

*ICDB Current Form Versions
March 14, 1996*

FORM CODE	FORM TITLE	DATE	VERSION
BACK	Background Information	January 1, 1994	3.0
BACKF	Background Information	January 1, 1994	2.0
CMED	Concomitant Medications	March 1, 1994	4.0
CYST	Cystoscopy	April 1, 1995	2.0
DEF1	Deferral Checklist #1	May 15, 1995	4.0
DEF2	Deferral Checklist #2	August 1, 1994	3.1
DIET	Dietary Habits	March 1, 1994	2.1
EXCL1	Exclusion Checklist #1	March 1, 1996	2.0
EXCL2	Exclusion Checklist #2	February 1, 1996	2.1
EXCL3	Exclusion Checklist #3	January 1, 1994	1.0
FHX	Family History	January 1, 1994	2.0
HEM	Hematology	January 1, 1994	1.0
INCL	Inclusion Checklist	February 17, 1995	2.2
MED	Medical Events & Patient Treatment Evaluation Form	November 1, 1994	2.1
MEDHX	Patient Medical History	November 1, 1994	2.1
MEDHXF	Patient Medical History Update	February 1, 1996	1.0
PHS	Physical Exam	March 1, 1994	3.0
PHYTRT	Physician's Evaluation & Treatment Plan	May 15, 1995	4.0
PREG	Pregnancy History	January 1, 1994	2.0
PRIOR	Prior Diagnoses & Treatment	January 1, 1994	2.0
PURG	Pain & Urgency Scales	January 1, 1994	1.0
QUL	Quality of Life	January 1, 1994	2.0
SYMPH	Symptom Questionnaire	April 1, 1994	4.0

*ICDB Current Form Versions
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FORM CODE	FORM TITLE	DATE	VERSION
SYMPTS	Symptom Questionnaire	March 1, 1994	4.0
SCR		January 1, 1994	2.0
SYMHX	Symptom History	January 1, 1994	2.0
URN	Macroscopic Urinalysis	January 1, 1994	1.0
UROD	Urodynamic Evaluation	January 1, 1994	2.0
VOID	Volume Voiding Profile	March 1, 1994	2.1
REIN	Patient Reinstatement Form	May 15, 1995	1.2
SLTR	Biopsy Slide Tracking Form	April 1, 1995	3.0
TRACK	Biopsy Specimen Tracking Form	April 1, 1995	3.0
WITH	Patient Withdrawal Form	May 15, 1995	1.2

Unchanged Forms During Major Revisions

January 1, 1994:

The following screening forms, identified by form code, remain unchanged from the original May 1, 1993 version:

INCL
EXCL1
DEF1
PURG
URN
DEF2
EXCL2
HEM
QUL
CYST
EXCL3

The following forms (as separate entities) have been eliminated completely:

SBACK
GYNHX

Comparison of Variables - Old (1993) to New (1994) Form

Form Group	Forms	No. of Variables	
		5/1/93	1/1/94
Initial	Pain and Urgency Scale (PURG)	6	6
	Inclusion Checklist (INCL)	13	14
	Exclusion Checklist #1 (EXCL1)	15	15
	Deferral Checklist #1 (DEF1)	15	16
	Background Information (BACK)	<u>44</u>	<u>15</u>
		93	66
Diet/Symp	Dietary Habits (DIET)	156	47
	Symptom Questionnaire (SYMPTS)	111	149
	Quality of Life (QUL)	<u>40</u>	<u>40</u>
		307	236
History	Symptom History (SYMHX)	102	28
	Medical History (MEDHX)	342	98
	Family History (FHX)	346	18
	Gynecological History (GYNHX)	165	0
	Additional Pregnancies (PREG)	72	15
	Prior Diagnoses and Treatments (PRIOR)	342	97
	Concomitant Medications (CMED)	<u>48</u>	<u>27</u>
	1,417	283	
Physical	Hematology (HEM)	11	11
	Urinalysis (URN)	10	10
	Physical Exam (PHS)	53	44
	Urodynamic Evaluation (UROD)	24	27
	Cystoscopy (CYST)	53	53
	Deferral Checklist #2 (DEF2)	12	13
	Exclusion Checklist #2 (EXCL2)	14	14
	Exclusion Checklist #3 (EXCL3)	<u>4</u>	<u>4</u>
	181	176	
Treatment	Physician's Treatment Evaluation (PHYTRT)	54	21
Voiding Log	Voiding Log (VOID)(avg. of 14 voids/day)	259	259
Sign-Off	Screening Phase Sign-Off (SCR)	<u>4</u>	<u>5</u>
		<u>2,315</u>	<u>1,046</u>

May 1, 1993

Form Group	Forms	No. of Variables
Initial	Pain and Urgency Scale (PURG)	6
	Inclusion Checklist (INCL)	13
	Exclusion Checklist #1 (EXCL1)	15
	Deferral Checklist #1 (DEF1)	15
	Background Information (BACK)	<u>44</u>
		93
Diet/Symptoms	Dietary Habits (DIET)	156
	Symptom Questionnaire (SYMPTS)	111
	Quality of Life (QUL)	<u>40</u>
		307
History	Symptom History (SYMHX)	102
	Medical History (MEDHX)	342
	Family History (FHX)	346
	Gynecological History (GYNHX)	165
	Additional Pregnancies (PREG)	72
	Prior Diagnoses and Treatments (PRIOR)	342
	Concomitant Medications (CMED)	<u>48</u>
	1,417	
Physical	Hematology (HEM)	11
	Urinalysis (URN)	10
	Physical Exam (PHS)	53
	Urodynamic Evaluation (UROD)	24
	Cystoscopy (CYST)	53
	Deferral Checklist #2 (DEF2)	12
	Exclusion Checklist #2 (EXCL2)	14
	Exclusion Checklist #3 (EXCL3)	<u>4</u>
	181	
Treatment	Physician's Treatment Evaluation (PHYTRT)	54
Voiding Log	Voiding Log (VOID)(avg. of 14 voids/day)	259
Sign-Off	Screening Phase Sign-Off (SCR)	<u>4</u>
		<u>2,315</u>

January 1, 1994

Form Group	Forms	No. of Pages	No. of Variables
Initial	Pain and Urgency Scale (PURG)	1	6
	Inclusion Checklist (INCL)	2	14
	Exclusion Checklist #1 (EXCL1)	1	15
	Deferral Checklist #1 (DEF1)	1	16
	Background Information (BACK)	<u>3</u>	<u>15</u>
		8	66
Diet/Symptoms	Dietary Habits (DIET)	2	47
	Symptom Questionnaire (SYMPTS)	12	149
	Quality of Life (QUL)	<u>4</u>	<u>40</u>
		18	236
History	Symptom History (SYMHX)	4	28
	Medical History (MEDHX)	5	98
	Family History (FHX)	1	18
	Gynecological History (GYNHX)	0	0
	Pregnancy History (PREG)	2	15
	Prior Diagnoses and Treatments (PRIOR)	4	97
	Concomitant Medications (CMED)	<u>1</u>	<u>27</u>
	17	283	
Physical	Hematology (HEM)	1	11
	Urinalysis (URN)	1	10
	Physical Exam (PHS)	6	44
	Urodynamic Evaluation (UROD)	2	27
	Cystoscopy (CYST)	3	53
	Deferral Checklist #2 (DEF2)	1	13
	Exclusion Checklist #2 (EXCL2)	1	14
	Exclusion Checklist #3 (EXCL3)	<u>1</u>	<u>4</u>
	16	176	
Treatment	Physician's Treatment Evaluation (PHYTRT)	2	21
Voiding Log	Voiding Log (VOID)(avg. of 14 voids/day)	4	259
Sign-Off	Screening Phase Sign-Off (SCR)	<u>1</u>	<u>5</u>
		<u>66</u>	<u>1046</u>

Background Information

January 1, 1994: (Version 3.0)

In order to reduce the size of this form and increase the quality of the data, we have:

1. combined questions #5 (father's race) and #7 (mother's race) into one question (patient's race).
2. combined questions #6 (father's Latino or Hispanic origin) and #8 (mother's Latino or Hispanic origin).
3. eliminated questions #9 and #10 regarding father's and mother's religion. Question regarding patient's current religion remains.
4. eliminated irrelevant questions #13 and #14 regarding number of children and adults living in patient's household.
5. condensed response categories in Question #15 regarding patient's level of education.
6. eliminated economic impact questions (#16-#26,#28-#30,#32-#35). We added a question "Have your urinary symptoms forced you to leave or change your job within the last two years?" Also, we can look at economic impact prospectively by following Questions #27 and #31 across time.
7. eliminated need for two screening phase background information forms. The form is now short enough for all patients to complete regardless of their eligibility status.

Biopsy Form

May 1, 1994: (Version 2.0)

Changes made per Dr. Tomaszewski after he piloted version 1.0.

July 1, 1995: (Version 3.0)

Changes made per Dr. Tomaszewski after he piloted version 2.0.

Concomitant Medications

January 1, 1994: (Version 3.0)

The following fields have been removed from the original form:

- self-reported/bottle
- dosage and number of doses
- the day for the start and stop date

The "reason" field remains in order to ensure that no IC treatments are recorded on this form; this field will not be coded and entered into the database. Providing this problem is resolved, the reason field will eventually be deleted.

March 1, 1994: (Version 4.0)

Major revisions have been made to this form per the February Steering Committee meeting. The form now requires a listing of all current medications at the first visit the form is completed for a patient. For every visit afterwards, only changes in medications should be indicated on the form. There are two sections to indicate these changes; one section requires listing old medications stopped since the last visit and the other section requires listing new medications started since the last visit.

Cystoscopy

April 1, 1995: (Version 2.0)

Questions #17-19:

The previous versions of the CYST, SLTR, and TRACK forms made it nearly impossible to implement interform logical checks. Each biopsy location was collected 2½ times (tracking forms, CYST bladder map, plus half of the responses on CYST questions 17-19) and each biopsy pathology was collected 1½ times (tracking forms plus half of the responses on CYST questions 17-19). As a result, the following changes were made to questions 17-19.

Questions 17-19 have been changed to collect the biopsy pathology. The locations are collected on the bladder map and this will result in the sites and pathologies each being collected twice (tracking forms and CYST form.) The new questions are the same as the questions used on the SLTR & TRACK forms which will make logical checks simple. An "other" response has been added for any other pathologies.

Question #11a:

While making the above changes, another CYST form problem was addressed. Question #11a has been a problem because sometimes a hydrodistention is performed but biopsies are not taken. Therefore, an additional response has been added and the codes & skip pattern instructions have been updated accordingly.

Deferral Checklist #1

March 1, 1994: (Version 3.0)

The narcotic deferral criteria (formerly Question #5) has been deleted per protocol change resulting from the February Steering Committee meeting.

August 1, 1994: (Version 3.1)

The shading on the checkboxes has been darkened for increased qualities of photocopies.

May 15, 1995: (Version 4.0)

The antibiotics (or antimicrobials) deferral criteria (formerly Question #5) has been deleted per protocol change resulting from the May Steering Committee meeting.

Deferral Checklist #2

March 1, 1994: (Version 3.0)

The narcotic deferral criteria (formerly Question #8) has been deleted per protocol change resulting from the February Steering Committee meeting.

August 1, 1994: (Version 3.1)

The shading on the checkboxes has been darkened for increased qualities of photocopies.

Dietary Habits

January 1, 1994: (Version 2.0)

In order to reduce the size of this form and increase the quality of the data, we have:

- removed the question regarding frequency because many project members feel that it is an irrelevant question
- removed specific foods. Deb Erickson placed the foods in three categories based on their effect on urinary symptoms (positive, negative, or no effect). While eliminating specific foods, we still maintained a balance of foods across the three categories.

Specifically, we have removed the following foods:

fruits & juices:	dairy products
apples or apple juice	American cheese
apricots	Swiss cheese
cantaloupe	all breads
figs, canned	other foods
guava or guava juice	carob
papaya or papaya juice	baked goods
plums	greasy foods
prunes or prune juice	beverages
raisins	alcoholic beverages other than
vegetables	beer or wine
broccoli	miscellaneous
onions - cooked	calcium supplements
onions - raw	mayonnaise
shallots, green onions	vitamin C supplements
all beans & nuts	white sugar
all meats/poultry/fish	

We have modified the following foods:

- replaced wine with red wine, white wine, and champagne
 - replaced citrus fruits with orange and grapefruit
 - combined tea and coffee
 - combined peaches and pears
- combined the "other foods" and "miscellaneous" categories into one "miscellaneous" category.
 - eliminated the instruction sheet (page #1) since the form is much simpler now.

March 1, 1994: (Version 2.1)

The question has been changed to indicate the effects of the foods on the patient's urinary symptoms if they consume the foods. This change was requested at the February Research Coordinators meeting.

Exclusion Checklist #1

August 1, 1994: (Version 1.1)

The shading on the checkboxes has been darkened to increase the quality of photocopies.

March 1, 1996: (Version 2.1)

The wording of Questions #5e and #5f was changed to reflect changes made to the protocol during the January 26, 1996 Steering Committee Meeting.

5e was "cystolysis" and is now "cystolysis or bladder denervation procedure."

5f was "neurectomy" and is now "neurectomy affecting bladder function."

Exclusion Checklist #2

August 1, 1994: (Version 1.1)

The shading on the checkboxes has been darkened to increase the quality of photocopies.

February 1, 1996: (Version 2.1)

The wording of Questions #5c and #5d was changed to reflect changes made to the protocol during the January 26, 1996 Steering Committee Meeting.

5c was "cystolysis" and is now "cystolysis or bladder denervation procedure."

5d was "neurectomy" and is now "neurectomy affecting bladder function."

Family History

January 1, 1994: (Version 2.0)

In order to reduce the size of this form and increase the quality of the data, we have:

- 1.reduced the questions to a simple presence/absence of 14 disorders among the patient's blood relatives, without regard to who has the disorder.
- 2.selected the list of disorders to be a subset of the disorders on the Patient Medical History form.

We removed the following disorders:

- bladder trouble
- heart disease
- high blood pressure
- drug allergies
- cancer (other than bladder cancer)
- psychological disorder(s)
- thyroid disorder(s)
- tuberculosis

- 3.removed the irrelevant questions (#1-4) on number of blood relatives in patient's family.
- 4.replaced colitis, diverticulitis, and diverticulosis with Ileitis or Crohn's disease to coincide with questions on the Patient Medical History form.
- 5.replaced the former "kidney disease, kidney stones" category with just "kidney stones".

Gynecological History

January 1, 1994: (Discontinued)

We have "slashed and burned" this form into non-existence: some questions have been deleted from the forms entirely, some have been moved to a "women only" section on the Medical History Form, some have been moved to the new Pregnancy History Form. Changes are:

- Questions #1 and #6 were moved to MEDHX. Part a to question #6 (age that patient started using tampons) was deleted.
- Questions 2-5 have been deleted entirely. Instead a question "Have you typically had regular menstrual periods?" has been placed on MEDHX.
- In the "Disease History" section, we have:
 - changed the initial question to "have you ever been *diagnosed* as having any of the following disorders?", and then removed the question "has a doctor told you that you have this disorder?"
 - eliminated the questions on vaginal bleeding, vaginitis, fibroid tumors, ovarian cysts, prolapsed uterus, and the open-ended others.
 - added an unknown category to the question regarding relation to urinary symptoms
 - moved the remaining diseases to a women only section on MEDHX.
- In the "Prior surgeries or procedures" section, we have:
 - removed the questions "how many times have you had this surgery?" and "if more than 1 time..."
 - added an unknown category to the question regarding relation to urinary symptoms
 - moved the surgeries to a women only section on MEDHX (deleted question 22 and removed the other options)
- Creation of a Pregnancy History Form comprised of many of the questions in the "Pregnancy history" section. The question on breastfeeding has been deleted. For other changes to this section, see the summary of changes for the PREG form.
- The section on Birth Control has been deleted, since we will get current birth control information on the MED Form.
- The "General Information" section was moved to MEDHX. Question #45 regarding DES use was deleted. We changed question 46, the date of the last pap smear, to "did you have a pap smear in the last year?"

Inclusion Checklist

August 1, 1994: (Version 2.1)

The shading on the checkboxes has been lightened to be consistent with all other eligibility checklists.

February 17, 1995: (Version 2.2)

The direction following the "no" response to question #7 has been changed from "Stop here" to "Go to the shaded box at the bottom of the page."

Medical Events and Patient Treatment Evaluation Form

January 1, 1994: (Version 2.0)

The following questions have been removed from the original form:

- (#1) Have you spoken to the doctor's office for any reason since your last scheduled contact with this clinic?
- (#2) Have you been to see a doctor for any reason since your last scheduled contact with this clinic?
- (#5) Are you currently seeing any of the following types of doctors for your urinary symptoms?
- (#8) Were there any complications from this surgery?
- (#16-#19) A series of questions on the patient's pregnancy conditions. Some of these data will instead be captured on the new Pregnancy History Form collected every two years, rather than every 3 months on this form. Some of these questions have even been removed from the Pregnancy History form per Deb Erickson.

Additionally, the following changes have been made:

- (#6-#7) "Within the last 3 months" has been changed to "since your last contact with this clinic".
- (#11) "Do you currently menstruate?" has been changed to "Have you reached menopause (either surgical or natural)?"
- a question regarding current methods of birth control has been added

November 1, 1994: (Version 2.1)

- Changed question #7 from "Have you reached menopause (either surgical or natural)?" to "Have you stopped menstruating?"

Patient Medical History

January 1, 1994: (Version 2.0)

The following changes were made to this form:

- Five (5) questions on menstrual history were added in a "women only" section. Four of these questions were formerly on the gynecologic history form--#1, #6 (excl part a), #46, and #47. One question was created by collapsing questions #2-#5 on the old gynecologic history form into "have you typically had regular menstrual periods"?
- The following 3 questions have been deleted from the table on disease history:
 - "did a doctor diagnose this disorder"
 - "were you treated for this disorder"
 - "if you were treated, are you currently being treated for this disorder"
- The following diseases have been deleted from the table on disease history
 - Colitis or diverticulitis or diverticulosis (#1)
 - bleeding disorder, heart disease, high blood pressure (#6-#8)
 - polyps, infertility, peyronies, (#9, #11, #16)
 - drug hypersensitivity (#35)
 - breast cancer, colon cancer, lung cancer, stomach cancer, other cancer (#22-#26)
 - abdominal cramping, panic disorder, bipolar disorder, headaches, hepatitis, thyroid disease, liver or gallbladder disease, numbness in legs, post-traumatic stress disorder, schizophrenia (#27, #28, #31, #37-#40, #46, #47, #51)
- Changes were made to the following questions in the disease table:
 - "kidney disease or kidney stones" (#12) was replaced with just "kidney stones"
 - mononucleosis (#45) was moved to be included with chronic fatigue syndrome and epstein barr virus
 - "sinusitis, allergic rhinitis, hayfever, or dust or pollen allergies" was broken into two separate categories, "sinusitis" and "hayfever, allergic rhinitis"
 - "depression" was changed to "clinical depression"
- Pelvic inflammatory disease and endometriosis were moved from the old gynecologic history form to a women only section in the disease table. D&C/D&E, hysterectomy, tubal ligation, and removal of both ovaries were moved to a women only section in the prior surgeries table.
- Question #52 (on bacterial cystitis) has been changed to only include part a.
- Question #54 (on bowel movements) has been deleted.
- The following 2 questions have been deleted from the table on prior surgeries:
 - "how many times have you had this surgery?"
 - "if more than one time, did you last have this surgery before, at the same time as or after your urinary symptoms?"

Patient Medical History (cont.)

- The following questions have been deleted from the table on prior surgeries
 - type of laparoscopy
 - reason for other bladder surgery
 - appendectomy, hemorrhoidectomy, scrotal surgery (#55j-m)
 - circumcision (#55o) (moved instead onto the physical exam form)
 - "abdominal or pelvic surgery" has been changed to "other abdominal or pelvic surgery"
- "Prostatectomy" has been changed to "prostate surgery (for benign disease)" on the prior surgeries table
- The section on health habits has been modified to include only a few simple questions on smoking and alcohol history

November 1, 1994: (Version 2.1)

- In questions #36 and #37, "in the past year" was changed to "in the past 12 months."

Physical Exam

January 1, 1994: (Version 2.0)

Only two minor changes were made to this form:

- the addition of a question on whether a male has been circumcised. (This question was formerly on the medical history form).
- the deletion of the four questions pertaining to a patient's vital signs (weight, height, blood pressure, and temperature)

March 1, 1994: (Version 3.0)

Two questions have been added to the Bimanual Vaginal Exam section:

- tenderness of introitus?
- clinical diagnosis of vulvodynia?

Physician's Evaluation and Treatment Plan

January 1, 1994: (Version 2.0)

The following changes have been made to this form:

- moved the doctor's assessment of whether patient may have IC (question #2) to the SCR form so that this question is answered after the patient has had a complete work-up.
- deleted questions #4 & #5 regarding diagnostic tests completed or ordered. Instead, a question has been added to address whether or not a biopsy will be completed for this contact. This question will aid the DCC in monitoring completion of the appropriate forms when a biopsy is done.
- changed the response categories in the third column ("Will the patient continue with this treatment?") in the table in Question #7. Previously, the categories were:

yes
yes, but with a lower dose
yes, but at a higher dose
no

There is no need to collect the lower/higher dose responses when the dosage amounts for the treatments are not collected. The new response categories consist of only "yes" and "no".

- removed the middle column "How effective is this treatment?" from the table in Question #7. Instead, we have inserted a question between Questions #7 and #8 which assesses the overall effectiveness of the patient's treatment regime. Assessing each individual component of treatment may be impossible to do. In addition, this overall assessment question completed by the physician can be compared with the treatment assessment question completed by the patient on the MED form.
- added more rows to the tables in Questions #7 and #9 so that as many as 5 current treatments and new treatments can be accommodated on the form.

March 1, 1994: (Version 3.0)

Major revisions have been made to this form per the February Steering Committee meeting. The form now requires a listing of all current treatments at the first visit the form is completed for a patient. For every visit afterwards, only changes in treatments should be indicated on the form. There are two sections to indicate these changes; one section requires listing old treatments stopped since the last visit and the other section requires listing new treatments started since the last visit

April 1, 1994: (Version 3.1)

The evaluation of the effectiveness of the current (Question #4) treatment has been moved from page 3 to page 1. The question has been re-structured to be consistent with the patient's assesment of the effectiveness of their treatment (Question #6 on MED form) and re-phrased similar to the same questions on Version 1.0 of this form.

May 1, 1994: (Version 3.2)

An erroneous skip pattern on page one has been corrected. The phrase "Please go to the next page." for the "no" response on Question #3 has been changed to "Please go to Question 4."

May 15, 1995: (Version 4.0)

The date indicated and type of cystoscopy indicated (formerly questions #3a & #3b) has been deleted per protocol change resulting from the May Steering Committe meeting.

Additional Pregnancies (before 1/1/94)
Pregnancy History (after 1/1/94)

January 1, 1994: (Version 2.0)

Pregnancy history is a new form comprised of questions collected formerly on the old gynecologic history form (GYNHX) and additional pregnancies form (PREG). For nulliparous patients, only two questions must be answered. Patients with at least 1 pregnancy must answer several questions that are not specific to any particular pregnancy, but refer to events that may have occurred during any pregnancy. With this modification, we were able to eliminate the table format of the form.

The following questions were removed from the original pregnancy table on the GYNHX form:

- (#30) How many weeks or months did this pregnancy last?
- (#31) On what date did this pregnancy end? (The due date is asked instead *only* for the patient's current pregnancy, if applicable).
- (#34) Did you make changes in your diet during this pregnancy to alleviate your urinary symptoms?
- (#35) Were you bedridden during this pregnancy because of your urinary symptoms?
- (#36a,c,d,e) During this pregnancy did you ever develop....hypertension or high blood pressure, toxemia, diabetes or high blood sugar, other pregnancy-related complications?
- (#38) Did you have any complications during your delivery?
- (#39) Were you catheterized during childbirth?

Modifications to questions from the original pregnancy table on the GYNHX form:

- questions #32 and #33, which address the relationship of the onset of urinary symptoms to pregnancy, have been re-worked into a series of three questions on the new PREG form.

The following questions was added to the new PREG form:

- Did your urinary symptoms improve during any pregnancy?

Prior Diagnostic Tests and Treatments

January 1, 1994: Version 2.0

The following changes were made to the original PRIOR form:

- In the first table, the following changes were made:
 - the question "how long ago did you last have this procedure" has been deleted.
 - questions 7-9 on other procedures have been replaced with common procedures, such as CT/CAT scan, hydrodistention, renal ultrasound, and voiding cystourethrogram.
- In the second table, regarding surgery for urinary symptoms, the following changes were made:
 - the last 3 questions, "how many times have you had this treatment", "how long ago did you first have this treatment", and "if more than one time, how long ago did you last have this treatment" have all been deleted
 - "bladder fulguration" has been changed to "bladder resection or fulguration"
 - questions 18-19 on other surgeries have been deleted
- In the third table, regarding bladder instillations, the following changes were made:
 - the last 3 questions, "how many times have you had this treatment", "how long ago did you first have this treatment", and "if more than one time, how long ago did you last have this treatment" have all been deleted
 - questions 28-30 on other instillations have been deleted
 - "DMSO alone" and "DMSO with other ingredients" have been collapsed into one "DMSO" category
 - questions on "steroids", "narcotics" and "elmiron" have been added
- In the fourth table on oral medications, the following changes have been made:
 - the last 3 questions, "in total how many years or months did you take this medication", "how long ago did you first start taking this medication", and "how long ago did you last take this medication" have all been deleted
 - brand names have been added for alpha-blockers and calcium channel blockers
 - questions 45-48 on other oral medications have been deleted
- In the fifth table on other possible treatments, the following changes have been made:

- the last 3 questions, "how many times have you had this treatment", "how long ago did you first have this treatment", and "if more than one time, how long ago did you last have this treatment" have all been deleted
 - questions 54-57 on other treatments have been deleted
-
- a separate "catch-all" table has been added for any other possible treatment that was not previously addressed in the preceding tables

Screening Phase Sign-Off Form

January 1, 1994: (Version 2.0)

This form has only a minor change:

- the physician's assessment of whether the patient has IC (formerly question #2 on the PHYTRT form) has been moved to this form so that this question is answered after the patient has had a complete work-up.

Symptom History

January 1, 1994: (Version 2.0)

For this version of the form, we have eliminated the following questions:

- (#2) length of time of symptoms before seeking medical treatment.
- (#4, #6) regarding seeing certain types of doctors for urinary symptoms
- (#10-#12) length of symptom flares and remissions. Question #9 regarding usual length of remission remains.
- (#14) items coinciding with a flare in symptoms.
- (#17) childhood bladder problems.
- (#18) occurrence of urinary tract infections any time before onset of symptoms. Question #16 regarding urinary tract infections at time of onset of symptoms remains.
- (#22-#24) birth control methods used 2 years before symptoms.
- (#20a, #25a, #25b, #26a, #27a) removed subsections to these questions and main yes/no/unknown question remains.
- (#28) recurrent vaginal infections but Question #27 regarding vaginal infections 6 months prior to symptoms remains.

The following questions have been modified:

- Question #13 has been changed to reflect a history question: "Have any of the following caused a flare in your symptoms?" Additionally, the following sub-items were deleted from the list: dehydration, car accident, surgery, toothache, sunburn, anesthesia, hormonal changes, and IVP.
- Question #5 has been modified from "What type of doctor was the first to diagnose your urinary symptoms as Interstitial Cystitis (IC)?" to "Was a urologist the first doctor to diagnose your urinary symptoms as Interstitial Cystitis?"
- the response format in questions #7 and #9 were changed from open-ended questions to categories.
- Question #19 has been changed to "Did you take any antibiotics within 2 months before your symptoms started?". The questions regarding specific antibiotics have been deleted.
- question #29 (menopause and hormone supplements) has been modified so that parts a & c are yes/no questions.

The following questions have been added:

- (#15) "Did your urinary symptoms start within 6 months of a cystoscopy?"
- (#14) "Did your urinary symptoms start within 6 months of a urethral catheterization?"

Symptom Questionnaire (Phone)

January 1, 1994: (Version 2.0)

This form has been changed only to coincide with the changes made to the large symptom questionnaire (SYMPTS).

March 1, 1994: (Version 3.0)

This form has been changed only to coincide with the changes made to the large symptom questionnaire (SYMPTS).

April 1, 1994: (Version 4.0)

The phrase "during the last 4 weeks" has been added to parts b and c of Question #6 to be consistent with Question #14 on the longer version of the Symptom Questionnaire.

Symptom Questionnaire

January 1, 1994: (Version 3.0)

We have made the following changes to this form:

- deleted parts h (pain during bowel movements) and i (pain relieved by bowel movements) of question #2.
- deleted questions #4, #5, #7, & #8 regarding worst and best frequency during the daytime and at night.
- modified response format on question #6 (average times awakened at night to urinate) from open-ended question to response categories given in question #3.
- added question to ask how often patient urinates in a 24-hour period. This question will address NIDDK criteria.
- deleted question #9 - "Why do you urinate as often as you do?"
- For questions #11-#17, part a, we ask the patient to respond "yes" or "no" to each type of pain that describes the pain/discomfort in each location, rather than asking the patient to choose the one word that best describes their type of pain. We are hoping that this reduces problems with having to create additional codes for patients who select more than one pain type anyway.
- For question #18, we have added a response category "does not apply".
- modified response categories on question #19 and #20 (relationship of symptoms to eating a meal and time of day) to yes/no/unknown.
- deleted question #23 - "When did you last have sexual intercourse?"
- combined questions #24 & #25 to pain/discomfort experienced during or after any sexual activity.
- Question #31 and #32 (the CHIP scale) have been deleted.

March 1, 1994: (Version 4.0)

Question #3 has been reworded per the February Research Coordinator meeting. The phrase "12 awake period" has been changed to "awake period" to reflect a change in the NIDDK criteria.

Urodynamic Evaluation

January 1, 1994: (Version 2.0)

This form has been modified per Dr. Wein based on discussion at the October 7, 1993 Steering Committee Meeting (see attached).

Voiding Log

January 1, 1994: (Version 2.0)

This form underwent only a minor change--the cover sheet now contains an example of how the voiding log should be completed by the patient.

March 1, 1994: (Version 2.1)

The instructions have been updated to indicate that the log should be completed using black ink and to emphasize the location of the pain and urgency scales on page 4. These changes were requested at the February Research Coordinator meeting.