# INSTRUCTIONS USRDS DIALYSIS MORBIDITY AND MORTALITY STUDY

Questions? Feel free to call the USRDS Coordinating Center anytime for clarification of any of the instructions pertaining to completion of the forms for the DMMS. Call 313 998-6611 and ask to speak with Corbin Wood or Liz Holzman.

Please read all instructions thoroughly before beginning your first record abstraction. The quality of the data collected depends on correctly completing the abstraction forms.

# **General Instructions and Overview**

Data abstraction of patient records for the Dialysis Morbidity and Mortality Study (hereafter referred to as the DMMS) is to be completed by personnel at the dialysis facilities. Take all information from the facility/unit records, including medical records, billing records, dialysis logs, patient rosters, hospital records and personal physician records. Do not take information from copies of HCFA ESRD Forms.

Please complete the forms in blue or black ink or dark pencil. Please PRINT legibly in CAPITAL LETTERS.

#### **Study Start Date**

The <u>Study Start Date</u> for the DMMS is <u>December 31, 1993</u>. The Study Start Date delineates the starting point from which data becomes relevant to the study. Thus, a patient who died on December 20, 1993 should <u>not</u> be included in the study since there will be no relevant data on this patient. However, a patient who died on January 4, 1994 <u>must</u> be included in the study since data from the period of December 31, 1993-January 4, 1994 is relevant to the study.

# Keeping Track of Completed Abstractions/Verifying Patient Demographic Information

Each dialysis facility has been given a **batch of forms** for data abstraction. The first page of each set of patient abstraction forms is the "**Patient Tracking Form/Patient Identification as of 12/31/93**". This form needs to be completed for each patient by the dialysis unit abstractor. This form helps us to keep track of completed abstractions and provides us with information about why an abstraction may not have been completed. This form assists you in locating the correct patient for record abstraction. *This form also* 

#### DMMS: General Information

*indicates which abstraction forms are to be completed for that particular patient. Please be sure to complete the abstraction forms that are specifically requested.* On the Patient Tracking Form/Patient Identification as 12/31/93 form, we have asked you to verify the patient's sex, date of birth, social security number, HIC number and modality of care.

The sample of patients for the DMMS has been selected randomly. **It is very important that all the data abstraction forms requested be completed on each and all of these patients**. Completion of forms on each patient ensures the randomness of the sample which is critical to the validity of all the data collected and analyzed. Thus, it is critical that you locate each patient's record. It is very important that you indicate the reason if you are unable to locate a record on a selected patient. The reason codes for <u>not</u> being able to locate a patient's records include:

- A: Patient stopped receiving treatment at this unit and transferred to another facility <u>prior</u> to the Study Start Date of December 31, 1993.
- B: Patient died prior to January 1, 1994 or on the Study Start Date of December 31, 1993.
- C: Patient was never treated at this unit.
- D: Other; Please specify with a written explanation.

On the **Patient Tracking Form/Patient Identification as of 12/31/93** there is a place to indicate the Reason Code and a Reason Explanation, if necessary. Only complete the Reason Explanation if Reason Code "D" has been used.

#### **Returning Forms to the ESRD Network**

Copies of completed forms should be submitted to the Network monthly. You have been provided with a Batch Cover Sheet which lists all the patients included in your batch of sets of patient abstractions forms. Please be sure to use the Batch Cover Sheet to indicate the date that each set of patient abstraction forms is returned to the Network. <u>Each month, when you return forms to the Network, make a copy of the</u> <u>Batch Cover Sheet and return it along with the completed forms</u>. <u>Be sure to retain</u> <u>your original Batch Cover Sheet</u>. Be sure to copy the Batch Cover Sheet and send it along with the forms every month that you return forms to the Network.

#### **Skipping Items**

If the answer to an item cannot be determined, **leave the item blank by leaving the box on the right empty** and **put a check mark in the small box to the left of the item number.** This will indicate that you looked for the information in all available records and decided that you could not determine an answer for the item. When information is not available to answer a question, checking the box on the left is important because it indicates that the item was not inadvertently skipped or forgotten.

#### Dates

Dates are either in month (mm) day (dd) and year (yy) format ,or in month and year format. **In all cases, month and day must be expressed in 2 digits.** For example, January is  $\emptyset$ 1 and November is 11. The first day of the month is  $\emptyset$ 1; the fifteenth day of the month is 15. The year is expressed by the last two digits of the year; e.g. 94 for 1994.

If you are able to report partial information only, do so but also put a check in the small box to the left of the item number. For example, if the records give the year of a transplant but not the month or day, enter the year in the appropriate box, leave the month and day blank and check the box to the left of the item number.

#### **Right Justification**

**<u>Right justify all entries</u>**. For example, if a patient has a serum creatinine of 9.8 (Item D:8), enter the item as follows:

# Comments Box

Each set of patient abstraction forms contains an Abstractor's "Comments Box". Please use this box to write any information that you believe is important to explain the response to an item. For some items, there are specific instructions to use the "Comments Box" for an explanation to a response.

## **Use of Abstractor Judgment**

A medical record may not state explicitly all the information that these abstraction forms are designed to capture. **The integrity of the data collection effort rests on the expertise and professionalism of the abstractors in interpreting the information contained in the medical record**. In many instances where specific information for an item is not in the record, the abstractor may be able to logically infer the answer to the item from other information in the record. For example, elevated blood pressure over a long period of time implies hypertension. Abstractors should not make inferences without very careful consideration but should make inferences when they believe that the record supports drawing a conclusion. An inference can be made when the abstractor feels that 8 or 9 out of 10 abstractors reviewing the same record would agree. Such inference can, however, only be made from information dated <u>before</u> the Study Start Date of 12/31/93. Use of abstractor judgment helps in obtaining the most complete set of data about a patient's history and medical status as possible.

# **Detailed Instructions by Questionnaire**

## **DMMS** Core Questionnaire

#### Section A: Patient and Facility Identification

### **General Notes**

If you cannot answer an item from 1-8 or if you find only partial information for any of these items, you must note the item number and the reason why in the "Comments Box". Also remember to put a check in the small box to the left of the item number if the information is either not available or if only partial information is available.

<u>Item</u>	<b>Description</b>	Abstractor Instructions
1.	Abstractor initials	Enter your initials.
2.	Date Completed	Enter the date that you complete the form.
3.	Race	Enter the appropriate code for race.
4.	Ethnicity	Enter the appropriate code for ethnicity.
5.	Patient Zip Code	Enter the zip code for the patient's address. If more than one is available, please provide the one closest to the Study Start Date of 12/31/93.
6.	Year of First ESRD Service a. Year of first chronic maintenance dialysis, regardless of setting	Please enter the year (yy) in which the patient began receiving a regular course of maintenance dialysis (at least weekly dialysis treatments) for permanent and irreversible chronic renal failure, whether in a hospital, outpatient or home setting.
	b. Earliest known year of chronic dialysis	<u>Complete this item only if 6a above is unknown</u> . Enter the year of earliest known chronic dialysis treatments.

7.	Current (or last known insurance)	Please answer for all categories of insurance. Indicate whether or not the patient has <u>each</u> of these types of insurance using the appropriate code. (More than one may be answered "yes".)
8.	Was patient enrolled in an HMO since starting chronic maintenance dialysis?	Please indicate using the appropriate code whether the patient was enrolled in a Health Maintenance Organization (HMO) at any time since starting chronic maintenance dialysis.

#### Section B: Patient History Prior to Study Start Date of 12/31/93

#### **General Notes**

#### "Hx" means history and "Dx" means diagnosis.

Abstractor judgment is very important in this section. If there is no specific mention of a particular disease, (e.g. hypertension) but there is convincing evidence that the patient has a history of this disease (e.g. elevated blood pressure readings), you should answer "suspected" (code 3). If an otherwise very complete medical record contains no information on whether the patient has a history of a particular disease, you should assume that there is no history of that disease (code 2). However, if all the available medical records are very sketchy and there is no mention of a history of a particular disease, the item should be considered indeterminate. In this case, leave the item blank and check the small box on the left.

Be careful to put checks in the small left hand boxes <u>only</u> for those questions for which you cannot determine an answer but <u>not</u> for items which the form specifically instructs you to skip. For example, if the patient does not have a history of diabetes, item B:6, enter "2" for no and skip items B:6a and B:6b and <u>do not check the left hand boxes</u> for the appropriately skipped items. Remember to use the Abstractor's "Comments Box" if you need to further explain any of your answers.

Any "yes" responses to the questions in Section B will signify that the stated disease process was present within ten years <u>prior</u> to the Study Start Date of 12/31/93. In other words, if a patient was diagnosed with lung disease in February of 1989, then the answer to question B:7 is "Yes" (code 2). If a patient has a cerebrovascular accident in February of 1994 and did not have <u>known</u> cerebrovascular disease as of 12/31/93, then the answer to question B:3a is "No".

<u>Item</u>	Description	Abstractor Instructions
1.	Regular cigarette smoking status prior to 12/31/93	Enter the correct code. "Active" means that the patient was a smoker as of 12/31/93. "Former" means that the patient was a smoker and stopped smoking any time prior to 12/31/93. "Smoker, current status unknown" means that the patient has a history of smoking but it is unknown whether the patient currently smokes or not. "Non-smoker" means that the record states that the patient was never a smoker <u>or</u> an otherwise complete record does not mention that the patient was ever a smoker.
2.	Hx of Coronary Heart Disease (CHD) or Coronary Artery Disease (CAD)	Enter yes, no or suspected for items 2a through 2g.
3.	Hx of Cerebrovascular Disease	Enter the code for yes, no or suspected for each of the two events listed. If 3a is yes, skip item 3b.
4.	Hx of Peripheral Vascular Disease (PVD)	Enter the appropriate code of yes, no or suspected, for items 4a through 4e.
5.	Hx of Heart Disease (other than CHD or CAD)	Enter the appropriate code of yes, no or suspected for items 5a and 5b.
6.	Prior Dx of Diabetes	Enter the appropriate code for yes, no or suspected. <u>Note</u> that the answer to this question can be yes even if diabetes was not considered the cause of ESRD. If no, skip to number 7.
	Was diabetes the cause of ESRD?	For 6a enter the code for yes, no or suspected.
	Insulin therapy during 1993?	For 6b enter the code for "active", "former" or "never". If the patient was on insulin therapy as of December 31, 1993 then the correct answer is "active". If the patient received insulin therapy anytime prior to December 31, 1993 (between Jan 1, 1994 and December 30, 1993) then the correct answer is "former". If the patient did not receive insulin therapy anytime in the past 10 years then the correct answer is "never".

7.	Hx of Lung Disease	Enter the appropriate code for yes, no or suspected.
8.	Neoplasms	Enter the appropriate code for yes, no or suspected. If no, skip to item 9. For 8. enter the appropriate code of 10-25 for the primary site of the neoplasm. You may enter up to two primary sites. Skin cancer other than melanoma need not be recorded. For item 8b, enter the 2 digit year of the date of first diagnosis of neoplasm.
9.	HIV Status	Enter the appropriate code for positive, negative, unknown or unable to disclose.
10.	AIDS Diagnosis	Enter the appropriate code for positive, negative, unknown, or unable to disclose.

#### Section C: Information at Start of Study

#### **General Notes**

With regard to items 2-5, please follow the directions below in determining the time frame for answering the questions. If, however, a change occurs in the month of December, 1993, please provide the **latest information for December.** For example, if a patient had a change in vascular access from a temporary line (subclavian) in the beginning of December, 1993 to AV fistula later in December, 1993, please indicate AV fistula as the vascular access in use.

With regard to questions 6-13, use information from the most recent psychosocial evaluation prior to 12/31/93. However, you may use data from older evaluations if necessary for completeness.

<u>Item</u>	<b>Description</b>	Abstractor Instructions
1.	Height	Enter the height in feet and inches or centimeters. <u>This</u> <u>item is required. Please make every attempt to obtain</u> <u>this information.</u> (This information can be from anytime during adult life.) If the patient is a bilateral amputee, please give the
		original height of the patient and check the box indicating that the patient is an amputee.

2.	Dry Weight as ordered	Enter the prescribed dry weight from December, 1993. If unavailable, list the lowest post dialysis weight within the last 2 weeks of 1993.
3.	Undernourished or cachectic	Enter the appropriate code for yes, no or suspected. Base your answer on information from the medical record in the period of October, 1993-December, 1993.
4.	Blood pressure (average of last 3 values from last week of 1993)	Use the average of the last 3 values from the last week of 1993.
	Predialysis	For item 4a, enter the average of the 3 systolic and diastolic blood pressure readings taken <b>before</b> each dialysis session during the last 3 treatments of December, 1993. Please indicate whether blood pressure was taken from a sitting position using the appropriate code for yes or no.
	Postdialysis	For item 4b, enter the average of the 3 systolic and diastolic blood pressure readings taken <b>after</b> each dialysis session during the last 3 treatments of December, 1993. Please indicate whether blood pressure was taken from a sitting position using the appropriate code for yes or no.
5.	Dialysis Information	Answers to questions about dialysis information should be based on data in the medical record from December of 1993.
	a. Dialysate	Enter the appropriate code for bicarbonate or acetate dialysate.
	b. Prescribed or usual hours per treatment	Enter the prescribed hours and minutes.
	c. # of dialysis sessions per week	Enter the prescribed or usual # of dialysis sessions <b>per week</b> during the month of December, 1993.
	d. Blood flow rate	Enter the blood flow rate in milliliters per minute. If the flow varies, enter the prescribed or most common "high" rate. If there is a range of the prescribed blood flow rate, then enter the mid of that range.

	e. Is the patient usually using a reused dialyzer?	Enter the appropriate code for yes or no.
	f. If reuse does not occur, please indicate the reason	Enter the appropriate code for why reuse does not usually occur.
	g. Highest weight loss during dialysis	Enter the highest weight loss (pre to post dialysis) within the last two weeks of December, 1993, rounded to the nearest pound or kilogram.
	h. Dialyzer type	See the code list on the back of the form for four digit codes for dialyzer type. If you use code 9999 (other), please enter on the lines provided the manufacturer and dialyzer model.
	i. Vascular access in use	Enter the appropriate code for the vascular access type, using the most recent information from December, 1993.
6.	Date of psychosocial evaluation	Enter the date of the evaluation in month, day and year format.
7.	Activities of daily living	For 7a, 7b, and 7c, please enter the appropriate yes or no code for each activity. Consider the patient to be capable of independent ambulating even if he/she can ambulate only with an assistive device (e.g. walker, crutches).
8.	Marital status	Enter the appropriate code.
9.	Living alone	Enter the appropriate code.
10.	Education	Enter the most appropriate code.
11.	Primary occupation before onset of ESRD	Enter the most appropriate code. Before ESRD means prior to the first maintenance dialysis treatment as reported in A:6.
12.	Employment level according to the following scale	For items 12a-12h, enter the appropriate code for yes or no. You may provide up to <u>two "yes" answers</u> in the column labeled "before ESRD". For instance, a patient who was employed full time for most of his adult life may have become disabled six months prior to the start of maintenance dialysis. <u>Please indicate</u> <u>"disabled" only if the disability kept the patient from</u> <u>working for more than 3 months</u> . However, <u>only one</u> <u>"yes" answer</u> should be given in the column labeled "on 12/31/93".

### Section D: Laboratory Data

#### **General Notes**

For items 1 and 2, use a time frame of all of calendar year 1993 in order to answer yes or no to these questions. For items 3-8, use information from December, 1993. If there are no data available from December, 1993, you may use data from November of 1993. For items 9 and 10, you must use data from December of 1993. For items 11, 12, and 13, use the most recent data from July-December, 1993.

Predialysis in this section means before the dialysis treatment of that day.

<u>Item</u>	<b>Description</b>	Abstractor Instructions
1.	Cardiomegaly by X-Ray	Enter code for yes or no. Use any available information from calendar year 1993.
2.	Left ventricular hypertrophy	For items 2a., and 2b. enter the code for yes or no. Use any available information from calendar year 1993.
3.	Serum calcium, predialysis	Enter the predialysis value to the <b>nearest tenth.</b> Use data from December, 1993. Only if necessary, use data from November, 1993. Use the most recent information available.
4.	Serum phosphorus or phosphate, predialysis	Enter the predialysis value to the <b>nearest tenth.</b> Use data from December, 1993. Only if necessary, use data from November, 1993. Use the most recent information available.
5.	Serum bicarbonate, predialysis	Enter the predialysis value to the <b>nearest tenth.</b> The patient's lab report may indicate "serum bicarbonate" or may indicate "CO <sub>2</sub> ". Use data from December, 1993. Only if necessary, use data from November, 1993. Use the most recent information available.

6.	Hematocrit	For hematocrit information, please make every attempt to provide data from a lab report, not from a hematocrit spun in the dialysis unit. If the only source of information is a hematrocrit spun in the dialysis unit, you may provide this data. Use data from December, 1993. Only if necessary, use data from November, 1993. Use the most recent information available.
	Hematocrit	For item 6a, enter the hematocrit percentage. If transfused, give the value <u>before</u> transfusion. Use data from December, 1993. Only if necessary, use data from November, 1993. Use the most recent data available.
	Hemoglobin	For item 6b, enter the value to the nearest tenth. If transfused, give the value <u>before</u> the transfusion. Use data from December, 1993. Only if necessary, use data from November, 1993. Use the most recent data available.
	Transfused in Dec, 1993	For item 6c, enter the appropriate code for yes or no based on whether or not there was a transfusion in the month of December, 1993. Use data from December, 1993 only. If the answer to 6c is no then skip to item 7.
	Number of transfusions	For item 6d, enter the number (from 0 to 9) of transfusions that occurred during the month of December 1993. If there were more than 9 transfusions, enter a 9. <b>Use data from December, 1993 only</b> .
7.	Was the patient taking EPO anytime in December of 1993?	Enter the appropriate code for yes or no. Use data from December, 1993 only.
8.	Serum creatinine, predialysis	Enter the predialysis value to the <b>nearest tenth.</b> Please <b>record an average of at least two values</b> . Use data from December, 1993. Only if necessary, use data from November, 1993. Use the most recent information available.
9.	# of dialysis treatments skipped during December 1-23, 1993.	Enter a number from 0-9 for the number of treatments skipped during the period of <b>December</b> <u>1-23</u> , 1993. <b>Dialysis treatments received elsewhere (e.g. inpatient</b> setting) should NOT count as skipped treatments.

10.	Number of treatments in December, 1993 shortened by more than 10 minutes	Enter the number, from 0-13 of <i>shortened</i> treatments during December, 1993. Do not include skipped treatments.
11.	Lipids	For items 11a and 11b enter the appropriate whole numbers using the most recent value from July-December, 1993.
12.	Serum intact PTH	Enter the value, <b>using the most recent data from July-</b> <b>December, 1993.</b>
13.	Serum aluminum	Enter the value, <b>using the most recent data from July-</b> <b>December, 1993.</b> If this data comes from measurements taken during a desferol test, please be sure to use the <u>baseline</u> measurement.
14.	Date of first ever chronic dialysis treatment.	Answer this question, only if the patient was newly diagnosed with ESRD in 1993. Enter the date of the first chronic maintenance dialysis treatment ever, using month, day and year format. Skip items 14 and 15 if ESRD was diagnosed before 1993.
15.	Serum creatinine before <u>first ever dialysis treatment</u>	Enter the value to the nearest tenth of the serum creatinine on the day of the first ever dialysis treatment.
16.	BUN and Weight	Note: If NONE of the information is available for a given month, skip that column in the table. <b>Do not enter zeros</b> .
	Date	<u>Date</u> : For each month, enter the day to which the values apply. If values are available for more than one day in a month, use the first day on which pre <u>and post</u> values are available.
		<u>BUN</u> : Enter the predialysis BUN and the postdialysis BUN for the day entered in the date row. If a postdialysis BUN is not available for that month, record the predialysis BUN only. Enter a <u>second predialysis BUN</u> value <b>only</b> if this value is available for the dialysis session <u>exactly two days after the session for which</u> <u>the first two (pre and post) values are entered</u> .

	Weight	Weights: Enter the predialysis weight and the postdialysis weight for the day entered in the date column, rounded to the nearest pound or kilogram. Check the appropriate units box to indicate if measurements recorded are in pounds or kilograms. Enter a second predialysis weight <b>only</b> if this value is available for the dialysis session <u>exactly two days after</u> <u>the session for which the first two (pre and post)</u> <u>values are entered</u> . NO weight needs to be recorded if NO BUN is recorded.
17.	Predialysis serum albumin	For item 17., enter the patient's predialysis serum albumin from the same day as referenced in the date row. However, if this data is not available, use any <b>value from</b> <b>the month entered in the date row</b> , to the nearest tenth. Complete 17 for each month of July, 1993 through December, 1993.
18.	Duration of dialysis	Enter the duration of the dialysis session. This should be the same dialysis session as the one referred to for the first value of predialysis BUN and weight. (NOT the dialysis session referred to for the second pre dialysis value of BUN and weight.).

#### Section E: Change in Patient Status

#### **General Notes**

<u>This section is to be completed by the Network. The Dialysis Facility/Unit</u> <u>should leave this section blank and proceed to the next page</u>. The Network should use the Network database to obtain the information to complete this section. Items in this section refer to events occurring to patients during the interval from the Study Start Date of December 31, 1993 to the date of Network abstraction. Information is provided about **any changes in the patient's status after December 31, 1993**. This section is very important and every attempt should be made to obtain the information requested. Leave items 1-4 blank if the event(s) did not occur but otherwise record any and all events that did occur. If the patient remained on center hemodialysis during the period of December 31, 1993 to the date of Network abstraction, items 1-4 will all be blank. If and only if items 1-4 are all left blank, complete item 5.

<u>Item</u>	<b>Description</b>	Abstractor Instructions
1.	Date first switched off center hemodialysis	Enter the date that the patient <b>first</b> switched off center hemodialysis. If more than one switch occurred between December 31, 1993 and the date of Network abstraction, be sure to enter the <b>first</b> date of switch.
		If a switch did occur, please enter the appropriate code for the reason.
2.	Date of death	In month, day and year format, please enter the date that the patient died.
3.	Date patient moved out of the Network region	In month, day and year format, please enter the date that the patient moved out of the Network region and became lost to follow-up
4.	Date of transfer to another dialysis unit within the Network	In month, day and year format, please enter the date that the patient transferred to another dialysis unit within the <b>same</b> Network. This does not include temporary transfers due to hospitalization.
5.	Date of last known center hemodialysis treatment	<b>This item should be completed only if E1-E4 are</b> <b>blank</b> . In month, day and year format, record the date of the last known center hemodialysis treatment

## **Anemia Questionnaire**

**General Notes** 

Be sure to right justify all of the values entered in this section.

Remember to check the small boxes on the left if an item cannot be determined. If an item is skipped because the instructions have directed you to do so, then do not check the small box on the left.

It is important to pay close attention to the time frame referenced for each of the questions in this section.

<u>Item</u>	Description	Abstractor Instructions
1.	Serum iron	Enter the appropriate value in whole numbers. Use the most recent information available from October through December, 1993.
2.	Total iron binding capacity (TIBC)	Enter the appropriate whole numbers. Use the most recent information from October through December, 1993.
3.	Ferritin	Enter the appropriate whole numbers. Use the most recent information from October through December, 1993.
4.	Transferrin saturation (if available)	Enter the appropriate percent. Use the most recent information from October through December, 1993.
5.	Hematocrit as of <u>October</u> , 1993	Enter the patient's hematocrit (percentage) <u>for October,</u> <u>1993</u>
6.	Iron Route of parental iron administration	For item 6a, enter the appropriate code for whether parenteral iron (called Iron dextran, Imferon, or Infed) was used during 1993. If the answer was no, skip items 6b-6e and go to item 7. If the answer was yes, continue on and answer items 6b6e. For item 6b., enter the appropriate code for route of parenteral iron administration (parenteral means intravenous (i.v.) or intramuscular (i.m.) not oral, not p.o.).

7.

8.

Date of last i.v. or i.m. p. iron administration during 1993	For item 6c, enter the date of last administration during 1993.
Dose of iron per administration <b>in mg</b> (most current)	For item 6d, enter the dose of iron per administration in mg in 1993. <b>If the information is available in ml, be sure to convert to mg</b> . Use data from the most current dose administered. (1 ml=50 mg).
Administrations of iron per week	For item 6e enter the # of administrations per week in 1993.
Was patient taking oral iron at the end of December, 1993?	Enter the appropriate code.
EPO (Prescribed or Administered)	For item 8, enter yes if the patient was on EPO as if $1/1/94$ (+/- one week). If not, then go on to item 7.
Units of EPO per administration	For item 8a, enter the # of units of EPO per administration for the week of January 1, 1994 ( $\pm$ 1 week). This number should be in 1000's of units. If this data is not available, give the prescribed EPO administration.
Units of EPO per week (sum total)	For item 8b, enter the total units of EPO administered for the same week as referenced in item 8a. Again, this number should be in 1000's of units.
Administrations of EPO per week	For item 8c, enter the total # of administrations for the same week referenced in items 8a and 8b
Route of EPO administration	For item 8d, enter the appropriate code for the route of administration of EPO.
EPO start date, if after ESRD	For item 8e, enter the start date for EPO if the start date was after the patient was diagnosed with ESRD. If the start date was before the patient was diagnosed with ESRD, check the appropriate box.
Most recent hematocrit before EPO start date	For item 8f enter the most recent hematocrit before the EPO start date entered in item 8e. This item will be left blank if EPO was started before a diagnosis of ESRD.

# **Nutrition Questionnaire**

#### **General Notes**

The table to be completed for this section requests the same information as requested in item D:16, D:17 and D:18 of the Core Questionnaire but is for the time period of January, 1994 through November, 1994. Information pertaining to pre and post BUN, pre and post patient weight and serum albumin is requested for the following months in **1994**: January, March, May, July, September and November.

<u>Item</u>	<b>Description</b>	Abstractor Instructions
1.	BUN and Weight	Note: If NONE of the information is available for a given month, skip that column in the table. <b>Do not enter zeros</b> .
	Date	<u>Date</u> : For each month, enter the day to which the values apply. If values are available for more than one day in a month, use the first day on which a set of values is available.
	BUN	<u>BUN</u> : Enter the predialysis BUN and the postdialysis BUN for the day entered in the date row. If a postdialysis BUN is not available for that month, record the predialysis BUN only. Enter a second predialysis BUN value <b>only</b> if this value is available for the dialysis session <u>exactly two days after the session for which</u> <u>the first two (pre and post) values are entered</u> .
	Weight	Weights: Enter the predialysis weight and the postdialysis weight for the day entered in the date column, rounded to the nearest pound or kilogram. Check the appropriate units box to indicate if measurements recorded are in pounds or kilograms. Enter a second predialysis weight <b>only</b> if this value is available for the dialysis session <u>exactly two days after</u> <u>the session for which the first two (pre and post)</u> <u>values are entered</u> . NO weight needs to be recorded if NO pre and post BUN is recorded.

2.	Predialysis Serum Albumin	For item 2., enter the patient's predialysis serum albumin from the same day as referenced in the date row. However, if this data is not available, use any <b>value from</b> <b>the</b> <u>month</u> <b>entered in the date row</b> , to the nearest tenth.
3.	Duration of dialysis	Enter the duration of the dialysis session. This should be the same dialysis session as the one referred to for the first value of predialysis BUN and weight and predialysis serum albumin (NOT the dialysis session referred to for the second pre dialysis value of BUN and weight).

### **Vascular Access Questionnaire**

#### **General Notes**

Please note that at the top of this questionnaire is a space for providing the date of the patient's first chronic maintenance dialysis treatment. (This date was also abstracted for the Core Questionnaire, Item 14 on page 3). Please be sure to complete this item.

This section covers information pertaining to vascular access. The following codes should be used throughout this section for type of vascular access:

1-AV-Fistula
2-PTFE graft, e.g. Goretex, Impra, Teflon
3-bovine graft
4-permanent catheter, e.g. subclavian Permcath (any site)
5-temporary internal jugular (IJ) catheter
5-temporary subclavian catheter
7-temporary femoral catheter
8-other

The following codes should be used for types of revisions:

medical declotting, e.g. urokinase thrombolysis
 balloon angioplasty with thrombolysis
 balloon angioplasty without thrombolysis
 surgical declotting, e.g. thrombectomy, Fogarty
 surgical revision of existing access
 creation of new AV fistula
 creation of new PTFE graft (Gortex)
 creation of other permanent access
 other

## <u>This section should be filled out only if the patient began chronic</u> dialysis during calendar year 1993 (1/1/93-12/31/93).

Please pay close attention to the date(s) referenced for each question. A window of +/-1 week means that if data is not available for the date requested, you can obtain the data from the week prior or the week following the date requested.

<u>Item</u>	Description	Abstractor Instructions
1.	Was a permanent access placed or attempted before the <u>onset of ESRD?</u>	Enter the appropriate code for yes, no or unable to determine.
2.	What type of access was in use at the <u>initiation of hemodialysis</u>	Enter the appropriate code for the type of vascular access in use at the initiation of hemodialysis
3.	What type of access was in use <u>1</u> <u>month after the start of</u> <u>hemodialysis</u> regardless of setting.	Enter the appropriate code for the type of vascular access in use at 1 month after the start of hemodialysis. If you enter code 5, 6, or 7, for a temporary access, then stop abstraction and do not go on to answer any further items.
4.	When was this access (item 3) placed?	Enter the date of placement of the access referred to in item 3.
5.	Highest blood flow during the 4th week of chronic hemodialysis.	Enter the highest blood flow (ml/min) during the 4th week of chronic hemodialysis(Use information from 3 dialysis flow sheets.)
6.	Highest venous pressure at this highest blood flow.	Enter the venous pressure (mmHg) at the highest blood flow recorded in item 5.
7.	First date of dialysis with all blood flows below 200 during any dialysis <u>after the first month of</u> <u>chronic hemodialysis</u> .	Enter the date of the first occurrence of all blood flows below 200 during any dialysis <b>after the 1st month of</b> <b>chronic hemodialysis</b> .
8.	Was recirculation tested <u>after the</u> <u>1st month of chronic</u> <u>hemodialysis?</u> .	Enter the appropriate code for yes or no. IF YES, enter the <u>first date of recirculation</u> , the <u>test result</u> and the <u>blood</u> <u>flow</u> at this recirculation test.
9.	Did switch to PD occur during this period.	Enter the appropriate code for yes or no for whether or not a switch to PD occurred during the period of one month after the start of chronic hemodialysis to the date of abstraction. IF YES, enter the date that the patient switched to PD.

10.	Were any procedures or revisions made to the access in use at 1 month?	Enter the appropriate code for yes or no. IF YES, please give, for up to two revisions or procedures, the <u>date(s)</u> and the <u>type(s)</u> . Please <u>use the codes</u> on the questionnaire provided for the type of revision. For each occurrence of a procedure or revision, please indicate using the appropriate code whether the access was completely clotted (i.e. the procedure or revision was not prophylactic).
11.	Did vascular access infection occur anytime from one month	Enter the appropriate code for yes or no. <b>Do not go</b> <b>beyond an 18 month period from one month after the</b>

occur anytime from one month after the start of chronic dialysis to the date of abstraction or 18 months? Enter the appropriate code for yes or no. **Do not go beyond an 18 month period from one month after the start of dialysis to the date of abstraction.** IF YES, enter up to two dates for two possible occurrences of vascular access infection. Along with each of these dates, enter the appropriate code for yes, no or not done.