

Annual Clinical Follow-Up Form

For completion by Clinician/Clinic Staff

SID_DI	HEIRS participant ID - de-identified	Char \$11.
dvisit	Date of form (Number of days from given date)	Num 4.
seensince	Q1. Have you seen this patient since the HEIRS the HEIRS clinical exam 1=Yes 2=No	Num 4.
diaghemo	Q2. What is this patient's current diagnosis? (check all diagnoses that apply) Hereditary hemochromatosis	Char \$1.
diagironover	Iron overloading anemia	Char \$1.
diagotherironover	Other iron overload	Char \$1.
diagporphyria	Porphyria cutanea tarda	Char \$1.
diaghep	Hepatitis	Char \$1.
diagnoironover	No iron overload	Char \$1.
Patientdied	Q3. Has the patient died? 1=Yes 2=No	Num 4.
Heptocellular	Q4. Has the patient had any of the following? 4a. Hepatocellular carcinoma or cholangiocarcinoma 1=Yes 2=No	Num 4.
Liverfailure	4b. Liver failure 1=Yes 2=No	Num 4.
Livertransplant	4c. Liver transplant 1=Yes 2=No	Num 4.
Livertransdate	4d. If yes, date of transplant (Number of days from given date)	Num 4.
liverbiopsy	Q5. Has the patient received any of the following? 5a. Liver biopsy 1=Yes 2=No	Num 4.
quanphlebotomy	5b. Quantitative phlebotomy 1=Yes 2=No	Num 4.
addevalironoverload	5c. Additional evaluation for iron overload 1=Yes 2=No	Num 4.

erytreatment	Q6. Was the patient treated by erythrocytapheresis? 1=Yes 2=No	Num 4.
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eryirondepleted	If yes, was iron depletion achieved? 1=Yes 2=No 3=Don't Know	Num 4.
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Q7. Please record the most recent results for:

serumferritin	7a. Serum Ferritin concentration µg/L	Num 6.
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serumferritindate	7b. Date (Number of days from given date)	Num 4.
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transferrin	7c. Transferrin Saturation %	Num 6.
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transferrindate	7d Date (Number of days from given date)	Num 4.
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If the patient has any of the symptoms or conditions below, please tell us how they have changed since the HEIRS Study Exam. If the patient has not had the symptom or condition, please check #4 (N/A-not applicable).

symptironover	Q8. Iron overload or hemochromatosis 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
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Symptanemia	Q9. Anemia 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
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symptsickle	Q10. Sickle cell anemia 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
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symptthalassemia	Q11. Thalassemia or other inherited 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
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symptbleeding	Q12. Unusual bleeding 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
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symptdiabetes	Q13. Diabetes 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptliverdisease	Q14. Liver disease 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptthyroiddisease	Q15. Thyroid disease 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptheartfailure	Q16. Heart failure 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptarrhythmia	Q17. Abnormal heart rhythm, heart beat or action/arrhythmia 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptheartattack	Q18. Other heart disease or heart attack 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptarthritis	Q19. Arthritis 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptosteoporosis	Q20. Osteoporosis 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.
symptporphyria	Q21. Porphyria cutanea tarda (blistering skin rash made worse by sunlight) 1=Improved 2=No Change 3=Worsened 4=N/A	Num 4.

symptlupus

Q23. Chronic inflammation, chronic
infection, autoimmune disease or lupus
1=Improved
2=No Change
3=Worsened
4=N/A

Num 4.

chemotherapy

Q24. Has the patient had chemotherapy
or bone marrow transplant since the
HEIRS clinical exam?
1=Yes
2=No

Num 4.