

**Annual Clinical Follow-Up Form Data Dictionary**

**For completion by Participants**

SID_DI	HEIRS participant ID - de-identified	Char \$11.
Dvisit	Date of form (Number of days from given date)	Num 4.
Dexam	Date of Study Exam (Number of days from given date) (date filled in by HEIRS staff)	Num 4.
Q1. Have you ever had any of the following?		
Addeval	1a. Additional evaluation for iron overload (outside HEIRS) 1=Yes 2=No	Num 4.
Phlebot	1b. Phlebotomy (blood removal) as treatment 1=Yes 2=No	Num 4.
Liverbiop	1c. Liver biopsy 1=Yes 2=No	Num 4.

If you have had any of the symptoms or conditions below, please tell us how they have changed since your HEIRS Study Exam. Please check the correct answer.

Swellfeet	Q.2 Swelling of feet or ankles 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
skincolor	Q.3 Change in skin color 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
wtloss	Q.4 Unexplained weight loss 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
fluid	Q.5 Abdominal swelling or fluid 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
weakness	Q.6 Chronic fatigue/weakness 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.

shortbreath	Q.7 Shortness of breath 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
jointstiff	Q.8 Joint stiffness/pain/ache 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
thirst	Q.9 Excessive thirst 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
polyuria	Q.10 Polyuria (excessive urination) 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
abdompain	Q.11 Unexplained abdominal pain or discomfort 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
confusion	Q.12 Unexplained confusion or memory loss 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
bleeding	Q.13 Unusual bleeding (vomiting or coughing up blood, blood in stool, or blood in urine) 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
arrhythmin	Q.14 Abnormal heart rhythm, heart beat or action/arrhythmia. 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
sexdrive	Q.15 For men only: Trouble having an erection or loss of sexual drive 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.

othchanges

Q.16 Have you experienced any other major changes in your health?

1=Yes

2=No

Num 4.

changepcp

Q.17 Have you changed primary care physicians, or are you seeing another doctor for treatment for iron overload?

1=Yes

2=No

Num 4.