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INTRODUCTION

- The advent of antiretroviral treatment for Human Immunodeficiency Virus (HIV) infection has changed a diagnosis of HIV from a certain death sentence to a controllable and treatable, chronic disease <sup>1</sup>.
- An up-to-date symptom measure and an HIV-specific QoL measure are needed in addition to widely used health-status tools to evaluate treatments for people living with HIV <sup>2</sup>.
- The present research aimed to design two instruments, each in UK and US English: the HIV-Dependent Quality of Life (HIVDQoL) Questionnaire and HIV Symptom Rating Questionnaire (HIVSRQ).

METHOD

- The format of the HIVDQoL and HIVSRQ are based on established -DQoL and -SRQ measures (e.g. ADDQoL for diabetes <sup>3</sup>, ThySRQ for hypothyroidism <sup>4</sup>, with copyright owned by co-author, Bradley).
- The initial draft HIVSRQ item list was revised following consultation with three HIV specialist clinicians.
- Participants were recruited via the internet by Opinion Health and were paid for their time.

METHOD

Table 1: Participant Details

		UK			
	N	Mean Age in Years	SD	Mean HIV Duration in Years	SD
Men	11	47	8.71	17	8.12
Women	3	51	15.28	12	1.53
		US			
	N	Mean Age in Years	SD	Mean HIV Duration in Years	SD
Men	8	51	12.85	20	11.59
Women	3	58	8.62	19	1.00

- Items were selected from existing -DQoL and -SRQ bank items and newly drafted as needed based on a review of relevant research, HIV specialist websites, and transcript analysis of 68 interviews conducted in UK, Germany and Spain <sup>5</sup>.
- In-depth telephone interviews of one hour, with questionnaires revised as needed between interviews, until no new content/changes were required. Following 10 UK interviews, a US linguist adapted the English for the US version. Eleven US interviews were then conducted followed by four additional UK interviews.

RESULTS

Interview Extracts

**If you woke up tomorrow to find that you no longer had HIV, how would that affect your QoL?**

‘It would be nice not having to pop the pills every night and worrying about being home in time to take them. Every time you take a pill it reminds you that what you’ve got is life threatening’ **Man aged 39, diagnosed 10 years**

How does living with HIV affect you?

‘of everything I guess that (erectile dysfunction) has had the most impact in terms of QoL .... I can tolerate the residual pain in my toes and feet but I do find the whole sexual thing difficult; it’s a mixture of stigma and difficulty talking about HIV... I’m wary about forming any long-term relationship that might turn into a sexual relationship’ **Man aged 61, diagnosed 14 years**

‘Have to take meds everyday which I hate doing. Meds are strong and toxic. Good and bad, I know without the meds I would not be alive, but I also know that they are causing damage’ **Woman aged 65, diagnosed 12 years**

Table 2: Quality of Life Domain Bank Items Summary of Changes / Additions for HIVDQoL

HIVDQoL Item List				
N	Domain	Exisitng	Adapted	New
1	Leisure	✓		
2	Work		✓	
3	Holiday		✓	
4	Out & About		✓	
5	Long Distance Journeys		✓	
6	Do Physically	✓		
7	Family	✓		
8	Friendships	✓		
9	Dates			✓
10	Close Personal Relationships		✓	
11	Sex Life		✓	
12	Physical Appearance	✓		
13	Self-confidence	✓		
14	Motivation		✓	
15	Stigmatised			✓
16	Conceal			✓
17	Future	✓		
18	Finance	✓		
19	Depend on Others		✓	
20	Fuss or Worry		✓	
21	Freedom to Eat	✓		
22	Freedom to Drink		✓	
23	Spiritual / Religious		✓	
24	Past		✓	
25	Children			✓
26	Sleep	✓		
Total		10	12	4

Table 3: Symptom Bank Items Summary of Changes / Additions for HIVSRQ

HIVSRQ Item List				
N	Domain	Exisiting	Adapted	New
1	Chest pain			✓
2	Palpitations		✓	
3	Short of breath		✓	
4	Cough	✓		
5	Excessively thirsty	✓		
6	Tired or lethargic		✓	
7	Feverish	✓		
8	Sick (nauseous)		✓	
9	Vomited		✓	
10	Diarrhoea	✓		
11	Generally unwell			✓
12	Abdominal pain		✓	
13	Indigestion or heartburn	✓		
14	Flatulence		✓	
15	Constipation	✓		
16	Bloated		✓	
17	Difficulty swallowing	✓		
18	Bleeding, sore or bruised gums	✓		
19	Dry mouth or lips		✓	
20	Mouth ulcers			✓
21	Nasal problems	✓		
22	Eye problems		✓	
23	Hair loss or thinning hair		✓	
24	Headaches	✓		
25	Minor illnesses or infections	✓		
26	Period problems		✓	
27	Jaundice		✓	
28	Muscle weakness	✓		
29	Muscle pains or cramps	✓		
30	Broken or fractured bone	✓		
31	Back pain	✓		
32	Pains or stiffness in your joints	✓		
33	Tingling or numbness hands or feet	✓		
34	Lack of sensation in your fingers & toes			✓
35	Down or depressed		✓	
36	Anxious, worried or panicky		✓	
37	Emotional or easily upset		✓	
38	Suddenly irritable or angry	✓		
39	Hallucinations	✓		
40	Hyperactive			✓
41	Difficulty thinking clearly or concentrating		✓	
42	Unsteady or uncoordinated	✓		
43	Dizzy or faint		✓	
44	Passed out or lost consciousness	✓		
45	Lacked interest in sex		✓	
46	Avoided sexual activity	✓		
47	Difficulty becoming sexually aroused	✓		
48	Problems with sexual function		✓	
49	Injection site reaction			✓
50	Dry skin		✓	
51	Itching		✓	
52	Night sweats		✓	
53	Swollen glands			✓
54	Skin rash		✓	
55	Skin that bruises or bleeds easily	✓		
56	Abnormal or vivid dreams			✓
57	Sleep problems		✓	
58	Excessively sleepy	✓		
59	Bad or strange taste in your mouth			✓
60	Discoloured Urine	✓		
61	Blood in Urine			✓
62	Poor appetite	✓		
63	Lipodystrophy			✓
64	Lost weight	✓		
Total		28	25	11

CONCLUSION

- Internet recruitment and telephone interviews worked well, eliciting information from a range of participants.
- Designing the two language versions simultaneously avoided subsequent linguistic validation, reduced unnecessary UK/US wording differences, and helped to simplify the wording.
- Existing templates and item banks from other condition-specific -DQoLs and -SRQs facilitated the design process, thus enabling participants and researchers to focus on the content.
- Comparisons across questionnaires for different conditions have now become possible.
- Psychometric development of the HIVDQoL and HIVSRQ will follow shortly.

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ENQUIRIES

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