

**RICE MAIN STUDY – 12-MONTH FOLLOW-UP COMPLETE INSTRUMENT
FEBRUARY 13, 2009**

REACHING RESPONDENT FOR FIRST TIME

>conf<

Hello, may I speak with [RESPONDENT]? My name is [NAME] and I am calling from the RAND Corporation in Santa Monica, California.

IF PERSON IS NOT THERE, ASK WHEN THEY WILL RETURN AND SET A CALL BACK.
DO NOT EXPLAIN THE STUDY IN DETAIL TO OTHERS IN THE HOUSEHOLD.

- <1> PERSON WHO ANSWERED IS [RESPONDENT]
- <2> [RESPONDENT] COMES TO PHONE
- <3> INFORMANT WANTS MORE INFO
- <4> NEW NUMBER FOR [RESPONDENT]
- <5> PERSON MOVED - NO NEW NUMBER AVAILABLE
- <6> NO SUCH PERSON/POSSIBLE WRONG NUMBER
- <7> NO INTERVIEW POSSIBLE - CODE OUTCOME AT NEXT ITEM
- <x> SCHEDULE CALL BACK
- <r> REFUSED [goto REFUSAL SCRIPT]

>inintro<

I'm calling to follow up with [RESPONDENT] about an interview she conducted with us on women's health being sponsored by the National Institutes of Health.

Is [RESPONDENT] available?

IF NEEDED: For confidentiality reasons, I'm not allowed to describe the study in detail to anyone other than [RESPONDENT].

- <1> YES, SPEAKING TO [RESPONDENT] [goto bday]
- <2> YES, [RESPONDENT] COMES TO THE PHONE [goto intr]
- <3> NEW NUMBER FOR RESPONDENT
- <4> PERSON MOVED - NO NEW NUMBER AVAILABLE
- <5> NO SUCH PERSON/POSSIBLE WRONG NUMBER
- <6> NO INTERVIEW POSSIBLE - CODE OUTCOME AT NEXT ITEM
- <x> SCHEDULE CALL BACK
- <r> REFUSED [goto REFUSAL SCRIPT]

INTRODUCTION OF STUDY TO RESPONDENT

>intr<

(Hello, My name is [NAME].) I'm calling to follow up with you about an interview you completed with us on [DATE OF BASELINE INTERVIEW]. The interview was part of a national study of women's health conditions being sponsored by the National Institutes of Health. To confirm, are you [RESPONDENT]?

IF NEEDED: For confidentiality reasons, I'm not allowed to describe the study in detail to anyone other than [RESPONDENT].

- <1> YES [goto bday]
- <2> NO [goto no1]

<3> NO INTERVIEW POSSIBLE - CODE OUTCOME AT NEXT ITEM
<x> CALL BACK
<r> REFUSES TO CONTINUE [goto REFUSAL SCRIPT]

>bday<

Thank you. To be sure I am speaking with the right person, what is your date of birth?

DATE OF BIRTH: [DISPLAY EXISTING DATE OF BIRTH]

INTERVIEWER: IS DOB CORRECT?

<1> YES, DOB IS CORRECT [goto yes1]
<2> NO, DOB IS NOT CORRECT [goto wrongp]
<x> CALL BACK
<r> REFUSES TO CONTINUE [goto REFUSAL SCRIPT]

>yes1<

(IF NEEDED): The interview included questions about your bladder symptoms, medical care and medications, and your general physical and mental health.

I'm calling you now because we would like to do a follow-up interview with you. This interview will be just like the first interview, except that we'll also ask you some additional questions about your general health. The interview will take up to one hour and we will send you a check for \$50 after the interview.

The purpose of this study is to help us learn what it is like to have bladder symptoms like the ones that you have. By participating, you will be helping us learn about the symptoms and quality of life of individuals with these conditions. Patient organizations for women with bladder symptoms specifically requested Congress to have this study conducted by the National Institutes of Health so it is important for women with bladder symptoms to take part.

The interview includes questions about your medical condition and possible symptoms and impact on your life. You are free to not answer any question or stop the interview at any time.
[goto intr2]

>no1<

Can I please speak with [RESPONDENT]?

INTERVIEWER: IF R IS NOT THERE, ASK WHEN SHE WILL RETURN AND SET A CALL BACK.
DO NOT EXPLAIN THE STUDY IN DETAIL TO OTHERS IN THE HOUSEHOLD!

IF NEEDED: For confidentiality reasons, I'm not allowed to describe the study in detail to anyone other than [RESPONDENT].

<1> YES - CONTINUE [goto intr]
<2> NO INTERVIEW POSSIBLE - CODE OUTCOME AT NEXT ITEM
<x> NOT AVAILABLE, SCHEDULE CALL BACK
<r> REFUSES TO CONTINUE [goto REFUSAL SCRIPT]

>intr2<

RAND will use the information you provide for research purposes only. RAND will protect the confidentiality of this information and will not disclose your identity to anyone outside of the research project staff, except as required by law.

We will not identify you in any reports we write. You do not have to take part in this study, and you can discontinue participation at any time for any reason.

You do not have to answer questions about any topic that you do not want to discuss. And I need to tell you that for purposes of quality control my supervisor may monitor this call.

START INTERVIEW

>TIME1<

[# 1. INCLUSION CRITERIA - CURRENT SYMPTOMS

>instr1<

First, I'd like to confirm the correct spelling of your name and your contact information to make sure we mail your \$50 to the correct address.

INTERVIEWER: IF ADDRESS INCOMPLETE, CODE NO AND ENTER CORRECT ADDRESS ON NEXT SCREEN.

I have your name and address as:

[DISPLAY EXISTING NAME AND ADDRESS]

Is that correct?

<1> YES [goto INTRO]

<2> NO

>newaddr<

[DISPLAY EXISTING ADDRESS]

What is your correct address?

INTERVIEWER: CHANGE ONLY THE FIELDS THAT NEED CORRECTING:

FIRST NAME:

LAST NAME:

STREET1:

STREET2:

CITY:

STATE:

ZIP:

>INTRO<

Thank you. Now we're ready to begin with the first question.

First, we'd like to ask you about your symptoms.

>RICEVS1<

In the past 3 months, have you ever had a feeling of pain, pressure, or discomfort in your lower abdomen or pelvic area -- that is, the part of your body that is above your legs and below your belly button?

<1> YES

<2> NO [goto hisens_st1]

<d,r>[goto hisens_st1]

>RICEVS2<

In the past 3 months, how much of the time have you had this feeling of pain, pressure, or discomfort in your pelvic area (that is, the part of your body that is above your legs and below your belly button)? Would you say...

- <1> Occasionally
 - <2> Some of the time
 - <3> About half of the time
 - <4> Most of the time
 - <5> All of the time
- <d,r>

>BACHKAIS3<

For how long have you been experiencing your pelvic pain, pressure, or discomfort?

Would you say:

- <1> Less than 3 months,
 - <2> 3 months or more, but less than 6 months,
 - <3> 6 months or more, but less than 12 months, or
 - <4> 12 months or more?
- <d,r>

>RICEVS4<

In the past 3 months, have you had a feeling of a strong urge or feeling that you had to urinate or "pee" that made it difficult for you to wait to go to the bathroom?

- <1> YES
 - <2> NO [goto RICEVS7]
- <d,r>[goto RICEVS7]

>RICEVS5<

Would you say this urge to urinate is mainly because of pain, pressure or discomfort or mainly because you are afraid you will not make it to the toilet in time to avoid wetting?

PROBE FOR R TO SELECT ONE ANSWER.

- <1> PAIN, PRESSURE, DISCOMFORT, OR
 - <2> FEAR OF WETTING
- <d,r>

>RICEVS6<

How much of the time in the past 3 months have you had this feeling of a strong urge or feeling that you had to urinate that made it difficult to wait to go to the bathroom? Would you say:

- <1> Occasionally
 - <2> Some of the time
 - <3> About half of the time
 - <4> Most of the time
 - <5> All of the time
- <d,r>

>RICEVS7<

In the past 3 months, before you urinate, as your bladder starts to fill, does your feeling of pain, pressure, or discomfort usually:

- <1> Get worse,

<2> Get better, or
<3> Stay the same?
<d,r>

>RICEVS8<

In the past 3 months, after you are finished urinating and you leave the bathroom, does your feeling of pain, pressure, discomfort, or urgency usually:

<1> Get worse,
<2> Get better, or
<3> Stay the same?
<d,r>

>RICEVS9<

In the past 3 months (when you were having symptoms), how many times on average have you had to go to the bathroom to urinate during the day when you are awake?

ENTER NUMBER OF TIMES:

<d,r>

>RICEVS10<

In the past 3 months, have you had one or more urinary tract or bladder infections that were diagnosed by a doctor or nurse?

NOTE: IF R SAYS "yes", PROBE FOR 1 OR MORE THAN 1

<1> Yes-- One
<2> Yes-- More Than One
<3> No [goto RICEVS13]
<d,r>[goto RICEVS13]

>RICEVS11<

Were you treated with antibiotics for urinary tract or bladder infection(s)?

<1> YES
<2> NO [goto RICEVS13]
<d,r>[goto RICEVS13]

>RICEVS12<

Did all of your symptoms disappear (each time) after you took antibiotics?

<1> YES
<2> NO
<d,r>

>RICEVS13<

In the past 12 months since your last interview, have you been diagnosed with a medical condition called endometriosis?

<1> YES
<2> NO [goto hisens_st1]
<d,r>[goto hisens_st1]

>RICEVS14<

Were you diagnosed (with endometriosis) with a laparoscopy under anesthesia, that is, a scope that allowed your doctor to look inside your abdomen, after you were put to sleep?

<1> YES
<2> NO
<d,r>

>RICEVS15<

Did you ever have hormone injection to treat endometriosis, such as depolupron?

<1> YES
<2> NO
<d,r>

>hisens_st1< [store 0 in HISENSE]

[if hisense_flg = 1]
[if RICEVS1 = 1]
[if RICEVS5 = 1 or RICEVS9 >= 10]
[store 1 in HISENSE]

>hispec_st1< [store 0 in HISPEC]

[if hispec_flg = 1]
[if RICEVS1 = 1]
[if RICEVS5 = 1 or RICEVS9 >= 10]
[if RICEVS7 = 1]
[if RICEVS12 = 2, d, r, or <>]
[if RICEVS15 = 2, d, r, or <>]
[store 1 in HISPEC]

[if RICEVS1 = 2, d, r, goto TIME4]
[if HISENSE = 0 and HISPEC = 0, goto STOPINT]
[if HISENSE = 1 and HISPEC = 0, goto TIME4]
[if HISENSE = 1 and HISPEC = 1, goto TIME4]

>TIME2<

[# 2. INCLUSION CRITERIA - PAST SYMPTOMS

>RICE2VS1< [if RICEVS1 = 1, goto TIME3]

In the past 12 months since your last interview, have you ever had a feeling of pain, pressure, or discomfort in your lower abdomen or pelvic area -- that is, the part of your body that is above your legs and below your belly button - that lasted for 3 months or more?

<1> YES
<2> NO [goto hisens_st2]
<d,r>[goto hisens_st2]

>RICE2VS2<

In the past 12 months since your last interview (when you were having symptoms), how much of the time have you had this feeling of pain, pressure, or discomfort in your pelvic area (that is, the part of your body that is above your legs and below your belly button)?

Would you say...

<1> Occasionally
<2> Some of the time
<3> About half of the time
<4> Most of the time

<5> All of the time
<d,r>

>BACH2KAIS3<

For how long did you experience your pelvic pain? Would you say:

<1> Less than 3 months,
<2> 3 months or more, but less than 6 months,
<3> 6 months or more, but less than 12 months, or
<4> 12 months or more?
<d,r>

>RICE2VS4<

In the past 12 months since your last interview (when you were having symptoms), have you had a feeling of a strong urge or feeling that you had to urinate or "pee" that made it difficult for you to wait to go to the bathroom?

<1> YES
<2> NO [goto RICE2VS7]
<d,r>[goto RICE2VS7]

>RICE2VS5<

Would you say this urge to urinate was mainly because of pain, pressure or discomfort or mainly because you were afraid you will not make it to the toilet in time to avoid wetting?

<1> PAIN, PRESSURE, DISCOMFORT, OR
<2> FEAR OF WETTING
<d,r>

>RICE2VS6<

How much of the time in the past 12 months since your last interview (when you were having symptoms), have you had this feeling of a strong urge or feeling that you had to urinate that made it difficult to wait to go to the bathroom? Would you say:

<1> Occasionally
<2> Some of the time
<3> About half of the time
<4> Most of the time
<5> All of the time
<d,r>

>RICE2VS7<

In the past 12 months since your last interview (when you were having symptoms), before you urinated, as your bladder started to fill, did your feeling of pain, pressure, or discomfort usually:

<1> Get worse,
<2> Get better, or
<3> Stay the same?
<d,r>

>RICE2VS8<

In the past 12 months since your last interview (when you were having symptoms), after you were finished urinating and you left the bathroom, did your feeling of pain, pressure, discomfort, or urgency usually:

<1> Get worse,
<2> Get better, or

<3> Stay the same?
<d,r>

>RICE2VS9<

In the past 12 months since your last interview (when you were having symptoms), how many times on average have you had to go to the bathroom to urinate during the day when you are awake?

ENTER NUMBER OF TIMES:

<d,r>

>RICE2VS10<

In the past 12 months since your last interview (when you were having symptoms), did you also have one or more urinary tract or bladder infections that were diagnosed by a doctor or nurse?

NOTE: IF R SAYS "yes", PROBE FOR 1 OR MORE THAN 1

<1> Yes -One
<2> Yes - More Than One
<3> No [goto RICE2VS13]
<d,r> [goto RICE2VS13]

>RICE2VS11<

Were you treated with antibiotics for urinary tract or bladder infection(s)?

<1> YES
<2> NO [goto RICE2VS13]
<d,r> [goto RICE2VS13]

>RICE2VS12<

Did all of your symptoms disappear (each time) after you took antibiotics?

<1> YES
<2> NO
<d,r>

>RICE2VS13< [if RICEVS1 does not equal 2, goto hisens_st2]

In the past 12 months since your last interview, have you ever been diagnosed with a medical condition called endometriosis?

<1> YES
<2> NO [goto hisens_st2]
<d,r> [goto hisens_st2]

>RICE2VS14<

Were you diagnosed (with endometriosis) with a laparoscopy under anesthesia, that is, a scope that allowed your doctor to look inside your abdomen, after you were put to sleep?

<1> YES
<2> NO
<d,r>

>RICE2VS15<

In the past 12 months since your last interview, did you ever have hormone injection to treat endometriosis, such as depolupron?

<1> YES

<2> NO
<d,r>

[#AT THIS POINT WE CALCULATE WHETHER R MEETS MINIMUM CRITERIA FOR PAST SYMPTOMS.
[#IF NO, COLLECT CONTACT INFO AND END INTERVIEW. IF YES, CONTINUE WITH SECTION 3

>hisens_st2< [store 0 in HISENSE]
[if hisense_flg = 1]
[if RICE2VS1 = 1]
[if RICE2VS5 = 1 or RICE2VS9 >= 10]
[if RICE2VS1 = 1]
[if RICE2VS5 = 1 or RICE2VS9 >= 10]]
[store 1 in HISENSE]

>hispec_st2< [store 0 in HISPEC]
[if hispec_flg = 1]
[if RICE2VS1 = 1]
[if RICE2VS5 = 1 or RICE2VS9 >= 10]
[if RICE2VS7 = 1]
[if RICE2VS12 = 2, d, r, or <>]
[if RICE2VS15 = 2, d, r, or <>]
[store 1 in HISPEC]

[if hispec_flg = 1]
[if RICE2VS1 = 1]
[if RICE2VS5 = 1 or RICE2VS9 >= 10]
[if RICE2VS7 = 1]
[if RICE2VS12 = 2, d, r, or <>]
[if RICE2VS15 = 2, d, r, or <>]
[store 1 in HISPEC]

>TIME4<

[# 4. DESCRIPTION AND HISTORY

>RICE4VS1<

In the past 3 months, when you had pain, pressure or discomfort in the pelvic area, how bad was it when it was at its worst?

On a scale of 0-10, with zero being no pain, pressure or discomfort and 10 being the pain, pressure, or discomfort as bad as you can imagine.

ENTER NUMBER 0-10:

<d,r>

>RICE4VS2<

In the past 3 months, when you had pain, pressure or discomfort in the pelvic area, how severe was it most of the time when you had pain, pressure, or discomfort?

On a scale of 0-10, with zero being no pain, pressure or discomfort and 10 being the pain, pressure, or discomfort as bad as you can imagine.

ENTER NUMBER 0-10:

<d,r>

>RICE4VS6<

In the past 3 months, about how many different doctors have you seen to have your bladder symptoms diagnosed and treated?

(PROBE IF NEEDED: Please give me your best estimate of how many doctors.)

ENTER NUMBER OF DOCTORS:

<d,r>

>RICE4VS6A<

In the past 3 months, have you had a medical visit with a urologist to diagnose or treat your bladder symptoms? A urologist is a doctor who specializes in medical conditions affecting the bladder and urinary tract.

<1> YES

<2> NO [goto RICE4VS7]

<d,r>[goto RICE4VS7]

>RICE4VS7<

In the past 3 months since your last interview, have you received a specific diagnosis from a doctor for your bladder symptoms?

<1> YES

<2> NO [goto RICE4VS11]

<d,r> [goto RICE4VS11]

>RICE4VS8<

What is the diagnosis that you received from a doctor? If you have received more than one diagnosis from a doctor or doctors, please tell me the diagnosis you think is most accurate for your symptoms.

RECORD DIAGNOSIS VERBATIM:

>RICE4VS9<

What kind of doctor(s) made that diagnosis? Was it:

<1> A family doctor or general internist?

<2> An obstetrician or gynecologist?

<3> A urologist?

<4> Or, Some other kind of medical doctor? What kind? (SPECIFY)

<d,r>

>RICE4VS10<

In what month and year did you receive that diagnosis?

ENTER MONTH: ENTER YEAR:

<d,r>

>RICE4VS11<

(Just to be sure) In the past 3 months since your last interview, have you been diagnosed by a doctor with Interstitial Cystitis?

PROBE IF CONFUSED ABOUT TERM CYSTITIS: Cystitis is also the name of a condition where a woman has a bladder infection that clears up quickly when treated with antibiotics and doesn't come back right away. This is not the condition we are asking about. The kind of cystitis we are asking about doesn't really go away completely after treatment with antibiotics.

<1> YES

<2> NO [goto RICE4VS14]
<d,r>[goto RICE4VS14]

>RICE4VS12<

In what month and year?

ENTER MONTH: ENTER YEAR:

<d,r>

>RICE4VS13<

What kind of doctor(s) diagnosed you with Interstitial Cystitis? Was it:

- <1> A family doctor or general internist?
 - <2> An obstetrician or gynecologist?
 - <3> A urologist?
 - <4> Or, Some other kind of medical doctor? What kind? (SPECIFY)
- <d,r>

>RICE4VS14<

(Just to be sure) In the past 3 months since your last interview, have you been diagnosed by a doctor with Painful Bladder Syndrome?

- <1> YES
 - <2> NO [goto RICE4VS17]
- <d,r>[goto RICE4VS17]

>RICE4VS15<

In what month and year?

ENTER MONTH: ENTER YEAR:

<d,r>

>RICE4VS16<

What kinds of doctor(s) diagnosed you with Painful Bladder Syndrome? Was it:

- <1> A family doctor or general internist?
 - <2> An obstetrician or gynecologist?
 - <3> A urologist?
 - <4> Some other kind of medical doctor? What kind? (SPECIFY)
- <d,r>

>RICE4VS17<

In the past 3 months, has a doctor looked at your bladder after putting you to sleep with general anesthesia or told you that he/she performed "hydro distension" or "bladder stretching?"

- <1> YES
 - <2> NO [goto RICE4VS19A]
- <d,r> [goto RICE4VS19A]

>RICE4VS18<

Did the doctor tell you you have Glomerulations?

These are sometimes called "little bleeding points" in your bladder or pe-tech-e-al hem-orr-ages.

- <1> YES
- <2> NO

<d,r>

>RICE4VS19<

Did the doctor diagnose you with Hunner's Ulcer?

<1> YES

<2> NO

<d,r>

>RICE4VS19A<

Has a doctor ever stretched your urethra in order to treat your symptoms?

This is sometimes called urethral dilation.

<1> YES

<2> NO

<d,r>

>RICE4VS20<

In the past 3 months since your last interview, have you had a menstrual period?

<1> YES

<2> NO

<d,r>

>RICE4VS21<

In the past 3 months since your last interview, have you been diagnosed by a doctor with any of the following?

- | | | |
|---|---------|--------|
| A. Fibromyalgia? | <1> YES | <2> NO |
| B. Chronic Fatigue Syndrome (CFS)? | <1> YES | <2> NO |
| C. Irritable bowel syndrome (IBS) or Spastic colon,
but NOT Inflammatory Bowel or Crohn's Disease? | <1> YES | <2> NO |
| D. Chronic Sinusitis? | <1> YES | <2> NO |
| E. Chronic Migraine, <u>not</u> including an acute
episodic migraine such as menstrual-related migraine? | <1> YES | <2> NO |
| F. Heart disease or heart attacks? | <1> YES | <2> NO |
| G. Chronic lung disease or emphysema? | <1> YES | <2> NO |
| H. Diabetes? | <1> YES | <2> NO |
| I. Cancer, other than skin cancer or bladder cancer? | <1> YES | <2> NO |
| J. Arthritis or rheumatism? | <1> YES | <2> NO |
| K. Vulvodynia or vulvar vestibulitis? | <1> YES | <2> NO |
| L. Overactive bladder? | <1> YES | <2> NO |
| M. Depression? | <1> YES | <2> NO |
| N. Panic Attacks? | <1> YES | <2> NO |
| O. Anxiety | <1> YES | <2> NO |

<d,r>

>SANDVIK23<

Did you visit any kind of physician for treatment of your bladder symptoms during the past 3 months?
Include any visits to any kind of medical doctor that you saw for bladder symptoms.

<1> YES

<2> NO [goto SANDVIK25]

<d,r>[goto SANDVIK25]

>SANDVIK24<

In total, how many visits to doctors did you make in the past 3 months for your bladder symptoms?

ENTER NUMBER OF VISITS:

<d,r>

>SANDVIK25<

Have you gone to an emergency room for your bladder symptoms in the past 3 months?

<1> YES

<2> NO [goto SANDVIK26]

[IF YES, ASK:]

How many times?

>SANDVIK26<

Have you been admitted to the hospital overnight for your bladder symptoms or treatment of your bladder symptoms in the past 3 months?

<1> YES

<2> NO [goto RICE4VS27]

[IF YES, ASK:]

How many times?

For how many nights in the past 3 months?

<d,r>

>RICE4VS27<

Is there one place in particular, like a doctor's office or clinic, where you usually go for most of your treatment of your bladder symptoms or bladder related condition?

<1> YES

<2> NO [goto RICE4VS31]

<d,r>[goto RICE4VS31]

>RICE4VS28<

What kind of doctor do you usually see there?

<1> A family doctor or general internist,

<2> An obstetrician or gynecologist,

<3> A urologist, or

<4> Some other kind of medical doctor?

<5> SEE NURSE OR OTHER KIND OF PROVIDER, NOT DOCTOR

<d,r>

>RICE4VS29<

I'd like to ask you about your insurance coverage. Have you been covered by Medicaid in the past 6 months? (Medicaid is a state program for low income persons or for persons on public assistance.)

<1> YES

<2> NO

<d,r>

>RICE4VS30<

Are you currently covered by Medicare? (Medicare is a health insurance program for 65 years old or over and for people who are disabled.)

<1> YES

<2> NO

<d,r>

>RICE4VS31<

Are you currently covered by any private health insurance that pays for or would pay for any part of hospital or doctor bills for care of your bladder or pelvic pain related condition? By private insurance we mean insurance that is provided through an employer or union or through paying for it directly. It is not paid for by a government program.

<1> YES

<2> NO

<d,r>

>RICE4VS32<

Have you received coverage from any other insurance program in the past 6 months? This includes any public programs such as Veterans Administration or a county program or any other kind of source that pays for your medical care.

<1> YES

<2> NO

<d,r>

>RICE4VS33<

[if SANDVIK23 = 2, d, or r]

[if SANDVIK25 = 2, d, or r]

[if SANDVIK26 = 2, d, or r]

[goto TIME5]

In the past 12 months, about how much have you paid, yourself, for your doctor visits and hospital care related to your bladder symptoms - money that was not paid by any kind of public or private insurance or paid back to you by insurance? Don't count what you paid for prescription drugs that you took at home.

AMOUNT SHE PAID FOR CARE IN PAST 3 MONTHS:

<d,r>

>TIME5<

[# 5. MEDICAL HISTORY AND MEDICATION MEASURES

>RICE5VS1<

Now, I'd like to ask some questions about the medications you have been taking.

In the past 3 months have you been taking medications for anxiety, such as tranquilizers or sedatives like Ativan, Valium, or Xanax?

<1> YES [goto RICE5VS1A]

<2> NO [goto RICE5VS1A]

<d,r>[goto RICE5VS1A]

>RICE5VS1A<

In the past 3 months have you been taking medication for depression, such as Zoloft, Paxil, or Prozac?

<1> YES
<2> NO
<d,r>

>RICE5VS2<

In the past 3 months have you been taking narcotic medications for pelvic pain like codeine, Oxycodone, Demerol, or methadone for bladder or pelvic pain?

<1> YES
<2> NO
<d,r>

>RICE5VS3<

In the past 3 months have you been taking medications for urinary incontinence and/or urgency like OxybutinIn (Ditropan, Ditropan XL, Oxytrol), Tolterodine (Detrol, Detrol LA), Darifenacin (Enablex), Solifenacin (Vesicare), or Trosipium (Sanctura)?

<1> YES
<2> NO
<d,r>

>RICE5VS4<

Have you taken any of the following drugs in the past 3 months?

- | | | |
|------------------------------------|---------|--------|
| a. Amitriptyline or Elavil? | <1> YES | <2> NO |
| b. Pentosanpolysulfate or Elmiron? | <1> YES | <2> NO |
| c. Hydroxyzine or Vistaril? | <1> YES | <2> NO |
| d. Dimethylsulfoxide or DMSO? | <1> YES | <2> NO |

<d,r>

>RICE5VS5<

In the past 3 months, have you had any bladder instillations either at home or in a doctor's office? This is where a medication is placed inside your bladder.

<1> YES
<2> NO [goto RICE5VS6]
<d,r> [goto RICE5VS6]

>RICE5VS5A<

How many instillations have you had in the past 3 months?

ENTER NUMBER:

<d,r>

>RICE5VS5B<

What medications were put into your bladder in the past 3 months?

DO NOT READ LIST. IF "COCKTAIL" ASK: What medication was in that cocktail?

CODE "1" FOR ALL THAT APPLY

1 DMSO

- 2 LIDOCAINE
- 3 HEPARIN
- 4 OTHER MEDICINE, NOT LISTED OR CAN'T RECALL
- 5 NO MEDICINE WAS INSTILLED

<d,r>

>RICE5VS6<

In the past 3 months, have you taken any antibiotics for bladder or urinary tract infections?

- <1> YES
- <2> NO [goto RICE5VS9]
- <d,r>[goto RICE5VS9]

>RICE5VS7<

How many days out of the past 3 months (90 days) did you take antibiotics for bladder or urinary tract infections?

ENTER NUMBER OF DAYS:

<d,r>

>RICE5VS9<

In the past 3 months, about how much have you paid, yourself, for your prescription drugs to treat your bladder symptoms, including pain - money that was not paid by any kind of public or private insurance or paid back to you by insurance?

TOTAL COST OF PRESCRIPTIONS IN LAST 12 MONTHS: @amt

<d,r>

>RICE5VS10<

Do you avoid having certain foods or drinks because they might make your bladder symptoms worse?

- <1> YES
- <2> NO [goto RICE5VS15]
- <d,r> [goto RICE5VS15]

>RICE5VS11<

In terms of convenience in your day-to-day life, how easy or difficult is it for you to avoid these foods or drinks? Would you say:

- <1> Very easy
- <2> Somewhat easy
- <3> Somewhat difficult
- <4> Very difficult?
- <d,r>

>RICE5VS12<

How easy or difficult is it to eat a healthy diet while avoiding these foods or drinks? Would you say it is:

- <1> Very easy
- <2> Somewhat easy
- <3> Somewhat difficult
- <4> Very difficult?
- <d,r>

>RICE5VS13<

What is the main reason you started to avoid having certain foods or drinks? Was it because:

PROBE FOR MAIN REASON

- <1> A doctor told you to do it,
 - <2> Other patients with bladder symptoms told you to do it,
 - <3> You noticed for yourself that certain foods or drinks made symptoms worse,
 - <4> You saw it on TV,
 - <5> You read it on a website, in a magazine, newsletter, or newspaper,
 - <6> You heard it in a support group,
 - <7> Or for some other reason? (SPECIFY)
- <d,r>

>RICE5VS14<

What other reasons did you have for starting to avoid having certain foods or drinks?

DO NOT READ CATEGORIES UNLESS RESPONDENT ASKS TO HAVE THEM READ AGAIN.

CODE "1" FOR ALL THAT APPLY

- 1 A DOCTOR TOLD YOU TO DO IT
- 2 OTHER PATIENTS WITH BLADDER SYMPTOMS TOLD YOU TO DO IT
- 3 YOU NOTICED FOR YOURSELF THAT CERTAIN FOODS OR DRINKS MADE SYMPTOMS WORSE
- 4 YOU SAW IT ON TV
- 5 YOU READ IT ON A WEBSITE, IN A MAGAZINE, NEWSLETTER, OR NEWSPAPER
- 6 YOU HEARD IT IN A SUPPORT GROUP
- 7 OR, SOME OTHER REASON
- 8 NO OTHER REASON

<d,r>

>RICE5VS15<

Are you doing any other kind of treatment or activities to help with your bladder symptoms, pain, or stress related to your bladder symptoms such as:

A. Herbal medicines or other kinds of over-the-counter medicines not recommended by your doctor?

- <1> YES
- <2> NO

B. Relaxation or stress reduction activities, such as massage, yoga, or meditation?

- <1> YES
- <2> NO

C. Taking part in a support group or using a website for patients with your medical condition?

- <1> YES
- <2> NO

D. Participating in religious activities or prayer?

- <1> YES
- <2> NO

<d,r>

>TIME6<

[# 6. SOCIODEMOGRAPHIC QUESTIONS

>RICE6intro<

Now, I have a few questions about your background.

>RICE6VS4<

How old were you on your last birthday?

ENTER AGE:

>RICE6VS5<

What was the highest grade or year of schooling you completed?

Let me read you all these categories and you can pick the best answer.

- <1> 8th grade or less
 - <2> Some high school
 - <3> Finished high school or equivalent GED
 - <4> Vocational, trade, or business school at high school level
 - <5> Some college or 2-year degree
 - <6> Finished college, 4-5 year degree
 - <7> Master's degree or equivalent
 - <8> Other advanced degree (Ph.D, medical, law, etc.)
- <d,r>

>RICE6VS6<

Now, I'd like to ask you about your employment. In the past month, were you working for pay at all?

- <1> YES [goto RICE6VS7]
 - <2> NO
- <d,r>

>RICE6VS6A<

Have bladder problems or pelvic pain kept you from working?

- <1> YES [goto RICE6VS12]
 - <2> NO [goto RICE6VS12]
- <d,r>[goto RICE6VS12]

>RICE6VS7<

What is your job title on your main job? What kind of place do you work at?

What does that place make or do?

JOB TITLE:

WORKPLACE:

MAKE OR DO:

>RICE6VS8<

In the past month, how many hours did you usually work for pay per week?

ENTER HOURS:

<d,r>

>RICE6VS9< [if RICE6VS8 >= 35, goto RICE6VS10]

Have bladder problems or pelvic pain kept you from working full time?

<1> YES

<2> NO

<d,r>

>RICE6VS10<

NOTE: PLEASE ENTER HOURS IF LESS THAN ONE DAY, OTHERWISE, ENTER THE NUMBER OF WHOLE DAYS. IF HALF A DAY OR MORE, ROUND UP TO A FULL DAY.

A. In the past month, how many days of work did you miss because of your bladder problem or pelvic pain? (EVERY DAY = 20 WORKING DAYS)

ENTER "0" IF LESS THAN ONE DAY:

ENTER HOURS:

B. How many days out of the past month were you working at the same time as you were bothered a great deal by bladder symptoms or pelvic pain?

IF NEEDED: That is how many days in the past month were you working while you were having symptoms or pain. (EVERY DAY = 20 WORKING DAYS)

ENTER "0" IF LESS THAN ONE DAY:

ENTER HOURS:

>RICE6VS11<

How much do you currently earn on your main job before taxes and other deductions?

(IF NOT SALARY OR HOURLY: How much do you earn in a typical week or month or year)?

ENTER DOLLARS:

ENTER UNIT:

(1) PER HOUR

(2) PER WEEK

(3) PER MONTH

(4) PER YEAR

<d,r>

>RICE6VS16<

Now, I'd like to ask you a few questions about you and your family. At this time, are you living alone or are there others in your household?

<1> LIVING ALONE [goto RICE6VS18]

<2> OTHERS

<3> NO USUAL PLACE TO LIVE, HOMELESS, OR MOVING AROUND [goto RICE6VS18]

<d,r>

>RICE6VS17<

Besides yourself, how many people live in your household?

ENTER NUMBER OF PEOPLE:

<d,r>

>RICE6VS18<

What was your total household income from all sources, before taxes, in [fill YEAR]?

TOTAL HH INCOME:

<d,r>

>RICE6VS19<

What is your current legal marital status? Are you now:

- <1> Married and living with your spouse
 - <2> Separated or married and living apart
 - <3> Divorced
 - <4> Widowed, or
 - <5> Never married?
 - <6> CODE IF VOLUNTEERED: SINGLE
- <d,r>

>RICE6VS20<

How many children have you ever given birth to, even if the child only lived for a short time?
ENTER "0" FOR NONE.

ENTER NUMBER OF CHILDREN:

IF 0, d,r, goto RICE6VS22]

>RICE6VS22<

Are you currently receiving Supplemental Security Income or SSI? By SSI, we mean Supplemental Security Income, not regular Social Security.

- <1> YES
 - <2> NO [goto RICE6VS23]
- <d,r> [goto RICE6VS23]

>RICE6VS22A<

Is this because of your bladder condition or for some other reason?

- <1> BLADDER CONDITION
 - <2> OTHER REASON
- <d,r>

>RICE6VS23<

Are you currently receiving financial support or money to pay bills from your parents, friends, or family members that do not live with you?

- <1> YES
 - <2> NO
- <d,r>

>TIME7<

[# 7. SF-36 GENERAL HEALTH PERCEPTIONS

>RICE7VS1<

The next few questions are about your health in general now. Please try to answer as accurately as you can. By health "in general" I mean your overall health, including bladder symptoms, but not only your bladder symptoms.

In general, would you say your health is:

- <1> Excellent
 - <2> Very good
 - <3> Good
 - <4> Fair
 - <5> Poor
- <d,r>

>RICE7VS2<

Compared to one year ago, how would you rate your health in general now?

- <1> Much better now than one year ago
 - <2> Somewhat better now than one year ago
 - <3> About the same
 - <4> Somewhat worse now than one year ago
 - <5> Much worse now than one year ago
- <d,r>

>RICE7VS3<

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports. Does your health now limit you a lot, limit you a little, or not limit you at all?

- <1> YES, LIMITED A LOT
 - <2> YES, LIMITED A LITTLE
 - <3> NO, NOT LIMITED AT ALL
- <d,r>

>RICE7VS4<

Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf. Does your health now limit you a lot, limit you a little, or not limit you at all?

- <1> YES, LIMITED A LOT
 - <2> YES, LIMITED A LITTLE
 - <3> NO, NOT LIMITED AT ALL
- <d,r>

>RICE7VS5<

Lifting or carrying groceries. Does your health now limit you a lot, limit you a little, or not limit you at all?

- <1> YES, LIMITED A LOT
 - <2> YES, LIMITED A LITTLE
 - <3> NO, NOT LIMITED AT ALL
- <d,r>

>RICE7VS6<

Climbing several flights of stairs. Does your health now limit you a lot, limit you a little, or not limit you at all?

- <1> YES, LIMITED A LOT
 - <2> YES, LIMITED A LITTLE
 - <3> NO, NOT LIMITED AT ALL
- <d,r>

>RICE7VS7<

Climbing one flight of stairs.

(Does your health now limit you a lot, limit you a little, or not limit you at all?)

- <1> YES, LIMITED A LOT
- <2> YES, LIMITED A LITTLE
- <3> NO, NOT LIMITED AT ALL
- <d,r>

>RICE7VS8<

Bending, kneeling, or stooping.

(Does your health now limit you a lot, limit you a little, or not limit you at all?)

- <1> YES, LIMITED A LOT
- <2> YES, LIMITED A LITTLE
- <3> NO, NOT LIMITED AT ALL
- <d,r>

>RICE7VS9<

Walking more than a mile.

(Does your health now limit you a lot, limit you a little, or not limit you at all?)

- <1> YES, LIMITED A LOT
- <2> YES, LIMITED A LITTLE
- <3> NO, NOT LIMITED AT ALL
- <d,r>

>RICE7VS10<

Walking several blocks.

(Does your health now limit you a lot, limit you a little, or not limit you at all?)

- <1> YES, LIMITED A LOT
- <2> YES, LIMITED A LITTLE
- <3> NO, NOT LIMITED AT ALL
- <d,r>

>RICE7VS11<

Walking one block.

(Does your health now limit you a lot, limit you a little, or not limit you at all?)

- <1> YES, LIMITED A LOT
- <2> YES, LIMITED A LITTLE
- <3> NO, NOT LIMITED AT ALL
- <d,r>

>RICE7VS12<

Bathing or dressing yourself.

(Does your health now limit you a lot, limit you a little, or not limit you at all?)

- <1> YES, LIMITED A LOT
 - <2> YES, LIMITED A LITTLE
 - <3> NO, NOT LIMITED AT ALL
- <d,r>

>RICE7VS13A<

In the past 4 weeks, have you had any of the following problems with your work or other regular daily activities, as a result of your physical health?

Have you ...

Cut down the amount of time you spent on work or other activities?

- <1> YES
 - <2> NO
- <d,r>

>RICE7VS13B<

(In the past 4 weeks, as a result of your physical health, have you ...)

Accomplished less than you would like?

- <1> YES
 - <2> NO
- <d,r>

>RICE7VS13C<

Were limited in the kind of work or other activities (in the past 4 weeks, as a result of your physical health)

- <1> YES
 - <2> NO
- <d,r>

>RICE7VS13D<

(In the past 4 weeks, as a result of your physical health, have you ...)

Had difficulty performing the work or other activities, for example, it took extra effort?

- <1> YES
 - <2> NO
- <d,r>

>RICE7VS14A<

In the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

Cut down the amount of time you spent on work or other activities?

- <1> YES
 - <2> NO
- <d,r>

>RICE7VS14B<

(In the past 4 weeks, as a result of any emotional problems, have you...)

Accomplished less than you would like?

- <1> YES
- <2> NO
- <d,r>

>RICE7VS14C<

Didn't do work or other activities as carefully as usual (in the past 4 weeks, as a result of any emotional problems)?

- <1> YES
- <2> NO
- <d,r>

>RICE7VS15<

In the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- <1> Not at all
- <2> Slightly
- <3> Moderately
- <4> Quite a bit
- <5> Extremely
- <d,r>

>RICE7VS16<

How much bodily pain have you had in the past 4 weeks?

- <1> None
- <2> Very Mild
- <3> Mild
- <4> Moderate
- <5> Severe
- <6> Very severe
- <d,r>

>RICE7VS17<

In the past 4 weeks, how much did pain interfere with your normal work, including both work outside the home and housework?

- <1> Not at all
- <2> Slightly
- <3> Moderately
- <4> Quite a bit
- <5> Extremely
- <d,r>

>RICE7VS18<

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time in the past 4 weeks . . .

Did you feel full of pep?

- <1> All of the time
- <2> Most of the time
- <3> A good bit of the time

- <4> Some of the time
- <5> A little of the time
- <6> None of the time
- <d,r>

>RICE7VS19<

How much of the time in the past 4 weeks, have you been a very nervous person?

- <1> All of the time
- <2> Most of the time
- <3> A good bit of the time
- <4> Some of the time
- <5> A little of the time
- <6> None of the time
- <d,r>

>RICE7VS20<

(How much of the time in the past 4 weeks,) have you felt so down in the dumps that nothing could cheer you up?

- <1> All of the time
- <2> Most of the time
- <3> A good bit of the time
- <4> Some of the time
- <5> A little of the time
- <6> None of the time
- <d,r>

>RICE7VS21<

(How much of the time in the past 4 weeks,) have you felt calm and peaceful?

- <1> All of the time
- <2> Most of the time
- <3> A good bit of the time
- <4> Some of the time
- <5> A little of the time
- <6> None of the time
- <d,r>

>RICE7VS22<

(How much of the time in the past 4 weeks,) did you have a lot of energy?

- <1> All of the time
- <2> Most of the time
- <3> A good bit of the time
- <4> Some of the time
- <5> A little of the time
- <6> None of the time
- <d,r>

>RICE7VS23<

(How much of the time in the past 4 weeks,) have you felt downhearted and blue?

- <1> All of the time
- <2> Most of the time
- <3> A good bit of the time

- <4> Some of the time
- <5> A little of the time
- <6> None of the time
- <d,r>

>RICE7VS24<

(How much of the time in the past 4 weeks,) did you feel worn out?

- <1> All of the time
- <2> Most of the time
- <3> A good bit of the time
- <4> Some of the time
- <5> A little of the time
- <6> None of the time
- <d,r>

>RICE7VS25<

(How much of the time in the past 4 weeks,) have you been a happy person?

- <1> All of the time
- <2> Most of the time
- <3> A good bit of the time
- <4> Some of the time
- <5> A little of the time
- <6> None of the time
- <d,r>

>RICE7VS26<

(How much of the time in the past 4 weeks,) did you feel tired?

- <1> All of the time
- <2> Most of the time
- <3> A good bit of the time
- <4> Some of the time
- <5> A little of the time
- <6> None of the time
- <d,r>

>RICE7VS27<

In the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities, like visiting with friends, relatives, etc?

- <1> All of the time
- <2> Most of the time
- <3> A good bit of the time
- <4> Some of the time
- <5> A little of the time
- <6> None of the time
- <d,r>

>RICE7VS28<

How TRUE or FALSE is each of the following statements for you.

I seem to get sick a little easier than other people.

- <1> Definitely true

- <2> Mostly true
- <3> Don't know
- <4> Mostly False
- <5> Definitely False
- <d,r>

>RICE7VS29<

How TRUE or FALSE is each of the following statements for you.

I am as healthy as anybody I know.

- <1> Definitely true
- <2> Mostly true
- <3> Don't know
- <4> Mostly False
- <5> Definitely False
- <d,r>

>RICE7VS30<

(How TRUE or FALSE is each of the following statements for you.)

I expect my health to get worse.

- <1> Definitely true
- <2> Mostly true
- <3> Don't know
- <4> Mostly False
- <5> Definitely False
- <d,r>

>RICE7VS31<

(How TRUE or FALSE is each of the following statements for you.)

My health is excellent.

- <1> Definitely true
- <2> Mostly true
- <3> Don't know
- <4> Mostly False
- <5> Definitely False
- <d,r>

>TIME8<

[# 8. COMPARATIVE SCALES

>OLS1<

Now I'd like to ask some questions that might sound similar to what we asked before but they are actually a little different and help us to make better comparisons with other people who have similar symptoms.

In the past month, how often have you felt the strong need to urinate with little or no warning? Would you say...

- <0> Not at all
- <1> Less than 1 time in 5
- <2> Less than half the time

- <3> About half the time
- <4> More than half the time
- <5> Almost always?
- <d,r>

>OLS2<

In the past month, have you had to urinate less than 2 hours after you finished urinating? Would you say...

- <0> Not at all
- <1> Less than 1 time in 5
- <2> Less than half the time
- <3> About half the time
- <4> More than half the time
- <5> Almost always?
- <d,r>

>OLS3<

In the past month, how often did you most typically get up at night to urinate?

Would you say...

- <0> None
- <1> Once
- <2> 2 times
- <3> 3 times
- <4> 4 times
- <5> 5 or more times?
- <d,r>

>OLS4<

In the past month, have you experienced pain or burning in your bladder?

Would you say...

- <1> Not at all
- <2> A few times
- <3> Fairly often
- <4> Usually
- <5> Almost always
- <d,r>

>OLS5<

In the past month, have you experienced discomfort or pressure in your bladder?

Would you say...

- <1> Not at all
- <2> A few times
- <3> Fairly often
- <4> Usually
- <5> Almost always
- <d,r>

>OLS6<

In the past month, how much has frequent urination during the day been a problem for you?

Would you say...

- <1> No problem
 - <2> Very small problem
 - <3> Small problem
 - <4> Medium problem
 - <5> Big problem?
- <d,r>

>OLS7<

In the past month, how much has getting up at night to urinate been a problem for you?

Would you say...

- <1> No problem
 - <2> Very small problem
 - <3> Small problem
 - <4> Medium problem
 - <5> Big problem?
- <d,r>

>OLS8<

In the past month, how much has the need to urinate with little warning been a problem for you?

Would you say...

- <1> No problem
 - <2> Very small problem
 - <3> Small problem
 - <4> Medium problem
 - <5> Big problem?
- <d,r>

>OLS9<

In the past month, how much has burning, pain, discomfort, or pressure in your bladder been a problem for you?

Would you say...

- <1> No problem
 - <2> Very small problem
 - <3> Small problem
 - <4> Medium problem
 - <5> Big problem?
- <d,r>

>OLS10<

Do you stay at home because of your bladder symptoms:

- <1> All of the time
 - <2> Most of the time
 - <3> About half of the time
 - <4> Some of the time
 - <5> None of the time
- <d,r>

>TIME9<

[# 9. SLEEP INVENTORY

>RICE9VS1<

The next questions ask about your sleep habits.

In the past month, how many hours of actual sleep did you get at night? (This may be different than the numbers of hours you spend in bed)

ENTER NUMBER OF HOURS:

<d,r>

>RICE9VS2<

In the past month, on average, what is the longest period of time (in hours) that you stayed asleep at night, without interruption?

ENTER NUMBER OF HOURS:

<d,r>

>RICE9VS3A<

In the past month, how often have you had trouble sleeping because you...

Had to get up to use the bathroom? Would you say:

- <1> Not during the past month,
 - <2> Less than once a week,
 - <3> Once or twice a week,
 - <4> Three or more times a week, or
 - <5> Every night or nearly every night?
- <d,r>

>RICE9VS3B<

(In the past month, how often have you had trouble sleeping because you...)

Felt general nervousness? Would you say:

- <1> Not during the past month,
 - <2> Less than once a week,
 - <3> Once or twice a week,
 - <4> Three or more times a week, or
 - <5> Every night or nearly every night?
- <d,r>

>RICE9VS3C<

(In the past month, how often have you had trouble sleeping because you...)

Had dreams related to having to urinate? Would you say:

- <1> Not during the past month,
 - <2> Less than once a week,
 - <3> Once or twice a week,
 - <4> Three or more times a week, or
 - <5> Every night or nearly every night?
- <d,r>

>RICE9VS3C2<

(In the past month, how often have you had trouble sleeping because you...)

Had feelings of urgency or needing to urinate? Would you say:

- <1> Not during the past month,
 - <2> Less than once a week,
 - <3> Once or twice a week,
 - <4> Three or more times a week, or
 - <5> Every night or nearly every night?
- <d,r>

>RICE9VS3D<

(In the past month, how often have you had trouble sleeping because you...)

Had bladder or pelvic pain? Would you say:

- <1> Not during the past month,
 - <2> Less than once a week,
 - <3> Once or twice a week,
 - <4> Three or more times a week, or
 - <5> Every night or nearly every night?
- <d,r>

>RICE9VS4<

In the past month, how would you rate your sleep quality overall?

- <1> Very good,
 - <2> Fairly good,
 - <3> Fairly bad, or
 - <4> Very bad?
- <d,r>

>RICE9VS5<

In the past month, how often have you taken medicine, either prescribed or "over the counter", to help you sleep?

Would you say:

- <1> Not during the past month,
 - <2> Less than once a week,
 - <3> Once or twice a week,
 - <4> Three or more times a week or
 - <5> Every night or nearly every night?
- <d,r>

>RICE9VS6<

In the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?

- <1> Not during the past month,
 - <2> Less than once a week,
 - <3> Once or twice a week,
 - <4> Three or more times a week or
 - <5> Every night or nearly every night?
- <d,r>

>TIME10<

[# 10. SEXUAL IMPACT

>SXIRAND1<

The next questions ask about your sexual behavior. Remember that your responses will be kept strictly confidential, and you do not have to answer any questions that make you uncomfortable.

Is it OK to go ahead with these?

- <1> YES
- <2> NO [goto MENT1]
- <d,r> [goto MENT1]

>SXIRAND2< [if RICE6VS20 >= 1, goto SXIRAND3]

Have you ever had sex with another person, including sex that turned you on even if there was no actual intercourse or orgasm?

- <1> YES
- <2> NO [goto MENT1]
- <3> NOT SURE
- <d,r>

>SXIRAND3<

As of now, do you have a partner whom you could have sex with if you want to?

- <1> YES
- <2> NO
- <3> NOT SURE
- <d,r>

>SXIRAND4<

In the past 12 months, how many times have you had vaginal intercourse?

ENTER NUMBER OF TIMES:

<d,r>

>NORC5<

In the past 12 months, how much of the time has your physical health interfered with your sexual activities? Would you say that it was:

- <1> all of the time
- <2> most of the time
- <3> some of the time
- <4> a little of the time or
- <5> none of the time?
- <d,r>

>NORC6<

In the past 12 months, how much of the time have emotional problems interfered with your sexual activities? Would you say that it was:

- <1> all of the time
- <2> most of the time
- <3> some of the time

- <4> a little of the time or
- <5> none of the time?
- <d,r>

>NORC7<

In the past 12 months, how much of the time has stress or pressure in your life interfered with your sexual activities? Would you say that it was:

- <1> all of the time
- <2> most of the time
- <3> some of the time
- <4> a little of the time or
- <5> none of the time?
- <d,r>

>skrand12< [if SXIRAND3 = 1, d, or r, goto TIME11]

>RAND12A<

How much of a problem was each of the following in the past 4 weeks?

Lack of sexual interest

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

>RAND12B<

(How much of a problem was each of the following in the past 4 weeks?)

Unable to relax and enjoy sex

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

>RAND12C<

(How much of a problem was each of the following in the past 4 weeks?)

Difficulty in becoming sexually aroused

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

>RAND12D<

(How much of a problem was each of the following in the past 4 weeks?)

Difficulty in having an orgasm

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

>RAND12E<

(How much of a problem was each of the following in the past 4 weeks?)

Bladder pain during sex

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

>RAND12F<

(How much of a problem was each of the following in the past 4 weeks?)

Bladder pain after sex, (or fear of bladder pain after sex)

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

>RAND12G<

(How much of a problem was each of the following in the past 4 weeks?)

Fear that sex would make bladder problems worse

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

>RAND12H<

(How much of a problem was each of the following in the past 4 weeks?)

Urge to urinate during sex

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

>RAND12I<

(How much of a problem was each of the following in the past 4 weeks?)

Pain in the genital area

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

>RAND12J<

(How much of a problem was each of the following in the past 4 weeks?)

Lack of sensation in the genital area

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

>RAND12K<

(How much of a problem was each of the following in the past 4 weeks?)

Dryness or poor lubrication of vagina

- <1> Not a problem
- <2> A little of a problem
- <3> Somewhat of a problem
- <4> Very much a problem
- <5> NOT APPLICABLE
- <d,r>

[IF ANY ITEM IN 12A THROUGH 12K IS CODED 4, CONTINUE WITH NORC13. OTHERWISE, SKIP TO NEXT SECTION.]

>NORC13<

Sometimes when people have problems like this, they go to someone like a doctor or other health professional for help. In the past 12 months, have you tried to get help from a doctor or other health professional for the sexual problem(s) you have experienced?

- <1> YES
- <2> NO [goto TIME11]
- <d,r>[goto TIME11]

>RAND14<

Was the problem resolved:

- <1> Completely
- <2> Partly
- <3> Or not resolved?
- <d,r>

>TIME11<

[# 11. MENTAL HEALTH (SERVICE USE, ANXIETY, PANIC, DEPRESSION, CONTROL)]

>MENT1<

In the next questions, we will ask you about your use of mental health services and your mental health in general.

Did you visit a mental health provider on an individual or family basis for emotional or personal problems during the past 12 months? By mental health provider we mean a psychiatrist, psychologist, psychiatric social worker, psychiatric nurse, or marriage or family counselor.

- <1> YES
- <2> NO [goto MENT2A]
- <d,r>[goto MENT2A]

>MENT2<

In total, how many visits to mental health providers did you make during the past 12 months?

ENTER NUMBER OF VISITS:

<d,r>

>MENT2A<

Did you visit any general doctors, such as a family doctor or general internist for emotional or personal problems during the past 12 months?

- <1> YES
- <2> NO [goto MENT3A]
- <d,r> [goto MENT3A]

>MENT2B<

In total, how many visits did you make to general doctors for emotional or personal problems in the past 12 months?

ENTER NUMBER OF VISITS:

<d,r>

>MENT3A<

Over the past 2 weeks, how often have you been bothered by any of the following problems? Let's start with:

Little pleasure or interest in doing things? Have you been bothered by this in the past 2 weeks:

- <1> Not at all,
- <2> Several days,
- <3> More than half the days, or
- <4> Nearly every day?
- <d,r>

>MENT3B<

How about: Feeling down, depressed, or hopeless?

(Have you been bothered by this in the past 2 weeks):

- <1> Not at all,
- <2> Several days,

- <3> More than half the days, or
 - <4> Nearly every day?
- <d,r>

>MENT3C<

Trouble falling asleep or staying asleep or sleeping too much?

(Have you been bothered by this in the past 2 weeks):

- <1> Not at all,
 - <2> Several days,
 - <3> More than half the days, or
 - <4> Nearly every day?
- <d,r>

>MENT3D<

Feeling tired or having little energy?

(Have you been bothered by this in the past 2 weeks):

- <1> Not at all,
 - <2> Several days,
 - <3> More than half the days, or
 - <4> Nearly every day?
- <d,r>

>MENT3E<

Poor appetite or overeating?

(Have you been bothered by this in the past 2 weeks):

- <1> Not at all,
 - <2> Several days,
 - <3> More than half the days, or
 - <4> Nearly every day?
- <d,r>

>MENT3F<

Feeling bad about yourself - or that you are a failure or have let yourself or your family down?

(Have you been bothered by this in the past 2 weeks):

- <1> Not at all,
 - <2> Several days,
 - <3> More than half the days, or
 - <4> Nearly every day?
- <d,r>

>MENT3G<

Trouble concentrating on things, such as reading a newspaper or watching television?

(Have you been bothered by this in the past 2 weeks):

- <1> Not at all,
- <2> Several days,
- <3> More than half the days, or

<4> Nearly every day?
<d,r>

>MENT3H<

Moving or speaking so slowly that other people could have noticed -or the opposite, being so fidgety or restless that you have been moving around a lot more than usual?

(Have you been bothered by this in the past 2 weeks):

<1> Not at all,
<2> Several days,
<3> More than half the days, or
<4> Nearly every day?
<d,r>

[#PERCEIVED STRESS

>PSTRES4<

Now, I'm going to ask about a slightly longer period of time, the past month.

In the past month, how often have you felt that you were unable to control the important things in your life?

<0> Never,
<1> Almost never,
<2> Sometimes,
<3> Fairly often, or
<4> Very often
<d,r>

>PSTRES5<

In the past month, how often have you felt confident about your ability to handle your personal problems?

<0> Never,
<1> Almost never,
<2> Sometimes,
<3> Fairly often, or
<4> Very often
<d,r>

>PSTRES6<

In the past month, how often have you felt that things were going your way?

<0> Never,
<1> Almost never,
<2> Sometimes,
<3> Fairly often, or
<4> Very often
<d,r>

>PSTRES7<

In the past month, how often have you felt difficulties were piling up so high that you could not overcome them?

<0> Never,
<1> Almost never,
<2> Sometimes,

<3> Fairly often, or
<4> Very often
<d,r>

>PSTRES8<

Now I am going to be asking about an even longer period of time, the past 3 months.

In the past 3 months, did you ever have a spell or attack when, for no apparent reason, your heart suddenly began to race, you felt faint, or you couldn't catch your breath?

<1> YES
<2> NO
<d,r>

>PSTRES9<

In the past 3 months, did you ever have a spell or an attack when all of a sudden you felt frightened, anxious, or very uneasy?

<1> YES
<2> NO
<d,r>

>PSTRES10<

In the past 3 months, have you spent a lot of time worrying about everyday problems?

<1> YES
<2> NO
<d,r>

>PSTRES11<

In the past 3 months, have you often been bothered by "nerves" or feeling anxious or on edge?

<1> YES
<2> NO
<d,r>

>TIME12<

[# 12. PERCEIVED CONTROL OVER BLADDER SYMPTOMS

>PCBLAD1<

To what extent do you believe you can do things to control your day-to-day bladder symptoms? Would you say:

<0> None,
<1> A little bit,
<2> Somewhat, or
<3> A lot?
<d,r>

>PCBLAD2<

To what extent do you believe you can do things to control the future course of your bladder symptoms? Would you say:

<0> None,
<1> A little bit,

<2> Somewhat, or
<3> A lot?
<d,r>

>PCBLAD3<

To what extent do you believe you can do things to control your feelings and emotions regarding your bladder symptoms? Would you say:

<0> None,
<1> A little bit,
<2> Somewhat, or
<3> A lot?
<d,r>

>TIME13<

[# 13. BLADDER SYMPTOM IMPACT

>BLADSI1A<

Sometimes medical conditions can make life difficult in a variety of ways and sometimes they don't make that much difference. Using any number from 1 to 7, where 1 is having a very small negative or bad effect and 7 is having a very large negative or bad effect, please rate each of the following in terms of how negatively, if at all, your bladder symptoms affect this part of your life. If there is no effect, rate it as zero.

Please rate:

The effect of your bladder symptoms on your ability to be employed outside the home at this time? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:
<d,r>

>BLADSI1B<
(Please rate:)

The effect of your bladder symptoms on your ability to carry out your home responsibilities? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:
<d,r>

>BLADSI1C<
(Please rate:)

The effect of your bladder symptoms on your ability to have enough money to live on? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:

<d,r>

>BLADSI1D<

(Please rate:)

The effect of your bladder symptoms on your ability to care for children or grandchildren? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.

(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:

<d,r>

>BLADSI1E<

(Please rate:)

The effect of your bladder symptoms on your social life? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.

(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:

<d,r>

>BLADSI1F<

(Please rate:)

The effect of your bladder symptoms on your feelings of self-worth? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.

(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:

<d,r>

>BLADSI1G<

(Please rate:)

The effect of your bladder symptoms on your interest in life? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.

(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:

<d,r>

>BLADSI1H<

(Please rate:)

The effect of your bladder symptoms on your energy level? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:
<d,r>

>BLADSI1I<
(Please rate:)

The effect of your bladder symptoms on your ability to care for yourself such as bathing, dressing, and grooming? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:
<d,r>

>BLADSI1J<
(Please rate:)

The effect of your bladder symptoms on your ability to take care of personal business such as attending school, banking, or shopping? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:
<d,r>

>BLADSI1K<
(Please rate:)

The effect of your bladder symptoms on your need to rely on others? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:
<d,r>

>BLADSI1L<
(Please rate:)

The effect of your bladder symptoms on your moods? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:
<d,r>

>BLADSI1M<

(Please rate:)

The effect of your bladder symptoms on your ability to get along with people and have friends? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:
<d,r>

>BLADSI1N<
(Please rate:)

The effect of your bladder symptoms on your feelings about yourself as a woman? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:
<d,r>

>BLADSI1O<
(Please rate:)

The effect of your bladder symptoms on your marriage or relationship? (1 is a very small negative effect, 7 is a very large negative effect)

IF NOT APPLICABLE FOR ANY ITEM ENTER ZERO.
(CODE 0 = NO EFFECT)

ENTER NUMBER 1-7:
< d,r>

>TIME14<

[# 14. SOCIAL SUPPORT

>SOC1<

Next, we'd like to know about your social support, including your friends and family.

How many people can you really count on to distract you from your worries when you feel under stress?
Would you say:

- <1> None,
 - <2> 1,
 - <3> 2 to 3,
 - <4> 4 to 6, or
 - <5> More than 6?
- <d,r>

>SOC2<

How many people can you really count on to help you feel more relaxed when you are under pressure or tense? Would you say:

- <1> None,
 - <2> 1,
 - <3> 2 to 3,
 - <4> 4 to 6, or
 - <5> More than 6?
- <d,r>

>SOC3<

How many people accept you totally, including both your worst and best points? Would you say:

- <1> None,
 - <2> 1,
 - <3> 2 to 3,
 - <4> 4 to 6, or
 - <5> More than 6?
- <d,r>

>SOC4<

How many people can you really count on to care about you, regardless of what is happening to you? Would you say:

- <1> None,
 - <2> 1,
 - <3> 2 to 3,
 - <4> 4 to 6, or
 - <5> More than 6?
- <d,r>

>SOC5<

How many people can you really count on to help you feel better when you are feeling generally down in the dumps? Would you say:

- <1> None,
 - <2> 1,
 - <3> 2 to 3,
 - <4> 4 to 6, or
 - <5> More than 6?
- <d,r>

>SOC6<

How many people can you really count on to console you when you are very upset? Would you say:

- <1> None,
 - <2> 1,
 - <3> 2 to 3,
 - <4> 4 to 6, or
 - <5> More than 6?
- <d,r>

>SOC7<

How many people can you really count on to support you when you are having bladder symptoms? Would you say:

- <1> None,
- <2> 1,
- <3> 2 to 3,

<4> 4 to 6, or
<5> More than 6?
<d,r>

>SOC8<

How many people have you told about your bladder symptoms? Would you say:

<1> None,
<2> 1,
<3> 2 to 3,
<4> 4 to 6, or
<5> More than 6?
<d,r>

>TIME15<

[# 15. PERCEIVED GENERAL CONTROL

>PGENCTRL<

Please indicate whether each statement is either true or false for you.

- | | |
|---|--------------------|
| a. I have little control over the things that happen to me | <1> True <2> False |
| b. There is really no way I can solve some of the problems I have | <1> True <2> False |
| c. There is little I can do to change many of the important things in my life | <1> True <2> False |
| d. I often feel helpless in dealing with problems of life | <1> True <2> False |
| e. Sometimes I feel that I am being pushed around in life | <1> True <2> False |
| f. What happens to me in the future mostly depends on me | <1> True <2> False |
| g. I can do just about anything I really set my mind to | <1> True <2> False |

d,r>

>TIME16<

[# 16. HEALTH CARE SATISFACTION

>SAT1<

Now, we'd like to ask about your satisfaction with your medical care.

Using any number from 0 to 10, where 0 is the worst medical care possible and 10 is the best medical care possible, what number would you use to rate the medical care that you have received for your bladder symptoms in the past six months?

(99) - NOT RECEIVING MEDICAL CARE FOR BLADDER SYMPTOMS

ENTER NUMBER 0-10:

<d,r>

[IF 99, goto SAT3]

>SAT2<

Using any number from 0 to 10, where 0 is the worst doctor possible and 10 is the best doctor possible, what number would you use to rate the doctor that you currently see for most of your bladder symptoms care?

(99) - NOT SEEING A DOCTOR FOR BLADDER SYMPTOMS

ENTER NUMBER 0-10:

<d,r>

>SAT3<

Using any number from 0 to 10, where 0 is the worst medical care possible and 10 is the best medical care possible, what number would you use to rate the medical care that you have received that is not related to your bladder symptoms in the past 6 months?

(99) - NOT RECEIVING MEDICAL CARE FOR NON BLADDER RELATED SYMPTOMS

ENTER NUMBER 0-10:

<d,r>

[IF 99, goto TIME17]

>SAT4<

Using any number from 0 to 10, where 0 is the worst doctor possible and 10 is the best doctor possible, what number would you use to rate the doctor that you currently see for care that is not related to your bladder symptoms?

(99) - NOT SEEING A DOCTOR FOR NON BLADDER RELATED SYMPTOMS

ENTER NUMBER 0-10:

<d,r>

>TIME17<

[#17. COPING WITH IC/PBS

>COPINGA<

Now we'd like to ask you about how you deal with your bladder symptoms.

In response to your bladder symptoms, how often in the past 4 weeks have you done each of the following?

Used the situation to change or grow as a person?

- <1> All of the time,
- <2> Most of the time,
- <3> A good bit of the time,
- <4> Some of the time,
- <5> A little of the time, or
- <6> None of the time

<d,r>

>COPINGB<

(How often in the past 4 weeks have you...)?

Avoided being with people in general?

- <1> All of the time,

- <2> Most of the time,
 - <3> A good bit of the time,
 - <4> Some of the time,
 - <5> A little of the time, or
 - <6> None of the time
- <d,r>

>COPINGC<

(How often in the past 4 weeks have you...)?

Kept yourself from thinking too much about your bladder symptoms?

- <1> All of the time,
 - <2> Most of the time,
 - <3> A good bit of the time,
 - <4> Some of the time,
 - <5> A little of the time, or
 - <6> None of the time
- <d,r>

>COPINGD<

(How often in the past 4 weeks have you...)?

Asked other people for advice and information?

- <1> All of the time,
 - <2> Most of the time,
 - <3> A good bit of the time,
 - <4> Some of the time,
 - <5> A little of the time, or
 - <6> None of the time
- <d,r>

>COPINGE<

(How often in the past 4 weeks have you...)?

Criticized or lectured yourself?

- <1> All of the time,
 - <2> Most of the time,
 - <3> A good bit of the time,
 - <4> Some of the time,
 - <5> A little of the time, or
 - <6> None of the time
- <d,r>

>COPINGF<

(How often in the past 4 weeks have you...)?

Tried to keep yourself from worrying about your bladder symptoms?

- <1> All of the time,
- <2> Most of the time,
- <3> A good bit of the time,
- <4> Some of the time,
- <5> A little of the time, or

<6> None of the time
<d,r>

>COPINGG<

(How often in the past 4 weeks have you...)?

Tried to keep your bladder symptoms from bothering you?

<1> All of the time,
<2> Most of the time,
<3> A good bit of the time,
<4> Some of the time,
<5> A little of the time, or
<6> None of the time
<d,r>

>TIME18<

>ADDIntro<

Now I'm going to ask you about some other health symptoms, not just your bladder symptoms.

>FM01<

Have you suffered from general pain during the past 3 months?

<1> YES
<2> NO [goto IBS01]
<d,r>[goto IBS01]

>FM02<

Did you have continuous pain during all 3 months?

<1> YES
<2> NO
<d,r>

>skfm03< [if FM01 = 1 and FM02 = 1, goto FM03]

>FM03<

Do you suffer from pain in both the upper and lower body?

<1> YES
<2> NO
<d,r>

>FM04<

Do you suffer from pain in both the right and left sides?

<1> YES
<2> NO
<d,r>

>FM05<

Do you suffer from pain in the back, neck, chest or buttocks?

<1> YES
<2> NO

<d,r>

>IBS01<

In the past 3 months, how often did you have discomfort or pain anywhere in your abdomen?

- <0> Never [goto CFS01]
 - <1> Less than one day a month
 - <2> One day a month
 - <3> Two to three days a month
 - <4> One day a week
 - <5> More than one day a week
 - <6> Every day
- <d,r>

>IBS02< [if RICE4VS20 = 2, goto IBS03]

Did this discomfort or pain occur only during your menstrual bleeding and not at other times?

- <1> YES
 - <2> NO
- <d,r>

>IBS03<

Have you had this discomfort or pain for 6 months or longer?

- <1> YES
 - <2> NO
- <d,r>

>IBS04<

How often did this discomfort or pain get better or stop after you had a bowel movement?

- <0> Never or rarely
 - <1> Sometimes
 - <2> Often
 - <3> Most of the time
 - <4> Always
- <d,r>

>IBS05<

When this discomfort or pain started, did you have more frequent bowel movements?

- <0> Never or rarely
 - <1> Sometimes
 - <2> Often
 - <3> Most of the time
 - <4> Always
- <d,r>

>IBS06<

When this discomfort or pain started, did you have less frequent bowel movements?

- <0> Never or rarely
- <1> Sometimes
- <2> Often
- <3> Most of the time

<4> Always
<d,r>

>IBS07<

When this discomfort or pain started, were your stools (bowel movements) looser?

<0> Never or rarely
<1> Sometimes
<2> Often
<3> Most of the time
<4> Always
<d,r>

>IBS08<

When this discomfort or pain started, how often did you have harder stools?

<0> Never or rarely
<1> Sometimes
<2> Often
<3> Most of the time
<4> Always
<d,r>

>IBS09<

In the past 3 months, how often did you have hard or lumpy stools?

<0> Never or rarely
<1> Sometimes
<2> Often
<3> Most of the time
<4> Always
<d,r>

>IBS10<

In the past 3 months, how often did you have loose, mushy or watery stools?

<0> Never or rarely
<1> Sometimes
<2> Often
<3> Most of the time
<4> Always
<d,r>

>CFS01<

In the past month, have you felt tired all the time?

<1> YES
<2> NO [goto ETIME]
<d,r>

>CFS01A<

For how long has this occurred? Would you say...

<1> Less than one month
<2> 1 to 6 months, or
<3> More than 6 months?

>CFS02<

Is this fatigue (or tiredness) relieved by rest?

<1> YES

<2> NO

<d,r>

>CFS03<

Does even minimal physical effort cause exhaustion?

<1> YES

<2> NO

<d,r>

>CFS04<

The next few questions are about physical symptoms that you may have experienced in the past 6 months.

In the past 6 months, have you had a sore throat?

<1> YES

<2> NO [goto CFS11]

<d,r>[goto CFS11]

>CFS05<

In the past 6 months, how often have you had a sore throat?

<1> A little of the time

<2> Some of the time

<3> A good bit of the time

<4> Most of the time

<5> All of the time

<d,r>

>CFS06<

In the past 6 months, how bad was your sore throat?

<1> Very mild

<2> Mild

<3> Moderate

<4> Severe

<5> Very severe

<d,r>

>CFS07<

Prior to this past 6 months, for how long had you had a sore throat?

<1> Less than 6 months [goto CFS11]

<2> 6-12 months [goto CFS11]

<3> More than 12 months

<d,r>

>CFS08<

For how many years have you had a sore throat?

RECORD NUMBER OF YEARS

<d,r>

>CFS11<

In the past 6 months, have you had tender lymph nodes or swollen glands in your neck or armpits?

<1> YES

<2> NO [goto CFS18]

<d,r>[goto CFS18]

>CFS12<

In the past 6 months, how often have you had tender lymph nodes or swollen glands?

<1> A little of the time

<2> Some of the time

<3> A good bit of the time

<4> Most of the time

<5> All of the time

<d,r>

>CFS13<

In the past 6 months, how tender were your lymph nodes or how swollen were your glands?

<1> Very mild

<2> Mild

<3> Moderate

<4> Severe

<5> Very severe

<d,r>

>CFS14<

Prior to this past 6 months, how long had you had tender lymph nodes or swollen glands?

<1> Less than 6 months [goto CFS18]

<2> 6-12 months [goto CFS18]

<3> More than 12 months

<d,r>

>CFS15<

For how many years have you had tender lymph nodes or swollen glands?

RECORD NUMBER OF YEARS

<d,r>

>CFS18<

In the past 6 months, have you been unusually fatigued or unwell for at least one day after exerting yourself in any way?

(IF NEEDED: Have you been unusually tired or did you not feel well for at least one day after doing any physical activity?)

<1> YES

<2> NO [goto CFS25]

<d,r> [goto CFS25]

>CFS19<

In the past 6 months, how often have you had unusual fatigue after exertion?

(IF NEEDED: How often have you been unusually tired after physical activity?)

- <1> A little of the time
- <2> Some of the time
- <3> A good bit of the time
- <4> Most of the time
- <5> All of the time
- <d,r>

>CFS20<

In the past 6 months, how bad was your unusual fatigue after exertion?

(IF NEEDED: How bad was your level of tiredness after physical activity?)

- <1> Very mild
- <2> Mild
- <3> Moderate
- <4> Severe
- <5> Very severe
- <d,r>

>CFS21<

Prior to this past 6 months, for how long had you had unusual fatigue after exertion?

(IF NEEDED: For how long have you been unusually tired after physical activity?)

- <1> Less than 6 months [goto CFS25]
- <2> 6 - 12 months [goto CFS25]
- <3> More than 12 months
- <d,r>

>CFS22<

For how many years have you had unusual fatigue after exertion?

(IF NEEDED: For how many years have you been unusually tired after physical activity?)

RECORD NUMBER OF YEARS

<d,r>

>CFS25<

In the past 6 months, have you had muscle aches or muscle pain?

- <1> YES
- <2> NO [goto CFS32]
- <d,r>[goto CFS32]

>CFS26<

In the past 6 months, how often have you had muscle aches or muscle pains?

- <1> A little of the time
- <2> Some of the time
- <3> A good bit of the time
- <4> Most of the time
- <5> All of the time
- <d,r>

>CFS27<

In the past 6 months, how bad were your muscle aches or muscle pains?

- <1> Very mild
 - <2> Mild
 - <3> Moderate
 - <4> Severe
 - <5> Very severe
- <d,r>

>CFS28<

Prior to this past 6 months, for how long have you had muscle aches or muscle pains?

- <1> Less than 6 months [goto CFS32]
 - <2> 6 - 12 months [goto CFS32]
 - <3> More than 12 months
- <d,r>

>CFS29<

For how many years have you had muscle aches or muscle pains?

RECORD NUMBER OF YEARS

<d,r>

>CFS32<

In the past 6 months, have you had pain in several joints?

- <1> YES
 - <2> NO [goto CFS39]
- <d,r>[goto CFS39]

>CFS33<

In the past 6 months, how often have you had joint pain?

- <1> A little of the time
 - <2> Some of the time
 - <3> A good bit of the time
 - <4> Most of the time
 - <5> All of the time
- <d,r>

>CFS34<

In the past 6 months, how bad was the joint pain?

- <1> Very mild
 - <2> Mild
 - <3> Moderate
 - <4> Severe
 - <5> Very severe
- <d,r>

>CFS35<

Prior to this past 6 months, for how long had you had joint pain?

- <1> Less than 6 months [goto CFS39]

- <2> 6 - 12 months [goto CFS39]
- <3> More than 12 months
- <d,r>

>CFS36<

For how many years have you had joint pain?

RECORD NUMBER OF YEARS:

<d,r>

>CFS39<

In the past 6 months, has unrefreshing sleep been a problem for you?

- <1> YES
- <2> NO [goto CFS46]
- <d,r>[goto CFS46]

>CFS40<

In the past 6 months, how often have you had unrefreshing sleep?

- <1> A little of the time
- <2> Some of the time
- <3> A good bit of the time
- <4> Most of the time
- <5> All of the time
- <d,r>

>CFS41<

In the past 6 months, how much of a problem was unrefreshing sleep?

- <1> Very mild
- <2> Mild
- <3> Moderate
- <4> Severe
- <5> Very severe
- <d,r>

>CFS42<

Prior to this past 6 months, for how long had you had unrefreshing sleep?

- <1> Less than 6 months [goto CFS46]
- <2> 6 - 12 months [goto CFS46]
- <3> More than 12 months
- <d,r>

>CFS43<

For how many years have you had unrefreshing sleep?

RECORD NUMBER OF YEARS

<d,r>

>CFS46<

In the past 6 months, have you had headaches?

- <1> YES
- <2> NO [goto CFS53]

<d,r>[goto CFS53]

>CFS47<

In the past 6 months, how often have you had headaches?

- <1> A little of the time
- <2> Some of the time
- <3> A good bit of the time
- <4> Most of the time
- <5> All of the time

>CFS48<

In the past 6 months, how bad were your headaches?

- <1> Very mild
 - <2> Mild
 - <3> Moderate
 - <4> Severe
 - <5> Very severe
- <d,r>

>CFS49<

Prior to this past 6 months, for how long had you had headaches?

- <1> Less than 6 months [goto CFS53]
 - <2> 6 - 12 months [goto CFS53]
 - <3> More than 12 months
- <d,r>

>CFS50<

For how many years have you had headaches?

RECORD NUMBER OF YEARS:

<d,r>

>CFS53<

In the past 6 months, have you had forgetfulness or memory problems, or difficulty with thinking or concentrating that caused you to substantially cut back on your activities?

- <1> YES
 - <2> NO [goto CFS60]
- <d,r>[goto CFS60]

>CFS54<

In the past 6 months, how often have you had forgetfulness or memory problems, or difficulty with thinking or concentrating?

- <1> A little of the time
 - <2> Some of the time
 - <3> A good bit of the time
 - <4> Most of the time
 - <5> All of the time
- <d,r>

>CFS55<

In the past 6 months, how bad were your forgetfulness or memory problems, or difficulty with thinking or concentrating?

- <1> Very mild
 - <2> Mild
 - <3> Moderate
 - <4> Severe
 - <5> Very severe
- <d,r>

>CFS56<

Prior to this past 6 months, for how long had you had forgetfulness or memory problems, or difficulty with thinking or concentrating?

- <1> Less than 6 months [goto CFS60]
 - <2> 6 - 12 months [goto CFS60]
 - <3> More than 12 months
- <d,r>

>CFS57<

For how many years have you had forgetfulness or memory problems, or difficulty with thinking or concentrating?

RECORD NUMBER OF YEARS

<d,r>

>CFS60<

Which of the following would you say has bothered you the most in the past 6 months:

READ OPTIONS:

- [if CFS04 = 1, DISPLAY] <1> sore throat
 - [if CFS11 = 1, DISPLAY] <2> tender lymph nodes or swollen glands in your neck or armpits
 - [if CFS18 = 1, DISPLAY] <3> unusual fatigue (or tiredness) for at least one day after exertion (or physical activity)
 - [if CFS25 = 1, DISPLAY] <4> muscle aches or pains
 - [if CFS32 = 1, DISPLAY] <5> joint pain
 - [if CFS39 = 1, DISPLAY] <6> unrefreshing sleep
 - [if CFS46 = 1, DISPLAY] <7> headache
 - [if CFS53 = 1, DISPLAY] <8> memory or concentration problems
- <d,r>

>ETIME<

[# AT END OF INTERVIEW

>thanks<

This is the end of the interview questions. You should receive your check in about 3-4 weeks. Since you participated in this interview we might want to check back with you in the future to see how you are doing and what is happening with your bladder symptoms. Would it be OK to keep your name and possibly contact you again in the future? You can decide then whether you want to participate in any future research or not.

OK TO RECONTACT:

- <1> OK OR NON COMMITTAL [goto TRACK1]
- <2> NOT OK TO RECONTACT [goto endsurvey]

>TRACK1< [optional all]

In that case, would you mind giving us some information that might help us contact you again? We may not be calling back for 3 months or more and you may have moved or changed your phone number by then.

May I have a cell phone number for you?

ENTER CELL PHONE:

DOES NOT HAVE CELL #:

>TRACK2< [optional all]

Do you have any other alternate phone numbers?

ENTER ALTERNATE:

DOES NOT HAVE ALTERNATE PHONE #:

>EMAIL1<

About how often do you usually read your personal e-mail on the Internet?

Would you say:

- <1> Every day
- <2> Several times a week
- <3> Once a week
- <4> Occasionally or
- <5> Never

>EMAIL2<

Not counting e-mail, how often do you use the Internet for personal tasks, for example, to search for information or for any other purpose, such as on-line shopping?

Would you say:

- <1> Every day
- <2> Several times a week
- <3> Once a week
- <4> Occasionally or
- <5> Never

>EMAIL3< [if EMAIL1 = 5 and EMAIL2 = 5, goto TRACK3]

Where do you use the Internet for your personal e-mail or other personal uses?

Is it mainly at:

- <1> Your home,
- <2> At work,
- <3> Or someplace else? (SPECIFY)

>EMAIL4<

For your personal Internet use, do you have Internet access using:

- <1> Telephone dial up
- <2> DSL, satellite or cable modem
- <3> Or some other way? (SPECIFY)

<4> NOT SURE

>TRACK3< [optional all]

May I have an e-mail address for you?

NOTE: EMAIL ADDRESS SHOULD BE IN THE FORM OF XXXX@@XXX.COM

ENTER EMAIL ADDRESS:

DOES NOT HAVE EMAIL:

>TRACK3B< [optional all]

May I have the name of a person who doesn't live with you, but who would know where you were if you moved? This could be a close friend or relative. We will only contact this person if we are not able to reach you.

ENTER FIRST NAME:

ENTER LAST NAME:

R - DOES NOT WANT TO PROVIDE NAME:

>TRACK3C<

How is this person related to you?

INTERVIEWER INSTRUCTIONS: CODE R'S RESPONSE(S). THIS SHOULD NOT BE A PERSON WHO IS CURRENTLY LIVING IN THE SAME HOUSEHOLD AS R.

RELATIVE

<1> MOTHER

<2> FATHER

<3> STEPMOTHER

<4> STEPFATHER

<5> GRANDMOTHER

<6> GRANDFATHER

<7> DAUGHTER

<8> SON

<9> AUNT

<10> UNCLE

<11> SISTER (INCLUDING HALF SISTER, STEP SISTER)

<12> BROTHER (INCLUDING HALF BROTHER, STEP BROTHER)

<13> OTHER RELATIVE

<14> HUSBAND/WIFE (NOT LIVING WITH R)

<d,r>

NON-RELATIVE

<15> FRIEND

<16> GIRLFRIEND (NOT LIVING WITH R)

<17> BOYFRIEND (NOT LIVING WITH R)

<18> COWORKER

<19> EX-HUSBAND/WIFE

<20> OTHER NONRELATIVE SPECIFY: (SPECIFY)

>TRACK4< [optional all]

What is his/her phone number?

ENTER PHONE #:

R - DOES NOT WANT TO PROVIDE PHONE #:

>TRACK5<

Do we have your permission to call him/her if we need to locate you in the future?

<1> YES

<2> NO
<d,r>

>endsurvey<

Thanks for taking part in this study of bladder conditions. We appreciate your time and your willingness to help out with research that we hope will ultimately benefit patients with these kinds of symptoms.