

Additional File 1 – Detailed Overview of Categories and Sub-Categories (and Codes) for the Document Analysis of Existing HIV-Specific Instruments

Episodic Disability Framework Components	Categories	Detailed Sub-Categories	Sub-Category Code (n=108)
A. Dimensions of Disability			
Episodic Disability (n=72 detailed sub-categories)	Symptoms / Impairments (n=44 detailed sub-categories)	Symptoms / Impairments Physical (SI) (n=31 detailed sub-categories)	fatigue / feeling tired / exhaustion / decreased energy level
			diarrhea / bladder
			nausea and vomit
			headaches
			rashes and skin sores, ulcers or discoloration
			ulcers and upset stomach – GI symptoms
			pins and needles & numbness and tingling (may or may not be secondary to neuropathy)
			pain (aches and pains)
			speech and swallowing problems
			decreased libido
			cardiovascular effects (secondary to stroke, myocardial infarction)
			cardiorespiratory impairments such as dyspnea, cough secondary to pneumonias
			decreased endurance / activity tolerance
			decreased balance (may or may not be secondary to stroke)
			fever and sweats
			weakness (may or may not be secondary to stroke or deconditioning)
			cramps (muscle and stomach)
			body composition changes (weight loss and gain may or may not be secondary to lipodystrophy)
			decreased appetite
			sleep loss / difficulty sleeping
			hair loss
			forgetfulness / difficulty focusing attention / making decisions / agitated
			shaky hands / tremor*
			change in handwriting*
			bruising / bleeding*
			dry mouth/mouth pain*
			vision loss*
			hearing loss*
			dizziness*
			swollen lymph or glands or feet*
			genitals, menstruation, etc*

Episodic Disability Framework Components	Categories	Detailed Sub-Categories		Sub-Category Code
Episodic Disability (continued) (n=72 detailed sub-categories)	Symptoms / Impairments (continued) (n=44 detailed sub-categories)	Symptoms / Impairments related to Stress, Anxiety, and Depression (SI-SAD) (n=2 detailed sub-categories)	stress, anxiety and depression (and nervous)	SI-SAD-1
			stress, anxiety and depression - suicide ideation*	SI-SAD-2
		Symptoms / Impairments related to Emotions (SI-E) (n=11 detailed sub-categories)	emotions (global)	SI-E
			fear	SI-E-1
			decreased self-esteem / confidence	SI-E-2
			shame /blame and embarrassment, guilt, regret and feeling alienated	SI-E-3
			loneliness	SI-E-4
			grief / bereavement*	SI-E-5
			adjustment difficulty*	SI-E-6
			feeling unsafe*	SI-E-7
			frustration / temper / agitated / anger / discouraged*	SI-E-8
			upset / distress / despair / hopelessness*	SI-E-9
			un-acceptance / not feeling loved*	SI-E-10
	Uncertainty (n=2 detailed sub-categories)	Uncertainty (UN)	worrying about the Future	UN-1
			impact of uncertainty on decision making	UN-2
	Difficulties with Day-to-Day Activities (n=22 detailed sub-categories)	Difficulties with Day-to-Day Activities (DAY)	difficulties with day-to-day activities (global)	DAY
			standing (indoors and outdoors)	DAY-1
			walking (indoors and outdoors)	DAY-2
			negotiating stairs	DAY-3
			transfers (moving from bed to chair, standing)	DAY-4
			dancing (and other leisure and recreational activities / vigorous activities e.g. exercise)	DAY-5
			activities of daily living –eating	DAY-6
			activities of daily living – bathing / hygiene	DAY-7
			activities of daily living – dressing	DAY-8
			household chores – cleaning	DAY-9
			household chores – dishes	DAY-10
			household chores – laundry	DAY-11
			household chores – cooking	DAY-12
			grocery shopping	DAY-13
			getting out paying bills (errands)	DAY-14
			attending doctor's appointments	DAY-15
			reaching*	DAY-16
			gripping*	DAY-17
			bending or lifting*	DAY-18
			sexual activity*	DAY-19
			balancing checkbook, paperwork for bills*	DAY-20
			driving*	DAY-21

Episodic Disability Framework Components	Categories		Detailed Sub-Categories	Sub-Category Code
	Challenges to Social Inclusion (<i>n=4 detailed sub-categories</i>)	Challenges to Social Inclusion (SOC)	parental roles	SOC-1
			work and school	SOC-2
			personal relationships (difficulty initiating or maintaining relationships either casual or intimate in nature with friends, family or partners	SOC-3
			difficulty engaging in other social / leisure activities (e.g. travel, joining the military)	SOC-4

B. Supplementary Content of Disability
(beyond dimensions of disability but within the *Episodic Disability Framework*)

Contextual Factors of Episodic Disability (<i>n=12 detailed sub-categories</i>)	Extrinsic Factors (<i>n=4 detailed sub-categories</i>)	Social Support (SUP)	level of support – finances / housing / insurance (environmental items)	SUP-1
			level of support – family / friends, etc.	SUP-2
			level of support – health care services, medications and personnel / transport	SUP-3
		Stigma (STIG)	stigma	STIG
	Intrinsic Factors (<i>n=8 detailed sub-categories</i>)	Living Strategies (STR)	living strategies – social interaction with others versus isolation / avoidance	STR-1
			living strategies – maintaining control – planning ahead, anticipating episodes, coping	STR-2
			living strategies – maintaining control – lifestyle	STR-3
			living strategies – attitudes and beliefs – outlook – hope & resiliency	STR-4
			living strategies –attitudes and beliefs – concerned about how will be remembered, breaking family line, destiny	STR-5
			living strategies-attitudes and beliefs – blocking HIV out of mind	STR-6
			living strategies – attitudes and beliefs – faith and spirituality	STR-7
		Personal Attributes (PER)	intrinsic factor-personal attributes (age, gender, ethnocultural background)	PER-1
Triggers of Episodes of Disability (<i>n=3 detailed sub-categories</i>)	Triggers of Disability (<i>n=3 detailed sub-categories</i>)	Triggers (TRIG)	trigger – serious illness / opportunistic infection occurrence	TRIG-1
			trigger – anti-retroviral medications	TRIG-2
			trigger – anti-retroviral medications – burden and impact on life	TRIG-3

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C. Extraneous Content Beyond the <i>Episodic Disability Framework</i>				
Other Topics Covered by Items Beyond the Episodic Disability Framework (<i>n=21 detailed sub-categories</i>)	Other (<i>n=21 detailed sub-categories</i>)	Other (O)	sexual behaviour*	O-1
			medications – changing / compliance*	O-2
			importance of activities / items*	O-3
			satisfaction / pleased*	O-4
			enjoyment and interest (of life, food, being with others, sex)*	O-5
			confusion (in relation to body appearance)*	O-6
			global health rating*	O-7
			global illness rating*	O-8
			quality of life*	O-9
			Do not resuscitate (DNR) item*	O-10
			global side effects of treatment*	O-11
			“other” open ended option*	O-12
			specific non-HIV related question*	O-13
			HIV-risk group question*	O-14
			implications of caring for someone else*	O-15
			types of medication taken*	O-16
			diagnostic tests / treatments taken / abnormal blood tests*	O-17
			number of days in hospital*	O-18
			number of days at home*	O-19
			number of days in bed*	O-20
			number of days cut down on things you usually do because of your health*	O-21

*Indicates new sub-categories derived from items in the existing instruments.