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(HCSUS) Measures of Health-Related
Quality of Life*

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**THE HIV COST AND SERVICES UTILIZATION
STUDY (HCSUS) MEASURES OF
HEALTH-RELATED QUALITY OF LIFE**

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Health-related quality of life (HRQOL) refers to how well an individual functions and his or her perceptions of well-being in physical, mental and social domains of life. HRQOL is particularly important for monitoring the care delivered to individuals with HIV disease due to its chronic debilitating course, and in light of the uncertain impact of current treatments on survival. In the *HIV Cost and Services Utilization Study (HCSUS)*, we included multi-item measures of physical functioning (9 items, $\alpha = 0.91$), role functioning (2 items, $\alpha = 0.85$), pain (2 items, $\alpha = 0.84$), general health perceptions (3 items, $\alpha = 0.80$), social functioning (2 items, $\alpha = 0.82$), energy (2 items, $\alpha = 0.74$), and emotional well-being (7 items, $\alpha = 0.90$). The emotional well-being items also formed several subscales: 2-item positive affect ($\alpha = 0.75$), 5-item negative affect ($\alpha = 0.89$), 2-item anxiety ($\alpha = 0.76$), and 3-item depression ($\alpha = 0.87$). We also included single-item measures of disability days, overall health, and overall quality of life.

The HCSUS HRQOL survey items were selected after reviewing the literature (Wu, Hays, Kelly, Malitz, & Bozzette, 1997) and careful consideration of the pros and cons of various decisions. For example, we decided against including a self-report cognitive functioning scale because of concern about the accuracy of this information for people who are most impaired in this domain. We selected physical functioning items to represent a range of functioning from very basic (feeding oneself) to quite advanced (vigorous activities) by examining published information about item difficulties (e.g., Haley, McHorney, & Ware, 1994). Our decisions were also constrained by the larger study with respect to respondent burden. Thus, we chose very abbreviated item sets to assess general health perceptions, role functioning, pain, social functioning, and energy.

CONSTRUCTION OF 14 HRQOL MEASURES

The 14 HRQOL measures are noted below with a listing of the items used to score each one. Each multi-item measure is scored as a “simple-summed scale” by averaging together the items in the scale. Items that were reverse scored to produce the same direction of scoring (e.g., higher score is better HRQOL) are noted below (reversed).

We imputed values for missing data with three objectives in mind: 1) to retain the correlation structure between all scales; 2) to add residual noise to regression predictions so as to not bias associations between scales; and 3) to constrain imputations to the range of the observed data. When respondents answered some but not all items in a scale, we imputed values for the missing items using another “donor” respondent randomly selected from among cases that had complete data and the same pattern of answers for the items that were answered by the respondent with missing data. For example, if a scale consisted of three items and a respondent answered “2” to the first item, “3” to the second item, and the third item was missing, we chose a donor from among respondents who answered the same way to the first two items and completed the third item. We used the donor’s response to the third item to impute the missing value. When respondents had missing data for all items in a scale, we imputed the scale score using a randomly selected donor from cases that had complete data and were closest to the observation with missing data. Distance was measured by the difference in predicted scale scores from a linear regression equation that predicted the missing scale from the other observed scales.

The HRQOL measures and items are shown below. A plus sign in first column within the parentheses following the item name means that this item is included in the *ACTG Quality of Life survey* (Wu, Hays, Kelly, Malitz, & Bozzette, 1997); a plus sign in the second column indicates that this is an SF-36 item (Ware & Sherbourne, 1992). An asterisk following the description of

the item indicates that it was included on the HCSUS short-form/proxy instrument, which was administered to approximately 5% of the total eligible baseline sample. The participant or a designated surrogate completed the short-form/proxy instrument if the participant was unable or unwilling to complete the long form.

Physical functioning (B08PHF01; 9 items):

B08A01A	(+ +)	8.A1a Vigorous activities*
B08A01B	(+)	8.A1b Climbing stairs*
B08A01C	(+)	8.A1c Walking more than 1 mile
B08A01D	(+)	8.A1d Walking one block
B08A01E	(+)	8.A1e Bathing or dressing*
B08A01F	()	8.A1f Preparing meals or doing laundry
B08A01G	()	8.A1g Shopping
B08A01H	()	8.A1h Getting around inside home
B08A01I	()	8.A1i Feeding yourself*

(ACTG instrument includes 4 physical functioning items; SF-36 includes 10 items)

Role functioning (B08ROF02; 2 items):

B08A02A	(+)	8.A2a Working at a job, doing work around house, going to school
B08A02B	(+)	8.A2b Some kinds/amount work or house/school work (ACTG

has 2 items; SF-36 has 7 items)

Pain (B08PAN01; 2 items):

B08A04	(+)	8.A4 Pain interfere with work	(reversed)
B08A10	(+ +)	8.A10 Amount of pain	(reversed)

(ACTG has 2 items; SF-36 has 2 items)

General health perceptions (B08GEH01; 3 items):

B08A06 (+) 8.A6 Excellent-poor health* (reversed)
B08A07A (+) 8.A7a Get sick easier than other people
B08A07B (+) 8.A7b Feeling bad lately

(ACTG has 3 items; SF-36 has 5 items)

Emotional well-being (B08EWB01; 7 items):

B08A08A (+ +) 8.A8a Calm and peaceful (reversed)
B08A08B (+ +) 8.A8b Downhearted and blue
B08A08D (+ +) 8.A8d Happy person (reversed)
B08A08E (+) 8.A8e Very nervous person
B08A08G (+) 8.A8g Down in the dumps
B08A08H () 8.A8h Anxious or worried
B08A08I () 8.A8i Depressed*

(ACTG has 3 items; SF-36 has 5 items)

Positive affect (B08EWB02; 2 items); subset of emotional well-being:

B08A08A (+ +) 8.A8a Calm and peaceful (reversed)
B08A08D (+ +) 8.A8d Happy person (reversed)

Negative affect (B08EWB03; 5 items); subset of emotional well-being:

B08A08B (+ +) 8.A8b Downhearted and blue
B08A08E (+) 8.A8e Very nervous
B08A08G (+) 8.A8g Down in the dumps
B08A08H () 8.A8h Anxious or worried
B08A08I () 8.A8i Depressed*

Anxiety (B08EWB04; 2 items); subset of negative affect:

B08A08E (+) 8.A8e Very nervous
B08A08H () 8.A8h Anxious or worried

Depression (B08EWB05; 3 items); subset of negative affect:

B08A08B (+ +) 8.A8b Downhearted and blue
B08A08G (+) 8.A8g Down in the dumps
B08A08I () 8.A8i Depressed*

Social functioning (B08SCF01; 2 items):

B08A05 (+ +) 8.A5 Social life interfered with (reversed)
B08A09 (+ +) 8.A9 Amount of time interfered with

(ACTG has 2 items; SF-36 has 2 items)

Energy (B08ENF01; 2 items):

B08A08C (+ +) 8.A8c Feel tired
B08A08F (+) 8.A8f Enough energy to do things* (reversed)

(ACTG has 2 items; SF-36 has 4 items)

Disability days (B08BED01; 1 item):

B08A03 () 8.A3 Imputed Days in bed because of health*

(ACTG has 0 items; SF-36 has 0 items)

Overall health (B07OVR01; 1 item):

B07B01 (+) 7.B1 Overall, how rate current health*

(ACTG has 1 item; SF-36 has 0 items)

Overall quality of life (B07OVR02; 1 item):

B07B02 () 7.B2 Overall, how rate quality of life*

(ACTG has 0 items; SF-36 has 0 items)

Descriptive statistics for the 14 HRQOL measures from baseline of HCSUS are shown below.

The weighted summaries are weighted by the HCSUS analysis weights to adjust for differential sampling probabilities and non-response.

Variable	N	Unweighted		-----Weighted-----			
		Mean	SD	Mean	SD	Min.	Max.
Physical functioning (b08phf01)	2864	77.59	24.74	78.91	24.08	0	100
Role functioning (b08rsf02)	2864	65.02	35.05	66.57	34.74	0	100
Pain (b08pan01)	2864	67.45	28.83	68.30	28.82	0	100
General health perceptions (b08geh01)	2864	52.28	29.12	54.04	29.17	0	100
Emotional well-being (b08ewb01)	2864	62.98	23.30	63.75	23.23	0	100
Positive affect (b08ewb02)	2864	55.45	25.00	56.02	25.06	0	100
Negative affect (b08ewb03)	2864	65.99	24.81	66.84	24.66	0	100
Anxiety (b08ewb04)	2864	62.16	28.35	62.96	28.29	0	100
Depression (b08ewb05)	2864	68.55	25.67	69.42	25.46	0	100
Social functioning (b08scf01)	2864	66.53	30.20	67.99	30.26	0	100
Energy (b08enf01)	2864	51.84	27.31	52.80	27.47	0	100
Disability days (b08bed01)	2864	3.83	6.53	3.60	6.36	0	28
Overall health (b07ovr01)	2864	70.40	22.21	71.23	22.06	0	100
Overall quality of life (b07ovr02)	2864	70.24	24.32	70.68	23.82	0	100

Note: All measures, except disability days (which ranges from 0-28 days in the past month) are linearly transformed to range between 0-100, with 100 being better HRQOL. To transform to a 0-100 scale, the measure is first scored so that a higher score is better HRQOL. Then, the minimum possible score is subtracted from the score and the result is divided by the difference between the maximum and minimum possible score. The final step is to multiple by 100. In equation form, the linear transformation is as follows:

$$\frac{(\text{Raw score} - \text{minimum possible})}{(\text{Maximum possible} - \text{Minimum possible})} * 100$$

CONSTRUCTION OF THREE HRQOL COMPOSITE SCORES

Ten scales are used to construct physical, mental, and overall HRQOL composite scores. For this purpose, we excluded emotional well-being and negative affect because the items in these scales overlap with the positive affect, anxiety, and depression scales already included. Overall health and overall quality of life are not included because these items represent an alternative (direct rating) approach to summarizing HRQOL.

B08PHF01 physical functioning (PHF)
 B08ROF02 role functioning (ROF)
 B08PAN01 freedom from pain (PAIN)
 B08GEH01 general health perceptions (GEH)
 B08EWB02 positive affect (PAFF)
 B08EWB04 freedom from anxiety (ANX)
 B08EWB05 freedom from depression (DEP)
 B08SCF01 social functioning (SCF)
 B08ENF01 energy (ENF)
 B08BED01 days in bed because of health (DIS)

The intercorrelations among these 10 HRQOL measures ranged from 0.31 to 0.72 (see below).

---	PHF	ROF	PAIN	GEH	PAFF	ANX	DEP	SCF	ENF	DIS
PHF	1.00	0.68	0.57	0.60	0.34	0.31	0.39	0.58	0.61	-.54
ROF		1.00	0.56	0.62	0.33	0.32	0.37	0.58	0.61	-.51
PAIN			1.00	0.61	0.38	0.39	0.42	0.59	0.57	-.49
GEH				1.00	0.52	0.49	0.55	0.65	0.72	-.51
PAFF					1.00	0.59	0.70	0.56	0.52	-.32
ANX						1.00	0.71	0.53	0.47	-.28
DEP							1.00	0.64	0.53	-.36
SCF								1.00	0.65	-.52
ENF									1.00	-.50
DIS										1.00

We examined various number-of-factor criteria (e.g., Guttman's weakest lower bound, scree test) and determined that two factors underlie the intercorrelations among the 10 HRQOL measures. Then, we obtained standardized scoring coefficients for these 10 scales using an oblique (Promax; Hendrickson & White, 1964) two-factor rotation (derived from weighted correlation matrix) because previous research has demonstrated that physical and mental health factors are significantly correlated (Hays, Marshall, Wang, & Sherbourne, 1994; Hays, Cunningham, et al., 1995):

Standardized Scoring Coefficients

	FACTOR1	FACTOR2	
B08PHF01	0.21920	-0.03691	physical functioning
B08ROF02	0.21151	-0.03438	role functioning
B08PAN01	0.14803	0.02610	freedom from pain
B08GEH01	0.18984	0.09650	general health perceptions
B08EWB02	-0.00915	0.21092	positive affect
B08EWB04	-0.01165	0.21463	freedom from anxiety
B08EWB05	-0.01158	0.38028	freedom from depression
B08SCF01	0.14263	0.14784	social functioning
B08ENF01	0.16290	0.09393	energy

B08BED01 -0.11225 0.00701 8.A3 Imputed days bed due health

Next, we transformed these measures into Z-scores by subtracting their mean and dividing by their standard deviation. All analyses were weighted using the HCSUS analysis weight.

```
PHF01_Z = (B08PHF01 - 78.9052012) / 24.0764768 ;
ROF02_Z = (B08ROF02 - 66.5738960) / 34.7380903 ;
PAN01_Z = (B08PAN01 - 68.2955052) / 28.8114617 ;
GEH01_Z = (B08GEH01 - 54.0371660) / 29.1687175 ;
EWB02_Z = (B08EWB02 - 56.0192117) / 25.0591867 ;
EWB04_Z = (B08EWB04 - 62.9614920) / 28.2847290 ;
EWB05_Z = (B08EWB05 - 69.4241641) / 25.4516220 ;
SCF01_Z = (B08SCF01 - 67.9887828) / 30.2560972 ;
ENF01_Z = (B08ENF01 - 52.7951897) / 27.4610870 ;
DDAYS_Z = (B08BED01 - 3.5980805) / 6.3625898 ;
```

We then multiplied each z-score by the corresponding standardized scoring coefficient and summed to obtain physical and mental health factor scores.

```
AGG_PHYS = (PHF01_Z * 0.21920) +
            (ROF02_Z * 0.21151) +
            (PAN01_Z * 0.14803) +
            (GEH01_Z * 0.18984) +
            (EWB02_Z * -0.00915) +
            (EWB04_Z * -0.01165) +
            (EWB05_Z * -0.01158) +
            (SCF01_Z * 0.14263) +
            (ENF01_Z * 0.16290) +
            (DDAYS_Z * -0.11225);
```

```
AGG_MENT = (PHF01_Z * -0.03691) +
            (ROF02_Z * -0.03438) +
            (PAN01_Z * 0.02610) +
            (GEH01_Z * 0.09650) +
            (EWB02_Z * 0.21092) +
            (EWB04_Z * 0.21463) +
            (EWB05_Z * 0.38028) +
            (SCF01_Z * 0.14784) +
            (ENF01_Z * 0.09393) +
            (DDAYS_Z * 0.00701);
```

We transformed the resulting factor scores linearly into T-scores (weighted mean=50, weighted SD=10).

```
b08ovr01 = 50 + ((AGG_PHYS + 2.43861E-15) * (10/0.9453130));
b08ovr02 = 50 + ((AGG_MENT + 6.83719E-15) * (10/0.9312730));
```

Averaging the two composite scores gave us our third composite, the overall. We also standardized this score (weighted mean=50 and SD=10).

```
b08ovr03 = 10 * (mean(b08ovr01, b08ovr02) - 50 / 9.2159249) + 50;
```

For each of the 3 HRQOL composite scores, the weighted mean is 50 and the SD is 10. The unweighted descriptive statistics for these composite scores are provided below (n = 2864):

Variable	N	Mean	SD	Min.	Max.
B08OVR01	2864	49.44	10.06	20.25	64.59
B08OVR02	2864	49.60	9.99	21.92	68.37
B08OVR03	2864	49.48	10.03	19.14	66.46

Note: All measures are T-scores.

The estimated reliabilities of the physical and mental health composite scores (Mosier, 1943) were 0.96 and 0.94, respectively, using 0.68 as the reliability estimate for the single-item disability measure (Revicki et al., 1994). Correlations between the composite scores, physical functioning, overall health, emotional well-being, and overall quality of life ranged from 0.40 to 0.98 and are provided below (n = 2864).

	Physical Health Composite	Physical Functioning	Overall Health	Mental Health Composite	Emotional Well-Being	Overall Quality of Life
Physical Health Composite	1.00					
Physical Functioning	0.84	1.00				
Overall Health	0.61	0.49	1.00			
Mental Health Composite	0.70	0.47	0.50	1.00		
Emotional Well-Being	0.58	0.40	0.42	0.98	1.00	
Overall Quality of Life	0.48	0.37	0.56	0.55	0.51	1.00
	B08OVR01	B08PHF01	B07OVR01	B07OVR02	B08WEB01	B08OVR02

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APPENDIX

Health-Related Quality of Life Items in Health Care Cost and Services Utilization Study

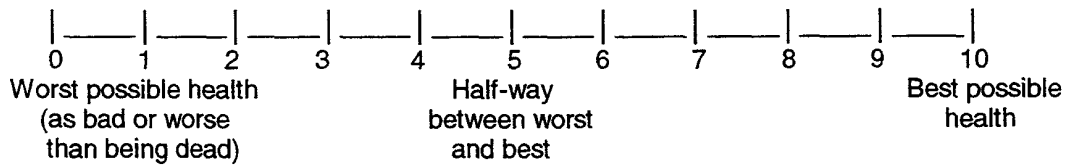
TSSST07B

These next questions are about your overall health and quality of life.

B1. (HAND R CARD 33). Overall, how would you rate your current health?

B07B01

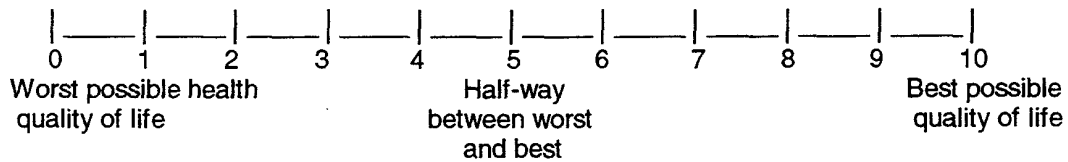
(Circle One Number)



B2. (HAND R CARD 34). Overall, how would you rate your quality of life?

B07B02

(Circle One Number)



A1. I'm going to read you a list of activities. Please tell me if your health limited you a lot, a little or not at all in doing each of these activities in the past four weeks. IF R SAYS HE/SHE DOES NOT DO ACTIVITY FOR REASON OTHER THAN HEALTH, CODE - NOT LIMITED AT ALL.

(Circle One Number on Each Line)

		YES, LIMITED <u>A LOT</u>	YES, LIMITED <u>A LITTLE</u>	NO, NOT LIMITED <u>AT ALL</u>
B08A01A	a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?	1	2	3
B08A01B	b. Climbing one flight of stairs?	1	2	3
B08A01C	c. Walking more than a mile?	1	2	3
B08A01D	d. Walking one block?	1	2	3
B08A01E	e. Bathing or dressing yourself?	1	2	3
B08A01F	f. Preparing meals or doing laundry? ...	1	2	3
B08A01G	g. Shopping?	1	2	3
B08A01H	h. Getting around inside your home? ...	1	2	3
B08A01I	i. Feeding yourself?	1	2	3

A2. During the past four weeks, has your health prevented you from (READ ACTIVITY) all of the time, some of the time, or none of the time?

(Circle One Number on Each Line)

		YES, FOR ALL OF <u>THE TIME</u>	YES, FOR SOME OF <u>THE TIME</u>	NONE OF <u>THE TIME</u>
B08A02A	a. Working at a job, doing work around the house, or going to school?	1	2	3
B08A02B	b. Doing certain kinds or amounts of work, housework, or schoolwork?	1	2	3
B08A02C	c. Taking care of paperwork for health insurance or medical bills?	1	2	3

A.3. During the past four weeks, how many days did your health cause you to stay in bed for ½ a day or more?

B08A03 DAYS: _____

NOTE: FOR CAPI, RESPONSE CAN'T BE >28.

A4. During the past four weeks, how much did pain interfere with your normal work (including work outside the house and housework)? Would you say:

B08A04 (Circle One)

Not at all,	1
A little bit,	2
Moderately,	3
Quite a bit, or	4
Extremely?	5

A5. During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Would you say:

B08A05 (Circle One)

Not at all,	1
A little bit,	2
Moderately,	3
Quite a bit, or	4
Extremely?	5

A6. In general, would you say your health in the past four weeks was:

B08A06 (Circle One)

Excellent,	1
Very good,	2
Good,	3
Fair, or	4
Poor?	5

A7. (HAND R CARD #35) Please indicate the extent to which the following statements are true or false for you during the past four weeks:

(Circle One Number on Each Line)

		DEFINITELY <u>TRUE</u>	MOSTLY <u>TRUE</u>	DON'T <u>KNOW</u>	MOSTLY <u>FALSE</u>	DEFINITELY <u>FALSE</u>
B08A07A	a. I seem to get sick a little easier than other people.....	1	2	3	4	5
B08A07B	b. I have been feeling bad lately	1	2	3	4	5

A8. (HAND CARD #36) How much of the time during the past four weeks (READ ITEM). Would you say all of the time, most of the time, a good bit of the time, some of the time, a little of the time, or none of the time?

(Circle One Number on Each Line)

		<u>ALL OF THE TIME</u>	<u>MOST OF THE TIME</u>	<u>A GOOD BIT OF THE TIME</u>	<u>SOME OF THE TIME</u>	<u>A LITTLE OF THE TIME</u>	<u>NONE OF THE TIME</u>
B08A08A	a. Have you felt calm and peaceful?	1	2	3	4	5	6
B08A08B	b. Have you felt downhearted and blue?	1	2	3	4	5	6
B08A08C	c. Did you feel tired?	1	2	3	4	5	6
B08A08D	d. Have you been a happy person?	1	2	3	4	5	6
B08A08E	e. Have you been a nervous person?	1	2	3	4	5	6
B08A08F	f. Did you have enough energy to do the things you wanted to do?	1	2	3	4	5	6
B08A08G	g. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
B08A08H	h. Have you been anxious or worried?	1	2	3	4	5	6
B08A08I	i. Have you felt depressed?	1	2	3	4	5	6

A9. During the past four weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? These answer choices are a little different. Would you say:

B08A09

(Circle One)

- | | |
|--------------------------------|---|
| All of the time, | 1 |
| Most of the time, | 2 |
| Some of the time, | 3 |
| A little of the time, or | 4 |
| None of the time? | 5 |

A10. How much bodily pain have you had during the past four weeks? Would you say:

B08A10

(Circle One)

- | | |
|--------------------|---|
| None, | 1 |
| Very mild, | 2 |
| Mild, | 3 |
| Moderate, | 4 |
| Severe, or | 5 |
| Very severe? | 6 |

