

Universal Data Collection

U.S. Department of Health
and Human Services
Public Health Service

Patient Refusal



HTC ID

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GENERAL INFORMATION

Date of Visit

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month day year

Date Form Completed

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month day year

Form Completed by:

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Data entered by:

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CDC Use Only

DEMOGRAPHIC INFORMATION

1. Patient Age

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 Years

2. Sex: Male Female

3. Factor Deficiency: (check all that apply)

VIII Mild Moderate Severe

IX Mild Moderate Severe

vWF

Other _____

4. Used Blood Products In the Last Year?

Yes No Unknown

5. Race and Ethnicity:

White (non-Hispanic)

White (Hispanic)

Black (non-Hispanic)

Black (Hispanic)

Asian/Pacific Islander

American Indian/Alaskan Native

Other _____

6. HTC Status:

Established Patient

New Patient

Transfer Patient

7. HTC Utilization (check one):

Frequent (visits HTC at least once per year)

Infrequent (visits HTC every 2 or 3 years)

Rare (visits HTC every 4 or more years)

First visit

REFUSAL INFORMATION

8. Has this patient participated (enrolled) in UDC in the past? (Check one):

Yes

No

9. When was the UDC presented to the patient?

(Check all that apply)

Prior to a scheduled visit

During a scheduled visit

During an unscheduled visit

Other (Specify) _____

10. Who presented the UDC to the patient?

(Check all that apply)

Physician

Nurse

Social Worker

Other (Specify) _____

11. How was the UDC presented to the patient? (Check all that apply)

Telephone call

Discussion with HTC staff during visit

Patient given consent form to read

Other (Specify) _____

12. What part(s) of the UDC was(were) not acceptable to the patient? (Check all that apply)

Data forms completion

Blood specimen for hepatitis testing

Blood specimen for HIV testing

Blood specimen for storage in national serum bank

Venipuncture required

Confidentiality concerns

Study is not applicable

Length of visit required

Other (Specify) _____

Comments:

PATIENT REFUSAL FORM

FORM COMPLETION: Complete this form once per year at the annual visit for each eligible patient who declines to give consent for participation in Universal Data Collection.

HTCID:

The unique 3-digit identifying number generated for each hemophilia treatment center (HTC).

General Information:

Enter the date of the visit and the date that this form was completed. Enter the initials of the person completing the form.

Demographic Information:

1. Patient Age:

Enter the patient's age in years as of the date of the visit. Use leading zeros before single-digit ages.

2. Sex:

Check MALE or FEMALE.

3. Factor Deficiency:

Check all of the factor deficiency diagnoses for which the patient is receiving care at the HTC. If OTHER, please write in the specific diagnosis. For patients with Factor VIII or IX deficiency, check the severity level of the hemophilia according to the following scale: MILD, if the baseline factor activity level is from 6% to 50%; MODERATE, if from 1% to 5%; SEVERE, if less than 1% of normal.

4. Used Blood Products in the Last Year:

Check YES, if the patient used any type of blood products in the last 12 months. Blood products include whole blood, blood fraction or component (platelets, cryoprecipitate, fresh frozen plasma, etc.) or factor concentrates including recombinant and highly purified products (BenefixTM). Check NO, if the patient did not use any blood products in the last 12 months. Check UNKNOWN, if it is unknown whether or not blood products were used.

5. Race/Ethnicity:

Check the racial/ethnic category that the patient considers him(herself) to be. Use the OTHER category to write in racial/ethnic groups not listed.

6. HTC Status:

Check ESTABLISHED PATIENT, if this patient has been seen at least once in the past at this HTC. Check NEW PATIENT, if the patient has never been seen at any HTC before. Check TRANSFER PATIENT, if the patient has been seen at another HTC but now plans to attend this HTC.

7. HTC Utilization:

Use the history of patient visits to the HTC to determine whether the patient utilizes the HTC on a FREQUENT, INFREQUENT, or RARE basis. Count only actual visits to the HTC, not phone contacts or written correspondence. Check FIRST VISIT, if the current visit is the first visit to the HTC.

8. Has this patient participated (enrolled) in UDC in the past:

Check YES if the patient has EVER been enrolled in UDC. Otherwise, check NO.

9-11. Refusal Information:

Describe when, by whom, and how the UDC information was presented to the patient.

12. Patient's objections to UDC:

Check the box(es) next to any of the choices provided that appropriately describe what part of parts of the UDC were objectionable to the patient or that otherwise caused him/her to decline participation. If the available responses are insufficient or inappropriate, check OTHER, and enter a short phrase that best describes any reasons given by the patient for nonparticipation in the UDC.

Comments: Use the space provided to clarify or further explain answers given in questions 1-12.