Fecal Incontinence Quality of Life Instrument

Q 1: In general, would you say your health is:

1 □ Excellent
2 □ Very Good
3 □ Good
4 □ Fair
5 □ Poor

Q 2: For each of the items, please indicate how much of the time the issue is a concern for you due to accidental bowel leakage.

<table>
<thead>
<tr>
<th>Q2. Due to accidental bowel leakage:</th>
<th>Most of the Time</th>
<th>Some of the Time</th>
<th>A Little of the Time</th>
<th>None of the Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I am afraid to go out</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. I avoid visiting friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. I avoid staying overnight away from home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. It is difficult for me to get out and do things like going to a movie or to church</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. I cut down on how much I eat before I go out</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. Whenever I am away from home, I try to stay near a restroom as much as possible</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. It is important to plan my schedule (daily activities) around my bowel pattern</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. I avoid traveling</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. I worry about not being able to get to the toilet in time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>j. I feel I have no control over my bowels</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>k. I can’t hold my bowel movement long enough to get to the bathroom</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>l. I leak stool without even knowing it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>m. I try to prevent bowel accidents by staying very near a bathroom</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Q 3: Due to accidental bowel leakage, indicate the extent to which you AGREE or DISAGREE with each of the following items.

<table>
<thead>
<tr>
<th>Q3. Due to accidental bowel leakage:</th>
<th>Strongly Agree</th>
<th>Somewhat Agree</th>
<th>Somewhat Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I feel ashamed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. I can not do many of things I want to do</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. I worry about bowel accidents</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. I feel depressed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. I worry about others smelling stool on me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. I feel like I am not a healthy person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. I enjoy life less</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. I have sex less often than I would like to</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. I feel different from other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>j. The possibility of bowel accidents is always on my mind</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>k. I am afraid to have sex</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>l. I avoid traveling by plane or train</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>m. I avoid going out to eat</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>n. Whenever I go someplace new, I specifically locate where the bathrooms are</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Q 4: During the past month, have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile?

1 □ Extremely So - To the point that I have just about given up
2 □ Very Much So
3 □ Quite a Bit
4 □ Some - Enough to bother me
5 □ A Little Bit
6 □ Not At All
**Scale Scoring**

Scales range from 1 to 4; with a 1 indicating a lower functional status of quality of life. Scales scores are the average (mean) response to all items in the scale (e.g. add the responses to all questions in a scale together and then divide by the number of items in the scale N.B. adjust for missing values ). (Not apply is coded as a missing value in the analysis for all questions.)

Scale 1. Lifestyle, ten items.

Q2A Q2B Q2C Q2D Q2E Q2G Q2H Q3B Q3L Q3M

Scale 2. Coping/Behavior, nine items.

Q2F Q2I Q2J Q2K Q2M Q3C Q3H Q3J Q3N

Scale 3. Depression/Self Perception, seven items.

Q1 Q3D Q3F Q3G Q3I Q3K Q4, (Question 1 is reverse coded.)

Scale 4. Embarrassment, three items.

Q2L Q3A Q3E
SAS Code for Scoring FIQL

1. Assumes variables are named as they appear in instrument.
2. Assumes data is stored in a SAS dataset.
3. Italics identifies code that needs to be changed by user depending on where data is stored and name of SAS dataset.

```sas
OPTIONS NOCENTER LS=110 PS=60;
TITLE 'SAS CODE TO SCORE FIQL';
libname MYDATA 'U:\ANALYSIS\fi\test_dbase';
*** SAS CODE FOR SCORING THE FIQL ***;
*** DATA STEP CODE ***;
DATA FIQLBASE; SET MYDATA.FIQLIN;
PROC SORT DATA=FIQLBASE OUT=FIQLSORT; BY ID;
data recode; set fiqlsort;
RVQ1=.; RVQ1=((1+5)-Q1); *REVERSE CODE Q1;
RQ1=.; RQ1=RVQ1*.8; *CHANGE Q1 TO A 4 POINT RESPONSE SCALE;
   IF (RQ1 GT 0) THEN DO;
     IF (RQ1 LT 1) THEN RQ1=1; *IT CAN VALUES BELOW 1 AND ABOVE 4;
     IF (RQ1 GT 4) THEN RQ1=4; *THIS CODE SET VALUES BELOW 1 TO 1 AND ABOVE 4 TO 4;
   END;
Q1=RQ1;

RQ4=.; RQ4=Q4*.67; *CHANGE Q4 TO A 4 POINT RESPONSE SCALE;
   IF (RQ4 GT 0) THEN DO;
     IF (RQ4 LT 1) THEN RQ4=1; *IT CAN VALUES BELOW 1 AND ABOVE 4;
     IF (RQ4 GT 4) THEN RQ4=4; *THIS CODE SET VALUES BELOW 1 TO 1 AND ABOVE 4 TO 4;
   END;
Q4=RQ4;

MFIQL1=NMISS(Q2A,Q2B,Q2C,Q2D,Q2E,Q2G,Q2H,Q3B,Q3L,Q3M); *# OF ITEMS WITH MISSING VALUES SCALE1;
MFIQL2=NMISS(Q2F,Q2I,Q2J,Q2K,Q2M,Q3C,Q3H,Q3J,Q3N); *# OF ITEMS WITH MISSING VALUES SCALE2;
MFIQL3=NMISS(Q1,Q3D,Q3F,Q3G,Q3I,Q3K,Q3Q); *# OF ITEMS WITH MISSING VALUES SCALE3;
```
MFIQL4=NMISS(Q2L,Q3A,Q3E);                      *# OF ITEMS WITH MISSING VALUES SCALE4;

DROP RQ1 RQ4; *DROP TEMPORARY VARIABLES;
DATA STANFIQL; SET RECODE;
** REPLACE MISSING RESPONSES WITH MEAN VALUE;

PROC STANDARD DATA=STANFIQL REPLACE OUT=FIMissrp; VAR Q2A Q2B Q2C Q2D Q2E Q2G Q2H Q3B Q3L Q3M Q2F Q2I Q2J Q2K Q2M Q3C Q3H Q3J Q3N Q1 Q3D Q3F Q3G Q3I Q3K Q4 Q2L Q3A Q3E;
RUN;

DATA FIQLMISR; MERGE STANFIQL FIMissrp; BY ID;

IF (MFIQL1 GE 5) THEN FIQLS1=.; ELSE
   FIQLS1=MEAN(Q2A,Q2B,Q2C,Q2D,Q2E,Q2G,Q2H,Q3B,Q3L,Q3M);
*DETERMINE SCORE FOR SCALE 1:
*ALLOWS UP TO 4 ITEMS TO HAVE MISSING VALUES;

IF (MFIQL2 GE 5) THEN FIQLS2=.; ELSE
   FIQLS2=MEAN(Q2F,Q2I,Q2J,Q2K,Q2M,Q3C,Q3H,Q3J,Q3N);
*DETERMINE SCORE FOR SCALE 2:
*ALLOWS UP TO 4 ITEMS TO HAVE MISSING VALUES;

IF (MFIQL3 GE 3) THEN FIQLS3=.; ELSE
   FIQLS3=MEAN(Q1,Q3D,Q3F,Q3G,Q3I,Q3K,Q4);
*DETERMINE SCORE FOR SCALE 3:
*ALLOWS UP TO 2 ITEMS TO HAVE MISSING VALUES;

IF (MFIQL4 GE 1) THEN FIQLS4=.; ELSE
   FIQLS4=MEAN(Q2L,Q3A,Q3E);
*DETERMINE SCORE FOR SCALE 3:
*ALLOWS UP TO 1 ITEM TO HAVE MISSING VALUES;

LABEL
FIQLS1='FIQL SCALE 1: LIFESTYLE'
FIQLS2='FIQL SCALE 2: COPING/BEHAVIOR'
FIQLS3='FIQL SCALE 3: DEPRESSION/SELF PERCEPTION'
FIQLS4='FIQL SCALE 4: EMBARRASSMENT';

DATA FIQLSCORE; SET FIQLMISR;
PROC MEANS DATA=FIQLSCORE N MIN MAX MEAN STD MAXDEC=2; VAR FIQLS1 FIQLS2 FIQLS3 FIQLS4; RUN;