDQ is a 35-item outcome measure developed to describe the health-related challenges experienced when living with HIV or other health conditions across six areas: physical, cognitive and mental-emotional symptoms and impairments; uncertainty or worry about the future; difficulties with day-to-day activities; and challenges to social inclusion. Participants were asked to rate the presence and severity of each health-related challenge and to indicate whether it fluctuated in the past week. The SF-HDQ possesses structural validity for use with adults living with HIV.

Sensibility: Using Feinstein’s sensibility criteria, comprising 19 statements (7-point response scale ranging from highly disagree to highly agree), participants living with HIV and HCPs were asked about perspectives on face and content validity, mode of administration, format and ease of usage of the SF-HDQ. See online supplemental file 2 for the Sensibility Questionnaire.

To describe the characteristics of the sample, we administered a global rating scale of disability whereby participants living with HIV were asked to check the box (minimum, moderate or severe) that best described how they would rate their health-related challenges (or disability) that day. Participants were also asked to complete a demographic questionnaire that comprised items including age, gender, concurrent health conditions, living situation, antiretroviral use and overall perception of health.

Interviews
Sensibility and utility: We asked about the utility of the SF-HDQ in practice and participants’ experiences with completing or perspectives on potentially administering the SF-HDQ. We also asked about perceived facilitators and challenges related to administering the SF-HDQ in a clinical setting and considerations related to administration including feasibility, format (electronic or paper), when to administer, who should administer, how often to administer and whether and how to communicate SF-HDQ score reports with the patients. See online supplemental file 3 for the Interview Guide.

Interviews were conducted by one interviewer in Canada, one in Ireland and two interviewers in the USA. Due to restrictions of the COVID-19 pandemic, most interviews were conducted using the video platform Zoom. All interviews were audio recorded, transcribed verbatim and deidentified for analysis. Data collection and analysis were done concurrently. We refined the interview guide twice over the course of the study, adding probing questions based on the analysis of earlier interviews.

Participants in Toronto, Ontario and Denver, Colorado were given a $230 (or equivalent) gift card as a token of appreciation. Participants in Dublin, Ireland were not given a token of appreciation in keeping with the research procedures at St James’s Hospital.

Analysis
SF-HDQ scoring
We calculated the median (IQR) of SF-HDQ scores. Severity domain scores were calculated using the algorithm developed through Rasch analysis. Presence and episodic scores included a simple sum transformed on a scale of 0–100 with higher scores indicating a greater presence, severity and episodic nature of disability.

Sensibility Questionnaire
Each sensibility item was rated on an ordinal scale of 1 (highly disagree) to 7 (highly agree). Participants selected the numeric response on the scale for each item. We calculated the median scores for each of the items. We considered the SF-HDQ sensible if median scores were ≥5/7 for adults living with HIV and ≥4/7 for HCPs for at least 80% of the items, and if no items had median scores of ≤3.

Interview data
We analysed interview transcripts using content analytical techniques. For sensibility assessment, we used directed content analysis, using initial coding categories derived from Feinstein’s Sensibility Framework. For utility and implementation considerations, we used a conventional content analytical approach. Transcripts from participants living with HIV and HIV HCPs were analysed collectively using the same coding scheme. The core qualitative team (MS, KKO’B, PS) met three times. They initially reviewed two transcripts independently and met to develop, by consensus, a preliminary list of codes and categories based on the interview guide and the two transcripts. The lead analyst (MS) coded five additional transcripts using the preliminary list of codes and then selected three transcripts for the core team to review and discuss. After all the transcripts were coded, the core team reviewed an additional three transcripts and coding reports from the full data set. At this meeting, the relationships between coding categories were discussed and key themes were identified. Finally, the larger full team met to review, interpret and finalise the themes in relation to our study objectives. NVivo V.11.0 (QSR International) software was used for data management.

Sample size
Our sample size estimation was based on our qualitative approach using interviews to assess sensibility and utility. Based on our previous sensibility assessment of the
original (long-form) HDQ (involving interviews with 22 adults living with HIV and five clinicians in one country)\(^27\) and the estimated number of interviews required to achieve an understanding of interview data (16–24 interviews)\(^38\) we anticipated a total of 30 adults living with HIV (10 per site) and 15 HCPs (five per site) for a total of 45 participants were sufficient to provide perspectives of sensibility and utility across sites.

**RESULTS**

We conducted 45 interviews (29 with adults living with HIV and 16 with HIV HCPs) between 3 March 2020 and February 2021, each approximately 45 min in duration. Sixteen interviews were held in person (five participants living with HIV in Toronto; and five people living with HIV and six HCPs in Dublin), and 29 interviews were conducted online through Zoom.

**Participant characteristics**

See table 1 for characteristics of the participants living with HIV. Eight participants in Toronto described having past experiences with the longer version of the HDQ, whereas no participant in Dublin or Denver had any prior experiences with the HDQ. Thirteen participants (46%) reported having minimum, 11 (39%) moderate and 4 (14%) severe health challenges.

Across the sample of adults living with HIV (n=29), the highest SF-HDQ presence and severity scores were in the cognitive (median score: 67) and mental-emotional (median score: 37) domains; and the highest episodic scores were in the mental-emotional and physical domains.

**Table 1** Characteristics of participants living with HIV

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample (n=29)</th>
<th>Toronto (n=10)</th>
<th>Denver (n=10)</th>
<th>Dublin (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years) (median, 25th, 75th percentiles)</td>
<td>57 (51, 63)</td>
<td>60 (55, 66)</td>
<td>49 (37, 63)</td>
<td>57 (53, 63)</td>
</tr>
<tr>
<td>Gender (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Woman</td>
<td>10 (35)</td>
<td>2 (20)</td>
<td>5 (50)</td>
<td>3 (33)</td>
</tr>
<tr>
<td>Man</td>
<td>19 (66)</td>
<td>8 (80)</td>
<td>5 (50)</td>
<td>6 (67)</td>
</tr>
<tr>
<td>Partnership status (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single, separated or divorced, or widowed</td>
<td>15 (66)</td>
<td>10 (100)</td>
<td>5 (50)</td>
<td>5 (56)</td>
</tr>
<tr>
<td>Married, common law, partner or relationship</td>
<td>8 (28)</td>
<td>0 (0)</td>
<td>5 (50)</td>
<td>3 (33)</td>
</tr>
<tr>
<td>Has children (%)</td>
<td>12 (41)</td>
<td>3 (30)</td>
<td>5 (50)</td>
<td>4 (44)</td>
</tr>
<tr>
<td>Living alone (%)</td>
<td>14 (48)</td>
<td>7 (70)</td>
<td>3 (30)</td>
<td>4 (44)</td>
</tr>
<tr>
<td>Employed (full time or part-time) (%)</td>
<td>7 (24)</td>
<td>1 (10)</td>
<td>4 (40)</td>
<td>3 (33)</td>
</tr>
<tr>
<td>Highest level of education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed university or postgraduate education (%)</td>
<td>6 (21)</td>
<td>2 (20)</td>
<td>4 (40)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Antiretroviral therapy use (%)</td>
<td>27 (93)</td>
<td>9 (90)</td>
<td>10 (100)</td>
<td>8 (89)</td>
</tr>
<tr>
<td>Undetectable viral load (&lt;50 copies/mL) (%)</td>
<td>26 (90)</td>
<td>10 (100)</td>
<td>10 (100)</td>
<td>6 (67)</td>
</tr>
<tr>
<td>Median number of concurrent health conditions (25th, 75th percentiles)</td>
<td>7 (4, 10)</td>
<td>10 (6, 14)</td>
<td>7 (5, 8)</td>
<td>4 (2, 11)</td>
</tr>
<tr>
<td>Common concurrent health conditions (≥30% of sample) (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health condition</td>
<td>17 (59)</td>
<td>8 (80)</td>
<td>5 (50)</td>
<td>4 (44)</td>
</tr>
<tr>
<td>Trouble sleeping</td>
<td>16 (55)</td>
<td>6 (60)</td>
<td>5 (50)</td>
<td>5 (56)</td>
</tr>
<tr>
<td>Chronic pain (joint)</td>
<td>15 (52)</td>
<td>7 (70)</td>
<td>5 (50)</td>
<td>3 (33)</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>12 (41)</td>
<td>6 (60)</td>
<td>3 (30)</td>
<td>3 (33)</td>
</tr>
<tr>
<td>High cholesterol</td>
<td>11 (38)</td>
<td>4 (40)</td>
<td>5 (50)</td>
<td>2 (22)</td>
</tr>
<tr>
<td>Osteopenia or osteoporosis</td>
<td>10 (35)</td>
<td>0 (0)</td>
<td>4 (40)</td>
<td>6 (67)</td>
</tr>
<tr>
<td>Chronic pain (muscle)</td>
<td>9 (31)</td>
<td>5 (50)</td>
<td>3 (30)</td>
<td>1 (11)</td>
</tr>
<tr>
<td>Cognitive decline</td>
<td>9 (31)</td>
<td>5 (50)</td>
<td>1 (10)</td>
<td>3 (33)</td>
</tr>
<tr>
<td>Gastrointestinal conditions</td>
<td>9 (31)</td>
<td>3 (30)</td>
<td>4 (40)</td>
<td>2 (22)</td>
</tr>
<tr>
<td>General health status (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>9 (31)</td>
<td>3 (30)</td>
<td>3 (30)</td>
<td>3 (33)</td>
</tr>
<tr>
<td>Very good</td>
<td>7 (24)</td>
<td>3 (30)</td>
<td>3 (30)</td>
<td>1 (11)</td>
</tr>
<tr>
<td>Good</td>
<td>7 (24)</td>
<td>3 (30)</td>
<td>2 (20)</td>
<td>2 (22)</td>
</tr>
<tr>
<td>Fair</td>
<td>3 (10)</td>
<td>0 (0)</td>
<td>1 (10)</td>
<td>2 (22)</td>
</tr>
<tr>
<td>Poor</td>
<td>2 (7)</td>
<td>1 (10)</td>
<td>1 (10)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

Characteristics reported for 28 of 29 participants (one participant from Dublin site did not complete).
Sensibility, utility and implementation considerations of the SF-HDQ

We describe sensibility findings derived in combination from the Sensibility Questionnaire and interview data. Results pertaining to utility and implementation considerations were drawn from the interview data. We reference quotations with each participant number (P), the target population: participant living with HIV (PLWH) or healthcare practitioner (HCP); and country: Canada (CAN), Ireland (IRE) or United States (US).

Sensibility

Collectively, results from the Sensibility Questionnaire and interviews indicate that the SF-HDQ possesses face and content validity and is easy to use with adults living with HIV. Sensibility Questionnaire results indicate the SF-HDQ met our criterion for sensibility with adults living with HIV (table 3) but not HCPs, because one item had a median score ≤ 3 (item 9—There were items missing in this questionnaire that should be included) (table 4).

However, the interview findings indicate that the SF-HDQ is comprehensive, represents health-related challenges (disability) living with HIV, adequately captures the episodic nature of disability and captures disability related to other conditions. Participants indicated that the SF-HDQ was easy to complete, and that the items were easy to understand (ease of usage) and the format was easy to use (adequate length, adequate response options). When asked about items missing from the SF-HDQ, a few participants commented on the importance of considering HIV stigma, HIV disclosure, addiction and substance use when measuring disability living with HIV. Participants also provided reflections on disability terminology.

SF-HDQ items represent health-related challenges (disability) living with HIV

Participants agreed that the items in the SF-HDQ capture the disability experienced living with HIV, indicating
the questionnaire possesses face and content validity. Participants remarked that the SF-HDQ was ’very comprehensive’ (CAN-PLWH-P20, IRE-HCP-P11), and that ’more or less, it covers everything’ (IRE-PLWH-P10). Similarly, an HCP described: ’I think almost all of [the items] capture something important that a lot of our clients’ experience’ (CAN-HCP-P2).

This was supported by responses on the Sensibility Questionnaire data, where participants indicated that the SF-HDQ captures all of the important elements of disability and is useful in describing disability experienced by adults living with HIV (tables 3 and 4).

**Importance of capturing the episodic nature of disability**

Both groups of participants indicated the importance of measuring the episodic nature of HIV in the SF-HDQ. One PLWH noted that asking about how health-related challenges fluctuated in the past week was ’probably one of the best questions’. HCPs also believed the questions about fluctuations were important. As one HCP noted:

> I think it needs to be understood that there is an episodic nature to HIV so that people can be more supportive of people when they say I’m just really not feeling up to coming and not getting frustrated or angry with them or punishing them for that. I think that kind of information needs to be documented.

(CAN-HCP-P1)

A range of viewpoints emerged on the ideal time frame for measuring fluctuations with health challenges. One PLWH reflected, ’Sometimes a week is not enough and sometimes it’s too much. But when you’re dealing with stuff, it fluctuates constantly’ (CAN-PLWH-P5). Similarly, an HCP noted: ‘I like that there’s a difference between like last week and this week, what’s happened. But it also changes from the beginning of the month to the end of the month for some of our clients’ (CAN-HCP-P3).

**SF-HDQ captures disability related to other health conditions**

Some participants indicated that health challenges captured in the SF-HDQ were not always HIV related. For
instance, one PLWH indicated that while struggling to maintain safe and stable housing was a prominent challenge, it was not attributed to their HIV status as stated in the item wording. ‘What do you mean I'm worried about my financial and my security living with HIV? What does that have to do with anything? What does HIV have to do with any type of financial anything?’ (US-PLWH-P11).

Similarly, participants described how living with uncertainty or worrying about the future was an important aspect of their health but explained that it related to ageing or living with other chronic conditions. Others attributed uncertainty to the COVID-19 pandemic, as this PLWH explained:

…uncertainty, you know I answered that quite a bit because so many things are uncertain…I was kind of basing it on right now with COVID and everything you know. But it kept stressing right now today and that’s also why I answered some of the things about kind of being lonely and stuff and social inclusion my answer to those because I would have answered those differently if it wasn’t COVID. (US-PLWH-P20)

Ease of usage and format
Participants reported positive experiences completing the SF-HDQ. Most described how the questionnaire was easy to complete, stating: ‘the questions were pretty much straightforward’ (US-PLWH-P12), and ‘the options are pretty easy to choose’ (US-HCP-P21). The majority described language in the SF-HDQ as easy to understand and ‘pretty accessible’ (IRE-HCP-P11). One participant explained:

I think the wording on it was really good and you know being able to read it without saying ‘can you help me’ with this or whatever was really good. That’s what I like is the fact that you know don’t give me these very big words … I was able to understand this survey without having to ask you ‘what does this mean?’ (US-PLWH-P11)
Most participants living with HIV thought that the length of the SF-HDQ was appropriate, describing how ‘It wasn’t too long and it wasn’t too short. In my opinion it was just right in the middle’ and ‘it didn’t take much time at all’ (US-PLWH-P12). These interview findings are supported by responses to the Sensibility Questionnaires demonstrating that participants found the SF-HDQ easy to understand and complete, has reasonable length and possesses adequate response options (tables 3 and 4).

Disability terminology
A few participants reflected on the term ‘disability’ as used to describe health-related challenges in the context of the SF-HDQ. An HCP reflected:

“It’s a label. It’s essentially calling someone disabled and especially in a world where we’re trying to move from you know living with HIV is no longer a disability. (US-HCP-P20)

Some participants similarly did not view themselves as disabled, as described by this participant: ‘I haven’t lost my hand or anything like that. I am not disabled. I’m not disabled through HIV or whatever’ (IRE-PLWH-P5).

Utility
Interview data on utility of the SF-HDQ reflected two themes: (1) clinical use of the SF-HDQ and (2) activities facilitated by the process of completing the SF-HDQ.

Clinical use of the SF-HDQ
The majority of participants believed the SF-HDQ would be useful in clinical practice, specifically describing health challenges, assessing change in disability over time and guiding referrals to health services and support.

Participants living with HIV and HCP participants described how the SF-HDQ could be used in a clinical setting to provide a snapshot at a point in time: ‘It gives you a basic understanding of what people with HIV are going through, what challenges they have’ (US-PLWH-P15). One PLWH reflected on how, ‘I think it can get to help to get to know somebody. Those questions they can probably get sort of a sense on what their day-to-day life is’ (US-PLWH-P12). Similarly, one HCP said, ‘I think it’s quite useful to get an idea from their patient about how HIV impacts on their day to day lives’ (IRE-HCP-P15).

Participants noted that the SF-HDQ could be useful for assessing change or stability of disability over time. One PLWH noted, ‘I would use it … maybe before the first visit or on a continuing basis to see how it changes’ (US-PLWH-P15). Similarly, an HCP participant described how administering the SF-HDQ once a year would be ‘good just to track how they are during the course of having HIV’ (IRE-HCP-P11). The same HCP noted that the SF-HDQ might be useful ‘if the patient states that they are in a bad place, it might be a useful tool to do it straight away just to see where they actually are comparatively and to the previous visit’ (IRE-HCP-P11).

Activities facilitated by the process of completing the SF-HDQ
Although the SF-HDQ is an outcome measure developed to describe health challenges living with HIV and other concurrent conditions, participants indicated that the process of completing the questionnaire can inform goal setting, facilitate communication (between patients and HCPs and between different HCPs), foster a multidimensional approach to care and facilitate self-reflection about one’s own health living with HIV.

Informing goal setting
Participants described the SF-HDQ as a tool to inform the process of goal setting. One PLWH referred to the SF-HDQ as a tool to ‘create a roadmap on how to treat this individual to get to an optimal outcome’ (US-PLWH-P19). An HCP participant identified how, ‘… it would be a good one for goal setting which was from a physiotherapy perspective as well’ (IRE-HCP-P11). An HCP articulated how the SF-HDQ could facilitate goal setting beyond impairment-related treatment goals to more broadly considering social participation, ‘I think to develop further goals that would be more to a participation level and more to a community level’ (CAN-HCP-P1). Another health practitioner explained how SF-HDQ results could be used to identify areas in which to focus on goals:

If you’re using it for an annual physical as something to do a global assessment, to look at the overall wellness of the patient and identify things to work on through the next year … that could be you know like a useful thing for the team to have access to, to identify goals for the patient to work on. (CAN-HCP-P4)

Facilitating communication
Both HCPs and participants living with HIV referred to how the SF-HDQ can ‘open up a conversation’ (IRE-PLWH-8) (US-HCP-P23) and how ‘it opens a door. It gives the health practitioner information of things that they need to ask about or deal with’ (CAN-PLWH-P5). One HCP described how the SF-HDQ ‘gives you the foundation to develop a conversation around all those items needed’ (IRE-HCP-P11), and how the SF-HDQ can identify areas to target interventions and referrals to services. One PLWH reflected:

It can be used to maybe start a conversation towards something that maybe they didn’t realize was there. So, it might be able to help a doctor or a physician to say ‘hey we also have these other programs that might help you because it seems like you have a little more anxiety’. So, I think it would be beneficial in that way. (US-PLWH-P13)

Some participants noted that the SF-HDQ could facilitate communication between clinicians. An HCP described, “It definitely would be helpful for communication like if we could fax it back with a referral or something as part of [the patient’s] treatment plan and things like that” (CAN-HCP-P2).

Some participants identified the SF-HDQ as a tool for encouraging self-reflection of one’s health living with
HIV which can facilitate discussions with one’s HCP and possibly between practitioners. One PLWH explained, ‘I liked it because it just really brings out the fact that wait, am I feeling lonely. It made me think about some things but actually I thought it was really good’ (US-PLWH-P11). Another person living with HIV shared, ‘some of the questions I never even really thought about. So it helps me to think about them. So they were good for me to look at’ (US-PLWH-P13). Similarly, an HCP noted:

It is a benefit I think because it’ll highlight things that maybe the patient hasn’t thought to bring up with the clinician they saw. Always it’s good for them maybe to think about things that maybe are impacting their life or their quality of life. (IRE-HCP-P13)

Fostering a multidisciplinary approach to care
Participants described how the SF-HDQ went beyond biomedical issues and highlighted the multidimensional nature of health and importance of a multidisciplinary approach to care. One PLWH believed that the SF-HDQ could be used ‘for people to really see how they feel, how they are, instead of just getting medication and take your medication … that is it’ (US-PLWH-P8). Similarly, an HCP noted how the questionnaire ‘could help us identify the needs of the patients outside of their actual physical needs as in their blood pressure, their bloods and things like that. So, the greater needs, you know the full holistic needs of the patient’ (IRE-HCP-P14). Another HCP from Toronto explained:

I think it’s great that it’s so comprehensive in a sense because it raises your awareness to issues that you know may not be aware of for certain patients right because the nature of family practice is people come in and they have a complaint of the day. Often with HIV it’s all focused on meds and med adherence and side effects and you know counts and stuff and it’s less focused on peoples’ overall wellness. I like it because it reminds us of the importance of the overall wellness and that taking the time to think outside the box … to think less about health counts and cell counts and more about peoples’ kind of lived experience every day. (CAN-HCP-P4)

Implementation considerations
Considerations for implementation of the electronic SF-HDQ spanned administration and communication of questionnaire scores in clinical practice.

Administration
Considerations pertaining to administration included burden of administration (time, conundrum of identifying health challenges with limited resources to address them, logistical issues of security, internet, space), and the importance of person-centred approaches for tailoring the mode of administration (use of technology, literacy, cognition) and offering flexible options for modes of processes of administration (format, location, timing and persons involved in administration).

Table 5 includes participants’ quotes related to perspectives on the burden of administration and the need for person-centred approaches for administration of the electronic SF-HDQ in a clinical setting.

Communication of scores
Participants had mixed preferences about communicating SF-HDQ scores among patients and practitioners. While most participants indicated preferences for HCPs to receive SF-HDQ of their patients, participants living with HIV preferences varied regarding their receipt of personal scores. For instance, some participants living with HIV did not want to know their SF-HDQ scores, in order to prevent them from worrying about their health or the meaning of the scores. Alternatively, some participants living with HIV expressed their interest in receiving their scores to provide further insights into and to help identify any changes in their overall health. Interview findings highlighted the importance of considering personal preferences for communicating SF-HDQ scores among persons living with HIV and their HCPs, and the importance of explaining and interpreting SF-HDQ scores with persons living with HIV (table 6).

DISCUSSION
Overall, the SF-HDQ appears to demonstrate sensibility for use with adults living with HIV and HIV HCPs across the three healthcare contexts. The SF-HDQ was considered to possess utility for describing health-related challenges across health dimensions, identifying areas for follow-up or intervention, facilitating goal setting and guiding referrals. The process of completing the SF-HDQ was described by participants as facilitating communication (including encouraging reflections on one’s health), and fostering a multidimensional approach to care.

Results from the interviews highlight the need to person-centred tailored approaches to administration, specifically providing options for mode of administration (ie, electronic-based and paper-based methods), timing of administration (ie, before, during, following an appointment) and considerations for how to communicate scores and score interpretations with patients, to account for differences between clinical settings and individuals.

Interview data indicate that participants felt the items in the SF-HDQ captured their experiences with disability. Overall, most participants described the language in the SF-HDQ as easy to understand and found the length of the questionnaire appropriate and feasible to complete. Many participants commented positively on how the SF-HDQ asked if challenges had fluctuated or changed in the past week, as they felt this was relevant to their experiences living with HIV.

Collectively, the questionnaire and interview findings suggest that the SF-HDQ possesses sensibility for use with adults living with HIV. Despite participants indicating
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<th>Implementation consideration</th>
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| **Burden of administration** | Time to administer and complete the SF-HDQ in clinical practice | ► I don’t think anyone in the clinic will or has time to do anything extra. (US-HCP-P20)  
► How would you do it in a post-COVID world when you’re trying to reduce waiting time? (IRE-HCP-P15) |
| **Conundrum of identifying health challenges with limited resources to address them** | It’s a great questionnaire but the problem is there’s no way that we can address the issues after it’s done and we have the information. (CAN-HCP-P23)  
► Well, I think if we’re going to ask all those questions, we need to have strategies in place to deal with all the answers and I’m not sure that we have at the moment. (IRE-HCP-P15) |
| **Logistical issues (security of tablets for electronic administration, internet, space)** | Gadgets tend to walk out the door. (IRE-HCP-P15)  
► To get a room and a computer…it’s challenging in a resource-stretched and starved environment. (IRE-HCP-P13) |
| **Person-centred approaches for tailoring mode of administration** | Use of technology — familiarity and comfort | ► I still find with a lot of our patients, particularly the over 50 group, that their IT skills might not what is required for this and that they might now have a computer and they might not have WiFi access. (IRE-HCP-P15)  
► Technology challenges definitely. I think most people with a tablet would go through it fairly quickly but there are probably people who are technologically challenged and it might be a little more difficult. (CAN-PLWH-P15) |
| | Literacy of disability and health challenge terminology in the questionnaire | ► I think [the wording] might be beyond the reach of some of the patients you want to capture. So, people who maybe haven’t had the chance to finish school, and we have a lot of them, or patients who are you know refugees, or you know English is not their first language. (IRE-HCP-P16)  
► I can think there might be, you know, depending on the education level of a participant, they might have trouble with some of the verbiage. (US-PLWH-P18) |
| **Flexible options for modes and processes of administration** | Cognitive health challenges that may influence the ability to complete the questionnaire | ► Because of the very real kind of neuro features of the HIV, especially with the long-term survivors. (CAN-HCP-P5)  
► I guess it would come down to their problems with their cognitive impairment and thought you know because people seem to have an awful lot of cognitive impairment problems that I’ve seen with HIV. (CAN-PLWH-03) |
| **Location of administration (home or clinic)** | Use of technology — familiarity and comfort | ► I think electronic I would prefer. But there are going to be people that need paper. (CAN-HCP-01)  
► It’s a lot easier than say a pen and paper. (US-PLWH-P12)  
► It was really easy to fill out online. (US-PLWH-P2) |
| **Timing of administration (prior to or after clinic appointment)** | Location of administration (home or clinic) | ► I would not want to do this during a clinic visit, … if you do it on the computer, that’s good. … Let’s say I’m going to have a visit tomorrow and you send it to me the day before. I can fill it out and send it and then not have to worry about it. Like I said, I would not want to go into a visit because I’m going into a visit to do whatever, get checked and I want to be gone. Then those that don’t have a computer, maybe send the questionnaire in the mail and you know put their please fill out before visit and then have them bring it in with them. (US-PLWH-11)  
► I prefer that [completing the questionnaire with a clinician in clinic] because if I am with her or him one by one, then I can ask a question, then you can answer me or you can ask me a question, then I can answer. If I heard her answer and I can ask an explanation. (CAN-PLWH-04) |
| **Person to administer (self, practitioner or administratively administered)** | Timing of administration (prior to or after clinic appointment) | ► I think like either during the appointment or after … if there’s a wait time before the client has to come in, then it’s a great time to take care of the survey because then they feel like no time is being wasted if they have something to do. (US-PLWH-13)  
► I think before an appointment because I feel like after an appointment, you’re ready to go. So, I think before an appointment would be ideal. Unfortunately, too because it may help bring out things that they forgot to talk about during their appointment. So, if they’re taking it beforehand it might help them think of things that they may have forgotten about. (CAN-PLWH-P16) |
| | Person to administer (self, practitioner or administratively administered) | ► I think it should come from your primary care doctor. (US-PLWH-14)  
► It could be that we do an intake and then sort of get an administrative person to meet with them before their next visit. Yeah, I think either of those options could work. (CAN-HCP-P2) |

CAN, Canada (Toronto, Ontario); HCP, healthcare practitioner; IRE, Ireland (Dublin); P, participant; PLWH, participant living with HIV; SF-HDQ, Short-Form HIV Disability Questionnaire; US, United States (Denver, Colorado).
Table 6  Implementation considerations of the electronic SF-HDQ in clinical practice: communicating scores

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| Consider personal preferences of patients when communicating scores among patients and healthcare practitioners | Participants living with HIV
- Personally, I would like to get my score because that would give me some insight into my overall health, you know, how is feeling overall. (CAN-PLWH-P2)
- I don’t know if I’d want to know [my score] or not to be quite truthful. I think that’s more for the clinician to know. So, I think you might make yourself worry too much about some things where I think you’ve got more problems than maybe you do. It could be negative to you. (CAN-PLWH-P3)
- It [seeing my score] would make me feel uncomfortable and I’d probably stay on topic too long on ones than another, you know, why is this so high and why is that so low... I honestly don’t want to see it because you don’t want to feel like a failure after. (CAN-PLWH-P3)
- Communicating questionnaire scores with healthcare practitioner team: I think it’s important because they’d see what’s actually going on with you. Again, they’d direct you to the right people like if you need to see a psychiatrist or you know, whatever or something else that may be going on in your health that you may not be really aware that’s a larger problem than it is. I may be thinking oh it’s nothing and they’re going we’ve got to deal with this. So it’s important they see it. (CAN-PLWH-P3).

Healthcare practitioners
- I would have a preference to share because I think if the patients have answered it themselves, I think they should be able to know what their results are or what they have answered about themselves or what the scoring would be. (IRE-HCP-P14)
- I think it’s beneficial because sometimes people may not think that they have a problem like a physical problem or a mental emotional. Maybe they think that it’s part of the way you’re supposed to feel. (IRE-HCP-P21)
- I’m not sure they would completely understand the nuances of it unless someone has a disability score of 90. But is that discouraging them and they’re doing okay or does that make them feel entitled that they deserve more? I mean I don’t know. I’m just throwing this out there. Medicine has a lot of nuances. (US-HCP-P23)

Importance of explaining the meaning of scores
- I think seeing them and knowing what they mean are two different things. I’d be happy to see them if I knew what they meant. (US-PLWH-P2)
- ...if they [persons living with HIV] are very depressed and they don’t have adequate support to help them process this then I think that it could be harmful. But that doesn’t mean that they shouldn’t have access to it because I think it’s their right to have access to their information. But that’s why I would give it with adequate explanation only... I think it’s okay [to give the patient a printout of their scores] only if it’s given with some explanation because like we’ve talked about there are varying levels of disability that we’re expressing. So, you want to make sure that you’ve given them all they need to process it. (US-HCP-P22)

CAN, Canada (Toronto, Ontario); HCP, healthcare practitioner; IRE, Ireland (Dublin); P, participant; PLWH, participant living with HIV; SF-HDQ, Short-Form HIV Disability Questionnaire; US, United States (Denver, Colorado).

items were missing that should be included in the SF-HDQ on the Sensibility Questionnaire (item 9), both groups indicated the SF-HDQ captured all elements of disability (item 6) (tables 3 and 4). These questionnaire results may be attributed to participants commenting in the interviews on the importance of considering HIV stigma, HIV disclosure, as well as addiction and substance use in the context of disability living with HIV. We recognise the importance of these concepts as they relate to disability. However, as intrinsic or extrinsic factors that can influence dimensions of disability, they are beyond the scope of disability and the SF-HDQ. Nevertheless, these findings highlight the benefit, need and importance of administering the SF-HDQ in combination with other PROMs (eg, HIV Stigma Scale,39 HIV Social Support Scale40) to fully understand the context in which disability may be experienced among adults living with HIV.

Some items in the SF-HDQ refer to HIV as the source of the challenge including: worrying about the future, worrying about finances, worrying about housing and concern around specific HIV blood tests. Participants questioned the need to specifically reference HIV in items related to uncertainty and social inclusion and items related to finance and housing, questioning the relevance of HIV specificity of items. Uncertainty and worrying about the future can be attributed to other factors (eg, the COVID-19 pandemic) and not solely HIV.39 41 Attributing specific health challenges to HIV can be difficult for an individual as the challenge may not be directly from HIV but from consequences of HIV such as treatment or concurrent health conditions experienced when ageing with HIV. Health challenges can also be compounded by certain factors affecting risk acquisition such as socioeconomic status or personal health.42 Results suggest revisiting the need for HIV specificity of items in the SF-HDQ. Future research should explore the refinement of the questionnaire, focused on measuring episodic disability as a health-related consequence of a health condition regardless of the source of disability. This has the potential to broaden the applicability of the questionnaire for use with other health conditions.

The term ‘disability’ was negatively perceived by some participants in the study. Some participants from the USA disliked the term, whereas Canadian participants were more familiar with the term ‘disability’ as used in the context of rehabilitation, and some were familiar with the HDQ. In the SF-HDQ preamble, we explain the concept of ‘disability’ as a description of health challenges, and that the term is not meant to label individuals who complete the questionnaire. Nevertheless, a few participants referred to how they do not consider themselves disabled citing concerns of negative connotations with ‘disability’ terminology. Changing the terminology of the SF-HDQ would mean changing the concept of interest measured, which has implications given the tool was grounded in conceptual foundation of the Episodic Disability Framework which was derived from the perspectives of adults living with HIV.43 44 We recommend revising the preamble.
of the questionnaire to remove references to the term ‘disability’ and to rename the questionnaire the Episodic Disability Questionnaire, to reflect the episodic nature of health challenges, while remaining grounded within the original conceptual foundation derived from the HIV community.

Participants had mixed preferences about completing the questionnaire at home on their own, or at the clinic on their own or with an HCP. Brief and comprehensive PROMs administered on the same day as a clinic visit can improve completion rates, provide immediate feedback on disability, enhance patient–practitioner communication and facilitate person-centred care. However, discomfort with technology and lack of access to web-based platforms can limit electronic questionnaire administration. SF-HDQ administration will be dependant on the context and characteristics of the population served which may differ within and across clinical settings. Future SF-HDQ guidance on SF-HDQ administration should consider what is important for standard (consistent) mode administration to ensure validity and reliability, and what aspects of administration may be flexible depending on the environment (menu of options).

Participants living with HIV had variable preferences about personally receiving their scores after completion of the SF-HDQ. Some participants noted that scores may provoke anxiety without clarity of the meaning of the scores, whereas the majority of HCP participants believed scores should be communicated and clearly interpreted with their patients. Future guidance on SF-HDQ administration should include details of communicating scores with patients and their interpretation. While results suggest that reviewing scores can help understand where health challenges occur across the six domains and facilitate a dialogue about specific areas someone may be struggling with, ultimately the interpretability of the SF-HDQ scores is unknown. Future work should assess the interpretability of SF-HDQ scores.

While health practitioners positively commented on the utility of the SF-HDQ, some expressed hesitancy to use the SF-HDQ to identify health challenges that they may not have the resources to be able to address in the clinic setting. Despite the barriers and limited access to rehabilitation, the SF-HDQ can play a role in the pathway of care with value in measuring and identifying health challenges in order to gain knowledge on the need for rehabilitation and other health or supportive services. Furthermore, in the absence of what HCPs feel they are unable to address, utilisation of the SF-HDQ may foster space to listen to patients’ concerns, acknowledge their experiences and share their narratives in a therapeutic dialogue with their practitioner.

Overall, results provide key considerations for SF-HDQ administration across three clinical settings in different countries highlighting the importance of tailoring implementation to the individual, cultural and clinical contexts. Strengths of our study included our mixed methods multisite approach with 45 participants, involving both patient and practitioner perspectives practitioners spanning three different clinical contexts, which enabled us to assess the utility of the electronic mode of SF-HDQ administration, and examine considerations for implementation across three different healthcare contexts. Measurement properties are specific to the context and population in which the tool is assessed, highlighting the importance of considering the characteristics of the participants living with HIV and clinical sites in this study. The Toronto sample also demonstrated greater presence, severity and episodic scores of disability compared with the other two sample populations (table 2). Our aim was not to compare sensibility and utility across sites, nor between adults living with HIV and HIV HCPs. Furthermore, given the heterogeneity across clinical contexts and target populations, we did not expect (nor was it a goal) to achieve saturation of themes. Rather, our aim was to obtain meaningful information through the exploration of the categories generated during the interviews, which could then be used to inform the SF-HDQ sensibility and utility across a diversity of sites and perspectives. Results highlight the need for personalised tailoring of administration dependent on personal preferences and context.

Given our SF-HDQ assessment was focused on electronic administration, this limited participation to individuals living with HIV who had access to and comfort with the use of technology in order to complete the questionnaires and, if the interview was conducted remotely, participate in a Zoom interview. Results highlight the importance of offering flexible options for SF-HDQ administration in the clinic setting including a paper-based option for those with barriers to electronic administration. Findings from this study will inform the development of a guidance document to guide administration and scoring of the SF-HDQ in clinical settings and increase knowledge about the intended utility of the questionnaire.

CONCLUSIONS

The SF-HDQ possessed sensibility and utility for use with adults living with HIV across the three clinical settings in Canada, Ireland and the USA. Clinical utility of the SF-HDQ included measuring health challenges and its change over time, guiding referrals to clinical specialists and services, informing goal setting, facilitating communication and fostering multidisciplinary approaches to HIV care. Considerations for implementation included flexible, person-centred approaches to mode and processes of administration, and communicating scores based on personal preferences among persons living with HIV and HIV clinicians. Future work should consider refinement of the SF-HDQ for implementation across different clinical and cultural contexts and future measurement property assessment.

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Contributors KKO’B and KME co-led the conceptualisation of the study objectives and design, and drafted the protocol, led the application for funding and are the colead investigators on the study. KKO’B, KME, CB and SCC are country and site leads on the research team, and were involved in the conceptualisation of the study design, development of the protocol, acquisition of funding and implementation of the study. PS, AMD, AMB, SEH and RH are coinvestigators and were involved in the conceptualisation of the study design and contributed to the development of the protocol, acquisition of funding and implementation of the study. KKO’B, PS, AMD, SSC, MS and RA were involved in the data analysis and interpretation. KKO’B, PS, AMD and MS drafted the manuscript. DAB, JH, NSC-S and MBoF were involved in guiding study implementation and participated in data interpretation. RA, NO’S, CM and MBoy were involved in participant recruitment and data collection. BT assisted with manuscript preparation. The authors possess expertise in HIV and rehabilitation (KKO’B, KME, CB, SCC, PS, AMD, AMB, RH, DAB, JH, NSC-S, MBoF, RA, BT, NO’S, CM, MBoy), with methodological expertise in measurement (KKO’B, AMD, RH, SEH) and qualitative research (PS, SCC, AMD, MS). All authors were involved in reviewing prior drafts of the manuscript. KKO’B was responsible for the overall content as the guarantor. All authors have read and approved the final manuscript.

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