

Form 58 12 & 24 MONTH FOLLOW-UP PATIENT SURVEY PART II

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)

FORM 58: 12 & 24 MONTH PATIENT SURVEY PART II, VERSION 09/06/02 (A)_rev07/01/06				
	SECTION A: GENERAL STUDY INFORMATIC	ON FOR OFFIC	E USE ONLY:	
A1. STUDY ID#:	LABEL	A2. VISIT #	F/U 12 MONTHS	FU12
			F/U 24 MONTHS	FU24
			F/U 36 MONTHS	FU36
			F/U 48 MONTHS	FU48
			F/U 60 MONTHS	FU60
			F/U 72 MONTHS	FU72
			F/U 84 MONTHS	FU84
			FAILURE	FAIL
A3. DATE FOR	M DISTRIBUTED: / / /	A4. STUDY	STAFF INITIALS:	
A5. MODE:	SELF-ADMINISTERED1	A6. WHICH	VERSION OF	ENGLISH 1
	INTERVIEWER-ADMINISTERED2	THIS FC	ORM WAS USED?	SPANISH 2

Introduction: Part II of the Patient Survey includes questions about costs in your daily life that are related to your problem of incontinence.

As with all of the information we collect for UITN, 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 <u>not</u> affect any of your services, benefits, or eligibility for coverage.

Part II should take about 15 minutes to complete. Ideally, you will be able to complete the Survey in one sitting.

There are three (3) parts to Part II of the Patient Survey. Please read the instructions at the start of each section carefully before you begin each new section. Try to answer every item, but do not dwell too long on any one question. We want <u>your</u> answers, so please try to complete the Survey 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.

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

	at					
	Contact Name	Phone	e number			
47.	What is the date that you are starting to fill out this Survey?	/_		_/		
		Month	Day		Year	

Section B: Expenses for Supplies, Laundering and Dry Cleaning

NUMBER OF SUPPLIES USED

Over the past 7 days, please record the average number of supplies you used <u>each day</u> for your urinary incontinence.

B1. Pantyliners or minipads (*Check one box only*)

\square_0	None (I did not use this product in the last 7 days)	₆ D 6
	1	₇ D 7
$_2$	2	₈ a 8
3	3	₉ D 9
4	4	10 IO
5	5	$_{11}$ more than 10

B2. Maxipads such as Kotex or Modess (Check one box only)

\square_0	None (I did not use this product in the last 7 days)	₆ D 6
1	1	₇ D 7
$_2$	2	₈ a 8
3 D	3	₉ D 9
4	4	₁₀ 10
5	5	$_{11}$ more than 10

B3. Incontinence Pads such as Serenity or Poise (*Check one box only*)

\square_0	None (I did not use this product in the last 7 days)	₆ D 6
1	1	₇ D 7
2	2	₈ D 8
3	3	₉ D 9
4	4	10 IO
5	5	$_{11}$ more than 10

B4. Diapers such as Depends or Attends (*Check one box only*)

\square_0	None (I did not use this product in the last 7 days)	6	6
1	1	7	7
2	2	\square_8	8
3 D	3	₉ D	9
4	4	10	10
5	5	11	more than 10

B5. Urethral pads such as Impress, Femassist (*Check one box only*)

- $_{0}$ None (*I did not use this product in the last 7 days*) ₆**D** 6 ₇**D** 7
- 1
- $_{2}$ **D** 2
- ₃**D** 3
- ₄**D** 4
- ₅**D** 5

10 10 $_{11}$ more than 10

₈**D** 8

₉**D** 9

B6. Toilet paper - number of <u>sheets</u> (Check one box only)

$_{0}\Box$ None (I did not use this product in the last 7 days)	6	51 to 60
$_{1}\Box$ 1 to 10	7	61 to 70
$_{2}\Box$ 11 to 20	8	71 to 80
$_{3}\Box$ 21 to 30	90	81 to 90
⁴ 31 to 40	10	91 to 100
₅ 41 to 50	11	more than 100

B7. Paper towels - number of <u>sheets</u> (Check one box only)

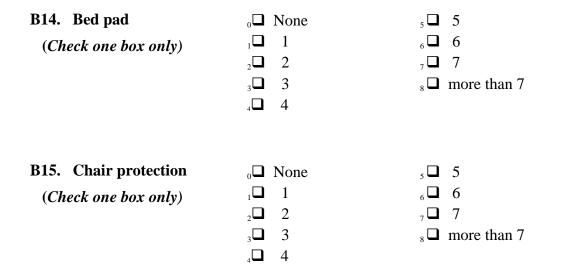
$_{0}$ None (<i>I did not use this product in the last 7 days</i>)	6	51 to 60
$_{1}\Box$ 1 to 10	7	61 to 70
$_{2}$ 11 to 20	8	71 to 80
$_{3}$ 21 to 30	90	81 to 90
₄ □ 31 to 40	10	91 to 100
$_{5}$ 41 to 50	11	more than 100

B8. Oth	er (Please describe what you used:)
	None (I did not use any other product in the last 7 days)	6	6
	1	7	7
2	2	8	8
3	3	90	9
4	4	10	10
5	5	11	more than 10

CHANGING AND WASHING CLOTHING AND LINENS

Over the last 7 days, how many <u>times per day</u> did you need to change and wash each of these items *because* of your urinary incontinence?

B9. Underwear (<i>Check one box only</i>)	$_0$ None $_1$ 1 $_2$ 2 $_3$ 3 $_4$ 4 $_5$ 5	$_{10}^{6}$ 6 $_{7}$ 7 $_{8}$ 8 $_{9}$ 9 $_{10}$ 10 $_{11}$ more than 10
B10. Incontinence pants (<i>Check one box only</i>)	$_{0}$ None $_{1}$ 1 $_{2}$ 2 $_{3}$ 3 $_{4}$ 4 $_{5}$ 5	$_{10}^{6}$ 6 7 7 8 8 9 9 $_{10}^{6}$ 9 $_{10}^{6}$ 10 $_{11}^{6}$ more than 10
B11. Clothing (pants, skirt) (<i>Check one box only</i>)	$_0$ None $_1$ 1 $_2$ 2 $_3$ 3 $_4$ 4 $_5$ 5	$_{10}^{6}$ 6 $_{7}$ 7 $_{8}$ 8 $_{9}$ 9 $_{10}$ 10 $_{11}$ more than 10
B12. Towels or wash clothes (Check one box only)	None None None None None None None None	$_{10}^{6}$ \bigcirc 6 $_{17}$ \bigcirc 7 $_{18}$ \bigcirc 8 $_{9}$ \bigcirc 9 $_{10}$ \bigcirc 10 $_{11}$ \bigcirc more than 10
B13. Bed linens (sheets) (<i>Check one box only</i>)	None None None None None None None $1 \square 1$ $2 \square 2$ $3 \square 3$ $4 \square 4$	$5 \square 5$ $6 \square 6$ $7 \square 7$ $8 \square more than 7$



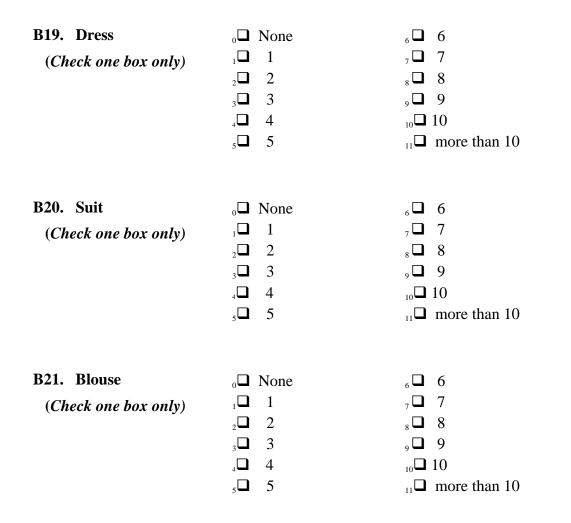
B16. How many loads of wash did you do during the last 7 days because of your incontinence?

(Check one box only)	$_{0}\square$ None	₅ □ 5
	$_1 \square 1$	₆ D 6
	$_2 \square 2$	₇ 🗖 7
	₃ D 3	$_{8}\Box$ more than 7
	₄ □ 4	

DRY CLEANING

How many items of clothing did you dry clean during the last 7 days because of your incontinence?

B17. Pants (<i>Check one box only</i>)	$\begin{array}{c c} {}_{0} \square & \text{None} \\ {}_{1} \square & 1 \\ {}_{2} \square & 2 \\ {}_{3} \square & 3 \\ {}_{4} \square & 4 \\ {}_{5} \square & 5 \end{array}$	$_{6} \square 6$ $_{7} \square 7$ $_{8} \square 8$ $_{9} \square 9$ $_{10} \square 10$ $_{11} \square$ more than 10
B18. Skirt (Check one box only)	$\begin{array}{c} 0 & \text{None} \\ 1 & 1 \\ 2 & 2 \\ 3 & 3 \\ 4 & 4 \\ 5 & 5 \end{array}$	$_{6}$ 6 7 1 7 8 8 9 9 $_{10}$ 9 $_{10}$ 10 $_{11}$ more than 10



LOSS OF EMPLOYMENT AND VOLUNTEER WORK

- B22. In the past year, did you limit or stop your employment or volunteer work due to your urinary incontinence?
 - $_{1}\Box$ Yes Ψ

 $_2\square$ No \rightarrow SKIP TO SECTION C

B22a. If yes, when did you stop or limit your employment or volunteer work DUE to incontinence?



B22b. How much additional money <u>per month</u> would you have earned if you had continued your work?

Section C: Matters of Health: The Health Utilities Index (HUI)

Instructions: This next section contains questions which ask about various aspects of your health. When answering these questions please think about your health and your ability to do things on a day-to-day basis, <u>during the past week</u>. To define the past week period, please think about the date this time 7 days ago and recall the major events that you have experienced during this period. Please focus your answers on your overall abilities, disabilities and how you felt during the past week.

You may feel that some of these questions do not apply to you, but it is important that we ask the same questions of everyone. Also, a few questions are similar; please excuse the apparent overlap and answer each question independently.

Please read each question and consider your answers carefully. For each question, please select <u>one</u> answer that <u>best describes</u> your level of ability or disability <u>during the past week</u>. Please indicate the selected answer by <u>circling</u> the number beside the answer.

All information you provide is confidential. There are no right or wrong answers; what we want is your opinion about your abilities and feelings.

C1. Which <u>one</u> of the following best describes your ability, during the past week, to see well enough to read ordinary newsprint?

Able to see well enough without glasses or contact lenses 1
Able to see well enough with glasses or contact lenses 2
Unable to see well enough even with glasses or contact lenses 3
Unable to see at all

C2. Which <u>one</u> of the following best describes your ability, during the past week, to see well enough to recognize a friend on the other side of the street?

Able to see well enough without glasses or contact lenses 1
Able to see well enough with glasses or contact lenses 2
Unable to see well enough even with glasses or contact lenses 3
Unable to see at all

C3. Which <u>one</u> of the following best describes your ability, during the past week, to hear what was said in a group conversation with at least three other people?

Able to hear what was said without a hearing aid 1
Able to hear what was said with a hearing aid 2
Unable to hear what was said even with a hearing aid
Unable to hear what was said, but did not wear a hearing aid 4
Unable to hear at all

C4. Which <u>one</u> of the following best describes your ability, during the past week, to hear what was said in a conversation with one other person in a quiet room?

Able to hear what was said without a hearing aid 1
Able to hear what was said with a hearing aid 2
Unable to hear what was said even with a hearing aid
Unable to hear what was said, but did not wear a hearing aid 4
Unable to hear at all

C5. Which <u>one</u> of the following best describes your ability, during the past week, to be understood, when speaking your own language with people who do not know you?

Able to be understood completely 1	
Able to be understood partially 2	
Unable to be understood 3	
Unable to speak at all 4	

C6. Which <u>one</u> of following best describes your ability, during the past week to be understood when speaking with people who know you well?

Able to be understood completely 1
Able to be understood partially 2
Unable to be understood 3
Unable to speak at all 4

C7. Which <u>one</u> of the following best describes how you have been feeling during the past week?

Happy and interested in life 1	
Somewhat happy 2	
Somewhat unhappy 3	
Very unhappy 4	
So unhappy that life was not worthwhile	

C8. Which <u>one</u> of the following best describes the pain and discomfort you have experienced during the past week?

Free of pain and discomfort	1
Mild to moderate pain or discomfort that prevented no activities	2
Moderate pain or discomfort that prevented a few activities	3
Moderate to severe pain or discomfort that prevented some activities	4
Severe pain or discomfort that prevented most activities	5

C9. Which <u>one</u> of the following best describes your ability, during the past week, to walk? Note: Walking equipment refers to mechanical supports such as braces, a cane, crutches or a walker.

Able to walk around the neighborhood without difficulty, and without walking equipment	1
Able to walk around the neighborhood with difficulty; but did not require walking equipment or the help of another person	2
Able to walk around the neighborhood with walking equipment, but without the help of another person	3
Able to walk only short distances with walking equipment, and required a wheelchair to get around the neighborhood	4
Unable to walk alone, even with walking equipment. Able to walk short distances with the help of another person, and required a wheelchair to get around the neighborhood	5
Unable to walk at all	6

C10. Which <u>one</u> of the following best describes your ability, during the past week, to use your hands and fingers?

Note: Special tools refers to hooks for buttoning clothes, gripping devices for opening jars or lifting small items, and other devices to compensate for limitations of hands or fingers.

Full use of two hands and ten fingers	1
Limitations in the use of hands or fingers, but did not require special tools or the help of another person	2
Limitations in the use of hands or fingers, independent with use of special tools (did not require the help of another person)	3
Limitations in the use of hands or fingers, required the help of another person for some tasks (not independent even with use of special tools)	4
Limitations in the use of hands or fingers, required the help of another person for most tasks (not independent even with use of special tools)	5
Limitations in the use of hands or fingers, required the help of another person for all tasks (not independent even with use of special tools)	6

C11. Which one of the following best describes your ability, during the past week, to remember things?

Able to remember most things	1
Somewhat forgetful	2
Very forgetful	3
Unable to remember anything at all	4

C12. Which <u>one</u> of the following best describes your ability, during the past week, to think and solve day to day problems?

Able to think clearly and solve day to day problems 1	
Had a little difficulty when trying to think and solve day to day problems)
Had some difficulty when trying to think and solve day to day problems	;
Had great difficulty when trying to think and solve day to day problems 4	ŀ
Unable to think or solve day to day problems	j

C13.	Which <u>one</u> of the following best describes your ability, during the past week, to perform basic activities?
	Eat, bathe, dress and use the toilet normally 1
	Eat, bathe, dress or use the toilet independently with difficulty 2
	Required mechanical equipment to eat, bathe, dress or use the toilet independently 3
	Required the help of another person to eat, bathe, dress or use the toilet 4
C14.	Which one of the following best describes how you have been feeling during the past week?
	Generally happy and free from worry 1
	Occasionally fretful, angry, irritable, anxious or depressed 2
	Often fretful, angry, irritable, anxious or depressed

Almost always fretful, angry, irritable, anxious or depressed...... 4

C15. Which <u>one</u> of the following best describes the pain or discomfort you have experienced during the past week?

Free of pain and discomfort	1
Occasional pain or discomfort. Discomfort relieved by non-prescription drugs or self-control activity without disruption of normal activities	2
Frequent pain or discomfort. Discomfort relieved by oral medicines with occasional disruption of normal activities	3
Frequent pain or discomfort; frequent disruption of normal activities. Discomfort required prescription narcotics for relief	4
Severe pain or discomfort. Pain not relieved by drugs and constantly disrupted normal activities	5

C16. Overall, how would you rate your health during the past week?

- C17. How did you complete the questionnaire? Please select the <u>one</u> answer that best describes your situation.?

By myself, <u>without any help</u> from anyone else	1	→ SKIP TO SECTION D
By myself, except <u>someone else circled</u> the answers on the questionnaire form for me	2	→ SKIP TO SECTION D
With the help of someone else.	3	→ SKIP TO SECTION D
This questionnaire was completed by a family member, <u>without help</u> from the subject or patient	4	

C17a. If this questionnaire was completed <u>without help</u> from the subject or patient, who completed it?

Section D: Matters of Money: Willingness to Pay

Please respond to these questions about how much money you would be willing to pay **out of your own pocket** for the treatments described. Assume that payments for these treatments are not covered by your health insurance or HMO, Medicare or Medicaid and that you must pay for them **out of your own pocket**.

D1. Imagine that a new treatment for incontinence becomes available that has no side effects. This new treatment reduces the number of times you *leak urine* by one quarter (25%).

For example, if you currently *leak urine* 4 times a day, with this new treatment you would *leak urine* only 3 times a day. Or if you currently *leak urine* every day, this would be reduced to 3 days out of 4.

What is the most money that you would be willing to pay <u>per month</u> out of your own pocket for this treatment? (*Check one box only*)

0	Nothing (I would not be willing to pay for this)	6	\$50
1	\$ 5	7	\$75
2	\$10	8	\$100
₃ 🗖	\$20	9 🗖	\$150
4	\$30	10	\$200
5	\$40	11	\$400

D2. Imagine that a new treatment for incontinence becomes available that has no side effects. This new treatment reduces the number of times you *leak urine* by one half (50%).

For example, if you currently *leak urine* 4 times a day, with this new treatment you would *leak urine* only 2 times a day. Or if you currently *leak urine* every day, this would be reduced to 2 days out of 4.

What is the most money that you would be willing to pay <u>per month</u> out of your own pocket for this treatment? (*Check one box only*)

0	Nothing (I would not be willing to pay for this)	₆ 🗖	\$50
1	\$ 5	7	\$75
2	\$10	8	\$100
3	\$20	9 🗖	\$150
4	\$30	10	\$200
5	\$40	11	\$400

D3. Imagine that a new treatment for incontinence becomes available that has no side effects. This new treatment cures your urine loss so that **you do not leak urine.**

What is the most money that you would be willing to pay <u>per month</u> out of your own pocket for this treatment? (*Check one box only*)

0	Nothing (I would not be willing to pay for	6	\$50
this)		7	\$75
	\$ 5	8	\$100
2	\$10	₉ 🗖	\$150
3	\$20	10	\$200
4	\$30	11	\$400
5	\$40		

security, pensions, interest, dividends, etc	presents your total personal income, including wages, social . in the last year? (<i>Check one box only</i>)
$_{0}\Box$ Less than \$5,000	_s □ \$70,000-\$79,999
₁ □ \$5,000-\$9,999	₉ □ \$80,000-\$89, 999
₂ □ \$10,000-\$19,999	₁₀ □\$90,000-\$99, 999
₃ □ \$20,000-\$29,999	¹¹ □\$100,000-\$119, 999
4 □ \$30,000-\$39,999	₁₂ □ \$120,000-\$139, 999
₅ □ \$40,000-\$49, 999	₁₃ □ \$140,000-\$159, 999
₅ □ \$50,000-\$59, 999	₁₄ □\$160,000-\$179,999
₇ □ \$60,000-\$69, 999	15 \$180,000 or more

D5. Which of the following categories best represents the combined or total income of your household, including wages, social security, pensions, interest, dividends, etc. in the last year? (Check one box only) $_{0}\Box$ Less than \$5,000 ⁸ \$70,000-\$79,999 ⁹ \$80,000-\$89, 999 ¹ \$5,000-\$9,999 ₁₀ \$90,000-\$99, 999 ² \$10,000-\$19,999 ³ \$20,000-\$29,999 ¹¹ \$100,000-\$119, 999 ₁₂**□**\$120,000-\$139, 999 ₄**□** \$30,000-\$39,999 ₅**□** \$40,000-\$49, 999 ₁₃**□** \$140,000-\$159, 999 ⁶ \$50,000-\$59,999 14**□**\$160,000-\$179,999 ⁷ \$60,000-\$69, 999 15 \$180,000 or more