



Form 07
BASELINE PATIENT SURVEY
PART I

Version 07/01/02 (A)

**The UITN is supported by cooperative agreements from
the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
in collaboration with
the National Institute of Child Health and Human Development (NICHD)**

Introduction: Thank you for agreeing to participate in the UITN program. This research study aims to compare the outcomes of two common surgical procedures performed to treat urinary incontinence.

We will ask you to complete a survey like this one at several time points in the study. This survey is called the Baseline Patient Survey Part I and is completed at a pre-surgical study visit. Part I contains questions about your expectations of the surgery, and measures of your current quality of life, an assessment of your capabilities in the performance of routine physical daily living activities and sexual activities.

As with all of the information we collect for this research study, all of your responses are completely confidential. Your responses are never linked with your name and your name never appears on any of the research documents. Providing this information will not affect any of your services, benefits, or eligibility for coverage.

The entire questionnaire should take about 15 minutes to complete. Ideally, you will be able to complete the survey in one sitting.

There are four (4) parts to Part I of the Baseline Patient Survey. Please read the instructions at the start of each section carefully before you begin each new section.

Please complete this questionnaire at your earliest convenience and return it to the Study Nurse as soon as possible. A self-addressed and stamped envelope is enclosed for your convenience.

Try to answer every item, but do not dwell too long on any one question. We want your answers, so please complete the questionnaire on your own. After you have completed the Survey, please check to make sure you have not missed any items. If you have any questions about any of these items, please call me

_____ at _____.

A8. What is the date that you are starting to fill out this Survey?

_____/_____/_____
Month Day Year

Section B: Expectations of Surgery

Women with urinary incontinence can be bothered by symptoms such as urine leakage, urgency to urinate, frequent urination, etc. It is also common for women to alter their lifestyle, limit social and physical activities, or feel certain emotions because of urinary incontinence. These questions ask you to tell us what expectations you have for symptom relief **after** you recover from your upcoming bladder surgery. This will help us to understand how you think that surgery will improve your symptoms, lifestyle, and/or emotions.

GENERAL INSTRUCTIONS: Please read the first column of each section and indicate a “Yes” or “No” answer to each question by circling **1** (Yes) or **2** (No). Then, for each question marked by a “Yes” answer, work across the page and tell us about what you expect to happen **after you recover from surgery**. Circle the one response that **best** describes your expectation.

This first section asks about **symptoms** that you might currently experience because of your bladder problem.

Do you currently experience any of the following symptoms?			IF YES, Circle the one response below that best describes how much better you expect this symptom to be after you recover from surgery.				
	Yes	No	No Better	Slightly better	Somewhat better	Much better	Completely better
B1. Urine leakage	Yes 1	No 2	1	2	3	4	5
B2. An urgency to urinate such that you fear not making it to the bathroom in time	Yes 1	No 2	1	2	3	4	5
B3. Frequent urination	Yes 1	No 2	1	2	3	4	5
B4. Any other symptoms? _____ (If <u>yes</u> , specify symptom)	Yes 1	No 2	1	2	3	4	5

This next section asks about **activities** that you might currently limit because of your bladder problem.

Do you currently limit any of the following activities because of your bladder problems?			IF YES, circle the one response that best describes how much more capable you expect to be able to perform this activity after you recover from surgery.				
	Yes	No	No more capable	Slightly more capable	Somewhat more capable	Much more capable	Completely capable
B5. Physical activities (e.g. housework, yardwork, going for a walk, dancing, jogging, golfing)	Yes 1	No 2	1	2	3	4	5
B6. Social activities (e.g. visiting friends, vacationing, going to church or temple).	Yes 1	No 2	1	2	3	4	5
B7. Sexual activity	Yes 1	No 2	1	2	3	4	5
B8. Any other activities? _____ (If <u>yes</u> , describe activity)	Yes 1	No 2	1	2	3	4	5

This section asks about **emotions** that you might currently experience because of your bladder problem.

			IF YES, circle the one response that best describes how much less you expect to be bothered by your emotions after you recover from surgery.				
	Yes	No	No less bothered	Slightly less bothered	Somewhat less bothered	Much less bothered	Completely not bothered
B9. Are you bothered by feelings of embarrassment, helplessness, frustration, and/or depression because of your bladder problems?	Yes 1	No 2	1	2	3	4	5
B10. Of all the symptoms, lifestyle restrictions or emotions that you experience because of your bladder problem, which <u>one</u> problem do you expect to improve the most after you recover from surgery? _____							

Section C: Quality of Life

These questions deal specifically with your accidental urine loss and / or prolapse. The symptoms in Section C have been described by women who experience accidental urine loss and/or prolapse. Please indicate which symptoms you are now experiencing, and how bothersome they are for you. Be sure to circle an answer for all items.

GENERAL INSTRUCTIONS: Please read the first column of symptoms and circle "Yes" or "No" for each symptom. Then, for each question marked by a "Yes" answer, work across the page and tell us how bothersome that symptom is for you currently.

Do you currently experience			IF YES, Circle the one response below that best describes how bothersome that symptom is for you.			
	Yes	No	Not at all bothersome	Slightly bothersome	Moderately bothersome	Greatly bothersome
C1. ...frequent urination?	Yes 1	No 2	0	1	2	3
C2. ...a strong feeling of urgency to empty your bladder?	Yes 1	No 2	0	1	2	3
C3. ...urine leakage related to the feeling of urgency?	Yes 1	No 2	0	1	2	3
C4. ...urine leakage related to physical activity, coughing or sneezing?	Yes 1	No 2	0	1	2	3
C5. ...general urine leakage not related to urgency or activity?	Yes 1	No 2	0	1	2	3
C6. ...small amounts of urine leakage (that is, drops)?	Yes 1	No 2	0	1	2	3
C7. ...large amounts of urine leakage?	Yes 1	No 2	0	1	2	3
C8. ...nighttime urination?	Yes 1	No 2	0	1	2	3

Do you currently experience

	Yes	No
C9. ...bedwetting?	Yes 1	No 2
C10. ...difficulty emptying your bladder?	Yes 1	No 2
C11. ...a feeling of incomplete bladder emptying?	Yes 1	No 2
C12. ...lower abdominal pressure?	Yes 1	No 2
C13. ...pain when urinating?	Yes 1	No 2
C14. ...pain in the lower abdominal or genital area?	Yes 1	No 2
C15. ...heaviness or dullness in the pelvic area?	Yes 1	No 2
C16. ...a feeling of bulging or protrusion in the vaginal area?	Yes 1	No 2
C17. ...bulging or protrusion you can see in the vaginal area?	Yes 1	No 2
C18. ...pelvic discomfort when standing or physically exerting yourself?	Yes 1	No 2

C19. Do you have to push on the vagina or perineum to empty your bladder?	Yes 1	No 2
C20. Do you have to push on the vagina or perineum to have a bowel movement?	Yes 1	No 2

IF YES,
Circle the one response below that best describes how bothersome that symptom is for you.

Not at all bothersome	Slightly bothersome	Moderately bothersome	Greatly bothersome
0	1	2	3
0	1	2	3
0	1	2	3
0	1	2	3
0	1	2	3
0	1	2	3
0	1	2	3
0	1	2	3
0	1	2	3
0	1	2	3
0	1	2	3

C21. Do you experience any **other** symptoms related to accidental urine loss or prolapse? YES 1
 NO 2 → **SKIP TO C22**

C21a. If yes, what is it (are they)? _____

C22. Please go back and review all of the symptoms in Section C above, items C1 – 21, and write below the one symptom that bothers you the most. For this item, please list **one** symptom only.

Some women find that accidental urine loss and / or prolapse affects their activities, relationships, and feelings. The questions in this section refer to areas in your life which may have been influenced or changed by your problem. For each question in this section, circle the one response that best describes how much your activities, relationships and feelings are being affected by urine leakage and / or prolapse.

To what extent has accidental urine loss and / or prolapse affected your

	Not at all	Slightly	Moderately	Greatly
C23. ...ability to do household chores (cooking, housecleaning, laundry)?	0	1	2	3
C24. ...ability to do usual maintenance or repair work done in home or yard?	0	1	2	3
C25. ...shopping activities?	0	1	2	3
C26. ...hobbies and pastime activities?	0	1	2	3
C27. ...physical recreational activities such as walking, swimming, or other exercise?	0	1	2	3
C28. ...entertainment activities such as going to a movie or concert?	0	1	2	3

To what extent has accidental urine loss and / or prolapse affected your

	Not at all	Slightly	Moderately	Greatly
C29. ...ability to travel by car or bus for distances less than 20 minutes away from home?	0	1	2	3
C30. ...ability to travel by car or bus for distances greater than 20 minutes away from home?	0	1	2	3
C31. ...going to places if you are not sure about available restrooms?	0	1	2	3
C32. ...going on vacation?	0	1	2	3
C33. ...church or temple attendance?	0	1	2	3
C34. ...volunteer activities?	0	1	2	3
C35. ...employment (work) outside the home?	0	1	2	3
C36. ...having friends visit you in your home?	0	1	2	3
C37. ...participation in social activities outside your home?	0	1	2	3
C38. ...relationships with friends?	0	1	2	3
C39. ...relationships with family excluding husband/companion?	0	1	2	3
C40. ...ability to have sexual relations?	0	1	2	3
C41. ...the way you dress?	0	1	2	3
C42. ...emotional health?	0	1	2	3

To what extent has accidental urine loss and / or prolapse affected your

	Not at all	Slightly	Moderately	Greatly
C43. ...physical health?	0	1	2	3
C44. ...sleep?	0	1	2	3

C45. How much does fear of odor restrict your activities?	0	1	2	3
C46. How much does fear of embarrassment restrict your activities?	0	1	2	3

In addition, does your problem with accidental urine loss and / or prolapse cause you to experience

	Not at all	Slightly	Moderately	Greatly
C47. ...nervousness or anxiety?	0	1	2	3
C48. ...fear?	0	1	2	3
C49. ...frustration?	0	1	2	3
C50. ...anger?	0	1	2	3
C51. ...depression?	0	1	2	3
C52. ...embarrassment?	0	1	2	3

Section D: Normal Activities

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?
(Circle one number for each activity)

	YES, I'm limited a lot	YES, I'm limited a little	NO, I'm not limited at all
D1. <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
D2. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
D3. Lifting or carrying groceries	1	2	3
D4. Climbing <u>several</u> flights of stairs	1	2	3
D5. Climbing <u>one</u> flight of stairs	1	2	3
D6. Bending, kneeling, or stooping	1	2	3
D7. Walking <u>more than a mile</u>	1	2	3
D8. Walking <u>several blocks</u>	1	2	3
D9. Walking <u>one block</u>	1	2	3
D10. Bathing or dressing yourself	1	2	3

Do you currently have any of the following problems with your work or other regular daily activities as a result of your physical health?

Circle one number for each activity.

	YES	NO
D11. Cut down on the <u>amount of time</u> you spent on work or other activities	1	2
D12. <u>Accomplished less</u> than you would like	1	2
D13. Were limited in the <u>kind</u> of work or other activities	1	2
D14. Had <u>difficulty</u> performing the work or activities (for example, it took extra effort)	1	2

Section E: Sexual Activities

This section covers material that is sensitive and personal. Specifically, these questions ask about matters related to your sexual activity **in the past 6 months**. For some women, sexual activity is an important part of their lives; but for others it is not. Everyone has different ideas on the subject. To help us understand how your bladder problems might affect your sexual activity, we would like you to answer the following questions from your own personal viewpoint.

There are no right or wrong answers. Remember, your confidentiality is assured. While we hope you are willing to answer all of the questions, if there are questions you would prefer not to answer, you are free to skip them. Please select the most appropriate response to each question by circling the answer you choose. Remember these questions are only relevant to sexual activity **in the past six months**.

E1. **In the past 6 months**, have you engaged in sexual activities with a partner?

Yes 1 ➔ **COMPLETE SECTION F BELOW**

No..... 2 ➔ **SKIP TO PAGE 11 AND COMPLETE SECTION G**

Section F: FOR WOMEN WHO HAVE ENGAGED IN SEXUAL ACTIVITY WITH A PARTNER IN THE LAST 6 MONTHS

F1. How frequently do you feel sexual desire? This feeling may include wanting to have sex, planning to have sex, feeling frustrated due to lack of sex, etc.

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F2. Do you climax (have an orgasm) when having sexual intercourse with your partner?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F3. Do you feel sexually excited (turned on) when having sexual activity with your partner?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F4. How satisfied are you with the variety of sexual activities in your current sex life?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F5. Do you feel pain during sexual intercourse?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F6. Are you incontinent of urine (leak urine) with sexual activity?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F7. Does fear of incontinence (either urine or stool) restrict your sexual activity?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F8. Do you avoid sexual intercourse because of bulging in the vagina (either the bladder, rectum or vagina falling out)?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F9. When you have sex with your partner, do you have negative emotional reactions such as fear, disgust, shame or guilt?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F10. Does your partner have a problem with erections that affects your sexual activity?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F11. Does your partner have a problem with premature ejaculation that affects your sexual activity?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

F12. Compared to orgasms you have had in the past, how intense are the orgasms you have had in the past 6 months?

Much less intense	Less intense	Same intensity	More intense	Much more intense
1	2	3	4	5

YOU ARE DONE WITH THIS QUESTIONNAIRE.

Section G: FOR WOMEN WHO REPORT NO SEXUAL ACTIVITY WITH A PARTNER IN THE LAST 6 MONTHS

G1. Do you have a partner at this time?

Yes 1

No 2

G2. How frequently do you feel sexual desire? This feeling may include wanting to have sex, planning to have sex, feeling frustrated due to lack of sex, etc.

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

G3. How satisfied are you with the variety of sexual activities in your current sex life?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

G4. Does fear of pain during sexual intercourse restrict your activity?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

G5. Does fear of incontinence (either stool or urine) during sexual intercourse restrict your sexual activity?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

G6. Do you avoid sexual intercourse because of bulging in the vagina (either the bladder, rectum or vagina falling out)?

Always	Usually	Sometimes	Seldom	Never
1	2	3	4	5

YOU ARE DONE WITH THIS QUESTIONNAIRE.