NATIONAL ANALGESIC NEPHROPATHY STUDY

ESRD PATIENT INTERVIEW

Phase I

Slone Epidemiology Unit
Boston University School of Medicine

July 2000

Note: The following is a printed version of the computerized forms that were used for conducting the NANS interview during Phase I. While it contains all of the key elements, it is not an exact representation of the screens or the computer program. For further details of the latter please see the Phase I Manual.

INITIAL INFORMATION

Form ID # _____   Hospital/Dialysis Unit _____

Interviewer ID #_____   _____ 1. Case   2. Control   Date of interview ____/____/____

DOB ____/____/____   Sex _____ 1. Male   2. Female

Age _____ (computer generated)

Marital status _____
1. Married or live-in partner
2. Separated
3. Divorced
4. Widowed
5. Never married
6. No answer

Do you consider yourself white, black or African-American, Asian or Pacific Islander, Native American, or something else?

☐ White
☐ Black/African-American
☐ Asian/Pacific Islander
☐ Native American
☐ Something else _____
   (Specify)

What is the highest year of school that you have completed?

☐ Less than 8th grade
☐ 8th through 11th grade
☐ 12th grade/high school graduate (include GED)
☐ Vocational school
☐ Some college (include 2 year college degree)
☐ 4 year college degree
☐ School beyond college
☐ Unknown

How tall are you without shoes? _____ feet, _____ inches <u>OR</u> _____ centimeters

How much do you currently weigh? _____ pounds, <u>OR</u> _____ kilograms

How much did you weigh 10 years ago? _____ pounds <u>OR</u> _____ kilograms

Diagnosis code

Diagnosis - Cases Only _____ ☐☐☐☐☐
(from medical record)

_____ ☐☐☐☐☐

_____ ☐☐☐☐☐

_____ ☐☐☐☐☐

EXCLUSION CRITERIA

Before starting dialysis:

Had you ever been told by a doctor that you had diabetes (sugar diabetes, diabetes mellitus)?

_____ 1. No
      2. Yes   Date diagnosed ____/____ ☐ Unknown
      3. Only during pregnancy   *(Month/Year)*
      9. Unknown

If yes, was the diabetes treated with insulin or pills?

_____ 1. No
      2. Yes
      9. Unknown

IF YES - COMPLETE INTERVIEW AND REVIEW DIABETIC STATUS WITH INVESTIGATOR

Did you ever have all or part of a kidney removed?

_____ 1. No
      2. Yes   ____/____   _____   ☐ Total nephrectomy
      9. Unknown   *(Month/Year)*   *(Reason)*   ☐ Partial nephrectomy

IF YES - TERMINATE INTERVIEW

Women <55 years of age

Are you currently pregnant?

_____ 1. No
      2. Yes
      9. Unknown

IF YES - TERMINATE INTERVIEW

RENAL HISTORY

When were you told for the first time that you had kidney disease?   _____/_____
                                                                               (Month/Year)

When did you have your first kidney dialysis?   _____/_____/_____
                                            (Month/Day/Year)

Before starting dialysis, did a doctor ever tell you that you had:

Albumin or protein in your urine?   _____   1. No
                                                 2. Yes   _____/_____
                                                 9. Unknown   *(Month/Year)*

Blood in your urine?

    _____   1. No
                      2. Yes   _____/_____
                      9. Unknown   *(Month/Year)*

Swelling of the legs, ankles, face, or elsewhere that might be due to kidney disease?

    _____   1. No
                      2. Yes   _____/_____
                      9. Unknown   *(Month/Year)*

A blood test that showed you have kidney disease (elevated BUN, creatinine)?   _____   1. No
                                                                        2. Yes   _____/_____
                                                                           9. Unknown   *(Month/Year)*

Anemia attributed to kidney disease?

    _____   1. No
                      2. Yes   _____/_____
                      9. Unknown   *(Month/Year)*

Before starting dialysis, had you ever been told by a doctor that you had any of the following:

                                       Month/Year

☐ Glomerulonephritis   _____/_____

☐ Obstructed kidney   _____/_____

☐ Infections involving your kidney   _____/_____

☐ Kidney disease due to diabetes   _____/_____

Did a doctor ever tell you that you were born with kidney or urinary problems (such as polycystic kidney disease, double ureter)?

    _____   1. No
                      2. Yes   _____
                      9. Unknown   *(Specify)*

<u>Before starting dialysis</u>:

Had you ever been told you had a kidney stone or had you ever passed a kidney stone or had "gravel" in your urine?

    ____   1. No
                2. Yes   ____ No. of times   ____ Age at 1st
                9. Unknown   occurrence

Had you ever been told you had a blockage in your urinary tract (narrowing of ureter or congenital valve problem in the urethra)?

    ____   1. No
                2. Yes   ____ No. of times   ____ Age at 1st
                9. Unknown   occurrence

Had you ever had a urinary tract infection (cystitis or bladder infection)?

    ____   1. No
                2. Yes   ____ No. of times   ____ Age at 1st
                9. Unknown   occurrence

    Were you given an antibiotic? ____ 1. No   2. Yes   9. Unknown   ____ No. of times

Had you ever had an x-ray of your kidneys?

    ____   1. No
                2. Yes
                9. Unknown

    If yes, did you receive an injection in your vein or bladder of a chemical to light up your kidneys?

        ____   1. No
                    2. Yes   ____ No. of times   ____ Age at 1st
                    9. Unknown   occurrence

Had you ever had:

                                                No. of times

☐ Barium enema   ____

☐ CAT scan or CT scan of the kidney   ____

☐ Ultrasound or sonogram of the kidney   ____

☐ Renal arteriogram or venogram (to look at the blood vessels)   ____

Before starting dialysis:

Did you experience any of the following:

	No	Yes	Unknown	Date of 1st occurrence (Month/Year)
Change in your pattern of sleep	____	____	____	____/_____
Unusual fatigue/tiring easily, lethargy/lassitude	____	____	____	____/_____
Change in the taste of food	____	____	____	____/_____
Severe loss of appetite for more than 1 week	____	____	____	____/_____
Nausea/vomiting that lasted more than 1 week	____	____	____	____/_____
Loin pain (the part of the side and back between the ribs and the pelvis)	____	____	____	____/_____
Muscle cramps that lasted for more than 1 week	____	____	____	____/_____

Did you ever have high blood pressure that required treatment with medication?

____ 1. No *(skip to diabetes)*
2. Yes ____ Age HBP diagnosed
3. Only during pregnancy *(skip to other medical history)*
9. Unknown

Had you ever been admitted to the hospital because of high blood pressure?

____ 1. No   No. of times   Years of admission
2. Yes   ____   _____ _____ _____ _____
9. Unknown

What is your highest blood pressure that was ever recorded? _____/_____
                                                         (systolic/diastolic)

OTHER MEDICAL HISTORY

Before starting dialysis, had you ever been told by a doctor that you had:

	No	Yes	Unknown	Age at diagnosis
Gout or high uric acid	____	____	____	____
Gastric or duodenal ulcer or gastrointestinal bleeding	____	____	____	____
Cancer or malignant tumor	____	____	____	

Specify _____ *Code* _____   ____

Specify _____ *Code* _____   ____

| Other major or chronic illness or a condition requiring surgery | ____ | ____ | ____ | |

Specify _____ *Code* _____   ____

Specify _____ *Code* _____   ____

Specify _____ *Code* _____   ____

Has there ever been a period lasting 3 months or more in your life when you had:

1. Frequent headaches or sinus pain?

        ____1. No
            2. Yes
            9. Unknown

                Year started   Frequency   Duration
        If yes: _____   [ ]   [ ][ ] months, years

                    (Repeat as necessary)

FREQUENCY CODES

1 = Daily
2 = 4-6 days per week
3 = 2-3 days per week
4 = 1 day per week

2. Arthritis, rheumatism, joint pain or back pain?

        ____1. No
            2. Yes
            9. Unknown

                Year started   Frequency   Duration
        If yes: _____   [ ]   [ ][ ] months, years

                    (Repeat as necessary)

FREQUENCY CODES

1 = Daily
2 = 4-6 days per week
3 = 2-3 days per week
4 = 1 day per week

3. Any other chronic pain condition (e.g., dental pain or fibromyalgia)?

        ____1. No
            2. Yes
            9. Unknown

                Year started   Frequency   Duration
        If yes: _____   [ ]   [ ][ ] months, years

                    (Repeat as necessary)

FREQUENCY CODES

1 = Daily
2 = 4-6 days per week
3 = 2-3 days per week
4 = 1 day per week

4. Trouble getting through the day?

       ____1. No
           2. Yes
           9. Unknown

FREQUENCY CODES

1 = Daily
2 = 4-6 days per week
3 = 2-3 days per week
4 = 1 day per week

Year started	Frequency	Duration
If yes: _____	☐	☐☐ months, years

(Repeat as necessary)

5. Trouble sleeping?

       ____1. No
           2. Yes
           9. Unknown

FREQUENCY CODES

1 = Daily
2 = 4-6 days per week
3 = 2-3 days per week
4 = 1 day per week

Year started	Frequency	Duration
If yes: _____	☐	☐☐ months, years

(Repeat as necessary)

ANALGESIC HISTORY

We are interested in obtaining information on any **pain medications** you may have taken on a regular basis; by that I mean, any medicines taken <u>at least once a week for at least 3 months</u> and taken **BEFORE STARTING DIALYSIS**.

These include medicines you may have obtained anywhere, including a doctor's prescription, a hospital or neighborhood clinic, a pharmacy, supermarket, store, friends, neighbors, or relatives.

To help you remember, I'm going to read a list of some medical conditions and the names of some specific medications.

Have you taken any medication at least once a week for at least 3 months for:

<u>PROMPT #1</u>

   A. Pain, headache, backache, toothache, sinus pain, menstrual pain, or stomach pain

   B. Muscle relaxant/spasms or arthritis/joint pain

   C. Gout/high uric acid, swelling or inflammation secondary to injury

   D. Fever, cough/cold, or influenza

<u>PROMPT #2</u>

BEFORE STARTING DIALYSIS, had you ever taken analgesics or pain killers at least once a week for at least 3 months:

   E. For nerves or to reduce stress

   F. To help you sleep

   G. To get through or manage the day

   H. To perk up

   I.   To feel better or when you just don't feel well

   J. To treat or prevent hangover

   K. To <u>prevent</u> headaches or other pain

   L. To <u>prevent</u> heart disease

   M. To <u>prevent</u> thrombosis or stroke

   N. To <u>prevent</u> "restless" legs

<u>PROMPT #3</u>

BEFORE STARTING DIALYSIS, had you ever taken any of the following products at least once a week for at least 3 months (read attached list):

<u>PROMPT #4</u>

BEFORE STARTING DIALYSIS, was there any other pain medication you took at least once a week for at least 3 months that we have not asked about?

TRADE NAME LIST

ACETAMINOPHEN	INDOCIN
ADVIL	LIQUIPRIN
ALEVE	MIDOL or MIDOL IB
ALKA SELTZER	MOTRIN or MOTRIN IB
ANACIN	NAPROSYN
ANAPROX	NAPROXEN
ASCRIPTIN	NORGESIC or NORGESIC FORTE
ASPIRIN	NUPRIN
BC POWDER	NYQUIL
BROMO SELTZER	NYTOL
BUFFERIN	ORUDIS
CLINORIL	PAMPRIN
COPE	PARAFON FORTE
CORICIDIN	PEPTO-BISMOL
DARVOCET	PERCODAN
DARVON	ROBAXISAL
DOAN'S	RUFEN
DRISTAN	SINE-AID
ECOTRIN	SINE-OFF
EMPIRIN	SOMA COMPOUND
EMPIRIN with CODEINE	SOMINEX
EQUAGESIC	STANBACK POWDERS
EXCEDRIN	SYNALGOS-DC CAPSULES
FELDENE	TALWIN COMPOUND
FIORICET	TYLENOL
FIORINAL	VANQUISH
GOODYS POWDER	VOLTAREN
IBUPROFEN	

Prompt #____   Drug name _____   Drug code ☐☐☐☐☐☐   Drug Book ☐

Prompt #	Year started	If unknown, year range	Fre-quency	Average # pills/ doses per day	If unknown, pill range	Duration			Duration unknown	Reason for use	
____	_____	_____ – _____	☐	☐	☐ – ☐	____	☐ months,	☐ years	☐	_____ *(Specify)*	_____ *(Code)*
____	_____	_____ – _____	☐	☐	☐ – ☐	____	☐ months,	☐ years	☐	_____ *(Specify)*	_____ *(Code)*
____	_____	_____ – _____	☐	☐	☐ – ☐	____	☐ months,	☐ years	☐	_____ *(Specify)*	_____ *(Code)*
____	_____	_____ – _____	☐	☐	☐ – ☐	____	☐ months,	☐ years	☐	_____ *(Specify)*	_____ *(Code)*

Prompt #____   Drug name _____   Drug code ☐☐☐☐☐☐   Drug Book ☐

Prompt #	Year started	If unknown, year range	Fre-quency	Average # pills/ doses per day	If unknown, pill range	Duration			Duration unknown	Reason for use	
____	_____	_____ – _____	☐	☐	☐ – ☐	____	☐ months,	☐ years	☐	_____ *(Specify)*	_____ *(Code)*
____	_____	_____ – _____	☐	☐	☐ – ☐	____	☐ months,	☐ years	☐	_____ *(Specify)*	_____ *(Code)*
____	_____	_____ – _____	☐	☐	☐ – ☐	____	☐ months,	☐ years	☐	_____ *(Specify)*	_____ *(Code)*
____	_____	_____ – _____	☐	☐	☐ – ☐	____	☐ months,	☐ years	☐	_____ *(Specify)*	_____ *(Code)*

FREQUENCY CODES

1 = Daily
2 = 4-6 days per week
3 = 2-3 days per week
4 = 1 day per week

Did your doctor or medical practitioner advise you to discontinue use of any pain medications based on a problem with your kidneys or the results of kidney tests?

    ____ 1. No
         2. Yes
         9. Unknown

    If yes, what was the name of the medication?

Drug code

When this was recommended, did you:

    ____ 1. Stop taking it and start something   Year stopped   Drug name
          else?   —————

Drug code

         2. Stop taking it without starting   Year stopped
           another pain medication?   —————
         3. Continue to take the medication?
         9. Unknown

Was there any other medication your doctor advised you to discontinue because of your kidneys?

    ____ 1. No
         2. Yes
         9. Unknown

    If yes, what was the name of the medication?

Drug code

When this was recommended, did you:

    ____ 1. Stop taking it and start something   Year stopped   Drug name
          else?   —————

Drug code

         2. Stop taking it without starting   Year stopped
           another pain medication?   —————
         3. Continue to take the medication?
         9. Unknown

FAMILY HISTORY

I would like to ask a few questions about the health of your immediate family (father, mother, brothers, and sisters).

Do or did any of them have any of the following: ____   1. No   Diabetes mellitus
                                                             2. Yes   High blood pressure
                                                             9. Unknown   End stage renal disease

If yes, complete section below.

	Diabetes mellitus	High blood pressure	End stage renal disease
Father	☐	☐	☐
Mother	☐	☐	☐
Brothers	☐	☐	☐
Sisters	☐	☐	☐

HABITS

Have you ever smoked cigarettes, cigars, or a pipe? _____ 1. No *(skip to next page)*   9. Unknown *(skip to next page)*
2. Yes

Have you smoked at least 100 cigarettes in your life? _____ 1. No *(skip to pipe)*   9. Unknown *(skip to pipe)*
2. Yes

Did you smoke cigarettes during the year before starting dialysis? _____ 1. No   9. Unknown
2. Yes

    For <u>ex-smoker</u>, time since stopping: _____ ☐ years

    For <u>current or ex-smoker</u>, years duration _____
                         number of cigarettes per day _____
                         age started smoking _____

Have you smoked a pipe at least 50 times in your entire life? _____ 1. No *(skip to cigars)*   9. Unknown *(skip to cigars)*
2. Yes

Did you smoke a pipe during the year before starting dialysis? _____ 1. No   9. Unknown
2. Yes

    For <u>ex-smoker</u>, time since stopping: _____ ☐ years

    For <u>current or ex-smoker</u>, years duration _____
                         number of pipefuls per day _____
                         age started smoking _____

Have you smoked at least 50 cigars in your life? _____ 1. No *(skip to alcohol)*   9. Unknown *(skip to alcohol)*
2. Yes

Did you smoke a cigar during the year before starting dialysis? _____ 1. No   9. Unknown
2. Yes

    For <u>ex-smoker</u>, time since stopping: _____ ☐ years

    For <u>current or ex-smoker</u>, years duration _____
                         number of cigars per day _____
                         age started smoking _____

Before starting dialysis, how often did you drink:

	Frequency	Number per day	
Decaffeinated coffee	☐	☐	☐
Regular coffee	☐	☐	☐
Regular tea	☐	☐	☐
Beer	☐	☐	☐
Wine	☐	☐	☐
Liquor	☐	☐	☐
Home distilled alcohol or moonshine	☐	☐	☐

Drinking pattern at age 30:

	Frequency	Number per day	
Decaffeinated coffee	☐	☐	☐
Regular coffee	☐	☐	☐
Regular tea	☐	☐	☐
Beer	☐	☐	☐
Wine	☐	☐	☐
Liquor	☐	☐	☐
Home distilled alcohol or moonshine	☐	☐	☐

FREQUENCY CODES

1 = Daily
2 = 4-6 days per week
3 = 1-3 days per week
4 = 1 or more days per month
5 = Less than once a month
6 = Ex-drinker for over 1 year
7 = Never
8 = Changed habits during past year
9 = Unknown

OCCUPATION

Now I would like to ask some questions about your employment history.

List all the jobs or occupations you have held for at least one year, starting with the most recent.

Job title	Industry code	Occupation code	# of years	year started
_____	☐☐☐	☐☐☐☐☐	____	____

Task _____

_____

| _____ | ☐☐☐ | ☐☐☐☐☐ | ____ | ____ |

Task _____

_____

| _____ | ☐☐☐ | ☐☐☐☐☐ | ____ | ____ |

Task _____

_____

| _____ | ☐☐☐ | ☐☐☐☐☐ | ____ | ____ |

Task _____

_____

| _____ | ☐☐☐ | ☐☐☐☐☐ | ____ | ____ |

Task _____

_____

| _____ | ☐☐☐ | ☐☐☐☐☐ | ____ | ____ |

Task _____

_____

| _____ | ☐☐☐ | ☐☐☐☐☐ | ____ | ____ |

Task _____

_____

INCOME

1. In general, would you say that your total annual household income is more or less than $20,000?

    ☐ More   ☐ Unknown *(skip to next page)*
    ☐ Less *(skip to 5)*   ☐ Refused *(skip to next page)*

2. Would you say that your total annual household income is more or less than $35,000?

    ☐ More   ☐ Unknown *(skip to next page)*
    ☐ Less *(skip to 6)*   ☐ Refused *(skip to next page)*

3. Would you say that your total annual household income is more or less than $65,000?

    ☐ More   ☐ Unknown *(skip to next page)*
    ☐ Less *(skip to 6)*   ☐ Refused *(skip to next page)*

4. Would you say that your total annual household income is more or less than $100,000?

    ☐ More *(skip to 6)*   ☐ Unknown *(skip to next page)*
    ☐ Less *(skip to 6)*   ☐ Refused *(skip to next page)*

5. Would you say that your total annual household income is more or less than $10,000?

    ☐ More   ☐ Unknown *(skip to next page)*
    ☐ Less   ☐ Refused *(skip to next page)*

6. How many persons are dependent on that income? ____

MISCELLANEOUS INFORMATION

Finally, I'd like to ask about any experiences with recreational drugs before starting dialysis. Please remember that everything you tell us will remain strictly confidential.

Have you ever used any of the following at least 50 times?

	No	Yes	Unknown	Refused
Marijuana (grass, pot, hashish)	____	____	____	____
Amphetamines (speed, uppers, stimulants)	____	____	____	____
Cocaine or crack	____	____	____	____
Heroin	____	____	____	____
Psychedelics (LSD, PCP, mescaline)	____	____	____	____
Other opiates or narcotics	____	____	____	____

Thank you so much for taking the time to answer our questions. Your information is important to our research and we very much appreciate your participation.

Source of information ____
1. Subject
2. Caretaker (leave note)
3. Surrogate (leave note)
4. Translator
9. Unknown

Reliability ____
1. Reliable
2. Unreliable
9. Unknown